Go Gentle
Australia

Submission to

Inquiry into Voluntary Assisted Dying

Select Committee | Queensland | April 2019

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"Palliative care services are not offering what a percentage of their patients desperately need. Palliative care has become a mantra chanted by … politicians and religious organisations opposing euthanasia."

– Clive Deverall, founder of Palliative Care WA

"While pain and other symptoms can be helped, complete relief of suffering is not always possible, even with optimal palliative care."

– Palliative Care Australia

"It is not the role of any health care team to suggest its ministrations can give meaning, purpose and dignity to a dying person's remaining life if that person feels that these are irretrievably lost … palliative care is a model of care, not a moral crusade."

– Professor Michael Ashby, Director, Palliative Care,
Tasmanian Health Service

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What's in this Submission

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Introduction

Since 2016, we have witnessed the two most comprehensive examinations of end-of-life care ever undertaken in Australia. Though conducted independently, these cross-party parliamentary inquiries, in Victoria and Western Australia came to the same conclusions:

- Even the best palliative care cannot relieve all suffering for terminally ill patients;
- Doctors and nurses are delivering inadequate pain relief to dying patients for fear of breaking the law;
- Family and friends are being traumatised as they watch loved ones die agonising deaths;
- Doctors are breaking the law to assist patients suffering untreatably to die – but having to do so in secret, without consultation, oversight, or regulation;
- Elderly and terminally ill people are taking their lives, often in horrific circumstances.

Both inquiries found Australia's existing end-of-life laws to be inadequate. Both recommended, by a clear majority, that Voluntary Assisted Dying (VAD) be legalised as part of a broader approach to better end-of-life care including more resources for palliative care.

These findings are supported by a raft of international, peer-reviewed evidence gathered from multiple jurisdictions with VAD laws in place. Jurisdictions where, after 10, 15 and even 20 years, there is still widespread public and political support for assisted dying; where fears about the abuse of the vulnerable have not been realised; and where there is no loss of faith in doctors or degradation in palliative care – in fact, their opposite.

More than anything else, this combined evidence shows that it is possible to write sensible and compassionate laws, with strong safeguards, to assist people to die good deaths.

> ***"The Victorian and Western Australian inquiries heard testimonies from people of all ages and from all walks of life, describing with great clarity the damage being done in the absence of VAD laws."***

It is clear from submissions already made public by this committee that Queensland is no different. Australians have long accepted that they should be free to make their own decisions about how their lives will end. It is a principle already established in Australian law.

Every opinion poll conducted on the issue over the past two decades has recorded more than 70 per cent support for giving terminally ill Australians access to VAD.

In the most recent polls, that support has grown to near 90 per cent.

In 2017, Victoria became the first state in Australia to pass an assisted dying law. It will come into effect in June this year. But that law, as significant as it is, covers only one in four Australians. There is an urgent need for VAD laws for all terminally ill people in this country.

Hastening death is already legal in Queensland. However, the laws as they currently stand are unfair, incoherent, and the source of mistreatment and abuse.

- Under Queensland law it is legal, if you are dying, and wish to hasten an end to your suffering, to do so slowly and painfully – by refusal of treatment, starvation and dehydration. This is not considered suicide.

- Under Queensland law, when your suffering can no longer be controlled, it is legal to be drugged into a coma, from which it is not intended you awake, by a doctor (though entirely at their discretion, depending on their beliefs).
- Under Queensland law, it is legal to end your suffering by taking your own life. We know now, as a result the parliamentary inquiries in Victoria and Western Australia, that suicides of the terminally and chronically ill are happening every week. Brutal, lonely deaths that leave ineradicable scars in the families and first responders left to pick up the pieces.

What is not legal under Queensland law, if you are dying, is to end your suffering quickly and painlessly, at a time of your choosing, with the support of your family and medical team.

Instead, we have a dangerously unregulated system where, as the Victorian Inquiry found:

> Doctors practice unlawful assisted dying despite its prohibition and despite prospective liability for serious crimes.
>
> This is happening without regulation, without support, without transparency or accountability, and from the evidence received, sometimes without consent.

We know from the Western Australian Inquiry and other research and doctors' accounts over the last two decades that this same unregulated practice of assisted dying is happening across Australia.

In this unregulated system no questions are raised about threats to vulnerable people. No one is examining, or vouching for, doctors' actions. Yet we are told by opponents to VAD that this is safer than a system where doctors are guided by strict regulations and held accountable by law.

Opponents also argue – in fact, it is their main argument – that if palliative care were properly resourced, no one need suffer so there would be no need for VAD. This argument doesn't just defy logic. It defies facts.

Here are Palliative Care Australia's own words.

> While pain and other symptoms can be helped, complete relief of suffering is not always possible, even with optimal palliative care.

> ***"While Go Gentle strongly supports greater resourcing for palliative care, all the resources in the world will not ease the suffering of all dying patients. It is not medically possible and palliative care's own words and statistics say so."***

So, too, do the powerful testimonies from doctors and nurses who have stood helplessly by in the face of terrible deaths.

All the resources in the world will not help hasten a dying patient's death, or alleviate their suffering quickly, if it goes against the beliefs of the treating doctor or institution to do so. There are too many testimonies now, from too many families, about terrible, prolonged deaths within palliative care, that attest to this.

Only a change in the law, which protects a patient's rights at the end of life, will do so.

Andrew Denton
Director, Go Gentle Australia

Part A

What The Evidence Shows

The need for Voluntary Assisted Dying laws in Australia

WHAT THIS SECTION IS ABOUT

The debate about Voluntary Assisted Dying (VAD) in Australia has transformed dramatically in the last three years. In that time, two comprehensive State parliamentary inquiries into end-of-life care have each put forward undeniable evidence of the need for such laws.

Of particular impact has been the evidence from State Coroners detailing the horrific suicides happening every week among the terminally and chronically ill. The need for legal reform is reflected in consistent polling over the last decade which shows that our parliaments are lagging behind public demand in addressing this issue.

This delay is even harder to explain because the core principle of Voluntary Assisted Dying – that a competent adult should be able to decide what is done with their body – is already established in Australian law.

1. PARLIAMENTARY INQUIRIES

Since 2016, two comprehensive cross-party parliamentary inquiries into end-of-life care – the first of their kind in this country – have found Australia's existing laws are inadequate when dealing with the needs and wishes of terminally ill Australians.

1.1 The parliament of Victoria's inquiry into end of life choices, 2016

Running over 10 months in 2016, with more than 1000 submissions and public hearings involving 154 witnesses, the parliament of Victoria's 2016 inquiry into end of life choices[1] found:

- Repeated examples of inadequate pain relief being delivered to dying patients by doctors for fear of breaking the law.
- The inability of palliative care, despite its many benefits, to relieve all suffering.
- People being put on trial for helping those they love find a merciful end.
- Doctors breaking the law in order to help suffering patients die, but having to do so without support, regulation, or accountability.
- Trauma experienced by families watching seriously ill loved ones refuse food and water

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[1] Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report", June, 2017 – https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/EOL_Report/LSIC_58-05_Text_WEB.pdf

to hasten an end to their suffering.

- People experiencing an irreversible deterioration in health taking their own lives, often in horrific circumstances. In Victoria, evidence from the Coroner showed that such suicides are happening at the rate of one a week.

1.2 The parliament of Western Australia inquiry into end of life choices, 2017/18

Running for 12 months, the 2017/2018 Western Australian inquiry into end-of-life choices received more than 700 submissions and held 81 public hearings[2]. It found that:

- Too many Western Australians are experiencing profound suffering as they die. This is, in part, due to inequitable access to palliative care. However, it is clear from the evidence that even with access to the best quality palliative care, not all suffering can be alleviated. Palliative care physicians themselves acknowledge this.
- According to national coronial data about suicide, around 10 per cent of suicides in Western Australia are by people with a terminal or debilitating illness. These people die lonely and often violent deaths; including through plastic bag and helium asphyxia, carbon monoxide poisoning, self-inflicted gunshot wounds, and by hanging.
- There are limitations to palliative care. This reality became clearer as more witnesses gave evidence of their experience of the death of those close to them. Some gave confronting evidence about the suffering of their loved ones, despite receiving the best palliative care available.
- Witnesses told of the prolonged suffering associated with particular diseases: motor neurone disease, Huntington's disease, Parkinson's disease and dementia can involve suffering over many months, and sometimes years, prior to death.

Both the Victorian and Western Australian parliamentary inquiries, when confronted with evidence of the impact of our existing laws, recommended that each state introduce legislation for Voluntary Assisted Dying.

2. PUBLIC DEMAND FOR BETTER END-OF-LIFE CHOICES

The reality about the inadequacies in our end-of-life laws is reflected in public responses to questions about whether or not Australia should legalise Voluntary Assisted Dying.

Consistent, reliable opinion polling in Australia over two decades has revealed support for VAD to be in excess of 70 per cent. Since 2012, this support has steadily increased, irrespective of variations in the questions asked and terminology used.

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[2] Joint Select Committee on End of Life Choices, "Inquiry into the need for laws in Western Australia to allow citizens to make informed decisions regarding their own end of life choices", Parliament of Western Australia, 23 August, 2018 – http://www.parliament.wa.gov.au/Parliament/commit.nsf/(EvidenceOnly)/702507C2CB874282482581870024 7E53?opendocument

Figure 1: Polls on Voluntary Assisted Dying – 2012 to 2018

Polling Body	Date	Question	Yes	Undecided/ Other	No
Newspoll	2012	Thinking about voluntary euthanasia, if a hopelessly ill patient, experiencing unrelievable suffering, with absolutely no chance of recovering asks for a lethal dose should a doctor be allowed to provide a lethal dose?	82.5%	4.8%	12.7%
Australia Institute	2012	If someone with a terminal illness who is experiencing unrelievable suffering asks to die, should a doctor be allowed to assist them to die?	71%	17%	12%
ABC Vote Compass	2013	Terminally ill patients should be able to legally end their own lives with medical assistance.	75.1%	9.4%	15.5%
Essential Media Communications	2014	When a person has a disease that cannot be cured, and is living in severe pain, do you think (a doctor) should be allowed by law to assist the patient to commit suicide if the patient requests it?	66%	20%	14%
Ipsos Mori	2015	Do you think that it should be legal or not for a doctor to assist a patient ages 18 or over in ending their life if that is the patient's wish, provided that the patient is terminally ill (where it is believed that they have 6 months or less to lie) are of sound mind, and express a clear desire to end their life?	73%	12%	15%
ABC Vote Compass	May 2016	Terminally ill patients should be able to legally end their own lives with medical assistance.	75%	9%	16%
Essential Media Communications	Nov 2017	When a person has a disease that cannot be cured, and is living in severe pain, do you think (a doctor) should or should not be allowed by law to assist the patient to commit suicide if the patient requests it?	72%	16%	12%
Review Partners	July 2017	Victorians supported the right of adults to choose to end their lives if they are suffering from a terminal illness.	72%	15%	13%
Roy Morgan Research	Nov 2017	If a hopelessly ill patient, with no chance of recovering asks for a lethal dose, should a doctor be allowed to give a lethal dose, or not?	85%	None	15%
ReachTEL	Aug 2018 QLD Only	Do you support or oppose terminally ill people with no hope of recovery being given the choice of legally ending their life with the assistance of medical professionals?	79%	4.2%	16.8%

Roy Morgan Research, which conducted the most recent national poll on the issue in 2017, found that 85 per cent of Australians said they supported allowing doctors 'to give a lethal dose'. This support was consistent across the country:

> ... with clear majorities in all six States in favour of allowing doctors to 'give a lethal dose' to patients. The State with the largest support is Western Australia in which 88% of respondents support allowing doctors to 'give a lethal dose'. All other states and city and country areas are over 80% in support of allowing doctors to 'give a lethal dose'.[3]

Queensland was just behind Western Australia at 86 per cent support. The result was confirmed by a subsequent ReachTEL poll in 2018 which recorded 79 per cent support in Queensland for the prospect of 'terminally ill people with no hope of recovery being given the choice of legally ending their life with assistance from a medical professional.'[4]

3. GLOBAL MOMENTUM

Public opinion in Australia reflects a growing acceptance of the need for VAD/VE (voluntary assisted dying/voluntary euthanasia) around the world. As of April 2019, VAD/VE was available in the Netherlands, Belgium, Colombia, Luxembourg, Canada, Switzerland, and in the US states of Washington, Oregon, Colorado, Hawaii, New Jersey, Vermont, Montana, Washington D.C. and California. In Australia, Victoria's Voluntary Assisted Dying Act will come into effect in June 2019.

Figure 2: Number of people globally with access to Voluntary Euthanasia/ Voluntary Assisted Dying laws

PRIOR TO 1996: **ZERO** → **BY 2019:** **200 MILLION**

Switzerland (1942 decriminalised)
Oregon (1997)
The Netherlands (2000)
Belgium (2002)
Washington (2009)
Luxembourg (2009)
Montana (2010)
Vermont (2013)
Quebec (2014)
Colorado (2016)
California (2016)
Canada (2016)
Washington DC (2017)
Colombia
Hawaii (2019)
New Jersey (2019)
Victoria (2019)

Australia passed the world's first Voluntary Assisted Dying law in the Northern Territory in 1996. However, only four people got to use it before it was rescinded by the federal government. Now 200 million people have access to VE/VAD worldwide. In Australia, once Victoria's law comes into effect on 19 June 2019, three quarters of Australians will still be denied access to a more compassionate end of life law.

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[3] Gary Morgan and Michelle Levine, "It's Official: Australians support assisted dying or euthanasia", Roy Morgan, 10 November, 2017 – http://www.roymorgan.com/findings/7373-large-majority-of-australians-in-favour-of-euthanasia-201711100349

[4] Editorial, "Poll finds Queensland backs voluntary assisted dying and changes to euthanasia laws", The Courier-Mail, 31 August, 2018 – https://www.couriermail.com.au/news/queensland/poll-finds-queensland-backs-voluntary-assisted-dying-and-changes-to-euthanasia-laws/news-story/c4ad4647516967dee4347b352c177464

4. THE PRINCIPLES OF VOLUNTARY ASSISTED DYING ARE ALREADY ESTABLISHED IN AUSTRALIAN LAW

In arguing against Victoria's proposed Voluntary Assisted Dying legislation, former Prime Minister Paul Keating wrote:

> No matter what justifications are offered for the bill, it constitutes an unacceptable departure in our approach to human existence and the irrevocable sanctity that should govern our understanding of what it means to be human.[5]

Keating's claim that assisted dying represents an 'unacceptable departure' in our approach to human existence is wrong in fact, and in law. So too his defence of the 'irrevocable sanctity' of human life.

Australian law has already decided that there are circumstances where it is permissible for the State to direct, or intervene, in order to allow a person who is suffering incurably to end their life.

4.1 Brightwater Care Group v Rossiter (2009)

The Australian Centre for Health Law Research provides the following summary of a key legal case in Western Australia, which involved Mr Rossiter, who was in a facility that cares for people with disabilities.

> *Brightwater Care Group v Rossiter* [2009] WASC 229
>
> Mr Rossiter was a quadriplegic who was kept alive by receiving artificial hydration and nutrition through a tube into his stomach. He had capacity and decided he no longer wanted to receive this treatment. He asked the facility that was caring for him to withdraw the tube. The Supreme Court was asked for declarations about the rights and obligations of the facility and the patient.
>
> The Court decided that as Rossiter had capacity, he was entitled to decide the treatment he wished to receive or refuse. The Court noted that the principle of autonomy prevailed over the sanctity of life, and decided that the duty of the facility to provide Rossiter with the necessaries of life did not apply given he was a competent person refusing treatment. A declaration was made that the facility caring for Rossiter could lawfully withdraw the treatment if Rossiter requested it.[6]

In his decision in *Brightwater Care Group v Rossiter*, the Chief Justice of Western Australia referred to "clear and unambiguous" common law principles, including the principle of autonomy or self-determination. He stated:

> Another principle well established at common law is the principle which has been described in the cases as the right of autonomy or self-determination. Lord Hoffmann has described this right as being related to **respect for the individual human being and in particular for his or her right to choose how he or she should live his or her life:** *Airedale National Health Service Trust v Bland* [1992] UKHL 5; [1993] AC 789, 826. Included within the right of autonomy or self-determination is the right, described as long ago as 1914 in the United States by Justice Cardozo, as the right of 'every human being of adult years and sound mind

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[5] Paul Keating, "Paul Keating: Voluntary euthanasia is a threshold moment for Australia, and one we should not cross", *The Sydney Morning Herald*, 19 October, 2017 – https://www.smh.com.au/opinion/paul-keating-voluntary-euthanasia-is-a-threshold-moment-for-australia-and-one-we-should-not-cross-20171019-gz412h.html

[6] Supreme Court of Western Australia, "Brightwater Care Group (Inc) -v- Rossiter [2009] WASC 229", 20 August, 2009 – http://www7.austlii.edu.au/cgi-bin/viewdoc/au/cases/wa/WASC/2009/229.html

> ... to determine what shall be done with his own body': *Schloendorff v Society of New York Hospital* 211 NY 125 (1914),129.
>
> **The principle is applied without regard to the reasons for the patient's choice, and irrespective of whether the reasons are rational, irrational, unknown or even non-existent:** *Re T (Adult: Refusal of Treatment)* [1992] EWCA Civ 18; (1993) Fam 95, 113 (cited with approval in *Ms B v An NHS Hospital Trust [18] and Hunter and New England Health Service v A* [15]). [Our emphasis]

An account of Mr Rossiter's legal victory, giving him the right to end his "living hell", can be found in the article "Perth Quadriplegic Wins Landmark Right to Die".[7]

Australian law has already decided that there are circumstances in which the principle of the sanctity of human life is not paramount.

4.2 Hunter and New England Area Health Service v A (2009)

This case concerned the obligation of a health service to provide dialysis to a patient who had lost consciousness following septic shock and renal failure in circumstances where the patient had apparently prepared a document some time earlier indicating that he would refuse dialysis.

McDougall J identified two conflicting interests recognised by the common law:

- a competent adult's right of autonomy or self-determination – the right to control his or her own body; and
- the interest of the State in protecting and preserving the lives and health of its citizens.[8]

McDougall J stated:

> It is in general clear that, **whenever there is a conflict between a capable adult's exercise of the right of self-determination and the State's interest in preserving life, the right of the individual must prevail** ... In *Airedale NHS Trust v Bland* [1992] UKHL 5; [1993] AC 789 at 859, Lord Keith of Kinkel said that the State's interest is not absolute, and does not compel treatment of a patient contrary to the patient's express wishes. In the same case, Lord Goff said (at 864) that:
>
>> [I]t is established that the principle of self-determination requires that respect must be given to the wishes of the patient, so that if an adult of sound mind refuses, however unreasonably, to consent to treatment or care by which his life would or might be prolonged, the doctors responsible for his care must give effect to his wishes, even though they do not consider it to be in his best interests to do so. ... [t]o this extent, **the principle of the sanctity of human life must yield to the principle of self-determination.**[9] [Our emphasis]

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[7] Editorial, "Perth quadriplegic wins landmark right to die", ABC News, Australian Broadcasting Corporation, 14 August, 2009 – https://www.abc.net.au/news/2009-08-14/perth-quadriplegic-wins-landmark-right-to-die/1391380

[8] Hunter and New England Area Health Service v A [2009] NSWSC 761; (2009) 74 NSWLR 88 at 90 [5] – Case Report available here: http://www.mondaq.com/australia/x/97538/Healthcare/Advance+Care+Directives+Hunter+and+New+England+Health+Service+v+A+2009+NSWSC+761

[9] *Hunter and New England Area Health Service v A* [2009] NSWSC 761; (2009) 74 NSWLR 88 at 92 [17] – Case Report included as an appendix here, at p. 20 – http://www.parliament.wa.gov.au/parliament/commit.nsf/(Evidence+Lookup+by+Com+ID)/504182F47CA615AF48258218000F911B/$file/20170926+-+EOLC+-+Sub+22+-+Mr+Kevin+Rickson.pdf

Go Gentle
Australia

Part B

Assisted Dying in Queensland Today

An incoherent, largely unregulated, and inequitable legal situation

WHAT THIS SECTION IS ABOUT

When it comes to Voluntary Assisted Dying, we are not starting with a blank page. Patients' deaths are hastened, or aided – legally and illegally – throughout Australia every week. Some deaths – because of the nature of our existing laws – are necessarily slow. As a result, they can be cruel, both for the person dying and their loved ones watching on. Others happen in secret. Many leave behind lasting trauma; for families, friends, doctors, nurses, and also first responders.

1. ASSISTED DYING TAKES PLACE IN QUEENSLAND TODAY, BUT WITH LITTLE, OR NO, REGULATION OR OVERSIGHT

1.1 Doctors illegally assisting people to die

Research and doctors' testimonies over the last 20 years show that this unregulated practice takes place around Australia. This was summarised by the Australia 21 Institute in their document "The right to choose an assisted death: Time for legislation?". Under the sub-title 'The law has failed' the study's authors write:

> Research among Australian doctors caring for seriously ill patients has documented current practices in some detail. According to that research, **voluntary, involuntary and non-voluntary euthanasia all occur in Australia in defiance of the law.** Some doctors have admitted publicly that they have acted with intent to end the patient's life but, despite this admission, they have not been prosecuted. [Our emphasis]
>
> Kuhse et al concluded that in 1995-1996, 1.8% of all deaths in Australia occurred as a result of voluntary euthanasia and 0.1% were due to physician-assisted suicide. Despite these actions being unlawful in Australia, the incidence was broadly comparable with that in permissive jurisdictions. Other research demonstrates that some doctors who treat terminally ill patients intend to shorten life (rather than only relieve pain) when they administer pain relieving medication, and so will be acting unlawfully.[10]

The Victorian Cross-Party Parliamentary Inquiry into End-of-Life Choices (2016) also found that:

> **Doctors practice unlawful assisted dying despite its prohibition and despite prospective liability for serious crimes.**

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[10] Bob Douglas, Lindy Willmott and Ben White, "The right to choose an assisted death: Time for legislation?", Australia 21, Health Law Research Centre, Queensland University of Technology, January, 2013 – http://australia21.org.au/wp-content/uploads/2013/08/J2056-Assisted-Death-Report_WEB.pdf

According to the report, this is happening without regulation, without support, without transparency or accountability, and from the evidence received, sometimes without consent.[11]

In their submission to the Western Australian Joint Select Committee Inquiry into End-Of-Life-Choices (2018), Doctors for Assisted Dying Choice told the committee about:

> ... an anonymous survey of Australian medical practitioners [that] indicated that 35% of doctors have, at the request of their patient, provided medical treatments with the aim to hasten and shorten the duration of suffering for their patients. Because under the current laws, these doctors could face criminal charges, these practices remain hidden and are unspoken.[12]

On 28 July 2018, AMA (WA) President Dr Omar Khorshid admitted that doctors routinely hasten death, telling 7 News (video used in a report in *The West Australian*):

> **We (doctors) shorten patients' lives regularly if that's the right thing to do at the very end of life.**[13]

1.2 Terminal Sedation

Terminal sedation is the practice of alleviating refractory suffering in patients by sedating them into a coma from which it is expected they will never awake.

According to the findings of the Victorian Committee, although widely practised, terminal sedation is:

> ... not centrally recorded, the extent of its use is unknown, and no guidelines exist to regulate it.[14]

This end-of-life practice remains equally opaque in Queensland, despite the State being one of four (along with South Australia, Western Australia and the ACT) to have introduced legislation dealing with the use of palliative medication.

In Queensland, a doctor must order the sedation, and the doctor must give written authorisation. Even so, according to the Australian Centre for Health Law Research:

> Whether or not palliative sedation is legal in Australia has not been considered by the Courts. However, it is likely that legality will depend on the circumstances of each individual case. For example, it would be lawful to use palliative sedation so long as it is performed to manage refractory symptoms, with the intention of relieving pain and suffering, not hastening or causing death, and the patient continues to receive nutrition and hydration.[15]

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[11] Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report: Chair's Foreword", June, 2017, p. xvi – https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/EOL_Report/LSIC_58-05_Text_WEB.pdf

[12] A Sanderson (MLA) and Hon. C J Holt (MLC), "Report 1 - My Life, My Choice: The Report of the Joint Select Committee on End of Life Choices: 4:133 'Unlawful Practices'", 40th Parliament, Parliament of Western Australia, August, 2018, p.146 – https://apo.org.au/sites/default/files/resource-files/2018/08/apo-nid188761-1227101.pdf

[13] Cathy O'Leary, "Perth pro-euthanasia Dr Alida Lancée cleared of wrongdoing by Medical Board", The West Australian, 28 July, 2018 – https://thewest.com.au/news/health/perth-pro-euthanasia-dr-alida-lancee-cleared-of-wrongdoing-by-medical-board-ng-b88908204z

[14] Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report: Section 6.3: Unlawful Medical Practice", June, 2017, pp.181-186, – https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/EOL_Report/LSIC_58-05_Text_WEB.pdf

[15] Ben White, Lindy Willmott and Penny Neller, "Palliative Medication: Palliative sedation - Is palliative sedation legal in Australia?", End of Life Law in Australia, Australian Centre for Health Law Research, Queensland University of Technology – https://end-of-life.qut.edu.au/palliative-care

1.3 Doctrine of Double Effect

Under the legally recognised principle of the Doctrine of Double Effect, doctors can give increasing doses of medication to a dying patient, which may have the unforeseen consequence of hastening their death as long as it is not their intention to do so.

Like terminal sedation, no guidelines exist, nor is any record kept, about the application of the Doctrine of Double Effect in Australia.

Because no one is examining, or vouching for, the doctors' intentions, there is no way of knowing if the Doctrine of Double Effect is shielding abuse, or collusion between doctors and family members.

1.4 How can an unregulated system be safer than a regulated one?

A common argument made against Voluntary Assisted Dying is that it can 'never be 100 per cent safe'. This is true of any law. The relevant question is: "Does Voluntary Assisted Dying make our end-of-life practices safer than they are now?"

Under Queensland's existing end-of-life laws, we are asked to take it on trust that doctors are assisting people to die in the right way, and for the right reasons, *even when they're doing so illegally*. No questions are raised about threats to vulnerable people. No further safeguards are suggested.

Compare this with Victoria's Voluntary Assisted Dying Act (2017), which contains multiple safeguards, requiring that doctors' actions when assisting a person to die be checked against strict, legally enforceable, criteria.

Any system which sends doctors the message "we think it's safer if you just keep breaking the law" is a system that does not properly protect either its doctors or their patients.

2. WHAT IS LEGAL IN QUEENSLAND TODAY FOR A DYING PERSON SEEKING TO HASTEN THEIR DEATH

In Queensland, your legal options if you are suffering beyond medical help as you die, and seeking to hasten your death, are a choice of three, hard roads:

- refusing all medical treatment, food, and water;
- committing suicide;
- terminal sedation – being slowly put into a coma by doctors.

2.1 The right to refuse treatment and/or sustenance

Recent parliamentary inquiries into end-of-life care and Voluntary Assisted Dying have confirmed that the law recognises a person's right to relieve suffering at the end of life by exercising:

- the right to refuse further medical treatment, and/or;
- the right to refuse food and water in order to hasten death.

The Australian Centre for Health Law Research provides extensive information on end-of-life law in Australia.[16]

The law is clear that every adult has the right to refuse medical treatment if the adult has 'capacity' or is 'competent'. Medical treatment given without consent is unlawful, unless it was provided in an emergency in order to save the person's life, and it was not possible to obtain consent from the person or their substitute decision-maker.

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[16] Ben White, Lindy Willmott and Penny Neller, "Legal Overview: Can an adult with capacity refuse life-sustaining treatment?, and; Must health professionals follow a decision to withhold or withdraw treatment made by a patient with capacity?", End of Life Law in Australia, Australian Centre for Health Law Research, Queensland University of Technology – https://end-of-life.qut.edu.au/stopping-treatment/adults

In relation to adults with capacity, the Centre states:

> **It is lawful for an adult with capacity to make their own decisions to refuse or accept medical treatment, even if the decision they make results in their death.** Doctors must respect those decisions to refuse treatment and, if directed to do so, doctors can legally withhold (not start treatment) or withdraw (stop treatment already started) life-sustaining treatment from adults, even if this might result in the person's death. It can also be lawful for a substitute decision-maker to ask that life-sustaining treatment be withheld or withdrawn from someone who can no longer make treatment decisions for themselves. [Our emphasis]

According to the Centre:

> An adult can refuse medical treatment on any grounds including for example, religious reasons **or personal beliefs about what is an acceptable quality of life.** [Our emphasis]

It is important to note that such refusal is not considered suicide. Death by this method is medically supported with mouth, and other comfort, care. It can, however, be long, slow, and psychologically painful for the person going through it, their family, and the medical team caring for them.

This was underlined by Associate Professor Richard Chye, Director of Supportive and Palliative Care at St Vincent's and Prince of Wales Hospitals in Sydney, speaking on the podcast "Better Off Dead". In answer to the question if dying this way was painful, he said:

> I think not physically but psychologically … it is a very painful way to go, and I remember a patient who committed suicide who decided to stop eating and drinking and then because she was told, 'If you do that, you will be dead in two or three days'. She committed suicide because it hadn't happened after two weeks.[17]

Dr Alida Lancée explained to the Western Australian Inquiry that it is not necessarily an option free of suffering:

> **Stopping eating and drinking is a way to bring forward death, but it can take weeks. The person would have to endure several days of hunger pains followed by the symptoms of metabolic effect of starvation,** which is ketotic acidosis. This causes headaches, confusion, breathlessness, delirium, agitation, weakness, muscle cramps and eventual sedation. Medical support is required to ensure these symptoms are controlled. When this is available, the process can be similar to terminal sedation.[18] [Our emphasis]

Professors Ben White and Lindy Willmott, from the Australian Centre for Health Law Research, describe 'voluntary palliated starvation' as an option being more commonly taken by people who are dying:

> This practice is occurring more frequently given the lack of options that patients have as they approach the end of their lives.[19]

The Victorian Inquiry into End-of-Life Choices wrote of the trauma families faced:

> … watching seriously ill loved ones refuse food and water to expedite death and finally relieve their suffering.[20]

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[17] Richard Chye in Andrew Denton, "Better Off Dead: #11 Whose life is it anyway?: Palliative care in Australia part 2", podcast, Thought Fox and the Wheeler Centre, published online by the Wheeler Centre on 15 March, 2016, (audio) – https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/11-whose-life-is-it-anyway
Transcript at Go Gentle Australia website, July 2017 – http://www.gogentleaustralia.org.au/transcripts2

[18] Dr Alida Lancée in "Inquiry into the need for laws in Western Australia to allow citizens to make informed decisions regarding their own end of life choices: Transcript of evidence", Session Six, Perth, 5 April, 2018, p.4 – http://www.parliament.wa.gov.au/Parliament/commit.nsf/(Evidence+Lookup+by+Com+ID)/AF83496EA799BE924825828A000C2036/$file/end180405.6.pdf

[19] Lindy Willmott, Ben White and Penny Neller, Letter to the Joint Select Committee on End of Life Choices, EOLC Sub 560, 23 October, 2017 – http://www.parliament.wa.gov.au/parliament/commit.nsf/(Evidence+Lookup+by+Com+ID)/5C9E02EB53E446D94825821E000FC3FB/$file/20171023+-+EOLC+-+Sub+560+-+Pro+Lindy+Willmot,+Prof+Ben+White+&+Ms+Penny+Neller.pdf

[20] Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report: Section 7: How the existing legal framework shapes end of life experiences", June, 2017, p. 193 – https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/EOL_Report/LSIC_58-05_Text_WEB.pdf

CASE STUDY: DULCIE'S STORY

DULCIE, 73, FROM MT. GRAVATT EAST, DIED OF NEUROENDOCRINE CANCER
HER STORY IS TOLD BY HER DAUGHTER, SANDIE.[21]

IT WAS LIKE A HORROR MOVIE

She had a neuroendocrine tumour in her abdomen and a life expectancy of two months if she elected not to have chemotherapy.

She had suffered a lifetime of major illnesses, but given her history and the prognosis even with treatment, she decided the fight would be too hard, and she chose to die.

She was transferred to hospital two weeks prior to her death where she was given a blood transfusion, which was in contradiction to her express wishes that nothing be done to prolong her life.

By this stage, the pain was becoming unbearable and she was drugged to the eyeballs all the time.

My beautiful mother lay in that bed, rotting in front of my eyes for an entire week. Once they stopped taking her obs and said she was nil by mouth, it meant that medications that she had been so heavily dependent on (and was addicted to) were no longer being administered.

In my opinion, that sent her into a violent withdrawal and she spent a lot of time thrashing about the bed, crying out, doubling over in pain, showing nothing but horror and agony on her face like an addict withdrawing.

> ***She was starving to death and by this stage was skeletal, and her dehydration was obvious.***

Her mouth was caked with thrush and because she had suffered very severe respiratory illnesses in her lifetime, the infected mucus was pooling on her chest, further preventing her from breathing.

I spent that whole entire week (day and night) by my mother's side, speaking on her behalf to try and get her more pain relief or a sip of water (until nil by mouth).

In the last couple of days as the infection on her chest took hold and her organs progressively shut down, she was gasping for breath the entire time.

Finally, she sat bolt upright in bed and her eyes flashed wide open with a look of terror on her face, then she fell back on the pillow and took her last breath. The mucus that had been pooling on her chest began to ooze out of her mouth, putrid, green sludge that just kept coming and coming.

That last week of her life was like a horror movie. It was entirely obvious that death was unavoidable, yet nothing was done to move it along so she could be spared the futile pain, suffering and indignity that she went through.

Her final days served absolutely no purpose to her or anyone else, and left me with a type of post-traumatic stress from having gone through it with her.

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[21] Andrew Denton and Glenda Downing (editor), *The Damage Done*, Go Gentle Australia, 2016. Free download available here – https://www.gogentleaustralia.org.au/shop

CASE STUDY: DULCIE'S STORY

According to The Australian Centre for Health Law Research:

> A fundamental principle of health law is **an adult's right to decide what is or is not done to their bodies.**[22] [Our emphasis]

This raises serious questions about what happened to Dulcie after invoking her legal right to refuse treatment, food, and water:

- Why was Dulcie given a transfusion in contradiction of her wishes to refuse all medical treatment?
- Why did Sandie have to push to get adequate pain relief and sedation for her mother?
- Why was Dulcie forced to endure a slow, painful and terrifying death from starvation and dehydration (and subsequent chest infection), when it was obvious that death was unavoidable?
- Why did Sandie have to watch her mother die this way?

Dulcie's experience robbed her of her autonomy, control and dignity. Her ordeal borders on mistreatment and abuse.

In allowing someone the legal right to refuse life-sustaining treatment, food and water, Queensland has already accepted the principle that a dying person has a right to hasten their own death.

As Dulcie's story demonstrates, they are just being told they have to do it slowly and painfully.

2.2 Committing suicide

In giving evidence to the Victorian Inquiry, Coroners John Olle and Caitlin English brought to light a very particular group of people: older Victorians, with no history of mental illness and from loving family relationships who, in Coroner Olle's words, were taking their own lives in "desperate and violent ways".

According to the Coroner, what these people had in common was that each was suffering an "irreversible decline", either from a terminal disease, multiple chronic illnesses, or permanent physical pain. He stressed that these were people of rational mind and, in his view, beyond the help of palliative care.

They included a 90-year-old man with brain cancer who shot himself repeatedly in the head and chest with a nail gun.

According to statistics gathered by the Coroner's Office over five years, these suicides are happening in Victoria at the rate of one a week.

In Coroner Olle's words:

> ... what seems to be a common thread through the family is this absolute sense of respect for someone they love [and] this absolute sense of helplessness. They know this person is screaming for help, but no-one is going to answer the call, not in this society. So, they have to die alone.[23]

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[22] Ben White, Lindy Willmott and Penny Neller, "Legal Overview: Can an adult with capacity refuse life-sustaining treatment?", End of Life Law in Australia, Australian Centre for Health Law Research, Queensland University of Technology – https://end-of-life.qut.edu.au/stopping-treatment/adults

[23] John Olle in Standing Committee on Legal and Social Issues, "Inquiry into end-of-life choices", Parliament of Victoria, Melbourne, 7 October, 2015 – https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/ELC_Transcripts/SCLSI_-_Coroners_Court_-_FINAL_-_End-of-life_choices_7_October_2015.pdf

In Western Australia, the Committee drew on statistics provided by the Coroner's Office and the National Coronial Information System (NCIS) to estimate that 10 per cent of suicides in WA in any given year were carried out by people with terminal or debilitating chronic illnesses.[24]

They found that:

> These people die lonely and often violent deaths; including through plastic bag and helium asphyxia, carbon monoxide poisoning, self-inflicted gunshot wounds and, by hanging.[25]

This pattern was corroborated by the South Australian Coroner, Mark Johns, in the podcast series "Better Off Dead". You can hear his testimony or read the transcript at the hyperlinks below.[26]

The Western Australian Inquiry found that evidence from international jurisdictions had reached similar conclusions:

> In the UK it has been estimated that around one in ten suicides is in the context of a terminal or severe chronic illness [...] and one in ten suicides in the USA has been determined to occur without an identifiable mental disorder.[27]

There is no reason to think that Queensland is immune from a similar pattern of suicides among the terminally and chronically ill.

In fact, Queensland's ageing population suggests the State may be even more susceptible. According to the latest Australian Institute of Health and Welfare statistics, there are 727,000 Queenslanders aged 65+ years. That is one in seven out of a population of five million.

The 2018 report from Queensland's chief health officer says that in 2016, **cancer accounted for almost one third (9227) of deaths in Queensland – 2499 of these deaths were people aged 65–84** (figure not provided for 85+).[28]

According to the Queensland Government, the number of new cancer cases in Queensland is among the highest in the world.[29] In Australia, Queensland has the highest rates of all major cancers for men and women – bowel cancer, breast cancer, prostate cancer, and melanoma.[30]

Even if only a small number of these older Queenslanders with cancer mirror the patterns in Victoria and Western Australia and take their lives, the impact upon the wider community – on family members, doctors, nurses, and also on first responders called to the scenes of such tragic deaths – will be far greater than any statistic can show.

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[24] A Sanderson (MLA) and Hon. C J Holt (MLC), "Report 1 - My Life, My Choice: The Report of the Joint Select Committee on End of Life Choices: 'Chair's Foreword'", 40th Parliament, Parliament of Western Australia, August, 2018, – https://apo.org.au/sites/default/files/resource-files/2018/08/apo-nid188761-1227101.pdf

[25] A Sanderson (MLA) and Hon. C J Holt (MLC), "Report 1 - My Life, My Choice: The Report of the Joint Select Committee on End of Life Choices: 'Chair's Foreword'", 40th Parliament, Parliament of Western Australia, August, 2018, – https://apo.org.au/sites/default/files/resource-files/2018/08/apo-nid188761-1227101.pdf

[26] Mark Johns in Andrew Denton, "Better Off Dead: #14 Australia's Dark Little Secret", podcast, Thought Fox and the Wheeler Centre, published online by the Wheeler Centre on 30 March, 2016, (audio) – https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/14-australia-s-dark-little-secret
Transcript at Go Gentle Australia website, https://www.gogentleaustralia.org.au/transcripts2

[27] A Sanderson (MLA) and Hon. C J Holt (MLC), "Report 1 - My Life, My Choice: The Report of the Joint Select Committee on End of Life Choices: 4.117 'Do people deliberately end their lives because of terminal or debilitating illness?'", 40th Parliament, Parliament of Western Australia, August, 2018, p.140 – https://apo.org.au/sites/default/files/resource-files/2018/08/apo-nid188761-1227101.pdf

[28] Young, Jeanette, "The health of Queenslanders 2018: Report of the Chief Health Officer Queensland", State of Queensland (Queensland Health), November, 2018, p.34 – https://www.health.qld.gov.au/__data/assets/pdf_file/0032/732794/cho-report-2018-full.pdf (Statistics calculated from data in Table 9)

[29] Queensland Government, "Information for Queenslanders: Health and Wellbeing - Men's Health - Cancer", updated 23 September 2015 – https://www.qld.gov.au/health/staying-healthy/men-women/men/cancer

[30] Liz Burke, "Australia's cancer hot spots revealed", news.com.au, 1 July, 2017 – https://www.news.com.au/lifestyle/health/health-problems/australias-cancer-hot-spots-revealed/news-story/372182126ea7a6a1f189848a481f8c8d
See also: Torrens University Australia, "Torrens University Pioneers Interactive Map Revealing Cancer Rates Across the Nation", 25 August, 2017 – https://www.torrens.edu.au/blog/general/torrens-university-cancer-research-findings

CASE STUDY: DIANA'S STORY

DIANA'S STORY TAKES PLACE IN MACKAY, QUEENSLAND.
HER FATHER, [redacted] SUFFERED FROM INOPERABLE PROSTATE CANCER.[31]

OUR FATHER SHOT HIMSELF IN THE HEART

On 14 June 1994, our father shot himself in the heart with a rifle.

He was in the bedroom; our mother was in the kitchen no more than five metres away, my 12-year-old nephew in the lounge.

Dad was diagnosed with inoperable prostate cancer at the age of 54 with a 10 to 15-year prognosis.

And so, began his long battle with an exploratory operation that ended in a careless removal of the catheter that left him 'leaking' constantly, but he didn't give up due to that little hurdle.

He devised his own special 'nappy' so that he could continue to play his beloved golf. I don't think they had Tenas then!

I can't remember the exact point when he started to decline but I do remember distinctly his last couple of months.

He had been admitted to the palliative care ward of our local private hospital and was cared for so wonderfully by the nursing staff.

At the beginning, he would entertain other patients, and us when we came to visit, by playing the piano (totally self-taught and unable to read music).

But he was being given painkilling drugs that had him hallucinating and we could sense his frustration at his lack of control. He couldn't conduct a reasonable conversation when friends came to visit.

Even though he had the best of care at the hospital, he was desperate to come home and, in the end, refused to go back.

> ***"I learned after his death he had begged his doctor for enough medication to safely and gently end his life when he knew all hope was lost."***

He had written a note which I still have; a small piece of paper roughly torn from a page, upper case letters, obviously written with a shaking hand:

I LOVE YOU ALL. ALWAYS DO YOUR BEST. DAD.

I can only wonder at the beautiful memory we could have had of Dad's last moments; whether he had chosen to have us present when he passed or not, at least he would have died with the dignity that was rightfully his.

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[31] Andrew Denton and Glenda Downing (editor), *The Damage Done*, Go Gentle Australia, 2016. Free download available here – https://www.gogentleaustralia.org.au/shop

CASE STUDY: DIANA'S STORY

In Queensland it has been legal for a dying person to bring an end to their suffering by suicide since 1979, yet the death of Di's father raises serious questions about the choices offered by our existing law:

- Why, when it was clear that there was no further treatment to help [redacted] was he denied a peaceful and dignified death with his family by his bedside?
- Why was no effort made by his doctor to help him when he begged for assistance to die gently?
- Why was [redacted] denied the opportunity to farewell those he loved?
- Why did he come to believe that taking his own life in this way was his only option?
- Why did his family have to witness the aftermath of his violent suicide?

[redacted] was a brutal and lonely death that left his family with ongoing trauma. It suggests a system that promotes mistreatment and abuse.

In allowing someone the legal right to commit suicide, Queensland has already accepted the principle that a dying person has a right to hasten their own death.

They are just being told they have to do it violently and alone.

2.3 Terminal Sedation: Being slowly put into a coma by doctors

Terminal – or palliative – sedation is the alternative held out by palliative care when pain can no longer be controlled: the promise of powerful drugs that will put the dying person into a coma from which they will not awake. Associate Professor, Dr Natasha Michael, Director of Palliative Medicine at Cabrini Health, Melbourne, defined it this way to the Victorian Committee:

> Continuous deep sedation is sometimes instituted in people where we feel that they have intractable pain that we just cannot manage.[32]

Because there is no record kept of its use, there is no way of knowing how widely terminal sedation is used, how often it is needed, who decides if it is, and on what basis.

The Australian Centre for Health Law Research says the primary purpose of terminal sedation is to:

> Sedate a patient near the end of their life in order to relieve their symptoms, not to cause or hasten their death.[33]

However, writing in the *Journal of American Medicine*, Dr Erich Loewy explains there is no meaningful ethical distinction between the foreseeable outcome of terminal sedation and that of Voluntary Assisted Dying:

> At least in law, and I would reasonably hold the same true for ethics, one is responsible not only for what one has clearly intended, but also for what one could reasonably foresee. In terminal sedation, not only is the patient's death clearly foreseen, it is in fact the end point of what is being done. **Clearly (and however it may be cloaked by the use of language), the intent here is more than just the clear goal of relieving pain and suffering.**

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[32] Natasha Michael in Standing Committee on Legal and Social Issues, "Inquiry into end-of-life choices", Parliament of Victoria, Melbourne, 16 September, 2015, p.10 – https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/ELC_Transcripts/Cabrini_Health_Dr_Michael-End_of_life_choices_16_September_2015.pdf

[33] Ben White, Lindy Willmott and Penny Neller, "Palliative Medication: Palliative sedation - What is palliative sedation?", End of Life Law in Australia, Australian Centre for Health Law Research, Queensland University of Technology – https://end-of-life.qut.edu.au/palliative-care

> Because the goal of relieving pain and suffering adequately can be attained only by obtunding the patient until death ensues, the patient's death becomes the end point and, therefore, one of the intended goals.
>
> **These goals do not differ from those of physician assisted suicide or, for that matter, voluntary euthanasia.**
>
> The difference is maintained for two reasons. The first reason is to escape legal difficulties; the second is a form of self-delusion aimed at giving comfort to the physician and the medical team.[34] [Our emphasis]

2.4 Terminal sedation does not save a person from suffering

It is important to keep in mind that terminal sedation doesn't save a patient from suffering – it is a response to suffering that has already been happening and which can no longer be controlled.

The suffering may have lasted days, or weeks, or months before sedation is employed – and that decision is entirely up to the doctor and their own personal beliefs.

According to Australia's foremost pain specialist, Professor Michael Cousins:

> About 10 per cent of cancer patients had pain that was so difficult to treat at the end of their life that they would be given drugs to sedate them until they die.
>
> It could be several days, or as much as a week before a person dies.[35]

And terminal sedation is not always effectively applied, as Australia's most senior palliative care physician, Professor Ian Maddocks, explains:

> **In reality, there are occasions where patients in terminal palliation do not receive adequate relief for their pain and suffering;** in these cases, patients can frequently experience distressing respiratory problems; they may regain consciousness; intolerable pain may not be relieved; and they may experience a prolonged, uncertain, albeit inevitable death.[36]

This is clearly demonstrated in the death of young Melbourne woman, Cassie Godden.

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[34] Erich H Loewy MD, "Terminal Sedation, Self-Starvation, and Orchestrating the End of Life", JAMA Internal Medicine, 161(3), 2001, pp.329-332 – http://jamanetwork.com/journals/jamainternalmedicine/article-abstract/647177

[35] Michael Cousins, quoted in Julia Medew, "Pain follows many cancer patients to the end", *The Age*, 12 February, 2010 – https://www.theage.com.au/national/pain-follows-many-cancer-patients-to-the-end-20100211-nv43.html

[36] Ian Maddocks in "Syme v Medical Board of Australia (Review and Regulation) [2016] VCAT 2150", Victorian Civil and Administrative Tribunal Administrative Division, Review and Regulation List, VCAT Reference No. Z164/2016, 97(c), 21-23 November, 2016 (Hearing), 20 December, 2016 (Date of Order), p. 31, link to document file here (automatic download) - https://tinyurl.com/y88ac64f

CASE STUDY: CASSIE'S STORY

CASSIE GODDEN, 18, FROM GIPPSLAND VICTORIA, DIED OF METASTATIC CANCER. HER STORY IS TOLD BY HER PARENTS, BRETT AND DIANNE.[37]

SHE WAS IN EXCRUCIATING PAIN AND DISTRESS

Further tests showed the melanoma had moved into her bone marrow. Doctors said there was nothing else they could do and Cassie bravely made the decision to refuse any further treatment.

She knew she was going to die.

She asked for a week to say her goodbyes; doctors gave her four days, saying they could now only make her "comfortable".

What rubbish.

Cassie was on huge doses of painkillers and was outwardly unresponsive – but could still feel pain. She regained consciousness long enough to acknowledge she was being given painkillers and occasionally speak to us.

Cassie asked the nurses for "the biggest dose they could give".

> ***On the third morning, she begged the nurse: 'Please tell me this is going to kill me.'***

She was in excruciating pain and distress. She had said her goodbyes, and wanted to go. The distress extended not just to her family and boyfriend, but to the medical staff.

Cassandra passed four days after ceasing treatment. The question of how she wanted to end her life was never broached. It was illegal to help her to die, so the question was never asked.

But having watched her die, hearing her ask for the biggest painkilling dose, and beg "Please tell me this is going to kill me", we have no doubt Cassie would have welcomed the choice to make an end-of-life decision.

Whether she would have acted and ended her life earlier, we will never know. But if all palliative care can do is keep you in an induced coma until your body gives out, it is not enough.

Doctors could do nothing more for her. She had said her goodbyes, but could not ask to be allowed to die at the time of her choosing.

Cassie was intelligent, understood her illness, did all the doctors told her to, participated in medical trials, and submitted to radiation, CT scans, blood transfusions and excruciatingly painful biopsies.

She maintained full control of her mental faculties and was capable of making an informed decision that the time had come to die.

Cassie was an adult, allowed to drive, drink, vote and leave home. But despite excruciating pain, she was not allowed to decide the time of her death.

Why do so many think it is acceptable to force humans to linger in this way?

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[37] Dianne and Brett Godden, "Brett and Dianne Godden: Our lovely Cassie had no choice but to die in agony", *Herald Sun*, 17 October, 2017 https://www.heraldsun.com.au/news/opinion/brett-and-dianne-godden-our-lovely-cassie-had-no-choice-but-to-die-in-agony/news-story/24fa5ce9c44f8f12694e6c17069a9481

CASE STUDY: CASSIE'S STORY

Under Australian law, decisions about terminal sedation (when, or even if, it is employed) and the speed at which drugs are administered are entirely in the hands of the treating doctor. The patient has no right to insist.

The Western Australian Inquiry noted this lack of transparency:

> It is of concern to the committee that many patients at the end of life, and their family members, are unaware of this treatment. In this context, it is also concerning that there is a lack of recording and data collection...[38]

Cassie's painful death raises questions about how decisions are made to employ terminal sedation and, once they are, how effective it is:

- Why did doctors claim they could make Cassie "comfortable" when there was clear evidence that sedation wasn't working?
- Why was Cassie's clear request for enough painkillers to stop her suffering not acted on?
- Why, despite having been allowed to make decisions about all other medical treatments, was Cassie denied the right to decide about how much suffering she had to endure as she died?
- Why did Cassie's family, boyfriend, and carers have to witness her prolonged and excruciating death?

Cassie's experience is similar to those of other terminally ill people in Queensland.

In allowing a dying person to be drugged into a coma, Queensland has already accepted the reality that there is some suffering that can no longer be managed by palliative care.

Patients are just being told that only a doctor can decide for them when they have suffered enough.

3. QUEENSLAND'S END OF LIFE LAWS ARE INCOHERENT AND INEQUITABLE

In 2013, following a roundtable on assisted dying involving doctors, lawyers, politicians and ethicists, the Australia 21 Institute concluded that Australia's existing end-of-life laws are incoherent:

- Withdrawal or withholding of life-sustaining treatment that results in a person's death may be lawful, but the provision of a lethal dose intended to cause death is not;
- Terminal sedation may be lawful, but can also be unlawful depending on the doctor's intention when giving the medication;
- Suicide is legal, but assisting someone to commit suicide is illegal;
- There is a lack of clarity about what is meant by "assisting" someone to die;
- Even in a clear case where a person has "assisted" another to die, some individuals are prosecuted and jailed for providing that assistance, and others are not.

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[38] A Sanderson (MLA) and Hon. C J Holt (MLC), "Report 1 - My Life, My Choice: The Report of the Joint Select Committee on End of Life Choices: 4:72 'Terminal Sedation in Western Australia'", 40th Parliament, Parliament of Western Australia, August, 2018, p.129 – https://apo.org.au/sites/default/files/resource-files/2018/08/apo-nid188761-1227101.pdf

The Institute also found that existing laws have not only failed, but that they are unfair:

> **The Rule of Law requires that law must apply equally to all, but this is not the case in this field.** Whereas some may be able to end their own life, another person's disability may prevent them from doing so. [Our emphasis]
>
> Further, a person who is ill and relying on life-sustaining treatment to survive (such as a respirator) may lawfully ask for that equipment to be turned off. Another person who is equally ill, but suffering from a different condition which does not require such treatment, cannot be assisted to die.
>
> At present, there are some who can access voluntary euthanasia and assisted suicide despite it being unlawful. Those people are generally able to do so because they possess some privilege. It may be privilege in terms of education or it may be in relation to contacts and connections one has within the medical or veterinary professions.
>
> The operation of the law cannot be justified if a privileged few are able to receive assistance to die, but others are not.[39]

Queensland's current end-of-life laws do not provide sufficient protection from intractable suffering to people at the end of life.

Neither do they provide sufficient protection, or clarity, to doctors faced with such suffering.

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[39] Bob Douglas, Lindy Willmott and Ben White, "The right to choose an assisted death: Time for legislation?", Australia 21, Health Law Research Centre, Queensland University of Technology, January, 2013, p.19 – http://australia21.org.au/wp-content/uploads/2013/08/J2056-Assisted-Death-Report_WEB.pdf

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Go Gentle Australia

Part C

Beyond Pain

Why more resources for palliative care alone will not address the need for Voluntary Assisted Dying

WHAT THIS SECTION IS ABOUT

The number one argument the Queensland Inquiry will hear against Voluntary Assisted Dying is that 'there would be no need for it if only palliative care were properly resourced'.

Australia has one of the best palliative care systems in the world. However, claims it can help everyone are untrue. The words and statistics from palliative care tell us so. The many testimonies from medical professionals and families of those who have died badly tell us so, too.

Even so, representatives of palliative care – speaking, not just from a medical, but also from an undeclared moral perspective – continue to argue that VAD is unnecessary because palliative care has the answers for all.

1. THE PERSUASIVE MYTH: PALLIATIVE CARE HAS ALL THE ANSWERS

1.1 The Argument

Parliamentary records around Australia show that two arguments dominate equally the thinking of politicians who vote against Voluntary Assisted Dying:

1. They are not convinced such laws can be safe.
2. They are persuaded that the solution to people dying badly is giving more resources to palliative care.

The image of palliative care being the answer to all suffering is vigorously promoted by many palliative care doctors around Australia and frequently by their peak representative bodies.

But **the political case that, if properly resourced, palliative care is the answer for all end-of-life suffering is a myth. It is a myth retailed to politicians by senior doctors, many of whom have appeared before parliamentary inquiries representing faith-based organisations** and who believe that assisting a person to die is immoral in the eyes of God.

The professional authority of these doctors, as experts on the care of the dying, has been accepted by many politicians without any exploration of their personal moral agendas.

Here are recent examples of this myth being spread:

South Australia, 2016

On Tuesday, 16 November 2016, representatives of Palliative Care South Australia briefed MPs ahead of the next day's debate to legalise Voluntary Assisted Dying in that state.

According to Cathi Tucker, Manager for the Office of Kelly Vincent MLC who attended the meeting and took notes, a question came from Labor MP Jennifer Rankine:

> It has been put to me that some people can't be treated with palliative care. Families suffer enormously through the dying process.

The answer was:

> What we can't deal with is the existential distress. **From the symptom perspective – with palliative sedation as the fall back – we can control everything**. [Our emphasis]

The debate in the lower house the next day led to a tied vote, with the legislation being voted down by Speaker of the House and committed Christian, Michael Atkinson. The MP who dramatically crossed the floor at the last minute to tie the vote was then Attorney-General, John Rau. Rau had been in attendance at the previous day's briefing by Palliative Care South Australia. Speaking to *InDaily* after the vote, he gave as his reason:

> My concerns were basically about palliative care, and in the end **I'm not convinced that … there's a substantial group – or even a small group – of people who are not able to be adequately comforted by palliative care**.[40] [Our emphasis]

Victoria, 2017

On 17 October 2017, a group of senior physicians addressed MPs in Victoria's Parliament House ahead of debate due to start that afternoon to legalise Voluntary Assisted Dying.

No contemporaneous notes of that meeting exist, however a record of what was said can be found in Hansard, firstly from Liberal MHR, Murray Thompson, on 17 October:

> It was tweeted earlier today that there are some examples of pain and suffering that are not able to be properly addressed. I put that question to a number of speakers at lunchtime. There was a geriatrician, a palliative care expert, an emergency physician, a general physician, a couple of oncologists, a psychiatrist and a GP. I was directed to the answer that medication can meet the pain relief needs of some 96 per cent of patients and that for the four per cent where there are difficulties, there can be palliative sedation so that no-one ought suffer. No-one need suffer in confronting their final days of life.[41]

On 2 November, Liberal MLC, Bernie Finn, told the Legislative Council:

> I was greatly comforted by a professor of palliative care who said in this house just a couple of weeks ago that **palliative care can control all the pain and deliver relief until death inevitably knocks.**[42] [Our emphasis]

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[40] Tom Richardson, "Why did these MPs change their vote on voluntary euthanasia?", InDaily, Adelaide, 17 November, 2016 – https://indaily.com.au/news/local/2016/11/17/why-did-these-mps-change-their-vote-on-voluntary-euthanasia/

[41] Murray Thompson, "Voluntary Assisted Dying Bill 2017 - Opening Speech", Murray Thompson, State Member for Sandringham website, 17 October, 2017 – http://www.murraythompson.com.au/news/article/voluntary_assisted_dying_bill_2017_opening_speech

[42] Bernie Finn, "Voluntary Assisted Dying Bill 2017", Council, second reading, Hansard, Parliament of Victoria, 2 November, 2017, p. 5602 – https://www.parliament.vic.gov.au/images/stories/daily-hansard/Council_2017/Council_Daily_Extract_Thursday_2_November_2017_from_Book_18.pdf

In The Media

On 18 October, Dr Stephen Parnis, formerly federal vice-president of the AMA, who was present at the briefing of MPs the previous day, stated the following to Sarah McVeigh on Triple J's "Hack Live":

> Parnis: And, when palliative care is done properly – and I've seen it, I've delivered it – **the causes of suffering go away,** and ...
>
> Sarah McVeigh: But, isn't it also true that, for some people, they don't?
>
> Parnis: Ah – maybe a tiny proportion. I have to say that the proponents of this law absolutely exaggerate the numbers. And when palliative care is delivered properly, **those sorts of horror deaths that some of the groups try and paint out, need never occur.** [43] [Our emphasis]

1.2 The Reality: Those Beyond the Help of Palliative Care

Australia's palliative care is well regarded by international standards, and we have heard many accounts of people receiving good palliative care that has eased pain and suffering.

However, we know that not all patients' suffering can be relieved by palliative care from five authoritative sources:

- Palliative Care Australia
- Doctors surveyed by the AMA
- Parliamentary inquiries conducted in Victoria and WA
- Multiple testimonies from families, carers, coroners, and first responders testifying to extreme suffering as people die despite the best efforts of palliative care
- Multiple testimonies from doctors and nurses, in particular palliative care doctors.

1.2.1 Palliative Care Australia

These are their words, published in the Policy Statement on Voluntary Euthanasia in 2006:

> While pain and other symptoms can be helped, **complete relief of suffering is not always possible, even with optimal palliative care.**[44] [Our emphasis]

The Palliative Care Outcomes Collaboration (PCOC) collates data from over 100 palliative care services throughout Australia to produce detailed analyses and benchmarking of patient outcomes.

PCOC's latest report, covering the period January to June 2018, analyses the palliative care experiences of 22,452 patients nationally.[45]

Patients are assessed over various phases of their illness, including the terminal phase. Patients' levels of distress are measured in relation to various categories of suffering that include, but are not limited to, 'pain'.

The 2018 report tells us that about two per cent of patients in the terminal phase suffer severe distress from pain.

It's crucial to appreciate that this single symptom – pain – is only one part of suffering that dying patients may experience. In the six months to June 2018, for example, 2.5 per cent of patients, 579 nationally, suffered severe distress from breathing difficulties during their terminal phase.

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[44] Stephen Parnis on "Hack Live" with Sarah McVeigh, Triple J, 5.30pm, 18 October, 2017 – recording provided to Go Gentle Australia by the Australian Broadcasting Commission and transcribed by us.

[45] Australian Institute of Health and Welfare, Australia's health 2016, Australia's health series no. 15, Cat. no. AUS 199, Canberra: AIHW, 2016, p. 3.

[46] Palliative Care Australia, "Policy statement on voluntary euthanasia", Canberra, 2006, p.2. Quoted by: Neil Francis, "AMA uncovered: How its own review exposed its assisted dying policy as indefensible", Dying for Choice, 27 March, 2017, p.20 – http://www.dyingforchoice.com/docs/AMAuncoveredFullReport27Mar2017.pdf

1.2.2 Doctors Surveyed by the AMA

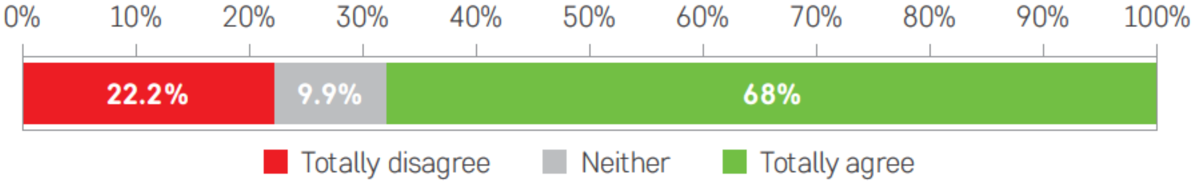
There is broad consensus within the medical community that palliative care, even when properly delivered, cannot always – as Dr Parnis claimed – make "the causes of suffering go away".[47]

In 2016, when the Australian Medical Association (AMA) asked its members:

> To what extent do you agree with the following statement? 'Palliative care and medical treatment cannot adequately alleviate the suffering of some patients'.

Nearly 70 per cent of respondents agreed that palliative care cannot adequately alleviate the suffering of some patients.[48]

Figure 3: Australian Medical Association Member Consultation Report – Palliative Care



1.2.3 Parliamentary Inquiries

A key finding of the Victorian Parliamentary Inquiry in 2016 was that there are:

> ... many benefits of palliative care, an area of medicine which has advanced significantly over the last decade. However, palliative care does have limitations, as described by Palliative Care Victoria, who explained that palliative care can sometimes be ineffective at relieving all suffering.[49]

The Western Australian Inquiry in 2017/18 came to a similar conclusion:

> Too many Western Australians are experiencing profound suffering as they die. This is, in part, due to inequitable access to palliative care. However, **it is clear from the evidence that even with access to the best quality palliative care, not all suffering can be alleviated. Palliative care physicians themselves acknowledge this.**[50] [Our emphasis]

Both inquiries accepted that some palliative care patients are beyond meaningful help from palliative care.

The Western Australian inquiry referred to "somewhere in the range of 2–5 per cent" of patients for whom palliative care was ineffective in relieving their symptoms as being consistent with the evidence, and also referred to "evidence from some health professionals that the figure may be even higher, perhaps as high as 30 per cent". [51]

These are the people for whom we argue Voluntary Assisted Dying is most needed.

1.2.4 Multiple testimonies from families, carers, coroners, and first responders testifying to extreme suffering as people die despite the best efforts of palliative care

These are many, and their stories are harrowing. In APPENDIX – 'When Palliative Care No Longer Works' – more than 100 examples of the limitations of palliative care are gathered from around Australia. Here is just one:

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[47] Stephen Parnis on "Hack Live" with Sarah McVeigh, Triple J, 5.30pm, 18 October, 2017 - recording provided to Go Gentle Australia by the Australian Broadcasting Commission and transcribed by us.

[48] Australian Medical Association, "Review of AMA Policy on Euthanasia and Physician Assisted Suicide - Member Consultation Report", 2016.

[49] Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report: 'Chapter 3 - Towards a Community Based Approach to Palliative Care'", June, 2017, p.51 – https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/EOL_Report/LSIC_58-05_Text_WEB.pdf

[50] A Sanderson (MLA) and Hon. C J Holt (MLC), "Report 1 - My Life, My Choice: The Report of the Joint Select Committee on End of Life Choices: 'Chair's Forward'", 40th Parliament, Parliament of Western Australia, August, 2018 – https://apo.org.au/sites/default/files/resource-files/2018/08/apo-nid188761-1227101.pdf

[51] A Sanderson (MLA) and Hon. C J Holt (MLC), "Report 1 - My Life, My Choice: The Report of the Joint Select Committee on End of Life Choices: '3.155: Limitations of Palliative Care", 40th Parliament, Parliament of Western Australia, August, 2018, p.92 – https://apo.org.au/sites/default/files/resource-files/2018/08/apo-nid188761-1227101.pdf

CASE STUDY: BARRY'S STORY

BARRY JOHN LANGBECKER, 74, FROM GYMPIE, QUEENSLAND, DIED FROM PARKINSON'S AND OESOPHAGEAL CANCER. HIS STORY IS TOLD BY HIS DAUGHTER, DENISE KAPERNICK.[52]

HE DID NOT PASS AWAY PEACEFULLY LIKE THE MOVIES PORTRAY

Due to the staph, he was not a suitable candidate for chemotherapy and the idea of operating was also eliminated as it was a major operation that would involve cracking his chest open and removing a considerable amount of the oesophagus and stomach, which would have been too much for his already unfit condition.

It was decided that he would instead undergo a course of radium to try to shrink the tumour enough so he could swallow (and keep) his food down, which he was now unable to do.

Unfortunately, this treatment did not reduce the tumour, so he continued to lose weight and strength until he eventually was unable to even swallow his own spit.

At this stage Dad knew his time was limited so, in an attempt to hasten his death, he stopped taking his staph medication in the hope the infection would return and end his time on earth quickly and painlessly.

... at 2am the next morning he suffered a catastrophic stroke, paralysing him completely down his left side, weakening his right side and leaving him totally bedridden.

He was unable to do anything for himself and was reliant on the nursing staff, my sister and me to feed him, wipe his face, clean him, roll him over, massage his legs and wipe away his tears.

As the weeks passed, his pain increased as the fluid built in his limbs and the morphine was not enough. The Parkinson's was also a factor for his pain as his muscles seized and spasmed.

> ***"The doctors tried fentanyl patches, increased his morphine doses and eventually commenced a morphine driver but his pain was still unbearable."***

He stopped asking the nurses to hoist him into a chair so he could be wheeled outside as the slightest movement would bring him to tears, even when we tried to trim his fingernails.

He put up an incredible fight against the staph, Parkinson's and the cancer, but the stroke robbed him of any quality of life and it was only at this time that he had no fight left and no desire to 'live' another day.

Dad lived seven weeks and three days after the stroke and this whole time he suffered, both mentally and physically. He did not pass away peacefully like the movies portray though. He drowned in his own phlegm and the noise of this is something I can never describe. His eyes were rolled back in their sockets and he was groaning and gurgling and his breaths were laboured, shallow and frantic.

My sister and I cried at his side, hoping that each breath was his last, but, as the hours passed, he continued his struggle for air until his body finally gave up and went silent.

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[51] Andrew Denton and Glenda Downing (editor), *The Damage Done*, Go Gentle Australia, 2016, p.36 Free download available here – https://www.gogentleaustralia.org.au/shop

CASE STUDY: BARRY'S STORY

- Why was Barry forced to struggle on for more than seven weeks, with intolerable suffering and pain?
- Why were there no alternative end-of-life options available to Barry other than stopping his medication in the hope that a staph infection would take him?
- Even though the 'slightest movement would bring him to tears', why was he offered nothing further once fentanyl patches, increased morphine doses and a morphine driver failed to manage his pain?

Barry's terrifying ordeal – and the distress experienced by his family – border on mistreatment and abuse.

For an insight into the realities of how some people die within Australian palliative care, here are hyperlinks to three episodes from the podcast "Better Off Dead".[53]

> Episode 10: Neither Hasten nor Prolong Death. Palliative Care in Australia Pt. 1
>
> Episode 11: Whose Life is it Anyway? Palliative Care in Australia Pt. 2
>
> Episode 12: Velvet Ray

These episodes feature the voices of palliative care doctors and nurses, as well as of families recounting the deaths of loved ones. Transcripts can be read at Go Gentle Australia's website.

1.2.5 Multiple testimonies from doctors and nurses

Some of Australia's most senior palliative care physicians have publicly acknowledged the limitations of palliative care. These include:

Clive Deverall, former president of Palliative Care WA

In an interview with ABC TV months before his death, Clive revealed that palliative care was not the answer for between four and eight per cent of patients:

> Certainly, I still embrace what palliative care stands for, but even with their clinical guidelines, they avoid the elephant in the room which is the very end-stage patients where symptoms cannot be controlled.
>
> Patients in that distressed state, those patients should be offered voluntary euthanasia.
>
> The take home message is that we have a cruel law at the moment that is prejudicial to the interests and wishes of patients, that needs to be changed.[54]

In notes found after his death, he wrote:

> I have attended so many palliative care meetings where problems have been discussed in context of the experience of individual terminally ill patients. The term 'palliative care nightmare' was used frequently when despite all the best efforts – clinically and despite access to all the drugs, the patient's developing symptoms of pain, nausea, panic and

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[53] Andrew Denton, "Better Off Dead" podcast, Thought Fox and the Wheeler Centre, published online by the Wheeler Centre, 2015-2016 (audio) – https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead?show_all=true
Transcripts available at Go Gentle Australia website – http://www.gogentleaustralia.org.au/transcripts2

[54] Claire Moodie, "'With his death he made a statement': Clive Deverall's widow speaks out on euthanasia", news report and video, ABC News, 20 September, 2017 (see quoted content in video at 4:00) – https://www.abc.net.au/news/2017-09-19/clive-deveralls-widow-speaks-out-on-euthanasia/8882854

> breathlessness as well as emotional distress could not be controlled. So called 'nightmare scenarios' became an item for discussion at some professional meetings and conferences. (Palliative Care Australia has recently acknowledged these scenarios.)
>
> Palliative care has been used as a mantra by politicians on all sides and health professionals to oppose euthanasia or to avoid having it debated.

Even if good, modern palliative care was available for each and every terminally ill patient – we would still have the 'nightmares'.[55]

Dr Roger Hunt, palliative medicine specialist and a life member of the Palliative Care Council of South Australia

Dr Hunt believes that, while palliative care is, without exception, helpful to dying patients:

> it is fanciful and misleading to claim that all suffering can be eliminated.

Dr Hunt reiterates that physical pain is not the only concern for terminal patients:

> ... all surveys of patients receiving palliative care show they have multiple concurrent symptoms and other forms of suffering.

He also reminds us that treatments for pain often compound the patient's misery because of their adverse effects. Pain management is complex and highly subjective and Dr Hunt points to the difficulty of defining a "simplistic" cut-off point at which "palliative care cannot help".

However, he notes that:

> Refractory symptoms* that are severe enough to require continuous sedation occur frequently. Depending on the clinicians and patient populations, 5% to 50% of palliative care patients can have continuous sedation prior to death.
>
> **Symptoms 'that cannot be adequately controlled despite aggressive efforts to identify a tolerable therapy that does not compromise consciousness'.*[56]

He concludes:

> The proportion of patients of palliative services who persistently request a hastened demise is 5% to 10% ... That is: 5% to 10% of patients who receive palliative care will experience suffering to the extent they will request VAD. The reasons are similar to those documented for people who access VAD in Oregon and the Netherlands (most of whom also receive palliative care).[57]

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[55] Noreen Fynn, "Submission to the Joint Select Committee on End of Life Choices (Western Australia)", 17 October, 2017 – http://www.parliament.wa.gov.au/parliament/commit.nsf/(Evidence+Lookup+by+Com+ID)/30D73154F4D00AFF48258219000B3C84/$file/20171017+-+EOLC+-+Sub+347+-+Ms+Noreen+Fynn.pdf
Noreen Fynn is the widow of Clive Deverall

[56] NI Cherny and RK Portenoy, "Sedation in the management of refractory symptoms: guidelines for evaluation and treatment", Journal of Palliative Care, 10(2), pp.31–8, 1994 – https://www.ncbi.nlm.nih.gov/pubmed/8089815

[57] Roger Hunt, "Re P.C. Figures", Email to Andrew Denton, Go Gentle Australia, 23 July, 2017.

Professor Michael Ashby, formerly Professor of Palliative Medicine at Monash University, now Director of Palliative Care, Tasmanian Health Service

In his affidavit in support of Lecretia Seales[58], a New Zealand woman dying of brain cancer who took her Government to court in 2015 seeking the right to legally end her own life, Ashby wrote:

> **Palliative care is unable to relieve suffering in all circumstances for all people.** Skilled palliative care can nearly always make a difference for the better but can be challenged by symptoms such as refractory cancer pain, fatigue, loss of function and independence, and by 'existential' suffering.
>
> ... Other physical symptoms that are addressed by palliative care with varying degrees of acceptable outcome for patients include mobility issues, agitation, breathlessness, incontinence and choking episodes.
>
> ... Many mentally competent end-of-life patients experience high levels of psychological and emotional suffering. As noted, palliative care takes a holistic approach. Palliative care teams tend to include social workers, psychologists, nurses and social care workers.
> [Our emphasis]

> ***While they do an admirable job, in my experience it is with psychological and emotional suffering that palliative care teams have to acknowledge significant limitations.***[59]

A number of testimonies from doctors attesting to the limitations of palliative care can also be found in APPENDIX: 'When Palliative Care No Longer Works'. Here is just one:

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[58] John Weekes and Jared Savage, "She never planned to be poster girl for right-to-die: Lecretia Seales dies hours after family received judge's decision", *NZ Herald*, 5 June, 2015 – https://www.nzherald.co.nz/social-issues/news/article.cfm?c_id=87&objectid=11460184

[59] Michael Ashby, "Affidavit of Michael Ashby", Lecretia Sales v Attorney-General, High Court of New Zealand, Wellington Registry, 23 April, 2015, reference CIV-2015-485-235, points 13, 19 and 20 – http://lecretia.org/wp-content/uploads/2015/10/redacted_affidavit_of_michael_ashby.pdf

CASE STUDY: DR X'S STORY

DR X'S MOTHER DIED FROM STOMACH CANCER. THE DOCTOR ALSO RECOUNTS THE EXPERIENCE OF A WOMAN WITH VULVAL CANCER.[60]

FIFTEEN YEARS ON, HER SUFFERING STILL MAKES ME SICK

I have witnessed the illness, suffering and deaths of many patients over the years.

Many deaths have been well managed with palliative care but there is a misconception that modern palliative care can alleviate most suffering and allow a dignified and reasonably comfortable death in nearly all cases.

This is simply not so.

The vision of a dying patient on a morphine drip surrounded by family and slipping away peacefully is not the reality in a significant proportion of patients.

Patients can suffer both physically, psychologically and existentially for weeks or months and can die in great suffering, often alone in the middle of the night and often in confusion, fear and distress gasping for breath or choking on their own fluids.

In my mother's case of linitis plastica (a form of stomach cancer), she had absolutely intractable and intolerable nausea and could not eat, and this was not adequately palliated despite maximum involvement of palliative care services.

It was dreadful to see her suffer without adequate relief. She asked me several times to be put out of her misery but she had to endure it to the end.

I can recall several other patients who were unable to be adequately palliated. In particular, I vividly recall one unfortunate young woman. She was dying of advanced vulval cancer and had the most awful ulceration with severe pain at the slightest movement or touch and offensive discharge, bleeding and odour.

Fifteen years on her suffering still makes me feel sick.

> ***Nothing except death gave her release and death did not come peacefully despite morphine and palliative care.***

Patients dying of advanced motor neurone disease are also faced with unbearable suffering, witnessing in full alertness a body that is paralysed and fearing choking to death as they lose every last vestige of independence and dignity.

For some this is intolerable, yet our society demands that they endure the full course of their illness no matter what their wishes.

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[51] Andrew Denton and Glenda Downing (editor), *The Damage Done*, Go Gentle Australia, 2016, p.126, Free download available here – https://www.gogentleaustralia.org.au/shop

CASE STUDY: DR X'S STORY

- Why was Dr X's mother's intolerable nausea not adequately palliated despite intensive palliative care?
- Why was Dr X put in a position where he could not act on his own mother's request to be 'put out of her misery'?
- Why was the woman with vulval cancer left to suffer in palliative care while enduring maximum indignity and excruciating pain?

The treatment enforced on these two women borders on mistreatment and abuse.

Please note the following stories from medical professionals in APPENDIX: 'When Palliative Care No Longer Works':

Dr Michael Cameron, p.136
Dr Geoff Wall, p.137
Dr Geoff Tresize, p.137
Nurse Coral Levett, p.138
Nurse Flora Metcalf, p.138
Dr X, p.138
Dr Alida Lancée, p.139
Dr Cheryl Wilson, p.139
Heather Bell (medical student), p.143
Nurse Kelly Somerville, p.145
Nurse Anne Korner, p.145
Nurse Carmel Hurst, p.146
Nurse Norma Kelly, p.149

2. THE ELEPHANT IN THE ROOM: WHEN RELIGION, ETHICS AND MEDICINE COLLIDE

> ***Even when suffering and death cannot be eliminated, they can nonetheless acquire a positive, life-giving and redemptive value, especially from the perspective of religious faith.***
>
> Catholic Health Australia's *Code of Ethical Standards for Catholic Health and Aged Care Services in Australia, 2008* [61]

2.1 Doctor as God – Doctor for God

Under Australian law, decisions about terminal sedation – when and how quickly it is administered – are entirely in the hands of the treating doctor.

Professor Lindy Willmott from the Faculty of Law at QUT, explains:

> ... the use of terminal sedation falls within the discretion of the individual doctor based on what he or she regards as good medical practice ... there is no law in Australia that specifically defines or specifically regulates 'terminal sedation'.[62]

Emeritus Professor Sheila McLean noted in the *QUT Law Review*:

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[61] Catholic Health and Aged Care Services, "Ethical Standards for Catholic Health and Aged Care", published by St Vincent's & Holy Spirit Health, 2008, point vii – https://tinyurl.com/y4v45cbe (cached version)
PDF download available here – https://tinyurl.com/y2jyl5t4

[62] Lindy Willmott, 'Question re Victorian Law on Palliative Sedation', Email to Andrew Denton, Go Gentle Australia, 24 July, 2017.

> it is possible to conclude … that **while terminal sedation decisions should be about the needs of the patient, all too often they depend to a large extent on the preferences of the patients' physicians.**[63]

Equally, the Doctrine of Double Effect is based solely on the doctor's intention. A doctor can provide pain relief which *may* result in the patient's death as long as death is not their *intention*.

In other words, with the exception of a dying person's legal right to refuse treatment, food, and water (or to commit suicide), all their end-of-life treatment options are based on what a doctor thinks is right.

But what of the doctor's intention?

What if the doctor believes that it is not moral to hasten somebody's death? Or that suffering has redemptive value? Or that your cancer can be 'good for you'? All of these things have been expressed by some palliative care physicians working in Australia.

In that situation, a dying patient may be faced with little option but to endure a death they do not want – a slow death – regardless of how clear and persistent their request for a quick one may be. (Palliative Care Australia acknowledges there are patients who make rational and persistent requests for help to die.)[64]

Our experiences in advocating for Voluntary Assisted Dying and improved palliative care have led us to believe that on too many occasions decisions are made within palliative care which are in accordance with the religious beliefs of the treating doctor or institution and not in accordance with the choices of the person who is dying or their family.

2.2 Care of the Dying: What the Vatican Instructs

Many of the accounts we have heard, including through the Victorian and Western Australian Inquiries, or which have come directly to us, relate to Catholic hospitals, hospices, doctors and nurses.

Catholic health and aged-care services form the largest non-government grouping of health and aged-care services.[65] However, the accounts are not limited to Catholic providers.

Palliative care has strongly Christian roots. The modern hospice movement was started in England by the Anglican nun Dame Cicely Saunders. Watching her husband dying of cancer, she observed that "as the body becomes weaker, so the spirit becomes stronger". Seeing no special place in the medical system for the dying – and realising that they needed care beyond the purely medical, including social, spiritual, and psychological care – she established the world's first purpose-built hospice, St Christopher's, in 1967.

In 1985, Pope John Paul II founded the Pontifical Council for Pastoral Assistance to Health Care Workers. Said to be inspired by faith and hope, he intended to offer a response to the challenges arising in the world of health care. In 1995, the first president of the dicastery, the late Fiorenzo Cardinal Angelini, published the *Charter for Health Care Workers*, translated into nineteen languages.[66]

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[63] Sheila A. M., McLean, "Terminal Sedation - Good Medicine?, Good Ethics? Good Law?", QUT Law Review, Volume 16, Issue 1, 2016, pp. 113-134 – http://www.austlii.edu.au/au/journals/QUTLawRw/2016/7.html

[64] Palliative Care Australia, "Position Statement on Euthanasia", March, 1999, states that PCA "Recognises and respects the fact that some people rationally and consistently request deliberate ending of life."Quote recorded by Dr Rodney Syme, South Australia Voluntary Euthanasia, "Euthanasia Fact Sheet", The VE Bulletin, Vol 16, No 3, November, 1999, South Australia, reproduced online by The World Federation of Right to Die Societies – https://www.worldrtd.net/euthanasia-fact-sheet-0

[65] Joint Select Committee on End of Life Choices, "Inquiry into the need for laws in Western Australia to allow citizens to make informed decisions regarding their own end of life choices", Transcript of Evidence, Parliament of Western Australia, Perth, 28 February, 2018, p.1 – http://www.parliament.wa.gov.au/Parliament/commit.nsf/(Evidence+Lookup+by+Com+ID)/1512F5C7DCBAD165482582440029A273/$file/180228+-+TS+-+Catholic+Health+Aust+St+John+of+God+Health+Care++Catholic+Homes+WA+-+FINAL.pdf

[66] The Pontifical Council for Pastoral Assistance to Health Care Workers, "The Charter for Health Care Workers", Vatican City, 1995 – http://www.vatican.va/roman_curia/pontifical_councils/hlthwork/documents/rc_pc_hlthwork_doc_19950101_charter_en.html

According to the *Charter for Health Care Workers* [67], released by the Vatican in English in 1995:

- The Church ... has always seen medicine as an important support for its own redeeming mission to humanity. [para 5]
- It follows that the work of health care workers is a sharing in the pastoral and evangelizing work of the Church. [para 5]
- **Borne 'in close union with the sufferings of Jesus', sickness and suffering assume 'an extraordinary spiritual fruitfulness'.** [para 54] [Our emphasis]
- For the Christian, pain has a lofty penitential and salvific meaning. [para 69]
- To help one to die means to help him to live intensely the final experience of his life. [para 116]
- The pleas of gravely ill persons who sometimes ask for death are not to be understood as implying a true desire for euthanasia; in fact, it is almost always a case of an anguished plea for help and love. [para 149]
- Death, then, must be evangelized: The Gospel must be announced to the dying person. [para 131]

In relation to pain relief for the dying, the Charter endorses medical assistance to alleviate pain, including palliative or symptomatic treatment but instructs that:

> **The most important assistance is 'loving presence' at the bedside of the dying person.** There is a proper medical-health presence which, though not deceiving him, makes him feel alive, a person among persons, because he is receiving, like every being in need, attention and care. This caring attention gives confidence and hope to the patient and makes him reconciled to death. **This is the unique contribution which doctors and nurses, by their being human and Christian – more than by their expertise – can and should make to the dying person,** so that rejection becomes acceptance and anguish gives way to hope. [para 117] [Our emphasis]

The point for doctors and nurses is to make faith and hope present and to apply one's skills in order to "make going to God easy for the patient". [para 118]

The Charter includes more detailed instruction on the use of painkillers for the terminally ill. It allows for their use, reasoning that:

> Human and Christian prudence suggests the use for most patients of medicines which alleviate or suppress pain, even if this causes torpor or reduced lucidity. With regard to those who are unable to express their wishes, one can reasonably suppose that they wish to take painkillers and these can be administered according to medical advice. [para 122]

However, it then refers to two problems with the use of painkillers for the dying. The first problem essentially describes the Doctrine of Double Effect, which is very well recognised in the Catholic moral tradition.[68] However, the Charter requires that there be "proportionate reasons" before it is permitted to use narcotics to alleviate suffering even though they hasten death [para 123].

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[66] The Pontifical Council for Pastoral Assistance to Health Care Workers, "The Charter for Health Care Workers", Vatican City, 1995 – http://www.vatican.va/roman_curia/pontifical_councils/hlthwork/documents/rc_pc_hlthwork_doc_19950101_charter_en.html

[67] The Pontifical Council for Pastoral Assistance to Health Care Workers, "The Charter for Health Care Workers", Vatican City, 1995 – http://www.vatican.va/roman_curia/pontifical_councils/hlthwork/documents/rc_pc_hlthwork_doc_19950101_charter_en.html

[68] Joint Select Committee on End of Life Choices, "Inquiry into the need for laws in Western Australia to allow citizens to make informed decisions regarding their own end of life choices', Transcript of Evidence, Parliament of Western Australia, Perth, 8 March, 2018, p.2 – http://www.parliament.wa.gov.au/Parliament/commit.nsf/(Evidence+Lookup+by+Com+ID)/0F66BD7CDFA1A0DB48258256000D0E6E/$file/180308+-+TS+-+Archbishop+&+LJ+Goody+Centre+-+FINAL.pdf
Specifically, the Archbishop says: "In the Catholic moral tradition ... taking whatever measures are available to us to relieve pain even if it means shortening a person's life – is both a justified and even a recommended action in the Catholic tradition."

The second problem the Charter[70] identifies is terminal sedation:

> There is also the possibility that painkillers will cause unconsciousness in the dying person. This use must receive special consideration.
>
> Without serious reasons, the dying person must not be deprived of consciousness. Sometimes the systematic use of narcotics which reduce the consciousness of the patient is a cloak for the frequently unconscious wish of the health care worker to discontinue relating to the dying person.
>
> In this case it is not so much the alleviation of the patient's suffering that is sought as the convenience of those in attendance. The dying person is deprived of the possibility of "living his own life", by reducing him to a state of unconsciousness unworthy of a human being. **This is why the administration of narcotics for the sole purpose of depriving the dying person of a conscious end is "a truly deplorable practice".**
>
> It is a different matter when there is a serious clinical case for the administration of analgesics which suppress consciousness, as **when there is violent and unbearable pain. In this case the anesthetic is said to be licit, provided certain conditions are fulfilled: that the dying person has fulfilled or could still fulfill his moral, family and religious obligations.** [paragraph 124] [Our emphasis]

The Charter instructs that it is legitimate for health professionals to refuse futile treatment, but that the "right to die in total serenity, with human and Christian dignity ... cannot be interpreted as the power to kill oneself or to give this power to others" [para 119].

Voluntary starvation is addressed as follows:

> The administration of food and liquids, even artificially, is part of the normal treatment always due to the patient **when this is not burdensome for him: their undue suspension could be real and properly so-called euthanasia.** [para 120] [Our emphasis]

An updated *New Charter for Health Care Workers*[70] was adopted in 2016 and published in English in 2018. The provisions in relation to dying are substantially the same as the original charter.

While the provisions outlined above suggest that the Charter does not prohibit sedation, including terminal sedation, or the acceptance of a person's decision to starve to death, it cautions against them in terms that empower the (Catholic) health care worker to make the decision, without any real regard for the wishes of the dying person or their family or carers.

Everything is assessed through the prism of the health care worker and their faith, and not through the wishes of the dying person. It applies without regard to whether the dying person is religious or not, and if they are, whether they are Catholic or of another faith.

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[69] The Pontifical Council for Pastoral Assistance to Health Care Workers, "The Charter for Health Care Workers", Vatican City, 1995 – http://www.vatican.va/roman_curia/pontifical_councils/hlthwork/documents/rc_pc_hlthwork_doc_19950101_charter_en.html

[70] Pontifical Council for Pastoral Assistance for Health Care Workers, New Charter for Health Care Workers, The National Catholic Bioethics Center, August, 2018 – http://www.fiamc.org/uncategorized/the-new-charter-for-health-care-workers-on-line/

CASE STUDY: RUDI'S STORY

RUDI DOBRON, 67, DIED IN A CATHOLIC HOSPICE IN MELBOURNE FROM CANCER OF THE THROAT. HIS STORY IS RECOUNTED BY JULIA MEDEW, HEALTH EDITOR FOR *THE AGE*.[71]

THE BARBARIC RELIGIOUS RITUAL OF DYING WITHOUT DIGNITY

As death crept closer for Dobron and he was admitted to [the] hospice, he gave staff an advance directive that documented his desire to die as quickly as possible.

The directive said he did not want to be artificially fed, nor did he want to be resuscitated ... He felt his quality of life had already deteriorated beyond repair. All he wanted was to slip quietly away.

[Rudi's partner, Bev] McIntyre remembers the directive being noted by a doctor.

But within days, Dobron's struggle to swallow meant he was offered artificial feeding through his stomach. He declined.

"Rudi felt that if he took any sustenance, his life would be prolonged, so he said no.

"He didn't want anything that would do that, particularly if it involved another operation, so the only option was to starve and dehydrate himself to death," McIntyre says.

Dobron made it clear to staff that he did not want any food or fluids, but McIntyre says the offers kept coming.

"I don't know whether the doctor had a duty to keep asking every day or not, but it annoyed Rudi.

"The girl who came around with the menus would come in every day, too. She just kept coming, even though Rudi was saying no."

As Dobron started to lose control of his bowels and was battling headaches in his second week, he told staff he wanted to be sedated.

His medical record states that on his 11th day in the hospice, he just wanted to be unaware.

The intervention was discussed but was not forthcoming. Soon after, Dobron's frustration with his situation peaked and he put pen to paper.

In a note handed to McIntyre, he wrote:

> ***I am dying of cancer of the throat. I can no longer control my bowels, nor eat or drink.***
>
> ***If I was a pet, I would have had a peaceful injection days ago.***
>
> ***But I am human and so I will have to go through the barbaric religious ritual of dying without dignity from dehydration over weeks.***

"Incidentally, I am an organ donor. By the end of this type of death, my kidneys and other now healthy organs will be dead. Can't eat or drink anything. Been still losing fluid for five days now getting increased dosage of morphine and other stuff."

"Rudi had reached the stage of not being able to swallow his own saliva, so he had to keep spitting.

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[71] Julia Medew, "A wish before dying", *The Sydney Morning Herald*, 24 September, 2010 – https://www.smh.com.au/national/a-wish-before-dying-20100924-15qo9.html

He would rinse out his mouth with soda water to eliminate what must have been intense dryness," McIntyre says.

Around this time, a staff member wrote in Dobron's file that he felt as if he was choking and he had a scared look in his eyes that they had not seen before.

Dobron was slowly deteriorating.

Over the next two weeks, he became progressively more dehydrated, with headaches, nausea, shortness of breath and a pressure sore.

He was embarrassed to be wearing a nappy for incontinence and had terrifying hallucinations.

His doctors say they responded to these symptoms in a way that allowed Dobron to stay alert and interactive, which they believe he wanted at the time.

But McIntyre says his physical and psychological suffering was not relieved the way she thought it would be.

*"All this time, the medics said he was not in pain and that he was comfortable, but I don't think that was the case. One day I was told he was peaceful, only to walk into his room and find him trying to get out of bed. He was very agitated at times, pulling off his bedclothes and writhing about his hallucinations. It was very hard to watch,"
she says.*

On Dobron's 27th day in the hospice, his file says he was fed up and anguished. His doctors increased the sedation he was receiving, but it was a week before he was unresponsive and another week before he died

He had been in the hospice for 47 days.

CASE STUDY: RUDI'S STORY

Rudi's medical records, obtained through Freedom of Information, are detailed in the book *A Time to Die* (2017) by Dr Rodney Syme.[72] They show that, despite exhibiting ongoing symptoms of physical, psychological and existential suffering, he did not receive 24-hour sedation until 32 days after he entered hospital. He eventually died a further 15 days later.

Speaking with Andrew Denton in 2019, Rudi's partner Bev McIntyre recounted what the experience was like for her:

> They knew from the very beginning that he didn't ... want to have a prolonged death.
>
> I can remember going home the last night before ... he died and ... I thought I just can't cope with going in here anymore you know. I felt I had reached the end of my tether. It was awful ... watching a person deteriorate and what they're going through ... the agitation and ... you know one time we went in there and he was taking off all his clothes. It wasn't a hot day. And he was just in a nappy you know and he'd lost control of bowel and bladder. That would be the height of indignity for Rudi. I spoke to Dr xxxx afterwards about that and he said 'religion didn't enter in to my decisions about Rudi's treatment'. They just say that they gave him the best treatment and they're still saying that.
>
> Andrew Denton: And how do you react to that?
>
> Bev McIntyre: Well it's bullshit. I mean ... the feeling is that I would never want to go in to a Catholic place if it was me ... I would never want anyone else to go in to a Catholic place.[73]

- Why was Rudi's advanced care directive, which stated his desire to die as quickly as possible, not adhered to?
- Why, having also made clear that he did not want to be artificially fed, was Rudi offered a feeding tube?
- Why was Rudi, having invoked his legal right to refuse food and water, offered food daily?
- Why, despite persistent symptoms of Rudi's suffering observed by hospital staff – difficulty swallowing, dehydration, incontinence, headaches, nausea, shortness of breath, pressure sores, hallucinations, fear in his eyes – did his doctors say that he was not in pain and that he was comfortable?
- Why, despite weeks of observable suffering, did it take 32 days for Rudi to receive 24-hour sedation?
- Why does the hospital continue to respond to Bev McIntyre's complaints about Rudi's death by saying they gave him the 'best of treatment'?

The treatment enforced on Rudi Dobron borders on mistreatment and abuse.

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[72] Rodney Syme, Time to Die, Melbourne University Press, 2017, Chapter 1 'Is this the best we can do?'.

[73] Bev McIntyre, Interview with Andrew Denton for Go Gentle Australia. Audio available on request.

2.3 Catholic Health Australia: 'The Mystery of Suffering and Death'

Catholic Health Australia's *Code of Ethical Standards for Catholic Health and Aged Care Services in Australia*, in relation to 'Solidarity and the mystery of suffering and death', among other things, states:

> Illness, disability and suffering are never good in themselves: health care properly seeks to relieve them. There are, however, limits to what health care can achieve. **Even when suffering and death cannot be eliminated, they can nonetheless acquire a positive, life-giving and redemptive value, especially from the perspective of religious faith.**[74] [Our emphasis]

The Code does not prohibit sedation, including terminal sedation, but states:

> Advances in palliative care are now such that the control of pain should not normally lead to side effects such as loss of lucidity or consciousness or to the shortening of life.[75]

Similarly, evidence to the Western Australian inquiry from the Reverend Dr Joseph Parkinson, Director of the LJ Goody Bioethics Centre, who appeared with the Catholic Archbishop of Perth, was to the effect that sedation will usually be provided on a temporary basis. In response to a question from the Chair in relation to how palliative care should treat people who are experiencing incredible pain at the end of their lives, the Rev Dr Parkinson said:

> If a patient wishes to have freedom from pain and full consciousness, that is probably a stretch too far for any medical system, even in ideal circumstances.
>
> ... If you are able to provide consciousness, if you are able to preserve consciousness with pain relief, that is great. But you will also have heard, I am sure, reference to palliative sedation – so dealing with if not the pain, then the agitation that can accompany pain at the end, that can be managed; patients can be given relief from that. It is not, as we have discussed, about killing a patient, it is about controlling pain. **The beauty of palliative sedation is that it is temporary, so it is reversible. A patient can be given a break, get relief, have a couple of days good solid sleep and then be brought out of that and be able to continue making their autonomous health care choices.** I think there might be a bit of a myth floating around that somehow medicine ought to be able to provide everything that I want. The fact is, it never has been able and probably never will be able to provide both full consciousness and complete freedom from pain.[76] [Our emphasis]

The question of terminal sedation is ethically vexing for many in palliative care. In a *Lancet* (2000) editorial, Professor Janet Hardy from the Mater Research Institute at the University of Queensland's Faculty of Medicine wrote:

> **The concept of sedation causes considerable unease in many palliative care workers,** most of whom are ardently opposed to any form of euthanasia or patient-assisted suicide. There is concern that sedation as the best means of symptom control in the dying patient is under-used because of fear of employing 'terminal sedation'.[77] [Our emphasis]

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[74] Catholic Health and Aged Care Services, "Ethical Standards for Catholic Health and Aged Care", published by St Vincent's & Holy Spirit Health, 2008, point vii – https://tinyurl.com/y4v45cbe (cached version)
PDF download available here – https://tinyurl.com/y2jyl5t4

[75] Catholic Health Australia, Code of Ethical Standards for Catholic health and Aged Care Services in Australia, Part II Decision Making in Health Care, Euthanasia 5.20, 2001, p 46 – Quoted here – https://myfuturecare.org.au/wp-content/uploads/2014/docs/St_Vincent%27s_Care_Services_education_material_2.pdf

[76] Rev. Dr Joseph Parkinson in Joint Select Committee on End of Life Choices, "Inquiry into the need for laws in Western Australia to allow citizens to make informed decisions regarding their own end of life choices", Transcript of Evidence, Parliament of Western Australia, Perth, 8 March, 2018, p.4 – http://www.parliament.wa.gov.au/Parliament/commit.nsf/(Evidence+Lookup+by+Com+ID)/0F66BD7CDFA1A0DB48258256000D0E6E/$file/180308+-+TS+-+Archbishop+&+LJ+Goody+Centre+-+FINAL.pdf

[77] Janet Hardy quoted in Rodney Syme, Time to Die, Melbourne University Press, 2017

In evidence from representatives of Catholic Health Australia, Catholic Homes, Catholic Homes WA and St John of God Health Care, the Western Australian Inquiry[78] was told that:

> Catholic aged care services would support the decision of a competent and 'mentally stable' person who requested palliated starvation, but they would look at why the person wished to end their life and they would address their distress or mental health issues and support them and their family to make informed decisions'.
> **- Ms Bernadette Brady, Executive Manager, Mission, Catholic Homes WA (p.12).**
>
> Catholic Health facilities rarely see people who are so severely distressed at the end of life that sedation is the only option.
> **- Dr Alison Parr, Director Medical Services, St John of God Health Care; Palliative Medicine Consultant (p.13)**
>
> Sedation is considered at the last 24 or 48 hours of life to alleviate suffering.
> **- Ms Natalie Joseph, Manager, Clinical Services, Catholic Homes (p.13)**
>
> Patients or their substitute decision-makers sometimes request an increase in palliative medication, knowing the risk is to hasten death, but this is usually 'a reflection of levels of distress and a signal for us as a team to spend more time with patients and families and explore that distress, and often with intervention and time and the multidisciplinary approach, we are able to support people through that'.
> **– Dr Alison Parr (p. 17)**
>
> This is the case in aged care too, where a request for an increase in palliative medication is 'an opportunity for people to give families information around what is available as well. Often people are so distressed and they think medication is the only answer to that distress. There may be other interventions we can make to address psychological distress, spiritual distress, issues around meaning and family relationships that would be adding to that distress. It is a multidisciplinary conversation that needs to take place as well'.
> **- Ms Bernadette Brady (p.17)**

In the accounts Go Gentle has heard, it is clear that, by the time desperate family members start pleading for something more to be done to better relieve the dying person's pain and suffering, pain and suffering is already extreme. To regard that as a suitable point to begin a discussion about their distress and family relationships is not what is required.

Clive Deverall, founding president of Palliative Care in WA, summed it up this way:

> And every day, in different settings, terminally ill patients – most with advanced malignancies and uncontrolled symptoms – are terminally sedated. Excellent. But that is the Lotto Life: the patient has to be lucky enough to find a doctor willing to help. And there is little or no transparency and a legal risk to the doctor and/or nurse.[79]

2.4 What Doctors Believe

In advocating for voluntary assisted dying, we have often been on the other side of the debate to some doctors who share a belief that there is spiritual growth to be found in suffering as you die. They argue for the sort of palliative care that the Vatican Charter promotes and their authority, as 'experts on the care of the dying', has been accepted without question by many politicians.

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[78] Rev. Dr Joseph Parkinson in Joint Select Committee on End of Life Choices, "Inquiry into the need for laws in Western Australia to allow citizens to make informed decisions regarding their own end of life choices", Transcript of Evidence, Parliament of Western Australia, Perth, 8 March, 2018, p.4 – http://www.parliament.wa.gov.au/Parliament/commit.nsf/(Evidence+Lookup+by+Com+ID)/0F66BD7CDFA1A0DB48258256000D0E6E/$file/180308+-+TS+-+Archbishop+&+LJ+Goody+Centre+-+FINAL.pdf

[79] Noreen Fynn, "Submission to the Joint Select Committee on End of Life Choices (Western Australia)", 17 October, 2017 – http://www.parliament.wa.gov.au/parliament/commit.nsf/(Evidence+Lookup+by+Com+ID)/30D73154F4D00AFF48258219000B3C84/$file/20171017+-+EOLC+-+Sub+347+-+Ms+Noreen+Fynn.pdf
Noreen Fynn is the widow of Clive Deverall

Their arguments are never presented as religious ones – only as medical – but they represent, nonetheless, a powerful belief system. The palliative care that they campaign to preserve enables them to practice in accordance with those beliefs without scrutiny or censure. What is more, they can do so regardless of whether or not those beliefs are shared by the dying person dependent on their care.

Here are some examples of those beliefs:

> Within one's suffering is an opportunity for growth ... It's interesting that people facing death grow spiritually ... To the point where they say 'It's been such a good journey. I've learnt so much. The cancer has been so good to me'.
> **- Dr Douglas Bridge, formerly of St John of God Health Care – also formerly head of palliative care at Royal Perth Hospital.**[80]
>
> ... the individualistic, secular public isn't interested in the spiritual benefits of suffering, or in considering whether there might be a higher good than simply avoiding suffering at all costs.
> **– Dr Megan Best, palliative physician, Greenwich Hospital, NSW and board member of Spiritual Care Australia.**[81]
>
> The ultimate root of pain is the sin of all humanity in which they so deeply and wilfully participate, and for which they deserve judgement. In particular, I see how precious is the help of a doctor who can show me the Lord's mercy in my pain both physically and spiritually.
> **- Robyn Bain, emergency doctor, now gospel minister.**[82]
>
> As Christians we have the privilege of entering into the pain of our patients and passing on the compassion and comfort of our God.
> **– Dr Murray Lean, pastor and medical doctor.**[83]
>
> Yes, they will say this suffering is very hard for them and they would prefer to die, and I would say to them, 'Yes, I acknowledge that you are feeling that way but I will continue to try and make you feel better so you don't have to feel that way' ... It is not ... my morals to say, 'Because I can't look after you, you are better off dead...' [Instead] I walk with the patient. I say to them, 'Yes, the pain is still there, but I will help you live with that pain'.
> **– Professor Richard Chye, head of palliative care at St Vincent's Scared Heart Hospice, Sydney.**[84]

The Charter, the Code and evidence of practice in Catholic health and palliative care services suggest that, while the Charter and Code allow a competent person's decision to refuse treatment or food and water to be honoured and for sedation, including terminal sedation, to be given at the end of life, there is a real risk that time and effort – perhaps *considerable* time and effort – will first be spent trying to convince the person to make a different decision or to avoid providing sedation due to the religious beliefs of the operator of the health care service before the person's choices are finally acted on.

An example of this is provided by palliative care physician, Dr Douglas Bridge of Western Australia. Dr Bridge believes that "within suffering is an opportunity for growth", and has spoken publicly of his "supreme Christian calling" in his work.[85]

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[80] Heather Dowling, "Healing at Journey's End", Crosslight, 3 March, 2013 – https://crosslight.org.au/2013/03/03/healing-at-journey's-end/

[81] Megan Best, "Modern healthcare: are we playing God?", The Briefing, Matthias Media, 3 December, 2012 – https://matthiasmedia.com/briefing/2012/12/modern-healthcare-are-we-playing-god/

[82] Robyn Bain, "Pain: What's the Point?", Luke's Journal, Christian Medical and Dental Fellowship of Australia Inc, Vol 23, No. 1, 2018, p.6 – https://issuu.com/lukesjournal/docs/lukes_journal_vol_23_issue_1

[83] Murray Lean, "Sharing Comfort through Christ", Luke's Journal, Christian Medical and Dental Fellowship of Australia Inc, Vol 23, No. 1, 2018, p.12 – https://issuu.com/lukesjournal/docs/lukes_journal_vol_23_issue_1

[84] Richard Chye in Andrew Denton, "Better Off Dead: #11 Whose life is it anyway?: Palliative care in Australia part 2", podcast, Thought Fox and the Wheeler Centre, published online by the Wheeler Centre on 15 March ,2016, (audio) – https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/11-whose-life-is-it-anyway
Transcript at Go Gentle Australia website – http://www.gogentleaustralia.org.au/transcripts2

[85] Heather Dowling, "Healing at Journey's End", Crosslight, 3 March, 2013 – https://crosslight.org.au/2013/03/03/healing-at-journey's-end/

Discussing the onset of increasing weakness, drowsiness, and inability to control thoughts, that can afflict a dying person, Dr Bridge quotes Dr Robert Twycross, who was recruited by Dame Cicely Saunders as a Clinical Research Fellow at St Christopher's, which Dr Bridge describes as the first modern hospice. Dr Bridge describes Dr Twycross as "a committed Christian" who was "aware of the spiritual dimension of suffering, which no amount of morphine could relieve", and quotes his writing from 1993, including:

> The possibility of such an outcome highlights the need to make every effort to deal with psychological 'skeletons in the cupboard' before the patient becomes too weak to address them. A few, however, resist every attempt to share what they have been hiding.[86]

Dr Natasha Michael, from Cabrini Health in Victoria, reinforces the instruction in the Sacred Congregation for the Doctrine of the Faith's "Declaration on Euthanasia" that:

> ***"The pleas of gravely ill persons who sometimes ask for death are not to be understood as implying a true desire for euthanasia; in fact, it is almost always a case of an anguished plea for help and love."***[87]

She writes:

> For many, suffering entrenches the mind, soul and spirit. It overwhelms through the loss of meaning, hope and emotional strength in the face of illness.[88]

Speaking to the Victorian Inquiry, Dr Michael explained that when a person says that their suffering is "so unbearable [that] I want to die", the solution is not to provide them with barbiturates, but to ask:

> How can I help you with these factors that are making you feel that death has to be the better option?[89]

If the dying person's wishes are honoured, it may only be after prolonged and determined advocacy from a family member or other substitute decision maker.

Pity the dying person who does not have access to such determined advocacy, and pity, too, the dying person who does have determined advocacy but who has to endure unnecessary pain and suffering waiting for their advocate's demands to have some effect.

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[86] Douglas Bridge, "Making Health Care Whole", Submission to the WA Parliamentary Joint Select Committee on End of Life Choices, October, 2017 – http://www.parliament.wa.gov.au/parliament/commit.nsf/(Evidence+Lookup+by+Com+ID)/EEC848CF38BA51AF4825821E000FBEF4/$file/20171023+-+EOLC+-+Sub+530+-+Mr+Douglas+Bridge.pdf

[87] Sacred Congregation for the Doctrine of the Faith, "Declaration on Euthanasia", Vatican – http://www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_19800505_euthanasia_en.html

[88] Natasha Michael, "Right to life: What treatment should doctors prescribe to end suffering?", The Age, 25 November, 2015 – https://www.theage.com.au/opinion/right-to-life-what-treatment-should-doctors-prescribe-to-end-suffering-20151125-gl7g98.html

[89] Natasha Michael in Standing Committee on Legal and Social Issues, "Inquiry into End-of-Life Choices" transcript, Parliament of Victoria, Melbourne, 16 September, 2015, p. 9 – https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/ELC_Transcripts/Cabrini_Health_Dr_Michael-End_of_life_choices_16_September_2015.pdf

CASE STUDY: JAN'S STORY

JAN RYDER, 77, DIED FROM BRAIN CANCER IN A FAITH BASED HOSPICE IN SYDNEY. HER STORY IS TOLD BY HER DAUGHTER, SHAYNE HIGSON.[90] (audio also available)

SHE KEPT ASKING, 'WHY ARE THEY TORTURING ME?'

Mum had an aggressive form of glioblastoma multiforme, and with multiple tumours they could not operate or do radiation therapy for fear of causing severe brain damage.

As the months passed Mum lost her ability to walk, she lost words and struggled to communicate, she was unable to write, unable to read, unable to talk on the phone and, towards the end, even listening to the radio or watching TV caused great discomfort.

She was sleeping more and more each day and she had headaches and constant nausea. But even when Mum was bedridden and it took two people to carry her to the toilet, and she couldn't even wipe herself, she still wanted to live.

Each day her condition worsened. The anti-nausea medication did little to ease her discomfort and as Mum's right side became more and more affected she could not even lie in bed peacefully. She was agitated and distressed.

Mum started to ask for some form of medication that would just knock her out but nothing the doctors prescribed achieved a peaceful state. She had had enough. She kept asking, "Why are they doing this to me? Why are they torturing me?"

Mum's greatest fear throughout her illness was that she would suffer another seizure. She had described it as like having a giant slamming back and forth inside your body but fortunately changes to her medication prevented this.

That is, until the end.

By the time she was admitted to hospital Mum could no longer swallow, so she was unable to take the anti-seizure medication. On that first night Mum suffered another seizure.

It took nearly an hour and a half to get the seizure under control because the nurses were only authorised to give small doses of medication, 15 minutes apart.

> ***"Mum didn't really like when the palliative care doctor came because Mum wasn't religious, and just the manner, the sort of questions that were being asked."***

I know that he meant well, but coming in and saying, "Well Jan, how are you feeling?", and she'd say how she was feeling.

This was early on when she could talk. And when she started asking and saying "I just want to be knocked out" and he said "Why?", she said "Because I want to stop thinking. I want to stop – shut down what I'm thinking". And he said, "Well what are you thinking about?" I mean she just sort

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[90] Shayne Higson, "We can do better", Open Drum, ABC, 1 September, 2015 – https://open.abc.net.au/explore/102194
Audio at: Shayne Higson in Andrew Denton, "Better Off Dead: #11 Whose life is it anyway?: Palliative care in Australia part 2", podcast, Thought Fox and the Wheeler Centre, published online by the Wheeler Centre on 15 March, 2016, (audio) – https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/11-whose-life-is-it-anyway
Transcript at Go Gentle Australia website – http://www.gogentleaustralia.org.au/transcripts2

of looked, you know. If she was the sort of person that would swear, I think she would sworn at him, because like what do you think she was thinking. I think she, that's what she said – "What do you think I'm thinking about?"

She knew that her life was coming to an end. She was about to lose the life that she was desperate to hang on to, and all the pleasure had gone out of it. She just wanted it to end.

I just know because I know my Mum, and that's the thing; they don't. They come in and they say things like that... I knew that Mum must be getting close to the end, and then to have someone not see that and to say that she might have depression – I was devastated.

She was very clear what she wanted and she'd said it right at the beginning as well. But they're not allowed to. That's the thing. You are not allowed to have a peaceful end, and once she went into hospital, that's when I really realised that it's just not allowed. It's not allowed. The terminal sedation which is the best option that we have now, does not guarantee a peaceful end ...

And she kept shaking. When she didn't stop shaking, we said "Can you give her more? It's not working".

He said, "I can only give her this amount and every 15 minutes. I'm not authorised to give her any more. If I give her more, it might end it".

And Rod and I just sort of said, "Well do you think – mum's dying", and he said, "I can't", and his face – he got a bit angry because I think he probably thought "What's this family doing. They're asking me to sort of up the dose", but it was, we just wanted her not to have to suffer.

So, every fifteen minutes we'd buzz the bell and he'd come in, and she was still shaking. It took five doses. I think it was Midazolam was the drug that they were using.

[We felt] completely powerless and angry ... that at such a terrible time that you are sort of battling this. It just shouldn't have to be like that. At one point my older sister ... she said to the GP, "What are we meant to do? Go down to Kings Cross on the street and try and score or something. What choice – what are you saying? What choice do we have?".

And the third night was probably the worst one. Then it definitely was pain. And I have to say that her face was just so contorted ... And then that's when they eventually put in that driver with the regulated amounts.

CASE STUDY: JAN'S STORY

- Why were Jan's clear requests for full sedation not adhered to?
- Why was Jan made to feel as though she was being tortured?
- Why was Jan, who was clearly dying and suffering, questioned as though she may have mental health issues?
- Why were Jan's seizures inadequately medicated, to the point where it took five different treatments with drugs to bring one attack under control?
- Why did it take repeated and emotional requests from the family before Jan was adequately sedated?
- Why did it take several days of suffering – until Jan's face was contorted in pain – before she was allowed a syringe driver with regulated analgesic?

The treatment of Jan Ryder borders on mistreatment and abuse.

2.5 What It's Like to Die in a Catholic Hospice: An Independent Six-Month Study

Alex Broom is Scientia Professor of Sociology and Co-Director of the Practical Justice Initiative, Centre for Social Research in Health, the University of New South Wales.[91] He spent six months 'embedded' in a Catholic hospice to observe what the end-of-life experience was like for patients. While acknowledging the many benefits hospice care brought to patients and their families, when it came to assisted dying, **he observed that the experience for many was deeply unsatisfactory:**

> A regular statement was, 'You wouldn't let a dog go through this'. Another comment was from an elderly man, who said, 'I came to palliative care because I thought they'd help, but you don't get help. They just keep you alive'.
>
> There are quite a significant number who view the hospice model as inhumane because it doesn't allow them to, essentially, be the masters of their own demise.[92]

Professor Broom described one dying patient who had tried to overdose on morphine at home and who ended up in the hospice:

> The hospice staff said to me, 'He's just not in a good place. He is psychologically not well, and he'll get to the point where he accepts that this is just part of the process'. I think what that captured was how an organisation and how **a profession, if it's not careful, can instill particular values around what is dignity, what is a good death and can subtly disallow people's opportunity to make decisions for themselves.**[93] [Our emphasis]

Professor Broom observed a "one-size-fits-all" moral and ethical code:

> What people don't realise is that on entering into the hospice you're entering into a contract, essentially, about how you can die. Hospices in Australia have a set of parameters around what is acceptable and what is ethical, and those are embedded in a particular series of

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[91] Alex Broom, Staff Profile, University of NSW – https://research.unsw.edu.au/people/scientia-professor-alex-broom

[92] Andrew Denton, "Better Off Dead: #10 Neither hasten nor prolong death: palliative care in Australia, part 1", podcast, Thought Fox and the Wheeler Centre, published online by the Wheeler Centre on 15 March, 2016, (audio) – https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/10-neither-hasten-nor-prolong-death
Transcript at Go Gentle Australia website – http://www.gogentleaustralia.org.au/transcripts2

[93] Andrew Denton, "Better Off Dead: #10 Neither hasten nor prolong death: palliative care in Australia, part 1", podcast, Thought Fox and the Wheeler Centre, published online by the Wheeler Centre on 15 March, 2016, (audio) – https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/10-neither-hasten-nor-prolong-death
Transcript at Go Gentle Australia website – http://www.gogentleaustralia.org.au/transcripts2

moral structures which have religious underpinnings and certain ideas about what is okay or not okay and the nature of suffering.

The loss of a person occurs often way before the point of death. You get that period of time when there is such suffering that for a lot of people – carers – there isn't much left of the person.

I think we need to acknowledge the fact that if we overvalue this so-called natural course of dying and we normalise suffering – as Pope Benedict said, assisted suicide is this false solution to the drama of suffering. I would suggest that that suggests he has not seen much suffering, because it's not much of a drama if you ask me. It's something much more malevolent than that.

> ***If we overvalue suffering, which I think has very religious puritan roots around the virtue of stoicism, there's not much virtue in it when you see it happening.***

There's not much virtue in it when you are in that space. In fact, if anything, it's degrading of a person and all of those around the person.

So, I think we have a set of values, but they're highly compromising in terms of other really important values, which are choice, expressing one's preferences, agency, and the most important one, which is dignity. [Our emphasis]

CASE STUDY: ELIZABETH'S STORY

ELIZABETH RICHARDS, 77, DIED FROM MOTOR NEURONE DISEASE IN A CATHOLIC HOSPICE IN MELBOURNE. HER STORY IS TOLD BY HER DAUGHTER, JANE.[94]
YOU CAN SEE JANE TALK ABOUT HER MUM'S DEATH HERE.[95]

NO-ONE LEFT HER BEDSIDE UNSCATHED

As my mother's MND progressed we placed our trust, and in fact our mother's life, in a system which only now I can say failed her dismally.

As it was, my dear beautiful mum went to palliative care to die. Her and our intention and understanding was that she would be cared for right up until the moment of death. And up until a few days before her death I cannot emphasise how exemplary her care was.

... not for a second did we envisage the horrific, inhumane and tortuous death to which she would succumb.

Mum was no longer under the care of her two neurologists but the palliative care specialist. Yet again we were assured that Mum would not suffer in the end and that terminal sedation would provide her with the least amount of pain and discomfort. She would supposedly be given adequate sedation to prevent any pain or associated anxiety. She would not, we were told, experience any thirst or hunger as a result of the withdrawal of fluids and nutritional supplements. "I promise you, you will not suffer at the end."

Mum did suffer. She had pain, breakthrough pain, because her prescribed dose was unable to adequately palliate her pain at all times. She managed to express to us her fear and, in one of her conscious moments, was able to convey to us that she wanted to be fed through her PEG tube. This was so very traumatic for all of us, many staff included.

We had been assured that Mum would be devoid of hunger and thirst, but no, the dying process is not a templated one and whilst her case may have been unusual it was nevertheless real and it was happening to my mother.

Mum suffered what I deem to be unnecessarily for days. Family members requested that her analgesia be increased. A request I made pleading for her analgesia to be substantially increased even if it meant hastening her obviously imminent death was directly replied to by the question,

> ***'Are you asking me to kill her?' No, I was not trying to have my mother murdered, I simply wanted her tortuous pain and existential suffering to end.***

We are told that death can be peaceful and that we should not fear it but no-one, even staff members, could leave her bedside unscathed. We chose not to allow young grandchildren and close friends to see Mum in her final hours.

This hideously prolonged death was visually ugly and this once beautiful, vibrant and radiant individual should not have been subjected to the haunting and unforgettable images that we were privy to.

My beautiful mum did not deserve to die the way she did.

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[94] Andrew Denton and Glenda Downing (editor), *The Damage Done*, Go Gentle Australia, 2016, pp. 44-47
Free download available here: https://www.gogentleaustralia.org.au/shop

[95] Go Gentle Australia, "Launch Video", 12 November, 2017 –
https://www.youtube.com/watch?v=V-npGbBzgHU&feature=youtu.be&list=PLXQBeKmhJGYzCVQl394Wx7WKtGxl0q1Bk&t=40

CASE STUDY: ELIZABETH’S STORY

- Why was Elizabeth’s family wrongly assured that she would not suffer?
- Why were they told that terminal sedation would minimise her pain and discomfort when it did not?
- Why was Elizabeth left to suffer the discomfort of thirst and hunger when her family had been assured that she would not?
- Why was Elizabeth left to suffer fear and anxiety when her family had been assured that she would not?
- Why were the family’s repeated requests for more analgesia rejected leaving Elizabeth to suffer breakthrough pain?
- Why was Elizabeth’s family left with final memories of her that they could only describe as ‘hideous’ and ‘ugly’?

The treatment of Elizabeth Richards borders on mistreatment and abuse.

2.6 Palliative Care: Real Value – and Real Limitations

Palliative Care Australia advertises their services as “person-centred”, with their primary goal being to “optimise the quality of life” of a person who is dying.[96]

In doing so, they cite the World Health Organisation’s definition of palliative care as being the:

> ... impeccable assessment and treatment of pain and other problems.[97]

Go Gentle acknowledges the important work done by palliative care – secular and religious – in Australia. For many, the services they offer at the end of life are of enormous value. **We continue to maintain that palliative care should be better funded at all levels of Government.**

However, Australia’s palliative care system is already ranked second in the world, behind the UK. The case studies listed above, and many other testimonies of suffering at the end of life accepted by the Victorian and Western Australian inquiries, cannot be explained simply by a lack of funding.

In their majority report, the Victorian Committee commented on:

> The trauma experienced by patients and their families when palliative care does not provide an adequate solution for their situation.[98]

By arguing that the solution to this trauma is simply to give more resources to palliative care providers is to ignore the reality that – for a substantial portion of those providers – personal or institutional beliefs dictate how a person’s suffering is to be treated, regardless of what the person may need, want, or request.

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[96] Palliative Care Australia, “National Palliative Care Standards” – https://palliativecare.org.au/standards

[97] Palliative Care Australia, “Understanding Palliative Care” – https://palliativecare.org.au/understanding-palliative-care-parent-menu

[98] Parliament of Victoria Legislative Council, Legal and Social Issues Committee, “Inquiry into end of life choices: Final Report: Section 7.1 ‘The legal framework and peoples’ end of life experiences’”, June, 2017, p.194 – https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf

No amount of extra resourcing is going to change that.

Professor Michael Ashby, Director of Palliative Care at the Tasmanian Health Service, says that:

> [While] religious groups still have a valuable role in reconnecting people to ancient traditions that can bring comfort and meaning to those facing death and loss ... It is not the role of any health care team to suggest that its ministrations can give meaning, purpose and dignity to a dying person's remaining life if that person feels that these are irretrievably lost ... **Palliative care is a model of care, not a moral crusade.**[99] [Our emphasis]

That doctors hold strong personal beliefs which may influence their treatment decisions is not at issue. We are not suggesting that they are wrong to do so, or that they should be required to act otherwise. Any proposed VAD law, rightly, protects and respects a doctor's right to act according to their conscience in providing end-of-life care.

What is at issue is an existing law which enables doctors to impose those beliefs on dying people dependent on their care. People who, in many cases, do not share those beliefs. People who are suffering as they die and who make persistent and rational requests to end their suffering quickly.

Until the religious elephant in the hospital room is addressed by a VAD law offering people the right to seek a better death, the trauma and suffering listed above (and also in the APPENDIX of this submission) will continue.

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[99] Michael Ashby (Professor of Palliative Care, Monash Medical Centre), in PA Komesaroff, JN Lickiss, M Parker, and MA Ashby, "The euthanasia controversy: Decision-making in extreme cases", Letter to the Editor, *Medical Journal of Australia*, No. 162, 20 November, 1995, pp. 596-97, https://www.ncbi.nlm.nih.gov/pubmed/7540716
See full text here: https://www.eurekastreet.com.au/article/denying-but-not-defying

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Part D

Responding To Key Arguments Against VAD

WHAT THIS SECTION IS ABOUT

A key speaker at the HOPE international anti-euthanasia symposium in Adelaide in 2015 was former New Hampshire state representative, now organiser of Living with Dignity in that state, Nancy Elliott. **Elliott spoke about effective tactics that can be used to make Australian politicians hesitate to support VAD legislation:**

> When you have lots of arguments, if one argument gets blown out of the water, you still have more, and each argument will reach somebody else ... Right now the disability argument is really kicking it ... It's very powerful. Now will it always be powerful? We don't know. Two, three, four years from now that may have holes kicked in it, just for different reasons, so we have to be flexible. You know, when one of our arguments dies, we need to be ready to pick up another one.
>
> Elder abuse? Elder abuse is excellent ... Suicide contagion is another very good thing to point out to your committees, and it has worked very well in the States.
>
> You don't have to win the legislators' hearts and minds. All you have to do is persuade them 'not this bill' and you have got your win'[100]

In keeping with this strategy, you will hear many arguments against VAD. Often, they are based on misrepresentation, or selective use, of facts. In this section, we respond by putting them in context

'NOT THIS BILL': 9 COMMON MYTHS USED TO MAKE POLITICIANS HESITATE

#1 VAD Laws Inevitably Lead to a Slippery Slope
#2 Elder and Disability Abuse: Vulnerable People will be Coerced to Die
#3 VAD Creates Suicide Contagion
#4 VAD Will Damage the Doctor-Patient Relationship
#5 People are Choosing to Die Because they Feel Like a 'Burden'
#6 The Legalisation of VAD Means that Palliative Care will Suffer
#7 VAD Leads to 'Doctor Shopping'
#8 The Drugs Don't Work
#9 VAD Breaks a Doctor's Oath to 'Do No Harm'

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[100] Nancy Elliott in Andrew Denton, "Better Off Dead: #1 The invasion of death", podcast, Thought Fox and the Wheeler Centre, published online by the Wheeler Centre on 15 March, 2016, (audio) – https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/1-the-invasion-of-death Transcript at Go Gentle Australia website – https://www.gogentleaustralia.org.au/transcripts1

MYTH #1. VAD LAWS INEVITABLY LEAD TO A 'SLIPPERY SLOPE'

1.1 The Argument

Opponents of voluntary assisted dying claim that VAD legislation inevitably results in the law being changed over time to allow more people and more conditions access. They point to the Netherlands and Belgium, claiming that laws which were originally only for the terminally ill, now extend to cover such vulnerable groups as people with mental illness and dementia – even children. This is the 'slippery slope'.

This 'slippery slope' argument is well summed up by former Prime Minister, Paul Keating:

> The experience of overseas jurisdictions suggests the pressures for further liberalisation are irresistible.[101]

1.2 The Reality

In response to Mr Keating's claim, the ABC's Fact Check published the following:

> In most jurisdictions where assisted dying has been legalised, little has changed regarding what practices are allowed or who can access assisted dying.
>
> There have been some changes, such as in Belgium, where 'competent minors' can now request euthanasia.
>
> In the Netherlands, doctors have published guidelines for providing euthanasia to severely disabled newborns. Though these guidelines may help doctors avoid jail, the practice itself remains illegal.
>
> Canada's framework is still new and may yet evolve as it is challenged in the courts.
>
> Despite pressure for change in the United States, there has been no further liberalisation in any of the five states involved. This includes Oregon, where the system has been operating since 1997.[102]

In 2015, the Victorian Parliamentary Inquiry:

> ... found no evidence of institutional corrosion or the often cited 'slippery slope'. Indeed, the regulatory framework has been unchanged in Oregon, the Netherlands and Switzerland for many years.[103]

Similarly, in 2018, Palliative Care Australia reported:

> A common concern across various jurisdictions has been that access to assisted dying pathways is a 'slippery slope' whereby vulnerable people may be at risk should safeguards fail. Whilst it is noted there have been amendments to legislated eligibility criteria over time, there is no evidence that assisted dying has substituted for palliative care due to erosion of safeguards.[104]

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[101] Paul Keating, "Paul Keating: Voluntary euthanasia is a threshold moment for Australia, and one we should not cross", The Sydney Morning Herald, 19 October, 2017 – https://www.smh.com.au/opinion/paul-keating-voluntary-euthanasia-is-a-threshold-moment-for-australia-and-one-we-should-not-cross-20171019-gz412h.html

[102] RMIT ABC Fact Check, "Fact check: Has assisted dying been a legal slippery slope overseas?", ABC News, 16 July, 2018 – https://www.abc.net.au/news/2017-11-10/fact-check-do-assisted-dying-laws-lead-to-a-slippery-slope/9116640

[103] Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report: 'Chair's Foreword'", June, 2017, p. xvii – https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/EOL_Report/LSIC_58-05_Text_WEB.pdf

[104] Aspex Consulting, "Experience internationally of the legalisation of assisted dying on the palliative care sector - Final Report 28", Palliative Care Australia, October, 2018, p. 8 – https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/12/Experience-internationally-of-the-legalisation-of-assisted-dying-on-the-palliative-care-sector-APEX-FINAL.pdf

1.3 Setting the Record Straight

1.3.1 Europe's Laws Were Never Written Only for the Terminally Ill

The legislation in Belgium and the Netherlands, written in 2002, has always been based on unbearable suffering, not whether a person has a terminal illness. In that time there has been one change to these laws.

Belgium

In 2014, Belgium extended its eligibility criteria to grant some children access to euthanasia.[105]

Robert Vander Stichele, a medical professor with Belgium's University of Ghent and member of the European consortium End of Life Care, said that this was the only expansion of what Belgium allows.

> When children are considered to be competent and autonomous, in exceptional circumstances they can be considered as being adults and given [euthanasia].[106]

Changes to Belgian laws occurred through the considered deliberate processes of parliament. In December 2013, the Belgian Senate voted 50-17 in favour of amending the Act to remove the formal age limit and to permit minors to access the regime subject to an assessment of capacity. In February 2014, the Belgian Chamber of Representatives, by a majority of 86-44 with 12 abstentions, passed the amendments.

For euthanasia to proceed in Belgium, doctors must first verify that a child is "in a hopeless medical situation of constant and unbearable suffering that cannot be eased and which will cause death in the short term". Once a child has expressed a wish for euthanasia in writing, child psychiatrists conduct examinations, including intelligence tests, to determine the child's level of discernment and ensure they are "not influenced by a third party". Parents can, however, overrule the request.

To date, three minors – one with brain cancer, one with cystic fibrosis, and one with muscular dystrophy – have used the law.[107]

The Netherlands

Professor Jocelyn Downie, an international health law expert who contributed to the Royal Society of Canada's End-of-Life Decision Making report[108], said that while some people claim the Netherlands originally excluded non-terminally ill patients from accessing euthanasia, this is not correct. "They never had that limit," she said.[109]

The Royal Dutch Medical Association (KNMG) told Fact Check that there have been no changes to the law since it was introduced. They said that although there is debate in the Netherlands about whether assisted suicide should extend to elderly people who consider their life to be "completed", the change requires separate legislation and is not supported by the KNMG.

However, there has been some change *outside* the law.

In 2004, doctors from the University of Groningen developed a protocol describing the conditions under which severely disabled newborns could be euthanased. The so-called 'Groningen protocol' was later adopted as a national guideline by the Dutch association of paediatricians.[110]

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[105] Rory Watson, "Belgium extends euthanasia law to children", British Medical Journal, 348 g1633, 2014 – https://www.bmj.com/content/348/bmj.g1633

[106] RMIT ABC Fact Check, "Fact check: Has assisted dying been a legal slippery slope overseas?", ABC News, 16 July, 2018 – https://www.abc.net.au/news/2017-11-10/fact-check-do-assisted-dying-laws-lead-to-a-slippery-slope/9116640

[107] Henry Samuel, "Belgian children, aged nine and 11, youngest ever to be euthanised", The Sydney Morning Herald, 8 August, 2018 – https://www.smh.com.au/world/europe/belgian-children-aged-nine-and-11-youngest-ever-to-be-euthanised-20180808-p4zw4l.html

[108] Udo Schüklenk, Johannes J M Van Delden, Jocelyn Downie, Sheila A M Mclean, Ros Upshur and Daniel Weinstock, "End-of-Life Decision-Making in Canada: The Report by the Royal Society of Canada Expert Panel on End-of-Life Decision-Making", Bioethics, 25 (Suppl 1), November, 2011, pp. 1–4 – https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3265521/

[109] Quoted in: RMIT ABC Fact Check, "Fact check: Has assisted dying been a legal slippery slope overseas?", ABC News, 16 July, 2018 – https://www.abc.net.au/news/2017-11-10/fact-check-do-assisted-dying-laws-lead-to-a-slippery-slope/9116640

[110] RMIT ABC Fact Check, "Fact check: Has assisted dying been a legal slippery slope overseas?", ABC News, 16 July, 2018 – https://www.abc.net.au/news/2017-11-10/fact-check-do-assisted-dying-laws-lead-to-a-slippery-slope/9116640

1.3.2 Assisted Dying Legislation Elsewhere

North America

The legislation in Oregon has been in operation for 21 years and has never been changed. It has formed the basis for other legislation in California, Vermont, Colorado, Washington, Washington DC and, more recently, Hawaii and New Jersey.

Australia

Legislation passed in Victoria in 2017, and most recently proposed in South Australia, NSW, and Tasmania, did not provide access for patients with dementia. It did not allow access through advance care directives. It did not allow access on the basis of a disability or mental illness. It did not allow for minors.

Each society writes laws according to what that society will tolerate. Parliament itself is not a slippery slope – there is a rigorous process of review, expert advice, debate and decision making.

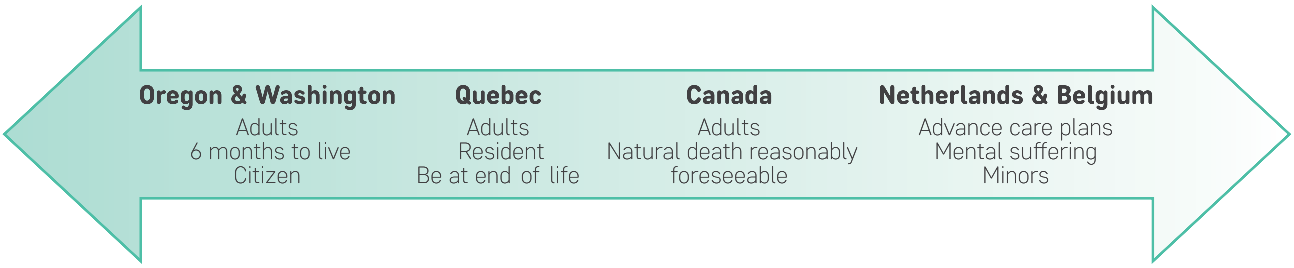
1.4 The Numbers of People Accessing VAD/VE Remain Extremely Low

The numbers of patients in each jurisdiction *has* increased over time – this is to be expected given ageing populations, disease profiles and community acceptance. However, as a percentage of all the people who die, the numbers have remained stable – and tiny: 2% of all those who die in Belgium; 4% in the Netherlands.

In Oregon, which has had a Death with Dignity Act (DWDA) in place for more than 20 years, it's less than 0.5% of people who die each year. In 2018, that number was 168 deaths in a population of 4.2 million people.

The key fact here, one often overlooked, is that all of these cases occur **within the scope of the existing legislation in those countries.**

Figure 4: Spectrum of Legislative Requirement [111]



As the majority report of the Victorian Parliamentary Inquiry Committee found after visiting Europe and North America:

> Instances of assisted dying are rare, even in jurisdictions where it is legal. Assistance in dying is, in the vast majority of cases, provided to people in what would otherwise be the final weeks of their lives.[112]

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[111] Aspex Consulting, "Experience internationally of the legalisation of assisted dying on the palliative care sector - Final Report 28: 'Figure 2-1 Spectrum of legislative requirement'",Palliative Care Australia, October, 2018, p.15 – https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/12/Experience-internationally-of-the-legalisation-of-assisted-dying-on-the-palliative-care-sector-APEX-FINAL.pdf

[112] Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report: Executive Summary'", June, 2017, p.xix – https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf

MYTH #2. ELDER AND DISABILITY ABUSE – VULNERABLE PEOPLE WILL BE COERCED TO DIE

2.1 The Argument

Legalising VAD will create subtle 'hidden coercion' of vulnerable people. This can happen when a vulnerable person perceives – or is made to feel – that they are a burden on their family, or society in general, and that they have a 'duty to die'. It is also argued that vulnerable elderly people may be 'steered' towards VAD by greedy relatives.

2.2 The Reality

Go Gentle acknowledges that the abuse of vulnerable people in Australia is a genuine problem, as evidenced by testimonies to the *Royal Commission into Aged Care Quality and Safety* and the recent announcement of a *Royal Commission into the Abuse and Neglect of Australians with Disabilities.*

2.3 Vulnerable People Have Not Been Exposed to Abuse

Repeated, independent and exhaustive reviews have shown no evidence of abuse of the vulnerable overseas. These include:

Royal Society of Canada End of Life Report 2011:

> What has emerged is evidence that the law is capable of managing the decriminalisation of assisted dying and that state policies on this issue can reassure their citizens of their safety and wellbeing.[113]

The Honourable Justice Lynn Smith, Carter v. Canada (Attorney General) 2012, after hearing exhaustive evidence for and against VE/VAD from numerous expert witnesses around the world:

> **This evidence serves to allay fears of a practical slippery slope** ... I have found that the evidence supports the conclusion that a system with properly designed and administered safeguards could, with a very high degree of certainty, prevent vulnerable persons from being induced to commit suicide while permitting exceptions for competent, fully informed persons acting voluntarily to receive physician-assisted death.[114]

Dr Linda Sheahan, Australian Palliative Care Physician, Churchill Fellowship Report, 2012.:

> **It is highly reassuring to review the data and find no evidence of increased risk to vulnerable groups.**[115]

Journal of the American Medical Association, 2016:

> Euthanasia and physician assisted suicide are increasingly being legalised, remain relatively rare, and primarily involve patients with cancer. Existing data do not indicate widespread abuse of these practices.[116]

Victorian Parliamentary Inquiry, 2015:

> Assisted dying is currently provided in robust, transparent, accountable frameworks. The academic literature shows that the risks are guarded against, and that robust frameworks help to prevent abuse.[117]

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[113] Udo Schüklenk, Johannes J M Van Delden, Jocelyn Downie, Sheila A M Mclean, Ros Upshur and Daniel Weinstock, "End-of-Life Decision-Making in Canada: The Report by the Royal Society of Canada Expert Panel on End-of-Life Decision-Making", Bioethics, 25 (Suppl 1), November, 2011, pp. 1–4 – https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3265521/

[114] Carter v. Canada (Attorney General), 2012 BCSC 886, paras. 1241 and 1367

[115] Linda Sheahan, "The Dorothea Sandars and Irene Lee Churchill Fellowship to study the interface between Palliative Care and legalized Physician Assisted Suicide and Voluntary Euthanasia", The Winston Churchill Memorial Trust of Australia, 30 May, 2013, p.64 – https://www.churchilltrust.com.au/media/fellows/2012_Sheahan_Linda.pdf

[116] J Emanuel Ezekial, Bregje D Onwuteaka-Philipsen, John W Urwin, and Joachim Cohen, "Attitudes and Practices of Euthanasia and Physician-Assisted Suicide in the United States, Canada, and Europe", JAMA - Journal of the American Medical Association, 316 (1), July 5, 2016, pp. 79-90 – https://jamanetwork.com/journals/jama/article-abstract/2532018

[117] Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report: 'Chapter 8 – Victoria Should Legalise Assisted Dying'", June, 2017, p. 212 – https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/EOL_Report/LSIC_58-05_Text_WEB.pdf

People with Disabilities WA and the Australian Federation of Disability Organisations, joint submission to the Western Australian Parliamentary Inquiry, 2018:

> **There is no evidence to suggest, from either Oregon or the Netherlands data, that people with disabilities are at heightened risk of assisted dying**. Vulnerable groups generally including women, ethnic minorities, people from lower socio-economic circumstances, children, people with a psychiatric disability or dementia were not found to be at any heightened risk of assisted dying. People with psychiatric disability (mainly depression) constituted 20% of referrals to the Netherlands assisted dying process, but none progressed. Likewise, in Oregon, none of the 292 people who have accessed assisted dying did so due to mental illness.[118]

Representatives of peak elderly and disability groups in Belgium, the Netherlands and Oregon also report no abuse of their members under these laws. You can hear their voices in Episode 13 of Andrew Denton's "Better Off Dead" podcast.[119]

2.4 Why Using VAD Law to Coerce A Relative to Die is Harder to Pull Off Than *Oceans 11*

Under the Victorian law, if you were a greedy child wanting to get your hands on the inheritance by using the VAD process to coerce your elderly parent to death, you would have to engineer – and hope you would get away with – the following:

Inducing Doctors to Make a False Assessment

First, your parent would have to convince two doctors that they are dying of an incurable disease that is causing them intolerable suffering. 'Dying' means in the advanced stages of that disease – with six months or less to live. We're talking about diseases with long histories and clear symptoms such as cancer, MND, multiple sclerosis.

And these just aren't any doctors. Both must be trained at a level beyond that of a GP (a fellow of a College) and one must be a specialist in the particular disease. They must assess the person's symptoms, their medical history, the medications they are on to determine whether or not their claim that they are suffering intolerably matches with those symptoms.

Both doctors must act independently of each other. And, by law, they must also go through all other treatment options available to the person, in particular, palliative care.

More than that, they have to be specially trained in assessing a patient for eligibility for VAD as well as having specific training designed to assess a patient's mental capacity and to identify signs of abuse or coercion. Currently this training does not exist in any other area of medical practice.

Both doctors may make multiple assessments of the patient. They may refer to others involved in their treatment. They must, by law, receive three separate requests for VAD from the patient – two verbal and one written, separated by a minimum of 10 days.

If either doctor has any doubts about a person's mental capacity, they must refer them to a specialist such as a psychologist or geriatrician. If either doctor, for any reason, believes that the person applying is not eligible, they can deny the request.

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[118] A Sanderson (MLA) and Hon. C J Holt (MLC), "Report 1 - My Life, My Choice: The Report of the Joint Select Committee on End of Life Choices: 5:98 'What the evidence says'", 40th Parliament, Parliament of Western Australia, August, 2018, p.176 – https://apo.org.au/sites/default/files/resource-files/2018/08/apo-nid188761-1227101.pdf

[119] Andrew Denton, "Better Off Dead: #13 Now they're killing babies", podcast, Thought Fox and the Wheeler Centre, published online by the Wheeler Centre on 24 March 2016, (audio) https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/13-now-they-re-killing-babies
Transcripts available at Go Gentle Australia website – http://www.gogentleaustralia.org.au/transcripts2
Affirmation of 'no risk to vulnerable groups' comes from: Illya Soffer, director of *Lederin* (Everyone In) representing 250 organizations for disabled people in the Netherlands; Pierre Gyselinck. president of the Catholic Association of Persons with Disabilities, Flanders, and president of the Belgian Disability Forum; Bob Joondeph, executive director of Disability Rights Oregon; Joeri Veen, spokesperson for ANBO,representing about 180,000 senior citizens in the Netherlands; Mie Moerenhout, director of the Flemish Council of the Elderly; Cherrie Brounstein, vice president of the board for Elders in Action, Oregon.

So, the bar even to be considered eligible for VAD is extremely high. But it gets even higher.

Persuading Doctors to Risk Their Careers … or Worse

It is almost impossible for someone to fake the symptoms of an advanced incurable illness. Which means that the only way for this elderly relative to be coerced to die through this law is for both doctors to make a wrongful assessment.

We know that most doctors act ethically; that they take seriously their oath of 'do no harm'. But let's assume that these doctors don't. The question is why would not one, but two, highly trained doctors allow somebody who clearly wasn't eligible, but was being coerced to apply by someone else, to access VAD?

Perhaps the greedy relative has offered them a cut of the inheritance? Possible, but highly unlikely as it is illegal for doctors to advertise in any way that they might participate in VAD. So, the relative would be taking a huge chance approaching any doctor hoping they might want to join in a conspiracy to convince someone to end their life. The chances of him finding two are even smaller.

Let's assume both doctors are tempted to join a conspiracy. They would be doing so at enormous risk.

The moment someone tries to go through this legislation they're under the spotlight, with every step of the process being reported in real time.

Both doctors have mandatory reporting requirements under the law. Within 7 days of assessing the patient, each must report their assessment to the voluntary assisted dying review board.

After the third, written request which, incidentally, has to be witnessed in the presence of the doctor by two independent witnesses (neither of whom is a beneficiary in the will or is directly responsible for their health care), the doctor has to complete a certificate for authorisation to prescribe the lethal drugs. This goes to the Department of Health and Human Services who won't sign off on it unless they are satisfied that all the legal requirements have been met.

By law, you also have to appoint a contact person – someone you trust – whose responsibility it is to return the lethal medication should it remain unused. Medication which, by the way, is formally tracked at every stage of the process. The pharmacist will not prescribe the medication until they've received this authorisation.

Everything both doctors do is checked – and checked against each other. If they act in a way that arouses suspicion they can be reported to the coroner, the police, or the Australian Health Practitioners Regulation Agency.

And there are serious penalties – which did not exist before this law – for those who break it: For inducing someone to request VAD, 5 years. For falsifying records, 5 years. For failing to report, 6 months.

A Conspiracy or Extreme Negligence

So, for someone to be coerced to die using this law it would require a conspiracy, or extreme negligence, of the medical profession and the State. It would assume that the witnesses are in on the act. And the contact person. And possibly the pharmacist. And the Department of Health and Human Services.

It assumes that others in the circle of care – nurses, perhaps other relatives, and friends – are completely oblivious to the fact that the patient is going through a stringent application process for VAD.

Of course, humans are capable of terrible things, but to carry off such a conspiracy involving so many people would be harder than *Oceans 11.*

Far easier, if you wanted to coerce an elderly relative to die, would be to do it outside of the Victorian law – away from the spotlight. Encourage them to stop taking their medication – or to take too much of it – take an overdose, or walk in front of a train.

Far easier to do it in Queensland today where none of these requirements exist and where we know that doctors do illegally assist people to die.

2.5 Queensland's Existing End-of-Life Laws Currently Enable Abuse of Vulnerable People

It is appropriate to raise concerns about elder abuse and disability abuse and coercion. But it is morally wrong in doing so to raise *hypothetical* concerns about the abuse of vulnerable people, as your reason not to address evidence of *actual* abuse happening right in front of us. Evidence accepted by the Victorian and West Australian Inquiries clearly shows that vulnerable people are being mistreated and abused within our medical system because of our existing laws. The case studies offered in Sections B, C & APPENDIX of this submission describe this abuse in disturbing detail.

To force a vulnerable person to suffer a painful and drawn out death against their wishes is abuse. To leave a dying person a choice only between further treatment which has become intolerable or suicide is coercion.

2.6 A VAD law will protect vulnerable Queenslanders

Elder and disability abuse is a serious problem. It is only made possible by abusers acting in what they believe to be secrecy. Under existing law, when Queensland doctors illegally assist a person to die, we do not know if that person has been subject to abuse or coercion.

We do not know – and do not ask – if a dying person's decision to refuse treatment, food and water has been made under pressure, subtle or otherwise.

A VAD law makes such abuse less likely, not more, by bringing practices that are currently happening in secrecy, into the light. It encourages better practice. It brings regulation and scrutiny to a space which is currently unregulated. It offers Queensland's vulnerable protections that they currently do not have.

It is not the prospect of VAD laws that heighten the risk of mistreatment and abuse, but rather their absence.

MYTH #3. VAD CREATES SUICIDE CONTAGION

3.1 The Argument

Opponents of VAD cite a phenomenon called 'suicide contagion', to suggest that voluntary assisted dying leads to an increase in suicides.

3.2 The Reality

There is no credible evidence of increased suicide rates as a result of assisted dying laws overseas. The Western Australian Parliamentary Inquiry 2017/18 found:

> Suggestions of suicide contagion are not supported in the evidence.[120]

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[120] A Sanderson (MLA) and Hon. C J Holt (MLC), "Report 1 - My Life, My Choice: The Report of the Joint Select Committee on End of Life Choices: 'Suggestion of suicide contagion are not supported in the evidence'", 40th Parliament, Parliament of Western Australia, August, 2018, p.179 – https://apo.org.au/sites/default/files/resource-files/2018/08/apo-nid188761-1227101.pdf

> Moreover, the data in European jurisdictions with assisted dying frameworks indicates that suicide rates either remained the same or fell. A 2014 Swiss government report shows that the suicide rate per 100,000 individuals has decreased steadily since 1942.[121]

In particular, claims have been made about 'suicide contagion' in Oregon, where Voluntary Assisted Dying has been legal for 21 years. Here is Father Anthony Kerin, episcopal vicar for life, marriage and family, representing the Catholic Archdiocese of Melbourne, testifying before the Victorian Inquiry into End-of-Life Choices:

> We have noted, for example, since Oregon legislated, that the standard suicide rate has increased remarkably and alarmingly ... when Oregon had a very, very low suicide rate prior to that. It is not yet the largest rate in the US, but it's getting there.[122]

Here is Oregon's State Health Officer, Katrina Hedburg, discussing allegations of a connection between Oregon's suicide rate and their Death with Dignity Law:

> So, we do track suicide, just like we track death with dignity, and suicides in Oregon have been higher than the national rate but that's been going on for ... decades. **We have not seen any change in the statistics around rates of suicide in Oregon before or after the Death with Dignity Act took place.**
>
> In Oregon ... the risk factors for suicide include a history of depression; of mental illness; previous suicide attempts. We know who is particularly at risk: older men who might be without their wife or their wife has died; veterans are at high risk of suicide. [We] have a number of groups and they're very different from the number who participate in Death with Dignity: equal parts men and women; the average age of 70; many of them are married and they have all been diagnosed with a terminal illness by definition otherwise they could not participate. **So I would say that there is nothing in our data to show that.**[123] [Our emphasis]

3.3 It is wrong to conflate Voluntary Assisted Dying with suicide

This is a deliberate, and false, conflation of two very different acts. This difference was underlined by the Western Australian Parliamentary Committee:

> It is important not to conflate suicide with assisted dying. It is possible to distinguish temporary suicidal ideation from an enduring, considered and rational decision to end one's life in the face of unbearable suffering.[124]

It is a difference that was clearly understood by the Chief New York Medical Examiner, Charles Hirsch, when investigating the deaths of office workers who jumped from the Twin Towers on 9/11.

Faced with a terrible choice – a slow, agonising death by fire, or a quick death by jumping – many chose to jump. Seeing this as a rational choice to avoid needless suffering, Hirsch refused to classify their deaths as 'suicides'.[125]

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[121] A Sanderson (MLA) and Hon. C J Holt (MLC), "Report 1 - My Life, My Choice: The Report of the Joint Select Committee on End of Life Choices: 5.110 'Suggestion of suicide contagion are not supported in the evidence'", 40th Parliament, Parliament of Western Australia, August, 2018, p.180 – https://apo.org.au/sites/default/files/resource-files/2018/08/apo-nid188761-1227101.pdf

[122] Standing Committee on Legal and Social Issues, "Inquiry into end-of-life choices", Transcript, Parliament of Victoria, Melbourne, 18 November, 2015, p.20 – https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/ELC_Transcripts/18112015_CORRECTED_EoLC_-_Catholic_Archdiocese.pdf

[123] Katrina Hedburg in Andrew Denton, "Better Off Dead: #9 Death with dignity in Oregon", podcast, Thought Fox and the Wheeler Centre, published online by the Wheeler Centre on 17 March, 2016, (audio) – https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/9-death-with-dignity-in-oregon
Transcript at Go Gentle Australia website – https://www.gogentleaustralia.org.au/transcripts1

[124] A Sanderson (MLA) and Hon. C J Holt (MLC), "Report 1 - My Life, My Choice: The Report of the Joint Select Committee on End of Life Choices: 5.103 'Distinguishing between suicide and assisted dying'", 40th Parliament, Parliament of Western Australia, August, 2018, p.177 – https://apo.org.au/sites/default/files/resource-files/2018/08/apo-nid188761-1227101.pdf

[125] Vickers, Matt, *Lucretia's Choice: A Story of Love, Death and the Law*, Text Publishing, 29 August, 2016, p. 231 – http://tinyurl.com/y36mt867

3.4 VAD laws offer a compassionate alternative to suicides happening in Australia every week

While 'suicide contagion' as a result of VAD laws is made up, suicides in Australia for those beyond the help of palliative care are not.

Evidence to the Victorian Parliamentary Inquiry from the Coroner's Office showed that, faced with the fear of an agonising death or with unmanageable suffering, terminally ill Victorians are committing suicide at the rate of one a week.[126] In Western Australia, the Parliamentary Inquiry found 10 per cent of all suicides in that State were by people with terminal or debilitating chronic illnesses.[127]

Former police officer Laurie Paul told the current Queensland Parliamentary Inquiry of attending countless suicides in his long career. But, he says, one in Townsville has stayed with him.

> We were directed to the back yard shed. There lay an elderly gentleman who had suicided – his elderly wife and family grieved for him upstairs.
>
> He had recently been advised that he had cancer and in his loving note to his wife of many years, outlined that he was of the view that he did not wish for her to suffer as he slowly died in front of her, and that she would have to nurse him in the last years of their lives.
>
> This was wrong and a sad indictment on our society.[128]

MYTH #4. VAD WILL DAMAGE THE DOCTOR-PATIENT RELATIONSHIP

4.1 The Argument

Those who oppose Voluntary Assisted Dying often refer to it as 'patient killing' and claim doctors' involvement in it violates the doctor-patient relationship.

4.2 The Reality

In countries where such laws have existed now for two decades, research shows that the opposite is true.

The latest (2017) OECD report on the Netherlands notes that satisfaction with health care in the Netherlands is high – 86% – compared to 70% across the OECD.[129]

Of Belgium in 2017, the OECD reports:

> Citizen satisfaction is among the highest ... at 90% of citizens satisfied ... significantly higher than the OECD [average], which amount[s] to 70% in the case of health care ... [130]

In Oregon, former President of the Oregon Medical Association, Dr Leigh Dolin, states that the work of doctors in end-of-life care has been better since VAD was legalised:

> I think we do a much better job because of this law ... Oregon's law has been a dramatic success. The dire fears that doctors would become less trusted, or worse, just hasn't happened.[131]

In her 2012 Churchill Fellowship Report, Australian palliative care physician Dr Linda Sheahan reported

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[127] A Sanderson (MLA) and Hon. C J Holt (MLC), "Report 1 - My Life, My Choice: The Report of the Joint Select Committee on End of Life Choices: 'Chair's Foreword'", 40th Parliament, Parliament of Western Australia, August, 2018, – https://apo.org.au/sites/default/files/resource-files/2018/08/apo-nid188761-1227101.pdf

[128] Tracey Ferrier, "Qlders appeal for assisted dying laws", *Stawell Times*, 26 March, 2019 – https://www.stawelltimes.com.au/story/5975032/qlders-appeal-for-assisted-dying-laws/?cs=9397

[129] OECD, "Government at a Glance 2017: Country Fact Sheet - Netherlands: 'Satisfaction and confidence across public services (2016)'", 2017 – http://www.oecd.org/gov/gov-at-a-glance-2017-netherlands.pdf

[130] OECD, "Government at a Glance 2017: Country Fact Sheet - Belgium", 2017 – http://www.oecd.org/gov/gov-at-a-glance-2017-belgium.pdf

[131] Leigh Dolin in Andrew Denton, "Better Off Dead: #9 Death with dignity in Oregon", podcast, Thought Fox and the Wheeler Centre, published online by the Wheeler Centre on 17 March, 2016, (audio) – https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/9-death-with-dignity-in-oregon
Transcript at Go Gentle Australia website – https://www.gogentleaustralia.org.au/transcripts1

no erosion of trust in doctors where assisted dying/voluntary euthanasia are legal:

> While I recognise and understand this fear, I do not believe it has been validated by the experiences of doctors and patients in jurisdictions where assisted death is legalised. There has been no erosion of trust, and not one clinician I spoke to felt that it had damaged the trust inherent in the doctor patient relationship.
>
> Indeed, the individual cases of physician assisted death tended to arise out of that trust, helping doctors shift their thinking to encompass assisted death, where it may have traditionally conflicted with their sense of moral responsibility.
>
> Many opponents to legalisation who feared this effect felt that this fear had eased since legalisation, and there were many stories of 'that one patient' with whom the trust and relationship were strong enough for the clinician to consider assisted death in that particular circumstance, despite their previous opposition. It was highly reassuring when PAS/VE arose out of this trust, rather than externally via a notion of pure patient 'right' to access assistance in dying.[132]

Neither do many Australian doctors fear damage to the doctor-patient relationship, as a 2016 AMA survey of members found:

> A majority (51.55 per cent) agreed that 'euthanasia can form a legitimate part of medical care'. And 45.43 per cent agreed that 'physician assisted suicide can form a legitimate part of medical care', while 13.32 per cent neither agreed nor disagreed.[133]

This is perhaps best summed up by Professor Ian Maddocks, Australia's most eminent palliative care physician, who believes that assisting someone to die can be a loving act:

> Voluntary assisted dying and palliative care go together. They have similar aims in relief of distress, and need to espouse similar approaches of compassion, lack of haste, involvement of family, transparency, clear consent, open reporting.
>
> The existence of such a law would have made me a better palliative care physician.
>
> It would have allowed me to travel through to the end with a patient under my care, who elected for Voluntary Assisted Dying.
>
> It is against proper loving medical practice, to have rigid provisos that limit what can be done.[134]

MYTH #5. PEOPLE ARE CHOOSING TO DIE BECAUSE THEY FEEL LIKE A 'BURDEN'

5.1 The Argument

Opponents of VAD argue that people in Oregon are using the Death with Dignity law to die, not because they are in pain, but because they fear becoming a burden to others.

Typically, they reference a 2006 review of the empirical literature on Oregon which states:

> In the most recent report published by the Oregon Public Health Division, of the 132 deaths for which data was available, 48% listed being a burden on family, friends or caregivers as a concern.[135]

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[132] Linda Sheahan, "The Dorothea Sandars and Irene Lee Churchill Fellowship to study the interface between Palliative Care and legalized Physician Assisted Suicide and Voluntary Euthanasia", The Winston Churchill Memorial Trust of Australia, 30 May, 2013, p.64 – https://www.churchilltrust.com.au/media/fellows/2012_Sheahan_Linda.pdf

[133] Robyn Maggs, "Pain, Choice and the Art of Dying with Dignity", *The Mercury*, 1 March, 2018 – https://www.themercury.com.au/news/opinion/pain-choice-and-the-art-of-dying-with-dignity/news-story/0304ece1d4e4e4d9c792c61ab0c5947e?fbclid=IwAR2WH1VXfwJX4774mF1J-BgE5bEQ7UalSJWMW3iVYy90bo58QJNc4EN-DqM

[134] Ian Maddocks quoted in Andrew Denton, "The Damage Done", Transcript of an address to the Literary Festival of Phillip Island, Victoria, 9 June, 2017 – http://www.dwdnsw.org.au/wp-content/uploads/2017/06/Denton-address-Phillip-Island-June-2017.pdf

[135] Oregon Public Health Division, "Oregon Death with Dignity Act: 2015 Data Summary", Oregon Health Authority, 4 February, 2016, p.6 – https://www.oregon.gov/oha/ph/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year18.pdf

5.2 The Reality

The information is correct. But, stripped of its context, the conclusion is misleading. On this question there are two other issues at play:

1. Where 'being a burden' sits on a patient's list of concerns.
2. What patients mean when they say they do not want to be a 'burden'.

'Being a burden' is not the only – or even the main – motivating factor in patients' decisions to avail themselves of Oregon's Death with Dignity option. The table below shows how low it rates on patients' overall list of concerns. 63.3 per cent of patients considered it a factor in contrast with the 95.1 per cent of patients, overall, for whom 'losing autonomy' was their important concern.

Figure 5: Characteristics – End of Life Concerns, Oregon Death with Dignity Act Data Summary 2018 [136]

Characteristics	2018		Total	
	(N=168)		(N=1,459)	
End of life concerns				
Losing autonomy (%)	154	(95.1)	1,322	(95.5)
Less able to engage in activities making life enjoyable (%)	152	(95.6)	1,300	(94.6)
Loss of dignity (%)	112	(79.4)	989	(87.4)
Losing control of bodily functions (%)	62	(46.3)	647	(56.5)
Burden on family, friends/caregivers (%)	91	(63.6)	654	(51.9)
Inadequate pain control, or concern about it (%)	43	(31.2)	375	(29.8)
Financial implications of treatment (%)	9	(7.3)	57	(4.7)

Read together, and *in context*, these two statistics support a different explanation of 'fear of being a burden' than opponents wish to convey.

George Eighmey was a member of the Oregon House of Representatives at the time their Dying with Dignity law was introduced in 1997. Mr Eighmey holds both bachelor of science and juris doctor degrees and is an attorney by profession.

He currently serves as president of America's Death with Dignity National Center. In both roles, he has been intimately involved in the end-of-life journeys of terminally ill patients and their families.

We asked Mr Eighmey to provide some clarity on the charge that Oregonians were choosing early deaths because they feared becoming a burden to their families. His response was that **this is an 'egregious' misrepresentation of the data.**

He reminded us that the list of reasons for using the law is a multi-choice *ranking*: 'Not wanting to be a burden' may be one of several answers supplied by patients. As we can see above, it is well down the list of reasons for seeking Physician Assisted Dying.

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[136] Public Health Division, Centre for Health Statistics, "Oregon Death with Dignity Act: Data Summary 2018", Oregon Public Health Authority, 25 February, 2019, p.12 – https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year21.pdf

Mr Eighmey rejects the implication that the 'burden' response means patients are acting against their own interests. Instead, he explains that concern about being a 'burden' relates to patients' grief at their loss of independence. It reflects a declaration by independent, self-reliant individuals, who do not *want* to be in the position of being 'waited on'.

Mr Eighmey further stated:

> These people in no way are made to feel a burden, in fact it is the exact opposite. Family members and care givers repeatedly assure the patient that they wish to take care of them and that [it] is an honor and privilege to do so. It is the patient who, despite appreciating the offer, still wishes to be independent.[137]

A balanced reading of the data suggests patients' concerns about being 'a burden' must be viewed within the context of their greater concerns about their loss of autonomy, dignity, control of bodily functions, and the many things which make life ... *life*. Altogether – including being a burden (remember, more than one category can be chosen) – these constitute *suffering*.

Most importantly, they must be viewed within the overriding context that the patient is dying.

Under Oregon law – and the Victorian VAD law due to come into effect in June 2019 – you can only access VAD if, according to the independent assessment of two doctors, you are terminally ill with six months or less to live (or 12 months in Victoria if you have a neurodegenerative illness).

In Oregon, all of the concerns on the list patients are asked to choose from – loss of autonomy, loss of dignity, burden on family, etc – sit within this all-embracing reality: a human being who is dying and who is suffering.

Nobody – not a single person – accessed voluntary assisted dying in Oregon because they felt like a burden.

They didn't choose to die because they felt like a burden.

They ticked 'being a burden' as just one of their end of life concerns because they were dying.

MYTH #6. THE LEGALISATION OF VAD MEANS THAT PALLIATIVE CARE WILL SUFFER

6.1 The Argument

Critics argue that the availability of Voluntary Assisted Dying will mean there is less funding, and less need, for palliative care.

6.2 The Reality

The existence of VAD laws in overseas jurisdictions does not result in a decline in palliative care. In fact, the exact opposite is true and Palliative Care Australia's own research says so.

Their October 2018 Report 'Experience Internationally of the Legalisation of Assisted Dying on the Palliative Care Sector', found:

> no evidence to suggest that the palliative care sectors were adversely impacted by the introduction of the legislation. **If anything, in jurisdictions where assisted dying is available, the palliative care sector has further advanced.**[138] [Our emphasis]

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[137] George Eighmey, email to Andrew Denton, Go Gentle Australia, 16 May, 2017.

[138] Aspex Consulting, "Experience internationally of the legalisation of assisted dying on the palliative care sector - Final Report 28", Palliative Care Australia, October, 2018, p. 5 – https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/12/Experience-internationally-of-the-legalisation-of-assisted-dying-on-the-palliative-care-sector-APEX-FINAL.pdf

According to the report, physicians in locations where VAD laws operate (Oregon, Washington State, the Netherlands, Belgium, Canada and the Canadian province of Quebec) have sought to improve their knowledge and understanding of end-of-life care support services, and access to palliative care has improved.

One of the 'key learnings' identified by the PCA report[139] (p.7) is:

> ... that the implementation of legislation may drive a stronger focus on upholding patient choice and autonomy, and there may be opportunities to introduce system improvements in palliative care, either as a direct or indirect consequence of the planned implementation of assisted dying.

The report notes (pp. 19-20) that in Oregon and in Washington State there has been an increase in the proportion of hospitals with a palliative care team since the introduction of VAD laws – 93% of all hospitals in Washington State and 89% of all hospitals in Oregon. This is high compared to the wider Pacific Coast region (77%) and the US as a whole (67%).

After Canada passed VAD legislation in 2016, the federal government committed $6 billion over 10 years for home and palliative care.

In Belgium, a 2014 study found the government's expenditure on palliative care had increased by an annual rate of 10 per cent since its VAD law was passed in 2002 and assisted dying is now integrated into palliative care.

In the Netherlands, palliative care has grown remarkably beside assisted dying, so much so that it is now almost on a par with the United Kingdom in terms of standard of palliative care, and ahead of the other countries without VAD legislation including Spain, France and Germany.

In Oregon, hospice care, initially opposed to change, has come to endorse assisted dying as a patient right, and an additional string to their palliative bow.

In 2018, 90.9 per cent of Oregonians who accessed Voluntary Assisted Dying were also in hospice care (p.5).

Professor Ian Maddocks, Australia's most senior palliative care physician, believes Australian palliative care will see a similar improvement after the introduction of VAD laws:

> Fears [by Palliative Care] of loss of reputation, trust and funding are quite unfounded. Palliative Care stands to gain in recognition and support through the introduction of VAD in Australia, just as has occurred overseas. Of the small number of dying persons who will consider the option of VAD (as many now do), only a tiny minority will satisfy its strict eligibility criteria. Most, if not all, will benefit from the continuing availability of Palliative Care.[140]

For more about the positive impact of VAD on palliative care around the world, read Australian palliative care physician Dr Linda Sheahan's 2012 Churchill Fellowship report on the impact of VE and VAD laws on palliative care in Europe and North America.[141]

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[139] Aspex Consulting, "Experience internationally of the legalisation of assisted dying on the palliative care sector - Final Report 28", Palliative Care Australia, October, 2018, pp. 5, 7 and 19-20 – https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/12/Experience-internationally-of-the-legalisation-of-assisted-dying-on-the-palliative-care-sector-APEX-FINAL.pdf

[140] Ian Maddocks, Correspondence with Go Gentle Australia, 2017

[141] Linda Sheahan, "The Dorothea Sandars and Irene Lee Churchill Fellowship to study the interface between Palliative Care and legalized Physician Assisted Suicide and Voluntary Euthanasia", The Winston Churchill Memorial Trust of Australia, 30 May, 2013, p.64 – https://www.churchilltrust.com.au/media/fellows/2012_Sheahan_Linda.pdf

MYTH #7. VAD LEADS TO ‘DOCTOR SHOPPING’

7.1 The Argument

Patients who may be refused access to voluntary assisted dying by their doctor continue to seek out other doctors until they find one keen to help.

7.2 The Reality

The law that passed in Victoria in 2017 specifically permits physicians to ‘opt out’ without sanctions or criticism. This may be on the grounds of religion. It may be because they are unwilling to participate in a process that is unfamiliar to them, because they have not been trained to the level the law requires, or because they view it as against their Hippocratic oath. Whatever their reason, a doctor has an absolute right not to participate.

When a doctor opts out, the patient must seek out another doctor who is not opposed to, or uncomfortable with, the decision to seek access to the law. This is called exercising one’s right, not ‘doctor shopping’.

The Australian Medical Association Code of Ethics states:

> Respect your patient’s right to choose their doctor freely, to accept or reject advice and to make their own decisions about treatment or procedures.
>
> ... When a personal moral judgement or religious belief alone prevents you from recommending some form of therapy, inform your patient so that they may seek care elsewhere.[142]

Every patient has the right to pursue a legal medical intervention to relieve their suffering and to seek a second opinion. It is what a well-informed patient does when facing his/her options at the end of life.

Keep in mind:

- Regardless of how many doctors a person sees, the bar for access to Victoria’s law remains the same: Two doctors, making independent assessments of the patient, must determine that they are terminally ill and with six months or less to live (or 12 months in the case of a neurodegenerative disease).
- People who successfully access these laws in Victoria are at the end stages of terminal illness. To be prescribed life ending medication they have to go through multiple medical assessments and find witnesses to support their application. It is extremely difficult for a dying person to go through the process multiple times.
- The work of doctors who assess patients to determine their eligibility for VAD is closely scrutinised. If they do not comply with the law, they risk losing their license or being sent to jail.

7.3 North America: The Facts

Figures from North America do not support allegations of doctor shopping. In Oregon, in 2018, 249 prescriptions for life-ending medication were written by 103 physicians.[143]

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[142] Australian Medical Association, “AMA Code of Ethics”, 2004 (editorially revised 2006) – https://ama.com.au/sites/default/files/documents/AMA_Code_of_Ethics_2004._Editorially_Revised_2006.pdf

[143] Public Health Division, Center for Health Statistics, “Oregon Death with Dignity Act: 2018 Data Summary”, Oregon Health Authority, 15 February, 2019, p.7 – https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year21.pdf

In Washington State in 2017, medication was dispensed to 212 individuals by 115 different physicians.[144]

In California in 2017, 241 unique physicians prescribed 577 individuals aid-in-dying drugs.[145]

In Colorado in 2018, prescriptions for aid-in-dying medication were provided by 66 unique Colorado physicians to 125 patients.[146]

Palliative Care Australia's 2018 report 'Experience Internationally of the Legalisation of Assisted Dying on the Palliative Care Sector' [147] found that, in Oregon:

> The distribution frequency shows that of the physicians involved in writing prescriptions, just under two thirds (62%) wrote only 1 prescription, where only a handful (3%) of physicians wrote more than 10 prescriptions.

The report also found that, rather than shopping around, patients established a clear relationship with their doctors:

> The Oregon Health Authority also collects data on the median duration of the patient–physician relationship, which was just over three months (13 weeks) and ranged from 1 to 1,905 weeks.

It is important to keep in mind that, no matter how many doctors a patient sees, the bar never lowers. They can only access VAD if they are legally eligible.

In twenty years, there have been no successful prosecutions of doctors in North America for failing to comply with Death with Dignity laws.

MYTH #8. THE DRUGS DON'T WORK

8.1 The Argument

Opponents point to a handful of cases from North America in which patients regurgitated some of the lethal dose, and six regained consciousness after taking the drugs and died later. This, they say, is evidence of the failure of the life-ending drug.

These were summarised in the Palliative Care Australia, report, 'Experience Internationally of the Legalisation of Assisted Dying on the Palliative Care Sector' as:

> In the US state of Oregon, over the period 1998 to 2015, there were complications reported for 2.4% of cases involving regurgitation of medication. A further 0.7% of patients regained consciousness after ingesting lethal medications.
>
> A small number of patients are reported to have a lapse in time between ingestion and death with the median time between ingestion of lethal medication and death 25 minutes but the range extending to more than four days. In Washington State, 67% died within 90 minutes with a range extending to 30 hours.[148]

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[144] Center for Health Statistics, Washington State Death with Dignity Act Report", Washington State Department of Health , Disease Control and Health Statistics Division, March, 2018, p.1 – https://www.doh.wa.gov/Portals/1/Documents/Pubs/422-109-DeathWithDignityAct2017.pdf

[145] California Department of Public Health, "California End of Life Option Act 2017 Data Report", California Government, June, 2018, p. 3 – https://www.cdph.ca.gov/Programs/CHSI/CDPH%20Document%20Library/2017EOLADataReport.pdf

[146] Center for Health and Environmental Data, "Colorado End-of-Life Options Act, Year Two 2018 Data Summary, with Updates to 2017 Data", Colorado Department of Public Health and Environment, 2018, p.2 – https://www.deathwithdignity.org/wp-content/uploads/2015/10/2018-CO-End-of-Life-Options-Act-Annual-Report.pdf

[147] Aspex Consulting, "Experience internationally of the legalisation of assisted dying on the palliative care sector - Final Report 28", Palliative Care Australia, October, 2018, p.23 – https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/12/Experience-internationally-of-the-legalisation-of-assisted-dying-on-the-palliative-care-sector-APEX-FINAL.pdf

[148] Daniel Mulino, "Minority Report: Chapter 4.6.8 'Failure of drugs performing as designed'", in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report'", June, 2017 – https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf

8.2 The Reality

- The life ending drugs have worked in 1127 cases out of 1133 cases in Oregon (1998-2016) and all cases in Washington.[150]
- A success rate in Oregon of 0.997 is considered by any medical rating as almost perfect.
- The regurgitations mentioned are not failures, they are simply cases where the patient had a slight negative reaction to the bitter taste of the medication or had been nauseous prior to taking the medication or had some form of blockage, but nonetheless they died peacefully.
- In six cases in Oregon where patients awakened, they may have ingested only a portion of the medication before they fell asleep, or they may have mixed the medications too far in advance and let it sit on a shelf, which caused a decrease in potency or crystallisation. In one case, more than 15 years ago, an inadequate dose for the patient's weight was prescribed.
- No medical procedure is perfect. A 0.997 level of success is extraordinarily high. A failure rate of 0.003% is not a valid argument against VAD.

MYTH #9. VAD BREAKS A DOCTOR'S OATH TO 'DO NO HARM'

9.1 The Argument

Many doctors cite the Hippocratic Oath 'to do no harm' as their reason for not supporting VAD. They believe that their job is to heal people, not assist them to die. It is a passionately held view and they are entitled to it.

9.2 The Reality

There are also many doctors who cite 'do no harm' as their reason for supporting VAD. They see it as the definition of harm to leave a dying patient to suffer when they have the means to help ease that suffering.

These are two powerful, but different, ethical views. Neither are wrong, but the law, as it currently stands in Queensland, only supports one.

A VAD law – by exempting those against from ever having to participate, while protecting those in favour, should they help a patient to die – acknowledges that both views are legitimately held.

9.3 Where Does the Australian Medical Profession Stand on Voluntary Assisted Dying?

The Australian Medical Association

The AMA, which represents less than one-third of Australian doctors, has released a position paper on VAD that states:

> Doctors should not be involved in interventions that have as their primary intention the ending of a person's life ... but that it is ultimately a matter for society and government.[151]

According to the AMA's Code of Ethics[152], doctors are obliged to:

> Respect the right of a severely and terminally ill patient to receive treatment for pain and suffering, even when such treatment may shorten a patient's life

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[150] Public Health Division, Center for Health Statistics, "Oregon Death with Dignity Act Data Summary 2016", Oregon Health Authority, Public Health Division, 10 February, 2017, p.10 – https://www.oregon.gov/oha/ph/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year19.pdf

[151] Australian Medical Association, "AMA Releases Position on Euthanasia and Physician Assisted Suicide", AMA, 5 December, 2016 – https://ama.com.au/edit-newsletter/ama-releases-position-euthanasia-and-physician-assisted-suicide

[152] Australian Medical Association, "AMA Code of Ethics", 2004 (editorially revised 2006) – https://ama.com.au/sites/default/files/documents/AMA_Code_of_Ethics_2004._Editorially_Revised_2006.pdf

The AMA Code of Ethics also recognises patient autonomy and states:

> Doctors should respect the patient's right to make their own health care decisions. This includes the right to accept, or reject, advice regarding treatments and procedures including life-sustaining treatment.

A survey of AMA members in 2016 found that:

- 51% agreed that VAD can form a legitimate part of medical care.
- 52% disagreed that "allowing doctors to lawfully provide euthanasia will negatively affect the trust patients have in doctors"
- almost 70% agreed that "there are patients for whom palliative care or other end of life care services cannot adequately alleviate their suffering".[153]

The Royal Australian College of GPs

The RACGP's submission to the Western Australian Joint Select Committee on end-of-life choices stated that:

> The RACGP neither supports or opposes the introduction of laws to legalise voluntary assisted dying, we believe both patients and GPs must be appropriately supported if any legislation for voluntary assisted dying comes into the clinical setting.[154]

The Royal Australian College of Physicians

The RACP released a November 2018 statement saying that:

> Our members are not unanimous in their support or opposition for legislative change. The existence of divergent views constrains the RACP from developing a single position on the legalisation of voluntary assisted dying ... On the specific issue of a competent adult in the last stages of incurable illness requesting voluntary assistance to die, the RACP supports a clinical approach of critical neutrality to encourage reflective dialogue.[155]

The Australian Medical Students Association

AMSA, representing 17,000 medical students, issued a statement in support of VAD in 2017. It called for laws:

> implementing [VAD] in a restrictive way with appropriate safeguards to protect vulnerable patients.[156]

The Australian Nursing and Midwifery Federation

The ANMF's position statement on assisted dying says:

> [We] support legislative reform so that persons who have an incurable physical illness that creates unrelieved, unbearable and profound suffering shall have the right to choose to die with dignity in a manner acceptable to them and shall not be compelled to suffer beyond their wishes.[157]

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[153] Australian Medical Association, "Review of AMA Policy on Euthanasia and Physician Assisted Suicide - Member Consultation Report", 2016.

[154] Timothy Koh and Sean Stevens, RACGP, letter re 'End of Life Choices – Public Submissions' to Ms Amber-Jade Sanderson MLA, Chair, Joint Select Committee on End of Life Choices, Legislative Assembly, Western Australia, 19 October, 2017 – http://www.parliament.wa.gov.au/parliament/commit.nsf/(Evidence+Lookup+by+Com+ID)/C032ADE9BD8FAFF448258219000B496B/$file/20171019+-+EOLC+-+Sub+435+-+The+Royal+Australian+College+of+General+Practitioners.pdf

[155] Royal Australian College of Physicians, "Statement on Voluntary Assisted Dying", November, 2018 – https://www.racp.edu.au/docs/default-source/advocacy-library/racp-voluntary-assisted-dying-statement-november-2018.pdf?sfvrsn=761d121a_4

[156] Kate Aubusson, "Medical students declare support for euthanasia, opposing AMA stance", WA Today, 25 October, 2017 – https://www.watoday.com.au/healthcare/australian-medical-students-association-throw-support-behind-voluntary-assisted-dying-putting-them-at-odds-with-amas-euthanasia-stance-20171025-gz7ngg.html

[157] Australian Nursing & Midwifery Federation, "ANMF Position Statement: Assisted Dying", reviewed and re-endorsed November, 2016 – http://anmf.org.au/documents/policies/PS_Assisted_Dying.pdf

9.4 The Hippocratic Oath: Some Background

The Hippocratic Oath was written by the Greek physician Hippocrates. Historically it has been an oath taken by doctors around the world.

Originating 2400 years ago, it begins by swearing allegiance to ancient Greek Gods, forbids women from entering the profession, outlaws surgery and requires doctors to train the sons of their friends free of charge.

The central idea of 'do no harm' contained within it is not always possible for doctors in practice.

Many medical procedures, such as chemotherapy, have side effects, and doctors may need to evaluate harms and benefits before advising a course of action.

Although doctors are expert advisers, it is the patient who makes the ultimate decision on which treatment, or none, represents the greater benefit and lesser harm. For example, an incurably ill patient with unremitting suffering may decide, after consultation and advice, that refusing any further treatment is the lesser harm.

In 2017, the World Medical Association revised the Declaration of Geneva, the modern successor to the Hippocratic Oath, which is more commonly used today by physicians across the world.[158]

The revised Declaration reflects changes over the decades in the relationship between physicians and their patients and between physicians themselves.

It makes specific reference for the first time to respecting the autonomy of the patient

9.5 Why VAD encourages better medical practice

We know from evidence accepted by both the Victorian and Western Australian Inquiries into end-of-life care that doctors illegally assist people to die throughout Australia. However, as the Victorian Inquiry found, they must do so:

> ... without regulation, without support, without transparency or accountability, and from the evidence received, sometimes without consent.[159]

When the leadership of the AMA argues against a Voluntary Assisted Dying law, what they are actually arguing for is that it is OK for doctors to keep practising in a way that is illegal and which leaves both them and their patients vulnerable as a result.

And even when doctors abide by the law, their patients remain vulnerable.

The 2016 Victorian Parliamentary Inquiry heard many accounts of "irremediable pain despite receiving palliative care". It reported that:

> ... some health practitioners are uncertain about the law relating to administration of pain relief which may have the unintended effect of ending a patient's life.[160]

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[158] World Medical Association, "WMA Declaration of Geneva", 9 July, 2018 – https://www.wma.net/policies-post/wma-declaration-of-geneva/

[159] Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report: 'Chapter 8 - Victoria Should Legalise Assisted Dying'", June, 2017, p. 207 – https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/EOL_Report/LSIC_58-05_Text_WEB.pdf

[160] Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report: Section 7.2.1: Protecting Lawful Medical Practice of Doctors", June, 2017, pp.181-186, – https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/EOL_Report/LSIC_58-05_Text_WEB.pdf
Based on submissions from: Australian Centre for Health Research, *Submission*, p. 6; Dr Ric Milner, General Practitioner, You Yang, Western Victoria Primary Health Network, *Transcript of evidence*, 29 July 2015, p. 37; Georgie Haysom, Head of Advocacy, Avant Mutual Group, Transcript of evidence, 25 November 2015, p. 11.

It found that doctors may be inhibited from ordering adequate pain relief – it only takes one complaint for a doctor to be in serious trouble. Thus, under-treatment of pain and other suffering at the end of life is common in nursing homes, hospitals and even in palliative care.

The fundamental reason for this inadequate treatment is lack of communication between patients, families and doctors about end-of-life matters. Many doctors close down such conversations because of potential legal or Medical Board problems. Even if willing to have a dialogue, they are frustrated by the current 'dead end' to such discussion – the lack of a legal option, or the ability to provide 'a key to the fire escape'.

The fact is that no doctor has been prosecuted in Victoria for hastening death in the last 60 years, but the fear of such prosecution is real, and damaging for patients.

If doctors don't feel protected, their patients will suffer.

9.6 Doctors are Not Being Asked to 'Kill'

Doctors who object to VAD portray it as though they are being asked to 'kill' a patient. In reality, under Victorian law what they're being asked to do is what they already do – make a careful diagnosis that a patient's condition is terminal, at its end stages, that their suffering is intolerable, and inform them of their treatment options.

If the patient meets the legal requirements for assistance to die, they write them a prescription. After that, it is up to the person whether or not they use it.

Only one person is being asked to make a life and death decision. Not the doctor. The person who is dying.

Even in the rare cases where the doctor administers the dose, because the dying patient can no longer swallow or ingest, they do so at the voluntary request of that patient.

A doctor's mission statement doesn't suddenly change under this law. They still want to alleviate suffering. Determining whether a patient is eligible for Voluntary Assisted Dying is no more a life and death decision than those already taking place between patients and doctors every day around Australia, such as removing life sustaining measures and ceasing futile treatment.

In fact, in many ways, it is less. Whereas ceasing futile treatment or removing life sustaining measures will inevitably lead to the patient's death, the offer of assistance to die has no such certainty. We know this from Oregon where more than 30 per cent of those provided with the lethal prescription choose not to take it.[161]

Of course, those doctors who ethically object need never participate. The very core of this law is that it is voluntary – for doctors as much as everyone else.

However, for those doctors currently faced with the agonising choice between secretly helping a patient to die and breaking the law – or abiding by the law and leaving that patient to die with great suffering – a VAD law provides protection. More than protection, it provides guidance and the opportunity to consult with colleagues and also the family of the person who is dying.

VAD is not a choice between life and death. It is a choice about the manner and timing of death.

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[161] In Oregon in 2018, 249 prescriptions were provided to dying Oregonians who qualified for the Act but only 168 people died using the medications (including 11 who had received prescriptions the previous year), 81 people (32%) did not either fill or use their prescription. Public Health Division, Centre for Health Statistics, "Oregon Death with Dignity Act: 2018 Data Summary", Oregon Health Authority, 15 February, 2019, p.3 – https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year21.pdf

Part E

Fear. Uncertainty. Doubt.

Tactics used to create an alarmist picture of assisted dying

WHAT THIS SECTION IS ABOUT

Queensland MPs will experience often-repeated anti-VAD tactics and misinformation campaigns during the parliamentary inquiry process and the subsequent parliamentary debate.

Many of the core anti-VAD arguments are presented as scare campaigns led by religious lobby groups such as Right to Life, HOPE, and the Australian Christian Lobby. These groups are well-organised and funded, and have strong links to sister organisations overseas.

For 20 years opponents to assisted dying have used misleading, cherry-picked, and distorted information – quoting in support 'experts' with a clear but undeclared anti-VAD bias – to persuade politicians not to support VAD legislation.

But in this debate – as in other matters of public policy – facts matter.

How do we know what we're being told is real?

1. IS THE EVIDENCE RELIABLE?

Law professors Ben White and Lindy Willmott, from the Australian Centre for Health Research[162] at QUT, are the leading researchers in Australia of end-of-life laws. They have commented on the need for politicians (and the public) to focus on facts, not rhetoric, in the debate on assisted dying legislation.

White and Willmott argue there is a need to identify whether opinion is based upon values (for example, the importance of autonomy or the sanctity of life) as opposed to facts (for example, as gleaned from the experience of assisted dying in other jurisdictions).

They argue differences of opinion based on individuals having different values is understandable in a complex issue such as this. However, if an opinion purports to be influenced by facts, it is critical that these facts are accurate and informed by empirical evidence:

> A starting point is to distinguish between claims that something should or should not happen (a moral claim about right and wrong), and claims that something is or is not happening (a factual or empirical claim). This distinction matters, because what justifies each type of claim is different.
>
> For example, a claim that the bill should not be enacted because it is wrong for doctors to be involved in deliberately bringing about the death of a patient is a moral claim. This moral

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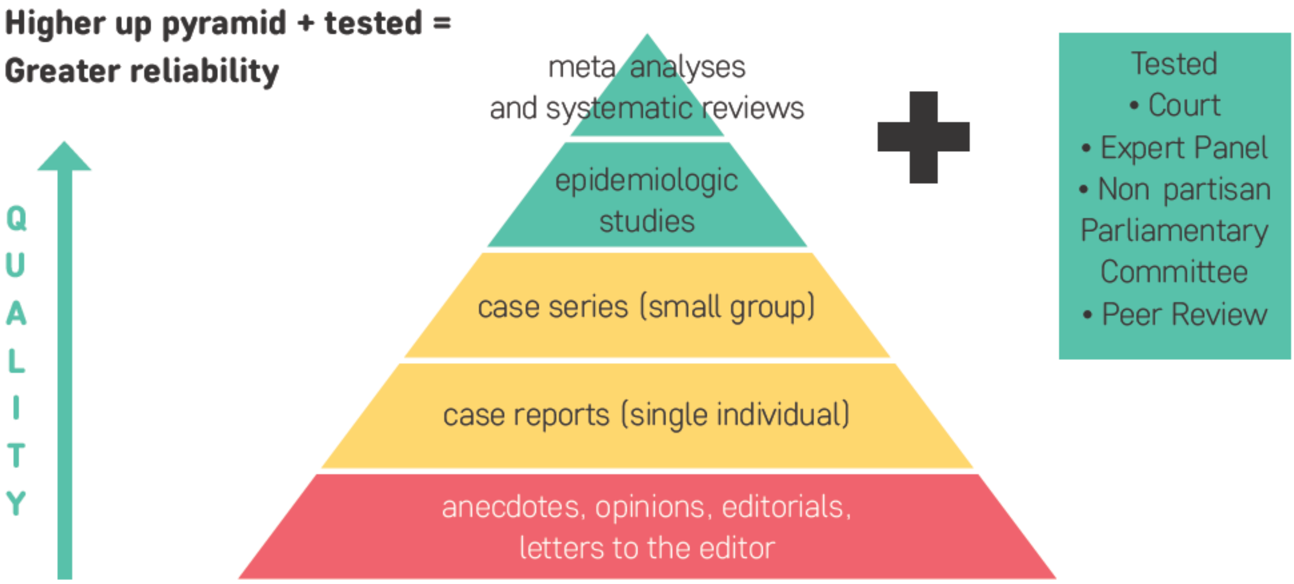
[162] Australian Centre for Health Research – https://www.qut.edu.au/law/research/achlr

> claim is based on values – that killing a person is always wrong, and/or it is wrong for doctors to be involved in such a practice.
>
> **Politicians should ask those making such claims what values they are relying on.** This allows them to assess if those values are justifiable in contemporary Australia, recognising that our society respects a plurality of viewpoints.
>
> On the other hand, a factual (or empirical) claim depends on evidence. For example, a claim that vulnerable people will be at risk if the bill is enacted is a factual claim. This claim should be supported by evidence, and politicians should ask the claimant for that evidence.
>
> If no evidence is provided for a factual or empirical claim, it should be ignored. If evidence is provided, the question then becomes: how reliable is it?[163] [Our emphasis]

White and Willmott argue that there are established ways to evaluate evidence, illustrated by the 'pyramid of quality' below.

Figure 6: The Pyramid of Evidence Quality (White and Willmott)



The researchers say key considerations include how high up the pyramid of quality the evidence is, and whether it has been robustly tested.

> An example of low-quality evidence is anecdotal evidence, which hasn't been independently verified, about a small number of cases in an overseas assisted dying regime.
>
> At the other end of the spectrum, high-quality evidence would be a peer-reviewed systematic review that analyses all existing research to determine what sorts of people are receiving assistance to die in a particular country.[164]

We would add an additional consideration: how recent is the evidence? Opponents of VAD laws have been known to present outdated data (sometimes pre-dating VAD laws) to lend weight to their claims. Evidence needs to be tested, not only for its accuracy, but also for its relevance.

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[163] Ben White, Andrew McGee and Lindy Willmott, "As Victorian MPs debate assisted dying, it is vital they examine the evidence, not just the rhetoric", The Conversation, 20 September, 2017 – https://theconversation.com/as-victorian-mps-debate-assisted-dying-it-is-vital-they-examine-the-evidence-not-just-the-rhetoric-84195

[164] Ben White, Andrew McGee and Lindy Willmott, "As Victorian MPs debate assisted dying, it is vital they examine the evidence, not just the rhetoric", The Conversation, 20 September, 2017 – https://theconversation.com/as-victorian-mps-debate-assisted-dying-it-is-vital-they-examine-the-evidence-not-just-the-rhetoric-84195

2. VICTORIA'S ASSISTED DYING LAW: EVIDENCE-BASED POLICY MAKING AT ITS BEST

In 2018, a first-time joint study by the 'right-wing' Institute of Public Affairs and 'left-wing' Per Capita Australia think tanks investigated 20 selected policy decisions in recent years by the federal Coalition government and the NSW Liberal and Queensland and Victorian Labor governments.

Seeking to assess the best examples of evidence-based policy making, they devised a set of ten criteria, including:

- Demonstrable, evidence-based need
- Public interest
- Consideration of alternatives, and
- Implementation choices

Despite differing outlooks, the IPA and Per Capita agreed overwhelmingly on what were good and bad policy processes.

Coming out at #1 – having passed nine of the ten criteria – was Victoria's Voluntary Assisted Dying legislation.[165]

For an insight into the kind of evidence which supported this legislation, go to PART G, Evidence Considered by the Victorian Committee into End-Of-Life Choices.

3. 'FUD': 5 TACTICS COMMONLY EMPLOYED TO CREATE AN ALARMIST PICTURE OF VAD

1. Manipulation of Official Figures
2. Selective Quoting from Official Reports to Suggest They Came to a Different Conclusion
3. Avoiding the Central Issue of 'Suffering' by Defining It Only as 'Pain'
4. Minimising Patient Distress: Assertions That 'Very Few Ask to Die'
5. Undisclosed Bias of Expert Sources

3.1 Tactic #1: Manipulation of Official Figures

3.1.1 The Tactic

Partially quoting from official reports to create an alarming, yet false, impression that euthanasia and VAD rates are growing uncontrollably. Here are two examples.

Creating a false impression of Voluntary Euthanasia in Europe

In Chapter 3 of his dissenting report to the Victorian Inquiry into End-Of-Life Choices, Final Report, MP Daniel Mulino opens by claiming:

> In all jurisdictions where euthanasia or assisted suicide is legal, there has been a sharp, sustained upward trend in the number of deaths – often over long periods of time.[166]

The following charts are used by Mulino to illustrate his claim of a sharp and sustained rise in Belgium and the Netherlands:

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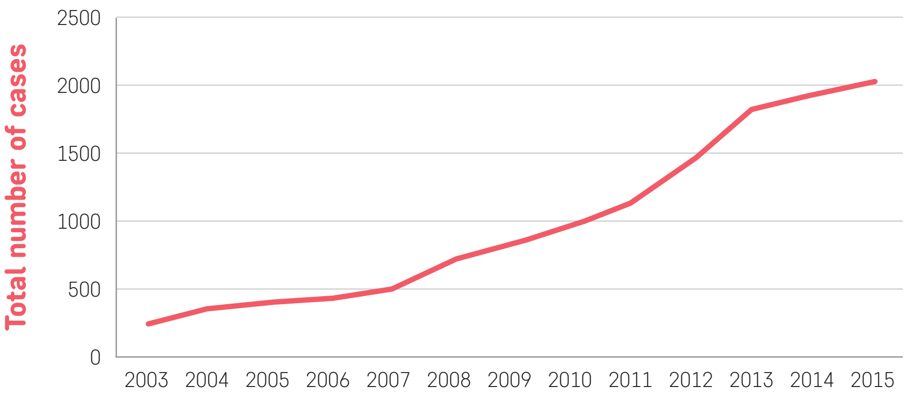
[165] Lesh, Matthew, "Evidenced Based Policy Research Project: 20 Case Studies", Institute of Public Affairs, October, 2018, p. 6 – https://ipa.org.au/wp-content/uploads/2018/10/IPA-Report-Evidence-Based-Policy-20-case-studies.pdf

[166] Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report', June , 2017, Chapter 3.1 'The frequency of euthanasia and assisted dying is rising rapidly' – https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf

Figures 7 and 8 (Figures 1 and 2 in Mr Mulino's minority report): Assisted deaths in Belgium and the Netherlands

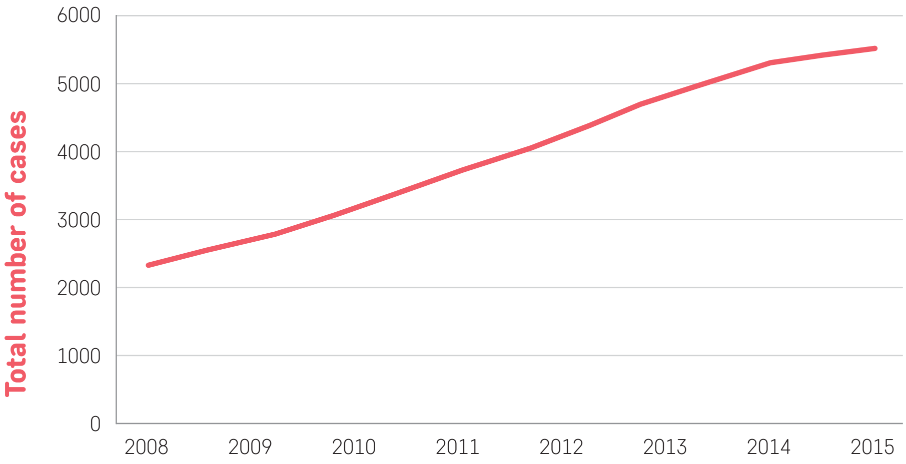
Figure 1: Belgium



Total Growth
2003 2015:
235 ⟶ 2012

Compound
Annual
Growth Rate:
19.6%

Figure 2: Netherlands



Total Growth
2008 2015:
2331 ⟶ 5516

Compound
Annual
Growth Rate:
13.1%

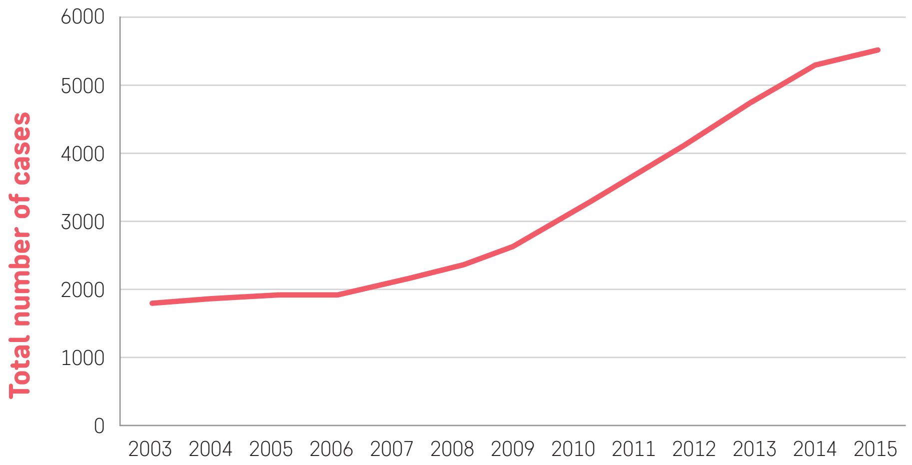
Taken at face value, they appear to confirm his claims. But closer inspection reveals crucial information that contradicts his analysis has been omitted.

Why does Mulino start Belgium's graph shortly after the introduction of their euthanasia Act, but only begins plotting the Netherlands data **five years after** their Act was introduced in April 2002? Why leave out the first five years? He offers no explanation.

But, when you factor in all the relevant data for the Netherlands (Figure 9, below), not just the years 2008–13, the reason becomes clear.

Figure 9: The full Netherlands assisted dying data, 2003-15 (Source - Official Euthanasia Commission reports) [167]

Figure 2: Netherlands



He has left out the first five years of Dutch euthanasia data, where the line is almost flat (and, indeed, shows a slight fall between 2005–06).

While it is true the graph still appears to show a relatively steep increase from around 2008, as an economist, Mr Mulino would know that, in statistics, context is everything. The raw data he presents is uncontextualised and offers no other explanation for an increase in numbers beyond assertions of a 'slippery slope'.

Euthanasia deaths do not occur within a statistical or societal vacuum. Mulino chooses not to include any of the following context:

- a predictably low initial take-up in the early years of the legislation
- a predictable increase in growth as patient and physician confidence in the process and safeguards increases
- population growth
- demographic changes (it is notable that the Global Financial Crisis occurred at about the same time as the upward trajectory begins, leading to greater stress-related disease and deaths)[168]
- terminal illness frequency
- reporting improvements
- the corresponding decrease in LAWER (life-ending acts without explicit request) deaths

Of more significance is Mulino's decision to omit data that is crucial if one is to make a balanced reading of the evidence.

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[167] Regional Euthanasia Review Committees (RTE), "Annual Reports, 2002-2015" – https://english.euthanasiecommissie.nl/documents/publications/annual-reports/2002/annual-reports/annual-reports

[168] See, for example, Nicola Mucci, Gabriele Girogi, Mattia Roncaioli, Javier Fiz Perex and Giulio Arcangeli, "The correlation between stress and economic crisis: a systematic review", Neuropsychiatric Disease and Treatment, 12, published online 21 April, 2016, pp.983–993 – https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4844458/

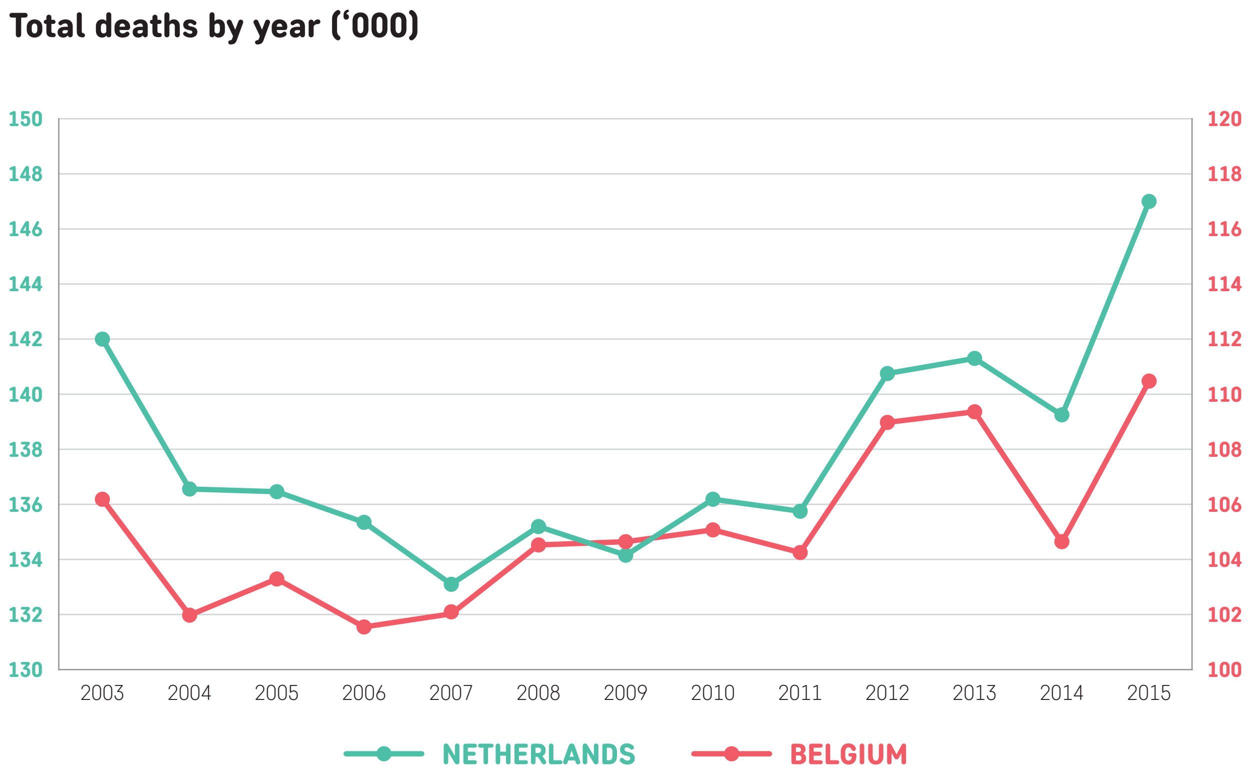
A Very Different Picture: Putting European Voluntary Euthanasia Figures in Full Context

In focussing solely on euthanasia deaths in Belgium and the Netherlands year on year, Mulino has left out the essential piece of qualifying information – **the total number of deaths, year on year, in both countries**.

It is only within this context that the data can be properly understood. An increasing number of VE deaths may look alarming in isolation, but it's misleading to show it this way; VE numbers will inevitably rise as the population and total number of deaths increase. So, the fairest and most accurate expression of the data is as a proportion of overall deaths.

Here is the official data for deaths each year, 2003–15:

Figure 10: Total deaths by year in the Netherlands and Belgium ('000) (Source - Official government mortality data)[169]



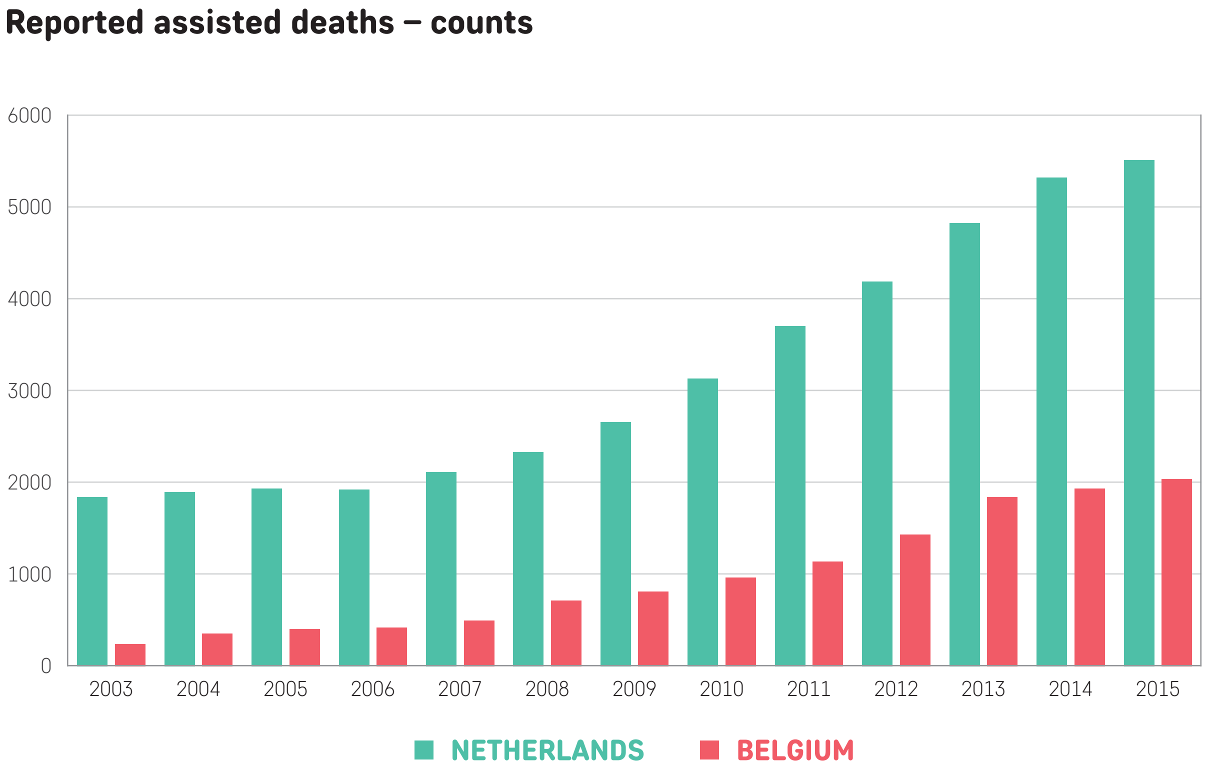
After an initial fall from 2003, since 2007 (and even with a spike down in 2014) there has been a rise in the annual total number of deaths in both countries, consistent with an increasing and ageing population. The rise in total deaths from 2007 to 2015 was approximately 11 per cent in the Netherlands and 8 per cent in Belgium. It is relative to these changes that assisted dying is properly assessed.

Now here is the official data for euthanasia deaths in the years, 2003–15 (not 2008–13 as shown in Mulino's chart of the Netherlands):

---

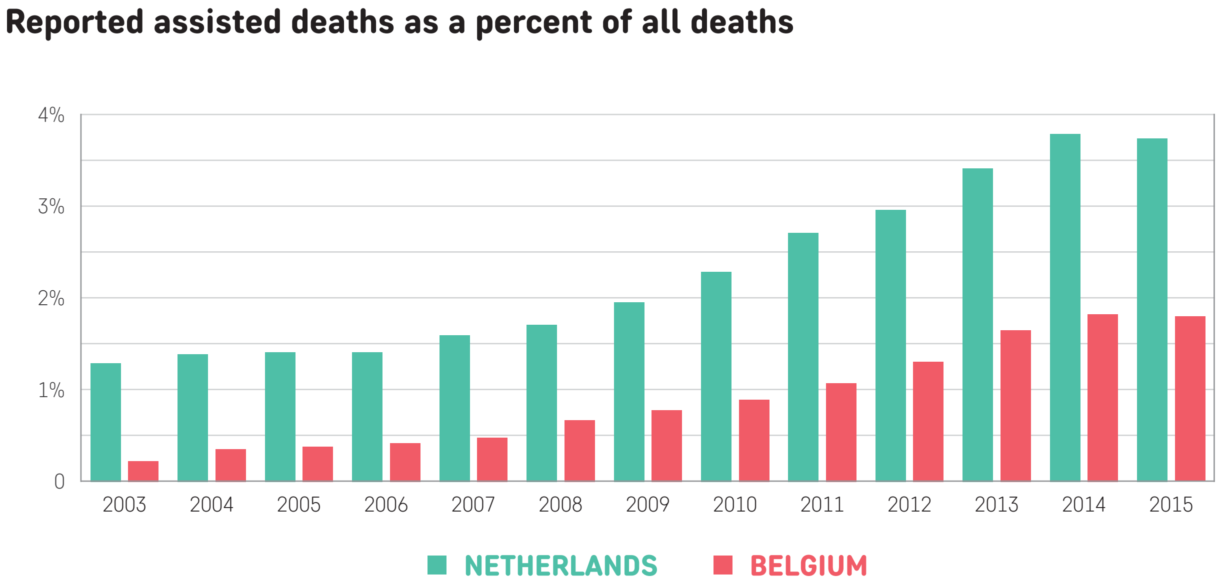
[169] The three graphs, Figures 10-12, in this section, were produced using data from official Euthanasia Commission reports and government mortality statistics by illness. The graphs are reproduced from: Neil Francis, "Assisted Dying Practice in Benelux Whitepaper 1", Dying for Choice, 15 December, 2016 – http://www.dyingforchoice.com/docs/AssistedDyingPracticeInBeneluxWhitepaper1b2016.pdf

Figure 11: Reported assisted deaths in the Netherlands and Belgium, raw counts (Source - Official Euthanasia Commission reports)[170]



And, finally, putting both together, euthanasia deaths as a percentage of all deaths:

Figure 12: Reported assisted death rates in the Netherlands and Belgium as a percentage of all deaths[171]



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[170] The three graphs, Figures 10-12, in this section, were produced using data from official Euthanasia Commission reports and government mortality statistics by illness. The graphs are reproduced from: Neil Francis, "Assisted Dying Practice in Benelux Whitepaper 1", Dying for Choice, 15 December, 2016 – http://www.dyingforchoice.com/docs/AssistedDyingPracticeInBeneluxWhitepaper1b2016.pdf

[171] The three graphs, Figures 10-12, in this section, were produced using data from official Euthanasia Commission reports and government mortality statistics by illness. The graphs are reproduced from: Neil Francis, "Assisted Dying Practice in Benelux Whitepaper 1", Dying for Choice, 15 December, 2016 – http://www.dyingforchoice.com/docs/AssistedDyingPracticeInBeneluxWhitepaper1b2016.pdf

When all the data is tabled the following becomes clear:

- Euthanasia deaths in Belgium and the Netherlands remain, as they have been since the inception of laws, a tiny percentage of all deaths. In the Netherlands, always around 4 per cent. In Belgium, never above 2 per cent.
- Euthanasia deaths have remained statistically tiny despite an upward trend in total deaths in both countries.
- There was a drop in total euthanasia deaths in 2014–15, which Mr Mulino doesn't report.

Using incomplete data to create a distorted picture, Mulino argues that:

> What appears to be manageable can rapidly lead to very large numbers and, in the case of euthanasia and assisted suicide, a very high proportion of overall deaths.[172]

The facts – all on the public record – contradict him. As does the Victorian Committee which, in their majority report having referenced all the data, confirmed that:

> In each jurisdiction, a relatively small number of total deaths each year are attributed to assisted dying.[173]

Creating a False Impression of Voluntary Assisted Dying in Oregon

In 1997 Oregon became the first state in the United States to enact a physician aid in dying (PAD) law, known as the Death with Dignity Act (DWDA).

Suggesting that the number of DWDA deaths in Oregon are escalating out of control, Mr Mulino writes:

> Annual growth rates in the order of 13–20 per cent are extremely high. It is worth noting that the impact of cumulative growth rates of this magnitude over the medium term can be deceptive. What appears to be manageable at first can rapidly lead to very large numbers and, in the case of euthanasia and assisted suicide, a very high proportion of overall deaths.
>
> For example ... the number of cases in Oregon is 725% higher over the 17 years following legalisation.[174]

The statistics sound alarming – and that is clearly Mr Mulino's intent. But, a fair and balanced reading of the evidence shows physician assisted deaths in Oregon in 2016 accounted for just 0.37 per cent of all deaths[175]– 133 out of nearly 36,000 deaths[176] – or fewer than four in every 1000 people.[177]

This is consistent with an unbroken trend since the law was enacted in 1997, as evidenced by the Oregon Public Health Division, Center for Health Statistics 2016 Report [178]:

- Since the law was passed in 1997, a total of 1749 people has had prescriptions written.

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[172] Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, '"Inquiry into end of life choices: Final Report", June, 2017, Section 3.3 'Challenges for the palliative care workforce in Victoria' – https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf

[173] Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report", June 2017, 'Introduction', p. 8 – https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf

[174] Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report'" June, 2017, Chapter 3.3 'The sustained and long-term nature of growth' – https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf

[175] Public Health Division, Center for Health Statistics, "Oregon Death with Dignity Act: Data Summary 2016", Oregon Public Health Authority, 10 February, 2017, p.10 – http://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year19.pdf

[176] Oregon Government, "Deaths by Age Group and Country of Residence: Oregon Residents 2016, Final Data", 2016 – http://www.oregon.gov/oha/PH/BIRTHDEATHCERTIFICATES/VITALSTATISTICS/DEATH/Documents/dage16.pdf

[177] Death with Dignity National Center, "Debunking Myths and Falsehoods About Death with Dignity Legislation", Fact Sheet.

[178] Public Health Division, Center for Health Statistics, "Oregon Death with Dignity Act: Data Summary 2016", Oregon Public Health Authority, 10 February 2017, p.10 – http://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year19.pdf

- Of that number, 1127 patients have died from ingesting the medication – less than 0.5% of all the deaths in Oregon annually.
- More than one-third of all prescriptions issued were not used.
- During 2016, the rate of deaths was 37.2 per 10,000 total deaths. In that year, 204 people received prescriptions (compared to 218 in 2015), of whom 133 people had been reported as having died from ingesting the medication.
- Of those 133 people, the median age at death was 73 years.
- Almost 80% of them were dying of cancer. Just under 7% from Motor Neurone Disease, and just under 7% from heart disease.
- Close to 9 out of 10 patients who used DWDA (89%) were enrolled in hospice care.

According to Dr Charles Blanke, professor of medicine at the Knight Cancer Institute in Oregon, the people who avail themselves of this end-of-life option are predominantly elderly, white, and well educated and almost all are under hospice care. A majority are suffering from cancer.[179]

Speaking from his long experience with the legislation, Doctor Blanke said:

> ... no evidence has emerged that the strict criteria are not being adhered to ... DWD deaths make up only a tiny fraction of Oregon resident mortality.

Dr Blanke's account provides the perspective of a leading specialist whose work immerses him in a system which provides VAD as a legal, medical option. The picture he paints – supported by publicly available statistics from the Oregon Public Health Division – is completely different from the account given by Mr Mulino (who, it must be remembered, did not travel to Oregon with the rest of the Victorian Inquiry Committee).

Alarmism: Raw Data About Oregon Presented out of Context

Oregon Public Health Division statistics show that, since 1997, the number of DWDA deaths in Oregon totals less than 0.5% of all deaths in the State annually.[180]

In 2016, that equated to 37 out of 10,000 deaths.

Yet Mr Mulino writes:

> What appears to be manageable at first can rapidly lead to very large numbers and, in the case of euthanasia and assisted suicide, a very high proportion of overall deaths.[181]

How does he reach this conclusion?

The graph below shows that after a slow, initial uptake, the rate of physician deaths in Oregon has risen, over the past 10 years, from just under 0.15 per cent in 2007 to 0.37 per cent of total deaths in 2016.

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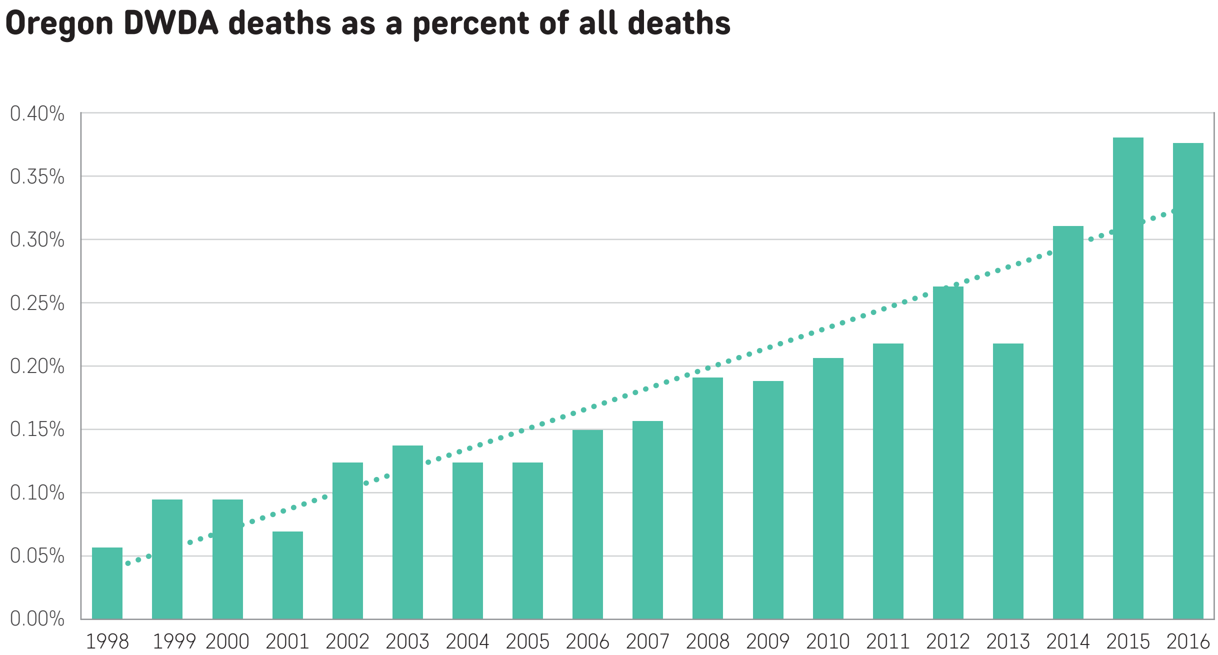
[179] Charles Blanke quoted in Roxanne Nelson, "Death With Dignity in Oregon: No Evidence of Abuse or Misuse'", Coverage from the Palliative Care in Oncology Symposium (PCOS) 2016, Medscape, 20 September, 2016 – http://www.medscape.com/viewarticle/869023

[180] Public Health Division, Center for Health Statistics, "Oregon Death with Dignity Act: Data Summary 2016", Oregon Public Health Authority, 10 February, 2017, p.10 – http://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year19.pdf

[181] Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report", June, 2017, Chapter 3.3 'The sustained and long-term nature of growth' – https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf

Figure 13: Oregon DWDA deaths as a per cent of all deaths 1998–2016 [182]



Mr Mulino's claim is distorted by his use of figures from the very early years of the Oregon legislation. The increase appears far more dramatic when it is compared with a very low initial number of just 16 deaths in 1998.

According to George Eighmey, who was a member of the House of Representatives in Oregon when the Dying with Dignity legislation was passed in late 1997, initial uptake was slow because it took time for patients to become aware of VAD as an option. Mr Eighmey says the dissemination of information was hindered, in the early years, by the concerted efforts of opponents to discourage physicians from participating. This, says Eighmey, made it difficult for terminally ill patients to find cooperating physicians.[183]

Not only have the number of DWDA deaths, as a percentage of all deaths in Oregon, remained statistically tiny, once again Mr Mulino fails to consider other valid reasons why the raw numbers would have risen since 1997:

- As in Europe, the increase in numbers is consistent with an ageing population and with the growing confidence of patients and physicians in considering VAD among a suite of end-of-life options.
- It is relevant, too, that Oregon's population has increased by 33 per cent during the period 1998–2017.
- Other US factors influencing the data, include the socioeconomic stress of the GFC, (leading to an increase in stress-related disease),[184] and patients' lack of access to affordable health care in the early (treatable) stages of disease.

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[182] Graph plotted by Neil Francis, Dying for Choice, using data from Public Health Division, Center for Health Statistics, "Oregon Death with Dignity Act: Data Summary 2016", Oregon Public Health Authority, 10 February, 2017, p.10 – http://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year19.pdf

[183] Information provided to Go Gentle Australia by George Eighmey, American politician, former member of the Oregon House of Representatives, and currently president of America's Dying with Dignity National Center.

[184] See, for example, Nicola Mucci, Gabriele Girogi, Mattia Roncaioli, Javier Fiz Perex and Giulio Arcangeli, "The correlation between stress and economic crisis: a systematic review", Neuropsychiatric Disease and Treatment, 12, published online 21 April, 2016, pp.983–993 – https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4844458/

If Mr Mulino's figure of a **"725% rise in the number of cases"** in Oregon was truly as alarming as he's tried to make it sound, you would expect an uproar in the Oregon medical community, legislature, law enforcement agencies, and media.

There is no such uproar. Oregon's DWD law remains little used and widely supported. No effort has been made, in more than 20 years, to either repeal or amend it.

Finally, it should be noted that simply stating figures – no matter how much they rise – does not, in itself, prove any fault in the system.

No reasonable person would suggest there should be an arbitrary cap on the number of terminally ill people who can access such a law.

The question is not the numbers but whether or not these people were eligible under the law.

In 21 years, not one person has ever been sued, or charged with misusing the law, except by opponents of the law whose allegations have all been shown to be inaccurate or false. In that same time, there has not been a single demonstrated case of coercion.

20 years of peer-reviewed research has also found no evidence of heightened risk to, or in fact any instances of abuse of, particularly vulnerable groups.

3.2 Tactic #2: Selective Quoting from Official Reports to Suggest they Come to a Different Conclusion

3.2.2 The Tactic

Selectively quoting from official reports and academic research to make an uncommitted reader or listener think that they have reached the opposite conclusion.

In 2013, Canadian, Alex Schadenberg, founder of the activist Euthanasia Prevention Coalition, published a book *Exposing Vulnerable People to Euthanasia and Assisted Suicide*. In it he claimed to use official research from Belgium and the Netherlands to show how doctors were ending the lives of hundreds of elderly and vulnerable patients without their consent.

When asked if he was accusing doctors of murder he said: "murders, manslaughter ... yes they are". [185]

Schadenberg's work was enthusiastically endorsed by a range of Australian politicians, with a foreword by Kevin Andrews MP. The book they endorsed turned out to be academically and morally fraudulent.

Here is Andrew Denton's account of meeting Schadenberg and uncovering his fraudulent claims, as submitted to the Victorian Inquiry into End of Life Choices:

The interesting conclusions of Alex Schadenberg – and why they matter in Australia

> The most interesting person I met at the HOPE Symposium in Adelaide was Canadian Alex Schadenberg of the Euthanasia Prevention Coalition. Alex travels the world addressing like-minded groups and giving them serious amounts of information with which to fuel their arguments.
>
> To meet Alex is to be bombarded with a multi-pronged attack direct from the Nancy Elliott playbook: elder abuse, disability abuse, invisible crimes, suicide contagion (He actually used the term 'suicide contagion' about Oregon. Said it's 'really happening' in that state now they

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[185] Andrew Denton, "Better Off Dead: #7 The Killing Fields of Belgium, Part 1", podcast, Thought Fox and the Wheeler Centre, published online by the Wheeler Centre on 1 March, 2016, (audio) – https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/7-the-killing-fields-of-belgium-belgium-part-1
Transcript at Go Gentle Australia website – https://www.gogentleaustralia.org.au/transcripts1

have Death With Dignity laws. You know, once the kids see grandpa do it legally, they'll think about doing it too. So, I checked with Katrina Hedberg, State Epidemiologist for the Oregon Department of Health. She said that, yes, Oregon does have a higher suicide rate than many other States in America and that they're not sure why. But that has been the case for the last 40 years and the introduction of Death with Dignity laws in 1997 hasn't caused those numbers to change one jot. So much for the contagion. Still, it sounds impressive when you say it quickly.

Alex's big thing is that he's about facts, not just conjecture. When I made the mistake of suggesting he was asserting something, he said:

'See, it's not even my assertion, 'This is what I think '. I'm just extrapolating the data. If this is the research, and it is, that's what they're saying. They published the information connected to it. You can look at the article. I'm not making anything up, which is the crazy thing about it.'

In his book *Exposing Vulnerable People to Euthanasia and Assisted Suicide,* Alex claims to have gone back to source documents and analysed major studies from the Netherlands and Belgium which prove that no assisted dying legislation can protect citizens from the possibility of abuse.

It's good methodology to go back to source documents rather than do what many others do, which is to work off other people's conclusions.

I was impressed, so I bought a copy of his book and then enlisted the help of Professor Margaret Otlowski, Dean of Law at the University of Tasmania, to help me determine if Alex's methodology was good, and his conclusions accurate.

As it turns out, neither hold. Because, when you follow Alex's trail and go back to the same source documents, an interesting thing happens.

Take a 2009 study published in the *New England Journal of Medicine* called 'Medical End-of-Life Practices under the Euthanasia Law in Belgium'. It focuses on "The unreported cases of euthanasia or those deaths occurring without explicit patient request".

Alex's conclusion, after analysing it, was:

> Most people who die by euthanasia without explicit request are from a different demographic group to those who request euthanasia and that this group is more vulnerable ... that is, they're elderly, often incompetent patients with cardiovascular disease or cancer, often dying in hospitals.

On the face of it, very disturbing. This seems to be proof that the elderly are being euthanased without their consent in Belgium – an argument used by critics as evidence of the 'slippery slope'.

But it's what was omitted that is most telling. What Alex left out is the author's own conclusions which directly contradict what he claims they are saying:

> We found that the enactment of the Belgian euthanasia law was followed by an increase in all types of medical end-of-life practices **with the exception of the use of lethal drugs without the patient's explicit request. No shift towards the use of life-ending drugs in vulnerable patient groups was observed.** [My emphasis]

That conclusion refutes absolutely the point Schadenberg makes. The studies show doctors were not using euthanasia drugs on vulnerable elderly patients.

It happens again with his analysis of the study 'Physician-Assisted Deaths under the Euthanasia Law in Belgium: A Population-Based Survey', appearing in the *Canadian Medical Association Journal* in 2010

After careful analysis, Schadenberg concludes that:

> ... the vulnerable die by euthanasia in Belgium and these deaths are not being reported, making it an invisible crime.

Once again, the original author's conclusions – peer-reviewed, unlike Schadenberg's – which directly contradict his, are omitted:

> As was shown in other research, **no evidence was found to support the fear that, once euthanasia is legalised, the lives of elderly patients would be more likely to be ended with assistance of a physician.** According to our findings, patients of 80 or older were underrepresented among euthanasia cases compared with all deaths even after controlling for diagnosis and place of death. The number of reported euthanasia cases in this age group did not increase significantly over time. Older patients thus seem not to be at higher or increasing risk of euthanasia after legalisation.
> [My emphasis]

There are other examples. For Professor Otolowski, author of a large body of recognised research in this field, Schadenberg's work is a cause for concern:

> I'm really concerned that especially if he is travelling the world with this, on tour to make a strong case against legalisation of euthanasia, that these arguments will get traction and that there isn't enough exploring beyond the immediate surface message to understand what is he relying on – is it valid data – and identifying where the gaps are in the account. Because as soon as a close and systematic review of that work of his is undertaken you realise that it's highly problematic.
>
> You could understand that some would, on a superficial read of his work, say 'Well this is just the evidence we've been wanting and needing to demonstrate that it would be dangerous to legalise euthanasia' and they would readily endorse it, but without recognising that there's so much more academic literature beyond his work and that in fact what he has done is to ignore a lot of the conclusions about practice in countries such as the Netherlands and Belgium. So, it's not an accurate portrayal of the current situation.

Why does this count in Australia? Because the foreword to Schadenberg's book is written by Kevin Andrews and it contains endorsements from half a dozen other Australian politicians, state and federal, as well. Their weight adds gloss to this counterfeit coin.

How easy, then, for this 'evidence' of a cold, heartless medical profession committing crimes in Belgium and the Netherlands, to slip onto the public record, uncontested? And once there to be repeated – perhaps even at this inquiry – until it is simply accepted as the 'truth' about what's happening under these laws?

You can learn more about Alex Schadenberg's misinformation techniques in SECTION F and hear him and Margaret Otlwoski speaking on this subject on the podcast "Better off Dead" or read the transcript (Episode 7) at the Go Gentle Australia website.[186]

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[186] Andrew Denton, "Better Off Dead: #7 The Killing Fields of Belgium, Part 1", podcast, Thought Fox and the Wheeler Centre, published online by the Wheeler Centre on 1 March, 2016, (audio) – https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/7-the-killing-fields-of-belgium-belgium-part-1

Misrepresenting Researcher Linda Ganzini to Create a False Picture About People with Depression Being Assisted to Die in Oregon

In Chapter 4 of his dissenting report to the Victorian Inquiry into End-Of-Life Choices, Final Report, MP Daniel Mulino turns to Linda Ganzini et al (2000) to support his argument that a significant proportion of people with depression are gaining access to assisted dying.[187]

> Ganzini et al, in a broad ranging review of instances of assisted dying in Oregon, found that twenty percent of the patients had symptoms of depression.

Mr Mulino's selection of words from Ganzini's report, leads the reader to conclude that, in the cohort of patients studied, 20 per cent who received assistance to die were suffering symptoms of depression.

But that's not true: it is, in fact, a clear misrepresentation of Ganzini's findings.

Mr Mulino's reference comes from page 559. The relevant section on this page reads:

> Twenty percent of the patients had symptoms of depression, a finding that is similar to the reported prevalence of depression in patients with terminal illnesses.[188]

Nowhere in the paragraph from which this sentence is extracted is there any suggestion that patients exhibiting symptoms of depression were given access to lethal drugs. A closer reading of the paper shows that 'the patients' referred to in the sentence are those who *requested* a prescription; not patients who received one.

Ganzini's paper tells us clearly and unequivocally how many of the 20 per cent of patients with symptoms of depression who requested assistance in dying were given a prescription for a lethal medication: None.[189]

Further she sheds important light on a question raised earlier in the discussion by Mr Mulino, when he says:

> Depression can impact on decision-making in a way that raises questions about the effectiveness of safeguards in relation to irreversible choices.[190]

In the same paragraph from which he took Ganzini's sentence, she explains:

> According to the physician's assessment, 20 percent of the patients had symptoms of depression, but 93 percent were competent to make medical decisions.[191]

Ganzini also contradicts Mulino's imputation that physicians in Oregon are providing lethal drugs to people with psychological disorders. Despite the fact most of these depressed patients were deemed competent, Ganzini's research shows that not one physician approved any one of them as a candidate for a lethal prescription.

Instead, patients with symptoms of depression were offered a suite of critical interventions, including, but not limited to, antidepressants and psychological and/or spiritual counselling.

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[187] Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report", June, 2017, Chapter 4.5.2 'Depression' – https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf

[188] Linda Ganzini, Heidi D Nelson, Terri A Schmidt, Dale F Kraemer, Molly A Deloris, and Melinda A Lee, "Physicians' Experiences with the Oregon Death with Dignity Act", New England Journal of Medicine, 342, 24 February, 2000, pp. 557-563 – http://www.nejm.org/doi/full/10.1056/NEJM200002243420806#t=article

[189] Linda Ganzini, Heidi D Nelson, Terri A Schmidt, Dale F Kraemer, Molly A Deloris, and Melinda A Lee, "Physicians' Experiences with the Oregon Death with Dignity Act'", New England Journal of Medicine, 342, 24 February, 2000, pp. 557-563 – https://www.nejm.org/doi/full/10.1056/NEJM200002243420806#t=article Ganzini states this specifically in the abstract of the article.

[190] Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report", June, 2017, Chapter 4.5.2 'Depression' – https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf

[191] Linda Ganzini, Heidi D Nelson, Terri A Schmidt, Dale F Kraemer, Molly A Deloris, and Melinda A Lee, "Physicians' Experiences with the Oregon Death with Dignity Act'", New England Journal of Medicine, 342, 24 February, 2000, pp. 557-563 – http://www.nejm.org/doi/full/10.1056/NEJM200002243420806#t=article

This was spelt out clearly in the abstract of Ganzini's study, published in the *New England Journal of Medicine*, which reads:

> Twenty percent of the patients had symptoms of depression; **none of these patients received a prescription for a lethal medication.**[192] [Our emphasis]

Contrast that with Mr Mulino's version:

> Ganzini et al, in a broad ranging review of instances of assisted dying in Oregon, found that twenty percent of the patients had symptoms of depression.

In fact, in respect to the "instances of assisted dying" studied in Ganzini's paper, none of the patients had symptoms of depression. Her paper concludes:

> ... after two years of legalized assisted suicide in Oregon, we found little evidence that vulnerable groups have been given prescriptions for lethal medication in lieu of palliative care.

By selectively and misleadingly quoting published research, Mr Mulino fails his declared standard of a "balanced reading of the evidence".

3.3 Tactic #3: Avoiding the Central Issue of Suffering by Defining it only as 'Pain'

3.3.1 The Tactic

By minimising the suffering and trauma in Victoria and Western Australia as a result of current laws, opponents seek to raise a question in the public's mind: If there's not much of a problem, do we really need a VAD law to fix it?

A key method they use to do this is to narrow the problem by carefully defining it only in terms of 'pain'. Pain, in most cases, can be ultimately dealt with by terminal sedation (though whether – and how well – that is applied, is another matter). 'Suffering', which is multi-faceted, cannot be easily treated by drugs, no matter how powerful.

3.3.2 Suffering versus Pain

In the second chapter of his dissenting Victorian report, 'Almost All Cases of Pain Are Currently Manageable', Daniel Mulino writes:

> In almost all cases where a patient experiences a great deal of pain, including terminal cases, the symptoms of that pain can be managed by current best practice in pain relief and palliative care ... moreover, **the proportion of patients for whom pain is manageable is rising**.[193] [Our emphasis]

Beyond his admission that there are patients for whom pain is unmanageable, Mr Mulino's narrow focus on 'pain' sidesteps the reality that the symptoms of someone who is dying can cascade to the point of being unbearable. They will almost certainly include pain but, individually and collectively they make up something else – *suffering*.

Roger Hunt MD, "a specialist in Palliative Medicine over three decades" and "a Life Member of the Palliative Care Council", explains how suffering is much more than just pain:

> Dying people have varied and sometimes intense suffering, including physical, emotional, and existential suffering. All surveys of palliative patients, including those in most renowned

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[192] Linda Ganzini, Heidi D Nelson, Terri A Schmidt, Dale F Kraemer, Molly A Deloris, and Melinda A Lee, 'Physicians' Experiences with the Oregon Death with Dignity Act', New England Journal of Medicine, 342, 24 February 2000, pp. 557-563 – http://www.nejm.org/doi/full/10.1056/NEJM200002243420806#t=article

[193] Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report", June, 2017, Chapter 2.1 'Pain relief is effective in almost all cases'– https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf

> hospices, show they experience multiple concurrent symptoms. **Severe refractory symptoms, including suffocation, pain, nausea and confusion, requiring palliation with deep sedation, have been reported in up to 50% of palliative care patients.**[194] [Our emphasis]

This is supported by Australia's Palliative Care Outcomes Collaboration, which measures the following stressors faced by patients in the dying phase: [195]

- Difficulty sleeping
- Appetite problems
- Nausea
- Bowel problems
- Breathing problems
- Fatigue
- Pain

In his book, *A Time to Die* (2017), urologist, Rodney Syme, a doctor who has assisted more than 100 patients seeking help to die, describes some of the ways in which dying people can suffer, none of which are directly related to physical pain:

> **Breathlessness:** one of the commonest symptoms experienced by dying people but is virtually universal in chronic heart and respiratory disease and some neurological diseases such as MND. The essence of breathlessness is a sensation, a perception, bound up with fear. It quintessentially encompasses the concept of distress, as opposed to pain. He quotes Dr Martin Cohen describing breathlessness as 'an even more distressing symptom than severe pain'.[196]
>
> **Cachexia ('wasting disease'):** the slow disintegration of the body as the cancer cannibalises its metabolism.
>
> **Choking:** Being unable to swallow your food due to an oesophageal blockage for fear that it will spill into your breathing tube and cause a bout of coughing and the fear of choking to death; Not even being able to swallow your own saliva, and having to repeatedly spit it out into a tissue.
>
> **Weight loss,** asthenia (physical weakness) and anorexia (loss of appetite): Often associated with chronic nausea. Among the most common symptoms afflicting patients with advanced cancer ... this complex of ailments ranks at the top of physical causes of suffering and causes psych-social distress. The syndrome devastates family relations, and makes the patient dependent on the family and healthcare institutions.
>
> **Nausea and vomiting:** Sometimes temporary and intermittent, as with chemotherapy, or persistent, as with many abdominal cancers.
>
> **Persistent diarrhoea:** Perhaps alternating with constipation, or the persistent constipation and abdominal pain associated with palliative opioids.
>
> **Faecal and urinary incontinence.** Untreatable ulcers: Puts the sufferer in an embarrassing and socially isolating state.[197]

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[194] Roger Hunt, "Submission 779: Inquiry into End of Life Choices", 11 August, 2015 – https://www.parliament.vic.gov.au/images/stories/committees/lsic/Submissions/Submission_779_-_Roger_Hunt.pdf

[195] Palliative Care Outcomes Collaboration, "Patient outcomes in palliative care: Results for Queensland January-June 2018", September 2018, Tables 32 and 33, pp.36-37 – https://ahsri.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow252860.pdf

[196] Martin Cohen, et al, "Treatment of intractable dyspnoea - Clinical and ethical issues", Cancer Investigation, Vol. 10, 1992, p. 317.

[197] Rodney Syme, *Time to Die*, Melbourne University Press, 2017, Chapters 5 and 6 'Suffering' and 'Palliative care'.

Dr Syme emphasises that, while many of these symptoms "may have no association with physical pain", they are associated with "huge psychic pain" instead.[198]

He explains how a combination of symptoms – to which he adds fatigue from both the disease and the burdensome nature of treatment; the many side-effects of multiple medications; loss of independence and control; depression; anxiety about what lies ahead; the sense of being a burden on those you love, and; the loss of enjoyment in life – may become increasingly intolerable over time, particularly if the only likelihood is that they will escalate.[199]

American anthropologist Frances Norwood (*The Maintenance of Life*, 2009),[200] describes the many losses experienced in suffering as "social death":

> There is something about a person that can die prior to the death of the body. Social death cannot be attributed to a single point in time nor to a strict set of behaviours. It is a series of losses – lost identity and lost ability to participate in social activities and relationships – that eventually culminates in a perceived disconnection from social life.[201]

In his book, *The Nature of Suffering and the Goals of Medicine* (2004), Dr Eric Cassell, (Emeritus Professor of Public Health at the Weill Medical College of Cornell University, a member of the Institute of Medicine of the National Academy of Sciences, and a Master of the American College of Physicians) describes suffering as:

> **An affliction of the person, not the body** [202]

Professor Cassel insists:

> **Not all suffering can be relieved, no matter how good the care ... and with even the very best treatment the suffering of some patients is terrible and unremitting.** Experienced clinicians know that even if you think you have seen the worst suffering possible, given time you will see someone suffering even more.[203] [Our emphasis]

Syme sums it up this way:

> These losses ... all relate to our fundamental existence as human beings, hence the term **existential suffering.** These existential losses are the very core of end-of-life suffering.[204] [Our emphasis]

Pain can, in most cases, be dealt with by increased doses of sedatives. This is what opponents allude to when they say "almost all cases of pain are currently manageable". But suffering, which is many-faceted, and at many levels, can go without effective relief for days, weeks, months, even years.

Suffering, not pain, is the heart of the matter. That's why Palliative Care Australia, themselves, admit:

> While pain and other symptoms can be helped, complete relief of suffering is not always possible, even with optimal palliative care.[205]

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[198] Rodney Syme, *Time to Die*, Melbourne University Press, 2017, Chapters 5 and 6 'Suffering' and 'Palliative care'.

[199] Rodney Syme, *Time to Die*, Melbourne University Press, 2017, Chapter 4 'Advanced Incurable Illness'.

[200] Frances Norwood, *The Maintenance of Life: Preventing Social Death Through Euthanasia Talk and End-of-Life Care - Lessons from the Netherlands,* Carolina Academic Press, 2009.

[201] Frances Norwood quoted in, Rodney Syme, *Time to Die*, Melbourne University Press, 2017, Chapter 5 'Suffering'.

[202] Cassell, Eric, The Nature of Suffering and the Goals of Medicine, Oxford University Press, 2004, p.xii. Google Books edition, 19 July, 2017 – https://books.google.com.au/books/about/The_Nature_of_Suffering_and_the_Goals_of.html?id=BiqTtq5uZZwC&redir_esc=y

[203] Cassell, Eric, *The Nature of Suffering and the Goals of Medicine*, Oxford University Press, 2004, p.xii. Google Books edition, 19 July, 2017, p. 289 – https://books.google.com.au/books/about/The_Nature_of_Suffering_and_the_Goals_of.html?id=BiqTtq5uZZwC&redir_esc=y

[204] Rodney Syme, *Time to Die*, Melbourne University Press, 2017, Chapter 5 'Suffering'.

[205] Palliative Care Australia, "Policy statement on voluntary euthanasia", Canberra, 2006, p.2.

3.3.3 Why Suffering, Not Pain, is the Worldwide Benchmark for VAD

While it suits opponents' purposes to focus only on pain (because pain can be largely dealt with by sedatives), it's relevant to note that no jurisdiction overseas uses this as a benchmark for eligibility to access their laws. In North America, it's terminal illness. In Europe, it's unbearable, hopeless and lasting suffering.

Pain is understood as too narrow a definition, and one which does not adequately address the complexities of dying.

There were many testimonies about suffering offered to the Victorian and Western Australian committees; people whom current laws fail to protect. These included testimony from Victorian Coroner, John Olle, of violent and lonely suicides as a result of such suffering, happening in Victoria at the rate of one a week.[206]

Yet opponents of VAD rarely mention them. It is relevant to ask why – for individuals and groups who claim to represent the needs of the vulnerable – these cases are unimportant?

3.3.4 What Suffering Looks Like

Lawrie Daniel had advanced multiple sclerosis. He took his life in 2016 because he could no longer live with his untreatable condition. This heartbreaking letter to his wife and children illustrates the deep suffering and distress that is beyond pain that Australians who have terminal and debilitating illnesses experience.

Watch the video of Lawrie's last letter:

Figure 14: Lawrie's Last Letter (Video) [207]

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[206] John Olle (Coroner) evidence to Standing Committee on Legal and Social Issues, Transcript: "Inquiry into end-of-life choices", Parliament of Victoria, Melbourne, 7 October 2015, p. 4, 9 July, 2017 – https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/ELC Transcripts/SCLSI - Coroners Court - FINAL - End-of-life choices 7 October 2015.pdf
Coroner Olle, for example, cites the case of an elderly man with advanced prostate cancer who killed himself with a nail gun.

[207] Lawrie Daniel, "Lawrie's Last Letter", YouTube video, Go Gentle Australia, 3 August, 2017 – https://www.youtube.com/watch?v=BQifyG LDmY&list=PLXQBeKmhJGYy2PryxZ-wgxp aso0PJYl-

3.4 Tactic #4: Minimising Patient Distress: Assertions that 'Very Few Ask to Die'

3.4.1 The Tactic

Opponents of VAD seek to minimise the number of 'problematic cases' by pointing to doctors and palliative care physicians who say they have rarely been asked for help to die.

In his Victorian dissenting report, Mr Mulino, for example, quotes Professor Peter Hudson, Director of Palliative Care at St Vincent's Hospital:

> ... less than 1 per cent of patients referred to the palliative care consultation service actually request euthanasia.[208]

He also cites Dr Natasha Michael, Director of Palliative Medicine at Cabrini Health in Melbourne.[209]

Putting aside that it is often nurses who, as primary caregivers, receive requests to die,[210] research from palliative care physicians shows that requests to die are not uncommon.

Roger Hunt showed that up to 25 per cent of patients considered a hastened death,[211] and, according to Dr Hunt, about 5 per cent asked for it 'earnestly'.[212]

In 2016 research by Australian palliative care physician Dr Linda Sheahan showed that:

- **97% of palliative care physicians had faced a request for assisted death**
- 80% of those requests came from a patient – almost half of those from a patient in concert with their family
- 15% of palliative care physicians had requests at least weekly for assisted dying, and another 27% at least monthly, and that;
- 30% of physicians were uncomfortable with such requests.[213]

3.4.2 Patients in Faith-Based Palliative Care Are Discouraged from Seeking Help to Die

Professor Hudson and Dr Michael appear regularly in reports from opponents of VAD. Yet these rarely reveal that they represent Catholic healthcare providers whose central tenet – "neither prolong nor hasten death" – puts them in opposition, both as a matter of policy and philosophy, to assisted dying. As Professor Hudson explained in his evidence to the Victorian Committee:

> Being a Catholic institution, St Vincent's position is quite clear. It does not condone euthanasia.[214]

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[208] Peter Hudson in Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report", June, 2017, Chapter 2.3 'Very few people ask to be killed – especially if they are aware of care options' - https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf

[209] Natasha Michael quoted in Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report", June, 2017, Section 2.3 'Very few people ask to be killed – especially if they are aware of care options', viewed 19 July 2017 – https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf

[210] Coral Levett, former President of the Australian Nursing & Midwifery Federation explains that patients' requests for euthanasia are often made to nurses, not doctors. If nurses know, from experience, that doctors will not accede to such requests, there is no point in passing them on. Ms Levett said: 'I would go the pan room and cry for 10 minutes because I didn't know what to do or say. I knew I couldn't do it. There was nothing I could do about it. Saying that to a patient who is begging you to die doesn't help. It doesn't change their view to tell them that it's against the law and that there is nothing you can do. They don't see anything other than their own distress and their own suffering. Sometimes you just had to sit there and hold the hand of the person dying so that they could squeeze it and ease their own pain.' Coral Levett, on Andrew Denton, "Better Off Dead: #4 It can never be perfect, so why try and improve it?", podcast, Thought Fox and the Wheeler Centre, published online by the Wheeler Centre on 17 February, 2016, (audio) – https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/4-it-can-never-be-perfect-so-why-try-and-improve-it.

[211] Roger Hunt, Palliative Medicine, 1995, cited in Rodney Syme, *Time to Die*, Melbourne University Press, 2017, Chapter 6 'Palliative Care'.

[212] Roger Hunt, "Roger Hunt: Terminally ill South Australians deserve more than being left to die in agonising, debilitating pain", The Advertiser, Adelaide, 15 November, 2016 – http://www.adelaidenow.com.au/news/opinion/roger-hunt-terminally-ill-south-australians-deserve-more-than-being-left-to-die-in-agonising-debilitating-pain/news-story/d5990e80c333e355a99d70991c8e3ed0

[213] Linda Sheahan, "Exploring the interface between 'physician-assisted death' and palliative care: cross-sectional data from Australasian palliative care specialists", Internal Medicine Journal, 46(4), 2016, pp.443-51 – https://www.ncbi.nlm.nih.gov/pubmed/26762669

[214] Peter Hudson evidence given to Standing Committee on Legal and Social Issues, Transcript: "Inquiry into end-of-life choices", Parliament of Victoria, Melbourne, 24 February, 2016, p.10 – https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/ELC_Transcripts/SCLSI-Hudson-Boughey-Philip-End-of-life_choices_24_February_2016-FINAL.pdf

Speaking to the Victorian Inquiry, Dr Michael explained that when a person says that their suffering is "so unbearable [that] I want to die", the solution is not to assist them, but to ask:

> How can I help you with these factors that are making you feel that death has to be the better option?[215]

This position has the practical effect of quashing any conversation patients in a religious healthcare institution, (or under the care of a physician with strong religious beliefs), may want to have about assistance to die.

Professor of Sociology at the University of NSW Alex Broom spent six months 'embedded' in a Catholic hospice to observe what the end-of-life experience was like for patients. While acknowledging the many benefits the hospice brought to patients and their families, he observed a "once-size-fits-all" moral and ethical code:

> What people don't realise is that on entering into the hospice you're entering into a contract, essentially, about how you can die.

> ***Hospices in Australia have a set of parameters around what is acceptable and what is ethical, and those are embedded in a particular series of moral structures which have religious underpinnings and certain ideas about what is okay or not okay and the nature of suffering.***[216]

The disempowered situation in which patients find themselves in religious healthcare institutions was confirmed by Dr Philip Redelman, a palliative care physician at St Vincent's Sacred Heart Hospice in Sydney:

> Look, you have to understand that it goes something like this in the hospice – you meet people and they say, 'I wish it was over tomorrow', and they say, 'But you wouldn't do that anyway'. I've already got my excuse before I even open my mouth ... once you come into hospital you lose control; you can't do anything about it.[217]

It is important to keep in mind that these are people who are dying and at their most vulnerable. Faced with an institution on which they are entirely dependent, and which fundamentally objects to any request for help to die, it is little wonder that they find it hard to ask.

3.5 Tactic #5: Undisclosed Bias of Expert Sources

3.5.1 The Tactic

Critics of VE/VAD fill official submissions to inquiries with 'expert testimony', without declaring the experts' strong bias against Voluntary Assisted Dying, or towards the Catholic Church and its values, most particularly the sanctity of life. A reminder of what those values are:

According to the 'Charter for Health Care Workers', released by the Vatican in 1995:

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[215] Natasha Michael in Standing Committee on Legal and Social Issues, "Inquiry into end-of-life choices", Parliament of Victoria, Melbourne, 16 September, 2015, p.9 – https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/ELC_Transcripts/Cabrini_Health_Dr_Michael-End_of_life_choices_16_September_2015.pdf

[216] Alex Broom in Andrew Denton, "Better Off Dead: #10 Neither hasten nor prolong death: palliative care in Australia, part 1", podcast, Thought Fox and the Wheeler Centre, published online by the Wheeler Centre on 15 March, 2016, (audio) – https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/10-neither-hasten-nor-prolong-death
Transcript at Go Gentle Australia website – http://www.gogentleaustralia.org.au/transcripts2

[217] Philip Redelman in Andrew Denton, "Better Off Dead: #10 Neither hasten nor prolong death: Palliative care in Australia part 1", podcast, Thought Fox and the Wheeler Centre, published online by the Wheeler Centre on 15 March 2016, (audio) – https://www.wheelercentre.com/broadcasts/podcasts/better-off-dead/10-neither-hasten-nor-prolong-death
Transcript at Go Gentle Australia website – http://www.gogentleaustralia.org.au/transcripts2

The Church ... has always seen medicine as an important support for its own redeeming mission to humanity.

- It follows that the work of health care workers is a sharing in the pastoral and evangelising work of the Church.
- Borne "in close union with the sufferings of Jesus", sickness and suffering assume "an extraordinary spiritual fruitfulness".
- For the Christian, pain has a lofty penitential and salvific meaning.
- To help one to die means to help him to live intensely the final experience of his life.
- The pleas of gravely ill persons who sometimes ask for death are not to be understood as implying a true desire for euthanasia; in fact, it is almost always a case of an anguished plea for help and love.
- Death, then, must be evangelised: The Gospel must be announced to the dying person.

Example 1: Palliative Care Victoria's Submission to the Victorian Inquiry into End-of-Life Choices, 'Living, Dying & Grieving Well'

Described as an "in depth consideration of the issue", based on "consultations with our members, discussions with international colleagues, and reference to available evidence", this is, on one level, a fully-understandable 'sell' for the virtues of palliative care and the need for it to be better-resourced.

But on a deeper level, it is an entirely partisan anti-euthanasia document badged with all the authority of Palliative Care Victoria having given the issue "in-depth consideration".

The first tell is in the footnotes.

Look carefully and you'll see that many of the key sources while they may look neutral or 'scientific' are actually deeply committed anti-euthanasia campaigners from around the world. Alex Schadenberg isn't there, but many of his arguments and associates are, including:

- High-profile anti-euthanasia campaigner and academic Professor Margaret Somerville, is extensively quoted.
- Anti-euthanasia campaigner Emanuel Ezekiel, from the Anscombe Bioethics Centre, Oxford, UK – a Roman Catholic academic institute.
- The European Institute of Bioethics – the go-to people in Europe when media need an anti-euthanasia quote.
- Brian Pollard, a frequent contributor to the anti-euthanasia forum Adelaide Centre For Bioethics and Culture.
- Professor Theo Boer, a former Euthanasia Review Committee member in the Netherlands, now a critic.
- As well as individual, unnamed doctors in Belgium and the Netherlands who oppose the laws.

Of course, there's nothing wrong with any of these people being cited. But because absolutely **no-one** is quoted to address their criticisms, the picture that is painted about the systems in Belgium, the Netherlands, and Oregon, is deliberately distorted.

Example 2: Dissenting report to the Victorian 'Inquiry into End-Of-Life Choices, Final Report', by MP Daniel Mulino

Having found the majority report wanting on the grounds that, in his view, it did not demonstrate a "balanced reading of the evidence", Mr Mulino populated his dissenting report with the following key sources:

Dr David Kissane

In his discussion on the Northern Territory and undiagnosed depression in terminally ill patients, Mr Mulino introduces us to Dr David Kissane.[218] Dr Kissane features five times in Mr Mulino's footnotes. Yet, there is no disclosure that Dr Kissane is a 'Knight of Obedience' in the Australian Association of the Order of Malta.[219] [220]

According to the Annual Review of this Catholic religious order, in 2014, the 'continuous pledge' of each Knight and Dame is:

> ... to keep faithful to the traditions of our Order, to practice and defend our faith against the enemies of religion.[221]

Professor Etienne Montero (aka Montero Redondo)

Professor Etienne Montero, is introduced in Mr Mulino's Chapter 4.3.2, 'Non-legislative and informal extensions within an existing frameworks', to support Mr Mulino's 'slippery slope' argument. Mr Montero is central to Mr Mulino's arguments. He appears in 12 of Mr Mulino's footnotes. Yet, not once does Mr Mulino disclose that Professor Montero also holds a position as an ordained priest in the order of Opus Dei. [222] [223]

At Professor Montero's 2017 ordination, the ordaining cardinal:

> ... invited the new priests to be 'priests'-priests, priests one hundred percent, as your holy Founder Saint Josemaria used to say. Exercise your priesthood with deep joy and ardent faith ... It doesn't matter what sort of ministry is entrusted to you; always and everywhere you are called to build up Opus Dei, the Work of God, in humility, obedience and charity'.

Neither does Mr Mulino mention that Professor Montero's evidence to the Court of British Columbia (in the *Carter vs Canada* case which paved the way for that country's PAD law), was found by the judge to be largely irrelevant and unconvincing.

Dr Kathleen Foley

Dr Foley (and her co-writer Dr Hendin) are introduced to us through their selective telling of the story of Kate Cheney's physician assisted death in Oregon. Mr Mulino relies heavily on evidence and opinions from Doctors Foley and Hendin, mentioning them 12 times in his footnotes. Yet, there is no disclosure of Dr Foley's 2017 appointment by Pope Francis to the Pontifical Academy of Life, a bio-ethical advisory body composed of pro-life, mostly Catholic, anti-choice doctors, scientists, professors and ethicists.[224]

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[218] Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report", June, 2017, Chapter 4.5.5 'Patients receiving inadequate pain relief or palliative care: Cases involving inadequate palliative care: the Northern Territory' – https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf

[219] Dr Ian Marshall, 'Message from the President', "Australian Hospitalier: The Annual Review of the Australian Association of the Sovereign Military Order of Malta", 2014, p. 6 – https://issuu.com/australianhospitaller/docs/2014_20australian_20hospitaller_20-

[220] The Hon. Sir James Gobbo, 'Report of the Sub Priory', in "Australian Hospitalier: The Annual Review of the Australian Association of the Sovereign Military Order of Malta", 2014, p. 8 – https://issuu.com/australianhospitaller/docs/2014_20australian_20hospitaller_20-

[221] "Australian Hospitalier: The Annual Review of the Australian Association of the Sovereign Military Order of Malta", 'Welcome', 2014, p.3 - https://issuu.com/australianhospitaller/docs/2014_20australian_20hospitaller_20-

[222] Opus Dei, "Cardinal Bertello ordains 31 priests from 16 countries", 29 April, 2017 – http://opusdei.org.au/en-au/article/ordinations-priestly-opus-dei-2017/

[223] Etienne Montero Redondo, Staff Directory Page, University of Namur, Belgium – https://directory.unamur.be/staff/emontero/publications?ordering=typeClassification&descending=True&_LOCALE_=en Included to verify that the Etienne Montero Redondo mentioned by Opus Dei is the same person referenced by Mulino.

[224] Junno Arch Esteves, "Pope names members for renewed Pontifical Academy for Life", Catholic News Service, 27 July, 2017 – https://www.ncronline.org/news/vatican/pope-names-members-renewed-pontifical-academy-life

Professor Alan Johnson

Mr Mulino presents evidence provided to the House of Lords Select Committee on Assisted Dying by the late Professor Alan Johnson.[225] Professor Johnson's position as Chairman of the ICMDA (the Association of National Christian Medical and Dental Societies), or the fact that the members of this organisation practice 'Christian medicine', are not disclosed.

In 2001, Professor Johnson spoke at Christian Medical Fellowship's Juniors' National Conference where he "expounded", over three days, "on godly wisdom in three highly illuminating talks".[226]

European Institute of Bioethics

Mr Mulino's discussion on voluntary euthanasia in Belgium is informed by insights from the European Institute of Bioethics (EIB), specifically to support his assertion that euthanasia is becoming "normalised".[227]

Founded in Brussels in 2001, the EIB is self-described as:

> ... a private initiative of a group of citizens (physicians, jurists, and scientists) who are closely interested in significant advances in medicine and biology, which confer on humankind unprecedented control over the course of human life.[228]

The EIB's goals are to inform the general public and influence policy makers on bioethical issues. But, says a report commissioned by European member of parliament Heidi Hautala, this is done from a firmly anti-choice perspective.[229]

Members of the EIB's Honour Committee include MEPs Miroslav Mikolasik and Anna Zaborska, both members of the Christian Democrats.

It appears the EIB is a front for a pro-life, anti-choice, astro-turf, faith-based lobby group.

The report prepared for Ms Hautala also reveals links between the EIB and another anti-choice group, Alliance Vita. According to the report, Alliance Vita "gained notoriety due to its stance against same-sex marriage and misleading websites presenting anti-abortion propaganda as 'counselling' to pregnant teenagers". In 2016, Alliance Vita and the European Institute of Bioethics were operating out of the same premises in Brussels.

Vermont Alliance for Ethical Health Care

In his discussion on Depression in Chapter 4.8, under the heading Noteworthy Independent Cases, Mr Mulino refers the reader to the Vermont Alliance for Ethical Health Care for additional information on the story of the death of Michael Freeland in Oregon.

Like the EIB, above, the Vermont Alliance for Ethical Health Care is a faith-centred group of medical doctors. Its President Dr Robert D. Orr was honoured in 2010 with the 'Servant of Christ' Award from the Christian Medical and Dental Associations. [230] [231]

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[225] Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report", June, 2017, Chapter 4.5.6 'Summary of evidence in relation to vulnerable people' – https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf

[226] Liz Croton, "Beyond the Bleep 2001 - Wisdom Which Works", in Christian Medical Fellowship Newsletter, No. 161, October, 2001, p.3 – http://admin.cmf.org.uk/pdf/cmfnews/cmfn161.pdf

[227] Daniel Mulino, 'Minority Report' in Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report", June, 2017, Chapter 4.4.1 'Belgium' – https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf

[228] European Institute of Bioethics, website – http://www.ieb-eib.org/en/

[229] Elena Zacharenko, "Perspectives on anti-choice lobbying: Study for policy makers on opposition to sexual and reproductive health rights in Europe", report commission by Heidi Hautala, Member of the European Parliament, Brussels, 24 November, 2016 – http://www.heidihautala.fi/wp-content/uploads/2017/01/SRHR-Europe-Study-_-Elena-Zacharenco.pdf

[230] Vermont Alliance for Ethical Health Care, 'About Us', website – http://www.vaeh.org/who-we-are/

[231] Center for Bioethics and Human Dignity, "Who is Robert D Orr?", undated – https://cbhd.org/orr-fellowship/robert-d-orr

3.5.2 The Danger of Using Expert Sources with an Undeclared Bias

As Neil Francis argued on ABC's *Religion and Ethics*, while the majority of Australian Catholics and Protestant Christians *support* voluntary euthanasia, most of the opposition *still* comes from faith-based groups and individuals. Francis uses statistical evidence to show that:

> … while a substantial majority of Australians support assisted dying, almost all the opposition to it is connected with religion – particularly among the most religious, who represent a small minority of the population' [232]

There is no doubt many of Palliative Care Victoria's – and Mr Mulino's – sources are highly trained medical professionals and academics. It is appropriate that their perspective on this complex issue be heard.

But to pass off documents as a "balanced reading of the evidence" or an "in depth consideration of the issue"when, in fact, they are dominated by deeply partisan anti-VAD activists is dishonest.

More than that, it undermines genuine attempts by our parliaments to properly address end-of-life care in Australia.

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[232] Neil Francis, "Opposition to Assisted Dying in Australia is Largely Religious, and Shrinking", ABC Religion and Ethics, 25 July, 2017 – http://www.abc.net.au/religion/articles/2017/07/25/4707589.htm

Part F

A Propaganda Case Study

Fatal Flaws

Fatal Flaws is a Canadian documentary film intended to cast a dark shadow over VAD. It is written, directed and fronted by Kevin Dunn – an apparently affable investigative reporter in the mould of *Bowling for Columbine's* Michael Moore.

Excerpts of the documentary were aired on commercial TV in Western Australia in 2018 and shown to MPs in Canberra, where its arguments are believed to have persuaded at least one Senator to withdraw support for a private member's bill to allow Territories to pass their own laws on VAD.

[redacted]

The Australian anti-euthanasia lobby group HOPE is now using the film as part of its messaging. It is also likely to be distributed in Queensland

During the course of the hour-and-20-minute-long film, Dunn embarks on a 50,000km journey, visiting Newfoundland, the Netherlands, Belgium and the United States, "in search of answers to questions about voluntary euthanasia and voluntary assisted dying".

The film begins with Dunn's elderly father, who is in treatment for advanced colon cancer. Based on his dad's plight, Dunn poses several serious questions:

> "What are [these laws] really saying to people with a terminal illness?"
>
> "... how do these laws affect society, over time?"
>
> "... is there a side to this story we *haven't* heard yet?
>
> "Where does it end? And have we gone too far?"
>
> "Is it *really* about' freedom'? About 'dignity'? Is everything we've heard about euthanasia dead wrong?"

Over the course of the film, Dunn seeks testimony from 'experts' – doctors, psychologists, journalists and politicians. He also interviews a number of 'ordinary' people who provide harrowing first-hand accounts of how voluntary assisted dying and euthanasia have affected them negatively.

These include a story of a young Nova Scotian woman with both physical and mental disabilities who was, allegedly, pressured to consider euthanasia in Canada in 2016; an alleged case of euthanasia without consent of a 94-year-old Dutch woman with pneumonia; a disability rights advocate, who recounts an incident in 2010 in which he felt pressured to forego life-saving antibiotics; and the reporter, himself, who meets a deeply depressed young woman in the Netherlands who tells of her wish to die after a long and unsuccessful treatment journey of serious mental health problems, yet wonders why "she seems so happy".

At face value, *Fatal Flaws* is persuasive. These seem to be compelling testimonies: hearing them encourages the viewer to question whether VE/VAD puts vulnerable groups at risk and is a recipe for elder abuse; the laws inevitably lead to a "tsunami of death" as they are broadened, weakened or ignored and; are even necessary given the existence of an 'alternative' of palliative care.

In this regard, the film achieves what it sets out to do – it sows fear, uncertainty and doubt about VAD in the minds of the viewer. A trailer for the film can be seen here.

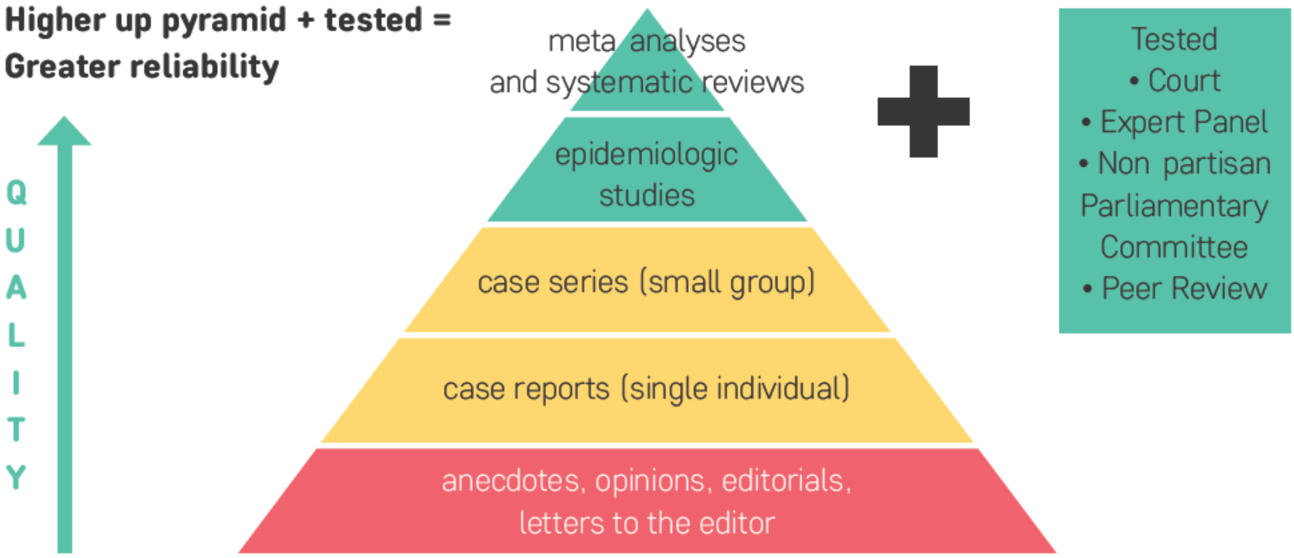
But *Fatal Flaws* is not what it seems. It is made by, and represents the views of, deeply conservative warriors of the Church.

What it presents as 'evidence' is little more than anecdote and opinion, none peer-reviewed or independently tested.

1. HOW RELIABLE IS THE EVIDENCE IN *FATAL FLAWS*?

As outlined elsewhere in this submission, there are recognised methods for establishing and verifying types of evidence.

During the Victorian debate on VAD in 2017, QUT law professors Ben White and Lindy Willmott and law lecturer Andrew McGee advised politicians (and the public) to consider the comparative weight of evidence when forming their conclusions about VAD.[233] They presented a 'scale' of reliability for evidence, as outlined below:



Assessed against this scale of reliability, the 'evidence' presented in *Fatal Flaws* rarely moves beyond the very bottom of the pyramid:

- it is not peer-reviewed
- it is not tested by a court, expert panel, or non-partisan parliamentary committee
- it does not show any systemic abuse
- it does not offer any further proof other than anecdotes or opinions.

Instead, *Fatal Flaws* focuses on other techniques. These include:

1.1 Arguing at the boundaries and 'the Straw Man'

Fatal Flaws locates its arguments at the farthest boundaries of VE/VAD law. Dunn never looks at how VE/VAD works for the vast majority of patients who utilise death with dignity laws in North America and Europe. Instead, he focuses on patients with dementia, disabilities and mental illnesses – people who (unless they are also terminally ill) do not have access to VE/VAD under Canadian, US or Australian law and represent only a tiny percentage of euthanasia deaths in Europe. In short, these are 'straw man' arguments.

For example, in 2017, 76.9 per cent of those who used the Death with Dignity (DWD) law in Oregon had terminal cancer (78.9 per cent the year before). Yet Dunn does not interview a single patient with terminal cancer in *Fatal Flaws*.[234]

In *Fatal Flaws*, Dunn is arguing against a law that doesn't exist, and is not even proposed, in Australia.

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[233] White, Ben, Lindy Willmott and Andrew McGee, "As Victorian MPs debate assisted dying, it is vital they examine the evidence, not just the rhetoric", The Conversation, 20 September, 2017 – https://theconversation.com/as-victorian-mps-debate-assisted-dying-it-is-vital-they-examine-the-evidence-not-just-the-rhetoric-84195

[234] Death with Dignity, "Annual Oregon Death with Dignity Reports", 2017– https://www.deathwithdignity.org/oregon-death-with-dignity-act-annual-reports/

1.2 Red herrings

Information intended to mislead and distract appears routinely in *Fatal Flaws*. Dunn throws up a litany of discredited arguments against VE/VAD: the 'slippery slope'; that doctors will euthanase patients without their consent; that VAD will encourage more suicides and, that vulnerable people such as the elderly, disabled and mentally ill are at risk of abuse.

The truth is there is no reliable evidence that any of these threats exist. Not from meta analyses, systematic reviews or epidemiological studies, nor from any of the comprehensive and forensic parliamentary and judicial inquiries that have assessed them. All have concluded that elderly people, people with disabilities and people with mental illness have not been made more vulnerable by VE/VAD laws (See PART D, pages 61–62 of this Submission.) Under the guise of defending vulnerable people, it is *anti-VAD campaigners like Dunn* who are exploiting them by using fear-mongering campaigns to advance their agenda.

This appears to be a deliberate tactic. Mid-way through the film, Dunn interviews anti-euthanasia advocate Nancy Elliot, a US 'law-maker' who worries about assisted dying and its 'slippery slope'. In 2015, Ms Elliott was a keynote speaker at an anti-euthanasia symposium (HOPE) in Adelaide. There she gave advice on how best to make politicians hesitate:

> When you have lots of arguments, if one argument gets blown out of the water, you still have more, and each argument will reach somebody else.
>
> Right now, the disability argument is really kicking it. It's very powerful. Will it always be powerful? We don't know. Two, three, four years from now that may have holes kicked in it, just for different reasons, so we have to be flexible.
>
> Elder abuse? Elder abuse is excellent. There is nobody in the world that denies that there is elder abuse, and some of the people that are on the left that are most concerned about elder abuse but might be against us can be turned to our side by explaining that this gives another avenue, a very final avenue, to abuse an elder. [235]

More about Nancy Elliott later.

1.3 Unsubstantiated accounts

As well as 'expert testimony', *Fatal Flaws* relies heavily on accounts from apparently 'ordinary' people. These help to personalise the issue and build a sense of fear, outrage and distrust of the medical profession.

As mentioned earlier, anecdote can be a useful tool for illustrating proven facts. But when used as stand-alone evidence, as it is in *Fatal Flaws*, it is notoriously unreliable and sits at the very bottom of the scale of reliable evidence. Dunn makes no effort to independently verify any of the stories recounted in his film, nor does he establish they are anything more than isolated cases or opinions.

1.4 What is missing from Fatal Flaws

Conspicuous by its absence throughout the film is any reference to the monitoring and oversight authorities, the auditing processes they apply, and the results they obtain. It is beyond belief that a careful researcher like Dunn did not seek out these bodies for interview.

Presumably he could gauge nothing out of them suitable for his purposes.

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[235] Nancy Elliott, quoted in Andrew Denton, "Voices from the Frontline: Submission to Victorian Parliament Legal and Social Issues Committee Inquiry into End of Life Choices", Submission 969, Victorian Parliament, 2015 – https://www.parliament.vic.gov.au/images/stories/committees/lsic/Submissions/Submission_969_-_Andrew_Denton.pdf

2. FATAL FLAWS: NOT WHAT IT SEEMS

Fatal Flaws is a slickly produced piece of filmmaking. But it is in no way a balanced or credible investigation despite its attempts to appear as one.

Perhaps most telling is Dunn's failure to inform his viewers of the source of his own opposition to VAD.

Throughout the entirety of his film he never once reveals that he is a staunch Catholic and son of Canadian Catholic 'pro-life' activists, and that he is head of his own pro-life media company.[236]

In an interview with a Catholic news network, Dunn explained how his company, Dunn Media, was founded:

> ... When I turned 50, I said to the Lord, I said, 'Lord, you know I'm doing all of this work and raising this family and I'm getting to mass and doing – but I want to do more.'
>
> And a few people talked to me: 'Could you do more for pro-life?'
>
> And I thought, 'You know what? I'll do this!'
>
> That's where the impetus came. (Starts at 5:59) [237]

In an interview with 'Jim and Joy' on the EWTN Catholic news network, Dunn reveals *Fatal Flaws* was funded by the Euthanasia Prevention Coalition (EPC), an organisation founded under the auspices of the Roman Catholic Diocese of London, Ontario and managed by its international chair, **Alex Schadenberg**.[238]

Schadenberg is Dunn's co-executive producer on *Fatal Flaws* and it was Schadenberg who offered to finance the film.

He is the author of the book *Exposing Vulnerable People to Euthanasia and Assisted Suicide* which selectively quotes from official reports to make fraudulent claims that doctors in Europe are using euthanasia laws to kill elderly people without their consent. (See PART E, pp.87–89).

Fatal Flaws seeks to make the same claims – claims that have been debunked here.[239]

Like Dunn, Schadenberg is also the son of Canadian Catholic pro-life pioneers.[240] In 2006 he was the recipient of the Archbishop Adam Exner Award for Catholic Excellence in Public Life.[241] It is no coincidence that Dunn and Schadenberg, like many of the 'experts' arguing against VAD in *Fatal Flaws*, are also committed opponents of abortion.

Both are using their time and money to defend the values of their Church, most particularly the sanctity of life. When it comes to end of life, it is worth reminding ourselves what those values are:

According to the 'Charter for Health Care Workers'[242], released by the Vatican in 1995:

- The Church ... has always seen medicine as an important support for its own redeeming mission to humanity.

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[236] Conlon, Mickey, "Dunn family lives pro-life message at home and work", Catholic Register, 3 December, 2016 – https://www.catholicregister.org/features/life-family/item/23754-dunn-family-lives-pro-life-message-at-home-and-work

[237] Dunn, Kevin, "Kevin Dunn, Part I", At Home with Jim and Joy, EWTN, 23 January, 2016 – https://www.youtube.com/watch?v=VgNRa08oo6k

[238] Pete Vere, "Alex Schadenberg: Battling the Onset of Euthanasia", The Interim, 19 July, 2007 – http://www.theinterim.com/issues/euthanasia-suicide/alex-schadenberg-battling-the-onset-of-euthanasia/

[239] Kenneth Chambaere, "Separating fact from fiction about euthanasia in Belgium", The Conversation, 22 April, 2016 – https://theconversation.com/separating-fact-from-fiction-about-euthanasia-in-belgium-58203

[240] Pete Vere, "Alex Schadenberg: battling the onset of euthanasia", The Interim, 19 July, 2007 – http://www.theinterim.com/issues/euthanasia-suicide/alex-schadenberg-battling-the-onset-of-euthanasia/

[241] Jean Ko Din, "Schadenberg honoured with Exner Award", Prairie Messenger: Catholic Journal, 8 June, 2016 – http://www.prairiemessenger.ca/16_06_08/cnews_16_06_08_2.html

[242] The Pontifical Council for Pastoral Assistance to Health Care Workers, "The Charter for Health Care Workers", Vatican City, 1995 – http://www.vatican.va/roman_curia/pontifical_councils/hlthwork/documents/rc_pc_hlthwork_doc_19950101_charter_en.html

- It follows that the work of health care workers is a sharing in the pastoral and evangelising work of the Church.
- Borne 'in close union with the sufferings of Jesus', sickness and suffering assume 'an extraordinary spiritual fruitfulness'.
- For the Christian, pain has a lofty penitential and salvific meaning.
- To help one to die means to help him to live intensely the final experience of his life.
- The pleas of gravely ill persons who sometimes ask for death are not to be understood as implying a true desire for euthanasia; in fact, it is almost always a case of an anguished plea for help and love.
- Death, then, must be evangelised: The Gospel must be announced to the dying person.

3. UNDECLARED BIAS: WHO IS IN FATAL FLAWS?

The hidden agenda of the filmmakers extends to the majority of the 'experts' and 'ordinary' people Dunn interviews.

Though presented as neutral, like Dunn and Schadenberg many commentators are undeclared warriors for their faith.

Virtually all have close connections with religious institutions and pro-life groups. Some are on the public record propounding controversial views that are on the fringes of the political and scientific mainstream.

There is a clear pattern of their use throughout the film.

Dr William Toffler

Dr Toffler appears in *Fatal Flaws* as a professor emeritus at Oregon Health and Science University. He comments on the "euphemisms used to drive the pro VE/VAD debate" and what he describes as the conflict of interest inherent in doctors taking part in assisted dying.

What the film fails to disclose is that Toffler is a member of the Catholic Medical Association, and an ultraconservative, anti-euthanasia campaigner who has extreme views on a range of issues including abortion and contraception.

Dr Toffler believes contraception is "against God's plan" and abortion and suicide are sins.[243]

In 2017 he toured Australia, sponsored by Right to Life. During the visit, it was revealed that he was part of a small minority in the Oregon Medical Association who opposed a woman's right to choose abortion and did so because God told him so. He has opposed Oregon's Death with Dignity law since before its inception.

He has also publicly aligned himself with the widely discredited view that there is a link between abortion and breast cancer, a theory opposed by, among others, the Australian Medical Association[244], the Cancer Council of Australia[245] and the Breast Cancer Network, Australia.[246]

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[243] Emma Reynolds, "Anti-euthanasia campaigner touring Australia with some very extreme views", news.com.au, 28 June, 2017 – https://www.news.com.au/lifestyle/health/health-problems/antieuthanasia-campaigner-touring-australia-with-some-very-extreme-views/news-story/feeb43fe98903ef73a21017c1dc7fc37

[244] Australian Medical Association, "Owler slams Minister for 'irresponsible' abortion remarks, AMA in Action, 19 August, 2014 – https://ama.com.au/ausmed-features/ama-news?page=12

[245] Cancer Council, "Abortion does not cause breast cancer" – https://www.cancercouncil.com.au/100629/cancer-information/general-information-cancer-information/cancer-questions-myths/medical-and-injuries/abortion-does-not-cause-breast-cancer/

[246] Breast Cancer Awareness Network (BCNA), "Myths about breast cancer" – https://www.bcna.org.au/breast-health-awareness/myths-about-breast-cancer/

Esmé Wiegman

Ms Wiegman is interviewed in *Fatal Flaws* as the CEO of the Dutch Patients Organisation. She expresses alarm about elderly people being coerced into ending their lives, and raises concerns about Dutch VE/VAD laws one day expanding to include people who are simply "tired of life".

Dunn never tells the viewer that Wiegman is a former politician[247] who was elected to parliament representing the Christian Union, an anti-LGBTQ, anti-abortion, bible-based party that formed after the merger of two right-wing political parties – the Reformatory Political Federation (RPF) and the Reformed Political League (GPV) – who believe in biblical-rule.

Catherine Glenn Foster

Ms Foster appears in *Fatal Flaws* as a lawyer and a "leading voice against assisted suicide in the USA". Foster, the CEO of Americans United for Life, characterises her work as "about the value of life. It's about caring, not killing".

Dunn never mentions that Foster also has close professional links to both evangelical Christianity and Catholicism[248] and is with the Charlotte Lozier Institute, an anti-abortion organisation.[249]

Interestingly, she previously worked for the Alliance Defense Fund (now the Alliance Defending Freedom) an organisation that has been described as "the 800-pound gorilla of the Christian right"[250] and which the Southern Poverty Law Centre classifies as a hate group. The ADF has tried to recriminalise gay sex in the US.[251]

Alexandra Snyder

Ms Snyder is interviewed by Dunn as "a lawyer fighting against the expansion of assisted dying laws" in the US. She is the CEO of Life Legal Defence Foundation, an organisation whose mission is "to give innocent and helpless human beings of any age, particularly unborn children, a trained and committed defense against the threat of death, and to support their advocates in the nation's courtrooms".[252]

She does not disclose that she is also an Evangelical Christian whose[253] "passion for pro-life work was kindled while serving as a volunteer at a pregnancy resource center in southern California. She started out working one-on-one with clients and leading a post-abortion Bible study."

Ms Snyder got her degree from Trinity, a private evangelical university which is part of the Evangelical Free Church of America, a group that vilifies LGBTQ people and believes homosexuality is a sin.

Annette Hanson

Dr Hanson, a forensic psychiatrist, is interviewed in *Fatal Flaws* to suggests that assisted dying is not about compassion or relieving suffering but "about changing the mindset of the medical profession" and making them "more comfortable about killing people". She is the daughter of a Lutheran minister, a member of the Evangelical Lutheran Church in Minnesota, and her family are alumni of Augburg University (associated with the Evangelical Lutheran Church).[254] [255]

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[247] Esmé Wiegman, Wikipedia – https://en.wikipedia.org/wiki/Esm%C3%A9_Wiegman

[248] Evidence from numerous sources including Catherine Glenn Foster's LinkedIn page, comments made on her public Facebook page, and her numerous educational and professional associations.

[249] Catherine Glenn Foster, Lozier Institute – https://lozierinstitute.org/team-member/catherine-glenn-foster/

[250] Alliance Defense Fund - Source Watch – https://www.sourcewatch.org/index.php/Alliance_Defense_Fund

[251] Equality Matters, "This Right-Wing Legal Powerhouse Wants to Make Gay Sex Illegal", Huffpost, 19 November, 2015, updated 6 December, 2017 – https://www.huffingtonpost.com/entry/this-right-wing-legal-pow_b_6185878.html

[252] Alexandra Snyder, Executive Director, "Life Legal Defense Foundation" https://lifelegaldefensefoundation.org/about/key-staff/alexandra-snyder-executive-director/

[253] GodTube, "Alexandra Snyder and the Fight Against Abortion - Popular Christian Videos", 2011 – https://www.godtube.com/watch/?v=DLYDLPNX

[254] Chester E Hoversten, Obituary, Geni, 2015 – https://www.geni.com/people/Chester-E-Hoversten-Rev/6000000039730984059

[255] Evidence from various links including Annette Hoversten-Hanson's LinkedIn profile and public Facebook page.

Dr Kenneth R Stevens

A radiation oncologist in Oregon, Dr Stevens tells Dunn of his concerns that an increasing number of people who are not terminally ill are choosing an assisted death, because they have "lost hope".

Dunn fails to tell viewers that Dr Stevens belongs to the Church of the Latter-day Saints, also known as the Mormons.[256] He is the son of missionary parents and is himself a two-time missionary. He got his degree from the University of Utah and identifies as a "Latter-day Saints Oncologist" here.[257]

The Latter-day Saints are opposed to euthanasia as well as LGBTIQ people.

Dr Bud Pierce

Dr Pierce tells Dunn about his fears that doctors will be forced to participate in assisted dying despite their moral objections. He doesn't disclose that he is an active member of Salem First Christian Church and, in 2011, served as an elder of the church, chairing its stewardship committee. [258] [259]

Kees van der Staaij

While in the Netherlands, Dunn interviews Kees van der Staaij, a Dutch politician, about his fears that Dutch voluntary euthanasia laws are expanding, and leading to a "slippery slope". Mr van der Staaij is the leader of a faith-based the Reformed Political Party [260], which believes in "organic suffrage" – i.e; restricted to the male heads of households. Women are not allowed to hold positions in the party, which strives towards a government totally based on the Bible.

Nancy Elliott

Ms Elliott is interviewed as a US politician who fears that if doctors are given the ability to participate in assisted dying "things will go the way they have in the Netherlands". Elliot says she believes assisted dying is "state sanctioned killing", and a development that gives "the government the right to decide who is deserving of death and who isn't". Viewers are never told she is also chair of the American arm of the Euthanasia Prevention Coalition, which provided the film's funding. A staunch Christian, Elliot has said elsewhere:

> ... this may be a political issue, but it is also a Christian issue. This is not just about politics. This issue, the church *owns* ...[261]

Dr Benoit Beuselinck

Dr Beuselinck (Belgium) is quoted in *Fatal Flaws* as saying "we can manage all pain with palliative care, including palliative sedation". He is a consultant oncologist of the Catholic University Hospitals of Leuven [262] and works at Catholic University of Leuven. [263]

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[256] Holland, John and Frances J Storrs, "Interview with Kenneth R. Stevens, Jr., M.D., F.A.C.R.", OHSU Digital Collections, 8 January, 2014 – https://digitalcollections.ohsu.edu/concern/etds/02870w009

[257] Ken Stevens, "LDS Oregon Oncologist Speaks of the Tragedy of Physician Assisted Suicide", originally published at Meridian Magazine, Church of Latter Day Saints, 4 November 2014 - (original link broken); the article is reproduced and referenced at the Mormon Lady blog – http://en.mormonlady.se/2014/11/06/assisterat-sjalvmord-sparar-pengar-den-cyniska-sanningen-om-aktiv-dodshjalp/

[258] Bud Pierce - Wikipedia – https://en.wikipedia.org/wiki/Bud_Pierce

[259] 76th Oregon Legislative Assembly 2011 Regular Session, "Senate Concurrent Resolution 4", 2011 – https://olis.leg.state.or.us/liz/2011R1/Downloads/MeasureDocument/SCR4

[260] Kees van der Staaij - Wikipedia – https://en.wikipedia.org/wiki/Kees_van_der_Staaij

[261] Nancy Elliott, "Exposing the Lies Surrounding Euthanasia and Assisted Suicide and Why the Christian Should be in the Fight", address to the Merrimack Valley Baptist Church (New Hampshire), 2 May, 2017, (audio - transcribed by us) – https://mvbc.org/member-login

[262] Simon Caldwell, "Palliative care nurses quit houses of euthanasia", Catholic Herald, 18 January, 2018 – http://catholicherald.co.uk/news/2018/01/18/palliative-care-nurses-quit-houses-of-euthanasia/

[263] Benoit Beuselinck - Wikipedia – https://en.wikipedia.org/wiki/KU_Leuven
Benoit Beuselinck, profile – https://www.researchgate.net/profile/Benoit_Beuselinck

Dr Charles Bentz

Dr Bentz (Oregon) does not disclose that he is employed by one of the biggest Catholic health care organisations in North America, the Providence St Vincent Medical Center[264] which is run by Providence Health & Services, a not-for-profit Catholic health care system operating multiple hospitals across five states, with headquarters in Renton, Washington. Providence Health & Services was started by the Sisters of Providence (Montreal, Quebec) in 1859.

Here's a video he did for Illinois Right to Life.[265]

Alex Van Vuuren

Alex Van Vuuren is mentioned in the end credits of *Fatal Flaws* with a "special thanks". Van Vuuren is from Cry For Life, an organisation that asserts, among other things, that abortion rights mean "the trains to Auschwitz are still rolling".[266]

4. PUBLICLY DISCREDITED

The tactics used by Dunn and Schadenberg in *Fatal Flaws* are not only alarming, they are discredited.

During a study into the tactics of pro-life advocates, investigative reporters Sofia Resnick & Sharona Coutts discovered:

> ... the scientific and medical claims of these groups and individuals have been publicly discredited in episodes ranging from lying to the public, presenting false data in scientific journals, and being forced to retract articles that proved to be works of fiction presented as fact. Other doctors and professors ... [who] carry impressive credentials, appear to be apt in their fields ... However, fueled by their religious or political beliefs (or both), many of these professionals have testified in support of unproven or discredited theories.
>
> ... They create nonprofits, staffed with die-hard ideologues, and set about producing and promoting bogus science, to build the illusion of dissent or doubt over conclusions drawn by peer-reviewed scientific or medical research. They develop their own 'research findings' to suit their ideological views. Then they deploy scare tactics, all with the goal of passing laws that suit their agenda.
>
> ... It's a strategy that anti-choice activists have been working on for decades.[267]

This 'stealth strategy' is extensively employed by VE/VAD opponents worldwide. As Eli Stutsman, Portland attorney and primary author of Oregon's Death with Dignity Act, observes:

"If our primary opponents were intellectually honest, they would admit that their opposition was faith based and would make a faith-based argument. But that doesn't resonate with the voters.[268]***"***

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[264] Charles J Bentz, MD, Staff Profile, Providence Health & Services – https://www.providence.org/doctors/profile.aspx?name=charles+j+bentz&first=charles&middle=j&last=bentz&city=portland&id=198018

[265] Charles Bentz, "Dr. Charles Bentz: Physician Assisted Suicide", Illinois Right to Life, 10 April, 2018 – https://www.youtube.com/watch?v=x_Kn3E5_q2k

[266] Jor-El Godsey, ""Cry for Life Conference", Heartbeat International – https://www.heartbeatinternational.org/cry-for-life-update

[267] Sofia Resnick and Sharon Coutts, "Anti-Choice 'Science': The Big Tobacco of Our Time", *Rewire News,* 13 November, 2014 – https://rewire.news/article/2014/11/13/anti-choice-science-big-tobacco-time/

[268] Eli Stutsman, Eli, "It's not easy to kill yourself in Oregon. Certainly not as easy as opponents suggest", Men's Health, October, 2006 – https://tinyurl.com/y6pprrjg

5. CONCLUSION

By any reasonable measure, *Fatal Flaws* fails the criteria by which information should be judged.

Virtually all Dunn's so-called 'evidence' of the threat posed by VE/VAD laws sits at the very bottom of the reliability scale.

This is in stark contrast to the numerous meta-analyses, systematic reviews, and peer-reviewed epidemiologic studies and case studies – tested by courts, expert panels and parliamentary inquiries – that have underlined the safety and effectiveness of assisted dying laws around the world.

The strategically hidden identities of the film's makers and participants; their undeclared, yet deeply conservative, pro-life views; and the failure to balance those views with other voices, makes the film intellectually dishonest and highly manipulative.

Part G

Evidence Considered By The Victorian Committee Into End-Of-Life Choices

In reaching its conclusion that:

> ... assisted dying is currently provided in robust, transparent, accountable frameworks. The reporting directly from such frameworks, and the academic literature analysing them, shows that the risks are guarded against, and that robust frameworks help to prevent abuse.[269]

what sources did the the Victorian Parliament's Legal and Social Issues Committee draw on?

1. PEER REVIEWED EVIDENCE

Firstly, there were the scores of publications and peer-reviewed academic papers listed in the Bibliography on pages 319–335 of the Report. These represented a range of views about VE and VAD. They included many papers providing long-term and wide-ranging research into the impact of these laws on vulnerable populations.

Evidence was drawn from papers from leading experts writing in a range of disciplines in a host of leading, peer reviewed journals. For example:

> *The Lancet*
>
> *British Medical Journal*
>
> *Journal of Pain and Symptom Management*
>
> *Canadian Medical Association Journal*
>
> *Journal of Medical Ethics*
>
> *Journal of Clinical Ethics*
>
> *Bioethics*
>
> *Journal of Law, Medicine and Ethics*
>
> *Social Science and Medicine*
>
> *JAMA Internal Medicine*
>
> *New England Journal of Medicine*

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[269] Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report", June, 2017, Section 8.4 'The Committee's decision - An assisted dying framework', p. 212, – https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf

2. EVIDENCE FROM OTHER INDEPENDENT INQUIRIES

The committee also benefited from the work of other independent inquiries, both in Australia and internationally. Some were set up by governments. Some were judicial in nature. Others were established by independent think-tanks or academic institutions. Like the Victorian Inquiry, these inquiries were informed by peer-reviewed studies and evidence from primary sources.
They included:

- Udo Schüklenk's (2011) report on the Royal Society of Canada's Expert Panel on End-of-Life Decision-Making [270]
- An expert legal analysis on the regulatory options in respect to VE and VAD legislation by QUT Law School academics Benjamin White and Linda Willmott (2012) [271]
- The report of the UK Commission on Assisted Dying (2011) [272]
- The Québec Select Committee on Dying with Dignity report from the National Assembly of Quebec (2012) [273]
- The final report from the External Panel on Options for a Legislative Response to Carter v. Canada, (2015) [274]
- The final report from Canada's Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying (2015) [275]
- A bioethical report and recommendations on the Canadian hearing from the University of Toronto (2015) [276]
- A report on a Patient-Centred Approach to Medical Assistance in Dying: A Patient-Centred Approach from Canada's Special Joint Committee on Physician-Assisted Dying (including a dissenting report) [277]

Both the Victorian Committee and the Canadian Special Joint Committee (2016), also had the benefit of the most extensive independent inquiry ever held into VAD/VE laws and their safeguards. This was conducted by British Columbia Supreme Court Justice Lyn Smith in 2012.

Justice Smith cross examined, among others, academics, doctors, palliative care specialists, lawyers, activists and ethicists. She accepted into the court record the findings of the Royal Society of Canada's Expert Panel on End of Life Decision Making (2011) and the Quebec Select Committee on Dying with Dignity (2012). Both, having conducted lengthy public investigations into end-of-life choices and protection of the vulnerable, recommended a law for assisted dying.

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[270] Udo Schüklenk et al., "End-of-life decision-making in Canada: The report by the Royal Society of Canada expert panel on end-of-life decision-making", Bioethics, vol. 25, no. s1, 2011 – https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3265521/

[271] Lindy Willmott et al., "Withholding and withdrawal of 'futile' life-sustaining treatment: Unilateral medical decision-making in Australia and New Zealand", Journal of Law and Medicine, vol. 20, no. 4, 2013 – https://www.academia.edu/25506567/Withholding_and_withdrawal_of_futile_life-sustaining_treatment_Unilateral_medical_decision-making_in_Australia_and_New_Zealand

[272] The Commission on Assisted Dying, "The current legal status of assisted dying is inadequate and incoherent…", Demos, London, 2011 - https://www.demos.co.uk/files/476_CoAD_FinalReport_158x240_I_web_single-NEW_.pdf?1328113363

[273] Select Committee on Dying with Dignity, "Dying with Dignity", National Assembly of Québec, Québec, 2012 – http://www.assnat.qc.ca/en/travaux-parlementaires/commissions/CSMD/mandats/Mandat-12989/index.html

[274] Harvey Max Chochinov, et al., "Consultations on physician-assisted dying: Summary of results and key findings – Final report", External Panel on Options for a Legislative Response to Carter v. Canada, 2015 – https://www.justice.gc.ca/eng/rp-pr/other-autre/pad-amm/index.html

[275] Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying, *Final report*, 30 November, 2015 – http://www.health.gov.on.ca/en/news/bulletin/2015/docs/eagreport_20151214_en.pdf

[276] University of Toronto Joint Centre for Bioethics Task Force on Physician Assisted Death, "After Carter v. Canada: Physician assisted death in Canada — Report and recommendations", University of Toronto, Toronto, Canada, 14 December, 2015 – http://jcb.utoronto.ca/docs/JCB-PAD-TaskForce-Report-2015.pdf

[277] KK Ogilivie and R Oliphant, 'Medical assistance in dying: A patient-centred approach – Report of the Special Joint Committee on Physician-Assisted Dying, Canadian Parliament, including a dissenting report', February, 2016 – http://eol.law.dal.ca/wp-content/uploads/2016/05/Special-Joint-Committee-on-PAD-FInal-Report.pdf

After hearing all the evidence, for and against, Justice Smith concluded:

> Empirical researchers and practitioners who have experience in those systems are of the view that they work well in protecting patients from abuse while allowing competent patients to choose the timing of their deaths.[278]

In their 2015 decision unanimously upholding Justice Smith's judgement on appeal, the Justices of the Canadian Supreme Court made note of the methodology that underpinned Justice Smith's conclusions:

> The trial judge's findings were based on an exhaustive review of the extensive record before her. While the majority of the evidence was presented in affidavit form, a number of the expert witnesses were cross-examined, both prior to trial and before the trial judge. The record was voluminous: the trial judge canvassed evidence from Canada and from the permissive jurisdictions on medical ethics and current end-of-life practices, the risks associated with assisted suicide, and the feasibility of safeguards.
>
> She reviewed the safeguards in place in each jurisdiction and considered the effectiveness of each regulatory regime. In each system, she found general compliance with regulations, though she noted some room for improvement. The evidence from Oregon and the Netherlands showed that a system can be designed to protect the socially vulnerable.

In conclusion, the Supreme Court found that the evidence established:

> ... [that the] predicted abuse and disproportionate impact on vulnerable populations has not materialized in Belgium, the Netherlands and Oregon.[279]

This deep archive of empirical research and literature, conducted and created by independent authorities laid a foundation for the Victorian Committee's conclusions.

3. EVIDENCE FROM PRIMARY SOURCES

Most powerful, however, was the knowledge gained by the committee from visiting Switzerland, the Netherlands, Oregon and Canada to learn firsthand how these laws operate. It is worth being reminded of just some of those the committee spoke with in these jurisdictions – this list is indicative, not exhaustive:

Legal

- Dr Frank Th. Petermann, President, Swiss Medical Lawyers Association
- Ms Maartje van der Linden, Legal Adviser, Directorate for Legal and Operational Affairs Ministry of Security and Justice
- Ms Jessica Prince, Senior Policy Adviser, Office of the Minister for Justice and Attorney General of Canada Parliament of Canada
- Ms Julia Nicol, Legal and Legislative Affairs Division, Parliamentary Information and Research Service, Library of Parliament, Parliament of Canada
- Mr Lane Shetterley, Chair, Oregon Law Commission

Medical

- Mr Eric van Wijlick, Senior Staff Member, Royal Dutch Medical Association (KNMG)

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[278] Carter v. Canada (Attorney General), 2012 BCSC 886, para. 685.
[279] Carter v. Canada (Attorney General), 2012 BCSC 886, para. 684.

- Dr Karima Velji, President, Canadian Nurses Association; Member, Provincial-Territorial Expert Advisory Group on Physician Assisted Dying
- Mr Bryan Boehringer, Chief Executive Officer Oregon Medical Association

Psychiatry

- Dr Harvey Max Chochinov, MD, PhD, FRCPC, Distinguished Professor of Psychiatry, University of Manitoba, Director, Manitoba Palliative Care Research Unit; Chair, External Panel on Options for a Legislative Response to Carter v. Canada

Palliative Care

- Ms Barb Hansen, MA RN CWON, Chief Executive Officer, Oregon Hospice and Palliative Care Association

Ethical

- Mr Gert Van Dijk, Medical Ethicist, Royal Dutch Medical Association & Senior Ethics Adviser, Euthanasia Review Board

Government

- Dr Marianne Donker, Director, Public Health Department Ministry of Health, Welfare and Sports
- Ms Cynara Corbin, Committee Joint Clerk, Special Joint Committee on Physician-Assisted Dying Parliament of Canada
- Ms Barbara Kagedan, Senior Policy Adviser, Senate of Canada Parliament of Canada
- Senator Elizabeth Steiner Hayward MD, State Senator, District 17 Oregon State Legislature Family Physician and faculty member; Director OHSU Knight Cancer Institute; Breast Health Education Program Board member; Oregon Academy of Family Physicians
- Representative Mitch Greenlick, Chair, House Committee on Health Oregon State Legislature
- Ms Sandy Thiele-Cirka, Administrator, House Health Care Committee, Senate Health Care Committee Oregon State Legislature
- Dr Katrina Hedberg MD MPH, State Epidemiologist and State Health Officer, Oregon Public Health Division, Oregon Health Authority

Academic

- Professor Bregje Onwuteaka-Philipsen, End of Life Care, Research Institute for Health and Care Research, VU University Amsterdam

It should be noted that the Committee also spoke with opponents of these laws in overseas jurisdictions.[280]

The gathering of primary evidence emphasised to the committee the serious level of research and oversight which underpins the operation of existing VE and VAD laws. As the majority report noted of the Netherlands:

> The Committee was impressed with the integration of research undertaken by universities and the provision of health services in the Netherlands. This research provides Dutch policy makers with detailed information about the treatment people receive at the end of life and how health services can be improved.

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[280] Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report", June, 2017, Section 8.4 'The Committee's decision - an assisted dying framework', p. 213 – https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf
Specifically, the Report says: "The Committee also met with opponents from overseas jurisdictions where assisted dying is legal, who expressed similar concerns [to those expressed by Australian opponents of the legislation]."

> Repeated cross-sectional surveys of Dutch doctors undertaken every five years are particularly useful as they specify the number of deaths due to all end of life decision making. This includes assisted dying, as well as refusal of treatment, intensified alleviation of symptoms and ending of life without explicit request.[281]

The combination of all these sources – independent committees of review, peer-reviewed academic literature, and primary evidence from those who work within VAD/VE regimes [282] – informed the Committee's majority conclusion that **there is *clear* evidence the robust safeguards in the proposed legislation** [283] **will "protect patients from potential abuse".** [284]

Finally, it is important to remember that, in all jurisdictions, the operation of these laws is subject to judicial and legislative review. It is deeply instructive then that in none of these societies has any attempt been made to wind back or repeal them.

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[281] Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report", June, 2017, Section 8.9.3 'Chair of end of life care', p.235. – https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf

[282] Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report", June, 2017, Appendix 4 'Legislation in jurisdictions that allow assisted dying', pp.283-287 – https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf
Specific safeguards are set out in Appendix 4.

[283] Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report", June, 2017, Section 8.5.3 'Criteria and safeguards' and 8.7.3 'Request must be properly considered', pp.217-227 – https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf
This section of the Report details the robust safeguards in the proposed legislation.

[284] Parliament of Victoria Legislative Council, Legal and Social Issues Committee, "Inquiry into end of life choices: Final Report", June 2017, Section 1.2.3 'Overseas research', p.8 – https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf, Specifically, the Report says: *"The Committee heard about the robustness of the medical systems in place where assisted dying is legal. Each framework has rigorous safeguards to protect patients from potential abuse."*

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Appendix
In Their Own Words

When palliative care no longer works

WHAT THIS SECTION IS ABOUT

What follows is a collection of first-hand testimonies of suffering within our medical system.

In light of the 'Pyramid of Evidence Quality' (PART D, p.78) – which states that the second-least reliable source of evidence is 'case reports (individual)' – it is worth remembering that the suffering detailed in these pages has been shown to be systemic by the following:

- Statistical evidence gathered by Palliative Care Australia
- Multiple testimonies from doctors and nurses
- The Victorian Parliamentary Inquiry into End-Of-Life Choices (2016)
- The Western Australian Parliamentary Inquiry into End-Of-Life Choices (2018).

Further, many of the people whose testimonies you are about to read have either appeared before committees of inquiry, or would be prepared to do so in future if asked.

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Ailsa Rice – Husband.
One long and suffering week for him and his family. He begged me to find some way to help him go. **[He] accepted palliative care but [was] denied at the end the compassion we show to our beloved animals.**

Elaine Buchan – Father.
His long suffering was painful to watch **as he withered away in palliative care for months.** The effect on my mother, sisters and brothers was heart wrenching ... the pain of seeing him slowly deteriorate to a birdlike form crushed us all. It was a totally undignified ending for him and a lasting picture of our father which was seared into each of our memories.

Janice Stanley – Mother. 103. Starving herself. 70. Facing further cancer.
My late dear Mother, at 103 years was only in a full aged care facility for the last few months of her life but found a way to end her suffering by starving herself to death & refusing all medications. **Every day in her last 12 months she had begged to die.**

I am a 70-year-old mother & grandmother with a family breast cancer gene variant & as such have battled the cancer twice in 16 years. I know the cruel reality as it gets harder to treat each time & options will not be there in the future. I want to know there is a peaceful choice to end my life if all else fails & it gets to a point of unendurable pain & suffering.

I have witnessed many dear friends with terminal cancer suffer cruelly in terrible pain & discomfort during the remaining months of their lives. **Palliative care has not eased the pain in many cases.**

Jenny Bosma – Mother-in-law. 96. Osteoarthritis in spine.
My darling mother-in-law passed away last year at the age of 96. She was a wonderful vibrant woman all her life raising five children and being a vital part of the Armadale community.

During the last five years she was in constant, terrible pain and would ask repeatedly for us to ring the doctor to help her die. We discussed the fact that we couldn't and it was against the law. She had a catheter in place & suppositories for bowel movements as the pain meds she was given made her very constipated for many of the last years, could no longer walk and had lost everything that she held dear to herself and her dignity. This went on for years and was ghastly to watch and not be able to help her. She became completely dependent, like a little child and was so sad to become what she wasn't.

She was a powerful energetic woman and it broke my heart and hers to suffer so greatly for no purpose but to appease others idea of how her end should be.

She wanted to choose her time and was to die but was denied that choice. She wanted change but it will be too late to help her and **no doctor or palliative care was able to help.**

Karen and Brett Barnes – Grandmother and mother. Starvation and dehydration.
People often talk of Palliative Care as being the other option to Euthanasia but I do wonder if they have actually witnessed someone dying under Palliative Care! I have witnessed my Grandmother and Mother die while receiving Palliative Care and it was horrendous.

To drug a person to the point of unconsciousness and deny them food or water until they die, seems unbearably cruel – not just for the person slowly dying but for loved ones by their side. It is a myth to believe because they are unconscious, they are not suffering. The opiate-based drugs my Mother took to try and manage her pain gave her terrifying delusions and dreams.

Who really knows what is going on in a person's mind as they slowly starve and dehydrate to death over 7–14 days!

Where is the kindness and compassion? If I allowed my pet dog to die under similar circumstances, there would be a public outcry!

Marguerite Laurence – Friend. Steve. Lung cancer. 66. Submission to WA inquiry.
Two months ago, I watched my friend of thirty years die of lung cancer. He was 66 years old, and he lived for two years after his illness was

diagnosed. By six months before he died the cancer had spread to his bones and he was in well-nigh unendurable agony for all that time.

When the time came that his pain needed hour by hour management he agreed to go into the Hospice. **When he was admitted he said that he was entrusting himself to the care of strangers only on condition that when he asked to be allowed to die his wish would be granted.**

He had watched his mother die in slow agony from cancer, and he did not want such a death for himself. Nor did he want his wife and children to have to witness his dying in such a way.

He was told that management of his pain and palliative care would assure his comfort and peacefulness until the time of his natural death.

Nothing could have been further from what transpired. The staff of the hospice did their very best within the limit of what they are allowed under the law to do, and it was not even close to being enough to help Steve in the last weeks of his life.

No more brave and resolute man walked the earth than Steve, and if he had had control of his circumstances he would have died by his own hand at a time of his choosing, having said goodbye to his beloved family and friends.

As it was, he had no autonomy, no control, no choice, and the last two weeks of his life were spent in unbearable pain. He was so heavily drugged with so-called pain-killers that he was hallucinating, but constantly aware at the same time of the agony, the extreme discomfort, the nausea, the indignity, the loss of his sense of self.

One of the worst aspects of this aftermath is [his wife's] impotent rage at the betrayal of her and Steve's trust. Where they should have been looked after, in a first world civilised country, where he should have been helped to die by his own doctor, with his family by his side, instead he was effectively imprisoned by the law governing how an individual may die.

There was no peace in his last days, his last moments.

Mark Cox – Father. Mesothelioma.
In the final stages of his illness, my father was in dreadful pain and would voice this to me on the telephone and say that he wished he could end it now, because he was not living, he was just in excruciating pain.

Unfortunately, palliative care did not work for my dad because he was allergic to both Pethidine and Morphine and whatever else they tried to give him to ease his suffering did not work.

It is for people like my dad, where palliative care does not see them through to a peaceful end, that I support a change in the law to allow terminally ill patients a choice at the end of their life ...

Morag du Bois – Husband. Stomach Cancer. Asbestosis.
I lost my husband of 43 years to untreatable stomach cancer. He had a huge blockage in his stomach and could not eat, so he basically starved to death. It was the most heartbreaking experience for me, his kids and grandkids to go through.
His main wish was to die at home. He also had asbestosis and for the last 2 months of his life he couldn't lay down as it was too much pressure on his lungs, so he sat up slumped over our pool table.

Silver Chain did all they could for him. The last two days of his life were horrific. He cursed at all of us demanding that we help him take his life. I cannot express enough what effect it has had on my family. He demanded that we give him a gun or a knife.

Peta Quinlivan – Husband. Rare neuroendocrine lung cancer.
Just twelve days before his passing ... At that stage of his illness (a rare type of neuroendocrine lung cancer, which ravaged his body to the point where it metastasised into his spine, ribs, shoulders and femur); my husband was barely able to move; and wasn't eating.

Despite the palliative care received in hospice by doctors, nurses and volunteers; my husband suffered terribly ... and as his enduring guardian, constantly beside him all day and all night, I suffered too.

My husband had no chance of any quality of life at all whilst in the final weeks of his life. Even the most-simple pleasures of being able to look out of the hospice window at the blue sky, see the beautiful waters of the bay or be comforted by me, his wife, were robbed from him.

Two years after his passing I am still traumatised by what he endured; especially the sounds of his suffering throughout the long, frightening nights when the effects of morphine began to wear off and my husband required 'breakthrough' painkillers. Although he couldn't speak, I knew when he was in pain.

Hospices are a wonderful asset in our society but without legalised medical assistance, to enable patients to die with dignity, there will continue to be unnecessary pain and suffering.

Sarah Chevin – Family Member.
I have personal experience of **how a family member died in a state of intense and unwanted suffering and at the hands of Palliation in WA.** It was not their decision to die alone without us by their side. It was horrific and the suffering was completely unnecessary.

Along with the deceit and trickery to get them to this stage was in my view, totally unnecessary and was totally unacceptable for both family members and the person in question. It is not fair on staff members or on doctors alike.

Sarah Graythwaite – Father. Lung cancer. Starvation.
My father died of lung cancer in January 2001.

His last days were spent being slowly starved to death. We are told it would hasten his demise. To watch my father become a skeleton was the hardest thing ever. It traumatised me.

We stayed with him at the hospice in Murdoch **literally willing him to die. That will haunt me until I die that I prayed to some unknown creature to hasten my father's suffering**. I was with him when he died. I'll never forget how his hands went slowly colder. His breathing more laboured and then stopped.

It was disgusting that we allow a human being to suffer like that. And their family members. And the poor staff who have to care for them and watch it all unfold.

William Phillip – Wife, Dorothy (Senior RN). Inoperable duodenal adenoma.
My late wife, Dorothy Maxine Philip died on January 7, 2017, after an illness of 3 years post diagnosis, at the age of 81.

By August 2016 Maxine was becoming very unwell, and had a period of most uncomfortable hospitalisation at the end of August. From then her condition steadily diminished, and we nursed her at home, with wonderful assistance from the Palliative Care service. From mid-November, she was completely bedfast, using an in-dwelling catheter, completely incontinent, and terrified.

She was fitted with a sub-cutaneous perfusion apparatus just after Christmas, which managed her pain levels better than oral meds. They did not reduce her terror, as she effectively drowned as her lungs gradually failed and became fluid-filled. Her death was horrible.

I believe that she should have been able to nominate while still totally aware, that her wishes to be assisted to die before the terrifying last stages were entered, to have been legally available.

Palliative care is a wonderful and humane service, but it does not, and cannot, help in extreme circumstances such as Maxine's.

Sian Briggs – Father (Gerald). Cancer of pleural lining.
When the end came, my dad's death was far more terrible than anything I ever could have imagined. **Palliative drugs were not coming close to controlling his pain.** For four days we sat in an airless room with him, as he screamed and bellowed and writhed and cried. The previous night he was so panicked from the rising pain level he had tried to get up and run from it. He crashed down, smashing his head and cutting it open. When the nurses found him on the ground, he was covered in blood and sobbing and begging to be "put down".

I'll never forget sitting next to my darling dad, as he lay there in a nappy, two twig-like bones for legs poking out, covered in purple bruises, drinking from a child's sippy cup with a black eye and stitches across his forehead. He looked heartbroken. His urine bag was filled with what resembled dark brown syrup. His left eye was hanging down. And he was in absolute agony. All we could do was hold his hand and play his favourite music and pray for it to end. **He endured an agonising 96 hours of torture before he finally passed. There was nothing remotely peaceful about it and his body never stopped writhing or shouting out.**

Jacqui – Mother (Eulalie). Liver cancer.
My mum had to go into palliative care to get her pain under control. In palliative care there would always be someone screaming out in pain, begging for a nurse to come. In the end they gave my mum so much morphine she was comatose. Her mouth was ulcerated, her lips were so dry. She wasn't awake or aware, we didn't know what pain she was suffering, she couldn't swallow, we couldn't give her fluids. What's the point in keeping someone alive like that when they're not going to get better?

My mum weighed 32kg when she died, you couldn't even help her in bed without her screaming in pain. I have PTSD as a result of everything I've been through.

Marcelle Van Soust – Ex-husband (Willem). Mesothelioma.
Each time he had a course of chemotherapy the aftermath was so appalling and made him so ill and weak that after a time we decided that if he continued down that path then the time he was told he had left would be spent so debilitated and weak, with an immune system destroyed by the very treatment meant to prolong his life. It just wasn't worth it.

At this point he was taking prescribed doses of Oxycontin, Oxynorm, Movicol and various other drugs for pain.

Silver Chain nurses had been assisting with his daily hygiene and the doctor prescribed his drugs which Silver Chain nurses administered via the push pump in his chest.

As the days went on the drugs became less and less effective and so the dosage was increased. The build-up of fluid in his abdomen was excruciatingly painful and was extracted by syringe from time to time; a very painful procedure.

The morphine causes bowel loops, which in turn causes excruciating pain, so not much use to anyone. The bowel loops caused by the morphine were just a further agonising part of this hideous process; a vicious cycle of pain and suffering. Morphine ceases to have any effect whatsoever and does not relieve pain in a patient with a terminal illness such as mesothelioma or any cancer for that matter.

Van had a locked push-pump in his abdomen which delivered his medication but because at that stage he had no fat under his skin, the very thing that was delivering supposed relief was itself, causing more pain.

Seeing a person lying in a bed, wasted away to a skeleton, who cannot breathe and is struggling and groaning and gurgling day after day, making hideous noises which can be heard out in the street is the most harrowing thing for both patient and carer.

Three days before he died, he was in such agony that it was decided to take him to Sir Charles Gairdner Hospital to see if a small procedure could be performed to relieve the pain in his abdomen. After many hours it was decided he was too weak for an anaesthetic. He was taken by ambulance back to my house where, after the worst three days of unimaginable hideous suffering, he died.

Suffering such as this is criminal and is totally unacceptable especially in a person for whom there is no cure and is going to die.

Gabrielle Rose – Friend Dylan.
I will email you Dylan regarding the death by starvation made necessery by the suffering of a dear friend. This cannot be shoved into the 'zed file', overlooked, or in the 'too hard' basket any longer. Our Premier needs to stand up for what is decent, just and more important than football stadiums, more roundabouts and all the other 'follies' on the list. The people are suffering. Mark McGowan needs to be a leader on this right now. Mark my words he'll garner the respect of the whole nation by doing so.

Jackie McCallum – Mother-in-law.
It is tragic watching them die. I watched my mother-in-law virtually starve to death until her organs failed. All I kept saying was "we wouldn't be allowed to let this happen to one of our pets".

It was the most heartbreaking thing I have ever had to watch..

Lyn Godier – Sister, Michelle. Adenocarcinoma.
She fought for 18 months. Had chemo which didn't work. Eventually the cancer was almost everywhere and she finally had to agree to be admitted to hospital, because her pain had become too hard to manage at home. She had been a nurse so she knew what was to come.

She had signed the paperwork for no medical intervention except pain relief. **For five weeks she ate nothing. Willing herself to pass away.**

We were so aware of her pain and suffering because we were there constantly.

Her pain increased as the cancer advanced. She was allergic to morphine.

Watching the nursing staff, the majority of whom did their utmost to keep her comfortable, holding back the tears because they could do no more.

My sister-in-law, who is a nurse, pressed the buzzer for more and more pain relief when Michelle's daughter and husband became distraught with watching the pain she was in.

I cannot fully express the horror of watching a loved sister die so wracked by pain, and by law nothing else could be done. Her son, in the end, couldn't face being there. Her beloved grandchildren were kept away because it would have been too much for them. Her youngest daughter couldn't bear to come and is now dealing with the grief of losing her mother as well as a sense of guilt.

She had lost the sight in her right eye and could barely see from her left eye so invasive was the cancer. She had tumours that could be felt on her arms, near her collarbone and on her thighs. She was so frail but she just had to suffer it out. How cruel is that?

Joan Smith – Husband, 61. Aggressive lymphoma.
He was diagnosed with aggressive lymphoma which was strangling his intestine.

His final three days were spent in hospital and on the third night he lapsed into semi-consciousness. He had been having litres of fluid drained from his abdomen at intervals during the treatment process, and in the early hours of the fourth day fluid in large quantities continued to rise into his throat and he was gurgling and drowning while he struggled dreadfully to get a breath. **All the while he kept raising his hand to his head imploring someone to help him. This inhumane action continued without ceasing for seven hours!!!**

Towards the end, one and a half litres of blood-soaked fluid gushed out of his mouth before he took his final breath. Those hours will haunt me forever. Why should anyone die that horribly?

As a practising Christian couple, we viewed the present law as ungodly. We are God's hands and feet, he has no other, and while we do nothing this horrendous practice will continue.

Bettina Arndt – Mother, 87. Broken hip. Pulmonary embolism.
She had a fall, broke her hip and ended up in a surgical recovery ward. Then she had a pulmonary embolism, which should have delivered the fast, peaceful death she so wanted. She lingered for two horrible weeks. Everything went wrong. She screamed every time the nurses turned her over.

But one evening a palliative care nurse happened to be on night duty. She asked what was going on. It turned out my mother was in terrible pain, having grown tolerant of her morphine level and missing the medication for her crippling arthritis. That superb nurse tried to fix things. She had her moved to a ward which had proper palliative care, arranged for higher morphine levels, less regular turning. But then my mother got terrible diarrhoea, which led to more pain, intrusion, endless assaults on her dignity.

It was devastating struggling so ineffectually to provide that peaceful death my mother so deserved. Here I was, an educated, assertive person, thoroughly familiar with the medical system having for many years taught both doctors and medical students. Yet I failed dismally. **Wandering the hospital corridors with me were other families totally crushed by their impotence to ease their parents' suffering.**

It is a total nonsense to suggest that the solution to a peaceful, dignified death is now available through palliative care.

And palliative care experts acknowledge that even with state-of-the-art palliative care, terminally ill patients can still experience distressing symptoms that make their lives unbearable – weakness, breathlessness, nausea, suffocation, psychological distress, confusion.

Spencer Ratcliffe – Partner, Deb. Cancer.
The doctors can only administer, as you would know, a certain amount of morphine over certain hours otherwise that can put the patient to sleep permanently, and obviously that's not allowed. So **as much as the patient may want that, the doctors are understandably – and nurses – scared stiff of overdosing their patients.**

The pain was getting so intense on this particular night that Deb sort of called out to me and said, 'Spencer, I need to walk. I must walk. I've just got to do something.'

We walked around the corridors of this hospital for six hours until she was allowed to have more morphine and **during those six hours – I've probably still got the marks – her nails were clawed into my back through sheer hell. We walked past doors that led into utility rooms and she'd scratch at the door.**

She had to do something to alleviate the horrendous pain she was in. I've never seen pain like it. I've been a journalist for 49 years.

They said, 'We're not allowed to give any more for another two hours and 14 minutes,' or whatever. 'It's all written down on the chart.' 'Why not?' I'd say. 'Because that's the amount the doctor says. We're not allowed to give any more than that.' 'Why not?' 'Because it's the legal limit that we're allowed to give.'

Deb was only allowed a certain amount every hour or two hours or whatever. But because the pain just keeps growing and growing and growing, the amount of morphine grows too but not in accordance with the pain. It's very hard to measure that, but you can tell **when someone's screaming in pain and they're just crying. 'Please can she have some more?' 'No.'**

I said, 'How can you just tell me that? How can you sit and watch her in such pain and tell me she can't have more morphine?' 'Because the doctor says I can't.'

Jessie Edney – Husband, John. Bowel cancer.
John had suffered for five years with terminal bowel cancer. He had had more than 60 per cent of his liver and half his bowel removed in two separate operations. He was on chemotherapy for most of that time. He then got cancer in his femur and it broke, another operation and weeks of rehabilitation to walk again.

We had heard positive things about palliative care at home and thought that would be for us. Unfortunately, it has left me regretting our decision. While the people from palliative care who visited were wonderful, caring and pleasant, John had a terrible, painful and frightening death.

John was struggling to breath, arms flailing, trying to speak but all that came out for ages was terrible gurgling noises. In final desperation I called an ambulance and by the time they arrived John was still in that terrible state. They said that it was too late to take him to hospital as he would be dead-on-arrival.

My wonderful husband died a terrible death and left me with a terrible image.

John had suffered for five long years and to watch him suffer so much for hours at the end was terrible.

Sandra McEwen – Friend, Graham. Brain lesions. CNS lymphoma.
Graham chose to have only enough mild chemotherapy to get him home to sort out his affairs. He knew he was aiming for a good time, not a long one, but sadly only had one day. A series of seizures sent him straight back to a small regional hospital, unable to communicate effectively for another six weeks.

He talked constantly, but his words jumbled, leaving him frustrated and angry. His eyes said it all, but occasionally complete sentences sneaked out. He'd say, 'This is hell!' and 'I'm over this mate! I've had enough. I want this finished.' He clearly understood everything we said to him.

At my request, the doctor withdrew the steroids that were 'calming' inflammation in his brain. Why prolong this palliative nightmare?

Ten days before he died Graham stunned his doctor by saying, 'I want this ordeal over by 3pm, and if not then ... by sundown.' I'd been relaying his scarce comments for weeks, but perhaps it was this clear statement from him that confirmed Graham's desire to die.

Drug regimes changed and things moved faster from there.

The next day Graham fell while trying to walk, and probably broke his hip. That hip remained a source of extreme pain until the morning he died, despite increasing doses of morphine.

Palliative sedation and medication for seizures were his only treatments. It was all his doctor could legally do.

Eventually pneumonia carried Graham off before the brain lesions did. I will never again hear anyone call it the 'old man's friend'. **There is nothing friendly about drowning in one's own phlegm. There is nothing good about listening to desperate, healthy lungs gasping and grasping at air for two days.**

I was left shocked and traumatised by witnessing Graham's death from pneumonia. But I walked out of that hospital and didn't have to go back. What of the poor nurses who helped us? They were clearly shaken.

They were the kindest, most compassionate people I've ever met. How often are they traumatised by bad deaths? Daily? Weekly? How can we, as a society expect them to carry such an appalling burden in their own lives?

Robyn Taubert – Mother, Betty, 84.
Stomach cancer.
Then at 84, she got stomach cancer, which blocked the exit of food from her stomach. She felt fine as long as she didn't eat; she was simply not hungry. She asked them to help her die. But no, **she had to remain in hospital while her body starved to death. By law, she had to have intravenous fluids, which only served to prolong the starvation process.**

In the last four weeks, her veins began to collapse so she was put through daily agony having someone constantly trying to find another vein. Being bedridden meant she was plagued by discomfort and bedsores.

She should not have been subjected to all that pain and indignity of the last four weeks – hurting her to keep her alive until she died.

Judith Daley – Mother, Catherine, 73.
Lung cancer.
She was literally walloped with a very virulent form of lung cancer. It was six weeks from diagnosis to death and it was as though she had been shoved off the cliff of wellness and was plummeting into a chasm where there was no safety net.

During those last few days she was frequently incoherent with pain and pleaded with us to 'make it stop', or to 'get something' for her.

By day 40 after her diagnosis she was ... restless and unable to remain still, tossing and turning and groaning and moaning.

My sister and I cornered this poor young doctor and demanded to know, 'Why is she suffering so much?' And he said, 'If I give her any more it will hasten her death.' My sister and I didn't even look at one another. We both said, 'Well do it.' He didn't react to those words but suggested we should go and have a coffee.

We all knew her condition was incurable and her pain was clearly intolerable.

When we returned, Mum gave every appearance of being at peace. She was no longer thrashing around and moaning but was serene and apparently in a deep coma. Kay and I stayed with her for the next nearly 20 hours until she died.

Her suffering could have gone on for days or weeks but for the kindness of that young doctor. We are eternally grateful to him.

Denise Kapernick – Father. Parkinson's and oesophageal cancer.

Due to the staph, he was not a suitable candidate for chemotherapy and the idea of operating was also eliminated as it was a major operation that would involve cracking his chest open and removing a considerable amount of the oesophagus and stomach, which would have been too much for his already unfit condition.

It was decided that he would instead undergo a course of radium to try to shrink the tumour enough so he could swallow (and keep) his food down, which he was now unable to do.

Unfortunately, this treatment did not reduce the tumour, so he continued to lose weight and strength until he eventually was unable to even swallow his own spit.

At this stage Dad knew his time was limited so, in an attempt to hasten his death, he stopped taking his staph medication in the hope the infection would return and end his time on earth quickly and painlessly.

... at 2am he suffered a catastrophic stroke, paralysing him completely down his left side, weakening his right side and leaving him totally bedridden.

He was unable to do anything for himself and was reliant on the nursing staff, my sister and me to feed him, wipe his face, clean him, roll him over, massage his legs and wipe away his tears. **As the weeks passed, his pain increased as the fluid built in his limbs and the morphine was not enough.** The Parkinson's was also a factor for his pain as his muscles seized and spasmed.

The doctors tried fentanyl patches, increased his morphine doses and eventually commenced a morphine driver but his pain was still unbearable. He stopped asking the nurses to hoist him into a chair so he could be wheeled outside as the slightest movement would bring him to tears, even when we tried to trim his fingernails.

He put up an incredible fight against the staph, Parkinson's and the cancer, but the stroke robbed him of any quality of life and it was only at this time that he had no fight left and no desire to 'live' another day.

Dad lived seven weeks and three days after the stroke and this whole time he suffered, both mentally and physically. He did not pass away peacefully like the movies portray though. He drowned in his own phlegm and the noise of this is something I can never describe. His eyes were rolled back in their sockets and he was groaning and gurgling and his breaths were laboured, shallow and frantic. My sister and I cried at his side, hoping that each breath was his last, but as the hours passed, he continued his struggle for air until his body finally gave up and went silent.

Sue Hayward – Brother, Paul. Advanced pancreatic cancer.

Paul had been diagnosed with advanced pancreatic cancer that had spread to his liver. Wednesday, he was told by his GP that he would benefit from palliative support.

In the emergency room he was very stressed and frightened. A blood test confirmed an infection in his liver. His kidneys were failing, as well as a thought that the cancer had gone to his brain.

Paul was put on fluids and antibiotics, which were both stopped the following day when I had spoken with the doctor stating that I wanted Paul to be made comfortable and allowed to pass with dignity.

A pump providing regular bursts of morphine was provided and sedatives given but they did not have any desired effect and, in my mind, were not given quickly enough. **Medication was administered only when Paul was in agony rather than topping it up before it got too severe. Once given it took a good 30 minutes to kick in.**

The morphine pump was again increased, as it was clear that nothing was keeping the pain at bay. More shots of sedatives were given every hour but nothing seemed to work. Paul was moaning and his arms were reaching out in agony, his hands clutching in fists. His eyes, a sight I will never be able to get from my mind, showed sheer terror as pain wracked his body.

I was sobbing and pleading for help...to do something...let me sign something...I wouldn't let an animal suffer so! I have never been more frantic and felt so utterly useless. I could not help my brother and I just wanted to run away. I couldn't even pump a fatal dose of morphine into him as the pump was locked up solid within a casing, the keys locked away in a cupboard somewhere.

For six hours this went on. Even the darling young nurse looked desperate as she explained hospital policy.

John Acton – Mother. Stroke.
Eleven years ago, my mother had a stroke and took seven months to die. As her principal carer I divided my days into good days and bad days.

A good day for me was when she said, 'John, I want to die.' A bad day was when she said, 'John, please kill me.'

That was the only thing in her whole life that she had ever asked of me, and I didn't love her enough to do it because of the legal consequences.

Eventually, she starved herself to death.

Jane Morris (nurse) – Mother. MND.
As my mother's MND progressed we were, on several other occasions, **assured that her death would be comfortable and pain free.**

We placed our trust, and in fact our mother's life, in a system which only now I can say failed her dismally.

As it was my dear beautiful mum went to palliative care to die. Her and our intention and understanding was that she would be cared for right up until the moment of death.

And up until a few days before her death I cannot emphasise how exemplary her care was.

… not for a second did we envisage the horrific, inhumane and tortuous death to which she would succumb.

Mum was no longer under the care of her two neurologists but the palliative care specialist.

Yet again we were assured that Mum would not suffer in the end and that terminal sedation would provide her with the least amount of pain and discomfort.

She would supposedly be given adequate sedation to prevent any pain or associated anxiety.

She would not, we were told, experience any thirst or hunger as a result of the withdrawal of fluids and nutritional supplements. I promise you, you will not suffer at the end.

Mum did suffer. She had pain, breakthrough pain, because her prescribed dose was unable to adequately palliate her pain at all times.

She managed to express to us her fear and in one of her conscious moments was able to convey to us that she wanted to be fed through her PEG tube.

This was so very traumatic for all of us, many staff included.

We had been assured that Mum would be devoid of hunger and thirst, but no, the dying process is not a templated one and whilst her case may have been unusual it was nevertheless real and it was happening to my mother.

Mum suffered what I deem to be unnecessarily for days. Family members requested that her analgesia be increased.

A request I made pleading for her analgesia to be substantially increased even if it meant hastening her obviously imminent death was directly replied to by the question, 'Are you asking me to kill her?'

No, I was not trying to have my mother murdered I simply wanted her tortuous pain and existential suffering to end.

We are told that death can be peaceful and that we should not fear it but no-one, even staff members, could leave her bedside unscathed.

We chose not to allow young grandchildren and close friends to see Mum in her final hours.

This hideously prolonged death was visually ugly and this once beautiful, vibrant and radiant individual should not have been subjected to the haunting and unforgettable images that we were privy to.

To end suffering when palliative care cannot is not an act of killing, it is an act of compassion and love and one that we should all aspire to.

My beautiful mum did not deserve to die the way she did.

I promise you, she did suffer at the end.

Sandie Wands – Mother, Dulcie, 73. Neuroendocrine cancer.
She had a neuroendocrine tumour in her abdomen and a life expectancy of two months if she elected not to have chemotherapy. She had suffered a lifetime of major illnesses, but given her history and the prognosis even with treatment, she decided the fight would be too hard, and she chose to die.

She was transferred to hospital two weeks prior to her death where **she was given a blood transfusion, which was in contradiction to her express wishes that nothing be done to prolong her life.** By this stage, the pain was becoming unbearable and she was drugged to the eyeballs all the time.

My beautiful mother lay in that bed, rotting in front of my eyes for an entire week. Once they stopped taking her obs and said she was nil by mouth, it meant that medications that she had been so heavily dependent on (and was addicted to) were no longer being administered. In my opinion, that sent her into a violent withdrawal and **she spent a lot of time thrashing about the bed, crying out, doubling over in pain, showing nothing but horror and agony on her face like an addict withdrawing. She was starving to death and by this stage was skeletal, and her dehydration was obvious. Her mouth was caked with thrush** and because she had suffered very severe respiratory illnesses in her lifetime, the infected mucus was pooling on her chest, further preventing her from breathing.

I spent that whole entire week (day and night) by my mother's side, speaking on her behalf to try and get her more pain relief or a sip of water (until nil by mouth).

In the last couple of days as the infection on her chest took hold and her organs progressively shut down, she was gasping for breath the entire time.

Finally, she sat bolt upright in bed and her eyes flashed wide open with a look of terror on her face, then she fell back on the pillow and took her last breath. The mucus that had been pooling on her chest began to ooze out of her mouth, putrid, green sludge that just kept coming and coming.

That last week of her life was like a horror movie. It was entirely obvious that death was unavoidable, yet nothing was done to move it along so she could be spared the futile pain, suffering and indignity that she went through.

Anne-Louise Kitto – Mother, 87. Heart failure and pulmonary fibrosis.
My mum had heart failure and pulmonary fibrosis. She was admitted to hospital in a very distressed state and with breathing difficulties. She was probably about 4'9" and 38 kilos by this stage.

Anyone who came into her hospital room – nurse, doctor, pink lady, dinner person – she would gently grab their wrist and say, 'Please let me die'. I turned up to the hospital one day and she was so distressed. I crawled into bed next to her and held her while she chanted forever, 'I'm so sick. What day is it today? I want to die today. Why can't I die today?'

The only way I could honour her wishes was to sign a 'nil by mouth' form, which I did. Can anyone explain to me what the difference is between me signing a form consenting to my mum being given a needle that would peacefully end her life surrounded by family who could say their final farewells and me signing a 'nil by mouth' form, which meant my mum had a very slow, seven-day death? They are both a death sentence, except one is humane and the other is cruel.

After a couple of days, she lost her voice, which was so frustrating for her. She couldn't even lift her arms so she could only communicate by frowning and opening and closing her eyes.

I had to watch her fingers and toes turn black. She died alone in the middle of the night.

Annie Sobey – Best friend, Rhoda, 72. MND.
When first diagnosed with motor neurone disease, her life expectancy was one year to 18 months. She did not realise the disease would become so debilitating in such a short space of time.

First bodily function to shut down was her swallowing. She could only eat puréed food and then thickened drink, progressing to not being able to swallow at all. A PEG tube was then inserted directly into her stomach to give her sustenance and keep her alive. Her speech was badly affected, her frustration intense.

She was being kept alive by the PEG feeding directly into her stomach. Her quality of life was nil. She was fully alert and conscious but trapped in the prison of a non-functioning body. The last week of her life was a horror I will never forget.

My dear friend's eyes were full of fear and terror. We requested more morphine for her, and the nursing staff agreed she needed it but by the time permission was given by the palliative care doctor hours would pass. She did not seem to get enough to calm her. The fact she was fully conscious and aware was the worst. Her suffering defied belief.

As her friend, I felt so very inadequate that I could not do something, anything, to take away the terror in her blue eyes that still sparkled, beseechingly begging for help.

She was a spiritual and quite religious being, who believed in the hereafter. She deserved a peaceful passing. The horror in her eyes in those last days will always be with me.

John Paynter – Partner, Mary-Anne Paynter. Stage 4 cancer.
My partner had stage 4 cancer and had many medical issues including a broken hip that was causing her much pain. She was rushed to the hospital on Easter Sunday with a high temperature.

On the last scan where she was making sense a clerical error meant that she did not receive her pain medication before the scan.

The last thing she said to me with tearful wide blue eyes was, 'I'm scared'. I will never be able to get over that.

It turned out that all the scans and all the pain were in vain since a later brain scan revealed that she had suffered a massive stroke ... 1 April I was told that it was too late to do anything about the stroke and that 'she is dying'. I and other family members were told that there was little chance of saving her and that surgery would likely be fatal. I begged them to perform the surgery since if she died on the operating table under general anaesthetic it would be a peaceful death. But they refused stating that they could 'do no harm'. They said they would keep her comfortable and she would probably be gone in 12 to 24 hours.

I had no idea what palliative care involved. They remove anything that would help her stay alive, including saline drips and antibiotics. One staff member told me that she will virtually die of thirst and that it can take several days or even weeks. She was given a steady infusion of morphine, a sedative a few times a day and a drug to help dry out her throat.

Days One to Four: For the first few days she was constantly gurgling and coughing in an attempt to clear her throat. She appeared terrified.

After much complaining on my part they finally included the sedative in her continuous feed and allowed 'breakthrough' sedation and pain medication once per hour instead of a longer period earlier. It was horrible to watch her with her face scrunched up in pain.

I begged too much for her to be euthanised to the point where the palliative 'care' nurse suggested that other family members should request breakthrough medication since the nurses did not trust my judgement and thought that I might 'do her harm' with a morphine overdose. The complete lack of any logic is in itself unbelievable.

Day Five: Still groaning and trying to cough, sometimes almost screaming. I asked the palliative 'care' nurse who was very sympathetic and doing what she could to stay and watch my partner. After a few minutes she went and spoke with the palliative 'care' senior doctor. They tripled her dosage of sedation and pain medication – too little too late.

Day Six: She was getting weaker and sometimes just couldn't get a breath. Fighting for life not knowing she had no chance – so incredibly cruel.

She fought the whole day. At about midnight when I asked for more relief to stop her needing to cough up the liquid

I was told 'we can only give that three times a day and she had some an hour ago'. My god! Were they afraid it might make her sick? I felt I was living in a Stephen King horror novel.

Day Seven: She finally got so weak that she stopped trying to cough and just breathed more and more shallowly. **At last the poor thing had some peace – after seven days of unnecessary and unbelievable cruelty.**

Anne Woodger – Father, 59. MND.
Over a space of six years he gradually lost the use of his fingers, hands, arms and legs. He lost his power to speak and to swallow food. He had to be toileted, usually by his wife who nursed him for the full duration of his illness. He dribbled and so, as an intelligent civil engineer he spent his long, long days in one chair by a window with a large bib on.

As his speech became difficult to understand and then non-existent, he would communicate using an E-Tran board. When my father could no longer eat food, he elected to have a feeding tube inserted into his stomach. This enabled PEG feeding and it is how he consumed his food and drink.

Approximately five years into his disease, my father asked me, via the E-Tran board, whether he could end his life. ... approximately six months later he asked me to contact his palliative care doctor to discuss his options. ... I understand my father indicated to the doctor that he wanted to cease PEG feeding.

The palliative care doctor then organised a family conference at our family home. My father, mother, brother, the doctor and myself attended. During this meeting, my father and the rest of the family talked about what he wanted to do.

The decision-making remained my father's. He knew that the muscles in his eyes were weakening and once he could no longer keep his eyes open and indicate letters on the E-Tran board, he would have no effective way to communicate his wishes. The palliative care doctor suggested that if and when my father was ready to act on his plans to contact him.

Sadly, the compassionate and considered decision-making about my father's end of life choices was followed with the cruel reality of his death. While the law respected his right to decide to end his life, it gave him no help to do it and insisted that he must die slowly of starvation and dehydration.

Dying this way can take days or even a fortnight, so my father needed access to reliable palliative care to relieve his suffering. Accordingly, he asked to be admitted to the local palliative care hospice where he knew he would have quick access to pain relief if he needed it. He did not want to risk being without necessary pain relief at home.

While the staff at the hospice were kind and considerate, there was no escaping the necessary steps of dying in this way. **Mucus solidified in the back of his throat and needed to be regularly prised out with cotton buds, causing him to gag. His mouth was dry and could only be swabbed with water. Nurses, unfamiliar with his routines, tried to turn and bathe him and struggled to get him comfortable. He was eventually sedated when muscle cramps were so overwhelming and painful for him. I hope the sedation was effective in managing that pain. He died after 12 days.**

Shayne Higson – Mother, Jan, 77.
Terminal brain cancer.
Mum had an aggressive form of glioblastoma multiforme, and with multiple tumours they could not operate or do radiation therapy for fear of causing severe brain damage.

As the months passed Mum lost her ability to walk, she lost words and struggled to communicate, she was unable to write, unable to read, unable to talk on the phone and, towards the end, even listening to the radio or watching TV caused great discomfort. She was sleeping more and more each day and she had headaches and constant nausea. But even when Mum was bedridden and it took two people to carry her to the toilet, and she couldn't even wipe herself, she still wanted to live.

Each day her condition worsened. We did everything we could to try to keep her comfortable. Every day I would rub her legs and feet because she said it felt like they were already dead. The anti-nausea medication did little to ease her discomfort and as Mum's right side became more and more effected she could not even lie in bed peacefully. She was agitated and distressed.

Mum started to ask for some form of medication that would just knock her out but nothing the doctors prescribed achieved a peaceful state. **She had had enough. She kept asking, 'Why are they doing this to me?' 'Why are they torturing me?'**

By 14 November Mum no longer wanted to eat and each day she asked, 'When will it end?' 'Just give me something to end it', but I couldn't. I was so afraid.

Mum's greatest fear throughout her illness was that she would suffer another seizure. She had described it as like having a giant slamming back and forth inside your body but fortunately changes to her medication prevented this. That is, until the end.

By the time she was admitted to hospital Mum could no longer swallow, so she was unable to take the anti-seizure medication. On that first night my worst nightmare came true and Mum suffered another seizure. It took nearly an hour and a half to get the seizure under control because the nurses were only authorised to give small doses of medication, 15 minutes apart.

I won't describe all the other things that Mum had to endure over the next four days but I want to point out that **under the current law, medical practitioners can only treat symptoms as they occur. That means a terminally ill patient, like Mum, has to suffer, whether it be nausea, pain, or other symptoms.**

Nothing is given in doses high enough to prevent suffering, all for the fear of giving too much and perhaps hastening the death.

[redacted]

[redacted] – Father [redacted], 81. Terminal oesophageal cancer. Suicide.

Dad was diagnosed with terminal oesophageal cancer and wasn't expected to live three months, but instead he suffered another 12 months. This cancer is a slow and painful death sentence. Although Dad was on a lot of medication there were days when it just wasn't enough and the side effects of the medications were unbearable. Dad got down to a weight of just 45 kilos.

Our beautiful Dad took his own life on Friday, [redacted] [redacted] 2015 at the home he shared with Mum and [redacted] son, [redacted]. Dad left behind a note expressing his desperation to the end. All he wanted was for someone to help end his suffering so that he could die in peace with dignity which is what he deserved.

What Dad went through, especially in the end, was horrific. He made the heartbreaking decision to take his own life, hanging himself in the backyard. [redacted], was the one to find Dad and that made the situation even worse, if that was possible.

[redacted] – Husband, [redacted], 65. Progressive supranuclear palsy Suicide.

PSP is an insidious brain disease slightly affecting the mind but particularly affecting the ability over around three to eight years to walk, talk, write, eat and see properly – those with it often die from choking. There is no cure. [redacted] was a very active person, doing triathlons, the Ironman, marathons, and went annually on bicycling, motorbike and heli-skiing holidays. All those things came to a halt as the PSP progressed slowly but steadily. Eventually he could only walk outside with me holding on to him.

Three years into the disease, [redacted] told me he would eventually have to take his own life. I told him he would have to tell me when as I would be terrified every time I came back into our apartment that I would find him dead. He said of course he wouldn't do that as it would spoil our home for me and I would afterwards have to leave.

I'll never forget that walk from the lift to our room. I opened the door and saw [redacted] lying flat on his back with his eyes open. I hadn't imagined he'd have his eyes open. I could feel myself falling to pieces as I phoned Reception and asked for someone to come as my husband was dead. They came and soon after two ambulance men arrived. By that time, I was in deep shock. One of them tried for about 20 minutes to calm me down. I was taken to another room nearby where there was a young policeman. Our room had become a 'crime scene'.

If [redacted] was alive today, he would be in a terrible state. He would no doubt be in a wheelchair, unable to speak or see properly,

and being fed through a tube. Just waiting fo a long, lingering death.

If voluntary euthanasia had been legal, Wayne would not have had to take his life so early and we would have had him a little longer. Our family and his close friends would have been able to know what he was intending and to say goodbye. They had all understood and it turns out goodbyes are important.

[redacted] – Grandfather, 70s.
Terminal cancer.
Suicide My grandfather was diagnosed with cancer during his 70s, and while he fought it off for a few years, he was eventually given a diagnosis of terminal cancer. So, **as the cancer took its usual toll of damage and destruction, his life became increasingly unbearable. He was in incredible pain, had become incontinent, lost his appetite and could often barely eat. He was unable to do any of the things that he loved and valued in life** and began struggling to stay awake or hold a conversation for any great length of time.

He documented his failing health – 'very hard to get up, hard to swallow, breathlessness, weak'. And later his wife would share with the police investigating that matter that he'd said 'life is hell, this isn't living' and he was in total despair due to his increasing state of infirmity.

One Friday night, when he could take it no more, he ended his life. We didn't know his plans, nobody did. One of his sons was a GP, and as such my grandfather had to be very careful not to implicate him in any of his actions. He decided not to stockpile any medication of any sort, or try and get hold of a barbiturate that might potentially implicate his son.

So instead he was left with a much more horrific means of dying if he was to do so at a time and way of his own choosing: [redacted]. He did it on a Friday evening so no-one would be interrupted from work the next day. He did it quietly, he did it totally alone, in his room [redacted]

[redacted], **I dread to consider the thoughts that ran through his head, the loneliness he must have felt, the emotions – perhaps of relief, perhaps of panic, perhaps of fear, undoubtedly of pain.**

His wife found him the next morning; she'd been asleep in the room next door. He'd left a note: 'I love you all more than words can say, look after one another'.

Three cases of suicide presented to the Victorian Inquiry into End of Life Choices by Coroner John Olle

Case 1: The first individual is a **59-year-old man**. He had a wife of 38 years, survived by his children and his wife, with whom he shared close and loving relationships. He had no mental health documented, **a medical history of metastatic colorectal carcinoma, multiple confirmed colorectal and liver metastases.** About two years before his death he underwent a liver resection for confirmed liver metastases and was subsequently treated with chemotherapy. **He underwent 22 cycles of treatment, and unfortunately a CT scan performed not long before his death showed evidence of progressive disease with a new liver lesion, which resulted in the cessation of his trial treatment. His GP informed the court that the cancer had now spread to his liver and his prognosis was not good.**

He was admitted to hospital with a fever, dry cough. Ultimately, he wished to go home. He would inform his son and family members he would rather take his life than live a life dying in a bed.

He was well aware of his suffering and what was ahead of him. So, he would rather die than stay in a ward. Ultimately, he was observed by a motorist on a major freeway in Victoria hanging from a bridge. A note indicated his intention to take his own life.

Case 2: A **75-year-old.** He lived with his wife, with whom he maintained a good relationship despite their divorce. He is survived by his daughters, with whom he shared close, loving relationships. He had no documented mental health history, and again a very long, complex medical history.

Not long before his death, some years, he was

diagnosed with prostate cancer, treated – radical treatments – sadly without improvement and increasing pain with poor prognosis. He expressed to others his belief that his life would be so much easier if someone could help him die.

He could not face his lot. **He ultimately** [redacted]

Case 3: Finally, a **90-year-old man**, survived by his family, again with whom he shared close, loving relationships. He was described as a delightful gentleman. He was extremely fit for his age and a proficient iPad user. He had no documented mental health history.

A very lengthy history included back pain, chronic obstructive pulmonary disease, asbestos exposure and the like. Not long before his death he was diagnosed with a solitary brain metastasis in a setting of metastatic melanoma. He expressed his wishes very clearly to his treating clinicians; he did not wish to have any invasive procedure done. His main priority was quality of life.

In the final four weeks of his life, his doctor explained, he remained frail. He had lost approximately six kilograms in the previous four weeks. He had a poor appetite. He looked malnourished and had nausea. His family stated that from about mid-December 2014 his wellbeing deteriorated. He felt generally unwell. He was dehydrated and had diarrhoea. He was vomiting uncontrollably. He had fevers. He was wobbly on his feet, even with the assistance of walking aids. He was diagnosed with likely viral gastroenteritis and was commenced on IV fluids for rehydration therapy. He improved as a result of the rehydration therapy markedly and was discharged home to the care of his grandson in January this year.

The family explained that when he learnt of his cancer he went downhill emotionally. He was depressed and angry that there was no cure. He often told his family he would rather do something to end it straightaway and that if he could no longer drive, he might as well be dead.

[redacted].

He was subsequently found dying [redacted] **He died ultimately from the injuries sustained from the** [redacted]**.**

[redacted] **– Father, 72. Asbestosis. Westmead Hospital, NSW. Suicide.**

My father's lungs were shot to pieces and when he reached the age of 72, fluid built up in those lungs and he was in excruciating pain. I took him to have blood tests and X-rays and finally the doctor said to take the X-rays to Westmead Hospital to have them read. My father had had enough. He was terrified of dying like a lot of his friends and on this night, he decided to take his own life. [redacted]. **It did not kill him immediately;** [redacted]

He was taken to Westmead and was given medication, oxygen and tube feeding. Then they wanted to perform a tracheotomy on him. I was appalled ... I said he wanted to go, just let him go. But no, that wasn't what they wanted to do. I checked for myself to see how his wishes should be carried out. I found out that I could have his medication stopped.

It took a week for my father to eventually pass away; at least he was finally at peace.

[redacted] **– Father,** [redacted]**, 73. Parkinson's. Suicide.**

He had noticed little things – for instance, it became difficult to comb his hair and to clean his teeth. When he walked he didn't swing his right arm. When he was finally diagnosed, Dad was devastated.

He enrolled in a six-week Catholic adult education seminar, and seemed to get some comfort from this.

Dad did everything he could to find an answer. He went to more doctors and lung specialists, had PET scans, MRIs and numerous blood tests. He completed a rehabilitation program for Parkinson's disease patients at Calvary Hospital, and changed his medication (which unfortunately made him vomit and created a metallic taste in his mouth).

Everything my dad loved to do – surfing, swimming, cooking, **walking his granddaughter to school – had been taken away from him. He became totally debilitated, unable to do more than sit in a chair, for days and weeks at a time.**

On Sunday 12 April 2015, my beautiful generous father [redacted]

It's bad enough that my dad had a progressive neurological illness and a range of other medical complications. Much worse than that was the terrible way that he ended his life.

[redacted] – Father. Inoperable prostate cancer. Suicide.

On 14 June 1994, **our father** [redacted]

He was in the bedroom; our mother was in the kitchen no more than five metres away, my 12-year-old nephew in the lounge.

Dad was diagnosed with inoperable prostate cancer at the age of 54 with a 10 to 15-year prognosis.

And so began his long battle with an exploratory operation that ended in a careless removal of the catheter that left him 'leaking' constantly, but he didn't give up due to that little hurdle. He devised his own special 'nappy' so that he could continue to play his beloved golf. I don't think they had Tenas then!

I can't remember the exact point when he started to decline but I do remember distinctly his last couple of months. **He had been admitted to the palliative care ward of our local private hospital and was cared for so wonderfully by the nursing staff.** At the beginning, he would entertain other patients, and us when we came to visit, by playing the piano (totally self-taught and unable to read music). **But he was being given painkilling drugs that had him hallucinating and we could sense his frustration at his lack of control. He couldn't conduct a reasonable conversation when friends came to visit.**

Even though he had the best of care at the hospital, he was desperate to come home and, in the end, refused to go back. I learned after his death that he had begged his doctor to give him enough medication to allow him to safely and gently end his life when he knew all hope was lost.

He had written a note which I still have; a small piece of paper roughly torn from a page, upper case letters, obviously written with a shaking hand:

I LOVE YOU ALL. ALWAYS DO YOUR BEST. DAD.

I can only wonder at the beautiful memory we could have had of Dad's last moments; whether he had chosen to have us present when he passed or not, at least he would have died with the dignity that was rightfully his.

[redacted] – Partner, [redacted], 66. Multiple Sclerosis. Suicide.

MS is a mystery illness, it manifests differently for everyone. [redacted] walking and balance were affected and were the most obvious symptom. His feet and toes had no feeling, and while he still could walk, he would walk barefoot down the street to our boat and not notice he had taken chunks out of his skin on the rough gravel road. In contrast to his feet, his skin elsewhere became extremely sensitive, making wearing clothes uncomfortable.

[redacted] experienced shooting pains through the left side of his body. He had spasms that often came at night. He had short sharp pains that would wake him. Pains under the skin that he called snakes and spiders. He had bladder infections. He gradually became incontinent. His bowels stopped working and he relied on fierce medications, which would suddenly send him exploding to the toilet, too bad if you were out and about! Some days his eyes were reluctant to focus.

By December 2013 he was assessed as high needs which meant **if he was admitted to nursing care, he would have been in the high care side of the nursing home, and they would have kept him alive against his wishes. The most devastating loss to him was when he began to lose the dexterity of his hands.** He never complained about pain but experienced a lot. Towards the end he was unable to sleep in a bed due to the pain and spasms when he lay down. He slept in an electric recliner chair.

His greatest fear was that he would get to a stage where he would not be able to end his life

because his hands would not work.

[redacted] had always been an advocate for assisted dying, dying with dignity. It was not a rash or spontaneous act, rather the considered position of a highly intelligent person facing a disease that wouldn't let up.

[redacted] died alone and without a word of goodbye because he had to protect me.

That is what upsets me the most – **he had to die alone and in an unnecessarily violent way.**

[redacted] – Mother, [redacted], MND.
Mercy killing.
Sadly, at the age of 70 she contracted motor neurone disease shortly after an accident/fall whereby she broke her ankle. Unfortunately, at the time of her diagnosis, my mother was given a prognosis of about five years. She was faced with the prospect of the next five years whereby this disease would travel up her body and she was likely to die slowly and possibly painfully. She would slowly lose muscle functions and they would be depleted in her lower and upper limbs. We all knew that this would progress until she was unable to talk, swallow or breathe.

My mother really came to her decision to die at home with dignity shortly after the death of her loving husband of 55 years (he was aged 87). I watched him in agonising pain – **he was gripping my hand and groaning to his last breath in the early hours of the morning.**

Our requests for more morphine were often denied and to this day, those two days can only be described as appalling and horrific. Our family had felt they had witnessed an inhumane and horrific way to die.

... with the progression of her disease, there was now very little muscle holding her small frame together. It was frightfully painful and debilitating. She had been confined to a wheelchair for years, **she was receiving 24-hour pain relief and 24-hour home care and she knew that within months she would choke to death.**

The legal implications and repercussions made my decision to be with my mother the day she wanted to die extremely distressing.

I wanted my mum's death to be a better experience for her, but overall simply wanted them both to not die alone. For them and me both, my most simple and purest wish was for them to not suffer. My want to hold their hand so tightly so that they knew I was with them was essential.

I was arrested a few days after my mother's passing, on a murder charge. I was interrogated by a police officer and received many abusive threatening phone calls. I was constantly harassed by news magazines. My family abandoned me. I was reduced to only a few close friends and I had to vacate my home.

Two years later I was informed that the DPP had decided that I had assisted in my mother's death, however, no further charges were to be laid. I endured two years of quite extreme distress.

[redacted] – Mother, [redacted], 40s.
Metastatic cancer.
She took my advice, and as a result she died as planned. Later I discovered that what I had done was illegal.

Three years earlier [redacted] had undergone an operation for bowel cancer. When she consulted me, she had just been told that the cancer had returned, in the form of secondary tumours in her liver and lung. These were discovered during routine antenatal care. A termination at 20 weeks had been performed so that she could access further treatment for her cancer. She understood treatment was unlikely to be curative.

Her greatest fear was of losing control over her body in the final hours and days leading up to her death. She asked me to advise her on a way she could end her life, at a moment of her choosing. She said she would know when that moment came.

I did some research and [redacted]. Since I could not prescribe for her, [redacted], from her general practitioner. Within a few weeks she had a supply, which she hoarded. [redacted]

[redacted]. When she had saved enough tablets, she stashed them away in a safe place. She was ready.

Three months later, [redacted] had tried every avenue she could to find a cure. She had completed the palliative therapy prescribed by her oncologist without any apparent benefit. She had flown to Germany to try laetrile therapy. She had spoken to alternative practitioners at home in Brisbane. Nothing she tried had any benefit. **She became weaker, lost weight, lost energy, and lost hope. She now spent most of her time resting at home, supported by her family.**

An episode of shortness of breath saw her admitted to hospital with a diagnosis of heart failure brought on by the tumours in her lungs. Oxygen and medication to make her heart beat more strongly relieved her symptoms. At visiting time that night, her family were treated to a vibrant, energised [redacted]. She wore make-up, she did her hair and she told jokes and stories, laughing as she had not done for weeks. Each of her family members had time with her alone, to share their thoughts and feelings at an intimate level. When visiting hours were over, she stayed in the hospital and slept well.

The first visitor the following day was her partner, [redacted] [redacted] told him that she had taken the tablets ten minutes earlier. He knew which tablets, and he rushed to a public telephone to call me.

Fifteen minutes later when I arrived at the hospital, she was dead. No autopsy was performed. [redacted] was buried a few days later.

Dr Barbara Westwood – Mother. Emphysema.
My mother suffered from emphysema and **the last few weeks of her life were just a torture for her** and also for those who loved her, especially for me. During that time, s**he begged me to end her suffering.** I didn't do it, but the guilt is still with me.

Dr Geoff Wall – Patient. End stage neuromuscular disease.
A fully paralysed patient on life support with end stage neuromuscular disease who could only communicate through eye movements. Once he realised he would never get off the ventilator, his mental status deteriorated to extremely fragile and he repeatedly indicated that he wished to die. His eyes would well with tears on mention of his home, family and pets.

The problem with ceasing artificial ventilation was that he would need almost an anaesthetic to overcome the feeling of suffocation as he died. If artificial ventilation is ceased as strong intravenous sedation is given, causing rapid death, some may believe this to be murder.

The potential for litigation is always present and may influence outcome, as in this case where a conflicted family could not reach a consensus and whatever medical staff did would be criticised. The patient remained on life support for 11 weeks until he died from pneumonia.

I can scarcely imagine what went through his mind, immobilised, staring at the ceiling for months, unable to say where he was hurting, with tubes in his windpipe, arm, stomach and bladder, 24-hour machines and alarms, no hope of recovery, begging to end it all and finally an awful septic death.

Current laws failed to protect both this patient's right to control his own fate, and the medical staff's freedom to implement his wishes.

[redacted] **– Two patients.**
He developed a rapidly aggressive form of multiple sclerosis and within eighteen months had become very disabled and only able to walk with difficulty using a walking stick. **At a visit to his home, in the presence of his wife, he asked me if I would assist him to die. I wanted to but my mind froze with the thoughts of a possible murder trial and the loss of my licence to practice.**

He was a practical man so did without my input. He asked his wife to go into the town to buy some magazines then called the police to say he was going to kill himself so that his wife would not find his body. [redacted]. **That a man should have to do this in civilised society is a great indictment of the maturity of that society.**

Another case which has worried me is a man in his sixties with late stage pharyngeal carcinoma with all its horrors. I was looking after him in the local 20-bed hospital but I did not bring up to him the possibility of my hastening his death and he was unable to speak due to the choking effect of the malignancy.

I spoke to his wife after as to whether he would have liked me to help him out and she said, 'Didn't you see him jabbing at his arm like you injecting him?' By this stage [redacted] **There is no palliative care for pharyngeal carcinoma apart from long-term complete sedation.**

Nurse Coral Levett – Various patients.
People's bodies at end of life do amazing things. Bones break. Organs fail. Even our neural receptors, our pain receptors, are hypersensitive, so we may have apparently little reason for pain but yet feel it and experience it. And **often we see at end of life no amount of pain relief can relieve that,** and people will ask the question. They ask you to help them end it, to finish it, to kill them. They will use all sorts of language but there is no mistake about it. People know when they've had enough. It can be very difficult for the nursing staff to, I guess, experience that imploring and begging to assist them to end their suffering when it happens.

Many of the deaths I've seen are extremely undignified. I can assure you **starving to death or dying of dehydration is not dignified.** It's just not. And the levels of pain – **people can scream for the last hours of their death in agony despite very high doses of opiates, morphine and other forms of relief.** It's less than dignified I think when you're in a public place surrounded by people that you may not know very well, when other people can hear you, hear your trauma, hear your suffering, and you're generally in a strange environment. To me that's not dignified.

Nurse Flora Metcalf – Friend. Asbestosis.
I have been overcome with inner distress over the **prolonged inhumane, unrelieved suffering, particularly of the incurable patients known to be terminally ill and in their final stages of life.** Even more sadly, several of my friends have become such patients.

One friend was diagnosed with end stages of asbestosis and was in an acute general hospital for around six weeks then transferred to a nursing home, where he died within weeks.

For the above period he suffered terribly. He never got relief from the constant cough that sounded like he was choking, nor relief or way of removing the huge ribbons of yellow-green-brown tenacious mucus accumulating and dripping from his mouth, throat and nose, and was constantly soiling his pyjamas and bedding. He had no energy. Continuous oxygen via nasal tubes seemed to add discomfort and annoy him with his unbearable, unrelieved, dreadful pain. Loudly he yelled out with the pain, and for staff who rarely responded to him, perhaps knowing they couldn't help him.

After being transferred to the nursing home he continued to thrash around the bed so much that his leg nearest the wall was bleeding from deep abrasions, caused by him desperately and repeatedly hitting it. He did a lot of screaming out with the pain, and 'can't someone help me?'

Too often pain breakthrough occurs in the suffering, terminal patients already receiving analgesia. With disbelief I observed the above situations also in acute public and private hospitals, some also under palliative care, and in 'modern' aged-care facilities.

Dr X – Mother. Stomach cancer. Woman with vulval cancer.
I have witnessed the illness, suffering and deaths of many patients over the years. Many deaths have been well managed with palliative care but **there is a misconception that modern palliative care can alleviate most suffering and allow a dignified and reasonably comfortable death in nearly all cases. This is simply not so.**

The vision of a dying patient on a morphine drip surrounded by family and slipping away peacefully is not the reality in a significant proportion of patients. **Patients can suffer both physically, psychologically and existentially for weeks or months and can die in great suffering, often alone in the middle of the night and often in confusion, fear and distress gasping for breath or choking on their own fluids.**

In my mother's case of linitis plastica (a form of stomach cancer), she had absolutely intractable and intolerable nausea and could not eat, and **this was not adequately palliated despite maximum**

involvement of palliative care services. It was dreadful to see her suffer without adequate relief. She asked me several times to be put out of her misery but she had to endure it to the end.

I can recall several other patients who were unable to be adequately palliated. In particular, I vividly recall one unfortunate young woman. She was dying of advanced vulval cancer and had the most awful ulceration with severe pain at the slightest movement or touch and offensive discharge, bleeding and odour. **Fifteen years on her suffering still makes me feel sick. Nothing except death gave her release and death did not come peacefully despite morphine and palliative care.** Patients dying of advanced motor neurone disease are also faced with unbearable suffering, witnessing in full alertness a body that is paralysed and fearing choking to death as they lose every last vestige of independence and dignity. For some this is intolerable, yet our society demands that they endure the full course of their illness no matter what their wishes.

[redacted] **– Patient, 80. Emphysema.**
Some five years ago, a 55-year-old woman came to see me in my clinic. She was distraught and desperate for help. She explained that her mother, who was in her 80s, had severe emphysema, was breathless at rest and any activity caused her to gasp for air. The respiratory physician had suggested home oxygen and inhalers, none of which relieved her severe breathlessness.

She went on to explain, through tears of distress, that on three occasions she had found her mother [redacted] and her mother's suicide attempts failed each time. Did I have any suggestions to help, she asked?

What to do? **My bags of tricks in my palliative care repertoire are mostly useless for severe breathlessness. I could try low dose morphine, but this would create hypoxia and confusion which would be very distressing in itself.**

I went to visit the mother, who lived with her daughter on a rural property, and confirmed her medical condition to be terminal and associated with severe distress. The mother confirmed a passionate wish to die and end her suffering, and a mental state examination confirmed she was of sound mind.

Over the coming weeks I did try the morphine to allow at least an attempt at symptomatic treatment and to give me, the patient, and her family, time to consider her options. The treatment did not relieve her symptoms and the mother was persistent in her wish to die.

After confirming the family's support of the mother's decision and their support for my position from a legal point of view, it was decided for me to arrive at 6.00 one morning to provide a lethal injection with the family by her side. The mother died a beautiful peaceful death with a smile on her face.

Dr Cheryl Wilson – Friend, Diane.
Metastatic breast cancer.
My friend, Diane, would not follow the doctors' advisement to go home to die when she was diagnosed with advanced metastatic breast cancer.

She was determined to fight this cancer. She had two young boys, a loving husband and a life worth living. The second oncologist agreed with the first but finally supported Diane's decision to fight and arranged for the chemotherapy and radiation. She was given four to six weeks to live. She lived ten years. We made a joke about doctors' prognoses; 'You've had so many expiration dates stamped on you!' I said. And we laughed as she lived past those dates. It was a hard ten years. Repeatedly the cancer returned and she fought back again and again.

I am still deeply affected by the memory of how she had to die. When her time came, **her bones were riddled with metastases and fractures. Breathing broke her ribs.** Can you imagine this type of pain? Multiple fractures throughout her body. I can't imagine it. No-one should be forced to live through it. I will never forget her words the day I called her at the hospital. Without saying hello or the usual pleasantries one begins a phone call with, my dear friend, the strongest, most courageous woman I have known immediately said, **'Oh my God Cheryl, my body won't stop. My body won't die. Oh God, Cheryl.' I'll never forget**

my friend begging for her agony to end.

She had lived with a great deal of pain and suffering from chemotherapy, radiation, surgeries and metastatic fractures and met it head-on with humour and strength. She was inspiring. **I cannot comprehend the torture she would have gone through. She didn't deserve that. No-one does. It was completely unnecessary. No-one benefited by forcing her to have to live that last month.**

Jason Tangen – Wife, Melanie, 38.
Pancreatic cancer.
I am an Associate Professor in cognitive science and my wife, Melanie, is a Lecturer in Science Communication... well... she was. At the moment, she's lying next to me in her hospital bed slowly dying from pancreatic cancer. She's 38. She was happy, authentic, fiercely intelligent, and loved her friends, food, wine, and words. It was a privilege to share the last 20 years with her.

It has been 10 days without any food or drink and she has now deteriorated to just a shell of the woman she used to be. She's not in pain. We've ensured that there's enough methadone coursing through her veins to soothe a small nation, but it's hardly dignified—she would not have wanted to go out like this.

I spend my days teaching The Science of Everyday Thinking, and it turns my stomach to hear Melanie's nurse ask whether we're waiting for anyone to arrive—because that must be why Mel continues to 'hold on'. As if she could slip out of consciousness simply by wishing it.

There was no explicit 'decision' to stop food and drink per se. Melanie just gradually stopped eating and drinking. First, she could only tolerate mango, apple sauce, or an icy pole. Eventually, she'd end up just throwing them up, even with her nausea medication. She could tolerate sips of water or ice chips for a bit, but eventually stopped asking for either. She just slept for longer and longer periods, and eventually she just didn't wake up. She was on a syringe driver by this point, which slowly administered methadone, a sedative, and anti-nausea meds subcutaneously. I asked the palliative care doctors to increase her methadone because she'd wake up at night groaning and distressed – it seemed like she was in pain. They were happy to oblige.

From that point on – about 5 or 6 days – she just slept and got weaker and weaker, and just withered away.

I should say that I don't want to vilify her palliative care doctors and nurses. They were absolutely heroic during this entire process. They genuinely cared for Melanie and myself and wept by my side when she eventually passed. This hands-off process where they just treat her pain, symptoms and keep her as comfortable as possible is just standard care. Everyone knew about the timeline of symptoms as she approached death: the 'death rattle', mandibular motion, radial pulselessness, etc. They explained them all and kept reassuring me that she wasn't suffering.

I have no doubt that she'd prefer to die much earlier in this process, but I honestly don't know when that would be. There's no easy decision rule, even in hindsight. I'm actually struggling with this at the moment because I want to leave very explicit instructions for my loved ones and doctors if I'm ever in the same situation. But I'm finding it nearly impossible to point to the precise moment where I'd say enough is enough. **The last five days or so were particularly bad. There were very few signs that Melanie was conscious at all, and letting her lie there gasping for air just seemed cruel.** But then her eyes might open a bit and I'd get a faint sign that someone was in there, and I just couldn't imagine making a decision to end that glimmer right up until her last breath. If the shoe was on the other foot, and I was in Melanie's position and had to decide when to pull the plug, I don't know if I'd sacrifice those last intimate moments we had together in her final days, snuggling in her tiny bed and weeping in the dark.

Graham Lovell – Wife, Susan. Melanoma / metastatic cancer. Victorian Inquiry.
My beautiful wife, Susan, my dearly loved wife of 40 years and mother of our three children, **died a terrible death in the** Alfred **hospital on** 24 October **two years ago. She died of thirst. She had no liquids for six days until she died.** I stayed with her day and night at the Alfred hospital

and had to fight to get morphine for her to prevent pain and suffering. It was a very difficult period.

This committee has already heard about doctors and nurses being afraid to provide sufficient pain relief medication to dying patients, and that was my experience.

Susan's story has been documented extensively in a confidential submission to this inquiry. The reason I am presenting today is that I do not want to see other totally vulnerable people suffer and die in pain, as Susan did. It is not appropriate.

The cancer spread to her brain, and she had brain surgery in August 2012, November 2012, February 2013 and September 2013. She had radiotherapy and terrible chemo treatment with interferon and temozolomide, as well as a range of other medicines. I can assure you interferon is a very nasty drug. It drove her to suicidal depression.

I found a knife, a boning knife, in the glove box of her car.

Susan had a hip operation to bolt her femur together two days later. The shock of the two operations was too much for her. Her system could not handle it. Her digestive system shut down, a condition known as ileus, and stopped food passing through and just blocked up. Over the next two weeks all attempts to get Susan's digestive system working failed and she became progressively weaker. She went from a situation where she was able to push herself up in bed using one leg to not even having the strength to do that.

Susan was declared palliative by the Alfred **medical staff on 15 October 2013.** At 1 o'clock on Friday, 18 October, Susan started shaking and had a seizure. She was no longer able to move, to talk or swallow, but she was able to respond to questions by squeezing fingers placed into her hands. There was no hope for Susan, and the medical decision was made that she was to die of dehydration – that is, given no fluids until she died. I have no problem with the decision that she was to die. She was finished. I have no issue with that. It is how she died that is of great concern.

Everyone was shocked to find that Susan was in pain and we were ignorantly sitting there, believing everything was all right and her pain relief was being controlled, and the hospital staff were not providing adequate pain relief to prevent suffering.

After that I insisted on morphine for Susan, as she cried out in pain due to the broken hip whenever she was turned in bed. In addition, **Susan's tongue was raw, as the skin had come off, her lips were cracking as she was breathing through her mouth and could not moisten or close it. The frequency and dosage of morphine was much less than the 5 milligrams per hour authorised by the medical staff, as Susan was typically given parsimonious 2.5 milligram doses at extended intervals, so she was effectively going in and out of pain. Instead of proactively working to prevent Susan's pain, the staff gave Susan very little morphine because she did not and could not tell them that she was in pain. I would be there with her, and she would be crying and calling out in pain every time she was moved.**

At 2.00 am on Sunday a nurse took exception to my request for more morphine and summoned the doctor.

On Sunday morning I asked for a syringe driver for Susan, which I only learnt about from a nurse through the night, so she could have continuous morphine. After much delay and procrastination this was fitted, but with a token dose of 10 milligrams per 24 hours, which would basically shut me up.

On Monday, 21 October, the palliative care staff were back and they tripled the syringe driver dose to 30 milligrams per 24 hours at my request, but Susan was still crying out in pain when moved. It is not only the moving, of course; it is the pain that she was experiencing between the moves, which we had no ability to assess, but from what had happened previously we were pretty sure she was in pain through that.

As Susan's body dehydrated it tried to extract every possible bit of liquid in her system. Her stomach, which had been bloated and very firm due to the blocked digestive system collapsed and became concave. As her body tissue dehydrated, her loose skin was pixelated, with numerous small flat spots, so cream was applied. Her urine flow progressively slowed,

and the concentrated urine was a dark orange colour before the flow finally stopped. Susan's mouth and tongue were raw and her lips cracked, so water spray and cream were applied regularly.

On Wednesday night Susan was desperately gasping for breath, as her desiccated body tried to pump her thickened blood through her system. This gasping became progressively worse in the early morning, and she was given morphine and a sedative. My beautiful Susan died at 3.00 am on Thursday, 24 October, as I was stroking her hair.

After watching Susan die so horribly over six days, I consider that she died a barbaric death.

I hate to think of how terribly Susan would have died if I was not with her for those days. In a civilised society human beings should not be forced to endure such pain and suffering when they are most vulnerable before death.

In a situation like Susan's, I see nothing at all achieved by having her die for six days from thirst and putting that person in such a vulnerable situation at the end of life through that trauma. I say nothing is gained for her, for the family. It is just devastating for everyone, and she had a terrible death.

Bev McIntyre – Partner, Rudi Dobron, cancer.
Victorian man Rudi Dobron, dying of cancer, whose suffering had reached such a crescendo he determined that he wanted to die.

With no quick means to end his life – the disease meant he could no longer swallow – Rudi invoked his legal right to end it as quickly as he could, by refusing all food and fluids.

He described his decision this way:

'I am dying of cancer of the throat. I can no longer control my bowels nor eat or drink. If I was a pet, I would have had a peaceful injection days ago. But I am human and so I will have to go through the barbaric religious ritual of dying without dignity from dehydration over weeks.'

Seeking support in this difficult choice, he entered the Caritas Cristi palliative care unit, having been assured that he could expect to die quickly and with minimal physical suffering.

Rudi's medical records, obtained through Freedom of Information, are detailed in the book A Time to Die. They show that, **despite exhibiting ongoing symptoms of physical, psychological and existential suffering, he did not receive 24-hour sedation until 32 days after he entered hospital. He eventually died a further 15 days later.**

All this, as the book's author says, taking place, not in a desert, but:

'In Kew, with all amenities at hand.'

Debbie Smith – Mother, 53.
Metastatic breast cancer.
My mother was diagnosed with breast cancer in 2005. She was 45. She had an emergency mastectomy, chemotherapy and radiation. For a time, she was in remission, but the cancer returned with a vengeance after it metastasised. Mum fought cancer for a period of eight years, with everything she had.

Her biggest complaint was her bowel, it just wasn't working due to her abdominal tumours and it gave her more pain than any person should ever have to endure. My mum would often say to me that she was scared of how she would die; she did not want to die in pain. I assured her that she would not and that we would trust that the system would take care of her and I would not leave her side. Well I was half right, I didn't leave her side, but the system did not keep her from suffering. **At that time, I didn't realise what our current palliative care system is legally bound by; I assumed that people would not be in pain and suffering at their end. A perfectly reasonable presumption, as it was common sense. I was wrong!**

We trusted that the system here in Australia would protect mum and provide relief from suffering, until nature took its course. That's what we were promised when she entered the Palliative Care facility in her final months. We were assured that mum would receive what she needed. We were told what we wanted to hear, but as the weeks went on we realised there was a catch. Mum had to be well enough to ask for pain relief and express her symptoms: i.e. pain, nausea, insomnia, anxiety, migraines, etc.

The problem with this was that the very same drugs that were given to relieve her suffering, also made her incoherent and drowsy, limiting her communication to crying and moaning in pain, and unable to speak. Although, her pain was evident even when she was incoherent. Each time the drugs wore off, she would become lucid, terrified and traumatised from her experience, with the pain and the side-effects from the drugs, which included hallucinations.

Each time she came around, the process began again. There came a point where she was so highly medicated and so close to death she couldn't communicate verbally, let alone open her eyes. This rendered her unable to ask for more pain relief. From this point the pain went on without intervention, as it was assumed she was no longer suffering, because she couldn't tell us with her words, but she would squeeze my hand in a desperate attempt to communicate.

Before she became incapacitated, she had shared the intricate details of what she was experiencing. Her bowel had not worked for some weeks she was completely compacted. The pain in her abdomen alone was excruciating. She had cancer in her bones, she was so fragile that when she rolled over in bed one day, she broke her ribs. Her head ached, as the cancer was also in the bone of her skull. She experienced a blood clot in her upper thigh, which naturally alarmed us, but the shock of the words of her doctor truly floored us. He said 'we can't do anything about the clot, and it might speed things up for you'. Only more painkillers were offered and mum was left waiting in fear of what would get her first. She shuddered at the sound of the elderly man in the room next door, who was drowning within. His guttural coughing and painful moans left us all distressed. Unfortunately, that sound was all too familiar to mum as she had nursed her own mother to her death, from the same disease (breast cancer), in the midst of her own cancer battle.

... you get to a point where a person you love is starving, scared beyond relief and suffering excruciating pain but you can't help. There was nothing we could do, except drip feed her enough drugs to keep her momentarily knocked out, but not enough to put her in a coma as this is illegal.

There are no words that adequately capture the helplessness we felt. It was soul destroying. A tightrope of fear and doubt, that at any moment we would find ourselves in regret, that perhaps we should have done more. The reality is, her fears became fact.

Even in a state of sleep she was suffering, she just wasn't able to tell us. Any person watching on could see that she was in pain. Her face was twisted, her body twitched and she moaned and whimpered. We know she was in pain, because she told us many times in her lucid moments. Often, that is all she could say.

My mother died after almost 6 weeks without food and I will be forever haunted by this experience. By the end she was a skin-clad skeleton.

Mum went on for over a month, on a diet of painkillers and ice chips. **During our interview with ABC, another man told me his grandfather was in his 90s and went 90 days without food waiting to die.**

It's worth noting that the doctors were as helpless as we were. They said they couldn't do anymore for mum, as it was not legal. Bound by protocols, they wanted to help end mum's suffering, but would have to face charges and risk losing their medical license if they did. After this experience it is now crystal clear to me that law reform is the only way we can give palliative care doctors the protection they need to act and most importantly, comfort and ease the burden of suffering for those who await an unavoidable death.

Heather Bell – Mother, Alison. Neurodegenerative illness.

In the space of two weeks [my mother] had become completely bedbound. She couldn't eat solid foods at all. She was struggling to speak and she was being put on a lot of painkillers. So, for the next seven days I slept on the floor next to her bed. She became in steadily increasing more pain and came to the point where we needed to put in a butterfly clip for morphine and then of course those morphine injections became more and more frequent until it in the last few days I had an alarm set on my phone every two hours that was titled 'morphine', **and I would wake up every two hours to my mother's screaming in pain.** And we would rush around finding the one registered nurse in that whole building. She would have to come and bring the morphine and I would spend 15, 20 minutes trying to soothe my mother, stop her screaming, stop her crying, stop her writhing around while the morphine kicked in. And then she would sort of go slack-jawed for another two hours, moan a lot in her sleep. So, I'm not under any delusion that she wasn't in pain during her sleep; she certainly was. And then sort of just lie there for the next two hours and wait for it to start again. And then on her last day I was holding her, because I think I knew and the nurse knew – we all knew it was the last night. **She weighed about 30, 35 kilograms; her shins were like razorblades under the bed. There was just – you could feel and see every bone in her body.**

HB: That was about seven days that this whole injections of morphine thing went on.

AD: Do you think there's any way in that last week where your mother could've been helped and not had any pain?

HB: I can absolutely tell you – **my father's a doctor, I'm a medical student – we were surrounded by the absolute best doctors, the best nurses. No-one wanted her to be in pain. If there was anything that could have in this world been done to alleviate her pain even the tiniest bit more, it would have been done.** There is absolutely no way, and I can say that absolutely.

HB: I was standing there watching my mother take last breaths and groaning even as she did so, and I watched the grey creep up her fingers until her entire body went grey. And then I came back half an hour later after they'd removed the catheters and everything and wiped the blood off her lips, because **her lips were so cracked and dry and everything was bleeding and there was conjunctivitis – just layers of pus – around her eyes because her body was just so susceptible to infection and nothing could be done. She couldn't close her eyes for the last week they would never close even when she was sleeping.** And I mean that's something I see all the time I mean I'm terrified of those images. I didn't sleep for an extremely long time. You can't put into words the toll that it takes on someone to see anyone in that state, let alone, you know, the person who brought you into the world.

AD: To whose benefit is someone like Alison kept alive in that situation?

HB: It's not to anyone's frigging benefit. No-one benefited. **The nurses were horrified, and they obviously will go through it again and again.** I certainly didn't benefit. My mum didn't benefit. I can't think of a single person who got anything out of that except for maybe the proverbial man on the moon who got a kick out of the fact that my mother didn't take her own life and so she's not a sinner, I suppose. I mean is that who we're running this little show for?

Anne Hammond – Uncle, Multiple Sclerosis.
My uncle was chief engineer on merchant ships all his life. **MS reduced him to a shell of a man, incapable of doing anything for himself, barely able to speak, who needed to be spoon fed, toileted and put to bed. Eventually he managed to use a kitchen knife to cut his own throat.** Sadly, his stepson found him, called an ambulance and 'saved' him from dying. Later at the hospital he succeeded in pulling out the IV line and ending his life. It should never have come to that. He should have been able to die quietly with dignity.

Betty Ogle, 84. Pancreatic cancer.
Although the hepatobiliary surgeon said she was medically fit to operate, he advised that the tumour was too advanced for curative surgery. Mum chose not to proceed with surgery. She was then referred to an oncology doctor for discussion about types of chemotherapy, their side effects and unlikelihood of cure or prolonged life span. After a few days pondering her position Mum chose not to proceed with chemotherapy, her rationale was that she already felt nauseated, didn't want to eat and was very tired so she wanted to make the most of her time without chemo side effects.

When it was time for the palliative care nurses to visit, Mum's first request was that she 'go with dignity'. At the time I did not ask Mum to verbally outline exactly what she meant by 'going with dignity' but I knew her well enough to know that not being able to wash or toilet herself, having bouts of pain requiring morphine and the incredible weakness that end stage pancreatic cancer delivers ... that Mum had reached her point of NO dignity. That's when she asked and HOPED that she could receive an injection to let her pass quietly and quickly on (die).

After being denied her request for an injection to relieve her suffering my mother endured another couple of weeks of intense bouts of pain and wasting of her body known as cachexia. When a continuous morphine infusion was commenced, she turned to me with a hope in her eyes and said, 'Does this mean I will go to sleep now?' I replied 'No, not instantly it may take some time yet Mum, perhaps a few more days'.

Eventually severe dehydration set in, pressure areas formed on her boney hips and she experienced terrible sensitivity and pain from simply trying to reposition her for comfort.

Next came the dreadful night of watching her struggle to breathe with the 'death rattle' and knowing she was still partially aware of all of this. This was not her idea of 'going with dignity' and all I could do was kneel beside her bed and apologise for not being able to do any more for her.

Brett and Diane Godden – Daughter, Cassie. Metastatic Melanoma.
Further tests showed the melanoma had moved into her bone marrow. Doctors said there was nothing else they could do and Cassie bravely made the decision to refuse any further treatment. She knew she was going to die.

She asked for a week to say her goodbyes; doctors gave her four days, saying they could now only make her 'comfortable'.

What rubbish.

Cassie was on huge doses of painkillers and was outwardly unresponsive – but could still feel pain. She regained consciousness long enough to acknowledge she was being given painkillers and occasionally speak to us.

Cassie asked the nurses for 'the biggest dose they could give'.

On the third morning, she begged the nurse: 'Please tell me this is going to kill me'.

She was in excruciating pain and distress. She had said her goodbyes, and wanted to go. The distress extended not just to her family and boyfriend, but to the medical staff.

Cassandra passed four days after ceasing treatment. The question of how she wanted to end her life was never broached. It was illegal to help her to die, so the question was never asked.

But having watched her die, hearing her ask for the biggest painkilling dose, and beg 'Please tell me this is going to kill me', we have no doubt Cassie would have welcomed the choice to make an end-of-life decision. Whether she would have acted and ended her life earlier, we will never know. **But if all palliative care can do is keep you in an induced coma until your body gives out, it is not enough.**

Kelly Somerville (Nurse) – Mother, Eileen, 63. Amyloidosis.
Kelly Arnett Somerville says her mother had the epitome of a bad death — drowning in her own blood in a hospital bed in front of her children.

Lucid and in pain, 63-year-old Eileen Keogh succumbed to a rare disease her daughter said robbed her of her quality of life and dignity.

Ms Somerville, a nurse, said there was nothing palliative care specialists could do to relieve her mother's suffering from amyloidosis and months of nauseating agony.

"She was alert, she was in pain and she was suffering, suffering terribly," Ms Somerville said.

"My mum died what I call the epitome of a bad death, she drowned in her own blood ... whilst watching me, her 'nursey', beseeching me with her eyes to help her.

"She was the most important patient I ever had in my entire life and I could not help her. I will live with that for the rest of my life."

Anne Korner (Nurse) – Husband. Metastatic cancer.
My husband had metastatic cancer from Melanoma and died a shocking death, though **he**

was administered morphine but not enough as he was under the palliative care doctors, who really only want to prolong life, which is very upsetting for the relatives.

Lee Packer – Mother.
My mum has just passed after 32 days on morphine, I was so distraught, an animal had more rights.

Pam Miller – Father, 94.
I have spent the last 5 years visiting my 94-year-old father in Queensland ... he died in 19 November.

He lingered unnecessarily for 3-4 days and 'comfortable palliative care' was not carried out for the second day as he was very distressed and quite able to talk to us, and if not for the fact that I was with him, it would have been more distressing for the staff at the nursing home.

At the end of the day I rang his GP and demanded more sedation as he was gasping for air and the doctor was repeatedly telling me he was comfortable.

My daughter experienced the distress of watching him choking for air for 12 hours. I said we would never put her through that.

The nurses at the aged care facility were wonderful. They felt as distressed as us that there was no end of life medication available in 2016.

I feel it is our duty as Baby Boomers to speak up and try to do something so that our children do not have to go through all this when our time comes.

[redacted] – Neighbour, [redacted], 81.
In January this year, **my 81-year-old neighbour starved herself to death while living in a nursing home. It took her 56 days to achieve her goal. She died a slow, painful death and her last words to me were 'no-one should try this'.**

Then she had a stroke which paralysed her down the right side. This made her frustrated and angry. She had to sell her car and rely on others (she was fiercely independent).

The weekend after her niece departed, [redacted] decided to commit suicide using an old blade to cut her wrists, but she cut them the wrong way and the blood clotted.

I could not fault her logic when she told me she didn't want to live any more. She couldn't turn the page of a book, prepare a meal, wash herself or walk unaided more than a couple of meters.

David Cade – Mother. Cancer.
Palliative care did not comfort David Cade's partner's mother, who had a tumour at the back of her mouth. **For six weeks she struggled with the pain of hunger and fought to breathe.**

"It was utterly cruel, inhumane and unmerciful for her to be forced to endure such a situation for those last six weeks," David wrote. "No doubt the nurses and doctors who administered 'palliative care' as the patient moaned in hunger and gasped for breath felt they were doing the best they could to make her comfortable, but in this case her agony continued. 'Palliative care' wasn't good enough. It did not relieve her suffering. The medical staff should have had the power to quickly end what must surely be one of the most awful ways to die."

Carmel Hurst (Nurse) – Mother.
Nurse Carmel Hurst's mother had not only an Advance Care Directive, but had paid for her own funeral. After a cardiac arrest, she was taken to hospital and put on a medical regime to suppress her pain and make her comfortable. Carmel agreed with this treatment, but her mother's pain got worse and worse.

Two doctors agreed 'in an unspoken way' to not do anything that might not lead to a change in care, which would be a de facto means of adhering to her Advance Care Directive and letting her die. But a third doctor ordered more tests as, he said, it was 'the right thing to do', even if it wouldn't lead to a change.

A series of confrontations resulted, as senior doctors ignored Carmel and her mother's Advance Care Directive. Doctors insinuated to Carmel that she was acting selfishly; she believed they saw her not as her mother's advocate but as their opponent. Her mother wanted to die, and eventually did.

But **she was kept alive in unnecessary pain, Carmel believed, because of the arrogance of**

doctors who thought it was 'all about them'.

Genevieve Allison – Mother, Alice.
Breast cancer.
We helplessly waited almost three weeks for our dear Mum to slowly die.

Three weeks too long.

When my mother lost her brave battle with breast cancer earlier this year, she had endured the painful disease for almost six years.

At 170cm tall and just 37 kg, she looked as anyone who was dying would look.

She fought so hard for so many years to stay just that little bit longer with us.

But eventually she made her final decision – she was too tired to keep fighting.

She told us through tears from her hospital bed and we said the only thing that she needed to hear: 'It's OK, you can let go.'

I've lost count of how many times we would repeat that phrase over the coming weeks. Because even after she had made her decision and we brought her home, the uphill battle had only just begun.

For three heartbreaking weeks, we watched her slowly fade. Her skin greyed and she lost her expression. She couldn't speak and began suffering from terminal restlessness.

She was constantly anxious and scared going to sleep at night for fear of being alone.

There were several close calls where we assembled on the bed to soothe her cries and tell her it was okay for her to stop fighting. But each time, her body would defy her and she would draw another breath.

We slept in shifts and rarely got dressed, too nervous to leave the house in case we were gone too long.

Angelique Flowers – Bowel cancer.
Angelique Flowers, young Melbourne woman **who dies horribly of bowel cancer despite having sought death with dignity** – a death which horrified her siblings but was 'approved' of by her religious parents who believed that a medicated death was against God's will. As featured in documentary *35 Letters:* https://www.youtube.com/watch?v=5DqXGLwmJsc

[redacted] – Husband, [redacted].
Multiple Illnesses. Suicide.
In the weeks before [redacted] took his own life, **I begged the doctors to put [redacted] in hospital on a morphine drip because the pain medication was not working any more. All the specialists that [redacted] saw said that there was nothing they could do any more.** I was refused and told that it would be illegal. The only legal alternative that we were given was nothing short of medical torture.

How can it be legal to keep someone alive to suffer another day but it is not legal to let them go?

Every day was worse than the last and I would like to point out that keeping someone 'alive' is not the same as 'living'.

[redacted] **quality of life was zero.** I have never known or even herd of someone who had so many diseases some of which contradicted each other.

[redacted] **did not want to die alone and asked me to stay with him and that is just what I did. 20 minutes after [redacted] told me he had taken the tablets he was unconscious. It took a total of three hours before [redacted] died and it was horrible.**

If that wasn't enough to deal with, I had four police officers turn up on my door and amongst other things telling me that I would probably go to jail. I must stress I did not help [redacted] commit suicide I just didn't stop him. There are many other people like [redacted] and people should have the right to say how they want to die and have their wishes carried out. In a hospital it would take minutes even seconds and be pain free. On their own the outcome is unpredictable and loved ones are put through the horrible aftermath.

Dean Ingerswen – Father. MND.
At present my father is dying a cruel and miserable death at the hands of Motor Neuron Disease (MND). In the space of just eight months he has gone from an independent, healthy and vital 75-year-old who lived on his own to someone who requires 24-hour nursing. **He can no longer use his arms, meaning he requires someone else to dress him, feed him, shower him,**

toilet him and care for him. He can no longer walk far and recently has switched to using a wheelchair to go further than 5m. He has also reached the point where he cannot stand up without assistance. In the next little while he will lose the ability to walk completely and become bed-ridden, susceptible to bed sores and similar ailments. But worse than that, MND has no cure or effective treatment. Those with MND die due to two reasons – an inability to breathe, or an inability to swallow. So, my father is staring down the barrel of dying via suffocation or starvation, and myself and my family will have to sit by his bedside and watch him suffer. Most frustrating of all, for his whole life he's been an advocate of assisted dying. How cruel that in his ultimate time of need he is stuck in a situation where his worst fears are playing out right in front of us all.

Tony Paul – Wife. Cancer.
My wife was a cancer patient for 12 months. She went through a whole process of going in and out of hospital, because they could not get the medications right. She had a host of allergies. But at the very end, with the cancer generating a lot of fluid, she was getting fluid drained from her body; she was getting fluid drained from her lungs – 2.25 litres out of one lung three days before Christmas.

It made a huge difference once they got it out. That is like three bottles of wine out of one lung. She went and had some fluid drained on the Thursday. On the Friday she was due for chemo, but she could not handle it, so we cancelled it. On the Saturday she collapsed, and by this time she had had a gutful of the hospital where she was being treated. At her express instructions we took her down to another hospital, and they were brilliant. They were up-front and said, **'Your lung's three-parts full of water now. It was only drained 36 hours ago. The more frequently it gets drained, the faster it will refill. We can drain your lung tonight, but it will need draining again tomorrow. What you want to do?' She said, 'I want to go home and die'.**

It is a shame that she did not have the facility of having her life terminated when she wanted it terminated. **Why did she have to come home on the Saturday night and drown, and drown again on Sunday? She was gasping for breath – I could hear her bubble, bubble, bubble – and on the Monday night she passed away.** So, there is a lot to it. Basically, a patient should have, especially when death is imminent, that right to say, 'Yes, I have had enough, and my family is around me'. We were lucky we had our two daughters living within a few hundred yards of the house. That was our caring team – the four of us: my son-in-law, two daughters and me. We had a daily roster up at the hospital. It worked well, but it just did not work for my wife, that is all.

Brian – Father. Cancer.
My father starved to death as the tumour in his stomach could not be removed, and no food could get in through the feeding tube. It was slow and painful, **each day he begged for it to end.** Good people are being made to be criminal bringing in illegal suicide drugs. We deserve the liberal value of a choice to end this suffering. I don't want a system where some doctors give extra happy drugs to send you off and some do not. I want euthanasia not to be a lottery, but taken out of the shadows and transparently regulated. People have a right to die peacefully.

Manda Quin – Father, Nana.
I tell everyone this: unless you've lived the dream of looking after a terminally ill loved one and watched them slowly, painfully die day by day, you'll never know the nightmare it really is. I've lived the nightmare. **My dad and nana both would have gone on their terms, not a slow agonising death.** My dad was in so much pain even the bed sheet touching him and the hospital gown hurt him a lot.

Kathleen Skidmore – Mother. Liver failure.
I lost my mother three years ago to liver failure. **I had to watch an active, intelligent woman suffer through losing her mind and her ability to take care of herself.**

Anna Lam – Father. Pancreatic cancer.
I will never forget Grand Final Day two years ago when, at the ripe age of 25, I saw my father take his final, gargled breath. He had been battling pancreatic cancer. **In the weeks before his death,**

I listened to his moans of pain and witnessed him struggle with the simplest things – breathing, going to the toilet, opening his eyes. I heard my once strong-as-an-ox Chinese father whisper in Mandarin (so that my Australian mother could not understand) that he wanted to die. Everyone should be able to make informed choices about their own life.

Anna Sewards – Father. Pancreatic cancer.
I am sorry, but I get cross when people like cancer patient Julie Morgan say she opposes the proposed assisted dying laws ('I don't want to feel like I have to go', 9/12). I am sympathetic towards her pain but she is free to make her choice. I watched my 54-year-old husband die from pancreatic cancer. **In vain he begged for release.** The experience has strengthened my resolve to say: You can only decide for yourself.

Lyn Rostirolla – Sister, Nicole, 46.
Huntington's Chorea.
Words are insufficient to describe this slow and cruel debilitating degenerative disease. Initially loss of balance, trouble swallowing and slurred speech, closely followed by mental health issues where terrible nightmarish episodes in your mind convincingly become your reality. You believe what you are thinking is real, although to everyone else it is obvious this is not so.

Fast forward four or so years and you can no longer talk, walk, shower, voluntarily move, eat independently or communicate, as you now stay forever more trapped in your mortal body.

This mere existence eventually transformed our beautiful girl into a skeleton shell of a person who relied solely on carers to puree spoon feed, toilet, wash and clothe her. This mere existence lingers and lingers for another four long and hopeless years.

Finally, her jaw refused to open and syringing food and water was no longer an option. It took eight agonising days for her body to shut down completely.

After painfully experiencing her Mother's debilitating disease, our beautiful Nicole pleaded with her family 15 years ago, not to let the disease take her in this same way.

Sitting beside her over the last 24 hours of her life, we were painfully aware that we could not honour her most important wish.

Norma Kelly – Nurse.
Appearance before Victorian Committee.
Sometimes they are not really right at the end, as everyone believes they are. It is only a few weeks since one lady came into hospital, a very old lady who had had mega amounts of treatment because she was advised that this was very near the end, she only had a few days left. She lived for nearly four weeks in awful pain, in awful suffering, and just wanting to go. She said, 'I can't even hear'. Right to die in five minutes, sort of thing. She said, 'Here I am', and she ended up like a limp little rag doll in the bed. I am sorry, but **sometimes it does not matter how much medication you give people, when you turn them over – and you must turn people, you must move them in the bed, otherwise they get dreadful pressure sores – they do respond and they do become kind of conscious for that little while. I have people looking right into my face and begging me, 'Why am I still here? Please can't you do something'.** It is not a very good thing to have happen to you.

Another lady – who was not an old lady; she was in her 60s – had stayed at home, lived on her own, had no family and was going to stay home. Palliative care went there and she could not even get out of bed, so they said, 'You have to go to the hospital; we can't walk away and leave you here'. She agreed; she said, 'Yes, all right. I will'. That went on and on, too. Because – I do not know – she was obviously a strong lady and her heart was strong, **we could not get rid of her pain. Out in the corridor we could hear her groaning and saying, 'Oh, pain'. It was just awful.**

Which brings about another issue. Junior doctors are not in a very good position about this. They are very hesitant to order large amounts of morphine or haloperidol or any of these drugs that are really going to knock the patient out, which is what we really need. They are just fearful of it. The patient keeps what we call breaking through with extra pain, and we cannot get it under control. At 11 o'clock at night I am sitting there with a lady looking at me, begging me to end it – 'Please, can't you do something? I know you can't, but can somebody?' That is really not good enough.

People are in pain and there are people you just cannot get out of pain.

That is where I am coming from.

Rod Henney – Three family members. Appearance before Victorian Committee.
I saw my grandfather suffer. **My father-in-law, every time I saw him he would say, 'Shoot me. For God's sake, shoot me!**' I saw my brother-in-law die, and I know for a fact – he had cancer, and they say three months is quick; it is not when you spend three months with someone with cancer – I know exactly what he would have done if he was well aware of where he was headed. He would have stopped it a lot sooner, because they say you are not in pain, but when you get shifted – and I know how tough this bloke was and his face was screwed up like you would not believe – there was something going on. He was not doing it just for the sake of doing it.

Kate Roach – Mother, Zelda. Emphysema.
'You wouldn't let your dog suffer the way I am suffering.'

Those were the words my maternal grandfather said to my mum shortly before he died of cancer in 1985. Full circle to 2016 and my mum was saying the same to me. She had been a strong advocate for euthanasia from when she had to watch her father dying by small degrees over weeks and weeks of endless pain.

My mum, Zelda, had emphysema and an irrational fear of hospitals and doctors. I believe this fear stemmed from watching her father go through such horrifying pain and the doctors not being able to put him out of his misery, even though he was begging them to day after day.

On the 15th of August 2016 my mum, not for the first time, sat on the side of her bed thinking about taking her own life. What stopped her was not knowing how to make sure as she said she 'did the job properly to leave this mortal coil' without medical assistance to support her. She was terrified that if she didn't do it properly, she would be worse off than she already was.

For my mum her worst nightmare came to pass on 8 September when she couldn't breathe and I had to call an ambulance. This was to be her one and only trip to hospital during her extended illness and it was weeks and months after the time she had long had enough of existing. If not for the terror of not being able to breathe, due to contracting a chest infection, she would never have allowed me to call an ambulance that night.

Over the next week she deteriorated, both mentally and physically, in the hospital until on the 15th of September she took her last breath.

At the end she was only 28 kilos, a skeleton with skin, who finally let go. It breaks my heart all over again to think how long she suffered, how often she had said she wanted to die, how that last month in particular was its own kind of torture for her every day.

Chris Cable – Mother, 83. Peritoneal cancer.
In January 2016 my mother was diagnosed with [final] stage peritoneal cancer – a type of cancer that was both inoperable and terminal. Initially her oncologist said that without chemotherapy she would have 'weeks not months' to live, and that without chemotherapy, there was no hope that she would make her 60th wedding anniversary in January 2017.

After accepting the hope that chemotherapy gave to prolong her life, the initial treatment started in early February, and lasted for a period of nine weeks. Every couple of weeks, Mum would get a report from the oncologist, indicating that the progress was 'going well'. However, at the end of her treatment, the prognosis was that the chemo had made very little difference, if any, and that perhaps a further treatment of a heavier duty chemo might be appropriate. The doctor advised this may or may not assist, but would also most likely impact on her health adversely for the duration of the treatment, including the normal chemotherapy side effects (hair loss, nausea etc).

At this stage (April 2016) Mum was 83, and decided that enough was enough – and that the treatment she already completed was all that she was prepared to put up with. For the next period she wanted to just be as healthy as possible, not have the side effects that the treatment would inflict. Mum wanted to be with the family. However long she had left.

At that stage palliative care was arranged, with a number of doctors assisting her with pain relief and dealing with the side effects of the cancer including (but not limited to) stomach problems, bowel problems, blood clots and sleeplessness. At one stage she was taking around 20 tablets each day for a range of issues that were the result of her cancer.

While Mum was well for a few months she deteriorated very quickly in late August–early September 2016. **During this time, the family watched her waste away in pain and discomfort. It got to the stage where she could not walk and even struggled to eat or drink.**

Watching someone go through this period has fundamentally changed my life and approach to how much people can suffer despite the best attempts by doctors. **'It's very hard to die' was the palliative care doctor's candid assessment of her progress during the last part of her life.**

Mum knew that at some stage she would get to a point of not wanting to be around. While some people think that this might be at the diagnosis stage of the illness, Mum had quite a few nice months of a largely comfortable existence enjoying the family, and spending up big on the grandchildren.

Toward the end of her life, while she was still of very sound mind, **Mum had clearly had enough of the consequences of her illness, and wanted things to end.** She asked me numerous times how she could end her life. We all had to back away for fear of being an accessory to suicide. **In the end I got the 3:00am call from Dad saying that Mum wasn't breathing well and was coughing up blood. No one should see their loved ones suffer like that.** Mum never woke up on that day.

Anne Holland – Parkinson's Disease.
My mother, Anne Holland, had Parkinson's disease. She knew that this would eventually kill her but she wanted to get the maximum out of life before that happened. She arranged her affairs and spent four years in nursing home care before she deteriorated. When she could no longer walk and because my father was also infirm, we moved her to a nursing home where her husband could visit daily. After four years and on one of her 'good days', she asked her GP – 'Can you help me die when I say I have had enough?' The obvious answer was no, of course, and I saw both fear and disappointment on her face. Just before she got to the stage of not being able to swallow and straight after a speech therapy session she said (read: shouted) to the GP – **'I've had enough! Let me go. I'm hungry, thirsty, incontinent and can't move, have ulcers and have said goodbye, now let me go!'** I heard her repeat this at least three times in the months before she died. I could see the fear in her eyes and I really wanted to help. Eventually when we could no longer give her food or water because she couldn't swallow and because she had requested that she not be fed by a tube, **the doctor asked permission to put her on palliative care and explained that this would dull the hunger and thirst issues while they starved her to death (my words) and that she would, if she was lucky, quickly get pneumonia and die in her sleep.**

We gave permission for palliative care since we felt there was no legal alternative. **We are still suspicious that her palliative care was there to make the onlooker feel good, not to substantively help mum. We can't tell what that was like from her side of the drugged fog but she only cried and moaned a little for about 10 days before she died – the documents would have said of pneumonia but that was far too simplistic.**

When supporting euthanasia, we have to be careful that it's not the onlookers we are pleasing but the patients. I'm convinced that Mum suffered, she knew she would and no-one knows what went on in her consciousness while waiting to starve.

David Swanton – Mother, Betty.
Pancreatic Cancer.
She said, in one of her last phone calls to me, that 'I was told that it would be painless, and I'm so cranky'.

My mum, Bet to her friends, had pancreatic cancer. From her diagnosis in April until her death in

September there were some bright moments, but we all knew there would ultimately be a downward slide. Even though **she was told that her death by cancer would be made painless, she interpreted that as meaning that there would definitely be no pain or suffering, and was confident that would be the case. Unfortunately, she was wrong.**

After medical advice, mum opted against major surgical intervention (though a couple of stents were inserted), chemotherapy or radiotherapy, not that those were really options for someone who was otherwise healthy, but was in her eighties and somewhat frail.

Her poor quality of life in the last months was not the fault of her palliative carers.

Her doctors and nurses at her hospital were professional, compassionate, and according to mum, 'excellent'. All staff were committed and sensitive to the needs of patients in pain and suffering. However, more money is needed for the palliative care hospital system.

Perhaps it is now moot, but **it is interesting to speculate what mum would have done if she knew that she would eventually have two episodes of excruciating breakthrough pain: one requiring dramatic ambulance attendance, and the other while in palliative care.** As well as these pain events, there is also a lack of dignity associated with this disease.

She was toileted and showered, there was a cocktail of pills and suppositories, ongoing and frequent injections of painkillers and antiemetics, cannulas, little vomiting episodes, dryness, artificial saliva sprays (because drinking was nil or minimal), lack of appetite, nil food for the last week, emaciation, and gurgling respiratory infections. And that was in addition to the bowel blockage, the appearance of being six-months pregnant, the threat of possibly vomiting fecal matter, and knowledge that she would not be sedated so that scenario could never arise. And perhaps she should have buzzed the nurses every half an hour for extra pain relief, rathe than waiting...

Until the last three days she still had a bit of spark. At that stage she indicated she would be happy to die then. She was then consumed by the disease, her optimism and vitality overrun as she drifted in and out of light sleep, signalling the onset of the inevitable. There was lots of hand-holding, lots of support, and distress at the discomfort of our loved one.

After her many pain events (minor events though were well managed in palliative care) and suffering, she died in the company of a nurse, while her loving husband and I, her eldest son, were but ten minutes away from being with her. She would have preferred dying in the company of her loving family and relatives, and preferably at home. Who wouldn't? If she could have chosen her time of death, then the family could have been there for her. The extended family has been devastated.

Bet suffered more than I could or would wish to endure.

Many patients would benefit if increased funding were made available for the palliative care system, which is more likely if voluntary euthanasia were a legal option. If I were in my mum's position, I would have chosen, intentionally, to die earlier, rather than suffer as mum did. If mum had been better informed and had chosen that option, she would not have suffered as much.

Bill Grace, 60. Lung and liver cancer.

The biopsy confirmed what we'd suspected, it was indeed metastatic. And they told us then that **there was nothing that could be done.**

We were referred to an oncology centre, where it was also confirmed that this was indeed terminal and they concurred with the time frame given. It was suggested that perhaps some chemo might give him a little more time, but even that was uncertain. Bill decided that he would rather take it as it came, rather than undergoing chemo that may make him sick and lessen the quality of life for possibly a bit more quantity.

I have to say that all Drs and staff that we dealt with were wonderful, and supportive. Medication was prescribed for comfort and to alleviate symptoms as much as possible, and we set about making the best of the time we had left together.

The next appointment at the oncology centre it was suggested that perhaps another dose of chemo might be considered, Bill said no and on this appointment it was suggested that they refer him to palliative care, which they did.

Our palliative care team was wonderful; I am at a loss for words to express my gratitude to each and every team member that joined 'our' journey. During our first visit Bill expressed his desire to remain at home, which they took on board and helped make it a reality.

August came and went and Bill was still with us. Most days were good, a few were not so good, pain relief was available and used when necessary.

He deteriorated further and in August (2 years from diagnosis) and September he was to the point of being hospitalised to investigate sources of pain and re-assessing his meds. By the time a bed was available he had rallied and only went in for a chest x-ray and some blood work, he stayed part of one day and called and said 'come get me', we returned the following morning for the x-ray and when it was determined that his lungs were not filled with fluid he opted to come home and remain on the same pain meds.

The following week, Bill's 60th birthday was upon us, one we never thought he'd see and he decided he wanted to go on a 'cruise'.

Bill began to deteriorate more quickly at this point, and needed additional pain relief. Once again, our palliative team stepped up and introduced us to another amazing Dr, our final palliative team member.

Pain killers became Bill's best friend making life tolerable, but not always pleasant, with me administering injections as needed. We had one last Christmas, and again made more memories surrounded with family and friends.

The final descent began just after the New Year, and decision was made that a syringe driver was necessary to manage the pain, with break through pain managed with additional meds. Bill's children got to come and see Dad one last time, and we lost him a few days after these final visits.

In this day and age, we are looked upon as inhumane if we don't end the suffering of a much-loved pet, we should be able to do the same for suffering loved ones. I find it unimaginable that our society does not allow terminal patients at the end of life to have the choice to end their suffering on their own terms.

Justine Martin – Mother. Multiple Sclerosis.
It was a cruel death, and happened over a 24-hour period. She had fluid in her lungs, and my brother and I had to sit there with her. It was traumatic for both of us.

She had a peg [feeding tube] in her stomach, and a breathing tube. She had no quality of life. She had lost the will to live a long time prior to that because of the MS.

She often spoke of ending her own life. She just didn't have the means to do it. Her biggest fear was becoming incontinent.

[redacted] – Father, [redacted]. MND.
He was diagnosed in June 2015. He died in April 2016.

From the beginning, we were worried about Dad ending up as just a pair of eyes on the couch, and not be able unable to talk or do anything for himself; he was so proud and capable.

We'd never seen him be vulnerable and weak and were scared about that, for him. I had reassured him that I would do anything I could so he wouldn't suffer. And I started looking into assisted dying, and what the possibilities were. I did all the research online and we ended up with a bottle of [redacted] in the cupboard.

The MND affected his lungs mostly, his breathing, so he could still move. But he was getting progressively worse; he started using a walker, and needed help going to the toilet. Mum's a trained nurse and she was able to keep him at home with **visits from the palliative carers; they tried really hard and they did what they could.**

Dad asked the doctor to help him die at one stage, and the doctor said he couldn't help him. He could only try to make him comfortable. We had the [redacted] on hand but he had so many drugs at the end, it got beyond the point where we could say he was making that decision for himself. He was suddenly on a breathing machine, and it all went too quickly for us to discuss it. We hadn't planned ahead. We thought we'd know when the time was right and it got away from us.

In some ways, at the end, it was merciful because it was quick. But **he really suffered. We'd hearing this primal groan for air. The machine wasn't giving him any air. It couldn't help him. He had a very horrible last night. He was contorted across the bed. He must have been drowning.**

Eleanor Marsh – Mother, Beverley. Lung cancer. Eleanor remembers her mother as strong, independent and caring. But Beverley's last days were harrowing.

"It was a horrible experience watching my mum go through it", Eleanor says, "I just wished I could help her.

"She wasn't the type of person to put any pressure on anyone else to look after her. She hated relying on other people."

The last eight days of Beverley's life were horrific for Eleanor and her brother as they witnessed their mother slowly deteriorate.

"It was the most horrifying and painful eight days of my life, and hers. I was told on the first day that she would die and it was just a matter of hours. But she didn't, **she lay gasping for air on a ventilator that was forcing her lungs open.**

"My brother and I were there through the eight days, and we just wanted her to pass because we could see her suffering," she says. "She was not conscious enough to talk but conscious enough just to breathe and moan. It was horrible."

When doctors finally removed Beverley's oxygen mask, Eleanor and her brother watched as she struggled for air. **"At one point she was saying help me, help me.** I gave her a drawing board so she could write down what she was saying, it was all scrambled, but I could still read it, it said "Endone", which was her daily medication that helped ease her pain. **The doctors wouldn't give it to her. They had taken her off all medications, because she was dying.**

"All they could do was supply her with intravenous morphine. Each dose was every two hours, and **when it would wear off my mum would start moaning and her eyes would roll.** It was so painful to watch.

"I know that her body had started to shut down, as there was only blood in her urine catheter. In the end, at day eight, I asked them if there was anything more they could do. The nurse came in and took off her oxygen mask, we then watched my mum painfully take her last breaths, and then giving up.

"It took about five minutes of her gasping. We watched her take her last breath."

Eleanor says her mum endured an unnecessarily cruel and painful death.

Samantha Lancey – Multiple family members. Over the past seven years my family has gone through hell watching loved ones suffer. I've lost three grandparents, an aunty and a close friend and they all suffered in the end, some more than others.

My grandfather was the first to go, he had cancer and it spread to his brain. I remember lying on the bed with him at his home looking at photos and laughing, then he screamed in pain. **His whole body was tense and you could see the tears running down his face from the pain,** I cried with him. He told me that if he was a dog, I would be charged with cruelty for letting him go on like this. **Pa was put into hospital and lived for another few months and the pain and suffering got worse, the more advanced the cancer got on his brain the more my grandfather became someone I didn't recognise mentally and physically.**

My grandfather was a very intelligent, kind and artistic man who **died a very confused, agitated and nasty man of skin and bones.** He would have been so ashamed of that.

My beautiful independent aunty was diagnosed with Motor Neurone Disease. It took them 16 months to diagnose it and she died within seven months, she was only 62. I'm not even sure I can put into words how debilitating this disease is and to watch someone go through it knowing there is no hope is just heart breaking. The problem with this disease is that your mind is still perfect but your body lets you down.

My aunty was put into care and we would visit regularly. I will never forget the day when I went to see her (at this stage she couldn't talk anymore and was getting fed through a PEG) she was just lying in bed and when I walked in the door she didn't even smile. She always smiled when I saw her. She leant over to get her note pad and her gown slipped off her back a bit, **I could see her spine and it looked like something from a horror movie.** I still have nightmares of it. She got her note pad and wrote 'I wish I was brave enough and capable to stop this'. **She died alone in palliative care, in pain** and not surrounded by people that love her. How can this be right?

My other grandfather died on the 3rd September 2016. This broke me. It's the first time in my life that I thought I could actually kill another person.

These are just a few things and feeling that we went through over the years, it's hard to put it all into words. **I must tell you that all the doctors, nurses and care staff that we have dealt with over the years have been amazing and I feel sorry for them as well, it must be very frustrating to watch people suffer knowing they would do something if they were allowed.**

My Pa and I always had a special bond, I just adored him. He fought in World War II and was my hero.

I myself am not scared of death but I'm petrified to think that I could suffer like they did.

[redacted] – Father, [redacted], 86. Multiple Myeloma. Suicide.

On 2 September 2015, after writing a letter each to my brother and me, compiling a list of people and services to contact, and writing a letter to the police, my father set about the lonely business of ending his life. **It would have taken him some time to set everything in place and I can only imagine how alone he felt.** He'd planned an easier ending that in the end he was unable to facilitate.

Dad was 86 years old on the day he became a [redacted] Champion in June 2014. A month later, he was diagnosed with Multiple Myeloma.

Dad was never depressed; he was a fighter and he battled that disease. But he could not bear to lose his autonomy; this to him would be a complete loss of self-dignity. For Dad anything less than being able to care for himself, to walk with ease, to cook without dropping things, anything less was not a good quality of life. To have carers washing him, to lie in a bed for weeks at a time, to be incontinent or incapacitated was not part of his life plan.

I had been staying with Dad, leaving to come home eight days before he decided to take his last journey. He was very unwell; he could only walk a few steps without becoming incredibly breathless and distressed. We had a beautiful weekend in spite of this; I asked him to return home with me and encouraged him to come: he could have lots of good company, I would ensure he would be comfortable and cared for.

'Dad, I am really good at palliative care, I have lots of experience,' I said.

He smiled at me, then gently declined.

Dad saw the oncologist again a couple of days later; he was told that there was nothing more they could do: he was now 'palliative'.

I can only think that on [redacted], or perhaps the day before, he realised he was deteriorating very quickly. He had to act quickly or he'd have been too ill to carry out his elaborate plan. The loneliness of it appals me.

Pam Parker – Father, John. MND, brain tumour.

Dad was 64 and in the throes of planning his retirement when on 10 May 2013 he was diagnosed with Motor Neurone Disease (MND), with the prognosis of 1 to 5 years life expectancy.

Dad kept working for as long as he could however due to his deteriorating health he finished up work and arranged house renovations for his future needs. At this point he had started using leg splints and crutches to move around but nothing was going to stop him from achieving his and Mum's dream of seeing more of the Australia that they loved. So, in April 2014 they set off travelling in their caravan.

Just a few weeks into their journey, on the 10th May 2014, while in Hervey Bay Qld. Dad was taken to the Emergency Department of the local hospital. He was experiencing numbness down his left arm with a burning sensation towards his fingers, accompanied by dangerously high blood pressure which was hard to bring under control. He was eventually airlifted to the Prince Charles Hospital in Brisbane, where he was examined over several days for suspected heart problems. A full body scan was carried out, and a growth was found in his brain. He was referred to the Royal Brisbane Hospital where he was diagnosed with a brain tumour in a location that was easy to be removed. He was told that without treatment, he could expect to live 3–12 months, with treatment his life expectancy was anywhere from 18 months to five years, and this was based on the tumour alone.

He underwent surgery and the tumour was formally diagnosed as a Stage 4 Glioblastoma Multiforme, the most aggressive of all brain tumours.

Dad's outlook on life didn't wain and he chose to have both surgery and treatment. At this stage, he had no pain and he wanted to live as long as he could.

Since his MND diagnosis in 2013 and during this period Dad's MND progressed up his legs, into his chest, throat and arms. He went from using walking sticks, to crutches, to a scooter, and finally a motorised wheelchair as his strength in his muscles deteriorated.

Dad had notably deteriorated by the time they returned from their travels in September with less core strength to hold himself upright. He was now more reliant on his ventilator due to the muscles weakening around his lungs which meant his lungs wouldn't inflate. He had previously only required this when he was resting in his chair or at night.

Dad's reduced strength meant that he required assistance, even to move slightly in his chair to relieve the pain of pressure from sitting. We would do this as a team, grabbing him by his pants on the front and back and lifting him. Dad wanted his legs stretched and his knees bent to relieve the stiffness, this was also painful.

In mid-October Dad was at serious risk of pneumonia as he did not have the strength to cough up the phlegm from a simple cold. On his way to hospital with breathing difficulty, Dad described to the ambulance officers what he thought was an anxiety attack about his inability to breathe, as well as a fear of falling when being lifted using a hoist or being rolled over in bed.

Around this same time, it was apparent to those around him that something else was occurring as Dad's speech became more slurred and the left side of his lip was starting to droop. It was assumed to be a result of the brain tumour. On 21 October 2015 after a follow up MRI, Dad was told that the tumour he had been treated for in April had now doubled in size. Treatment was no longer offered. Just seven days later Mum was advised that the tumour was 3.5 x 5.1 x 4.3 cm in size and that we should be planning for a Christmas with Dad in November.

During October and November Dad became even more reliant on the ventilator and needed it most of the time. However, as the muscles weakened in his throat and voice box, he was less able to project his voice, and communicating his needs through the ventilator's mask was even more difficult.

He was constantly sucking on lozenges as his lack of saliva production led to a constantly dry mouth. He was now incontinent and also required support to eat and drink.

In the three days before he went to hospital, Dad developed a severe bladder infection and also had an enlarged prostate. On 10 November 2015, in significant pain from his UTI, Dad was admitted to Calvary Health Care Bethlehem Caulfield (specialist MND hospital) where his pain and deteriorating condition was managed. On arrival at the hospital, we were told to prepare for Dad to pass at any time. His kidneys were starting to shut down and he was passing a significant amount of blood through his urine.

Dad was in hospital for another 18 days until he passed, and over that time he deteriorated such that he could no longer eat, his inability to swallow put him at risk of choking and he didn't have the strength to cough anything up. His bowels had become impacted and he was no longer able to suck on lozenges to relieve his dry mouth which now required regular wetting with a sponge but this had to be done quickly as he needed his mask on to breathe.

He had lost all movement apart from his right arm but eventually even this reduced to a 'thumbs up or down', or a squeeze.

He was in pain from not being able to move his body and then in pain from being gently moved and stretched.

Eventually, he was unable to express if he needed moving, what he wanted moved, if the pain from being moved was too much or what else might be hurting. This inability to communicate was due to the MND and brain tumour and not that he was unconscious or heavily medicated.

One day my brother and I were sitting next to Dad and heard him making noises but we weren't sure if he was in pain or if he was upset. From a 'thumbs up or down' we were able to establish that **he was upset and crying, which was the first time throughout his journey that we had witnessed him cry.** We did not feel we were able to offer much comfort as we could not determine if they were tears of fear or tears of pain or if, in fact, he had something he wanted to say.

On 21 November, seven days before he died, Dad developed small blisters around his right eye, which were diagnosed as shingles. The blisters spread down part of his face and although he was not able to communicate, the pain he was feeling was obvious as the mask he needed for breathing lay directly across the shingle blisters. Upon checking Dad's swollen eye, the doctors advised us that as a result of the shingles, an abscess was eroding the back of his eyeball. His medication was increased to deal with the pain.

During his final two days, Dad pushed off his breathing mask and survived on extremely shallow breaths. On the day of his passing I asked the nurse if today would be the day as his fingertips were turning purple due to a lack of oxygen. She said that it would be, and it was.

Dad died on 28November 2015 in a room filled with love.

[redacted] – Multiple Sclerosis.
Took his own life.
https://www.gogentleaustralia.org [redacted]
[redacted]

Jessica Edwards – Father, Tim. Mesothelioma.
Tim Edwards passed away 16 February 2018, after fighting mesothelioma to the bitter end for the better part of two years. Tim acquired meso (as he called it) from being exposed to asbestos during a summer job when he was 18 to fund the cost of his university. Almost five decades later the disease took over is body and he could no longer breath.

Tim approached death as he approached everything in life, practically and with extreme clarity of mind even though throughout his disease he suffered from depression, extreme breathlessness and a never-ending list of painful symptoms from the multiple rounds of chemotherapy and the disease itself. In the final months of Tim's life, **he was in a great deal of pain, could barely eat or drink and could not breathe or function without the support of the oxygen machine. His heart and lungs were surrounded by the cancer, he had multiple pulmonary embolisms and a plethora of secondary medical issues.**

Tim was an outspoken advocate for assisted dying and believed strongly in having the right to choose when and how he ended his life. Tim's passions in life were his family, his dogs, the outdoors and changing the world for the better. Tim's disease progressed to a level that these passions were taken away from him and it was at this point that Tim should have rightly been entitled to call it quits. His disease was terminal. He had only two choices remaining to him – dying well or dying horribly.

In the end, Tim's position on assisted dying worked strongly against him, **with his palliative care doctors and nurses, in my view, under-treating him and one of them repetitively lecturing a grieving family about the illegality of assisted dying (even the day before he passed away). In the final days of his life, we took turns sitting with him and watching his sleep and at one point when he woke up, he looked at me and asked me when they were going to let him go and by them, he was referring to the palliative care staff. All I could do was look at him in tears and say I don't know – this is not the way it should be.**

When Tim passed away the first feeling I had was not sadness, it was a feeling of immense relief. Relief that his suffering was done, relief that he no longer needed to be **poked and prodded by palliative care staff for no good reason** and relief from a feeling that we had somehow failed him by letting him suffer the way he did in his final days.

https://dwdnsw.org.au/tim-edwards-choosing-the-moment/

Yvonne McChlery – Mother, 73.
Multiple Sclerosis.
Mum died aged 73 in May 2012, having suffered from MS since 1981. **For the last three years she could barely see or speak, couldn't walk, and was incontinent in both bladder and bowel. As my aunt said, the only thing of Shona's that works is her ears.** I flew to NZ three weeks before her death and met with her GP and the nursing home representative. I put it to them that Mum had signed a NZ Dying with Dignity form that said, in part, 'I fear indignity more than I fear death', and yet **here she was in possibly the most undignified state one could imagine.**

They agreed to take her off all medication at that point. I noticed then she had a little rattle in her chest, and hoped that it might end up in pneumonia. Sure enough, it did. Three weeks later I got a call from the home asking me whether I'd like her to be put on drugs for pneumonia. My brother and I said no, and she died the next morning. At the viewing of her body I was struck by how peaceful she looked. Still a bit wonky from the strokes she'd had, but finally she was no longer suffering.

Hannah Baker – Mother. Renal Cell Carcinoma.
When I was 18, I became the full-time carer for my mother who passed away horribly and tragically from renal cell carcinoma (a form of kidney cancer). **It took 10 months for her to die and not one moment of that consisted of any kind of respite or quality of life,** once she got sick, she stayed sick and I'm sure it was sheer determination and stubbornness that allowed her to live for as long as she did after diagnosis.

I was so young and completely unprepared for what faced us and it has inherently changed who I am as a person.

Sarah McDonald – Father.
My father, a Dr, died last year. **His death was everything he didn't want** but he didn't want to break the law. Eventually the Drs did help us fulfil his wishes but I am **still traumatised by the horror and with guilt about the medicalised torture** that went on. He was a humane, compassionate, loving good man who respected his patients to have the birth they wanted and have autonomy and power as they brought new life into the world.

Dr Alida Lancee – Three Stories.
I was in a meeting with a senior palliative care specialist. She had just completed a ward round in the palliative care ward. She received a call from the ward nurse that a dying patient in her 90s had reduced breathing rate and had become unresponsive after the morphine injection, which she had administered 20 minutes prior for severe pain. The palliative care specialist asked the nurse to administer an injection of Narcan (a morphine antidote) to reverse the effects of the morphine. I asked the specialist why she had asked for the Narcan as this is known to potentially lead to severe rebound pain and distress and the patient was very elderly and dying. **She replied that she did not want the family to think that she had caused the patient to die with the morphine. She agreed that in her opinion the woman was better off not having the Narcan and be allowed to die comfortably, but she did not want any trouble for her or the hospital.**

One of the doctors in our group describes the last days of his father:

"My father died 10 years ago in a Perth Palliative Care Unit. He had terminal bowel cancer and was admitted for terminal care, knowing he would not be coming out – short of breath, emaciated, great discomfort. After a few days, it was decided to relieve his pain via subcutaneous morphine. This essentially put him to sleep, and he was not given any intravenous fluids.

"After 24 hours, he was clearly very dehydrated and I enquired of the treating palliative care specialist as to whether the morphine could be increased as **he seemed to be suffering – restlessness, gasping, dry as a chip. He made it clear that**

this would be seen as hastening death and was not allowed. We therefore plodded on for another 24-hours before eventually he succumbed."

I spent three months working in the Palliative Care Unit at a Perth Hospital. People in the last days/weeks of their terminal illness would be transferred from nearby hospitals. They would have their malignant ascites drained, or an excruciating bone metastasis irradiated, and would die, more comfortably, a few days or weeks later. The situation however was different for one lady. She had pancreatic cancer, was stick-thin, had no pain, no appetite and no energy. She paced the ward (slowly), a quiet but frustrated observer. Toward the end of my placement, she tearfully implored the consultant "when is my time..?" With the permission of his patient (of course) and her family, the head of the unit commenced terminal sedation, and his patient died a day or two later. **Two nurses objected strongly to what he had done and threatened to report him.** I don't know whether or not they did, as I left the unit shortly afterwards.

Kay Setches – Friend. Oesophogeal cancer.
My dearest friend is now dying! **She has cancer of the oesophagus and is starving to death.** This critical stage has been continuing now for 1 week. Even prior to that Margaret was very incapacitated. It is horrible.

Dr Janet Fitzpatrick – Husband.
Cancer of the liver, pancreas and throat.
A peaceful death at that stage would have been wonderful. Instead **he had 10 days in hospital when he was in pain, his tracheostomy tube was constantly blocked with thickened mucus**, he could not communicate or recognise us.

[redacted] – Uncle, [redacted],
end-stage cancer. Suicide.
My uncle killed himself this year, [redacted]. My mum's brother. He had run the end road with cancer. He was 86 ... He lived in Canberra. He was facing palliative care, he was in dreadful pain. So sadly, **he went to a reserve near his home** [redacted]

... and his family went through a lengthy process included DNA matching of one of my first cousins (his children) to identify his body knowing it could not possibly be otherwise. His wife, my auntie [redacted] and my first cousins feel strongly, if another humane option was available, he may have chosen this action, he may have chosen palliative care, who knows. There are no words for this anguish.

Dr. Doug Gaze – wife, 53, pancreatic cancer.
Mother, 88, stomach cancer.
[Over 26 years] I have witnessed a lot of changes with the growth of palliative care, and that has certainly been a great development and should be supported and improved.

Over my time I have been involved in the care of quite a number of people in their final illnesses, the majority of those being cancer deaths, and some of those deaths have been pretty grueling.

Some of those deaths were very drawn out and very difficult for all involved, and symptoms of course include intolerable pain – but in some respects pain is not the worst symptom because it can be managed generally pretty well – nausea, vomiting, bowel obstructions, severe oedema of the legs, jaundice with the unbearable itching that goes with it, pressure sores, faecal impaction and incontinence, ulcers, confusion, haemorrhage, choking et cetera.

The majority of deaths that I have witnessed have been well managed with good palliative care. It is the ones that were not so well managed that stick in the memory, and those are the ones that drive my views.

One gentleman I particularly remember who had advanced prostate cancer and had been to his specialist. He had secondaries in his spine. His specialist told him there was a risk he would become paraplegic, following which [redacted]. I would rather patients have another way out.

It is important, in my opinion, that the committee understands that although palliative care can well manage the majority of patients, it cannot manage the suffering of all patients, and that suffering is not just physical; some of it is psychological or existential or spiritual.

We do currently practice a form of passive physician-assisted death by withdrawing treatments and increasing doses of morphine and midazolam, but that process can still take days, sometimes weeks, and can be quite grueling. I do not see a fundamental difference from a more active form of physician-assisted death; I think the intent is what is crucial. But that said, personally I would have great difficulty giving somebody an injection which I knew had the effect of killing them.

I do not see this as a slippery slope, but rather a compassionate response of a progressive and caring society to a very difficult issue

Sue Hendy, CEO, Council of the Ageing, Victoria
We have experiences of that whether that is in the medical system, helping people along with the extra morphine and that fine line between whether that is an assisted death or not versus circumstances where one of our peer educators – we have older people who work as our presenters, and we call them peer educators – had breast cancer return after some years and did not want to go through the full extent of that death, but could not get assistance, **so she took a huge amount of medications and her [redacted] because she did not want to come alive after this medication.**

He was charged, and I think he got a nine-month good behaviour bond or something.

Imagine what his life was like, that that was the only choice they had.

So, there are examples where people, because of the lack of choices, are having shocking deaths, and people around them have to go through that experience.

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Go Gentle Australia Limited is a registered charity.

Go Gentle Australia is a health promotion charity founded by Andrew Denton. It was established to help relieve the distress, helplessness and suffering experienced by Australians with terminal illnesses, their families and carers. We are about a better conversation around death, dying and end of life choices, including voluntary assisted dying. More at **www.gogentleaustralia.org.au**

Hummingbird House submission for the Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying

Date submitted: 15 April 2019

End-of-life and palliative care: Issues for consideration

17. What are the palliative care services offered in Qld?

Establishment

Hummingbird House, Queensland's only children's hospice was established following a recommendation from the The Parliamentary Committee Inquiry into Palliative Care Services in Queensland (2013) which identified a specific gap in services for children with a life limiting condition and recommended a paediatric hospice in Queensland. The recommendation stated that "*(t)he hospice should provide end-of-life care, respite care for children and adolescents with a life-limiting condition, information and advice on accessing services and bereavement counselling and support for families, including siblings."*

Service description

Hummingbird House is a community hospice service, which has a state wide reach. This service is comprised of a 9-bed licensed private healthcare facility (8 guest-in-care suites, and one purpose-built suite for after death care) based in Chermside, family support, creative therapies, allied health, and community outreach for clinical and family support service delivery. Hummingbird House is fully accredited under the National Safety and Quality Health Service Standards. Wesley Mission Queensland is the clinical operator for HH.

Within the Clinical Skills Capability Framework (CSCF) Hummingbird House provides state-wide hospice care for children who are likely to die before the age of 21, within the facility, or within the child's home. Our current Clinical Services Capability Framework is:

- Medication Services - level 4
- Palliative Care Services – Children up to and including 21 years of age level 4
- Rehabilitation Services – Children up to and including 21 years of age level 5

Currently, Hummingbird House admits guests for:

a) care at end of life;
b) care after death;
c) symptom management – e.g. pain, seizures, sleep difficulties;
d) acute carer stress;
e) specialist short stay breaks (e.g. respite); and
f) step-down transition care.

In addition, HH is licensed to provide specialist nursing, allied health, and family support service input in a child's care, which are all provided at no cost to families.

Since opening in 2016, HH has received referrals for over 220 families from across Queensland. Of those, 19 did not meet our admission criteria. In hospice, there has been an average bed occupancy rate of 95%, while extensive community based support (in home care, end of life and after death care) also takes place, for families in Brisbane and in more regional areas. Funding constraints have limited capacity to 5 - 6 of the 8 guest-in-care overnight beds onsite, with a focus primarily on providing symptom management, chronic carer fatigue, family centred short break stays, and care at the end of life. Despite HH having a state-wide remit, the majority of families who access services at HH are local to the south-east corner of Queensland. The challenges around this will be discussed below.

In the almost 3 years since opening, Hummingbird House has seen many service milestones:

- The development of a truly family-focussed, child-centred model of care
- Development of a care pathway for transfers from Neonatal Intensive Care Units
- Transfers of high acuity guests from Paediatric Intensive Care Unit and Oncology units.
- Care of a guests with a tracheostomy.
- Outreach support in the home for symptom management and end of life care.
- Compassionate extubation at Hummingbird House.
- Participatory approaches to end of life, and after death care with majority of families choosing to be actively involved.
- Admission (after death) of newborns and children to the Hummingbird suite from hospital and home, allowing HH team to provide family centred care and support.
- Retrieval of organs post-death by the DonateLife team at Hummingbird House.
- Family-led funerals and memorials supported by HH staff, both in community and onsite at Hummingbird House.

Aims of Hummingbird House

Hummingbird House exists to complement other services that support children with a life-limiting condition and their families, contributing to the comprehensive provision of statewide paediatric palliative care. The contribution of care from Hummingbird House significantly enhances the holistic wellbeing of children living with a life-limiting condition, and their families. The service offers a truly individualized care for children and their families – through the use of an evidence based assessment called an HNA (Holistic Needs Assessment). This allows families and support staff to approach engagement from a family and network centered approach – and formulating goals which speak to the overall wellbeing of the child and family, rather than being purely service specific. This approach draws on public health approaches to palliative care, whereby communities and networks are recognized, valued, engaged and strengthened as part of caring for and supporting families living with chronic illness. We hear consistently from families that key needs are access to specialist respite care, enhanced symptom management, opportunities for increased social participation, and increased choices in relation to care at end of life. Hummingbird House is a service designed to meet these needs, both from within the facility based at Chermside and through a team of skilled staff who outreach into the family's community and home.

Through collaboration and an evolving and responsive model of network-focused, family-focused, child-centered care, Hummingbird House aims to:

- Provide a state based hospice service for Queensland children with life-limiting conditions
- Provide care that is responsive to the individual needs of every child and family, recognising that every child and every family is unique
- Provide comprehensive paediatric palliative care including respite care, symptom management and end of life care to Queensland children and their families living with a life-limiting condition.
- Provide support and care to families throughout the trajectory of their child's condition and beyond; while simultaneously seeking to build capacity and develop support networks for families, to foster the development of caring, supportive and long-lasting relationships in their communities.

Philosophy of Care

The care provided by Hummingbird House is based upon the ethical principles of autonomy, beneficence, and non-maleficence. Any treatment considered is offered within the context of respect to the anticipated benefits and burdens and should be undertaken only when the benefits proportionately outweigh the burdens. Herein lies the challenge – the ability of Hummingbird House staff to predict benefits and burdens within the complex contexts of uncertainty and varying values is a challenging one, and any decision-making is done in full consultation with the child and their family. It is an important tenet underpinning the philosophy of care provided by HH that the child can exercise their agency around decision-making, either through assent or consent.

Hummingbird House care is also deeply committed to the construct of equity. This represents an organisational belief that there are some things which children who access HH services should have, that they have basic needs that should be fulfilled, and that our policies should be directed with impartiality, fairness and justice towards these ends. Currently, HH service delivery is challenged around the concept of equity of access to services for those who reside away from the south-east corner of Queensland.

The care HH offers is inclusive and embracing to all who come through the door. In circumstances when Hummingbird House staff are unable to directly assist with needs, they will link families to the most appropriate providers ensuring families are compassionately and efficiently transferred to the care of a more appropriate service. Our model of network-focused, family-centred care means that a significant investment is made into the time staff spend assessing and identifying family needs, and understanding their hopes and wishes. Hummingbird House has always promoted care of the entire family as opposed to just the child, and seeks to invest significant resources into developing families and community capacities for care and support.

This model of care ensures that the family is constructed as a whole. Whoever is important to the child is important to HH. This naturally extends into the area of care after death. HH is able to accept referrals for children after they have died. The work undertaken in the after-death space is integral in assisting families with meaning-making, ritual and ceremony surrounding the death. Family members are able to spend time with their deceased child, create memories and have an active role in the planning of their funeral or remembrance ceremony. This is all done whilst on-site at HH, or in their own home.

Hummingbird House has five family accommodation suites, two adjacent to care floor guest suites and three located on the lower level. HH always remains open to urgent end of life referrals. HH offers families a range of options when their child is staying at the House. They may stay at the House for the duration of the stay, they may remain on-site for only part of the stay or they may choose to leave their child in the care of HH staff.

Care will be provided on a needs-based analysis, and planned with the care team and the family, reflecting the predominant needs of the child and family. The voices and experiences of families matter and their comments will be heard and acted upon. All staff are open and honest, communication and care will be delivered with compassion.

Model of care

Hummingbird House is a nurse-led service. This is a conscious decision on behalf of the HH team as HH is primary health care service. This is well suited to using the clinical acumen and expertise of experienced nurses. HH has two Nurse Practitioners who work across in-hospice and in-community settings, leading the team. This affords HH to be able to meet the dynamic needs of their communities by providing equitable and accessible healthcare in ways that underscore the family-focused, child-centred model of care. They work alongside a team of medical practitioners who are onsite in a sessional capacity.

Components of the Direct Care Team

Medical care is provided via local GPs working on a roster to provide comprehensive 24-hour medical cover, supported by the two Medical Leads.

Nursing care is provided by specialist Nurse Practitioners, Clinical Nurses, Registered Nurses, Enrolled Nurses and Personal Care Workers, all of whom have demonstrated training, education and competence in the specialist area of paediatric nursing and/or palliative care.

Family Support is provided by a dedicated team with specialist skills focused on supporting the family unit. The team includes specialist practitioners with training, education and competence in the areas of family therapy, play therapy, sibling support, counselling, bereavement, care at end of life, and care after death.

Allied Health care is provided by staff who have demonstrated training, education and competence in their specialist area. The specialist skills of the Allied Health team members include music therapy, occupational therapy, paediatric physiotherapy, art therapy, and others determined by the unique needs of the child and family.

Clinical Oversight and Advisory Committee (COAC)

While HH is in the palliative care "business", it requires a level of diligence and vigilance which is not standard or required in adult palliative care. This includes attention to consent and guardianship in this vulnerable population. Therefore at HH where the focus is on quality of life - comparable performance criteria adopted by hospitals which focus on intensive treatment and cure, do not typically align. In practical terms, this looks like intensive care without any prospect of recovery, with lower rates of limitation of resuscitation plans, and by necessity, it requires highly skilled clinical practitioners and specialised equipment.

This is why COAC is integral to operating HH. This group of volunteers who hold expertise in the health community provides advice to Hummingbird House via oversight of the safety and quality of services delivered by Hummingbird House. This includes providing recommendations from clinical incident analyses and providing guidance on quality improvement activities undertaken by Hummingbird House. It also guides the focus and strategic development of the service and acts as an external check on how the service operates.

It ensures that all relevant facets of clinical care are robust, based on best practice standards, meets relevant compliance standards, and has auditable systems with appropriate outcome measures developed to ensure ongoing service review.

Core Membership is made up of a Healthcare Ethicist (Chair), Obstetrician & Gynaecologist, Health Economist, Clinical Governance expert, General Paediatrician with a special interest in paediatric palliative care, Consumer with the lived experience of caring for a child with a life-limiting condition (recruitment pending), and General Paediatrician/Child Protection Specialist.

Delivery of Care

Referral Pathways

Referrals to Hummingbird House can come from any professional involved in the care of a family, child or young person. We receive referrals from a wide variety of sources including the child's lead clinician, PPCS, other paediatric specialities, GPs, Social Workers, and allied health workers.

Referrals are reviewed and discussed with the multi-disciplinary team to ensure that all potential needs are considered and accommodated where possible. These may be routine or urgent and are responded to within an appropriate time frame for the specific needs. Early access and referral to Hummingbird House is the preferred pathway of care, whereby a relationship with the child, family and staff of Hummingbird House has been established before the first stay, however, this approach is not always possible.

Care Pathways

The pathways of care at Hummingbird House reflect the significant needs of families and focus on 5 principle care pathways:

- Short break stays (Planned Respite Care)
- Urgent / Unplanned Respite Care (e.g. acute carer stress)
- Symptom Management
- Care at End of Life
- After Death Care

Admissions to Hummingbird House (2017 – 2018)

- Average length of stay for short break stay – 3 nights
- Average stay for care at end of life prior to the child's death – 4.5 days (while the mean score is 2-3 days, there are 3 outliers of 9, 14 & 26 days)
- Average stay after the child's death if the child's death occurred at HH – 3.75 days
- Average stay after the child's death if admitted after death - 4.15 days

Based on the experiences of the other two Australian children's hospices, it was estimated that HH would see around 12 - 15 deaths per year. Since opening in 2016, we have had the privilege of providing (in-hospice or in-home) care at end of life for over 52 children and supporting families (to 15 April 2019). This includes care at end of life, overnight after-death-care, and a combination of end-of-life and after-death-care. It should be noted that these figures do not capture the families with whom HH is working intensively in the immediate grief and loss time, or ongoing grief and bereavement spaces. As one can appreciate, this can involve working with a significant number of family and community members, such as schools, faith groups, workplaces etc. The area of family support is one of the growth areas for HH, and is currently majority funded by philanthropic sources.

Across the spectrum of paediatric palliative care – from symptom management, to family engagement – there are many significant differences in the needs and care of children receiving palliative care, as compared with the adult population. Hummingbird House is able to (and regularly does) receive referrals as early as diagnosis in the antenatal period through to the age of 21. This vast range in age also brings with it unique challenges in care, resulting in the need for a highly skilled and broad range of clinical skills.

In April 2017, HH began working closely with perinatal clinicians to offer a service for families whose baby is likely to die shortly before, during or after delivery. Since then, twenty-two neonates ranging in age from antenatal through to 21 days of age and their families have been welcomed into the service by the HH team. These families often accept the invitation so they can be present with their newborn in a home-like environment at a difficult and significant time in order to facilitate ways of expressing their love, grief and care. For some families this includes specific ceremonies and rites, while for others, HH staff can assist families to craft simple, homemade rituals in their process of farewelling their child's body. In addition, with care and support, many families value being able to partake in ordinary activities during such an unordinary time - using the backyard and other areas of the HH to create memories and spend time together as a family, including with their pets, wider family and community members. Families have overwhelmingly spoken to the beneficial impact on their initial bereavement experience during this time.

18. Are palliative care and end-of-life care services meeting the current needs of Queenslanders?

There is an opportunity to increase a child's access to expert, timely palliative care in a setting that best suits their and their family's needs. Within Queensland and Northern New South Wales, the prevalence of children with chronic and complex needs living with a life-limiting condition is at least 12:10,000 (i.e. 1,200 children). It is estimated that whilst some of these children will have an uncomplicated course and can be managed by their primary physician, 20-30% will require a degree of support from a specialist palliative care team. More recent reports have estimated that the prevalence of children with life-limiting conditions is increasing.

At the same time, medical treatments and technology are improving and the number of children who die is reducing in number. Despite this, there will always be a significant number of children who die in Queensland every year, approximately 500 per year, including a number with pre-existing life-limiting disorders. There is, therefore, a need to have an interdisciplinary team of paediatric trained health care providers within the state whose primary aim is to provide best practice palliative care to these families. This can be through consultation, collaboration as well as in systemic approaches to the healthcare system (e.g. education and development of care plans).

Children who survive infancy with chronic disease will have complex issues and some will have the propensity to have life-threatening deteriorations as they grow older. Co-ordination of care between specialists and health care disciplines is a critical component of the care provided to these families. Transition to adult care will occur for some patients and families and needs careful advance planning.

In Queensland each year, there are approximately 400 children with life-limiting disorders who would be considered particularly fragile, and at risk of dying within the next 12 months. Supporting this number of fragile children at HH is extremely challenging, let alone supporting those who are not at risk of dying specifically within the next 12 months. It is here that our strong relationship with the Paediatric Palliative Care Service at the Queensland's Children's Hospital is vital. The two services can work collaboratively to meet the needs of the children who are fragile.

19. Do the standards of palliative care & end- of -life care provided in Queensland meet clients' and the community's expectations?

Community standards and client expectations around palliative care and care at end of life within the paediatric setting are still evolving. This is a challenging notion that one's child is most likely going to die before you. Therefore, there don't tend to be many established conversations at community level about this difficult concept. Families who live with and love a child with a life-limiting condition are very keen to have this conversation, yet are unable to find avenues to do so. Hummingbird House is seen by families as a safe place in which to discuss their thoughts, fears, hopes and wishes around their child's illness, death and after death care. When a child is approaching death, the option exists for them to be at home, at hospital or at a hospice, according to the family's wishes. This is in line with the principle of the right service in the right place at the right time.

As the child grows and their condition progresses, it is preferable for children to be looked after in the hospital closest to their home and this can be achieved with the support of health professionals and families locally. However, this is often not achievable for children with very complex needs due to the specialist nature of symptom management and lack of ability to provide holistic care for the whole family. This is where hospice care uniquely comes into its own – with an ability to provide care that meets both of these challenges.

A study of 700 children in Australia, Canada and the United Kingdom in cities which had a children's hospice found that there was an overall even distribution for location of death in which 35.1% of children died at home, 32.1% died in a paediatric hospice facility, 31.9% in hospital and 0.9% at another location.

There is recognition that palliative care needs to be integrated into the care of children with life-threatening illnesses. A dedicated palliative care service improves communication, symptom control and quality of life in children and young people with advanced illness. A system-wide approach by a children's hospital in managing children with life-threatening illness can allow a more consistent, yet flexible, approaching to care for children and families.

To understand more about the lived experience of caring for a child with life-limiting illness, and to develop a clear understanding of the resources that exist currently within Queensland, Hummingbird House has recently appointed a Community Development worker (the first such appointment in the Australian hospice sector). This position will work with local communities to enhance and augment their latent abilities to provide compassionate and effective support, nurturing, and care for not only the child who is at end of life but also for their family.

This work which is modelled on the concept of Compassionate Communities Network, in conjunction with other vital community-outreach work undertaken by the QCH PPCS team, will see an increase in resources and skills available to communities. A ‘compassionate community’ is a community that has been encouraged and taught how to promote and integrate social approaches to dying, death and bereavement in the everyday life of individuals and communities.

20. How will demand for palliative care & end-of-life services change in Queensland as the population increases and ages, and what changes to the delivery of these services will be needed to meet future demands?

Children who are more and more fragile in their medical condition will be cared for by their family in their home as they are often too stable to warrant admission to an acute care facility. This results in a marked increase in carer fatigue. This is evident in the clear increase in acuity seen in children who access services at Hummingbird House in the time between its inception and current service delivery. The number of newborns born at the cusp of viability will increase.

This will inevitably result in an increased demand for expert care at end-of-life services. Therefore, Hummingbird House is looking to develop its outreach service and delivery of services via alternative modalities such as telehealth and the development of compassionate communities. A stand-alone facility, based in a larger metropolitan city is not sufficient to meet the growing demand for family-focussed, child-centred palliative care. This is discussed further in the section addressing challenges in regional, rural and remote Queensland.

21. How can the delivery of palliative care and end-of-life services in Queensland be improved?

As Queensland's only children's hospice, Hummingbird House has a remit to provide palliative care in both the facility at Chermside and within the child's home, no matter where in Queensland they live. Currently, this arm of the service is still being developed and relies very heavily on community fundraising. This arm will see staff fly/drive to the child’s community to provide in-home respite care, family support, and grief and bereavement support to the entire community. By travelling to the child’s community, we can extend the child and family centred care HH offers outside of the south-east corner.

Working closely with Queensland Children’s Hospital, other paediatricians and other clinical staff in regional centres, this outreach model of care will help ensure equitable access to child and family focussed palliative care and provide choice regarding the nature and location of end of life care. This results in prudent use of financial, as well as clinical, resources and supports families in the community where they live and grieve.

There currently exists a major shortfall in the provision of a state-wide service. This applies to every component of paediatric palliative care: from respite, care at end of life through to grief and bereavement support. These aspects of care are not permanently funded, aside from modest funding support for PPCS and at present, there is no prospect of this changing. There also exists a major lack of access for in-community care and neonatal service for all communities throughout Queensland.

22. What are the particular challenges of delivering palliative care and end-of-life in regional, rural and remote Queensland?

The total land mass of Queensland covers 22.5% of the Australian continent, an area of 1,730,648 square kilometres. The other two children’s hospices are in Victoria (with an area of 227,594 km^2), and New South Wales (with an area of 809,444 km^2) respectively. The geography required to be covered by HH is enormous, and requires careful, evidenced-based planning as to how best meet these needs. Current funding does not allow for this aspect of the service.

As is well known by all those who are delivering services in a state-wide capacity, it is the tyranny of distance that is the biggest hurdle to overcome. How to best meet the needs of regional, rural, and remote communities is to afford them the opportunity for equitable access to Hummingbird House: both in terms of spending some time in the hospice in Brisbane for a short break stay, and in accessing the suite of services we can offer to them in their home community.

The need for a 'bricks and mortar' facility has been met with the building of Hummingbird House. It is now planned that this facility will be the hub for a 'spoke and hub' model of care around Queensland.

This is a model which arranges service delivery assets into a network consisting of an anchor establishment (hub) which offers a full array of services, complemented by secondary establishments (spokes) which offer more limited service arrays. The Family Support and Clinical teams are both committed to an outward-looking, community-based model of care, which seeks to utilize and develop capacity within existing networks, rather than unnecessary duplication of service.

Key geographical areas such as central, northern and western Queensland would be well suited to a HH presence both within the local regional health facility and community support organisations. Consideration around what this looks like for HH is part of an ongoing project developing the model of care for the state-wide arm of HH. This would see a more community-focused responsive service for families who live outside metropolitan areas.

HH in Brisbane works in partnership with Children's Health Queensland in delivering services for families within their communities. This is based around the Compassionate Communities model and seeks to identify strengths and build capacity in existing community networks, rather than replicate already established services currently working with families. This approach, while not only being more resource efficient, will also augment and enhance integrated service delivery. This will be achieved by a combination of network mapping, interdisciplinary meetings, telehealth and visits to family homes.

23. What are the particular challenges of delivering palliative care and end-of-life for Aboriginal and Torres Strait Islander communities?

Hummingbird House has provided care for babies, children, and young people who identify as Aboriginal, particularly in the care at end of life and after death care. Feedback provided from families and other important members of the child's community has been positive, with important learnings made.

During these occasions, the HH team has provided care that is based on cultural humility which is an integral component of the individualised approach to care. This approach allows us to work with children and families to help us recognise their specific needs. Whilst there is the deeply respected notion of returning to homelands and to be close to family and country for the final stages of their life, this is not something HH has asked to provide with regards to children. Although the HH team does carry an awareness that these lack of requests may arise from a perceived intergenerational disconnection from culture and country arising from past government policies.

The current challenge for HH is increasing awareness of our service within regional, rural, and remote Aboriginal and Torres Strait Islander communities. Currently, HH is working with local advisory groups to enhance and refine our model of care which will see us liaising with key stakeholders with the view to understanding more about how we can craft a service that meets the individualised needs of a broader range of the community.

We acknowledge that accessing palliative care that is culturally appropriate does have its barriers, and we are committed to and engaging in compassionate conversations that are focussed on understanding how we can best meet the needs of all those who access HH services. HH would welcome an opportunity to rectify the current dearth of research knowledge around this area.

24. What are the key priorities for the future?

Subjective Wellbeing

HH is a community palliative care service. As such, the care we provide is not limited to in-hospice clinical and therapeutic services, it extends into the community, to family homes - supporting guests both before and after death. While families regularly speak to the benefits of the care they receive – especially in regard to death care – with families often describing their experience as 'the best death possible' – HH is also committed to working in evidence-based frameworks, such as the Compassionate Communities framework – which adopts a Public Health Approach to Palliative Care.

In regard to after death care, we have heard consistently from families at an anecdotal level that the unique level of after death care and invitations to participate in the processes of being with their child's body, memory making, rituals and co-creating funeral ceremonies has a profound effect on their initial grief experience, providing valuable opportunity for meaning-making.

There is a significant paucity of evidence globally documenting the care of children in a hospice environment at end of life and after death. This includes the benefits that families can experience in caring for their child after death and the subsequent benefits on their grief experience. There is some limited research emerging from the UK over the past decade, however, there is no published evidence in Australia speaking to after death care in a hospice environment. This highlights the innovative nature of work taking place at HH, and we are committed to documenting this through published research.

HH is beginning to work in partnership with the Health Economist to develop a tool that can measure the efficacy of the work HH does with families and children. An overall measure of subjective well-being (SWB) that assesses and joins up different stages of the treatment process, and the different people affected, could potentially be used to capture the full impact of HH services throughout the time a child and family engages with HH. This allows the overall quality of care to be determined and valued according to its direct effect on families' lives.

SWB has a demonstrated effect on outcomes at all stages of the treatment experience and improved health and quality outcomes are shown to consistently enhance SWB. Furthermore, SWB measures are shown to be a suitable method to value the impact of healthcare on the families and carers of guests and, in this way, can join up health outcomes to show wider effects of treatment on families' lives.

Funding

Hummingbird House is proud to be in partnership with both the State and Federal Governments with regards to service creation and funding. It was initially anticipated that HH would cost $3.2 million to operate however our current operating cost for 5/6 beds (inclusive of in-community work) is around $4.5 million. This is largely due to an increase in the clinical acuity and fragility of children who now are eligible to access HH services since HH was first conceptualised, coupled with a strong community component to the care delivery.

Until 2020, Hummingbird House will receive $800,000 of State Government funding and $800,000 of Federal Government funding each year. As it costs around $4.5M to operate Hummingbird House, we must find other funding sources to meet the $2.4 million gap every year, to operate as a free service to Queensland families. It is vital to the forward planning of HH service delivery that there is certainty around funding that ensures we can meet our potential and current remit.

However, HH acknowledges that it must be an active partner in our relationship with funding bodies. To this end, there are a number of potential income streams which remain underdeveloped. These coupled with a strong community base from which to draw support and philanthropy will combine to comprise the necessary funds to operate HH.

The NDIS is a new way of providing people with disability across Australia with sufficient financial resources to facilitate optimal participation in life as a part of their community. Children referred to HH will be eligible for funding packages to support the various services offered by HH. This will see HH moving to having 2 'NDIS-funded' beds available for families to book as part of their care packages. Respite packages can be delivered either in-home or within HH. Only children who meet HH eligibility criteria can access care packages within HH. This will see HH having a stream of income derived from NDIS.

As HH is a private licensed health care facility, it has the ability to garner Medicare and Private Insurance revenue. Medicare billing arises from our ability to receive referrals from Medicare eligible referrers, and then deliver services. The multi-disciplinary panel meeting held every Thursday is one that attracts Medicare funding, along with Medical and Nurse Practitioner reviews in-home or at HH, and some allied health services are also eligible for Medicare rebate. As HH does not undertake procedures, Medicare funding is limited to a finite list of item numbers.

Second tier default benefit is a safety net for HH as we have demonstrated compliance with a range of quality and service criteria. This is in place until a contract is negotiated with health funds. Work is currently underway to ensure that every family signs financial consent on admission, explaining the use of Medicare and Private Insurance rebates (if they hold private insurance).

What looks different than we thought it would?

Whilst the service Hummingbird House provides bears some resemblance to the service that was originally conceptualised and funded, HH has a different model of care to the other children's hospices in Australia in that HH provides more occasions of service around care at end of life, emergency symptom management, and have strong relationships with the major paediatric hospitals and department such as Paediatric Intensive Care and Neonatal Intensive Care in their states.

Some key areas experienced which were not anticipated in the first 3 years of operations include:

- Guests have increasing acuity, often being transferred directly from PICU/NICU.
- All our guests have highly complex medications, including receiving large doses of anticonvulsants or analgesics, which often necessitates that two registered staff oversee administration.
- An increasing number of newborns, directly from NICU for care at end of life and children on non-invasive ventilation.
- Provision of support for children and young adults with complex behavioural issues arising from conditions such as Rett Syndrome and Battens Disease.
- An increased number of referrals as our reputation grows amongst clinicians in hospitals and the community. These connections have evolved through the deep and respectful relationships we have with QCH and Queensland Health more broadly.
- The budgetary impacts of the high level of acuity and the challenge of appointing suitably trained and experienced staff which satisfies the requirements set out under the CSCF
- Approximately 25%* of HH families have some contact with the Department of Communities, Child Safety and Disability Services. A significant amount of staff time is spent establishing relationships with various case workers/managers from around the State and seeking the relevant documentation required to provide care for guests who are under Department guardianship or in foster care. *(2016 – 2018 HH admission data)

Learnings

Business as imagined saw HH providing service to relatively stable children with complex high-care needs. This is the model of care provided in other children's hospices in Australia. However, since opening HH, the team delivers a higher level of complex care than either of the other two hospices in Australia, particularly in the area of care after death. This is in part because HH has strong links with CHQ.

HH receives a significant number of referrals for children who are much more fragile and closer to end of life. This is particularly relevant in the newborn cohort HH works with, as these guests are likely to die within hours, days or weeks of referral. Other guests are referred to HH as we can provide expert care for children with complex needs in their homes or HH.

The lessons learned from this is that this level of care requires a specific skill mix in the team: Clinical nurses who can manage care delivery and decision-making in the facility 24/7, supported by specially trained GPs and consultant medical staff. The use of Nurse Practitioners, with their enhanced skill set in diagnosing and prescribing, is an opportunity for HH to deliver this care but at a more manageable cost. In addition, the Family Support Manager guides and leads the staff with a holistic model of care to guests and families both living with illness as well as after death care.

Care after death is emerging as a speciality for HH. While this practice is long established in UK Children's hospices, there is no equivalent service in Queensland for children to be transferred after death to a home-like facility, where a family can stay with their child with 24/7 support.

Hummingbird House is emerging as a world leader in the paediatric hospice context. This is due in part to the ongoing bi-partisan support at State and Federal levels. Hummingbird House is on the cusp of taking paediatric hospice care to the next level in terms of in-hospice and in-community care. The entire team at HH, and more broadly at Wesley Mission Queensland are committed to ensuring that we can capitalise on this once-in-a-generation opportunity.

There is no doubt that Hummingbird House meets (and has exceeded) the recommendation made by the The Parliamentary Committee Inquiry into Palliative Care Services in Queensland (2013). The opportunity exists now for further recommendations to be made that would assure the future of Queensland’s only children’s hospice as a state-wide service.

We have welcomed the opportunity to contribute to the community discussions around this key area of community health care, and thank the Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee for the opportunity to do so. The team at Hummingbird House would accept an opportunity to discuss this submission in person, should the opportunity arise.

The Honourable Mr Aaron Harper
Chair
Health Committee
Parliament House Qld 4000

April 15th 2019

Dear Mr Harper,

Re: Queensland Parliamentary inquiry into Aged Care, End of Life Care, Palliative Care & Voluntary Assisted Dying

On behalf of the Directors, Staff & Volunteers of Katie Rose Cottage Hospice I extend our thanks to the committee for the opportunity to provide input into the above inquiry. Our submission predominately refers to the provision of palliative care in South East Queensland and the views expressed are those of the Directors, Staff, Volunteers & the Sunshine Coast Community associated with Katie Rose Cottage Hospice.

Kindest regards,

Carol Raye

Carol Raye
Chair
Katie Rose Cottage Hospice Limited

Introduction:

This submission refers to the terms of reference and specifically items relating to End of Life and Palliative Care sections of the issues paper. We have provided an overview of Katie Rose Cottage as part of our introduction.

There is significant scope to do better in this sector in terms of choice for our community.

Fundamentally choice appears to be what is sought and creating/providing different options for people should be a priority. In relation to the Sunshine Coast there is a clear 'gap' in the provision of residential 24/7 end of life care Hospice Services. Note: our services are offered at 'no personal cost' to the patient.

Note: Dove Cottage in Caloundra is the only choice (other than hospital based Hospice beds & "in home" services) Although it should be noted that Cittamani Hospice services (non - residential) does not cover north of Peregian Beach and Little Haven Hospice Service (non - residential) is based further north in Gympie.

In respect to the end of life journey the Gratton Institute's 'Dying Well' Report (referenced earlier) talks about a range of choices primarily centred around the majority of people (>70%) wishing to die at home but only a small percentage (~14%) able to.

Dying at home can be logistically difficult but where possible more outreach services should be established to help relieve the pressure on hospitals – in fact hospitals should be primarily used to cure or focus on treatable conditions. The load being reduced on hospitals should be a priority.

The significant 'reduced costs' to that of a public bed hospital cost should be considered and in addition the broader support services offered at our 24/7 facility such as in - house counselling support, family support & post grieving support are an important part of the Hospice service.

Most people will die in a hospital, aged persons home, their own home. Dying in a hospital is not ideal in our view as it does not allow for life to be honoured, for a person to be treated with the dignity and attention they deserve. There is recognition that it is not always that simple, there are unexpected, unforeseen deaths and a hospital death is unavoidable, specifically those with an acute condition. Where the condition of degeneration is chronic then another choice could be is a smaller, intimate and professional operated service. Death comes to all and access 'choices' to end of life care must be recognised as a fundamental right & a recognised component of health care in our community.

Hospices, if more widely adopted could be considered (4 -10 beds are common place in the UK, NZ and Europe) as a partner in the healthcare system by providing either another option or play a part in the end of life process, for example home support / aged care support until a point is reached or where it gets too difficult to manage at home.

Hospices are characterised by being smaller, more intimate and focussed on the needs of the dying person.

A hospice can be government operated or ideally not for profit operated, but either way the service should be at no charge.

In practice a person receiving palliative care / end of life care could be looked after at home via outreach services, if that is their choice. Bear in mind that not all people wish to die at home, and importantly many people do not have a 'home', as a consequence other options, other choices are required.

Aged care homes could be an option for long term palliative care, home an option for some, but when a person nears the end days of their life hospices are very viable option.

Wider development / use of hospices should be seriously considered as an option to relieve pressure on hospitals and other facilities, also thought to provide a place for many who have no-one or no place to go**.**

'Hospices' can also be quite different. Katie Rose is a 'cottage' hospice based on an English model of care. It is considered a 'one step from home' facility and whilst very informal on the surface, behind the scenes it is characterised by very strong professional care, accredited to all accepted standards.

Recommendations:

- Primarily, palliative care / end of life care needs to genuinely honour one's life. The care should be provided in the manner the patient seeks ie. all about them (if ever there is a time in a person's life where they get to decide it should be the end journey)

- Focus on hospitals for curative, treatable conditions.

- Introduce 'hospice/s' (metropolitan or regional) as a very real option for end of life.

- Accept different forms of hospice to reflect different choices – 'clinical hospice' experience as opposed to a 'cottage hospice' facility – a one step from home experience.

- Provide more in home, outreach services which 'connect' directly with hospice if home treatment becomes difficult or problematic.

- Improve connection across the health care system for palliative care / end of life care.

- NFP hospice (such as Katie Rose Cottage Hospice Limited) needs be an accepted option for the community and an encouraged option by government and partnered by / with government funding.

To date Katie Rose Cottage Hospice Limited has provided high level specialised end of life care to 22 in house guests & their families there is a recognised need for this type of service to be an option for our community.

We again, thank you for the opportunity to provide input and extend a formal invitation to the committee to visit our Hospice in Doonan to see 'first hand' the facility, meet the staff & meet with members of the community to see the positive impacts the facility has offered family members of those who have passed at the Hospice

KRCH Overview

Our charity, established in November 2016 to open a new Hospice, now has 230 volunteers working across the organisation, either in the Hospice, Gardening Team, Admin Support and our Op Shop operations, truly a remarkable result, in a short time, for a newly established charity.

The Sunshine Coast community sees the importance and benefits of having their own community Hospice, clearly indicated by their continued support for us. The charity is a wonderful example of a community driven, operated and supported primary health service.

Katie Rose Cottage Hospice, has operated a Day Hospice Service since late 2017, commenced 24/7 operations in August last year and, at the time of writing this letter, I can advise we have cared for 22 guests, who have passed away and who have, along with their families, been supported on their 'end of life' journey.

We are grateful to many substantial donors, community groups and individuals who have supported us and to those who choose to raise money for Katie Rose Cottage through their own various activities. We value and respect all our donors and supporters and we are humbled by the enormous assistance offered to us.

We are a Registered Charity [CH2898] registered with the ACNC as a Public Benevolent Institution and hold DGR [Deductable Gift Recipient] status that enables a donor to receive a Tax Deductable Receipt.

Local couple, Peter and Marilyn Williams chose to support our charity after being inspired by the service we have created and donated $1M to enable the purchase of our property. They formed 'The Warm Handshake Foundation' so they can see the benefit of their donation, Peter's philosophy being "better than a cold handshake from the grave" and indeed, they remain engaged with us and visit often. So, we have a 'forever home and' now we must work hard to keep it open!

We know it is important that a choice for quality specialist 'end of life' care, as far as our model offers, should be available in the community when and where we need it…that is why we offer such a unique 'home away from home' environment to our guests and their families. To those who pass away at our Hospice and their loved ones, our professional Nursing Care team and volunteer support staff, become friends, towers of strength and shoulders to cry on. Thanks to the support of donors, and engagement with government for partnership, we can be sure they will be there when they are most needed.

We can only continue to offer this expert care with support from our community and you may wish to consider supporting us in ensuring we can help people live their last days with respect and dignity. Our major cost, and core business, is the provision of **nursing care.** Our nursing care team covers three eight hour shifts across the day [21 shifts per week**]** KRCH is currently undertaking accreditation

KRCH offers a choice for Palliative and End of Life Care and can make a real difference to the lives of those in our community facing a terminal illness.

The Pharmacy
Guild of Australia

13/04/19

Health Committee
PARLIAMENT HOUSE QLD 4000
careinquiry@parliament.qld.gov.au

Dear Sir/Madam

Submission to the Inquiry into Aged Care, End-of-Life and palliative care, and voluntary assisted dying.

Thank you for the opportunity to provide a submission to The Queensland Parliament's Health Committee Inquiry into Aged Care, End-of-Life and palliative care, and voluntary assisted dying. The Pharmacy Guild of Australia (Guild) welcomes and supports the need for the committee to consider improvements in the future delivery of aged care and end of life services to Queenslanders.

About the Pharmacy Guild of Australia

The Guild represents the owners of community pharmacies providing health and medicines services that are valued by all Australians. Community pharmacy is consistently seen by the Australian public as a trusted and valued part of our nation's health care system.

There are 1,140 community pharmacies across Queensland, delivering highly accessible professional health services, medicines and medication advice.[1]

- 95% of these pharmacies report they are open weekends and/or trade extended hours
- 9 pharmacies in Queensland supply PBS medicines via the Remote Area Aboriginal Health Services (RAAHS) Program under Section 100 of the *National Health Act 1953*.

Community pharmacy owners have professional and ethical training and responsibilities that qualify them to operate pharmacy businesses as vital health care hubs in communities across the State.

Views of the Pharmacy Guild of Australia

The views of the Guild are formed around the levels of service their members offer to Queenslanders through the delivery of medication and health related services to Aged Care facilities and medication related services to palliative care patients in the community and in Aged Care facilities. It is through this lens which we offer our submissions to the committee.

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[1] Guild Data 2019

The delivery of medication and health related services in Aged Care System

Finding adequately trained staff to deliver services to the aging in the community and in residential aged care facilities (RACFs) is a challenge now, and will likely continue as the Australian population ages. Professional staff, both employed by and contracted to aged care facilities are spending an increasing amount of time fulfilling the medication requirements of RACFs. Professionals involved in this area of aged care, (general practitioners (GPs), registered nurses (RNs), and pharmacists are experiencing increasing demands on their time with no further funding or resources to deliver services.

The current continuum of medication supply involves a complicated workflow with a myriad of options for delivery. The medication is ordered by a GP on a hard copy prescription or medication chart that they sign. This is the legal document the RACF needs so that their staff can administer the medicine to the residents.

Pharmacists can only legally claim for dispensing from this chart/document on the Pharmaceutical Benefits Scheme (PBS), if it is on a national residential medication chart (NRMC) that is compliant with the *Queensland Health (Drugs and Poisons) Regulation 1996*. This is also complicated by the limitations of NRMC charts in that currently Controlled Drugs (Schedule 8) and Authority-Required PBS items cannot be supplied from a NRMC. These items can be ordered by the GP on the NRMC chart, but a separate prescription is required for them to be supplied on the PBS. Once supplied to the RACF, medications are administered to the residents by RNs at which point the RN needs to record the administration of this medicine on the chart. This represents the simplest and most streamlined supply of medication in a RACF. There are a number of permutations and combinations of the above that happen in practice.

While we don’t have data, anecdotally the uptake of NRMCs in aged care is small. It is so small, that currently there are trials in New South Wales and South Australia with a new electronic charting system that will streamline the process from the prescribing through dispensing to administering to the patient. The older practice of GPs having to issue traditional prescriptions for all of their RACF patients is still common. This means double handling for both GPs and pharmacists in the supply chain. GP’s writing orders at least twice. Pharmacists dispensing GPs orders to supply medication and ‘marking off’ (virtually re-dispensing medication) when then the prescription is provided by the GP. The number one complaint from GPs and pharmacists servicing RACFs is the administrative burden faced by them doing work two to three times on multiple systems to service the one patient. Faced with increasing funding restraints, GP’s and pharmacists are finding it more and more challenging to service RACFs.

The options for RNs to record administration of medications are also many and varied. Signing for medication may occur on the original chart, on signing sheets provided by the pharmacy, or on a digital platform facilitated by the pharmacy.

The Guild’s recommendation is that it should be compulsory for the supply of medication in RACFs to be via the use of a standard document either an NRMC or more ideally a digital prescribing platform. A single digital platform for all medication related matters in an RACF would provide efficiencies that would enable all professionals in the medication continuum to better utilise their skills to improve patient outcomes.

In addition to improvements that can be made in RACF’s, the Guild recognises that in most settings waiting times for access to RACF’s are increasing and Queenslanders are staying in their homes longer. Staying in their homes longer is a good outcome in most cases, but: who delivers their medication when they or their carers are unable to; who ensures they take their medication as prescribed by their doctor; who makes sure their medication is suitable for them when they are visiting multiple specialists as well their regular GP? Community pharmacy offers services in all these instances with deliveries to their local community, dose administration aids (DAA), and medication audits (MedsChecks), but these services need to be adequately funded if upscaling is required.

End of life and palliative care

For the community pharmacy network of Queensland, there can be particular challenges in delivering palliative care or end of life care to patients. These are mainly focused around supply and expense, but generally lead to the same outcome, an unnecessary admission to a state hospital or a less than ideal outcome for patient. Over 70 per cent of people would like to spend the end of their life at home while only 10 per cent get to experience that possibility.[2] With regards to expense, the issue is concerned with a federal issue of listing of medication on the PBS. While there are special listings on the PBS for palliative care medications, there are a number of medications that are indicated for managing pain or symptoms in end of life that are not listed on the PBS. Examples of these medications are midazolam injection and haloperidol injection that are used to manage agitation, nausea and dyspnoea (laboured breathing) in the end stages of life. For a concessional patient whose medications are subsidised on the PBS, the increased cost associated with obtaining these medications privately is a deterrent. As a patient of a state hospital, someone receiving end of live care can obtain this medication at a reduced cost. The end result is an unnecessary admission to hospital.

Concerning supply of medication in end of life and palliative care, Community pharmacists can struggle to anticipate which medicines to stock. There are a number of strategies that can be used to manage symptoms during the end stages of life, with lots of varying combinations of medications. Some medications used in palliative care can be expensive or in the case of morphine (a relatively inexpensive medication) the quantities that may be required in an acute episode of care can be so large, carrying adequate stock for sporadic/episodic care can be an economic risk for a pharmacist. This is less of an issue in metropolitan areas where there may be multiple pharmacies servicing an area, there is more and varied stock spread across the pharmacies, and there is choice for the patient or carer. For regional, remote, or aboriginal and Torres Strait Islander communities this is more of an issue as there are less pharmacies servicing the area. In all cases where there is inadequate stock or the system falls down, patients will end up having to present at hospital.

The Guild supports and recommends policies and systems that support people requiring palliative care to live in the community for as long as possible and have the potential to reduce admissions to hospital and poor health outcomes due to medicine management issues.

Voluntary Assisted Dying

As an organisation, the Guild would accept any decision of the elected members of the State of Queensland with regards to legislating for or against Voluntary Assisted Dying (VAD). The Guild also acknowledges that this matter is a contentious issue and some pharmacists will see this as incompatible with their personal beliefs and conscience. The Guild recognises that some pharmacists will have a moral, religious or conscientious objection to the supply of medicines that may be used in the assisted dying of terminally ill patients. The Guild respects the decision of some pharmacists not to be involved in a professional capacity in dispensing these medicines for this purpose. This right is enshrined in the Victorian legislation, and we believe any legislation introduced into Queensland should ensure that the pharmacist has no obligation supply or to provide a referral to another practitioner.

Nevertheless, pharmacists and community pharmacy should be considered an integral part of the successful implementation and delivery of any legislated pathways that provide consumers with access to medications for the purpose of assisting a person to voluntarily end their life.

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[2] ABC news 'The World Today'. (2017, June 2). *Where do you want to die? Most Australians say at home, but end life in hospital*. Retrieved from https://www.abc.net.au/news/2017-06-02/where-do-you-want-to-die-at-home-or-hospital/8584318

The Australian Health Practitioner Regulatory Agency and the Pharmacy Board of Australia must be consulted and provide input into the development of any proposed legislation considering such laws to ensure that any pharmacist involvement in the voluntary assisted dying process will not inadvertently lead disciplinary action which may affect their registration. This also applies to proprietor pharmacists who live and/or practise in another jurisdiction but own a pharmacy in a jurisdiction where the pharmacists they employ may be involved in the voluntary assisted dying process.

Any proposed legislation must also contain protections for health professionals who conscientiously object to voluntary assisted dying. The Guild does not believe pharmacists should be sanctioned if they choose not to dispense medications for the purpose of voluntary assisted dying if it is against their religious or moral views.

Any voluntary assisted dying legislation, or regulations designed to facilitate the operation of this legislation also include provisions that forbid any activities that would publicly identify pharmacies that are/are not dispensing such medications, acknowledging that there may be a need for a government department to have a secure and confidential database.

In Conclusion

The Guild supports measures that enable Queenslanders to transition through all stages of their life seamlessly and if they wish at home. Community pharmacy is positioned ideally to aid in this. In the aged care system, prior to admission to a RACF, patients can be well served by a suitably funded system that deliverers medication safely and effectively to them in their home. Once in a RACF the Guild recommends that it should be compulsory for the supply of medication to be via a standard document which ideally would involve a digital prescribing platform. If Queenslanders are of the 70 per cent of people who wish to die in their own home, the Guild supports and recommends policies and systems that enable them to live in their home and reduce admissions to hospital due to medicine management issues or due to the expense of supplying their medications in the home setting. With VAD, the Guild recognises that community pharmacy should be considered an integral part of implementation and delivery of legislated pathways that provide consumers with access to medications for this purpose.

Our State President Trent Twomey would like to be present at the public hearings regarding these matters. Should you have any questions regarding this submission, or to arrange attendance at a public hearing, please contact the Queensland Branch of the Pharmacy Guild of Australia on [redacted].

RACGP
Royal Australian College *of* General Practitioners

Healthy Profession.
Healthy Australia.

15 April 2019

Committee Secretary
Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee
Parliament House QLD 4000
careinquiry@parliament.qld.gov.au

Dear Committee Secretary,

RE: RACGP Submission to the Queensland Parliamentary Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying.

The Royal Australian College of General practitioners (RACGP) Queensland holds that while voluntary assisted dying impacts on medical practice it is fundamentally an issue of community values, best decided through the democratic and Parliamentary process.

As far as voluntary assisted dying does impact on medical practice, general practitioners (GP) are likely to be at the forefront of this area. As the peak body representing over 80% of the GPs in Queensland, the RACGP believes the interests of GPs and their patients must be protected. The RACGP Queensland holds that the legislation must ensure the following minimum standards:

1. Patient safety is always protected. Sufficient safeguards must be in place to ensure patients are fully equipped to make these decisions and are free of coercion and bias.
2. Medical practitioners must be protected, particularly those who choose to conscientiously object from providing the services. Medical practitioners require a clear framework and enabling them to practice without fear of legal or other retribution. Practitioners who decide not to become involved in voluntary assisted dying required the same protections and clear process as those who do.
3. Clear eligibility criteria. Eligibility criteria for access to voluntary assisted dying should be clear to provide certainty and clarity to the community and health practitioners.
4. Recognise and optimise end of life palliative care services. A multidisciplinary team approach often delivers optimal end-of-life care in a shared-care arrangement. In many cases, this will be coordinated through a GP and may be augmented by specialist palliative care services where needed.

The RACGP Queensland welcomes the opportunity to address the inquiry in person. To arrange a suitable time please contact Dr Bruce Willett, Chair RACGP Queensland, via [redacted] State Manager RACGP Queensland, on [redacted] or [redacted]

Yours sincerely,

Dr Bruce Willett
Chair, RACGP Queensland

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Dying with Dignity
Tasmania (Inc)

SUBMISSION TO THE QUEENSLAND INQUIRY ON AGED CARE, END-OF-LIFE AND PALLIATIVE CARE AND VOLUNTARY ASSISTED DYING IN QUEENSLAND

APRIL 2019

ATTACHMENTS

ATTACHMENT 1: Tasmanian *Voluntary Assisted Dying Bill 2016* (with minor numbering corrections)

ATTACHMENT 2: DwDTas paper, Comparison of Voluntary Assisted Dying Safeguards – March 2018

1. OVERVIEW OF THIS SUBMISSION

- DwDTas has similar purposes and objectives as Dying with Dignity Queensland (DWDQ) but is a separate organisation. We have had a close relationship through the national alliance of the Australian organisations and have very similar purposes and objectives, but the views expressed in this submission are those of DwDTas alone.
- Like DWDQ, DwDTas is strongly committed to better laws and services to enable people to achieve their end of life wishes. DwDTas promotes, encourages and provides practical support for end of life and advance care planning, supports and encourages improved palliative care and other end of life services, and has been very actively involved for many years in the promotion and development of principles- and evidence-based voluntary assisted legislation. More information about the DwDTas organisation, objectives, priorities and activities is available on our website.
- This DwDTas submission deals largely with the issue of voluntary assisted dying legislation, with the aim of providing information and perspectives that may not otherwise be provided to the Committee. DwDTas has had very active involvement in Tasmanian Voluntary Assisted Dying Bills and their underpinning research and considerations. (See sections 2 and 3). DwDTas has also had very active involvement in encouraging and supporting people to do advance care directives, appoint an Enduring Guardian and undertake other end of life planning and preparation. We comment on this matter in Section 4.
- We expect that DWDQ, other organisations and individuals will argue effectively for the principles and the reasons for voluntary assisted dying legislation generally and will present to the Committee commonly available information and views. Recent, thorough inquiries in Victoria and WA have produced excellent reports covering these broad issues.
- In our view, however, important information and understanding about the details of overseas legislation have not been considered adequately in the debate on the details of VAD laws in Australia, particularly in relation to Canada.
- The conclusions reached in Tasmania are very similar to those reached in Canada, including rejection of the US model, in Oregon and other States, as a suitable or the most effective model for VAD. We are concerned that the basis of the Victorian law is the US model, but with even greater restrictions. We argue that additional restrictions do not make laws safer, but make them much less effective by creating overly burdensome requirements and unnecessary hurdles and barriers to access to VAD.
- Proposed legislation in Tasmania is different in some key respects from the Victorian law. It appears that the WA law will also be different in some key respects. Other States need to decide on this for themselves. In Section 3 we identify the basis for our conclusions that the Canadian approach is generally more relevant and suitable for Australia than other overseas models and will be much more effective in meeting the needs and wishes of our community. We have found that some adaptations are necessary to meet our circumstances and we have also taken into account and learned from implementation issues in Canada.
- The current situation in Tasmania is that we have started consultation with MPs and other groups (eg COTA, doctor representative groups) and individuals on our proposal

for the Voluntary Assisted Dying Bill 2019. The aim is to reach a broad consensus on a principles and evidence-based safe and effective voluntary assisted dying option for Tasmanians. The intention is for a Bill to be introduced and debated in the Parliament later in 2019, with support and co-sponsorship across all Parties and independents.

- Our proposed 2019 Bill is largely the same as the last VAD Bill (see Attachment 1), with amendments to address concerns raised in the last debate, to provide additional details, updating and greater clarity of some provisions to improve the understanding and implementation of the Bill, and to improve the effectiveness of the Bill by learning from other jurisdictions, eg about known issues found in the implementation of other legislation.

- DwDTas and Tasmanian MPs have reached different conclusions on some key aspects of VAD legislation from those made in other States, by our DwD colleagues and others. This includes the eligible medical condition, doctor-administration as well as self-administration of the drugs for an assisted death, the roles and responsibilities of doctors at the time of self-administration of drugs and the safe handling of drugs, and the responsibility for oversight, monitoring and scrutiny of assisted deaths. (See section 3 for more details.)
- Tasmania was the first to use the term ‘voluntary assisted dying’ for its 2013 Bill and the term has been used consistently here to include both doctor-administration and self-administration of the drugs for an assisted death. Other States have followed our lead, but it is important to note that the term is being used differently in some instances to mean self-administration of drugs for an assisted death.
- Our conclusions have been based on extensive and in-depth research, analysis and broad consultation on the issue of voluntary assisted dying legislation have been, and contributed significantly to last two Tasmanian Voluntary Assisted Dying Bills. DwDTas has worked very closely with MPs, particularly the proponents of the Bills, the *Voluntary Assisted Dying Bill 2013* and the *Voluntary Assisted Dying Bill 2016,* and on the detailed proposal and consultation before the 2013 Bill.

- Broad consultation in Tasmania has included public consultation and consultation with medical and legal experts, and those with particular knowledge, experience and expertise, including doctors and nurses. Most important of all has been the consultation with the people most affected – those who want VAD because of their current situation and people whose loved ones have had harrowing personal experiences that could have been avoided if VAD had been available.

- DwDTas has made a significant contribution to the research, analysis and consultation on voluntary assisted dying legislation in relation to the broad issues, principles and evidence showing the need for the legislation and the effectiveness of safeguards against potential risks and abuses, as found by every recent thorough review and inquiry. Claims made by opponents about risks and abuses of such legislation have been monitored and carefully checked. We have reached the same conclusions as all recent, thorough reviews and inquiries that the claims about potential risks and abuses have no basis in credible evidence or reasonable assumptions and conclusions.

- DwDTas and proponents of the Tasmanian Bills have also focused on the details of existing legislation elsewhere; detailed implementation data, issues and problems; analysis of the different models of VAD and their relevance and suitability for the Tasmanian situation. Particular attention has been given to the relative effectiveness of the different approaches to meet the wishes of the Tasmanian community, the needs of the people who want VAD and the needs of the doctors who will be assessing requests and providing assisted dying under the law.
- The laws must have effective safeguards and the evidence is very clear what they are. Recent thorough inquiries in Australia (eg Victoria and WA) and elsewhere (especially multiple reviews in Canada) have reached consistent findings that existing laws provide rigorous, accountable voluntary assisted systems with safeguards that have effectively prevented potential risks and abuses. (See section 2.) But some laws are much more effective than others in meeting the needs and wishes of the community and those most closely involved, the people making requests for VAD and their doctors, while retaining effective safeguards. The Australian laws must also be workable in our circumstances and in the particular State, learning from overseas experience but adapting to meet local conditions.
- It has been our experience through close involvement at each stage of the process of development of the VAD laws in Tasmania that many practical issues only became apparent at the time of drafting the detailed provisions of the legislation. It is at that time that critically important practical issues must be taken into account. These include: how will that impact on the very seriously ill people with great suffering who will be eligible for VAD generally and in these real-life cases; how will that impact on the doctors involved; how has that issue been addressed elsewhere and what is suitable in our context; is there a better and more suitable alternative for our circumstances; how will that work for people living in different parts of the State; what resources will be necessary to do it that way; etc.

2. OVERVIEW OF THE CURRENT SITUATION OF VOLUNTARY ASSISTED DYING LEGISLATION

- This section provides a relatively brief overview of the current situation involving voluntary assisted dying legislation in Australia and overseas and some key issues. It includes links to reliable, trusted sources of relevant information which are independent of DwDTas.
- Voluntary assisted dying laws are now long established, thoroughly scrutinised laws. The number of laws is increasing because of overwhelming evidence that they are needed, are working safely and are highly valued wherever they have been introduced. There are now 18 jurisdictions with a form of legal voluntary assisted dying; 14 of them with specific legislation, including Canada whose law and its implementation are particularly relevant to the proposed Tasmanian legislation.
- All recent, thorough reviews that have produced detailed findings and recommendations about voluntary assisted dying legislation have reached consistent, evidence-based and well-argued conclusions about why we need VAD legislation and the effectiveness of safeguards and prevention of risks. This has included the Parliamentary inquiries in Victoria and WA that have produced lengthy reports. For example:
  - the WA inquiry report, *My Life, My Choice,* identified the two core reasons for voluntary assisted dying legislation: *Unnecessary suffering at end of life, and broad community agreement regarding individual autonomy, form the basis for the Committee's recommendation that the Western Australian Government draft and introduce a Bill for Voluntary Assisted Dying.* (The report is available from the WA Parliament website - http://www.parliament.wa.gov.au.)
  - the Victorian inquiry conclusion is very similar to the WA and other reviews: *The Committee is satisfied, through its research into international jurisdictions, that assisted dying is currently provided in robust, transparent, accountable frameworks. The reporting directly from such frameworks, and the academic literature analysing them, shows that the risks are guarded against, and that robust frameworks help to prevent abuse.* (The report is available at https://www.parliament.vic.gov.au/images/stories/committees/SCLSI/EOL_Report/LSIC_58-05_Text_WEB.pdf.)

- There have been other major reviews in Canada and the UK that have produced very similar findings. (A list and links are available at http://dwdtas.org.au/key-resources/.)
- All claims made in the debate on this issue need to be checked against reliable independent sources of accurate, relevant, reliable information. Many fallacious and misleading claims are made about VAD based on poor quality, inadequate data and misunderstanding or deliberate misinterpretation of the data. It is disturbing that the same poorly based claims continue to be made even when they have been refuted repeatedly by every recent, thorough review, including the Australian ones in WA and Victoria.
- In the case being put against VAD there are also many omissions of critically relevant facts, principles and issues. The major omission from many commentaries about VAD is

acknowledgement of the people who will be eligible for their doctors' assistance under the law, of their intolerable and unrelievable suffering and of respect for their voluntary, informed wishes as competent adults about the end of their lives. There is too frequently a failure to acknowledge the evidence that even the best palliative care cannot adequately relieve some people's severe suffering. What is also usually missing is acknowledgement of the significant safeguarding roles and responsibilities of doctors within an accountable system of independent monitoring, scrutiny and public reporting to Parliament.

INCREASING ACCEPTANCE OF THE EVIDENCE - 18 JURISDICTIONS AND COUNTING

- There is an increasing rate of acceptance by parliamentarians of the evidence of the need for voluntary assisted dying (VAD) legislation and the effectiveness of safeguards to prevent risks and abuses.
- There are **18 jurisdictions with a form of legal voluntary assisted dying**, all but one in Western liberal democracies similar to ours. Over 100 million people live in the jurisdictions that have legal VAD.
- **Fourteen of those jurisdictions have specific legislation** for doctor-provided VAD, passed by democratically elected parliaments, with detailed requirements for eligibility, the significant roles and responsibilities of doctors, and the monitoring, scrutiny and reporting of assisted deaths.
- Laws in chronological order: Oregon (1994 but came into operation in 1997), the Netherlands (2002), Belgium (2002), Luxembourg (2008), Washington (US) (2009), Vermont (2013), California (2015), Quebec Province in Canada (2015), Canada (2016), Washington DC (2016), Colorado (2017), Victoria (2017), Hawaii (2018 – came into operation on 1 Jan 2019) and New Jersey (March 2019 – to come into operation in approximately 4 months' time).
- In three US States – Oregon, Washington and Colorado - the laws followed majority votes in citizen ballots. In two jurisdictions, Montana State in the US and Columbia in South America, legal VAD relies on court decisions. In Switzerland, the Criminal Code 1942 allows someone to assist a person to suicide as long as it is not for selfish reasons. Assisted suicide is legal in Germany but it bans commercial operations, such as Dignitas, which operate in Switzerland.
- **Over 50% of the laws have been passed in the last 4 years** and this pattern of increasing acceptance is similar to other contentious law reform. The first Australian State to pass VAD legislation was Victoria. The Voluntary Assisted Dying Act 2017 will come into operation in June 2019. A comprehensive official overview of the law is available on the website of the Victorian Department of Health at https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/voluntary-assisted-dying/vad-overview.
- It is interesting to note the admirable ethical positions of Catholic Governors in New jersey and California who signed their State laws into operation and did not use their right of veto. As recently as 12 April 2019, the New Jersey Governor, Phil Murphy, was reported to be "a lifelong Catholic" and "revealed that he wrestled with whether to sign the legislation" but stated: "I have concluded that, while my faith may lead me to a particular decision for myself, as a public official I cannot deny this alternative to those who may

reach a different conclusion. I believe this choice is a personal one and, therefore, signing this legislation is the decision that best respects the freedom and humanity of all New Jersey residents." (Source: https://abc7ny.com/politics/nj-law-will-allow-terminally-ill-to-get-life-ending-medication/5245953/) His comments are similar to those of the Californian Governor, Jerry Brown in October 2015 who wrote in a letter to the State's lawmakers who had passed the End of Life Option Act: "I do not know what I would do if I were dying in prolonged and excruciating pain. I am certain, however, that it would be a comfort to be able to consider the options afforded by this bill. And I wouldn't deny that right to others."

- **The number of laws is very likely to increase further in 2019 and 2020**. In November 2018, the WA State Government accepted the recommendations of the WA Parliamentary inquiry into end of life choices and became the second in Australia to announce it would introduce VAD legislation. A Bill is to be prepared for debate in 2019. Debate and some progress towards legislation is occurring in other Australian States and in other Western jurisdictions, eg Spain. Progress is being made towards legislation in numerous other US States, eg Death with Dignity summary showing 19 more States considering the issue this year or session of Parliament (available at https://www.deathwithdignity.org).

VAD LEGISLATION MEETS DEMONSTRATED NEEDS, WISHES AND SUPPORT ACROSS THE COMMUNITY

- Parliamentary and community debates and multiple reports, articles and commentaries about the jurisdictions that have passed VAD laws show that the most common reasons for the laws are:
  - **to meet the needs of people with intolerable and unrelievable suffering** caused by serious, incurable medical conditions where there is no chance of recovery or improvement; and
  - **to respect people's wishes for the end of their lives and their voluntary, informed choices** made in accordance with their own beliefs, values, what is important to them and their individual circumstances.

- The evidence is very clear that, despite the best skills and efforts of doctors and other health professionals working in palliative and end of life care, **some people experience intolerable suffering that cannot be relieved adequately**. There is reliable data and expert opinion supporting this and many, many testimonials, as provided to inquiries such as the Victorian and WA inquiries into end of life choices and in the media. See also examples on our website and given in previous debates on the 2013 and 2016 Tasmanian VAD Bills.

- There is **no evidence that doctors are providing VAD to people because they feel a burden**, or have been coerced or manipulated into requesting VAD. Most of the claims about people feeling a burden are based on an inaccurate and distorted interpretation of Oregon reports.

- The evidence is very clear that **some people are taking desperate action including violent suicides** when they have serious illness and great suffering. Harrowing evidence was provided by State Coroners to the Victorian and WA inquiries into end of life options about such suicides that seem to be approximately 10% of all suicides.

- Legislation for doctor-provided voluntary assisted dying is a very rare political issue where **support is higher than for any other comparable issue, and the support is very high across**

the community, across religious and political affiliation, age groups and gender in Tasmania, elsewhere in Australia and in other comparable countries. The latest major survey, the Roy Morgan poll in November 2017 found that 85% of national and Tasmanian respondents said 'yes' to the question: "If a ***hopelessly ill*** patient with ***no chance of recovering asks for*** a lethal dose, should a doctor be allowed to ***give*** a lethal dose, or not?". (Full report available at http://www.roymorgan.com/findings/7373-large-majority-of-australians-in-favour-of-euthanasia-201711100349.) This finding is consistent with other reputable polls over many years (see our paper *Support for Voluntary Assisted Dying Law Reform, available at* http://dwdtas.org.au/wp-content/uploads/2013/05/Paper-Community-Support-Apr-15.pdf). The Tasmanian Bills reflect the wish of the community for this 'last resort' option.

- The report of the 2018 Council on the Ageing (COTA) survey states: *On the topic of assisted dying, **overwhelming support is evident, at 84%** - with results highly consistent across all states and territories. Some differences were found by religion, where support was highest among those with no religion (95%), and lowest among those who identified as Baptist (53%) or Catholic (74%). The large majority of survey participants were also open to investigating it for themselves if they had a terminal illness or incurable condition.* (Report available at https://www.cota.org.au/wp-content/uploads/2018/12/COTA-State-of-the-Older-Nation-Report-2018-FINAL-Online.pdf)
- **Support by doctors of a legal VAD option seems to be increasing** and it is reasonable to assume that close to half of our doctors support an option as provided for in the proposed Tasmanian Bill. In the AMA 2016 survey of its members: *More than half of respondents (52%) believe euthanasia [doctor-administered drugs] can form a legitimate part of medical care and 45% believe the same for physician assisted suicide [self-administration of drugs].* In addition, *For those who agreed euthanasia and physician assisted suicide should be provided by doctors, the vast majority (> 90%) supported it in the case of a person suffering an incurable illness associated with unrelievable and unbearable suffering' while less (<71%) supported it for a terminal illness.* (See more details see AMA report on our website in the Doctors and VAD section - http://dwdtas.org.au/the-next-tasmanian-vad-bill-2019/.)
- **Medical associations around the world are reviewing their policies on VAD** and many are adopting a more neutral or supportive stance after extensive consultation with their members. This includes the Canadian Medical Association, which also consulted widely with the community before adopting its "Principles-based Recommendations for a Canadian Approach to Assisted Dying". The approach recommended is very similar to the last two Tasmanian Bills and our proposal for the 2019 Bill. The CMA subsequently supported the Canadian legislation. (The CMA document is available at https://www.cfpc.ca/uploadedFiles/Resources/_PDFs/cma-framework_assisted-dying_final-jan2016_en.pdf.)
- The **Royal Australasian College of Physicians** is the Australian medical association that has conducted **the most extensive consultation process before adopting a more neutral policy on VAD**. In November 2018, the College published an updated policy, Statement on Voluntary Assisted Dying, which states: *The RACP respects and supports all its members and does not believe it is appropriate or possible to enforce a single view on a matter where individual conscience is important. The RACP recognises that legalisation of voluntary assisted dying is for governments to decide, having regard to the will of the community, to*

research, and to the views of medical and health practitioners. (Policy is available at https://www.racp.edu.au/docs/default-source/advocacy-library/racp-voluntary-assisted-dying-statement-november-2018.pdf?sfvrsn=761d121a_4.)

- The UK **Royal College of Physicians** has now adopted a neutral position after a survey of its members.
- The **Royal Australasian College of GPs** welcomed the passing of the Victorian legislation and we will consult with them on the details of the 2019 Tasmanian Bill.

VOLUNTARY ASSISTED DYING LAWS PROVIDE AN ESTABLISHED, SCRUTINISED, SAFE AND RESPONSIBLE OPTION

- Legal doctor-provided voluntary assisted dying (VAD) is now **long established, with decades of combined experience which has been subjected to rigorous, thorough scrutiny**. The earliest legislation still in operation is the Oregon *Death with Dignity Act* 1994 which began operation in 1997. The most recent law, passed in Hawaii in 2018, came into operation on 1 January 2019. Voluntary assisted dying has been provided in the Netherlands under legally sanctioned duty of care principles and court judgements for years prior to their 2002 legislation.
- **Multiple recent thorough reviews, including parliamentary inquiries**, have gathered a massive amount of evidence and the views of the community and experts. After carefully examining the evidence and views, the reviews and inquiries have reached **consistent conclusions about the need for, and safety of, a legal VAD option**, as well as action on other end of life issues.
- The extensive 2018 WA report, *My Life, My Choice*: *The Report of the Joint Select Committee on End of Life Choices,* which resulted from the WA parliamentary inquiry, documents the review and presents arguments, evidence and findings and recommendations about a range of issues including VAD. It follows the Victorian inquiry into end of life choices and passing of the Victorian *Voluntary Assisted Dying Act 2017*, and numerous other reviews, chiefly in Canada. This includes by the Canadian Supreme Court (see https://scc-csc.lexum.com/scc-csc/scc-csc/en/item/14637/index.do), the Royal Society of Canada (see https://rsc-src.ca/en/end-life-decision-making) and Parliamentary inquiries in the national and Quebec Parliaments. (See for example, the Canadian Parliament Joint Select Committee report, Medical Assistance in Dying: A Patient-centred Approach at http://www.parl.ca/DocumentViewer/en/42-1/PDAM/report-1.)

- Key points made in the WA report, supported by all but one member of the Committee, are:
  - ➢ *Unnecessary suffering at end of life, and broad community agreement regarding individual autonomy, form the basis for the Committee's recommendation that the Western Australian Government draft and introduce a Bill for Voluntary Assisted Dying.*
  - ➢ *It is clear from the evidence that even with access to the best quality palliative care, not all suffering can be alleviated. Palliative care physicians themselves acknowledge this.*
  - ➢ *Overwhelmingly, people want to live. For those left behind, the protracted death of a loved one from a terminal or chronic illness can be devastating.*
  - ➢ *How we die has changed over the last 60 years. Medicine and the law have not kept pace with this change, nor with changes in community expectations.*

  - ➢ *Having weighed the evidence, the committee concurs with findings by similar parliamentary inquiries in Victoria and Canada that risks can be guarded against and vulnerable people can be protected.*
  - ➢ *Those who fundamentally oppose the introduction of Voluntary Assisted Dying lack rigorous evidence to back up their claims. They will inevitably criticise this process.*

- The WA Committee carefully examined overseas practices and claims based on fears about the risks of VAD legislation. It found: "***there is no evidence that vulnerable groups, including people with disabilities, are at heightened risk of assisted dying"*****; no evidence to suggest the slippery slope has occurred in the jurisdictions that have legislated for voluntary assisted dying; and *"reports of suicide contagion are not supported in the evidence"*.** The Victorian and other reviews reached similar conclusions. None of the reviews have found evidence that VAD laws have reduced trust in doctors, or caused negative effects to the doctor-patient relationship or on support for, and ongoing improvements in, palliative care practices and services.

- The WA inquiry recommended a framework for a proposed voluntary assisted dying law in WA. A discussion paper has been issued by a 'Ministerial Expert Panel' for further consultation before the legislation is debated later this year. The DwDTas will be making a submission expressing concerns about some aspects and explaining our different approach.

- The report of the ACT Select Committee on End of Life Choices has been released but it includes very limited coverage of the issue of VAD legislation and no recommendations. While still in operation, the Commonwealth *Euthanasia Laws Act 1997* prevents the ACT from debating and passing VAD laws.

DIFFERENCES IN APPROACHES, DETAILS AND OUTCOMES NEED CAREFUL ATTENTION

- All recent, thorough reviews, such as the Victorian and WA inquiries, have found that all the voluntary assisted dying systems are working safely, without the feared abuses or risks to certain groups considered vulnerable to manipulation and coercion. However, there are **significant differences, as well as similarities, in their legal requirements and in their effectiveness in meeting the needs and wishes expressed by the community**. The details of these differences have received limited attention in the Australian inquiries but they are relevant and important in determining what is an effective as well as a safe law here. An effective law will meet the needs and wishes of the Tasmanian community and be practical and workable in the Tasmanian situation. We will cover key issues and data in our detailed proposal for the 2019 VAD Bill and why we believe the Canadian model is most suitable for our own situation and why the US/Oregon model adopted by Victoria is not the most suitable or effective.

- There are **two broad models of legislation**, the US model and the Canadian/European model. There are some differences between the Canadian and European laws. Main areas of difference between the laws are in the eligible medical condition, administration of the drugs and oversight, monitoring and reporting. Detailed information is available in the DwDTas paper, Comparison of Voluntary Assisted Dying Safeguards – March 2018, which is an attachment to this submission. (Also available at http://dwdtas.org.au/wp-content/uploads/2017/04/Comparison-of-safeguards-across-legislation-Mar-2018.pdf)

- The US model has been specifically designed for aspects of that culture and medical system that do not apply in Australia (eg it is only when individuals have a prognosis of terminal illness with 6 months or less to live that they can access federal funding that makes end of life hospice care affordable). This model of VAD laws helps very few people compared to other equally safe VAD systems, because of much more restrictive eligibility and greater barriers in access to doctors, no provision for support of people at the time of self-administration to suitable and affordable drugs.

- We have followed the situation in Canada in great detail since the prestigious Royal Society of Canada published its peer-reviewed, extensive report on end of life decision-making in 2011. There have been multiple reports, commentaries, academic articles and debates in that country nationally and in provinces such as Quebec since then. We have found the Parliamentary debate on the national legislation for medical aid in dying to be important for an adequate understanding of the legislation, particularly the Second Reading speech of the responsible Minister at the time.

- Our website includes a great deal of information particularly on the Canadian approach which we have found to be most relevant to the Australian situation because of our historical, cultural, medical and legal system similarities. Canada was also able to take into account information and analysis of the pros and cons of all other legislation in its long development and consideration process leading to its medical aid in dying legislation. It also had the advantage of the involvement and positive contribution of the Canadian Medical Association on behalf of all its members including who support VAD and are prepared to provide it and those who do not.

- The eligible medical condition is a core aspect of all VAD legislation in determining who will and who will not have access to legal doctor-provided VAD. There is a great deal of misinformation and misunderstanding about the differences:
  - **Terminal illness and a timeframe prognosis have never been requirements in the Netherlands, Belgium and Luxembourg, and they are not requirements in the Canadian or Quebec Province laws**. Eligibility requirements include serious medical conditions **and** intolerable/unbearable suffering which may result from serious chronic, neuro-degenerative as well as terminal conditions. People access VAD because of the seriousness of their condition and of the suffering, not because they have a particular medical condition.
  - In Canada, there is a requirement that "natural death has become reasonably foreseeable, **taking into account <u>all of their medical circumstances</u> without a prognosis necessarily having been made as to the specific length of time that they have remaining**" (our emphasis). The second part of the requirement is frequently left out and ignored, resulting in a serious misunderstanding of its relevance, significance and interpretation. It should also be noted that this requirement has caused serious difficulties in interpretation, has needed a legal case to clarify it more and is subject to a legal challenge later this year. The clarification is also not always reported as fully as it needs to be.
  - **US laws do not include a suffering requirement and provide a very limited VAD option only for those in the limited circumstance of having a prognosis of 6 months or less to live and who can orally ingest the lethal drugs**. The laws are designed to link with restricted US Medicaid funding **for** 'hospice' treatment where it is necessary for people to have a prognosis of 6 months or less to live before they can access the federal funds.

(The Victorian law is based largely on the US model with additional restrictive requirements not found in any other law.)

- The data shows that **there are similarities in who accesses VAD, regardless of the differences between the laws**. The average or median age is early 70s with very few under 40. The major reason for people accessing VAD is intolerable/unbearable suffering due mainly to cancer, neuro-degenerative (such as motor neurone disease), respiratory and cardio-vascular conditions. Suffering due to psychiatric illness is involved in a very small percentage of assisted deaths, eg 1.3% in the Netherlands in 2017.
- **Assisted deaths are a very small proportion of all deaths**, from very low in US States (eg 0.46% of all deaths, 2018 Oregon report – available at https://www.oregon.gov/oha) to 4.4% in the Netherlands (2017 report – available with all other annual reports at https://english.euthanasiecommissie.nl/the-committees/documents/publications/annual-reports/2002/annual-reports/annual-reports). The Canadian law came into operation in June 2016 and the latest report for Jul-Dec 17 (available at https://www.canada.ca/en/health-canada/services/publications/health-system-services/medical-assistance-dying-interim-report-june-2018.html) reports that assisted deaths were 1.07% of all deaths and increasing as the law becomes more trusted. In Belgium, assisted deaths are close to 2% of all deaths. The reason for the differences is not because some laws are safer than others, but because some are more effective in meeting people's needs. Eligibility is very restricted in the US and there are major problems related to the suitability and cost of drugs for oral ingestion (and there will be in Victoria). Access to participating doctors is much higher in the Netherlands.

PALLIATIVE CARE AND VAD – BOTH ARE NEEDED NOT 'EITHER/OR'

- It's a case of both VAD and palliative care, not 'either/or'. The same can be said for improved advance care planning. **VAD provides an option for people who are still competent to express their wishes**. DwDTas has worked for many years to encourage and assist people to do their end of life planning and express their wishes through an advance care directive or enduring guardianship which come into effect **when they are no longer capable of expressing them**.
- VAD is not a replacement for palliative and other end of life options that work effectively to meet most people's needs and wishes. **We support doctor-provided voluntary assisted dying that provides a 'last resort' option for a small proportion of competent adults for whom current options don't work adequately.** That is, it enables them to achieve an end to intolerable suffering that is otherwise unrelievable through an assisted death when, where and with whom they choose. It meets the needs and wishes of those who will never again be free of intolerable suffering and the devastating effects of their serious, incurable medical condition. **By taking a 'last resort' approach, the proposed Tasmanian Bill acknowledges the importance of palliative care and other end of life care**, requires doctors to provide information on palliative care and other options, and to provide assisted dying only when they agree with the people requesting VAD that there are no relevant options left to improve the person's condition or relieve their intolerable suffering.
- We are very fortunate to have high-quality palliative care in Tasmania, which we support very strongly. Many people are assisted by palliative and other end of life care that meets their wishes and circumstances. It is essential that improvements continue in the number

and quality of palliative care services in Tasmania including better home-based care. As the respected Tasmanian Professor of Palliative Care, Michael Ashby, commented in his evidence to the 2016 House of Assembly Inquiry into Palliative Care: *There isn't a single area of medicine that has a 100 per cent score, so why would palliative care be any different?* ***Any claims by us that we can relieve all pain are patently nonsense.*** *I think it is very foolish of certain people in our specialty around the world to convey the impression that they can. I don't think anybody these days would make that claim.* ***What I can say is that we can nearly always make a difference for the better***. (Our emphases) (p51 of the Inquiry Report - http://www.parliament.tas.gov.au/ctee/House/Reports/Report%20-%20Inquiry%20into%20Palliative%20Care%20in%20Tasmania%20(TABLED).pdf).

- In Australia reliable data exists in the detailed reports that are provided by over 100 palliative care services to the Palliative Care Outcomes Collaboration (at https://ahsri.uow.edu.au/pcoc/reports/index.html). Their reports, including the latest national overview in September 2018, demonstrate the significant achievements of and improvements in palliative care services across the country including Tasmania. They also confirm Professor Ashby's expert assessment and the evidence that has been provided to multiple inquiries that there are limitations on what palliative care is achieving and can achieve. For example, there is a PCOC benchmark that 60% of patients with moderate to severe suffering will have that reduced to mild or absent suffering, and this is not being met by most services despite their best efforts. In Professor Ashby's 2016 paper, How we die, provided as evidence to the House of Assembly Inquiry into Palliative Care, he reports that the PCOC data showed that in Tasmania "approximately 50 per cent of patients who have an episode of moderate/severe pain at the beginning of an episode of palliative care will report no pain at the end of the episode of care". (Paper is available at http://www.parliament.tas.gov.au/ctee/House/Submissions/Submission%20No.%2018%20-%20Michael%20Ashby%20-%20Appendix%20i.pdf.)
- Palliative Care Australia has recently received two important relevant reports on VAD in relation to palliative care to inform their policy and advice to politicians. The report, Experience internationally of the legalisation of assisted dying on the palliative care sector, October 2018, found: *An assessment of the palliative care sectors following the introduction of assisted dying for each of the in-scope jurisdictions provided no evidence to suggest that the palliative care sectors were adversely impacted by the introduction of the legislation. If anything, in jurisdictions where assisted dying is available, the palliative care sector has further advanced. Where jurisdictional data is available, there are consistently high levels of patient involvement in palliative care services at the time of the death through assisted dying"* . (p5). (Report is available at https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/12/Experience-internationally-of-the-legalisation-of-assisted-dying-on-the-palliative-care-sector-APEX-FINAL.pdf).
- The other report, Reflections and Learnings: Assisted Dying in Canada and the United States, November 2018, provides valuable first-hand observations from people with experience where VAD is legal and can help to inform the law and its implementation here. (Report is available at https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/12/PalliativeCare-Refelctions-and-Learnings_FINAL.pdf)

3. VOLUNTARY ASSISTED DYING LEGISLATION IN TASMANIA

BACKGROUND

- There have been three recent voluntary assisted dying Bills in Tasmania:
  - *Dying with Dignity Bill 2009* moved by the Leader of the Greens, Nick McKim. It was defeated at the Second Reading stage in the House of Assembly when most Labor and all Liberal MPs voted against it.
  - *Voluntary Assisted Dying Bill 2013,* co-sponsored by the then Premier Lara Giddings, and the then Minister for Education and Leader of the Greens, Nick McKim. It narrowly failed to pass the Second Reading stage in the House of Assembly when there were 13 in favour, including the Acting Speaker, and 12 opposed. All but 2 Labor MPs and all Greens MPs supported it. No Liberal MPs voted for it.
  - *Voluntary Assisted Dying Bill 2016,* debated and voted on on 24 May 2017. It was co-sponsored by Lara Giddings, then Leader of the Opposition, and then Leader of the Greens, Cassy O'Connor. It was defeated in a vote of 16 – 8. One Liberal MP, 4 Labor MPs and 3 Greens MPs voted for it, with 13 Liberal and 3 Labor voting against it.
- DwDTas was not involved in the development of the 2009 Bill and there was no community consultation on it. DwDTas was very actively involved in the in-depth research, analysis and consultation for the detailed proposal that preceded the 2013 Bill, Voluntary Assisted Dying: A Proposal for Tasmania. (Available from http://dwdtas.org.au/wp-content/uploads/2013/05/Voluntary-Assisted-Dying-A-Proposal-for-Tasmania.pdf) That very active involvement continued with the development of the Voluntary Assisted Dying Bill 2013, the subsequent 2016 Bill and the development of the 2019 proposal for consultation to reach a broad consensus.
- The intensive work on the 2013, 2016 and 2019 Bills has been done by people with significant knowledge, skills and experience in relation to the issue of voluntary assisted dying, in relation to the Tasmanian community and in the development and implementation of policy and legislation. This includes the proponents of the Bills and other people involved who have significant skills and experience in the development and implementation of policy and legislation. This includes the President of DwDTas, Margaret Sing, a former senior public servant with over 40 years' relevant experience.

AIMS OF THE PROPOSED 2019 BILL

- The Bill we propose has the following key aims which are consistent with those of the last two Bills:

  (1) **Last resort option for people who are seriously ill and with intolerable suffering which is otherwise unrelievable:** The principal aim is that the law provides a 'last resort' option of doctor-provided voluntary assisted dying for competent adults making repeated voluntary, informed requests: (a) who are seriously and incurably ill, with medical prognoses there is no reasonable chance of recovery or permanent improvement in their condition, (b) who have persistent suffering which is intolerable to them, and (c) the people making requests and their doctors agree there are no relevant options left to relieve their suffering or to improve their medical condition to the people's satisfaction.

COMMENT: A 'last resort' option:

- is consistent with the support of the vast majority of the Tasmanian community as expressed in multiple opinion surveys especially those done by Newspoll and the latest Roy Morgan poll
- recognises the value, importance and effectiveness of palliative care and other end of life care and options in meeting most people's needs and wishes, but not all
- is consistent with detailed data on who accesses voluntary assisted dying overseas
- will result in assisted deaths being a very small percentage of all deaths.

(2) Proven rigorous, accountable system with effective safeguards: The law will provide a rigorous and accountable system of requirements and procedures that are consistent with reliable, comprehensive evidence about effective safeguards against risks and abuses (eg to people considered 'vulnerable').

COMMENT: All the recent, thorough reviews have found that existing VAD laws have effective safeguards against identified risks and feared abuses, regardless of the differences between them.

The requirements and procedures in the proposed Tasmanian VAD Bill 2019 are consistent with the substantial evidence of what are effective safeguards, including eligibility requirements for the people wanting to access VAD; requirement for repeated requests; a rigorous procedure involving multiple checks of the voluntariness of the requests, the competence/capability of the people and the persistence of the person's wish for VAD; at least two registered medical practitioners with extra referrals as necessary; protection of the wishes of those who do not want to participate; and accountability involving reports by doctors to an independent body with statutory powers and responsibilities for information and education, monitoring, scrutiny and reporting to Parliament.

(3) Effective in meeting the needs and wishes of Tasmanians requesting VAD and of their doctors

The law will be as effective as possible in meeting the needs and wishes of the Tasmanians requesting voluntary assisted dying and of the doctors assisting and supporting them. The law will show care and respect for them, careful consideration of their different needs and the significance of their choices and responsibilities. This includes the wishes of the people concerned for as peaceful and comfortable a death as possible, when, where and with whom they want it to be. This will at times involve a balancing of different needs.

COMMENT: All the thorough reviews show that VAD laws are working safely regardless of the differences between them. However, in our view, they have given inadequate attention to their effectiveness in meeting people's needs and wishes and their relevance and suitability for the Australian situation. We have given particular attention to the Tasmanian situation and do not accept that the US/Oregon model is an effective or suitable model for Tasmania for a number of reasons. We are particularly concerned about aspects of the Victorian VAD Act 2017 which is close to the Oregon model but with even greater restrictions. The Canadian approach provides a much more suitable and effective model for the Australian situation generally, including Tasmania.

IMPORTANT PROVISIONS TO BE RETAINED

- Our proposed 2019 Bill retains some key provisions of the last Bill, the most important of which are:

- ➢ **the eligibility requirements** as in Sections 10 and 11, including age (18 and over), residency, voluntariness and eligible medical condition. The wording of the competence requirement is likely to be changed to 'decision-making ability' in line with a recent review of the Guardianship and Administration Act by the Law Reform Institute of Tasmania.

- ➢ **eligible medical condition** with no requirement to be added for a prognosis of months to live (as in Victoria) or for the person's death to be "reasonably foreseeable" (as recommended in WA). There is considerable evidence of the problems associated with a prognosis of months to live (eg very unreliable, the provision is not effective and a prognosis can be clinically undesirable) or the that the person's death needs to be "reasonably foreseeable" because of the vagueness of the term. It is frequently claimed inaccurately that the Canadian legislation requires that the person's death is "reasonably foreseeable". The requirement is in fact more extensive allowing the person's total medical circumstances to be taken into account. The requirement is also subject to legal challenge because it is more restrictive than what was proposed by the Canadian Supreme Court in its February 2015 judgement that required the Government to introduce legislation for medical assistance in dying.

- ➢ **the 'last resort' requirement as in S22(2) and (3)**, ie at the end of the rigorous process of three requests, and at least two doctors have confirmed the person meets eligibility requirements, the medical practitioner who has accepted the initial request and become the 'primary medical practitioner' must discuss with the person whether there are any relevant treatment options available that may adequately and to the satisfaction of the person improve their medical condition or relieve their suffering, and both must be satisfied there are no other relevant treatment options to do this.

- ➢ **the qualifications of the doctors involved.** In particular, the requirements for participating medical practitioners should not be changed to include the additional qualifications specified in the Victorian legislation. They have not been necessary in every other jurisdiction for safe and effective legislation and they are unnecessary and unwarranted barriers to access to assisted dying in Tasmania. Accessing doctors willing to provide VAD is the biggest barrier to access to VAD by people who are otherwise eligible. This problem will be even greater if there are unnecessary restrictions on the doctors who can be involved.

- ➢ **roles, responsibilities and procedures for the registered medical practitioners involved**, including the particular role and responsibilities of the 'primary medical practitioner', that at least two registered medical practitioners independent of each other must confirm eligibility criteria are met and the provision for other referrals, if necessary, to provide additional information for the doctors deciding eligibility or to provide assistance to the person making the request for VAD.

- ➢ **the procedures requiring three self-initiated requests**, including one written request witnessed by 2 people, one of whom must be independent of the person, and the advice of the person on when they want the assistance to die.

- ➢ **voluntary assisted dying may be provided through doctor-administration or self-administration of the drugs** unless alternative effective options can be determined for doctor-administration, support of the people self-administering and arrangements for the safe handling of drugs. (See potential amendments below). There is evidence of major problems and challenges associated with self-administration of drugs through oral ingestion. See, in particular, relevant Canadian reports, The Oral MAiD Option in Canada, Part 1,: Medication Protocols, and Part 2: Processes for Providing (available at https://camapcanada.ca/resources/) . We will be monitoring the Victorian law to determine if there is evidence that the costly and cumbersome process for the preparation and delivery of the drugs for self-administration from the Alfred Hospital in Melbourne is working effectively, and the drugs available for self-administration are acceptable for the people concerned and are not an unnecessary barrier to voluntary assisted dying. (See also potential amendments below).
- ➢ **independent oversight, monitoring, reporting and other powers and responsibilities of the Registrar**. This is a system of oversight which is suitable for the Tasmanian situation for consistency and for the protection of the privacy of people and their doctors, given the relatively small numbers of people who are likely to access VAD and the social and professional linkages in a small community.

AMENDMENTS

- We are arguing that amendments that are proposed to the Bill before and during debate in the Parliament must take into account the impact on the people wanting VAD and the doctors providing it, the effectiveness of the Bill and be consistent with reliable evidence and reasonable assumptions about risks. It is important to avoid unnecessary barriers or burdensome requirements for the seriously ill people with great suffering who want voluntary assisted dying or for their doctors. They limit the effectiveness of the law when there is no evidence or reasonable arguments that they are necessary to prevent specific risks.
- We are proposing some amendments to the Bill and raise other potential amendments for consideration in the consultation on the Bill:
  - ➢ to address concerns raised at the time of the last Bill
  - ➢ to provide additional details, updating and greater clarity of some provisions to improve the understanding and safe and effective implementation of the Bill, and
  - ➢ to improve the effectiveness of the Bill by learning from other jurisdictions about known problems found in the implementation of other legislation so that people otherwise eligible are not unfairly prevented from accessing the legal option they want for the end of their lives.
- We will provide to the Queensland inquiry details of likely amendments to 2016 Bill and the final 2019 Bill after our broad consultation.

4. END OF LIFE PLANNING

- Good and timely end of life planning can save an enormous amount of confusion, pain and cost for the person concerned and for members of their family when there is an accident or serious illness. Yet we know that people are often understandably reluctant to think through and formally set down their wishes about their treatment in case they are unable to say what they want at the time. Similarly, the Will can often 'be left till later', as can learning what needs to be done on the death of a family member. People also often find it difficult to find the advice that they need when they decide to set down their wishes properly. Formal choice of the right person to speak for you if you cannot speak for yourself can also be critically important but difficult.
- We are very strongly of the view that it is particularly important to make it easy for everyone to complete these steps and to review them at intervals. But, in our complex society, ensuring that your carer/successor can find and deal with your affairs as you wish requires preparation of a number of legal documents in advance. To add to the complexity, some of the documents differ from State to State.
- Some years ago, DwDTas looked in-depth at the issue of end of life planning in the State. We found that:
    - while much of the information needed for planning was available on search, the various elements were in different places, not always easy to find and set out in purely formal terms
    - there was no systematic coverage of the personal and family issues or advice on alternative choices
    - there was nothing that brought together all these issues in a way that provided comprehensive help to anyone wishing to work out and set down their plans; and
    - public understanding was poor and in consequence was often neglected, left too late or undertaken with insufficient care.
- We therefore:
    - developed and tested a comprehensive manual that seeks to cover ALL personal, family and formal aspects of EoLP from the individual's viewpoint (can be downloaded free at http://dwdtas.org.au/guide-to-end-of-life-planning/)
    - prepared and ran free workshops over a number of years across Tasmania and provided personal advice and support on request (which has included advice that the person should seek professional help on particular issues).
- These have been very valuable in encouraging and assisting with good and timely EoLP While the Manual is written round Tasmanian law, virtually all of it would apply across Australia, but sometimes with different forms to be completed. The contents of the manual include Document storage and accessibility, The Will and treatment of Superannuation Funds, To Notify on my Death, Expressing your wishes about financial matters, Expressing your wishes about health and lifestyle issues (Enduring Guardianship, Advance Care Directive and Medical Goals of Care (MGOC), Organ Donor, Funeral arrangements and Useful websites. We believe that a similar full and impartial scope of advice and associated workshops and assistance in planning should be offered throughout Australia, preferably by a government funded organisation or organisations established for the purpose.

5. CONCLUSION

We would be happy to provide additional information as requested or to provide oral evidence in a hearing.

Attachments to this submission include:

- A copy of the Tasmanian Voluntary Assisted Dying Bill 2016 that forms the basis of our proposed 2019 Bill.
- DwDTas paper, Comparison of Voluntary Assisted Dying Safeguards – March 2018.

This version is the original Voluntary Assisted Dying Bill 2016 as debated on 24 May 2017 with amendments to correct minor numbering and wording problems as identified in the Parliament by Lara Giddings in her speech and the part of her speech delivered by Scott Bacon

TASMANIA

VOLUNTARY ASSISTED DYING BILL ~~2016~~

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VOLUNTARY ASSISTED DYING BILL 2016

(Brought in by Larissa Tahireh Giddings and Cassandra Stanwell O'Connor)

A BILL FOR

An Act to provide for medical assistance in specific and restricted circumstances to enable the voluntary death of competent adults with intolerable and unrelievable suffering due to advanced incurable and irreversible medical conditions, to provide for appropriate safeguards, monitoring and reporting, and for related purposes

Be it enacted by Her Excellency the Governor of Tasmania, by and with the advice and consent of the Legislative Council and House of Assembly, in Parliament assembled, as follows:

PART 1 – PRELIMINARY

1. Short title

This Act may be cited as the *Voluntary Assisted Dying Act 2016*.

2. Commencement

This Act commences on a day to be proclaimed.

3. Interpretation

(1) In this Act, unless the contrary intention appears –

adult means a person who has attained the age of 18 years;

assisted death means the death of an eligible person that, either directly or indirectly, is the result of the administration of prescribed medication, to the eligible person, in accordance with this Act;

assisted dying prescription means a prescription for medication to end an eligible person's life in accordance with this Act;

assisted dying request means an oral request or a written request;

competent, in relation to a person, means the person –

(a) has the ability to make and communicate, to health service providers, informed decisions in relation to the person's medical treatment, including communicating through persons familiar with the person's manner of communicating; and

(b) is not suffering from a psychiatric or psychological disorder, or depression, to a degree that may cause the judgement of the person to be impaired;

counselling means a consultation between a psychiatrist, or psychologist, and a person to determine, in the opinion of that psychiatrist or psychologist, whether or not the person –

(a) is competent to make an assisted dying request; and

(b) is making that request voluntarily;

diagnosed means diagnosed by a medical practitioner;

eligible medical condition means a medical condition that meets the requirements of section 11(1);

eligible person – see section 9;

eligible request – see section 10;

health service provider means –

(a) a person who provides a health service; or

(b) a person who holds themselves out as being able to provide a health service;

informed decision – see section 12;

initial oral request means a request under section 13;

oral request means an initial oral request or subsequent oral request;

medical practitioner means a person who holds general registration under the *Health Practitioner Regulation National Law (Tasmania) 2010* in the medical profession;

pharmacist means a person who holds general registration under the *Health Practitioner Regulation National Law (Tasmania 2010)* in the pharmacy profession;

prescribed medication, in relation to an eligible person, means medication that is prescribed to the eligible person under an assisted dying prescription;

primary medical practitioner, in relation to a person, means a medical practitioner who accepts primary responsibility for an assisted dying request made under this Act;

psychiatrist has the same meaning as in the *Mental Health Act 2013*;

psychologist means a person who holds general registration under the *Health Practitioner Regulation National Law (Tasmania) 2010* in the psychology profession;

Registrar means the Registrar appointed under section 32(1);

regulations means regulations made under this Act;

secondary medical practitioner, in relation to a person, means a medical practitioner who has accepted a referral in respect of the person from the person's primary medical practitioner;

subsequent oral request means a request under section 21(1);

written request means a request that is made under section 17(1) in a form approved by the Minister.

(2) If a person makes an oral request under this Act, the wording of the oral request is taken to comply with this Act if the wording of the oral request implies the relevant intention or if such an intention may be inferred from the oral request.

4. Application of Act

(1) Nothing in this Act authorises a medical practitioner, or any other person, to end the life of a person by any means, except in accordance with this Act.

(2) Any action taken in accordance with this Act does not, for any purpose, constitute a crime under the *Criminal Code Act 1924*.

(3) Nothing in this Act authorises any person to provide, under this Act, a lower standard of care for a person than would otherwise be provided to that person.

5. Act does not derogate from certain Acts

This Act is in addition to, and does not derogate from, the *Poisons Act 1971* or any other Act, or any provision of another Act, that is prescribed for the purposes of this section.

6. Act binds Crown

This Act binds the Crown in right of Tasmania and, so far as the legislative power of Parliament permits, in all its other capacities.

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7. Functions and powers of Minister

(1) The Minister has power to do all things necessary or convenient to be done in connection with, or incidental to or related to, the performance or exercise of the Minister's functions or powers under this Act.

(2) The Minister may delegate any of his or her functions or powers under this Act, other than this power of delegation.

PART 2 – ELIGIBLE REQUESTS FOR ASSISTED DEATH

Division 1 – Preliminary

8. Circumstances in which assistance may be provided under this Act

A person's primary medical practitioner may only assist in the death of a person, in accordance with this Act, if the person's primary medical practitioner is satisfied that the person is an eligible person.

9. Eligible person

For the purposes of this Act, a person is an eligible person if the person's primary medical practitioner is satisfied that –

(a) the person has made an initial oral request, a written request and a subsequent oral request; and

(b) each assisted dying request made by the person is an eligible request; and

(c) the person has made an informed decision to end their life.

10. Eligible request

(1) For the purposes of this Act, an assisted dying request is an eligible request if the person making the assisted dying request –

(a) is an adult; and

(b) is a Tasmanian resident; and

(c) is competent; and

(d) is making the request voluntarily; and

(e) is diagnosed with an eligible medical condition; and

(f) complies with the relevant provisions of this Act.

(2) For the purposes of subsection (1)(b), evidence of a person's Tasmanian residency may include, but is not limited to, evidence that the person currently –

(a) holds a drivers licence issued under the *Vehicle and Traffic Act 1999*; or

(b) is enrolled to vote in Tasmania.

11. Eligible medical condition

(1) For the purposes of this Act, an eligible medical condition –

(a) is the advanced stages of a serious incurable and irreversible medical condition, whether caused by illness, disease or injury, as diagnosed by a medical practitioner who has specialised qualifications, or experience, in diagnosing and treating the medical condition; and

(b) the person's medical condition, or associated medical treatment, or complications resulting from the medical condition or treatment –

(i) is causing persistent suffering for the person that is intolerable for the person; and

(ii) there is no reasonably available medical treatment or palliative care options that would, having regard to both the treatment and any consequences of the treatment, relieve the person's suffering in a manner that is acceptable to the person; and

(c) there is no reasonable prospect of a permanent improvement in the person's medical condition.

12. Informed decision

(1) For the purposes of this Act, an informed decision is a decision made by a person at any time after the person has received the information specified in subsection (2) from the person's primary medical practitioner.

(2) The following information is specified for the purposes of subsection (1):

(a) the medical diagnosis of, and medical prognosis for, the person;

(b) the processes and procedures for making assisted dying requests including, but not limited to, the information specified in subsection (3);

(c) the various methods of administration of medication that is likely to be prescribed to the person under an assisted dying prescription;

(d) the potential risks that are associated with the administration of medication that is likely to be prescribed to the person under an assisted dying prescription;

(e) the probable result of the administration of medication that is likely to be prescribed to the person under an assisted dying prescription;

(f) all other reasonable treatment options available to the person including, but not limited to, palliative care;

(g) any other medical or treatment information that is considered, by the person's primary medical practitioner, to be relevant.

(3) Information to be provided under subsection (2)(b) is to include –

(a) that a person must make an initial oral request, a written request and a subsequent oral request to be an eligible person for the purposes of this Act; and

(b) the waiting periods that apply, or may apply, as part of the processes and procedures under this Act; and

(c) that the primary medical practitioner is required to be on the same premises (but not necessarily within sight of the person) if the person intends to self- administer the medication that is likely to be prescribed to the person under an assisted dying prescription; and

(d) the possible complications that may occur after the medication, that is likely to be prescribed to the person under an assisted dying prescription, is administered to the person; and

(e) any steps the primary medical practitioner may take, if such a complication occurs.

(4) For the purposes of subsection (1), a person is taken to have received the information specified in subsection (2) if –

(a) the information was provided to the person in language and terms understandable to the person; and

(b) the primary medical practitioner is satisfied that the person understands the information and is competent to use it to make a decision whether or not to proceed with a request for an assisted death; and

(c) after the information was so provided, the person was satisfied with any answers given by the person's primary medical practitioner to any questions the person had in respect of the information.

Division 2 – Process for assisted dying requests

13. Initial oral request for assisted death

If a person wishes to access an assisted death, he or she may make, to his or her primary medical practitioner, an oral request for an assisted death.

14. Responsibilities of primary medical practitioner after initial oral request

(1) On receipt of an initial oral request from a person, the person's primary medical practitioner must –

(a) discuss with the person his or her reasons for requesting an assisted death; and

(b) examine the person and review the person's relevant medical records; and

(c) provide the person, in accordance with section 12, with the information specified in that section to ensure that the person can make an informed decision to end their life.

(2) If the primary medical practitioner reasonably suspects that the person is not competent to make the initial oral request, or is not voluntarily making the initial oral request, he or she must refer the person for counselling and discuss with the person the reasons for the referral.

(3) If the primary medical practitioner is satisfied, or becomes satisfied after counselling, that the person's initial oral request is an eligible request, they must -

(a) inform the person that he or she may make a written request, subject to requirement of section 17 (2);

(b) inform the person that he or she may rescind any assisted dying request made by the person at any time and in any manner the person thinks appropriate; and

(c) recommend to the person that the person notify family and friends significant to the person of the person's request for an assisted death.

(4) If the primary medical practitioner is not satisfied that the initial oral request is an eligible request, he or she must inform the person that the person's initial oral request is not an eligible request and the reasons why the initial oral request is not an eligible request.

15. Responsibilities of person performing counselling

(1) If a person has been referred for counselling under section 14(2), the person who performs the counselling must state, in a written report to the person's primary medical practitioner –

(a) that the person performing the counselling has counselled the person; and

(b) in the opinion of the person who performs the counselling –

(i) whether or not the person being counselled is competent to make the initial oral request; and

(ii) whether or not the person being counselled has voluntarily made the initial oral request.

(2) A written report under subsection (1) –

(a) is to be in a form approved by the Minister; and

(b) may contain any other information that the person who performed the counselling considers relevant; and

(c) is to be provided as soon as is reasonably practicable after the counselling of the person.

(3) Nothing in this section prevents a person's primary medical practitioner from referring the person to a psychiatrist, or psychologist or any other person, at any time, or for any reason, the primary medical practitioner thinks appropriate.

16. Receipt of written report from person performing counselling

(1) If a person's primary medical practitioner receives a written report under section 15(1), in respect of the person, that states that in the opinion of the person who has performed the counselling –

(a) the person is competent to make an assisted dying request; and

(b) the person has voluntarily made the initial oral request –

the primary medical practitioner must accept the report as confirmation that the requirements of sections 10(1)(c) and 10(1)(d) have been met.

(2) If a person's primary medical practitioner receives a

written report under section 15(1), in respect of the person, that states that in the counsellor's opinion –

(a) the person is not competent to make an assisted dying request; or

(b) the person has not voluntarily made the initial oral request –

the primary medical practitioner must inform the person of the counsellor's opinion, that the person's initial oral request is not an eligible request and the reasons why the initial oral request is not an eligible request.

17. Written request for assisted death

(1) Subject to subsection (2), a person who has made an eligible initial oral request may make, to his or her primary medical practitioner, a request in writing for an assisted death.

(2) A written request under subsection (1) must not be made by a person until at least 48 hours after the person made the initial oral request.

(3) A written request by a person must be –

(a) completed and signed by –

(i) the person; or

(ii) if the person is unable to complete or sign the written request, an adult designated by the person to complete or sign on his or her behalf, in the person's presence and under the person's express direction; and

(b) witnessed by at least two adults, in the presence of the person, who have observed the written request being completed and signed in accordance with paragraph (a).

(4) A person making a written request must not designate, under subsection (3)(a)(ii), any of the following persons to complete or sign, or complete and sign, the request on his or her behalf:

(a) the person's primary medical practitioner;

(b) a person who has provided counselling under this Act to the person making the written request;

(c) a witness to the written request.

(5) One of the witnesses to a written request by a person must not be any one of the following:

(a) a person related by blood, marriage or adoption to the person making the request;

(b) a person in a caring relationship, or family relationship or significant relationship, within the meaning of the *Relationships Act 2003* with the person making the written request;

(c) a person who, at the time of witnessing the written request, would make a financial gain or benefit, either directly or indirectly, as a result of the death of the person making the written request;

(d) a person who is the owner, operator or employee of a health service provider from whom the person making the written request is receiving medical treatment, or is a patient at a facility operated by the health service provider.

(6) The following persons must not be a witness to a written request by a person:

(a) the person's primary medical practitioner;

(b) if the person is referred for counselling under this Act, any person who performed the counselling;

(c) another person who completes or signs the written request for or on behalf of the person making the written request.

18. Responsibilities of primary medical practitioner after written request

(1) After receiving a written request from a person, the person's primary medical practitioner must confirm whether or not in his or her opinion the written request is an eligible request.

(2) If the primary medical practitioner is not satisfied that the person's written request is an eligible request, he or she must inform the person and discuss with the person the reasons why he or she is of the opinion that the request is not an eligible request and any action that may be taken to enable the request to become an eligible request.

(3) If a person's primary medical practitioner is satisfied that the person has made an eligible request, the primary medical practitioner must –

(a) refer the person to a secondary medical practitioner for confirmation of the primary practitioner's opinion that the person's written request meets the requirements of section 10(1)(c), 10(1)(d) and 10(1)(e); and

(b) discuss with the person the information provided to the person under section 12(2)(b) and 12(2)(e), including any new relevant information; and

(c) determine, as agreed with the person as a result of that discussion, the steps the primary medical practitioner may take if complications occur after administering the medication that is likely to be prescribed to the person under an assisted dying prescription; and

(d) provide any additional relevant information requested by the person; and

(e) caution the person about the importance of –

  (i) having another person present when the medication, that is likely to be prescribed to the person under an assisted dying prescription, is administered to the person; and

  (ii) not administering that medication in a public place; and

(f) recommend to the person that he or she notify family and friends significant to the person of the person's intention to request an assisted death.

19. Responsibilities of secondary medical practitioner

(1) A medical practitioner may only accept a referral under section 18(3)(a) if he or she is independent of the primary medical practitioner.

(2) For the purposes of this Act, a medical practitioner is independent if, in relation to the primary medical practitioner, he or she:

(a) is not an employer or employee;

(b) is not responsible for supervising or is being supervised;

(c) does not know or believe there is any other connection that would affect his or her objectivity.

(3) After a secondary medical practitioner accepts a referral under section 18(3)(a), the secondary medical practitioner must –

(a) examine the person referred under section 18(3)(a) and the person's relevant medical records; and

(b) assess the person so referred and determine, in his or her own medical opinion, whether the written request of the person so referred meets the requirements of section 10(c), (d) and (e).

(4) After examining a person referred under section 18(3)(a), the secondary medical practitioner must, in a written report to the person's primary medical practitioner –

(a) confirm that the secondary medical practitioner

–

(i) has examined the person and the person's relevant medical records under subsection (3)(a); and

(ii) has assessed the person under subsection (3)(b); and

(b) state the determinations made by the secondary medical practitioner as a result of such an assessment.

(5) A written report under subsection (4) -

(a) is to be in a form approved by the Minister; and

(b) may contain any other information that the secondary medical practitioner considers relevant; and

(c) is to be made as soon as is reasonably practicable after the examination of the person referred.

20. Receipt of written notice from secondary medical practitioner

(1) If a person's primary medical practitioner receives a written report under section 19(4) that does not confirm, the primary medical practitioner's opinion that the person's written request meets the requirements of section 10(1)(c), (d) and (e), the primary medical practitioner may refer the person to another secondary medical practitioner.

(2) If the person's primary medical practitioner receives a written report under section 19(4) from the other secondary medical practitioner referred to in subsection (1) that does not confirm, to the satisfaction of the primary medical practitioner, the primary medical practitioner's opinion that the person's written request meets the requirements of section 10(1)(c), (d) and (e) –

(a) all existing assisted dying requests of the person are rescinded; and

(b) the person's primary medical practitioner must inform the person that his or her assisted dying requests are rescinded and the reasons for the rescission.

21. Subsequent oral request for assisted death

(1) Subject to subsection (2), a person who has made an eligible written request may make, to his or her primary medical practitioner, another oral request for an assisted death.

(2) A person's subsequent oral request must not be made under subsection (1) until –

(a) the person's primary medical practitioner has received a written report under section 19(4) that confirms the primary practitioner's opinion that the person's written request meets the requirements of section 10(1)(c), (d) and (e); and

(b) at least 7 days after the person made the written request.

22. Responsibilities of primary medical practitioner after subsequent oral request

(1) If a person's primary medical practitioner is satisfied that the person's written request is an eligible request, the person's primary medical practitioner is to –

(a) accept any subsequent oral request made by the person and confirm that the request is an eligible request; and

(b) if it is an eligible request, inform the person that he or she is now an eligible person for the purposes of this Act.

(2) After accepting a subsequent oral request from a person, the eligible person's primary medical practitioner must discuss with the eligible person whether there are any relevant treatment options available that may adequately and to the satisfaction of the eligible person –

(a) improve the eligible person's medical condition; or

(b) relieve the eligible person's suffering.

(3) If the eligible person and the eligible person's primary medical practitioner are satisfied there are no relevant treatment options available as discussed under subsection (2), the primary medical practitioner must inform the eligible person that –

(a) he or she may rescind the subsequent oral request at any time and in any manner the eligible person thinks appropriate, and offer the eligible person an opportunity to rescind any assisted dying request made by the eligible person; and

(b) the primary medical practitioner will only issue an assisted dying prescription in respect of the eligible person when requested to do so by the eligible person; and

(c) the primary medical practitioner will only deliver the assisted dying prescription to a pharmacist for filling when requested to do so by the eligible person.

Division 3 – Discharge of assisted dying requests

23. Issue of assisted dying prescription

(1) An eligible person's primary medical practitioner must not issue an assisted dying prescription in respect of the eligible person unless –

(a) the eligible person has requested that the assisted dying prescription be issued; and

(b) the primary medical practitioner is satisfied that –

(i) each assisted dying request by the eligible person, that has not been rescinded, is an eligible request; and

(ii) the eligible person has made an informed decision to end his or her life; and

(iii) at the time of making the request under paragraph (a), the eligible person was competent to make the request and is making the request voluntarily; and

(c) immediately before issuing the assisted dying prescription, the primary medical practitioner has offered the eligible person a chance to rescind any assisted dying request made by the eligible person.

(2) After issuing an assisted dying prescription in respect of an eligible person, the primary medical practitioner

must –

(a) personally deliver the assisted dying prescription to a pharmacist as discussed and agreed with the eligible person; and

(b) once the assisted dying prescription has been filled, personally collect the prescribed medication from the pharmacist; and

(c) retain possession of the prescribed medication until the prescribed medication is to be administered.

24. Administration of prescribed medication

(1) For the avoidance of doubt, prescribed medication may be administered to an eligible person by –

(a) the eligible person; or

(b) the eligible person's primary medical practitioner.

(2) For the purposes of this Act, administration by the eligible person may include oral ingestion or the activation of a medical device that delivers the medication.

(3) If an eligible person intends to self-administer prescribed medication, the eligible person's primary medical practitioner must –

(a) offer the eligible person a chance to rescind any assisted dying request made by the eligible person before dispensing the prescribed medication to the eligible person for self-administration; and

(b) remain on the same premises as the eligible person (but not necessarily within sight of the eligible person) until, and while, the eligible person self-administers the prescribed medication; and

(c) take any steps, as determined under section 18(3)(c), the primary medical practitioner considers necessary.

(4) If an eligible person's primary medical practitioner intends to administer the eligible person's prescribed medication, the primary medical practitioner must –

(a) offer the eligible person a chance to rescind any assisted dying request made by the eligible person before the primary medical practitioner administers the prescribed medication; and

(b) take any steps, as determined under section 18(3)(c), the primary medical practitioner considers necessary.

(5) Nothing in this Act authorises a person to take or administer prescribed medication in a public place.

25. Return of prescribed medication

(1) If –

(a) a primary medical practitioner has collected an eligible person's prescribed medication from a pharmacist; and

(b) after collecting the prescribed medication, the eligible person rescinds any of his or her assisted dying requests –

the primary medical practitioner must return, as soon as practicable, the prescribed medication to the pharmacist.

(2) If –

(a) a primary medical practitioner has collected an eligible person’s prescribed medication from a pharmacist; and

(b) not all of the prescribed medication is administered to the eligible person –

the primary medical practitioner must return, as soon as practicable, any remaining prescribed medication to the pharmacist.

Penalty: Fine not exceeding 50 penalty units.

Division 4 – Miscellaneous

26. Primary medical practitioner not to refuse assisted dying request in certain circumstances

For the avoidance of doubt, a person's primary medical practitioner is not to refuse a request made by the person under this Act solely on the basis that the person declines, or is unable, to contact any family or friends significant to the person.

27. Rescission of assisted dying request

(1) A person may rescind, at any time and in any manner the person thinks appropriate, any assisted dying request made by the person regardless of the mental state of the person at the time of the rescission.

(2) If a person rescinds an assisted dying request, all assisted dying requests made by that person that exist at the time of that rescission are rescinded.

(3) For the avoidance of doubt, nothing in this Act prevents a person from making an initial oral request after any previous assisted dying request by the person has been rescinded in accordance with this Act.

28. Record requirements

(1) A person's primary medical practitioner is to record, or file, the following information or documents on the person's medical records:

(a) the primary medical practitioner's medical diagnosis of, and medical prognosis for, the person;

(b) each assisted dying request made by the person;

(c) each determination by the primary medical practitioner as to whether or not the person –

  (i) is competent; or

  (ii) is making an informed decision to end his or her life; or

  (iii) is voluntarily making an assisted dying request;

(d) each written report provided to the primary medical practitioner under section 15;

(e) each written report provided to the primary medical practitioner under section 19(4);

(f) each time the primary medical practitioner –

  (i) informed the person that he or she may rescind an assisted dying request made by the person; and

  (ii) offered the person an opportunity to rescind an assisted dying request made by the person;

(g) the steps intended to be taken to fulfil the assisted dying request of the person, including a notation of the prescribed medication;

(h) after the prescribed medication has been administered to the person, the steps taken to fulfil the assisted dying request of the person, including any steps taken by the primary medical practitioner, or that the primary medical practitioner is aware were taken, in respect of any complications that occurred after the administration of the prescribed medication;

(i) a note by the primary medical practitioner that he or she has complied with all relevant requirements of this Act;

(j) any other document or information as prescribed.

(2) A person's primary medical practitioner must send, to the Registrar, a copy of the records required to be kept in respect of the person under subsection (1) as soon as practicable after the record is made, or filed, under that subsection.

Penalty: Fine not exceeding 50 penalty units.

(3) No later than 14 days after the death of an eligible person in accordance with this Act, the eligible person's primary medical practitioner must –

(a) ensure that a copy of each record required to be kept in respect of that eligible person under subsection (1) has been sent to the Registrar in accordance with subsection (2); and

(b) send to the Registrar a copy of the notification given under section 35 of the *Births, Deaths and Marriages Registration Act 1999* in respect of the eligible person; and

(c) send to the Registrar a copy of any other information that the primary medical practitioner considers relevant.

Penalty: Fine not exceeding 50 penalty units.

(4) A pharmacist who dispenses prescribed medication under the authority of this Act must file a copy of any record made under the *Poisons Act 1971* in respect of that medication with the Registrar no later than 14 days after making the record.

Penalty: Fine not exceeding 50 penalty units.

PART 3 – IMMUNITIES AND LIABILITIES

29. Effect of Act on wills, contracts and statutes

(1) Any provision of a will, contract or other agreement, whether written or oral or made before or after the commencement of this section, is invalid to the extent that the provision attempts to affect whether or not a person may make or rescind an assisted dying request under this Act.

(2) No obligation owing under a contract, whether written or oral or made before or after the commencement of this section, is to be conditioned, or affected, by the making of or rescinding of an assisted dying request under this Act.

30. Insurance or annuity policy

(1) The sale, procurement or issuing of any life, health or accident insurance, or annuity, policy or the rate charged for any policy is not to be conditional on, or affected by, the making or rescinding of, or the failure to make or rescind, an assisted dying request by a person.

(2) The act of a person self-administering prescribed medication to end his or her life in accordance with this Act is not to affect any life, health or accident insurance, or annuity or policy that may be held in respect of the person.

(3) The act of a person to end the life of another

person in accordance with this Act is not to affect any life, health or accident insurance, or annuity or policy that may be held in respect of that other person.

31. Immunities

(1) In this section –

participate in activities means to perform functions and duties under this Act, other than –

(a) making an initial medical diagnosis of, and medical prognosis for, a person; or

(b) providing information about this Act to a person on the request of that person; or

(c) providing a person with a referral to another medical practitioner; or

(d) a person contracting with the person's primary medical practitioner, or a secondary medical practitioner of the person, to act outside the course and scope of the medical practitioner's capacity as an employee or independent contractor of another health service provider.

(2) Except as provided under sections 37, 38 and 39 –

(a) no person is subject to civil or criminal liability, or professional disciplinary action, for anything done in good faith and without negligence in compliance with this Act, including:

(i) assisting with the preparation of medication or medical devices for the self-administration; or

(ii) administration by the primary medical practitioner of medication under this Act; or

(iii) being present when an eligible person self-administers medication or is administered medication by the primary medical practitioner under this Act.

(b) no professional organisation or association, or health service provider, may subject a person to censure, discipline, suspension, loss of licence, loss of privileges, loss of membership or other penalty for participating in activities, or refusing to participate in activities, under this Act; and

(c) no assisted dying request by a person for, or the provision by a primary medical practitioner of, medication under this Act –

(i) constitutes neglect for any purposes; or

(ii) provides the sole basis for the appointment of a guardian; and

(d) no health service provider is under any duty, whether by contract, statute or any other legal basis, to participate in activities, or to assist in the participation of activities, under this Act.

(3) Despite subsection (2)(d), if –

(a) a health service provider is unable, or unwilling, to participate in activities under this Act; and

(b) as a result, a person transfers his or her care to another health service provider –

the health service provider unable or unwilling to participate in activities is to transfer, if requested to do so, a copy of the person's relevant medical records to the new health care provider.

(4) Despite any other provisions of this Act –

(a) a health service provider (the ***prohibiting provider***) may prohibit another health service provider from participating in activities under this Act, on the premises of the prohibiting provider, if the prohibiting provider has notified the other health service provider of the prohibiting provider's policy regarding participating in activities under this Act; and

(b) a prohibiting provider may subject the other health service provider to any one or more of the following sanctions if the prohibiting provider has notified the other provider, prior to the other provider's participation in activities under this Act on the premises of the prohibiting provider, that the prohibiting provider prohibits participation in activities under this Act on the premises of the prohibiting provider:

(i) if the other provider is a member of the prohibiting provider's staff, loss of privileges, loss of membership or other sanction in accordance with any by-laws or guidelines of the prohibiting provider;

(ii) termination of lease or other property contract;

(iii) other non-monetary remedies provided by a lease or other property contract, not including –

(A) the loss or restriction of medical staff privileges; or

(B) exclusion of the other provider from any board or group operated by the prohibiting provider;

(iv) termination of contract, or other non-monetary remedies provided by a contract, if the other provider participates in activities under this Act while an employee or independent contractor of the prohibiting provider, unless the other provider is participating in those activities while acting outside the course and scope of his or her capacity as an employee or independent contractor of the prohibiting provider.

(5) A prohibiting provider that imposes sanctions under subsection (4)(b) must, in imposing those sanctions, follow all due process and other procedures the prohibiting provider may have in relation to the imposition of the sanctions.

PART 4 – REGISTRAR

32. Appointment of Registrar and staff

(1) The Minister is to appoint a person as the Registrar for the purposes of this Act.

(2) To assist the Registrar in the performance of his or her functions under this Act, the Minister may appoint such other officers as are necessary.

(3) During any illness or absence of the Registrar, or during any vacancy in the office of the Registrar, the Minister may appoint a person as Acting Registrar to carry out the functions of the Registrar.

(4) Any function performed, or power exercised, by an Acting Registrar has the same force and effect as if it were performed or exercised by the Registrar.

(5) A person appointed under this section –

(a) is appointed subject to and in accordance with the *State Service Act 2000*; and

(b) may hold the office in conjunction with State Service employment.

33. Functions and powers of Registrar

(1) The Registrar may do any one or more of the following:

(a) review a death that occurs as a result of assistance provided under this Act, for the purpose of monitoring compliance with this Act;

(b) investigate, report and make recommendations to the Minister on any matter relating to the operation or administration of this Act;

(c) communicate to appropriate authorities any concerns the Registrar has about compliance or non-compliance with this Act;

(d) distribute information, and provide education, relating to –

  (i) the functions of the Registrar; and

  (ii) the operation of this Act;

(e) perform such other functions, or exercise such other powers, as may be prescribed.

(2) The Registrar has the power to do all things necessary or convenient to be done in connection with, or incidental to or related to, the performance or exercise of his or her functions or powers under this Act.

(3) The Registrar may delegate any of his or her functions or powers under this Act, other than this power of delegation.

34. General record requirements

(1) The Minister is to notify the Registrar of –

(a) any records, or other documents, required to be kept by the Registrar for the purposes of this Act; and

(b) the form and content of such records; and

(c) the manner in which such records, or other documents, are to be kept.

(2) The Registrar is to keep records and documents, for the purposes of this Act, in accordance with the requirements of the Minister under subsection (1).

(3) Unless otherwise notified by the Minister, the Registrar may keep any records, or documents, electronically.

35. Annual report

(1) The Registrar must, on or before 31 October in each year, give the Minister a report detailing the administration and operation of this Act during the financial year ending on the preceding 30 June.

(2) On receiving that report, the Minister is to cause a copy of the report to be tabled in each House of Parliament within 10 sitting-days after the copy of the report is given to the Minister.

PART 5 – MISCELLANEOUS

36. Use of interpreter, third party or other means of communication

(1) A person may not make an assisted dying request under this Act unless –

(a) each of the following persons is fluent in the same language as the person making the assisted dying request:

(i) the person's primary medical practitioner;

(ii) each secondary medical practitioner who examines the person;

(iii) each person who provides counselling to the person under this Act; or

(b) an interpreter is present at each time of communication between –

(i) the person making the assisted dying request; and

(ii) each person referred to in paragraph (a) who is not fluent in the same language as the eligible person.

(2) For the purpose of subsection (1)(b), a person is an interpreter if –

(a) the person is fluent in the same language as –

(i) the person making the assisted dying request; and

(ii) the person referred to in subsection (1)(b)(ii); and

(b) each person referred to in paragraph (a), including the proposed interpreter, agrees to that person acting as an interpreter.

(3) If a person is unable to speak adequately to communicate orally, as required under this Act, the person is taken to have communicated orally for the purposes of this Act if the person communicates –

(a) in writing; or

(b) through another means that enables the person to be understood aurally; or

(c) through another person familiar with the person's manner of communication.

37. Offences relating to written requests

(1) A person making a written request must not ask another person to complete or sign the written request on his or her behalf if, at the time of asking, the person making the request knew, or reasonably ought to have known, that the other person was not permitted under section 17(4) to complete or sign the written request.

Penalty: Fine not exceeding 200 penalty units.

(2) A person must not complete or sign, or complete and sign, a written request on behalf of another person if, at the time the person completes or signs, or completes and signs, the written request, he or she knew, or reasonably ought to have known, that he or she was not permitted under section 17(4) to complete or sign, or complete and sign, the written request.

Penalty: Fine not exceeding 200 penalty units.

(3) A person making a written request must not ask another person to witness that written request if, at the time of asking, the person making the written request knew, or reasonably ought to have known, that the other person was not permitted under section 17(5) or (6) to witness the written request.

Penalty: Fine not exceeding 200 penalty units.

(4) A person must not witness a written request if, at the time of witnessing the request, the person knew, or reasonably ought to have known, that he or she was not permitted under section 17(5) or (6) to witness the request.

Penalty: Fine not exceeding 200 penalty units.

38. Offences relating to documents generally

(1) In this section –

assisted dying document means a document made, recorded or filed for the purposes of this Act;

modify, in relation to a document, includes to alter, forge, conceal or destroy the document.

(2) A person must not modify, rescind or reinstate an assisted dying document with the intention, or effect, of causing life-sustaining procedures or artificially administered nutrition to be –

(a) withheld or withdrawn from another person, resulting in the hastened death of that person; or

(b) maintained or continued in respect of another person, resulting in the prolonged life of that person.

Penalty: Fine not exceeding 200 penalty units or imprisonment for a term not exceeding 5 years, or both.

(3) A person must not modify, rescind or reinstate an assisted dying document for the purpose of causing another person's death.

Penalty: Fine not exceeding 200 penalty units or imprisonment for a term not exceeding 5 years, or both.

(4) A person must not modify, rescind or reinstate an assisted dying document for any purpose that is not otherwise specified in this section.

Penalty: Fine not exceeding 200 penalty units or imprisonment for a term not exceeding 5 years, or both.

(5) A person is not guilty of an offence under this section if that person has been lawfully authorised to modify, rescind or reinstate the document.

39. Offence to coerce or exert undue influence

(1) A person must not coerce or exert undue influence on another person to make an assisted dying request.

Penalty: Fine not exceeding 200 penalty units or imprisonment for a term not exceeding 5 years, or both.

(2) A person must not coerce or exert undue influence on another person to destroy or rescind an assisted dying request.

Penalty: Fine not exceeding 200 penalty units or imprisonment for a term not exceeding 5 years, or both.

(3) A person must not coerce or exert undue influence on a medical practitioner to –

(a) perform any function, or exercise any power, under this Act in respect of an assisted dying request; or

(b) refuse to perform any function, or exercise any power, under this Act in respect of an assisted dying request.

Penalty: Fine not exceeding 200 penalty units or imprisonment for a term not exceeding 5 years, or both.

(4) For the avoidance of doubt, subsection (1) does not apply to a medical practitioner in so far as the medical practitioner is complying with appropriate medical standards and any guidelines that apply in the circumstances.

40. Offences generally

(1) Nothing in this Act limits liability for civil damages resulting from negligent conduct or intentional misconduct by any person.

(2) The penalties in this Act do not preclude criminal penalties applicable under another Act for conduct which is inconsistent with the provisions of this Act.

41. Death certificates

(1) Nothing in this Act prevents an eligible person's primary medical practitioner from signing the certificate given to the Registrar under section 35(3) of the *Births, Deaths and Marriages Registration Act 1999* in respect of the eligible person.

(2) For the purposes of section 35(1) of the *Births, Deaths and Marriages Registration Act 1999*, the cause of death of an eligible person who dies as a result of assistance provided in accordance with this Act is taken to include –

(a) the eligible medical condition of the eligible person; and

(b) that assistance has been provided under this Act resulting in the death of the eligible person.

42. General information requirements

(1) The Minister may make guidelines to facilitate the collection or provision of information relating to compliance with this Act.

(2) Any information collected or provided in accordance with subsection (1) must not be made available for inspection by the public, unless otherwise authorised under this Act or any other Act.

(3) A person who collects, or provides, information under this Act does not contravene the *Personal Information Protection Act 2004* in respect of that information if the information is collected or provided in accordance with this Act or any guidelines issued under this Act.

43. Regulations

(1) The Governor may make regulations for the purposes of this Act.

(2) The regulations may be made so as to apply differently according to matters, limitations or restrictions, whether as to time, circumstance or otherwise, specified in the regulations.

(3) The regulations may –

(a) provide that a contravention of any of the regulations is an offence; and

(b) in respect of such an offence, provide for the imposition of a fine not exceeding 50 penalty units and, in the case of a continuing offence, a further fine not exceeding 10 penalty units for each day during which the offence continues.

(4) The regulations may authorise any matter to be from time to time determined, applied or regulated by any person or body specified in the regulations.

(5) The regulations may adopt, either wholly or in part and with or without modification, and either specifically or by reference, any standards, rules, codes or specifications, whether the standards, rules, codes or specifications are published or issued before or after the commencement of this Act.

(6) A reference in subsection (5) to standards, rules, codes or specifications includes a reference to an amendment of those standards, rules, codes or specifications, whether the amendment is published or issued before or after the commencement of this Act.

44. Review of Act

(1) The Minister is to cause a review of the operation of this Act to be carried out as soon as

practicable after the fifth anniversary of its commencement.

(2) In causing the review to be undertaken, the Minister is to ensure the public is given a reasonable opportunity to make submissions on the operation of this Act.

(3) The persons who carry out the review are to give the Minister a written report on its outcome.

(4) The Minister is to cause a copy of the report to be tabled in each House of Parliament within 10 sitting-days of that House after it is given to the Minister.

45. Administration of Act

Until provision is made in relation to this Act by order under section 4 of the *Administrative Arrangements Act 1990* –

(a) the administration of this Act is assigned to the Minister for Health; and

(b) the department responsible to that Minister in relation to the administration of this Act is the Department of Health and Human Services.

Dying with Dignity Tasmania (Inc)

COMPARISON OF VOLUNTARY ASSISTED DYING SAFEGUARDS[1] - MARCH 2018

All regulatory frameworks for doctor-provided voluntary assisted dying are working safely, regardless of the differences

As the Victorian inquiry into end of life choices and all other recent thorough reviews have shown, all the regulatory frameworks for doctor-provided voluntary assisted dying are robust, working safely regardless of the differences between them. This is because they all have multiple safeguards but, in particular, are all doctor-safeguarded and have the additional safeguard of regulated oversight with careful monitoring, scrutiny and reporting. As the Victorian inquiry concluded: *The evidence is clear that assisted dying can be provided in a way that guards against abuse and protects the vulnerable in our community in a way that unlawful and unregulated assisted dying does not.*[2]

Importance of establishing a framework that suits the values and circumstances where the law is being introduced

The differences between assisted dying legal approaches reflect the significantly different cultures and history of law reform, and priorities given to particular principles and values, and the medical systems in different societies. The Victorian inquiry makes this critically important point: "[T]*hese jurisdictions* [with legal assisted dying] *highlight the importance of establishing a framework that suits a particular jurisdiction's medical and legal culture and of providing the appropriate safeguards within that framework*" (p205). (See also page 217)

The framework must be workable in the circumstances in which it is being introduced as determined by rational risk assessment. Extra hurdles do not increase the safety - they decrease the effectiveness of the legislation. This is because they create unnecessarily onerous burdens on people who are at the end of their lives with intolerable suffering; create burdensome bureaucracy on doctors which is a disincentive to their participation and has a flow-on effect on people who want and would be eligible for assistance but cannot access it.

This analysis compares key safeguards in the Tasmanian *Voluntary Assisted Dying Bill 2016*[3] with those in overseas legislation and the Victorian *Voluntary Assisted Dying Act 2017*[4] passed on 29 November 2017. The Victorian legislation will not come into operation until mid-2019.

A new Tasmanian Bill, likely to be similar to the last one, will come before the newly elected State Parliament in 2018/9. The current situation, following the State election on 3 March 2018, is that a majority of the House of Assembly supports voluntary assisted dying legislation in principle. Also, the vast majority either voted for the *Voluntary Assisted Dying Bill 2016* or have indicated they are likely to vote for a similar Bill. We believe the support in the Legislative Council is similar.

The Tasmanian 2016 Bill provides a 'last resort' assisted dying option through a regulated doctor-safeguarded framework that includes strong safeguards, is workable and meets a number of aims. The Bill is based on thorough research and analysis of existing legislation and relevant proposals. There has also been thorough reconsideration of the *Voluntary Assisted Dying Bill 2013* in the light of the comments and concerns at the time of the 2013 debate and, since then, the significant reports, Parliamentary debates and policy by medical organisations[5]. A DwDTas summary of the Bill[6] provides a brief overview of the Bill, its aims and background information.[7] Additional comparisons are available, including in the Tasmanian 2013 Proposal[8] and in the report of the Victorian inquiry into end of life choices.

LEGISLATION

Oregon	The Netherlands	Belgium	Quebec, Canada	Canada	Victoria
Death with Dignity Act 1994 Commenced operation 1997	*Termination of Life on Request and Assisted Suicide Act 2002* Commenced operation 2002	*Act on Euthanasia 2002* Commenced operation 2002	*An Act respecting end of life care* (2014) Commenced operation December 2015	*An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)* (2016) Commenced operation June 2016 As provided for in the Act, independent reviews are underway to report by December 2018 to the Government on the possible extension of the legislation to mature minors, advance requests and to requests where mental illness is the sole underlying medical condition. (§241.31 9.1(1)) .	*Voluntary Assisted Dying Act 2017*

AGE

Oregon	The Netherlands	Belgium	Quebec, Canada	Canada	Victoria
The patient must be an adult aged 18 years or older (§2.01(1)).	Under the 2002 Dutch law, a patient aged between sixteen and eighteen years that "may be deemed to have a reasonable understanding of his interests" may request euthanasia or assisted suicide. In these cases the parent and/or guardians must be consulted but do not have a veto on the final decision (§2(3)). Patients aged between twelve and sixteen and "may be deemed to have a reasonable understanding of his interests" may also request euthanasia or assisted suicide, provided the parents and/or guardian give their consent (§2(3)).	Under the 2002 Belgian law, the patient had to have "attained the age of majority or is an emancipated minor" (§3(1)). An amendment to the law was made in February 2014, after very extensive community and Parliamentary debate, to allow that "a child of any age can be helped to die, but only under strict conditions. He or she must be terminally ill, close to death, and deemed to be suffering beyond any medical help. The child must be able to request euthanasia themselves and demonstrate they fully understand their choice. The request will then be assessed by teams of doctors, psychologists and other care-givers before a final decision is made with approval of the parents."[9] It was expected that this provision would be very rarely used and this has turned out to be the case: the first and only death under the provisions occurred in September 2016, of a 17 year old.[10]	26. Only a patient who meets the following criteria may obtain medical aid in dying: (1) be of full age, …	241.2 (1) A person may receive medical assistance in dying only if they meet all of the following criteria: … (b) they are at least 18 years of age … Note that, as provided for in the Canadian Act, a review is under way related to requests by mature minors for medical assistance in dying. (See in 'eligible medical condition')	9(1)(a) the person must be aged 18 years or more

Tasmanian *Voluntary Assisted Dying Bill 2016*

S10(1)(a) requires the person to be "an adult".

ELIGIBLE MEDICAL CONDITION

	Terminal illness[i]	Specified Timeframe	Specified suffering	
Oregon[11]	Yes	Yes	No	The Oregon (and other US) law allows a prescription for lethal drugs to be provided to people who have a terminal illness and who qualify for free federally funded palliative care. This occurs when someone has a prognosis, "within reasonable medical judgement" their death is expected within 6 months.[12] (§1.01(12)).
Netherlands	No	No	Yes	The patient's suffering must be "lasting and unbearable" (§2(1)(b)), and that there be "no other reasonable solution for the situation he was in" (§2(1)(d)). There is no requirement that the patient be diagnosed with a terminal illness.
Belgium	No (except children)	No	Yes	Section 3 states that "the patient is in a medically futile condition of constant and unbearable physical or mental suffering that cannot be alleviated, resulting from a serious and incurable disorder caused by illness or accident." There is no requirement that the cause of the patient's suffering be due to a terminal illness.
Quebec	No	No	Yes	To obtain medical aid in dying the patient must: 3. be at the end of life [undefined] 4. suffer from an incurable serious illness; 5. suffer from an advanced state of irreversible decline in capability; and 6. suffer from constant and unbearable physical or psychological pain which cannot be relieved in a manner the person deems tolerable." (§26)
Canada	No	No	Yes	A person may receive medical assistance in dying if … they have a grievous and irremediable medical condition. (§241.2 (1)(c)) A person has ***a grievous and irremediable medical condition*** only if they meet all of the following criteria: (a) they have a serious and incurable illness, disease or disability; (b) they are in an advanced state of irreversible decline in capability; (c) that illness, disease or disability or that state of decline causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable; and (d) their natural death has become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining. (§241.2 (2)) The Minister of Justice and the Minister of Health must, no later than 180 days after the day on which this Act receives royal assent, initiate one or more independent reviews of issues relating to requests by mature minors for medical assistance in dying, to advance requests and to requests where mental illness is the sole underlying medical condition, and report to Parliament within two years of the start of a review. (§9.1) Canadian Health Dept advice - ("People with a mental illness are eligible for medical assistance in dying as long as they meet all of the listed conditions. However, you are not eligible for this service if: you are suffering only from a mental illness; death is not reasonably foreseeable when considering all the circumstances of your medical condition; or a mental illness reduces your ability to make medical decisions"
Victoria	Yes[13]	Yes[14]	Yes	S9 (1) For a person to be eligible for access to voluntary assisted dying— … (d) the person must be diagnosed with a disease, illness or medical condition that— (i) is incurable; and (ii) is advanced, progressive **and will cause death**; [our emphasis][ii] (iii) is expected to cause death within weeks or months, **not exceeding 6 months** [our emphasis] [iii]; and

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[i] That is, an illness or condition that is likely to result in death. See for example, the definition in the South Australian *Consent to Medical Treatment Act 1995*.

[ii] This differs from the recommendation of the Victorian inquiry into end of life choices that the person must be "suffering from a serious and incurable condition" not the more restrictive requirement that it "will cause" the person's death. See also Endnote 13.

[iii] The inquiry's recommendation was that the person must be "at the end of life (final weeks or months of life)" but did not specify the number of months. (See also Endnote 14)

				(iv) is causing suffering to the person that cannot be relieved in a manner that the person considers tolerable. 9(4) Despite subsection (1)(d)(iii), if the person is diagnosed with a disease, illness or medical condition that is neurodegenerative, that disease, illness or medical condition must be expected to cause death within weeks or months, **not exceeding 12 months** [our emphasis][iv] 9(2) A person is not eligible for access to voluntary assisted dying only because the person is diagnosed with a mental illness, within the meaning of the Mental Health Act 2014. 9(3) A person is not eligible for access to voluntary assisted dying only because the person has a disability, within the meaning of section 3(1) of the Disability Act 2006.

Special notes:

1. ‘Eligible medical condition’ is the requirement that differs most between legislation because it is the section of the law most strongly related to the culture and fundamental principles, values and priorities of the place where the law is being introduced. As the Victorian inquiry report put it, an assisted dying framework must reflect “the values and culture unique to a particular jurisdiction”, including the medical and legal culture.
2. Contrary to the most common misunderstanding about assisted dying legislation:
   - “terminal illness” is not, and has never been, a requirement in European legislation – the key cultural value is compassionate ending of unbearable suffering; and
   - demonstrating suffering is not, and has never been, a requirement in Oregon and other US States – the key cultural value is individual autonomy.

Tasmanian *Voluntary Assisted Dying Bill 2016*

The approach taken in the Tasmanian Bill is supported by many public surveys and the 2016 AMA member survey[15].

Because of the unreliability of prognoses, the Tasmanian Bill does not require them but considers people to be at the end of their lives if they meet the stringent medical requirements and the ‘last resort’ provision, ie they are at the end of lives that will never again be free of intolerable and unrelievable suffering and the devastating effects of the advanced stages of serious, incurable and irreversible medical conditions. The evidence from overseas shows that almost all those who choose and are provided voluntary assisted dying have unbearable suffering due to cancer, neuro-degenerative conditions, chronic heart disease and chronic pulmonary obstructive disease.

S11 - “For the purposes of this Act, an eligible medical condition –
(a) is the advanced stages of a serious incurable and irreversible medical condition, whether caused by illness, disease or injury, **as diagnosed by a medical practitioner who has specialised qualifications, or experience, in diagnosing and treating the medical condition**; and

(b) the person’s medical condition, or associated medical treatment, or complications resulting from the medical condition or treatment –
    (i) is causing persistent suffering for the person that is intolerable for the person; and

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[iv] The Voluntary Assisted Dying Bill originally included 12 months for all conditions.

(ii) there is no reasonably available medical treatment or palliative care options that would, having regard to both the treatment and any consequences of the treatment, relieve the person's suffering in a manner that is acceptable to the person; and

(c) there is no reasonable prospect of a permanent improvement in the person's medical condition."

'Last resort' provision

S22 (2) and (3) provide the 'last resort' requirement. **S22(2)** states that the person's doctor "must discuss with the eligible person whether there are any relevant treatment options available that may adequately and to the satisfaction of the eligible person – (a) improve the eligible person's medical condition; or (b) relieve the eligible person's suffering". **S22(3)** requires the doctor to provide assisted dying only "If the eligible person and the eligible person's primary medical practitioner are satisfied there are no relevant treatment options available as discussed [under S22(2)]".

DOCTOR/NURSE[16] SAFEGUARDS

Oregon	The attending physician is defined as "the physician who has primary responsibility for the care of the patient and treatment of the patient's terminal disease" (§1.01(2)). The attending physician must "refer the patient to a consulting physician for medical confirmation of the diagnosis, and for a determination that the patient is capable and acting voluntarily" (§3.01(d)). The consulting physician must be qualified to make a professional diagnosis and prognosis regarding the patient's disease. Section 3.03 states that "if in the opinion of the attending physician or the consulting physician a patient may be suffering from a psychiatric or psychological disorder or depression causing impaired judgement, either physician shall refer the patient for counselling." The request for assistance can only proceed once the counsellor determines that the patient is not suffering from depression. The patient must be informed about palliative care options in accordance with Section §3.01(c)(E).
The Netherlands	Under Dutch law only physicians can provide assistance with assisted suicide or voluntary euthanasia. The physician does not need to be the patient's primary physician but it is required "that the physician must know the patient sufficiently well to assess whether the due care criteria are met." The patient's physician must consult another "independent physician who has seen the patient and has given his written opinion on the requirements of due care" (§2(1)(e)). As shown by the judgements and professional advice provided by the review committees, consultation requirements are expected to be more stringent if the patient's suffering is the result of a psychiatric disorder.
Belgium	The role of the attending physician is not defined. However, the Act does state that the physician must have "several conversations with the patient spread out over a reasonable period of time" in order "to be certain of the patient's constant physical or mental suffering and of the durable nature of his/her request" (§3(2)(2)). The patient's physician must consult another physician who is required to review the medical record, examine the patient, confirm the patient's constant and unbearable physical and mental suffering that cannot be alleviated (§3.2.3). The consulting physician must be independent of both the patient and the attending physician and be competent to give an opinion about the disorder in question (§3.2). If there is a nursing team that forms part of the patient's regular care, the attending physician must discuss the patient's request with the nursing team (§3.2.4). An additional requirement exists for patients who are "not expected to die in the near future" (§3.3). The physician must refer the person for examination and a report from a second independent physician who is a psychiatrist or a specialist in the person's disorder.
Quebec	The patient's physician must "obtain the opinion of a second physician confirming that the criteria set out in section 26 have been met. The physician consulted must be independent of both the patient requesting medical aid in dying and the physician seeking the second medical opinion. The physician consulted must consult the patient's record, examine the patient and provide the opinion in writing. (§28(3))
Canada	***medical practitioner*** means a person who is entitled to practise medicine under the laws of a province. ***nurse practitioner*** means a registered nurse who, under the laws of a province, is entitled to practise as a nurse practitioner - or under an equivalent designation - and to autonomously make diagnoses, order and interpret diagnostic tests, prescribe substances and treat patients. (§241.2 (3) Before a medical practitioner or nurse practitioner provides a person with medical assistance in dying, the medical practitioner or nurse practitioner must … (e) ensure that another medical practitioner or nurse practitioner has provided a written opinion confirming that the person meets all of the criteria set out in subsection (1); (f) be satisfied that they and the other medical practitioner or nurse practitioner referred to in paragraph (e) are independent. The medical practitioner or nurse practitioner providing medical assistance in dying and the medical practitioner or nurse practitioner who provides the opinion referred to in paragraph (3)(e) are independent if they (a) are not a mentor to the other practitioner or responsible for supervising their work; (b) do not know or believe that they are a beneficiary under the will of the person making the request, or a recipient, in any other way, of a financial or other material benefit resulting from that person's death, other than standard compensation for their services relating to the request; or (c) do not know or believe that they are connected to the other practitioner or to the person making the request in any other way that would affect their objectivity. (§241.2 (6)) Medical assistance in dying must be provided with reasonable knowledge, care and skill and in accordance with any applicable provincial laws, rules or standards. (§241.2 (7))

Victoria	10 (1) Each co-ordinating medical practitioner and consulting medical practitioner must— (a) hold a fellowship with a specialist medical college; or (b) be a vocationally registered general practitioner. (2) Either the co-ordinating medical practitioner or each consulting medical practitioner must have practised as a registered medical practitioner for at least 5 years after completing a fellowship with a specialist medical college or vocational registration (as the case requires). (3) Either the co-ordinating medical practitioner or each consulting medical practitioner must have relevant expertise and experience in the disease, illness or medical condition expected to cause the death of the person being assessed. S7 A registered health practitioner who has a conscientious objection to voluntary assisted dying has the right to refuse to do any of the following— (a) to provide information about voluntary assisted dying; (b) to participate in the request and assessment process; (c) to apply for a voluntary assisted dying permit; (d) to supply, prescribe or administer a voluntary assisted dying substance; (e) to be present at the time of administration of a voluntary assisted dying substance; (f) to dispense a prescription for a voluntary assisted dying substance. In addition, under S17 the co-ordinating medical practitioner must not commence the first assessment (after the person's first request) unless the practitioner has completed approved assessment training. Under S26, the consulting medical practitioner must not commence a consulting assessment unless the practitioner has completed approved assessment training. 18(2) If the co-ordinating medical practitioner is unable to determine whether the person's disease, illness or medical condition meets the requirements of the eligibility criteria, the co-ordinating medical practitioner must refer the person to a specialist registered medical practitioner who has appropriate skills and training in that disease, illness or medical condition.

Tasmanian *Voluntary Assisted Dying Bill 2016*

Safeguard of specialised diagnosis: Before a person commences the process for assisted dying, under **S11, Eligible medical condition**, he/she must have a diagnosis of their medical condition from "a medical practitioner who has specialised qualifications, or experience, in diagnosing and treating the medical condition".

In **S3**:

- **medical practitioner** is defined as "a person who holds general registration under the *Health Practitioner Regulation National Law (Tasmania) 2010* in the medical profession".
- Doctors' participation is entirely voluntary:
  - ➢ **primary medical practitioner** "in relation to a person, means a medical practitioner who accepts primary responsibility for an assisted dying request made under this Act"
  - ➢ **secondary medical practitioner** "in relation to a person, means a medical practitioner who has accepted a referral in respect of the person from the person's primary medical practitioner".

Significant responsibilities of primary medical practitioner:

- There are many sections of the Bill that set out the responsibilities of the primary medical practitioner and the action that must be taken at each stage of the process to ensure that rigorous examination is undertaken of requests and only those persons who meet all the eligibility requirements receive an assisted death, including referrals to other medical professionals. (See in particular **S14** for responsibilities after initial oral request, **S18** after written request, and **S22** after subsequent oral request.)

- The primary medical practitioner cares for and supports persons to the end of the process, including the delivery of the prescribed medication and being available to administer the medication or to support the person who is self-administering and, if there are complications, to assist as agreed (**S18(3)(c)**).
- The primary medical practitioner has the responsibility for the strict requirements for safe handling of medication.

Confirmation by independent second medical practitioner: A person cannot receive an assisted death until a secondary medical practitioner confirms the opinion of the primary medical practitioner on the key criteria of competence, voluntariness and eligible medical condition.

S18(3) [At the time of the written request], "if a person's primary medical practitioner is satisfied that the person has made an eligible request, the primary medical practitioner must –

(a) refer the person to a secondary medical practitioner for confirmation of the primary medical practitioner's opinion that the person's written request meets the requirements of section 10 (c) [competence], (d) [voluntariness] and (e) [eligible medical condition]".

S19 sets out the responsibilities of a secondary medical practitioner who must be **independent** of the primary medical practitioner. ***S19(1)*** *states that "A medical practitioner may only accept a referral [from a primary medical practitioner] if he or she is independent of the primary medical practitioner".* **S19(2)** sets out the requirements for independence. **S20** sets out the responsibilities of the primary medical practitioner on receipt of the written report from the secondary medical practitioner in the event that it supports or does not support the primary medical practitioner's opinion.

Compared to other legislation and proposals, the Tasmanian Bill has much more specific and detailed provisions on the significant record keeping and reporting responsibilities of doctors under the legislation, and associated offences and penalties. These are significant additional safeguards related to the Registrar's official monitoring, scrutiny and Parliamentary reporting. Detailed record requirements for the medical practitioner are set out in **S28** -

(1) A person's primary medical practitioner is to record, or file, the following information or documents on the person's medical records:
(a) the primary medical practitioner's medical diagnosis of, and medical prognosis for, the person;
(b) each assisted dying request made by the person;
(c) each determination by the primary medical practitioner as to whether or not the person –
    (i) is competent; or
    (ii) is making an informed decision to end his or her life; or
    (iii) is voluntarily making an assisted dying request;
(d) each written report provided to the primary medical practitioner under section 15;
(e) each written report provided to the primary medical practitioner under section 19(2);
(f) each time the primary medical practitioner –
    (i) informed the person that he or she may rescind an assisted dying request made by the person; and
    (ii) offered the person an opportunity to rescind an assisted dying request made by the person;
(g) the steps intended to be taken to fulfil the assisted dying request of the person, including a notation of the prescribed medication;

(h) after the prescribed medication has been administered to the person, the steps taken to fulfil the assisted dying request of the person, including any steps taken by the primary medical practitioner, or that the primary medical practitioner is aware were taken, in respect of any complications that occurred after the administration of the prescribed medication;
(i) a note by the primary medical practitioner that he or she has complied with all relevant requirements of this Act;
(j) any other document or information as prescribed.

(2) A person's primary medical practitioner must send, to the Registrar, a copy of the records required to be kept in respect of the person under subsection (1) **as soon as practicable after the record is made, or filed**, under that subsection.
Penalty: Fine not exceeding 50 penalty units.

(3) No later than 14 days after the death of an eligible person in accordance with this Act, the eligible person's primary medical practitioner must –
(a) ensure that a copy of each record required to be kept in respect of that eligible person under subsection (1) has been sent to the Registrar in accordance with subsection (2); and
(b) send to the Registrar a copy of the notification given under section 35 of the Births, Deaths and Marriages Registration Act 1999 in respect of the eligible person; and
(c) send to the Registrar a copy of any other information that the primary medical practitioner considers relevant. Penalty: Fine not exceeding 50 penalty units.

TYPE OF ASSISTANCE

Oregon	The Netherlands	Belgium	Quebec, Canada	Canada	Victoria
Person must self-administer the lethal dose through oral ingestion. Doctor administration of the drugs is not permitted, even when there are complications.[17]	Both self and doctor-administration are legal.[18]	Doctor administration is provided for in the law, defined as "intentionally terminating life by someone other than the person concerned, at the latter's request" (§2). Self-administration has been determined to be legal as well.	Only doctor-administration is allowed. If all conditions are met, "medical aid in dying may be administered to a patient requesting it, the physician must administer such aid personally and take care of the patient until their death." (§29) Self-administration is not allowed under the law.	Both self and doctor-administration are legal. ***medical assistance in dying*** means (a) the administering by a medical practitioner or nurse practitioner of a substance to a person, at their request, that causes their death; or (b) the prescribing or providing by a medical practitioner or nurse practitioner of a substance to a person, at their request, so that they may self-administer the substance and in doing so cause their own death.	Person must self-administer the poison or controlled substance or the drug of dependence to be supplied by the co-ordinating medical practitioner for the purpose of causing the person's death. The exception is administration by the co-ordinating medical practitioner only if he/she "is satisfied that— (a) the person is physically incapable of the self-administration or digestion of an appropriate poison or controlled substance or drug of dependence". The Act contains multiple relevant sections including Division 2, Voluntary Assisted Dying permits.

Tasmanian *Voluntary Assisted Dying Bill 2016*

The Bill provides for both self-administration and doctor-administration of the drugs for assisted dying. **S24** - (1) … "prescribed medication may be administered to an eligible person by –

(a) the eligible person; or
(b) the eligible person's primary medical practitioner.

(2) For the purposes of this Act, administration by the eligible person may include oral ingestion or the activation of a medical device that delivers the medication. (Protection is provided in **S31(2)(a)(i)** for someone "assisting with the preparation of medication or medical devices for the self-administration" which would all happen with the supervision of the primary medical practitioner.)

(3) If an eligible person intends to self-administer prescribed medication, the eligible person's primary medical practitioner must –
(a) offer the eligible person a chance to rescind any assisted dying request made by the eligible person before dispensing the prescribed medication to the eligible person for self-administration; and
(b) remain on the same premises as the eligible person (but not necessarily within sight of the eligible person) until, and while, the eligible person self-administers the prescribed medication; and
(c) take any steps, as determined under section 18(3)(c), the primary medical practitioner considers necessary.

REGULATORY MONITORING, SCRUTINY AND REPORTING

Oregon	Section 3.11 sets out the reporting requirements to be undertaken by the Department of Human Services. Section 3.11 also requires "any health care provider upon dispensing medication … to file a copy of the dispensing record with the department [of Human Services]." The Department of Human Services is required to prepare an annual report on the operation of the Act (§3.11(3)).
The Netherlands	Regional review committees are established under Section 3 of the Act. For the physician to be protected by the legal defence provided by the 2001 Act, he or she must report the case to the municipal pathologist (§20(2)). The municipal pathologist is responsible for forwarding the file to the relevant review committee. The review committees are required to provide an annual report on their activities (§17).[19]
Belgium	The Belgian Act establishes a Federal Control and Evaluation Commission (§6). Section 5 states that "any physician who has performed euthanasia is required to fill in a registration form … and to deliver the document to the Commission within four working days. Section 7 details the information the physician is required to provide about the patient. The Commission is responsible for reviewing all cases of euthanasia to ensure they were undertaken in accordance with the Act (§8). If the Commission believes that the statutory criteria have not been met they will refer the case to the public prosecutor (§8).
Quebec	"All information and documents in connection with a request for medical aid in dying, regardless of whether the physician administers it or not, including the form used to request such aid, the reasons for the physician's decision and, where applicable, the opinion of the physician consulted, must be recorded or filed in the patient's record." (§31) The Act also provides for "a commission on end-of-life care" with the mandate to examine any matter relating to end-of-life care" (§35 - 42). "A physician who administers medical aid in dying must give notice to the Commission within the next 10 days and send the Commission, in the manner determined by government regulation, the information prescribed by regulation." (§41)
Canada	Filing information - medical practitioner or nurse practitioner: 241.31 (1) Unless they are exempted under regulations made under subsection (3), a medical practitioner or nurse practitioner who receives a written request for medical assistance in dying must, in accordance with those regulations, provide the information required by those regulations to the recipient designated in those regulations. Filing information -pharmacist: (2) Unless they are exempted under regulations made under subsection (3), a pharmacist who dispenses a substance in connection with the provision of medical assistance in dying must, in accordance with those regulations, provide the information required by those regulations to the recipient designated in those regulations. (3) The Minister of Health must make regulations that he or she considers necessary (a) respecting the provision and collection, for the purpose of monitoring medical assistance in dying, of information relating to requests for, and the provision of, medical assistance in dying, including (i) the information to be provided, at various stages, by medical practitioners or nurse practitioners and by pharmacists, or by a class of any of them, (ii) the form, manner and time in which the information must be provided, (iii) the designation of a person as the recipient of the information, and (iv) the collection of information from coroners and medical examiners; (b) respecting the use of that information, including its analysis and interpretation, its protection and its publication and other disclosure; (c) respecting the disposal of that information; and (d) exempting, on any terms that may be specified, a class of persons from the requirement set out in subsection (1) or (2).
Victoria	Part 9 provides for an **Assisted Dying Review Board** and sets out in detail the functions and powers, membership and procedure and reports. The Board is to consist of a Chairperson, a Deputy Chairperson (if appointed) and an unspecified number of members appointed by the responsible Minister. There are no specific qualifications for membership except as provided in 95(2): "A person is eligible for appointment as a member of the Board if the Minister is satisfied that the person has the appropriate knowledge and skills to perform all of the duties and functions of a member of the Board". This is different from the recommendation of the Victorian inquiry into end of life choices that members include a doctor, a nurse, a legal professional and a community member. However, S100 states: "(1) Subject to the approval of the Minister, the Board may co-opt any person with special knowledge or skills to assist the Board in a particular matter. (2) A person who has been co-opted to assist the Board is to be considered to be a member of the Board until the period of co-option ends."

	The functions and powers include monitoring, reviewing the exercise of any function or power under this Act, promoting compliance with the requirements of the Act, referring any issue identified by the Board in relation to voluntary assisted dying to relevant persons or bodies, (eg the Chief Commissioner of Police, the State Coroner or the Australian Health Practitioner Regulation Agency) conducting research, consulting, providing information, etc. For the first 2 years 6 monthly reports must be provided to parliament and thereafter annual. There are numerous requirements for the medical practitioners involved to provide reports or copies of forms to the Board, including: • 21(2) Within 7 days after completing the first assessment, the co-ordinating medical practitioner must complete the first assessment report form and give a copy of that form to the Board. • 30(1) The consulting medical practitioner must— … (b) complete the consulting assessment report form and give a copy of it to— (i) the Board; and (ii) the co-ordinating medical practitioner for the person. (2) The consulting medical practitioner must give the copy of the consulting assessment report form to the Board within 7 days after completing the consulting assessment.

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As well as being a doctor-safeguarded system, like other legal assisted dying, the Tasmanian Bill provides for the additional safeguard of a rigorous monitoring, scrutiny and reporting arrangement. The Tasmanian approach is for this to be done most effectively and safely through a Registrar with statutory powers.

Part 4 provides for the appointment of a Registrar with the following functions under **S33 (1)** -

(a) review a death that occurs as a result of assistance provided under this Act, for the purpose of monitoring compliance with this Act;
(b) investigate, report and make recommendations to the Minister on any matter relating to the operation or administration of this Act;
(c) communicate to appropriate authorities any concerns the Registrar has about compliance or non-compliance with this Act;
(d) distribute information, and provide education, relating to – (i) the functions of the Registrar; and (ii) the operation of this Act;
(e) perform such other functions, or exercise such other powers, as may be prescribed.

General record requirements of the Registrar are covered in **S34** and an Annual Report to Parliament is required in **S35**.

S28 sets out the requirements for medical practitioners to record, file and submit reports including:

(2) A person's primary medical practitioner must send, to the Registrar, a copy of the records required to be kept in respect of the person under subsection (1) as soon as practicable after the record is made, or filed, under that subsection. Penalty: Fine not exceeding 50 penalty units.
(3) No later than 14 days after the death of an eligible person in accordance with this Act, the eligible person's primary medical practitioner must –
(a) ensure that a copy of each record required to be kept in respect of that eligible person under subsection (1) has been sent to the Registrar in accordance with subsection (2).

VOLUNTARINESS

Oregon	The Netherlands	Belgium	Quebec, Canada	Canada	Victoria
The patient's request must be voluntary. Both the patient's doctors and the witnesses to the patient's written request are required to confirm that the request is being made voluntarily by the patient (§2.02, §3.01(a) and §3.02).	The patient's request must be voluntary (§2(1)(a)).	The patient's request must be "voluntary, well considered and repeated and is not the result of any external pressure" (§3(1)).	"Before administering medical aid in dying the physician must (1) be of the opinion … after…(a) making sure the request is being made freely, in particular by ascertaining that it is not being made as a result of external pressure.	241.2 (1) A person may receive medical assistance in dying only if they meet all of the following criteria: [including] (d) they have made a voluntary request for medical assistance in dying that, in particular, was not made as a result of external pressure	20 (1) The co-ordinating medical practitioner must assess the person as eligible for access to voluntary assisted dying if the co-ordinating medical practitioner is satisfied that— … (c) the person is acting voluntarily and without coercion. There are very detailed requirements for the requests including Division 2 – First request; Division 5 – Written declaration and Division 6 – Final request … The Written Declaration Form is included in Schedule 1 of the Act. Also in that form are sections for two Witness Declarations and Interpreter Declaration if necessary, which make clear what the requirements are. S8 requires that voluntary assisted dying must not be initiated by registered health practitioner. See also 18(1) in Competence section.

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S10(1) "For the purposes of this Act, an assisted dying request is an eligible request if the person making the assisted dying request – … (d) is making the request voluntarily".

The greatest guarantee of voluntariness is that the person must initiate every one of the three requests - initial oral, written and subsequent oral – and advise the primary medical practitioner when the prescription is to be issued (**S23(1)(a)**). The person must also be offered numerous opportunities to rescind their request. The written request (**S17**) must be witnessed under **S17(3)(b)** by "at least two adults" one of whom needs to be independent (see **S17(4), (5) and (6)**.

The primary medical practitioner must be convinced that each request is voluntary. If in doubt, he/she must refer the person to a psychiatrist or a psychologist for counselling (**S14(2)**). The voluntariness must also be confirmed by a second medical practitioner. A person cannot receive an assisted death until a secondary medical practitioner confirms the opinion of the primary medical practitioner on voluntariness. (See section below on Doctor Safeguards).

COMPETENCE

Oregon[20]	The Netherlands	Belgium	Quebec, Canada	Canada	Victoria
The patient must be capable of making and communicating health care decisions to their doctors (§1.01(3)). If either the attending or consulting physician are of the opinion that "the patient may be suffering from a psychiatric or psychological disorder or depression causing impaired judgement" they must refer the patient for counselling (§3.03).	The patient's request must be "voluntary and carefully considered" (§2(1)(a)). It is practice for the attending physician to consult a psychiatrist if he or she suspects the patient is incompetent.	The patient must be "legally competent and conscious at the moment of making the request" (§3.1).	To obtain medical aid in dying, a patient must "be capable of giving consent to care" (§26(2)). (There is no specific requirement in this Act for the doctor to refer the patient for psychiatric or psychological assessment.)	Capable of making decisions with respect to their health; (§241.2 (1)(b)) They give informed consent to receive medical assistance in dying after having been informed of the means that are available to relieve their suffering, including palliative care. (§241.2 (1)(e)) (There is no requirement for the doctor to refer the patient for psychiatric or psychological assessment.)	9 (1) For a person to be eligible for access to voluntary assisted dying— ... (c) the person must have decision-making capacity in relation to voluntary assisted dying; Section 4 defines Meaning of decision-making capacity at some length 18 (1) If the co-ordinating medical practitioner is unable to determine whether the person has decision-making capacity in relation to voluntary assisted dying as required by the eligibility criteria, for example, due to a past or current mental illness of the person, the co-ordinating medical practitioner must refer the person to a registered health practitioner who has appropriate skills and training, such as a psychiatrist in the case of mental illness.

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Under the Tasmanian Bill, the person has to be competent at the time of each request, in order for that request to be an eligible one.

Person must be competent
S10(1) "For the purposes of this Act, an assisted dying request is an eligible request if the person making the assisted dying request – ...
(c) is competent"

S3 (Interpretation) - ***competent***, in relation to a person, means the person –
(a) has the ability to make and communicate to health care providers, informed decisions in relation to the person's medical treatment, including communicating through persons familiar with the person's manner of communicating; and
(b) is not suffering from a psychiatric or psychological disorder, or depression, to a degree that may cause the judgement of the person to be impaired.

S14(2) - "If the primary medical practitioner reasonably suspects that the person is not competent to make the initial oral request, or is not voluntarily making the initial oral request, he or she must refer the person for counselling and discuss with the person the reasons for the referral". **S3** - "**counselling** means a consultation between a psychiatrist, or psychologist, and a person to determine, in the opinion of that psychiatrist or psychologist, whether or not the person – (a) is competent to make an assisted dying request; and (b) is making that request voluntarily". **S15 and 16** - set out requirements to be met in relation to counselling and reporting. **S15(3)** "Nothing in this section prevents a person's primary medical practitioner from referring the person to a psychiatrist, or psychologist or any other person, at any time, or for any reason, the primary medical practitioner thinks appropriate".

INFORMED DECISION

Oregon	**The Netherlands**	**Belgium**	**Quebec, Canada**	**Canada**	**Victoria**
The patient must be making an informed decision and the attending physician is required to inform the patient of "his or her medical diagnosis, … prognosis, the potential risks associated with taking the medication to be prescribed, the probable result of taking the medication to be prescribed, and the feasible alternatives, including, but not limited to, comfort care, hospice care and palliative care" (§3.01(c)).	The request must be informed and the physician is required to "inform the patient about the situation he was in and about his prospects" (§2(1)(c)).	Section 3.1 states that the patient's decision must be "well considered." The physician must "inform the patient about his/her health condition and life expectancy, discuss with the patient his/her request for euthanasia and the possible therapeutic and palliative courses of action and their consequences" (§3.2.1).	The patient's physician must make "sure that the request is an informed one, in particular by informing the patient of the prognostic and of other therapeutic possibilities and their consequences" (§28(1)(b)) The physician must make sure that such a decision is made freely and provide the person with all information needed to make an informed decision, in particular information about other therapeutic possibilities, including palliative care. ((§5)	They give informed consent to receive medical assistance in dying after having been informed of the means that are available to relieve their suffering, including palliative care. (§241.2 (1)(e))	If the co-ordinating medical practitioner is satisfied that the person requesting access to voluntary assisted dying meets all the eligibility criteria, the co-ordinating medical practitioner must inform the person about a range of matters set out in §19(1), including palliative care options available to the person and the likely outcomes of that care. In addition, under 19(2), the co-ordinating medical practitioner must, if the person consents, take all reasonable steps to fully explain to a member of the family of the person— (a) all relevant clinical guidelines; and (b) a plan in respect of the self-administration of a voluntary assisted dying substance for the purpose of causing death.

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S12 contains very detailed requirements on the information to be provided to the patient including those above for other legislation. For example, **S12(2)** - (f) all other reasonable treatment options available to the person including, but not limited to, palliative care.

RESIDENCY

Oregon	The Netherlands	Belgium	Quebec, Canada	Canada	Victoria
The patient must be a resident of Oregon (§2.01).	Residency is not mentioned in the Act but is effectively required in practice.[21]	Residency is not mentioned in the Act but is effectively required in practice.	26(1) requires a person to be an insured person within the meaning of the Health Insurance Act (chapter A-29)	241.2 (1) A person may receive medical assistance in dying only if … (a) they are eligible — or, but for any applicable minimum period of residence or waiting period, would be eligible — for health services funded by a government in Canada; …	9(1)(b) the person must— (i) be an Australian citizen or permanent resident; and (ii) be ordinarily resident in Victoria; and (iii) at the time of making a first request, have been ordinarily resident in Victoria for at least 12 months;

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S10(1)(b) requires that a person be a Tasmanian resident. **10(2)** states: For the purposes of subsection (1)(b), evidence of a person's Tasmanian residency may include, but is not limited to, evidence that the person currently –
(a) holds a drivers licence issued under the Vehicle and Traffic Act 1999; or
(b) is enrolled to vote in Tasmania.

WAITING PERIODS

Oregon	The Netherlands	Belgium	Quebec, Canada	Canada	Victoria
15 days between two oral requests and 48 hour period between written request and dispensing of the prescription	No	No, with the exception that for those whose deaths are not otherwise imminent there is a one month waiting period	No	10 days between written request and assisted dying "or — if they and the other medical practitioner or nurse practitioner referred to in paragraph (e) are both of the opinion that the person's death, or the loss of their capacity to provide informed consent, is imminent — any shorter period that the first medical practitioner or nurse practitioner considers appropriate in the circumstances" (§241.2 (3)(g))	38 A person's final request must be made— (a) subject to subsection (2), at least 9 days[v] after the day on which the person made the first request; and (b) in any case, at least one day after the day on which the consulting assessment that assessed the person as eligible for access to voluntary assisted dying was completed. (2) Subsection (1)(a) does not apply if the co-ordinating medical practitioner for the person considers that the person's death is likely to occur before the expiry of the time period specified in that subsection, and this is consistent with the prognosis of the consulting medical practitioner for the person set out in the consulting assessment report form.

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There must be a minimum of 9 days between the initial request and the administration of drugs for an assisted death, including under **S17(2)** at least 48 hours between initial oral request and written request, and under **S21(2)(b)** at least 7 days between written request and subsequent oral request.

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[v] The Victorian inquiry recommended that there be no waiting periods.

Endnotes

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[1] The original of this paper was dated January 2017, with an update in May 2017. At that time the Victorian information included only recommendations from the Victorian inquiry into end of life choices. This version in March 2018 includes information from the Victorian legislation, the *Voluntary Assisted Dying Act 2017*.

[2] As the Chair of the Victorian inquiry says in his foreword to the June 2016 report of the Victorian inquiry into end of life choices: "While these jurisdictions differ significantly in their assisted dying models, **what they all have in common is robust regulatory frameworks that focus on transparency, patient-centred care and choice**. We found **no evidence of institutional corrosion or the often cited 'slippery slope'**. Indeed, the regulatory framework has been unchanged in Oregon, the Netherlands and Switzerland for many years."

The same points are made elsewhere in the report, backed up by substantial evidence:

- Concerns raised in arguments against legalising assisted dying — such as the inability to implement and maintain effective safeguards — have not eventuated in jurisdictions where assisted dying is legal. The Committee did not find compelling evidence to support the negative consequences predicted by these claims. (p205)
- **The evidence is clear that assisted dying can be provided in a way that guards against abuse and protects the vulnerable in our community in a way that unlawful and unregulated assisted dying does not**. The Committee is satisfied, through its research into international jurisdictions, that assisted dying is currently provided in robust, transparent, accountable frameworks. The reporting directly from such frameworks, and the academic literature analysing them, shows that the risks are guarded against, and that robust frameworks help to prevent abuse. (p212)

See also the ABC Fact Check in November 2017 which refuted Paul Keating's claim that the experience of assisted dying legislation in "overseas jurisdictions suggests the pressures for further liberalisation are irresistible" - http://www.abc.net.au/news/2017-11-10/fact-check-do-assisted-dying-laws-lead-to-a-slippery-slope/9116640 .

[3] Available at http://www.parliament.tas.gov.au/bills/Bills2016/pdf/73_of_2016.pdf

[4] http://www.legislation.vic.gov.au/Domino/Web_Notes/LDMS/PubStatbook.nsf/f932b66241ecf1b7ca256e92000e23be/B320E209775D253CCA2581ED00114C60/$FILE/17-061aa%20authorised.pdf

[5] Particular attention has been given to the extensive consultative process, reports and parliamentary debates in Canada, including the reports, submissions, policies and advice of the Canadian Medical Association, eg Principles-based Recommendations. The 2016 Tasmanian Bill is consistent with the new AMA policy even though the Bill was moved in the Parliament before the new policy and its report on the review and member survey was issued.

[6] Available at http://dwdtas.org.au/wp-content/uploads/2016/11/Tasmanian-VAD-Bill-Summary-29-November-2016.pdf .

[7] DwDTas has more material to support an informed, rational debate on this issue, to be added to the website and sent directly to MPs. We are happy to respond to specific queries at any time.

[8] This information has been prepared by Margaret Sing, President, Dying with Dignity Tasmania. The information in these tables, other than the Quebec, Canada and Victorian inquiry details, is taken from Giddings, L and McKim, N, Voluntary Assisted Dying: A Proposal for Tasmania, Feb 2013 (obtainable at http://dwdtas.org.au/wp-content/uploads/2013/05/Voluntary-Assisted-Dying-A-Proposal-for-Tasmania.pdf). The original document includes additional tables comparing other provisions including Voluntariness, Written Request, Residency Requirement, Age of patient, Identity of the Attending Doctor, Family Notifications, Due Medical Care and Opportunity to Rescind Request. It also includes considerable additional detail on the similarities and differences between the legislation in different jurisdictions.

[9] http://time.com/7565/belgium-euthanasia-law-children-assisted-suicide/

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[10] http://www.rte.ie/news/2016/0917/817198-euthanasia/

[11] The Oregon requirements are the same or similar to those in other US States in these key criteria, but there are some differences which should be noted in the particular legislation (Washington, Vermont, California, District of Columbia) or court judgements (Montana) which determine the legal conditions for voluntary assisted dying.

[12] The 6 month timeframe is included in the Oregon and other US States for a reason specific to the US situation that does not apply in Australia (or other countries). (See for example, the Report of the Victorian inquiry into end of life choices, p223.) It is a requirement because the architects of the legislation wanted to be sure that people would not choose assisted dying merely because they could not afford palliative care. When people in the US have their doctor's prognosis of 6 months or less to live they are eligible for free access to palliative care (hospice) services through federal funding. This is obviously very important in the very expensive US health system. Consequently, 90.5% of those who have accessed assisted dying in Oregon have been enrolled for hospice care. (See latest Annual Report for 2017) However, it is also clear from the Oregon Annual reports that the prognoses are unreliable and some people live for a considerable period beyond 6 months. For example, the duration from first request to death ranges from 15 to 1009 days. In other words, at least one person (and maybe more) lived for nearly 3 years, despite their 6 month prognosis.

[13] This represents a major difference between the recommendation of the Victorian inquiry into end of life choices and the final Act. The inquiry did not require the person to have a terminal illness – ie one that will cause the death of the person. The inquiry had adopted the approach of all jurisdictions other than the US, including Canada, that the person should be "suffering from a serious and incurable condition which is causing enduring and unbearable suffering that cannot be relieved in a manner the patient deems tolerable". The restriction was recommended by the Victorian Government's Expert Panel without explanation or justification for the restriction. The requirement means that someone with a serious chronic but not terminal incurable condition (for example, a spinal condition) may not be eligible even though they meet all the other requirements including intolerable suffering. This was the situation for Kay Carter in Canada in the case that led to the Supreme Court judgement in February 2015. On our website we include two examples in the Tasmanian context – Elizabeth Godfrey and Joan Fitznead.

[14] This also represents a major difference between the approach taken by the Victorian inquiry, and all legislation other than in the US, that a specific timeframe prognosis is not a reliable way to determine that someone is at the end of their life. The Victorian inquiry report states: "The Committee's view is that assisted dying in Victoria should be provided only to those who are at the end of life, as determined by a primary doctor and an independent secondary doctor. … Doctors are best placed to assess whether a patient is at the end of life. The Committee trusts the judgement of doctors, specialists and health practitioners in determining whether a patient is at the end of life, according to the nature of their condition and its likely trajectory. The Committee believes that empowering doctors to make this assessment is preferable to allocating an arbitrary time limit based on factors that are not applicable to the Victorian context. For example, the six-month requirement specified in the Oregon framework which is based on access to hospice benefits is not applicable to the Australian context which provides universal health care" (p223-4).

Prognoses of months to live are notoriously unreliable and they have been generally rejected elsewhere (except the US where they are related to access to federal funding). An article by respected academic Professor Colleen Cartwright of Southern Cross University identifies these issues - https://theconversation.com/the-six-month-amendment-could-defeat-the-purpose-of-victorias-assisted-dying-bill-87941 . A timeframe prognosis or an 'end of life' requirement was not included in the Canadian Supreme Court judgement in February 2015 that led to the national Canadian medical aid in dying legislation. The legislation was passed with a requirement added by the Government: 241.2 (2)(d*) their natural death has become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining*. This requirement is to be legally challenged. It has been described as "one of the most confusing and controversial elements" of the legislation (see for example, https://impactethics.ca/2017/07/28/in-a-nutshell-ii-ontario-court-decision-maid/). It has been criticised chiefly because it could prevent people who would have been able to access medical aid in dying under the Supreme Court decision from doing so under the legislation (see for example http://www.cbc.ca/news/politics/liberal-mps-call-for-changes-proposed-assisted-dying-1.3542505 and the views of the family of Kay Carter, the main person in the case decided by the Supreme Court - http://www.cbc.ca/news/politics/doctor-assisted-suicide-bill-carter-family-speaks-out-1.3546472).

The Victorian Coroner's evidence to the Victorian end of life choices inquiry is also critically important to this issue. The evidence was research done by the Coroners Office involving suicides of people who had "decline/deterioriation in physical health due to incurable and irreversible conditions". The Coroner specifically noted three different groups

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– people diagnosed with terminal illness “expected to die within a specified period of time”; people with “incurable chronic disease that was not expected to cause death in the foreseeable future” (eg Huntington’s, Parkinson’s, MS, diabetes, MN, osteoarthritis) and people with “permanent physical incapacity and pain that could not be relieved as a result of injury”. The Victorian legislation will allow those in the first group to access voluntary assisted dying. A DwDTas analysis provides more details and links to the Coroners submissions and evidence at a hearing. See also Chapter 6 of the report of the Victorian inquiry.

[15] In the AMA member survey, 91% of the AMA members who believed ‘euthanasia’ should be lawfully allowed for a competent adult supported it in the circumstances of “an incurable illness associated with unrelievable and unbearable suffering” and only 64% for the much narrower circumstances of a “terminal illness”. See also the details of successive Newspolls and Tasmanian EMRS polls in the DwDTas paper on community support, as well as the more recent 2016 Essential poll and the November 2017 Roy Morgan poll.

[16] Canada is the only jurisdiction that legally allows for nurse practitioners (NPs) to take part in the direct provision of medical assistance in dying.

[17] Information on complications has, since mid-2010 been collected only when the physician or another health care provider is present at the time of death so the situation in a large number of cases is not known. Complications may include difficulty ingesting/regurgitated, seizures and regaining consciousness after ingesting DWDA medications. (Source: Annual report for 2017.) One of the major issues in the US is the cost and accessibility of the most effective drugs. (See for example http://scienceline.org/2017/05/death-with-dignity/?utm_content=bufferfd4af&utm_medium=social&utm_source=facebook.com&utm_campaign=buffer and http://www.npr.org/sections/health-shots/2016/03/23/471595323/drug-company-jacks-up-cost-of-aid-in-dying-medication.

[18] As in all jurisdictions with both self and doctor-administration, doctor-administration is involved in the vast majority of instances. The second interim report in Canada comments that research has shown that “providers are less comfortable with self-administration due to concerns around the ability of the patient to effectively self-administer the series of medications, and the complications that may ensue” and “ although pharmacists can compound drugs for use in a self-administered assisted death, no drug commonly used for self-administration in international jurisdictions has been submitted for market approval in Canada, making access to these medications challenging in some communities”.

[19] Annual Reports of the Review Committees are accessible at https://english.euthanasiecommissie.nl/documents/publications/annual-reports/2002/annual-reports/annual-reports .

[20] The Vermont legislation, *An act relating to patient choice and control at end of life*, May 2013, includes another alternative: “(8) The physician either verified that the patient did not have impaired judgment or referred the patient for an evaluation by a psychiatrist, psychologist, or clinical social worker licensed in Vermont for confirmation that the patient was capable and did not have impaired judgment.”

[21] The Dutch Ministry of Foreign Affairs advises that it is impossible for people to travel to the Netherlands to seek an assisted death ‘given the need for a close doctor-patient relationship. The legal procedure for the notification and assessment of each individual case of euthanasia requires the patient to have made a voluntary, well-considered request and to be suffering unbearably without any prospect of improvement. In order to be able to assess whether this is indeed the case, the doctor must know the patient well. This implies that the doctor has treated the patient for some time’. (Source: Lewis and Black, The effectiveness of legal safeguards in jurisdictions that allow assisted dying. January 2012; p10)

Response to inquiry into aged care, end-of-life and palliative care

Centacare*CQ*

Centacare*CQ* is the official Catholic social service agency for the Catholic Diocese of Rockhampton. We serve all people without regard to religion, age, economic circumstance or ethnicity. We have provided community care programs in Central Queensland for close to 25 years, including HACC, Commonwealth Home Support, Home Care Packages and current Qld Community Care Services (QCCS). We deliver NDIS supports to a growing number of clients. At present, we deliver community care services in and around Blackwater, Emerald, Yeppoon, Rockhampton, Bundaberg and Mackay. This includes extensive experience with clients in rural areas.

As a provider of services that support people to remain living safely in their community, Centacare*CQ* is affected by the impacts of the ageing population: increasing demand, increasing complexity as people are living longer, more people wish to live in their own home longer, and the home care sector has an ageing workforce. Funding and resourcing to meet demand and increasing complexity are also issues that we are grappling with. Our team has responded to some of the questions raised in this inquiry, as outlined below.

Aged Care:

Is the aged care system meeting the current needs of older Queenslanders, including those people with special needs? Why or why not?

In brief, there are many parts of the system that don't meet current needs, including at the entry point. However, people who are already "in the system" have their needs met, until it's time to transition to a higher level or from CHSP to a package. These issues are dealt with later in this response.

Observations from our staff include:

- People seeking aged care services (potential clients) are still struggling to use My Aged Care – while there have been some improvements since it was first introduced, it's still confusing and frustrating for people, particularly those who are not regular users of online services. The webinar for providers has helped, but as it's aimed at providers, that doesn't help people seeking services

- There have been instances where people have had an assessor visit them, then they call our service and say “we’ve had our ACAT, can we get services now” – so they haven’t understood what the assessor has done, and aren’t clear on what should be happening next.
- We have received referrals for people for CHSP where the request is for 6 types of service. When our staff talk to the clients and ask if they had thought about a home care package, they’ve said “what’s a home care package” – leaving the impression that the clients either aren’t being given the information, or that the assessor hasn’t noticed that they didn’t understand the information
- In other instances, clients who are on CHSP and are re-assessed and eligible for a package, refuse the package because they believe it will leave them out of pocket.
- There are definitely gaps in supports for people with dementia and for LGBTI community members
- An issue that comes up for us fairly regularly is that the information on the portal about what services are available in a particular area is not accurate. As an example, people call us because they see our advertisement, for yard maintenance . The myagedcare service finder has listed a variety of providers that are situated outside the local area . When clients contact these providers they are told they do not have capacity or they do not deliver in the area. Clients are telling us that they don't trust what's on the portal and just call us directly. We end up doing the work of linking them into appropriate services (ours or other service providers, depending on where they are and what they need). This is work we are not funded to do.
- In some areas, particularly the more rural areas of our region, staffing levels are an issue as recruitment is getting tighter – supply of workers isn’t keeping pace with demand, which makes it difficult to provide the services that clients need when they need them

Are the current waiting times for both residential and home care places adequately meeting the needs of older Queenslanders?

Only if you can call "eventually" an adequate response. Examples of waiting times for current clients include:

Date they entered list	Area	HCP Details	Time Waited	Expect Wait time (interim Package)	Expect Wait time full package	Priority
7/11/18	Bundaberg	Approved HCP2.	130 Days	1-3 Month (1)	9 – 12 Months (2)	Medium
31/01/19	Bundaberg	Approved HCP3	45 Days	3-6 Months (2)	12 Months+ (3)	Medium
30/11/18	Bundaberg	Approved HCP3	107 Days	12 Months+ (2)	12 Months+ (3)	Medium
23/05/18	Rockhampton	Approved HCP3	298 Days	6- 9 Months (2)	12 Months+ (3)	Medium
08/01/18	Rockhampton	Approved HCP3	433 Days	1-3 Month (2)	6- 9 Months (3)	Medium

This is not a comprehensive list, and only being included to illustrate that no, the waiting times are not adequately meeting the needs.

Other examples include:

- In Bundaberg, we have 115 clients on CHSP waiting to transition to home care packages or upgrade; we have 68 home care packages
- In Rockhampton and Blackwater, we have 200 clients on CHSP waiting to transition to home care package or upgrade; we have 113 home care packages (all currently filled)

Our Mackay team observes that people are being admitted to hospital or passing away before a package becomes available. In Mackay, there is an example of a person with a home care package, waiting for a place in a residential facility, being admitted to hospital in Mackay in early September 2018, and at the time of writing this response still being in hospital. However, the client was offered a transfer to the Bowen Hospital as Mackay hospital didn't have space. This transfer was declined as Bowen is 190km from Mackay. In addition, after 28 days in hospital a co-payment is triggered ($60 per day). For this particular client, the inadequacy of the waiting times has also resulted in increased financial stress.

Do the standards of residential aged care, home care and other aged care services provided in Queensland meet clients' and the community's expectations? Can you give examples?

This question is difficult to answer. Providers can meet standards without necessarily meeting the client and/or community expectation. There will no doubt be many examples through the Royal Commission that will demonstrate that client and community expectations are not being met. An example is taking into account client preference under consumer directed care – it's impossible to meet expectations re preference for a particular worker, especially when our favoured workers are not just the preferred worker for one client.

In some cases, we are meeting expectations more than in previous years. Our social group programs are an example of this, where the coordinators spend a good amount of time and energy finding out from clients the types of activities they would like to see on the program, and finding ways to make these happen.

How will demand for aged care services change in Queensland as the population increases and ages, and what changes to the aged care system will be needed to meet future demands for aged care?

Population ageing has multiple impacts for home care providers. More of the population would prefer to live at home, meaning greater demand of home care services. People are living longer, and this coupled with a desire to choose to live in a home setting rather than in a residential setting will drive demand for more allied health and nursing supports than what is currently in the mix for community care workforce. More focus will be needed on how to successfully work when the "workplace" is actually people's homes, not just for home care workers but for allied health and other health professionals.

An additional issue is that the care workforce median age is 45, significantly higher than the general working population (median age 39) (Dept of Jobs and Small Business Labour Market Information Portal http://lmip.gov.au/default.aspx?LMIP/GainInsights/IndustryInformation). To meet demand, there will need to be investment in promoting the roles in the community care industry, and strategies to attract, recruit and retain workers.

Are there enough residential aged care places (beds) available in aged care facilities, in areas and at the levels of care that are required?

As previously outlined, the case of the client from Mackay waiting in hospital for an aged care place is one example of a shortage of beds in residential care. Staff across our region report that this has improved in recent years – previously clients on home care packages were being sent home from hospital when they had been assessed as needing to transition to residential care, due to a shortage in beds. So while it's improved, there are still not enough beds.

Are adequate numbers of home care packages available in areas at the levels required?

As with the previous examples of people waiting for packages, there are regularly long waits for transition to a higher care package. Sample data from our clients is tabled below, and indicates that the availability of packages across the levels is not adequate.

Date Entered Waitlist	Area	Current Interim Package	Committed Interim Date	Time waited for interim	Expect Wait time full package	Time Waited	Priority
22/05/18	Bundaberg	HCP (3)	1/02/19	255 Days	1-3 Month (4)	299 Days	High
01/06/18	Bundaberg	HCP (1)	9/01/19	222 Days	6- 9 Months (2)	289 Days	Medium
20/07/16	Rockhampton	HCP (3)	16/02/18	576 Days	3-6 Months (4)	970 Days	Not Known
17/02/17	Rockhampton	HCP (3)	02/11/18	623 Days	12 months + (4)	758 Days	Not Known
01/03/17	Rockhampton	HCP (3)	21/11/18	630 Days	12 months + (4)	746 Days	Medium

Are there sufficient staff in the aged care sector to meet current and future workloads?

Recruitment is already difficult in response to recent increases in demand. With the ageing population and the ageing workforce, it is unlikely that recruitment will become easier in the medium term. There is a particular shortage of male care workers. The demand for allied health workers is increasing, and the introduction of the NDIS is also adding to this demand. The Workability project that is working in Queensland on strategies to build sector workforce supply and capability to meet demand under the NDIS (http://workabilityqld.org.au/), has identified potential shortfalls in allied health workers, including allied health assistant (VET qualifications) and allied health professions. The demand for care workers is also projected to outstrip supply, and this will have flow on impact to the aged care workforce supply in coming years. Without serious investment in community care workforce, there will continue to be unmet demand in Queensland.

Is the mix of staff appropriate for different settings within the aged care sector?

With people living longer and more preference to remain living at home or in an independent living arrangement (rather than residential facility), the complexity of home care work is increasing. The mix of staff in home care will need to change significantly to meet demand, in particular with increased representation from allied health and nursing staff.

Do aged care staff receive training that is appropriate and adequate to prepare them for the work?

While training has improved in recent years, there are still instances of people coming into roles with appropriate qualifications but unable to perform the work because of the lack of experience built into the training packages. As people are living longer and home care packages are increasing in complexity, the need for workers to be exposed to high needs and complex client work prior to being rostered to provide supports will become greater.

Are suitable health care services being provided within residential aged care settings and/or aged care providers?

We generally find that there are good and responsive allied health providers that we can refer to; however, there is high demand for these services, and that demand is increasing. For example, there is currently between a 2 and 3 week wait for an occupational therapist in Mackay.

How can the delivery of aged care services in Queensland be improved?

- Increase education and understanding of the system for people looking to enter and their families. Consider the Nurse Navigator role that has been implemented in Queensland Health – a similar Navigator role for aged care entry could be useful
- More flexibility to transition between packages, and increase the available packages
- Smooth out the processes – when a client needs changes, rather than going back to the RAS for assessment, provide the option for the service provider to assess then transition as needed
- Invest in the workforce
    - More experiential learning e.g. increase traineeships rather than certificates, to provide on the job training while becoming qualified
    - Provide internship or placement in high needs facilities for currently skilled workers in the home care workforce, to ensure readiness to work with higher needs clients in home care. Do this now, rather than waiting for the wave of demand
    - Invest in promoting the jobs – strategic approach to attract people to work in the industry from every age and background
    - Focussed investment on increasing workers in allied health
    - Increase content on the processes/ continuum of ageing, so that workers have a greater understanding of the changes that will happen for their clients

- Improve the entry criteria for service providers - this will likely emerge from the Royal Commission
- Increase case management time when clients are transitioning from CHSP to a package

Are there alternative models for the delivery of aged care services that should be considered for Queensland?

The model is good but needs improvement to the assessment processes. There is inconsistency, with clients with similar needs in similar situations being assessed with very different outcomes. Improve the review/ re-assessment process so that providers can assess, plan and implement – often times the funds are there, but there is a bottleneck in the assessment process, so the client and the service provider have to wait for "permission" to meet the client's changed needs.

Consider a cap on unspent funds, so that clients are encouraged to use the services that are available to improve their outcomes.

Look at some of the dementia care models being used overseas and consider application of these.

What are the key priorities for the future?

Provide support that enables new users to navigate and understand their choices in aged care, including family/informal carers

Invest in workforce, in terms of promotion of the industry to help attract more people into relevant training/education; investing in the skills of current workers, particularly to grow skills to manage complex care at home; improving the training system so that it meets the needs of service providers.

Provide more packages; and improve the access for people transitioning between CHSP and packages, or from one level to the next.

End-of-life and palliative care

Are palliative care and end-of-life care services meeting the current needs of Queenslanders? Why or why not?

We are hearing that more and more people would like the option of dying at home. This was highlighted in the Productivity Commission report on Introducing Competition and Informed User Choice, which noted that surveys conducted by Palliative Care Australia consistently show that 70% of Australians would prefer to die at home. While it's not practical in every case, where a "good death" in a home setting is possible in theory, the system doesn't currently support it. This means that people can't choose to die at home, not because they shouldn't but because the service that are needed to support their choice are not in place.

A recent example from Bundaberg: a residential care client who was known to be in the last stages of their life, remained in the ward of the care facility with other clients. The family was with them, but visitors to other residents were also coming in and out of the area. The staff tried their best, but often couldn't answer questions from the family, as they didn't have the clinical knowledge of what was occurring. In this instance, without an appropriate space for within the residential facility that allowed a peaceful and respectful experience, hospital would have been a more appropriate option.

Support for families when family members are in palliative or end-of-life care could be better.

Do the standards of palliative care and end-of-life care provided in Queensland meeting clients' and the community's expectations?

It's unclear what client and community (including family) expectation is. There is a gap in readiness – some education about what to expect.

How will demand for palliative and end-of-life services change in Queensland as the population increase and ages, and what changes to the delivery of these services will be needed to meet future demands?

As the population increases and ages, there will be an increase in the number of people dying, and hospitals and residential care providers will struggle to keep pace. Demand for the option of dying at home will increase, so it's important to get the model to support this right (before the increase overwhelms the current system). Closer engagement/ integration with home care services will be needed. Closer engagement with universal services that can provide supports for families to ensure the option to die at home doesn't leave families without the services they need (ie people generally have access to a social worker in the hospital and residential settings).

How can the delivery of palliative care and end-of-life care services in Queensland be improved?

Greater investment in enabling people to die at home, and where possible to enable palliative care at home. It's important that this is considered as a new piece of the system, not "bolted on" to current services – there needs to be a specific and intentionally funded model to increase palliative care in community and the option to die at home.

Pastoral care needs to be improved in the current system, and included in any emerging models for palliative and end-of-life care.

What are the particular challenges of delivering palliative and end-of-life care in regional, rural and remote Queensland?

Availability of resources such as medical staff with skills and experience. Availability of beds in small locations. There are current examples of people being sent well out of their local area to access hospital or residential facilities that are appropriately resourced. There is not a well-coordinated mobile workforce that can support the smaller medical and community resources to ensure that staying in rural areas is one of the options. We could look at models such as the SES, where people sign up to be activated for "away" work when needed. These folk have skills maintained and are deployed according to need. Managing risk for lone workers is another challenge.

What are the key priorities for the future?

Designing and funding appropriate models to meet client and community expectations. Recognising and understanding just what are client and community expectations.

Pharmaceutical Society of Australia

Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying

April
2019

Pharmaceutical Society of Australia - submission

Purpose

The purpose of this submission is to provide the views of the Pharmaceutical Society of Australia (PSA) to the Issues Paper on the *Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying* in Queensland.

About PSA

PSA is the only Australian Government-recognised peak national professional pharmacy organisation representing all of Australia's 31,000 pharmacists working in all sectors and across all locations.

PSA is committed to supporting pharmacists in helping Australians to access quality, safe, equitable, efficient and effective health care. PSA believes the expertise of pharmacists can be better utilised to address the health care needs of all Australians.

PSA works to identify, unlock and advance opportunities for pharmacists to realise their full potential, to be appropriately recognised and fairly remunerated.

PSA has a strong and engaged membership base that provides high-quality health care and are the custodians for safe and effective medicine use for the Australian community.

PSA leads and supports innovative and evidence-based healthcare service delivery by pharmacists. PSA provides high-quality practitioner development and practice support to pharmacists and is the custodian of the professional practice standards and guidelines to ensure quality and integrity in the practice of pharmacy.

General comments

The use of medications is the most common intervention we make in healthcare.[i] The safe and appropriate use of medicines transforms people's health.

Pharmacists are experts in medicines, with a primary responsibility to ensure medicines are used safely, effectively and judiciously. This includes the custody, preparation, dispensing and provision of medicines, together with systems and information to assure the quality of use.[ii] These responsibilities are completely aligned with the principles for Quality Use of Medicines (QUM) outlined in Australia's National Medicines Policy (NMP).[iii]

It is a fundamental competency and expectation that pharmacists "collaborate and work in partnership for the delivery of patient-centred, culturally responsive care". Pharmacists are readily accessible primary health care providers with unique expertise around quality use of medicines, medication management and medication safety. Patient needs vary, and as such pharmacists must be integrated as core members of the multidisciplinary health care team.

As recently outlined in PSA's *Medicine Safety: Take Care* report, Australians are experiencing significant medication-related problems every day leading to unnecessary hospitalisations and costs to the health care system. The need to formally include pharmacists in the health care team and to appropriately recognise their contribution to patient care has never been more urgent. The report highlights that 98% of aged-care residents have at least one medication-related problem, with an average of 3.2 problems per person, and that over half of residents are exposed to at least one potentially inappropriate medicine.[iv]

To address the medication-related problems highlighted in the *Medicine Safety: Take Care* report, PSA developed *Pharmacists in 2023: For patients, for our profession, for Australia's health system,* as a plan to see the role of pharmacists optimised as healthcare professionals and to embed them as principle partners in the Quality Use of Medicines in Australia. One of the key 11 actions in this report, is to embed pharmacists within healthcare teams to improve decision making for the safe and appropriate use of medicines. Among other practice settings such as General Practice, this includes residential aged care facilities.

Aged Care

Australia's population is aging, and currently 3.8 million people or 15% of the total population are aged 65 or over.[v] With this growth in the aging population, more and more older Australians are entering residential care services.[vi] The health of older people can be complicated by the presence of many chronic conditions, and the subsequent need to take multiple medications. The care and medication management of aged care residents are becoming more and more complex, as people are older and frailer when they enter aged care facilities.[vii]

While the need to treat multiple conditions is recognised, the risk of adverse drug events increases with the number of medications prescribed. When this risk is combined with the age-related changes in how medications act, and are cleared from the body, it leads to medication-related problems being commonly reported in older people. Therefore, medication management services play a paramount role in supporting the safe and effective use of medicines for those living in residential care facilities.[viii]

Australian studies published over recent years provide clear evidence that the high rates of antipsychotic prescribing in residential aged care facilities continue to be a significant concern.[ix],[x] Australian evidence suggests that between 40% and 50% of residents could be receiving potentially inappropriate medications, such as sedatives and anticholinergic drugs.[xi]

The Australian and New Zealand Society for Geriatric Medicine (ANZSGM) 'Prescribing in Older People' position statement recognises the role of 'clinical pharmacy services' including medication reviews as part of a targeted approach to identify and manage polypharmacy.[xii]

The knowledge and expertise of pharmacists is essential in the unique situations presented in residential aged care facilities. Many older people have multiple chronic health conditions and this has a number of potential consequences.

- Older people may be prescribed multiple medicines (polypharmacy), resulting in a significant increase in the potential for adverse effects and drug interactions.
- Many age-associated health conditions can modify the pharmacokinetic and pharmacodynamics properties of a medicine, increasing the variability in response to medicines.
- More than one medicine is often needed to manage each health condition. As more medicines are added to the medication regimen, the increased 'pill burden' increases the risk of poor adherence, confusion and adverse effects. [xiii]

As such, medicine use in older people can often require prescribing of unusual doses and combinations of medicines or the need to tailor for specific individual needs such as swallowing difficulties, impaired sight and hearing difficulties. Pharmacists also assess the effects of individual medicines and/or polypharmacy on the falls risk for patients and make recommendations accordingly to reduce the risk. Pharmacists have specific training to respond to individualising medication treatment.

The elderly are also at increased risk of adverse or suboptimal effects of medications, not only as a result of their complex medication regimens and disease states, but also due to frailty and functional decline compared to younger populations. The frequently reported occurrence of medication misadventure in residential aged care facilities has many causative factors including general poor health status, high use of medicines, polypharmacy and the extensive over prescribing of sedatives and psychotropic medicines among this population.

PSA believes strongly that pharmacists must have a greater role in the residential aged care sector to utilise their unique medicines expertise to ensure the safe and optimal use of medicines in residential aged care facilities.

The role of a pharmacist embedded in an aged care facility would be non-dispensing, complementing parallel roles of community, hospital and general practice pharmacists, but importantly would undertake comprehensive medication reviews, identify and resolve multiple medication related problems and provide pharmacotherapy advice to prescribers, nursing staff, carers and residents.

As outlined in PSA's *Pharmacists in 2023: For patients, for our profession, for Australia's health system,* the role of a pharmacist embedded in an aged care facility would include:

- **Education and training** of other health professionals and facility staff in the quality use of medicines and medicines information;
- **Clinical governance activities** around using medicines appropriately including leading programs and systems to reduce use of high risk medicines such as antipsychotics and benzodiazepines, and provide stewardship of opioid and antimicrobial use;
- **Resident-level activities** identifying, preventing and managing medication-related problems, reducing polypharmacy and optimising medicines use; and
- Supporting **achievement of accreditation standards** related to medication management.

There are significant benefits for both residents and the Queensland healthcare system for embedding pharmacists as part of the multidisciplinary health care team in aged care facilities. The benefits include, but are not limited to:

- The reduction in the use of psychotropic medicines/chemical restraints, improving quality of life for residents through reduced side effects (sedation, weight gain, impaired cognition etc.);
- The reduction in hospitalisations from medicine-related adverse events;
- More rational use of opioid medicines, resulting in improved pain management and alertness of residents;
- More rational and targeted use of antimicrobials in accordance with local resistance patterns and treatment recommendations; and
- Increased staff access to pharmacist's expertise in medicines and medication management within the residential care facility.

PSA recommends that there should be 0.5 full-time equivalent (FTE) pharmacists per 100 aged care residents in order to perform the recommended activities.

A recent six-month pilot study by the University of Canberra and Goodwin Aged Care Services, incorporating an on-site clinical pharmacist in a residential aged care facility, found the pharmacist's advice resulted in the prevention of 85 potential incidents of drug related problems such as inappropriate drug administration, adverse drug reactions, inappropriate prescribing and incorrect dosing.

The pharmacist's interventions also prevented four potential hospital admissions, estimated to save $25,460 for the public health care system through avoiding those hospitalisations. A survey of the staff and residents of the facilities involved found they were extremely positive about the role of the pharmacist, strongly agreeing that employing an on-site pharmacist would be beneficial.

Pharmacists can also provide a valuable role in supporting transitions of care. Adverse drug events can occur any time a change to a medication regimen is implemented, however transitions between care settings has been identified as particularly high risk. The importance of medication reconciliation by a pharmacist is well-evidenced to reducing errors during transitions of care, particularly when transferring from hospital to residential aged care facilities.

Pharmacists can currently provide medication reviews to residents in aged care, through the 6th Community Pharmacy Agreement-funded Residential Medication Management Review (RMMR) program. However, the 6th Community Pharmacy Agreement program rules place restrictions such as limiting reviews to every two years regardless of need such as recent hospitalisation, significant changes in treatment, or changes in physical or cognitive function. This current model where many RMMR's are not undertaken by local pharmacists provides a barrier to timely review. Embedded pharmacists are more likely to be able to obtain the best possible medication history on admission to a facility through liaison with the patient, as well as sources including their former GP, community pharmacy, and hospital admissions and discharges. This allows ongoing medication reconciliation across transitions of care to be assessed and facilitated.

The *Review of National Aged Care Quality Regulatory Processes* commissioned by the Minister for Aged Care Ken Wyatt, highlighted ongoing difficulties in the management of medicines within the aged care environment. One of the key recommendations from this review was that aged care resident medication management reviews should be conducted on admission to a nursing home, after any hospitalisation, upon any worsening of medical condition or behavior, or on any change in medication regime.[xiv]

Counseling of older residents takes time and sometimes needs to be opportunistic rather than scheduled. An embedded pharmacist has the ability to monitor changes in a resident's condition over time and to follow up outcomes of medication changes. An embedded pharmacist has the opportunity to develop meaningful relationships with health professionals, both onsite and visiting, as well as residents and families. A collaborative relationship allowing discussion of Quality Use of Medicine issues is more likely where contact is frequent and ongoing.

Quality of care standards and guidelines for residential aged care facilities make reference to quality use of medicines such as medication management requirements. The PSA encourages the Committee to examine the range and extent to which these are undertaken within Queensland facilities, and the reported variation in oversight through multidisciplinary Medication Advisory Committees (MAC). The Committee should also look to identify whether the principles of the Commonwealth Government's Quality Use of Medicine strategy, a central objective of the National Medicines Policy, are currently being met within aged care facilities in Queensland

Medicines are complex and medication errors cost Australia more than $1.2 billion annually. PSA believes clearly defining the roles and utilising the expertise of pharmacists in aged care facilities would ensure appropriate prescribing, a reduction in medication errors, and clinical, operational and economic benefits through the safe and optimal use of medicines.

PSA strongly recommends that the Queensland Government allocate funding to embed pharmacists into its 63 public sector aged care services located within Queensland to assist in improving the health outcomes of residents.

PSA, as the peak body for pharmacists, requests the opportunity to be further consulted to provide expert advice on any changes to and subsequent implementation of aged care services in Queensland.

End-of-life and palliative care

In Australia, the demand for palliative care services is increasing due to the aging of the population and increases in the prevalence of cancer and other chronic diseases that accompany aging.[xv]

As stated previously, it is a fundamental competency and expectation that pharmacists "collaborate and work in partnership for the delivery of patient-centred, culturally responsive care". This includes during end-of-life and palliative care of Queenslanders, and pharmacists should be embedded within healthcare teams to improve decision making for the safe and appropriate use of medicines during these stages of life.

Palliative Care Australia considers access to medicines as a key focus for patients so that a person and their family or carer is able to access appropriate medicines as and when required within a quality use of medicines safety and regulatory framework.[xvi] As the custodians of safe medicine use, pharmacists are an integral part of this.

The National Consensus Statement issued by the Australian Commission on Safety and Quality in Health Care highlights medication review as a key end-of-life care intervention.[xvii] This would include review to determine whether certain medications should no longer be prescribed or administered.[xviii]

The Statement also outlines the importance of developing consistent processes for accessing palliative care medications that might improve timeliness of treatment for distressing symptoms. Systems should be in place to provide clinicians with access to essential palliative care medications 24 hours a day and 7 days a week in alignment with National Safety and Quality Health Service Standard 4 (Medication safety).[xix]

A study in 2011 showed that the inclusion of a pharmacist in a community multidisciplinary palliative care team undertaking various roles has great benefits for the team, patients and carers with a foreseeable outcome of fewer hospital admissions for the palliative care patient and the reduction in the prescribing of unnecessary medications.[xx]

PSA is aware of projects occurring within various Primary Health Networks (PHNs) looking at supporting the increasingly preferred option of palliative care in the home, focussing on end-of-life care which involves pharmacists as part of the team. As outcomes from these projects become available, PSA encourages the Committee to review them and consider them as part of this inquiry.

PSA, as the peak body for pharmacists, can provide expert advice and requests the opportunity to be further consulted on any changes and subsequent implementation of end-of-life and palliative care services within Queensland.

Voluntary assisted dying (VAD)

PSA does not advocate for, or against, the availability of voluntary assisted dying (VAD).

PSA supports the timely and equitable access to high quality palliative and end-of-life care for all Australians, and calls for greater awareness and education of these to remove misconceptions and biases to care.

As experts in medicines and their use, pharmacists provide a vital role in all instances that a medication is supplied. Pharmacists must be an integral part of the implementation and delivery of any legislated pathways that provide access to medications for the purpose of assisting a person to voluntarily end their life.

PSA believes the diversity of pharmacist opinion on VAD must be respected, acknowledging some pharmacists will support it, while others may conscientiously object to participating. And in doing so, pharmacists must practise in accordance with the *PSA Code of Ethics for Pharmacists*, to appropriately facilitate continuity of care for the patient.

Should the Queensland Government proceed with a VAD scheme in Queensland, PSA as the peak body for pharmacists, requests to be involved and consulted on the development of the scheme, taking into consideration the critical role pharmacists play in the Quality Use of Medicines.

Summary

On behalf of the pharmacy profession, PSA appreciates the opportunity to contribute comments to this Inquiry to help inform the Committee on its recommendations to the Queensland Government.

Pharmacists are committed to being core members of the health care team that delivers high quality, patient-centred primary care. Integration of pharmacists in collaborative care teams will benefit patients through improved access to timely and more seamless care.

PSA welcomes the opportunity to give evidence at the public hearings and as the peak professional body for pharmacists, should be involved in any changes to the healthcare system that have implications on pharmacy practice.

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Inquiry into aged care, end-of-life and palliative care, and voluntary assisted dying

The Queensland Parliament's Health Committee is considering how aged care, end-of-life and palliative care are delivered for Queenslanders. The committee is also considering, and seeking views on, whether voluntary assisted dying should be allowed in Queensland.

We want all Queenslanders to have their say on these important issues. See the committee's issues paper for more information. Let us know your views below.

The committee is taking comments for the inquiry until 15 April 2019.

Return by 15 April 2019

Please send your comments to:

Health Committee
PARLIAMENT HOUSE QLD 4000
Fax: 07 3553 6699

Or scan and email it to:
careinquiry@parliament.qld.gov.au

Your details:

~~Mr~~/Ms/~~Mrs~~/~~Dr~~: Nancy Rowe

Day time phone number: ( ) [redacted]

Email address: [redacted]

Address: [redacted] MOURA *Postcode:* 4718

What would you like to tell the committee?

See Attached Submission

1

See Attached Submission

Please attach extra pages as required

Publication of your comments:

The committee may publish your comments as a submission. For comments provided by individuals, the committee will first remove personal contact details such as phone numbers, street addresses and email addresses.

I agree with the publication of my comments as a submission ☑ Yes ○ No

Request for the comments to be treated confidentially by the committee:

If you have provided personal information or other information you would like to be kept confidential by the committee and not published, please explain briefly your reasons why:

Are you providing comments on behalf of others or an organisation? ☑ Yes ○ No

If yes, please tell us the name of the person or persons or organisation: Moura Community Advisory Group (MCAG)

Their daytime phone number: : Chairperson MCAG Debbie Elliott [redacted]

What is your relationship with that person or persons, or your role in the organisation? Secretary MCAG

I am authorised by ......MCAG...... **to provide these comments on their behalf.**

Signature:......M Rowe...... **Date:** ......15/4/19......

Need Help?

If you have any questions about the inquiry or making a submission, please call the committee secretariat:

07 3553 6626 or 1800 504 022 Free call

Focus of this submission is on delivery of aged care services in rural/regional areas.

This submission is on behalf of Moura and district communities in Central Queensland based on contributions of community members to aged, palliative and respite care surveys in 2013 and 2017, ongoing feedback and contributions from community members over many years and our community involvement with Central Queensland Hospital & Health Service to secure an aged care extension to Moura Community Hospital as a Multi Purpose Health Service (MPHS) – see Attachment 1 for an example of the needs originally identified in terms of aged care.

Identifying Need: Community - a rich source of information

- It is the strong belief of community members and highest priority that aged care services be available for individuals in their home town. As a community we want to provide a local caring place for our elderly once they are in need of high care.
- A major driving force is the need to alleviate the stress, social and economic burden caused for our elderly and their families by pressure of having to relocate many hours away for care (See Attachment 2 for letter outlining impact on elderly and family of not having a high care aged service close by).
- It is an honour to care for those in our community who have given so much and to stop the practice of forcing them to leave their hometown for their end of life journey. We trust that completion of an aged care wing for Moura MPHS and associated outdoor purposefully landscaped area will deliver the hopes and dreams of our elderly for end of life close to family and friends.
- Since Moura's successful application for Federal allocation of 8 aged care places an interim measure is in place with one aged care bed. The impact of having this bed in place was immediate and demonstrates how critical it is for rural and remote communities to have equitable access to services close to family (See Attachment 3 for letter detailing how valuable access to local high care is for the elderly and family).
- Moura community is working in partnership with CQHHS to secure funding for the aged care extension (See Attachment 4 for Background Information)

Innovation: Connections, Partnerships & Technology

- Continue to support and enable communities to be active participants in planning and delivery of services through processes such as Community Advisory Groups. Moura is an example of how making sure community has a voice has helped build strong partnerships between multiple stakeholders, especially CQHHS.
- See Attachment 5 for brochure that demonstrates what underpins innovation in Moura in terms of ensuring community are able to communicate needs and work successfully with government to achieve positive outcomes.
- Community voice leads to community ownership, understanding and willingness to partner. Led by the Community Advisory Group a very active FB page ensures information is shared and there is an open forum for conversation – see 'Let's Keep Moura Hospital Open' Facebook page, 2000 followers.
- Moura community have recently ensured a free women's health clinic was maintained and facilitated building of an emergency landing site due to community funding that included

contribution by industry. Smaller communities are generous and willing to contribute funding to maintain or enhance health services.

- For smaller communities having modern modular facilities allows for easier extension of infrastructure such as aged care. On site medical practices are also of great benefit along with services such as tele-health reducing the need for elderly to travel for specialist support. Aged Care as part of a MPHS also has access to visiting specialists and often dental services.

Att. 1

Community Survey Update: Demand for Aged Care, Respite & Palliative Care Services for Moura Hospital

01-02-2014

- 154 Surveys returned within a 2 week period - approximately 62%
- 14 respondents aged 80 and over
- 17 respondents aged 75 – 79
- 27 respondents aged 70 – 74

Key points from 80 and over age group

- 71% have been outpatients of Moura hospital within last 2 years
- 79 % have been inpatients of Moura hospital within last 2 years
- 5 respondents would use aged care at the hospital now, a further 7 consider they would use aged care at the hospital within 5 years and a further 2 within 5 to 10 years
- 3 respondents would use respite now, a further 8 consider they would use respite within 1- 5 years and 2 within 5 to 10 years
- 1 respondent may need palliative care now, 10 consider they may need palliative care from 1-5 years
- 80 % of respondents are very concerned about their future if aged care, respite services and palliative care are not available at Moura hospital
- All respondents know of at least 12 elderly people who have had to recently move away from their homes and families to access aged care facilities. These people have had to move to locations such as Biloela, Rockhampton, Emerald, Brisbane, Yeppoon and Gladstone.
- Respondents report that these forced moves have had a high level of impact on the well being of the elderly and their families

'Growing old presents its own trauma at losing one's independence. Knowing ongoing care is available at Moura Hospital adds greatly to my peace of mind – that of family too.'

'As an aged person we do not know what is ahead of us, but knowing the hospital is there is a great comfort. I have private health insurance and this is a help for the hospital'

'This is a very stressful time for me at the moment. I have lived in Moura for 43 years and do not want to move from here to access services'

Att.4.

Moura Multi-Purpose Health Facility: Aged Care Extension
Key Points & Background Information

- The Australian Federal Government have approved 8 high care aged beds for Moura in the 2018-2019 Flexible Aged Care Places (Multi-Purpose Services) Allocations Round
- The Australian government financial provision for the operation of 8 aged care beds is subject to Central Queensland Hospital & Health Service (CQHHS) obtaining capital funding from the Queensland government to establish the appropriate infrastructure
- Works is estimated at approximately 7 million including all site works, project management, equipment fit-out and contingencies
- CQHHS are currently developing a proposal for a capital works program to secure funding for the aged care extension
- CQHHS is bidding for capital funding in competition with Hospital & Health Services across the State

Background Information:

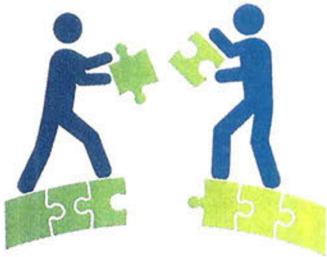
- The successful Aged Care application for Moura was developed by CQHHS in conjunction with the Moura Community Advisory Group representing the Moura and district communities.
- The proposal was underpinned by two community surveys conducted by the Community Advisory Group in 2013 and 2017 and by ABS census data. Evidence from the surveys and ABS census data demonstrated the need for aged care places in Moura.
- It is vital to have the aged care facility in place as soon as possible as there is an extensive waiting list of people for residency.
- As acknowledged with the successful allocation of 8 aged care beds Moura has the population to sustain a Multi Purpose Service (MPS). Neighbouring communities of Theodore and Baralaba with populations of 438 and 314 both have MPS's with waiting lists
- Moura is one of Queensland's oldest coal mining towns. There are multi-generational families in the workforce. Many families have retired in Moura. As such there is an aging population.
- Moura also services nearby agricultural communities of Banana and Bauhinia. These rural communities have an aging population who seek to stay in their communities and close to family.
- Moura has a community owned Independent Living Retirement Village. Over time residents are looking to transition to a higher care facility in their home town.
- In recent times 'grey nomads' are choosing to take advantage of cheap housing prices. This trend is expected to continue adding to the aging population of the town.
- Moura MPHS (formerly Moura Community Hospital) was the first rural area in Queensland to use innovative modular design. The current contemporary and modern facility is ideally positioned for an innovative aged care extension.
- The Moura community already have significant funds in place to assist with provision of an outdoor area and to assist with resourcing areas of the aged care facility.
- Many older people from the Moura community and district are anxiously waiting for the aged care extension for the Moura MPHS for their end of life journey.
- Moura community have been major players in shaping the Aged Care Project and believe there is opportunity to make the Moura Aged Care Extension a reality by 2020 with the support of all levels of government.

Moura Community Advisory Group (MCAG)

Moura Community Advisory Group (MCAG) are pleased to work with our community and relevant health stakeholders to ensure that Moura and district have a strong voice in health services decision making, planning and delivery for our area.

Strengthening relationships

Community members need to be confident to ask questions and contribute ideas into ways that health care is designed and delivered. MCAG ensures there is a shared awareness and understanding of community and consumer needs and the capacity of health services to deliver.



Successful communication

MCAG listens to and involves community, keeping them informed via multiple channels such as our active Facebook page 'Let's Keep Moura Hospital Open' with over 2000 members. This medium gets immediate feedback on issues or problems that need attention. Local media championed our community hospital campaign running features and networking with regional newsrooms.

Leading change by

- Understanding consumer/community needs
- Encouraging mutual respect and trust
- Building positive partnerships
- Safeguarding a strong community voice
- Using multiple communication channels
- Looking for opportunities
- Focusing on agreed outcomes
- Embracing innovative delivery
- Being inclusive and transparent
- Enabling shared decision making
- Celebrating success
- Sharing our story

Key contacts

Debbie Elliott:
MCAG Chairperson
Phone: [redacted]
Email: [redacted]

Trevor Davis:
Director of Nursing
Moura Community Hospital
Phone: [redacted]
Email: [redacted]

Developed in partnership with Moura Community Advisory Group (MCAG) and Central Queensland Hospital and Health Service.

Central Queensland Hospital and Health Service. This document was reviewed in April 2017, Version 1.0. Print ID P1648 v1.0 02052017
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Changing lives for the better
Central Queensland Hospital and Health Service

Moura Community Hospital

Consumer engagement and partnerships

Keeping Connections Strong

Moura Community and Central Queensland Hospital and Health Services

Living our values
Care Integrity Commitment Respect

Queensland Government

Keys to engagement

Collaboration

Innovation

Sharing and understanding

Humility

Learning together

Helpfulness

- Be inclusive, open and transparent
- Communicate early
- Make time frames reasonable
- Listen and work together
- Mutual faith and trust

Building positive partnerships

"We are at the start of a process that is seeking to involve the community, the health service, the health service Board and the Queensland Government as equal contributors to the engagement process. The outcome of the Moura Hospital issue has potential to be seen as a benchmark for other rural communities of Queensland. We need to embrace the opportunity we have been given and ensure that Moura Hospital is Strong, Smart and Sustainable."

Debbie Elliott
Chairperson Moura Reference Group (2013)

Grassroots engagement

Moura community has a powerful story to tell about engagement, partnership building and leadership for positive change.

Achieving change

Moura now has a contemporary and modern facility with:

- Innovative modular design
- Quick onsite build
- Capacity for easy extension

Current projects

Multi-purpose extension for aged, respite and palliative care

Development of an emergency landing site

Enabling and embracing different delivery models

Public/Private Dental Service

Telehealth Services

Moura Community

Engaged

Active

Empowered

Positive

Strong Consumer Voice

Our Success Story: Moura Community & Central Queensland Hospital & Health Service

Moura, a small rural community in Central Queensland, has a powerful story to tell about passionate grassroots engagement, partnership building and leadership. In 2013 a decision by the Central Queensland Hospital and Health Service Board to turn the Moura hospital into a treat and transfer centre was overturned by community through a passionate campaign that attracted state-wide attention. A Reference Group comprising community and management of Central Queensland Hospital and Health Service (CQHSS) engaged in weekly meetings over three months to negotiate a better way forward. A contemporary and modern hospital facility was the result of this engagement. Formation of a Community Advisory Group was welcomed as an opportunity to maintain community energy and enthusiasm and to work together with government and health authorities.

Today the Moura Community Advisory Group (MCAG) partners with CQHHS to ensure the health needs of Moura and district continue to be met:

- Health consumers are now better informed, consulted and involved in shaping the way services are designed and delivered in the community.
- Increased number of consumers access services due to community assistance with advertising and promoting services.
- Tools such as the very active Facebook page 'Let's Keep Moura Hospital Open' helps keep in touch with community and provides a forum for immediate feedback on healthcare issues.

Keeping connections strong between community and health service providers has achieved positive culture change:

- Community members are more confident to ask questions and contribute ideas into ways that healthcare might be better delivered.
- Healthcare services are open and willing to listen to and work with community.
- There is a shared awareness and understanding of community and consumer needs and the capacity of the health service to deliver.
- Strong and inclusive leadership in community and government has fostered a spirit of trust and helpfulness.

Key Contacts:

Debbie Elliott MCAG Chair E[redacted]
Trevor Davis DON Moura Community Hospital [redacted]
Kristine Jones MCAG Member [redacted]
Nancy Rowe MCAG Member [redacted]
Graeme Torrance CQHHS [redacted]
Anne-Marie Kinsella CQHHS [redacted]

Health Consumers Queensland submission

Queensland Parliament

Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee

Inquiry into Aged Care, End-of-Life and Palliative Care, and Voluntary Assisted Dying

15 April 2019

Contact:

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About us

Health Consumers Queensland is the peak organisation representing the interests of health consumers and carers in the state. Health Consumers Queensland is a not-for-profit organisation and a registered health promotion charity and we believe in improving health outcomes for people in Queensland.

Consumers are people who use, or are potential users, of health services including their family and careers. Consumers may participate as individuals, groups, organizations of consumers, consumer representatives or communities.

Our priority focus is on consumer engagement that influences and leads improvements and delivers better health outcomes for all Queenslanders. We achieve this through our Queensland-wide health consumer network, tailored training and skills development programs, and maximising opportunities for consumer representation at all levels of the health system.

Consumer engagement is when health consumers actively participate in their own healthcare and in health policy, planning, service delivery and evaluation at service and agency levels.

HCQ HEALTH CONSUMERS QUEENSLAND

STRATEGIC DIRECTION 2018-2023

MISSION
Health Consumers Queensland enables and empowers consumers to influence, lead and drive better health outcomes

VISION
Consumers and community partnering with the health system for consumer-centred health care for all Queenslanders

VALUES
Leadership
Positive Impact
Fairness
Innovation
Partnership
Zing/Zest

Our Six Strategic Objectives

1. Enabling health consumers and healthcare staff statewide
We build consumer, staff and system capacity to design a health system together through collaborative, integrated and consumer-centred approaches by providing support, strategic advice, training and advocacy.

2. Acting as an agent of change for consumer-centred health care
In partnership with consumers and healthcare staff, we act as a strong voice on system wide issues to influence key decision makers, policies and models of care to deliver a high quality consumer-centred health care system for all Queenslanders.

3. Enhancing effective partnerships
We develop and grow effective organisational partnerships locally, nationally and internationally to achieve consumer-centred health care for all Queenslanders.

4. Building and using evidence
We support consumers and staff to be involved in co-creating the evidence base for health system development and transformation. We act on the evidence of the human lived experience of the health system to build capacity of consumers and to leverage system change.

5. Being transparent and enduring
We demonstrate transparency and responsiveness on behalf of consumers, community and our funders. We maintain strong leadership and governance to assure organisational sustainability and longevity. We support the passion, energy and courage of our staff and members of our Network.

6. Addressing the social determinants of health
We acknowledge that systemic reform of the health system requires recognising the social determinants of health and co-designing models of care that address them.

Areas of Focus

Our areas of focus in implementing our strategic objectives

In partnership with consumers (including vulnerable groups) and staff, we act as a strong voice on system wide issues such as:

- **Healthcare Rights:** Breaches of healthcare rights which prevent fair, just and affordable access to healthcare;
- **Quality & Safety:** Where quality and safety and/or consumer experiences are of concern;
- **Healthcare Standards:** Embedding healthcare standards around consumer engagement, comprehensive care and health literacy; or
- **Systemic Issues:** Complex, dificult or contentious systemic issues.

Introduction

Health Consumers Queensland along with COTA Queensland, Palliative Care Queensland and Carers Queensland have partnered with Clinical Excellence Queensland, Queensland Health to undertake consultation with consumers and carers on "*What matters to them in relation to ageing, end-of-life care and dying*".

Our submission is based on the outcomes of the first stage of the consultation process involving 20 kitchen table discussions held across Queensland over a two-week period in March 2019 with 183 community members. The kitchen table discussions were hosted and facilitated by consumers and carers within their own community. Each host was provided with five key questions for their discussions.

Thirteen key themes emerged from the consultation with a consistency of feedback across the 20 sessions:

1. Staying at home (care in the home)
2. Access to quality and timely care and support
3. Better Information and knowledge, better navigation and choice
4. Voluntary Assisted Dying – Dignity and Choice
5. Care Choice (choice around what I need/individualized)
6. Informal Support System (family carers, volunteers, community)
7. Workforce (paid support workers/health professionals)
8. Palliative Care
9. Emotional Support, Burden and Risk
10. Financial Support, Burden and Risk
11. Communication
12. Transport
13. Housing

Our submission is also based on our Board's input and consumer-focused principles of person-centred, integrated health care:

- Accessibility - safe, affordable and high quality services, treatments, preventative care and health promotion activities.
- Respect - healthcare that meets consumers' unique needs, preferences and values
- Choice – a responsive health system which ensures consumer choices in prevention, treatment and management options
- Participation - patient involvement in health policy to ensure that policies are designed with the patient at the centre.

Recommendations

Recommendation 1:

Our consultation showed that the current aged care system is in urgent need of system reform and that the majority of consumers want to remain at home and be cared for at home.

Our recommendation is for an improvement and greater focus on access to quality and timely care, resources and support for people wanting to maintain their independence and remain in their own home or with their family through ageing and end-of-life stages. This includes:

- Access to home help and care packages appropriate to the individual's needs, with the necessary equipment and modifications to support being able to stay at home. Timelines and turnarounds for care packages should be based on 'need' and not the 'system'.
- Home care packages to be reviewed to take into consideration the social determinants of health, the need for intellectual stimulation, and be more socially inclusive and culturally appropriate i.e. visits to cattle sales as part of social engagement for rural and remote people.
- Quality and timely care is also reliant on systems working together and having in-home care services that are tailored to the person and respectfully provided.
- More qualified paid support workers, more opportunities for additional education for paid support workers to facilitate quality, respectful care to people in their own homes.
- Provide training and education opportunities and the necessary supports to enable family members to care for their loved ones at home.
- More knowledge of what supports are available to carers to keep their family member at home is required i.e. Palliative Care in the home and not in a facility.
- There needs to be a reduction in financial burden on family carers to enable more people to be cared for at home. Reduce the focus on the combined income of the home in determining care packages.
- There is a preference for community living for those in care or without families, clusters of share homes and facilities with a small number of beds. Care facilities within their existing community network is a preference.
- Facilities need to be less institutional in their structure and environment and more home-like environments for people to want to access these facilities.
- Reduce the requirement in rural and remote communities for people to be placed in care facilities often at a great distance from their local town, families and friends
- Increase in the use of telehealth for specialist appointments.
- Provide more culturally appropriate care with a focus on ethnically cultural in-home care with broader definitions around care activities to ensure cultural needs are being met.

Recommendation 2:

Choice of care and individualized care were another consistent message throughout the consultations. Consumers clearly indicated they want choice when it comes to care and end-of-life options, to know what choices are available to them and where care is delivered.
People should be supported to have the right to dictate their care and the location of that care.

- Provide care choices that enable integrity and preserve identity.
- Provide more clarity in relation to a person's rights and ensure their decisions are respected and acted on.

In relation to voluntary assisted dying (VAD) our consultation indicated that many wanted this to be made legal. Three aspects were particularly highlighted in discussions relation to VAD:

1. Choice to decide timing of death
2. Choice of VAD due to other options of care not being satisfactory (i.e. palliative care and nursing homes)
3. Current health system focus on "keeping people alive"

Many indicated they want to 'control the time of death' and 'decide when it is over'. For some life should be ended when it is no longer dignified. They ask for choice on how and when they die, if they want to be alone or with their family.

The preference of VAD in relation to current care options was highlighted.

We suggest there needs to be better/more flexible/more accessible palliative care services as people may be choosing VAD as their only alternative to sub-par palliative care services, rather than VAD being their preference regardless of services available.

Recommendation 3:

Reduce the emotional and communication challenges for both the patient and their family/carers by providing Queenslanders with better access to information and knowledge to make informed choices and decisions. They need better quality information, seamless communication and easier navigation to support their decision making in regard to ageing, end-of-life and palliative care, and dying.

- Provide programs and education towards improving not only health literacy but death literacy of Queenslanders.
- Information that is currently provided on care packages and options is deemed to be 'too complicated when already overwhelmed', as is the documentation for Advanced Health Directives. More consumer friendly forms are required and more consultation with consumers to develop the forms and promotion of Advanced Health Directives.
- Improve clarity and understanding of associated forms and their purpose i.e. Advanced Health Directives, Statement of Choices and Power of Attorney.
- Establishing a navigator role similar to nurse navigators with Queensland Health would provide a level of support to patients and their families that may not currently be available. This would support consumers to understand the decisions they need to make, the choices and options available to them towards the end stage of life. This would reduce the burden on both the patient and their family in making their choices, also helping them navigate the challenging paperwork requirements.

Recommendation 4

Our consultation identified the need for more education about what palliative care is, what is available to consumers and how to access palliative care. In addition, knowledge of where palliative care can/is provided (such as in the home) appeared to be limited, resulting in the need for better community education on the role of palliative care at the end stage of life.

- Provide increased access to equitable palliative care practice across Queensland
- Provide care packages, funding and workforce training to enable more palliative care at home and to increase palliative care beds close to a patient's home and community.
- For some people diagnosis is taking too long and this is impacting on their ability to access palliative care for their loved one.
- People with chronic conditions should have access to palliative care support.
- Improve and increase education opportunities for clinical staff caring for patients at the end stage of life.
- Provide personal care courses for family carers to better support their family member/loved one.
- Consider funding courses for family carers and their family members on grief and loss (including children) through the use of narrative therapy models.
- Support and fund Palliative Care Queensland's program to establish Compassionate Communities throughout Queensland.

Recommendation 5

Genuine ongoing consultation on Voluntary Assisted Dying to be undertaken with Queenslanders of all age groups and demographics, with particular consideration given to young people transitioning from paediatric palliative care services into adult services, and the carers of paediatric palliative care consumers.

- Establish a community reference group early on, with the necessary safeguards and protocols in place to ensure engagement on VAD legislation, implementation and oversight is meaningful. Engage high quality facilitators who can advise on the consultation questions and how to address the topic with consideration of the social and emotional determinants.
- Health Consumers Queensland in partnership with Palliative Care Queensland, COTA Queensland and Carers Queensland be funded to continue to hear the voice of community on these important subjects through Kitchen Table Discussions which are led by consumers and carers consulting with their own community members. This provides an avenue for community members whose voice isn't always heard to have their say in a safe and supported environment.

Conclusion

Health Consumers Queensland strongly believes there is a need to re-develop and re-think aged care, end-of-life and palliative care services in Queensland to meet the needs and expectations of the community.

Health Consumers Queensland is undertaking a second phase of consultation on ageing, end-of-life care and dying during the months of April, May, June and July. This will inform our position on the Voluntary Assisted Dying aspect of the Parliamentary Inquiry.

phn
QUEENSLAND PHNs
An Australian Government Initiative

15 April 2019

Committee Secretary
Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee
Parliament House
George Street
Brisbane QLD 4000

Sent to: careinquiry@parliament.qld.gov.au

Dear Committee Secretary

Re: Queensland PHNs submission to Queensland inquiry into aged care, end-of-life and palliative care and voluntary assisted dying

This submission is made on behalf of the Queensland Primary Health Networks (QPHNs). There are thirty one PHNs established across Australia, seven of which cover the state of Queensland. The PHNs are funded by the Commonwealth Department of Health with the aim of increasing the efficiency and effectiveness of medical services for patients, particularly those at risk of poor health outcomes, and improving coordination of care to ensure patients receive the right care in the right place at the right time.

The focus of the QPHNs is on primary care, particularly through the support of General Practitioners, and on working with a range of government and community organisations, service providers and the community to develop and better integrate health and community care services.

PHNs play a key role in coordinating primary healthcare to improve whole-of-life health and wellbeing across our region.

We work with a wide range of primary healthcare services and health professionals to improve access to and delivery of services for patients, with a particular emphasis on those most vulnerable people at risk of poor health outcomes.

Aged care has been identified as a priority for PHNs across Australia.

This response addresses aged care and palliative care and end-of-life care within the scope of the Inquiry issues paper. A collective view on voluntary assisted dying is not included in this submission.

- *Appendix 1: List of co-signed organisations to this Queensland PHNs submission*
- *Appendix 2: Brisbane North Palliative Care Collaborative submission to Queensland Health Palliative Care Services Review*
- Health alliance co-design workshops with RACFs and community service providers

Thank you once again for the chance to comment and the Queensland Primary Health Networks look forward to working closely with the Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee to improve aged care, palliative care and end-of-life care for all Queenslanders.

Yours sincerely

Abbe Anderson

Abbe Anderson
Chair
Queensland Primary Health Networks

Aged care

Queensland PHN submission in response to issues for consideration:

1. **Is the aged care system meeting the current needs of older Queenslanders, including those people with special needs? Why or why not?**

The collective view of PHNs across metropolitan, regional and rural Queensland is the demand for both residential and in-home aged care services outweigh supply.

This is evidenced by long wait times, variability in the quality of services and the misalignment between services delivered and the expectations of older people accessing those services.

Consumer expectations and knowledge of aged care services also varies as older people, their carers and families struggle to navigate increasing system complexity. Even those with good health literacy, and those who work in the sector still struggle when seeking care for themselves or their families.

My Aged Care is not meeting the needs of older people and for those who are using it, the satisfaction rates (while within standards of call centres) are lower than communities expect. Many frail aged people who are living at home report they are not phoning MAC for assessment to the home care services due to cognitive challenges, hearing or dexterity issues and are ‘giving up’, therefore falling between the cracks and not accessing ANY in home support services.

Many people who are vulnerable require support and assisted access into the system, which may include outreach, and this is all unfunded at present, relying on those providers with specialist staff and care models to provide assistance.

The system is also not set up well to support couples, either for in-home services or residential care. There are many structural and financial barriers to supporting couples when one or both require care.

The aged system requires better integration with the health system and primary health networks offer a mechanism to achieve this.

Post Hospital Discharge Services

In our collective experience, many people accessing state funded services on discharge from hospital are missing out on services, or receiving services for a shorter duration than is within the program guidelines, i.e. they may be entitled to and need 12 weeks of care, but are only receiving four weeks due to competing demand for services.

There remains ongoing misalignment with My Aged Care and older people receiving support services as a timely response.

In-home services delivered under the Commonwealth Home Support Program (CHSP) and Home Care Packages (HCP)

Complementing the experience of older people and their families and carers, service providers tell us that as in-home care providers, they have a lack of flexibility within program structures to allow them to adapt to meet consumer expectations, i.e. being flexible with funding across activities. Greater flexibility would also make transition from hospital and other services smoother as well and better accommodate changing needs over short periods of time.

A lack of acuity tool for CHSP makes it difficult to prioritise needs in an environment of high demand, capped supply and wait lists.

Meanwhile for service providers delivering Home Care Packages, there is increased tension between consumer choice and competition for services, which puts commercial pressure on providers to balance client acuity and complexity, waiting lists, unspent funds and client preferences.

Consumers find the system complex and difficult to navigate, understand and make informed decisions, often requiring the supports during a period of crisis.

Residential aged care

People residing in residential aged care should have the same equity of access to health services as people in the community. The ACFI has not supported adequate clinical care provision and the Resource Utilisation Classification Study makes recommendations to move to a better system.

Qld Ambulance Service (QAS) have reported regular inconsistency in Advance Care Planning documentation for RACFs, and no access to afterhours medical advice for palliative care patients, which result in QAS having no choice but to inappropriately transport the patient to HHS ED.

Many residential aged care facilities continue to use outdated models of care that do not meet current consumer expectations. The introduction of standardised care pathways for acutely unwell residents would provide guidance on alternatives to hospital presentation.

Surveys of residents and families report too little care time by staff, inadequate clinical care when residents are unwell or at end of life, inadequate access to allied health services including psychological therapies and diversional therapies, minimal access to the outdoors and low rates of visitors if any for many residents.

Social isolation is increasingly recognised as a major contributor to poor psychological and physical health.

This speaks to unacceptable treatment of older people by our care system and community.

Respite fails to provide short-term relief for carers

In residential aged care, there are inadequate systems to support respite care for older people who need to move in and out of respite to give their family or carer a break.

Older people who do get into respite within residential aged care often struggle to get out again because of funding constraints limiting the opportunity for only short term episodic care provision. The system is incentivised to support older people in residential aged care as a permanent occupant. If more people were able to be accommodated for interim periods for rehabilitation (e.g.: post hospitalisation as with Transition Care Program) they may be reabled to return home. It is a clear message from older people that the majority would like to remain in their own homes and as independent as possible for as long as possible.

Data shows that people are entering residential aged care at an older age than previously, with higher care complexities and for shorter periods of time prior to death. The care system has not responded well to these complex health care needs.

System favours larger providers

Bigger providers have the advantages around economies of scale but smaller providers are often more agile and flexible in meeting individual needs. The ACFA report demonstrates that particularly rural RACFs and smaller providers of residential care are losing money and experiencing workforce availability issues.

Older people, their families and carers tell us that for in-home services delivered under the Commonwealth Home Support Program, they want consistency and continuity, i.e. they want to have the same care worker at the same time each week, and to have a say in how services are delivered. Variability across service providers is noted, for example some will provide a five-hour window for service delivery, while others will provide specificity of appointment times. It is commonly the large providers who only offer a time frame range.

Longstanding, large community care service providers, who to date have absorbed the impact CHSP funding limitations and long HCP wait lists, are now in financial deficit and have put all new community nursing admissions on hold, stating 'lack of capacity', increasing the demand on other community service providers who do not have adequate staffing levels and increasing therefore avoidable presentations to ED.

Discharge referrers from Hospitals favour large organisations for services such as Nursing and Allied Health even when there are more culturally appropriate services available through other providers. The lack of distribution of referrals to a range of providers means that it is difficult for the small to medium organisations to invest in their clinical services and staff e.g.: 7 days per week nursing. The result is that older people experience multiple organisations coming into their homes to provide various activities. Greater continuity and consistency would see one wrap around service.

Community service providers not incentivised to facilitate access for older people experiencing disadvantage

Older people who experience disadvantage do not have the same equity of access to in-home and residential aged care services as other older people in the community. This includes older people from culturally and linguistically diverse communities, Aboriginal and Torres Strait Islander people, those who are homeless or at risk of homelessness, those with cognitive impairment and those experiencing mental illness.

These older people may be unlikely to proactively access services, i.e. they are not going to ring a call centre or provide their personal details over the phone. Many are also resistant to and untrusting of government and service providers and reticent in regard to institutionalised care.

Currently the system relies on community service providers facilitating access to aged care services for older people who experience disadvantage. Service providers are not paid for this system facilitation role, despite them being best placed to support people experiencing vulnerability through their existing outreach models and established trusted relationships with communities.

In addition, it is challenging for these service providers to remain viable given their costs of delivering services and supporting older people experiencing vulnerability is already higher than commercial providers.

Without community service providers undertaking this service, it is anticipated that older people experiencing vulnerability would fall through the cracks and miss out on aged care services.

New models of care to work-around system failures

Private and public hospitals struggle to navigate My Aged Care for safe discharge of their patients back home.

The proliferation of system navigators (such as those in aged care, mental health and disability services) is reflective of the complexity of the system and the difficulty that patients and their carers have in understanding and accessing different parts of the system. Simplifying and integrating the different system components should be a reform goal.

2. **Are the current waiting times for both residential and home care places adequately meeting the needs of older Queenslanders?**

   Cherry-picking leads to lack of equity of access within residential aged care.

   Data releases on waiting times for both residential and home care places show that needs are increasingly not being met as budget and package releases are not keeping up with demand.

   In residential aged care the data is only part of the story. While there are increasing numbers of vacancies in residential aged care, there are often long waiting lists at certain facilities, i.e. those in particular geographical locations, or where the facility has a strong reputation or is regarded as a high quality service.

   As a result, these facilities are able to cherry pick older people with less complex needs and Queensland Health owned facilities are left to pick up the most complex patients, e.g. bariatric patients entering residential aged care who require costly equipment and present with challenges accommodating the needs of these older people within the residential aged care pricing structure.

3. **Do the standards of residential aged care, home care and other aged care services provided in Queensland meet clients' and the community's expectations? Can you give examples?**

   The new aged care quality standards place a greater emphasis on consumers and true consumer engagement. However the standards are at a minimum level of quality. Surveys of residents pre announcement of the Royal Commission into Aged Care saw results of 1 in 4 agreeing that the quality of care is good and having trust in the care.

   For in-home services, clinical governance is becoming more critical as we see an increase in the complexity of clients and examination of if the clinical standards go far enough.

   System fragmentation and lack of coordination are known issues but the standards are not measuring how well providers work with GPs and allied health (this interface should be measured and barriers identified (e.g.: difficult to engage with primary care professionals).

4. **How will demand for aged care services change in Queensland as the population increases and ages, and what changes to the aged care system will be needed to meet future demands for aged care?**

   Rationing will be the only way to meet the demand, user pays is already happening with consumers contributing $5B in 17/18 and thus the move to a safety net rather than universal system.

   There needs to be a prioritisation of need, embedding of the wellness approach, funding prevention to delay the need for services (active@home and social inclusion services).

   Allowing an easier movement between step up and step down (like mental health), if you are on Level 4 when you get out of hospital and receive intensive support, you improve and only need level 2 leading to not fully utilising these funds. A greater application of rules around unspent funds are needed.

   QCC funding for under 65 years, these patients needing home care services must now have an NDIS assessment first, therefore slowing down the access time to home care support services and increasing the risk of avoidable hospitalisations. The disconnect between disability and aged care services also puts people at risk.

5. **Are there enough residential aged care places (beds) available in aged care facilities, in areas and at the levels of care that are required?**

   ACFA data shows an increase in available beds overall (some additional but also decreasing occupancy) but this is variable across regions e.g.: rural and remote. The current move to shift investment to in-home services is effecting the market as is the Royal Commission, where the number of smaller providers is decreasing and the larger companies are increasing with profits and losses relative. Much of the bed stock will require replacement over the next 10 years. While there are new contemporary facilities being constructed, there are also examples of new constructions of old models of care.

6. **Are adequate numbers of home care packages available in areas at the levels required?**

   127,000 people on the waitlist, the length of time people are waiting and the number of people waiting for higher levels of package care while accessing CHSP suggest the current cap is inadequate.

   The availability of CHSP continues to decline as a flow on effect as HCP clients receive top up services from CHSP and there are now limited services availability.

7. **Are there sufficient staff in the aged care sector to meet current and future workloads?**

   A key workforce enabler is appropriate staff provision ensuring numbers and appropriate skill mix based on clinical requirement and level of resident ability and personal needs.

   Barriers to sufficient numbers of skilled staff are funding, recognition of the value of the workforce, valuing the residents and aged care in general as a society.

   Staffing numbers should be sufficient to allow the release of staff to attend professional development opportunities without impacting on the care provided to residents. Non-mandatory non-compliance training should be seen as necessary for quality care provision as it is in the health sector.

   Moving from a compliance mindset to a continuous quality improvement approach is a key workplace cultural enabler. This requires leadership and commitment to creating a workplace culture, free from fear and potential retribution for both staff, visiting staff, consumers and their carers/families.

8. **Is the mix of staff appropriate for different settings within the aged care sector?**

   There needs to be an adequate number and mix of personal carers, enrolled nurses, registered nurses, clinical nurse practitioners, allied health and visiting medical officers including general practitioners with timely access to geriatricians, psychiatrists and other medical specialties.

   Another important enabler relates to the quality of the workforce. Recruitment should include adequate screening of the suitability of the workforce with a strong focus on attitudes and mind sets, as well as knowledge and skills. A workplace funded continuing education program should be mandatory as it is an important component in quality assurance and staff retention.

9. **Do aged care staff receive training that is appropriate and adequate to prepare them for the work?**

   Aged care staff face a range of barriers to accessing training and the level of training undertaken by the majority of staff doesn’t support the early identification of a deteriorating resident until they are acutely unwell. The development and implementation of national clinical pathways for both nurses and care workers may be a strategy to improve quality and consistency of care with better outcomes for residents.

Nurses in RACFs have suggested peer support strategies such as an 1800 number that can be called day or night when they are on their own, and could benefit from the advice and support from an experienced colleague.

Importantly, improving the clinical care in RACFs cannot be achieved by the facilities alone. Collaboration across aged care, primary health care and tertiary healthcare services is required and PHNs could be effective mechanisms to facilitate this.

10. What are the costs to the public health system of caring for elderly people in hospitals whilst they are waiting for residential aged care places to become available?

There is a plethora of evidence that hospitalisation is detrimental to frail elderly people. In addition to the economic costs of the hospital bed versus residential care costs, the individual has poor health outcomes.

11. Are suitable health care services being provided within residential aged care settings and/or aged care providers?

No. The current funding models and silos (hospital, community care, primary health care, residential) do not support adequate clinical care.

12. Is the current aged care system making an appropriate contribution to the health of older Queenslanders, within the context of the broader health system in Queensland?

Social Isolation is recognised as a major factor in psychological and physical health but there is insufficient investment into social connection as a preventative measure.

13. How can the delivery of aged care services in Queensland be improved?

A move to value based care and outcomes commissioning would allow greater flexibility to meet the needs of individuals and populations to achieve better health outcomes and lower costs. The current funding models and streams across jurisdictions and sectors is not conducive to coordinated and integrated care that supports an elderly person to move along the care continuum as required.

14. Are there alternative models for the delivery of aged care services that should be considered for Queensland?

There are many pilot projects that demonstrate how care can be improved by achieving greater health outcomes, presentations to hospitals reduced and costs reduced, however the funding systems prevent sustainable funding to allow the projects to be replicated at scale and sustained.

Activity based funding in hospitals where the expertise lies and constant levels of funding without the clinical resources are barriers to evidence based care.

See Q 13 above.

15. How will the model of aged care develop with evolving technology and medical practices?

16. What are the key priorities for the future?

Commissioning approach to care provision based on outcomes rather than activity

A greater investment in the workforce at all levels to support quality gerontological care.

The Aged Care Workforce Strategy recommendations (based upon the David Tune review) address the ways to improve the capacity and capability of the workforce in health and community sectors.

End-of-life and palliative care

Queensland PHN submission in response to issues for consideration:

1. What are the palliative care services offered in Queensland?

Throughout Queensland, generalist palliative care is available in a variety of healthcare settings including neonatal units, paediatric services, general practice, residential aged care facilities, acute hospitals, and generalist community services. In addition, specialist palliative care services are also available through a variety of settings, including inpatient settings, hospices and community-based specialist services. Palliative care can also be provided in the home by family and carers with the support of specialist outreach services, general practitioners and generalist community services.

However, service provision is inequitable across regions, with access to services often dependent on diagnosis and geography. This is particularly prevalent in rural and remote areas, but also occurs in metropolitan areas where access to services, in particular specialist palliative care, can differ greatly between hospital and health services.

2. Are palliative care and end-of-life care services meeting the current needs of Queenslanders? Why or why not?

Current palliative care and end-of-life care services do not meet the needs of all Queenslanders. Queenslanders should be receiving timely palliative care in the place of their choice, however this does not always occur.

There are a number of under-served groups that experience various barriers in accessing and choosing the care they wish to receive. These groups include:

- Aboriginal and Torres Strait Islander people
- People from diverse cultural and religious backgrounds
- Refugees
- People who are lesbian, gay, bisexual, transgender or intersex
- People with a disability
- People experiencing homelessness
- People who are incarcerated

Carers may also experience barriers to accessing the care and support they need, including knowing what services are available and engaging a specialist palliative care service or general practitioner to visit the palliative person in their home, particularly after hours. There is also a need for better coordinated respite care and bereavement support for carers both before and after the person they are caring for passes away.

Structural or system barriers to access and choice also exist such as the limited number of specialist palliative care services, concentration of specialist services within metropolitan areas, lack of generalist palliative care providers and siloed funding mechanisms.

Residents of residential aged care facilities are often not afforded the same level of palliative care as people living in the broader community. Contributing factors to the provision of inadequate palliative care in some residential aged care facilities include:

- Current policy settings do not provide the incentives needed to ensure quality care is available to all people in residential aged care who would benefit from it. For example, the current funding structure in residential aged care has no incentive for a palliative or end of life diagnosis with additional funding. The Resource Utilisation and Classification Study recommendations are a way to rectify this and ensure that residential aged care funding for palliative care is sustainable into the future.
- Lack of residential aged care staff experience and knowledge in palliative care

- Lack of medical input from both general practitioners and specialist palliative care services

3. **Do the standards of palliative care and end-of-life care provided in Queensland meet clients' and the community's expectations?**

   Each Queenslander will have different expectations about the palliative care they would like to receive and how they can have a good death. This includes the setting of their care as they approach end of life and the preferred location for their death. A person-centred approach should therefore be embedded in all palliative care planning so that individuals, carers and families are actively engaged in care planning and ongoing needs assessment.

   Research suggests that many people would prefer to die at home, however most do not. Consumers and key stakeholders often report difficulty assessing palliative care services in the home, and lack of assistance for family and carers. This results in many people dying in acute hospital facilities rather than their preferred location.

   Investment is needed into community-based models that are flexible and promote care in the place a person chooses. Service models must allow providers to respond quickly when an individual's condition changes, to avoid inappropriate or unnecessary emergency department presentations at the end of life and support people to remain in their home, if they choose, for as long as possible.

4. **How will demand for palliative and end-of-life services change in Queensland as the population increases and ages, and what changes to the delivery of these services will be needed to meet future demands?**

   As the Queensland population ages, the number of people dying with chronic conditions and complex needs will increase. Comorbidity will be an increasingly significant factor in palliative care due to multi-morbidity, chronic progressive illnesses with longer disease courses, and diseases with complex symptoms and high symptom burden.[1] In addition, an increase in deaths from dementia means that a change in focus in palliative care provision towards people living with dementia will be required.

   An ageing workforce and shortages of medical and nursing staff trained in palliative care will place increased pressure on services to meet this rising demand.[2] As a result, a robust population and needs-based planning approach is required along with adequate funding and investment to ensure appropriate care models and staff are available to provide quality palliative care where and when it is needed. This will involve a shift from current models of palliative care which centre around specialist palliative care providers working primarily in metropolitan-based hospital settings, to service delivery in the community. This requires greater collaboration between specialist and generalist palliative care providers such as general practitioners and community services.

5. **How can the delivery of palliative care and end-of-life care services in Queensland be improved?**

   There are a number of ways that the delivery of palliative care and end-of -life care in Queensland can be improved. Consistent with Palliative Care Queensland priorities for 2019,[3] Queensland PHNs would like to see:

   Changes to current models of care

   A system that allows for the palliative person to be cared for in the setting of their choice and the preferred location for their death. This will require a shift in focus from specialist palliative care in acute settings to more community-based models

   A person-centred approach embedded in all palliative care planning so that individuals, carers and families are actively engaged in care planning and ongoing needs assessment. This should include a continued focus on advance care planning.

Where people can't be cared for entirely at home, improved pathways for transition between settings over the course of the palliative process to ensure that people receive more coordinated and integrated palliative care.

MBS item numbers that better enable both generalist and specialist palliative care to be provided across the health sector. This includes changes to enable general practitioners and nurse practitioners to facilitate family meetings and advance care planning discussions, and support hoe visits, after hours support and palliative care in residential aged care

Better funding models, infrastructure (i.e. telehealth) and innovative models of specialist palliative care to support Queenslanders living in rural and remote locations to receive the majority of their care in their community if this is what they choose.

Palliative care scripted funding for in-home end of life care from individual HHS's needs to be increased, with contracts to service providers to be more flexible to match client clinical need. E.g. Currently only scripting 'one hour of care per day', ideally should be worded in HHS contracts '28 hours of care per month'.

Specialist palliative care

Improve access to specialist palliative care, especially in rural and remote areas

Equitable funding for all specialist services, in line with cancer and other relevant health services in each HHS

Home based palliative care

Improved timeliness of access to home care packages

Develop wrap around home care packages, which specialist services can deliver and flex to meet individual needs

Improved funding and support for general practitioners to provide palliative care in the community

24-hour access to specialist palliative care support for all GPS and RACFs regardless of region

Nursing on call services that are available in the event of an acute episode after hours

Greater multidisciplinary health professionals within palliative care, including occupational therapists, social workers, dietitians, bereavement counsellors and psychologists

Residential aged care

The evidence base shows that Palliative Care Nurse Practitioners add value by improving the coordination of care, achieving better integration with General Practitioners, specialists and allied health, supporting facility staff and improving communication, involvement and decision making of the resident and their families and carers.

Workforce

Increased investment in the palliative care workforce, including support for career pathways as well as modelling of future demand.

Improved education in palliative care for all heath professionals across primary care, community care, aged care and disability.

Invest in workforce, including but not limited to post graduate scholarships and research grants.

Supported mentorship in the delivery of palliative care, in particular for general practitioners and nurses in residential aged care.

Public health approaches to palliative care

Improved death literacy and understanding of palliative care amongst consumers

Greater support for Palliative Care Queensland's Compassionate Communities project to act as an advocate and awareness raiser amongst Queensland communities

Community-based networks and activities build local capacity to support people who are reaching the end of their life

More people are preparing, using and maintaining advance care plans, including within general practice, residential aged care facilities and for people with dementia

6. **What are the particular challenges of delivering palliative and end of life care in regional, rural and remote Queensland?**

Recruitment challenges for Palliative care in regional Qld results in inequity of in home care services for regional Australians. E.g. After 18 months of recruitment still no Palliative Care Physician for WBHHS, as they only have funding for .5FTE. This is acerbated by long term Palliative Care Outreach Physician for WB and CQ, Dr Peter Whann retiring July 2019 with no succession planning or backfill in place.

7. **What are the particular challenges of delivering palliative and end of life care for Aboriginal and Torres Strait Islander communities?**

There are a number of cultural and systemic factors that act as barriers to Aboriginal and Torres Strait Islander people receiving quality and culturally appropriate palliative care in Queensland.

Cultural considerations include, the importance of dying on country, a preference for traditional healing, and kinship and caring rules and roles. Systematic barriers can include significant levels of fear and distrust of institutions and organisations, due to previous negative experiences and long-standing transgenerational trauma. Language and communication issues (i.e. taboos around discussing death and dying) between health professionals and Aboriginal and Torres Strait Islander people can also present a barrier.

8. **What are the key priorities for the future?**

Queensland PHNs would like to see the following key priorities in palliative and end of life care provision recognised across the state:

- A shift from current models of palliative care which centre around specialist palliative care providers working primarily in metropolitan-based hospital settings, to service delivery in the community.
- Better access to specialist palliative care services, particularly in rural and remote areas.
- Better support for general practitioners to provide home based palliative and end of life care, including after hours and in residential aged care facilities.
- A move from siloed funding mechanisms to funding models that are equitable and more supportive of palliative care provision.
- Improved communication between services, including real-time access to clinical information for health professionals
- Improved palliative care education, support and mentorship for all health professionals, with a particular focus on general practitioners and residential aged care staff.
- An increased focus on advance care planning in all settings of care, in particular general practice and residential aged care.
- Flexible and holistic models of service delivery for under-served groups, including Aboriginal and Torres Strait Islander people.

- Improved support for carers, including access to information, support to navigate the palliative care system, coordinated respite care and bereavement support.
- The uniform collection of quality consumer outcome data across all sectors.
- Improved death literacy and understanding of palliative care among consumers
- Community-based networks and activities that build local capacity to support people who are reaching the end of their life

Appendix 1

List of co-signed organisations

- Brisbane North PHN
- Brisbane South PHN
- Central Queensland, Wide Bay, Sunshine Coast PHN
- Darling Downs and West Moreton PHN
- Gold Coast PHN
- Northern Queensland PHN
- Western Queensland PHN

References

1. Palliative Care Australia 2018, Palliative Care 2030 – working towards the future of quality palliative care for all, PCA, Canberra.

2. National Palliative Care Strategy

3. Palliative Care Queensland (2019) Palliative Care in Queensland Priorities for 2019. Published on website: www.palliativecareqld.org.au/publications-positions-submissions

Submission to:

Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying in Queensland

AUSTRALIAN CHRISTIAN LOBBY

ACL Truth made public
AUSTRALIAN CHRISTIAN LOBBY

About Australian Christian Lobby

Australian Christian Lobby's vision is to see Christian principles and ethics influencing the way we are governed, do business, and relate to each other as a community. ACL seeks to see a compassionate, just and moral society through having the public contributions of the Christian faith reflected in the political life of the nation.

With more than 125,000 supporters, ACL facilitates professional engagement and dialogue between the Christian constituency and government, allowing the voice of Christians to be heard in the public square. ACL is neither party-partisan nor denominationally aligned. ACL representatives bring a Christian perspective to policy makers in Federal, State and Territory Parliaments.

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Qld Parliamentary Health, Communities, Disability Services
and Domestic and Family Violence Prevention Committee
Queensland Parliament

15 April 2019

Dear Committee

Re: Submission to the Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying.

The Australian Christian Lobby (ACL) welcomes the opportunity to provide a submission to the Committee considering end of life choices in Queensland.

The ACL has endeavoured to respond to the questions raised by the Issues Paper which discussed Aged Care, Palliative Care and Voluntary Assisted Dying. We are concerned primarily with ensuring the dignity of the human person is preserved in all aspects of health care and were troubled by the simultaneous discussion of end of life care and assisted suicide. This alone, is an issue of serious concern.

The ACL has outlined its views on these matters to the Committee in the attached submission.

Please feel free to contact me if I can be of further assistance in the consideration of this matter. I would be pleased to meet to discuss our submission or any other aspect in respect to this review and would appreciate an opportunity to present to the committee if appropriate.

Wendy Francis
Director | QLD & NT

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Contents

Introduction

The ACL commends the Queensland government for giving careful consideration to the care needs of older citizens. The prioritisation of the needs of the vulnerable is a hallmark of every compassionate society and, since aging is inevitable for those who are blessed with long life, it concerns every Queenslander to ensure that the needs of the elderly have been anticipated and provided for.

The ACL is deeply concerned, however, to find that the legalisation of euthanasia forms any part of such a conversation. Euthanasia is fundamentally irreconcilable with a recognition of inherent human dignity. Acceptance of state-sanctioned killing, even if for ostensibly compassionate motives, requires more than a simple change to the law: it represents a paradigm shift from an ethical and legal framework that declares the deliberate taking of life by private citizens (including medical professionals) as morally insupportable in absolute terms to one which allows relative and circumstantial evaluations to be made about different lives on a case-by-case basis. Euthanasia can only be contemplated by putting aside the current legal recognition of the unique and infinite value of the human person, to instead embrace the acknowledgment that some lives are not worth living. This submission will elaborate on several reasons why the legalisation of euthanasia is at variance with the Queensland Government's declared aims to promote an "age-friendly community" in the state.[1]

There are currently numerous serious problems in both aged care and palliative care in Queensland. Previous under-commitment by the government has been exposed in recent public statements of Queensland's health care professionals who point to:

- lack of palliative care specialists. (For example, Rockhampton ought to have eight palliative care specialists; they have one);
- the fact that aged care facilities have no trained palliative care nurses;
- inadequate financial support for aged care facilities;
- insufficient funding for home care packages (so that patients often die before they receive these);
- critically deficient numbers of nurses working in remote communities.[2]

Until these deficiencies are comprehensively addressed, the dangers that inevitably attend the legalisation of euthanasia can only be magnified. The vulnerability created for the elderly is self-evident: given sufficiently deplorable conditions, anyone might be persuaded to look on suicide as a blessing.

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[1] https://www.communities.qld.gov.au/seniors/queensland-age-friendly-community

[2] Marszalek, Jessica, "Euthanasia cannot be legalised in QLD until palliative care improved". http://online.isentialink.com/couriermail.com.au/2019/04/05/0a18efc2-8301-4181-9c51-fa861bd4c57f.html (Accessed 8 April 2019).

It is therefore unfortunate that, when the need for remedial attention to correct serious deficiencies in palliative care and aged-care is so apparent, this Issues Paper not only raises the possibility of legalising euthanasia but appears to give this disproportionate weighting. The swathe of suggestions on possible implementations of euthanasia together with a table of countries which practice euthanasia and a summary of their practices, contrasts strikingly with a complete absence of recommendations about the implementation and/or improvement to the aged care or palliative care sectors. Perhaps an Inquiry that was serious about aged care and palliative care might have provided a similar comparison of how such care is practiced in other countries to enable an assessment of best practice and suggestions for the improvement of existing arrangements. The absence of this discussion is therefore concerning; it could be taken as an indication of the government's pre-established determination to legalise euthanasia in spite of the particularly unsafe environment. The ACL hopes, however, that this unfortunate impression does not reflect that true case.

Even those who advocate for euthanasia in other circumstances (the ACL does not share the view that euthanasia can ever be legalised safely) might query the timing of this Inquiry. Not only is the environment particularly unsafe in Queensland, but the results of the Federal Royal Commission into Aged Care are still pending. After the two initial rounds of hearings, it is already clear that the Royal Commission will uncover serious deficiencies in the provision of aged care. Recommendations for serious reform can be confidently anticipated. Since any findings of this Queensland Inquiry at variance with the recommendations of the Royal Commission can be expected to be superseded within such a short time frame, the efforts of the government would perhaps be better directed to monitoring and improving the quality of existing aged care, rather than running a soon-to-be-redundant inquiry in parallel with the Royal Commission.

RECOMMENDATIONS

1. Improve aged care
2. Ensure best practice palliative care is available throughout Queensland
3. Implement holistic care for Indigenous Australians.

The ACL submits that, if the above are implemented, there will be no need for euthanasia.

AGED CARE

The Inquiry addresses some questions to the public that would benefit from targeted expert examination. Question 10, for example, about the cost of hospital stays compared to the cost of residential aged care could be answered with reference to Queensland Health data. Further questions relating to the availability of aged care, staffing levels, disability care, indigenous care, rural and regional availability, increased demands due to an aging population require an analysis of hard data and comparison with international best practice. The responses provided below are necessarily brief and indicative and do not represent the detailed quantitative and qualitative study this subject rightly deserves.

1. Is the aged care system meeting the current needs of older Queenslanders, including those people with special needs? Why or why not?

The ACL submits that current standards of aged care in Queensland are inadequate. Staffing levels are low and staff training is inadequate. In combination, these conditions breed the further problems of poor morale and high rates of staff turnover as staff become disillusioned with the reality of aged care. An assistant nurse in an aged care facility made the following observation about her colleagues:

> What I see is that people who take on this job to make a positive difference in people's lives don't last. Fresh ideas and a positive view on ageing are not supported by management. It is no wonder that the aged care sector faces high turnover. Despite the need for thousands of new assistants-in-nursing (AINs), people leave constantly for other jobs where they are not forced to turn a blind eye to people's basic needs.[3]

And in relation to the care provided, she notes:

> The facility I work at, which is probably typical of others, is more like a sweatshop or factory line than a residential care facility for Australia's elderly. We simply do not have the time to provide holistic care. On some days, even providing the basics of daily life, like brushing teeth, showering and toileting are a challenge.[4]

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[3] Anonymous. "Diary of an assistant nurse: People go without showers so others are not left in their faeces." https://www.theguardian.com/commentisfree/2019/apr/05/diary-of-an-assistant-nurse-people-go-without-showers-so-others-are-not-left-in-their-faeces?CMP=share_btn_link (Accessed 6 April 2019).

[4] Ibid.

3. Do the standards of residential aged care, home care and other aged care services provided in Queensland meet clients' and the community's expectations? Can you give examples?

There are clear examples were standards are below expectation. One assistant nurse in aged care comments that there are frequent staff shortages which result in serious lack of care. She says:

> On those days, if residents request a shower we have to decline because the priority may be to change another resident's incontinence pad so they do not continue to lay in their own faeces.[5]

4. How will demand for aged care services change in Queensland as the population increases and ages, and what changes to the aged care system will be needed to meet future demands for aged care?

There will be greater demand for both aged care facilities and in-home care, but the political will to provide for this is not in evidence. The focus on euthanasia in these circumstances is concerning.

5. Are there enough residential aged care places (beds) available in aged care facilities, in areas and at the levels of care that are required?

Again, deficiencies are apparent. There is a great need for palliative care nurses in aged care facilities, which would ease the burden on hospitalisation of people at end of life.[6]

In addition, there is a shortage of all staff in all areas of aged care, from qualified nurses to assistant nurses and personal carers.[7]

6. Are adequate numbers of home care packages available in areas at the levels required?

There are insufficient home care packages available. Some patients die before home care packages are implemented.[8]

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[5] Ibid.

[6] Marszalek, Jessica, "Euthanasia cannot be legalised in QLD until palliative care improved". http://online.isentialink.com/couriermail.com.au/2019/04/05/0a18efc2-8301-4181-9c51-fa861bd4c57f.html (Accessed 8 April 2019)

[7] Op cit. Anonymous.

[8] Op.Cit. Marszalek.

7. Are there sufficient staff in the aged care sector to meet current and future workloads?

There are not sufficient staff at present so it is difficult to see how future needs may be met without urgent and extensive planning. The Royal Commission will no doubt provide recommendations on this subject, or Queensland could look to international best practice to correct the current deficiency.

8. Is the mix of staff appropriate for different settings within the aged care sector?

There is a serious shortage of trained palliative care nurses in Aged Care facilities. There is a need for staffing ratios to ensure adequate care is provided for the residents.[9]

9. Do aged care staff receive training that is appropriate and adequate to prepare them for the work?

The evidence available and the testimony of staff in aged care facilities and the experience of the families of the aged, suggests that current levels of training are deficient.

10. What are the costs to the public health system of caring for elderly people in hospitals whilst they are waiting for residential aged care places to become available?

This information should be available from Queensland Health.

11. Are suitable health care services being provided within residential aged care settings and/or aged care providers?

Unfortunately, anecdotal evidence of the provision of sub-standard care in nursing homes abounds. The ACL knows of specific cases where elderly relatives have to be taken to other professionals, e.g. podiatrists, because those who visit the centre are not sensitive to patients' needs or provide a poor service and where the dietary requirements for diabetics are not well attended to, resulting in poor health outcomes. It is also too frequently the case that those unable to feed themselves are neglected.[10]

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[9] Op. cit. Anonymous

[10] Ibid.

13. How can the delivery of aged care services in Queensland be improved?

Again, this question would best be answered by a detailed expert study. In broad terms, it seems clear that areas for improvement include;

- Improved staff ratios
- More qualified nurses in facilities
- Nurses trained in palliative care
- Commitment to retaining quality staff through better pay and conditions.

16. What are the key priorities for the future?

The priority must be to ensure best outcomes for the aged and their families – to ensure that:

- the elderly and their families are fully supported in caring for their loved ones as they reach the end of their lives;
- those who do not have family support are fully provided for;
- wholistic care is available, taking into account more than just the physical body but the social, emotional, spiritual needs of each patient;
- staff caring for the elderly are highly motivated, properly supported, fully trained;
- regional Queensland is adequately resourced so that distance from the city does not result in reduced levels of care;
- in-home care is available to those who want it.[11]

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[11] Op.Cit. Marszalek.

PALLIATIVE CARE

The Issues paper raises eight questions relating to palliative care which, even taken together, cannot do justice to such a complex and specialist field of medicine. Palliative care involves a wholistic approach to patient care. As well as attending to pain relief, palliative care encompasses the patient's spiritual, psychological and relational needs. A palliative care practitioner will assess which aspect of life is causing suffering and address those issues which may not be about physical pain, but which might concern fear or hopelessness. The palliative care practitioner also includes attention to the well-being of family members. This wholistic approach to end of life care is apparently not well understood by the community. The Cancer Council both acknowledges and responds to this community confusion about palliative care on its website, seeing the need to clarify, for example, the distinction between euthanasia and palliative care.[12]

Palliative care seeks neither to hasten or postpone death.[13] Indeed, the Specialist Palliative Care Practitioners oppose the discussion of euthanasia when there is inadequate provision of palliative care. When euthanasia becomes "one of the options" that must be offered to the patient, this is antithetical to the aims of palliative care and serves to complicate already difficult and emotionally intense family situations.

17. What are the palliative care services offered in Queensland?

I have personal experience of Queensland's palliative care services as two of my sisters have died from cancer and they were cared for in their last days by palliative care medical staff. I will always be very grateful for the care they received. However, medical experts in the field refer to the standard of services offered in Queensland as appallingly inadequate to cater for the level of need and seriously under-resourced. (See comments for question 18 below.)

18. Are palliative care and end-of-life care services meeting the current needs of Queenslanders? Why or why not?

These services are acknowledged to be inadequate. According to Dr Greg Parker, head of Queensland Specialist Palliative Care Services Directors the following issues are of concern:

- Patients requesting at-home care packages were often dead before they were delivered.
- Regional Queensland has had one palliative care specialist for the past 12 years but should have 8.

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[12] https://www.cancercouncil.com.au/cancer-information/advanced-cancer/palliative-care/key-questions/is-palliative-care-the-same-as-euthanasia/ (Accessed 2 April 2019).

[13] Goiran, Nick; Minority Report for the Joint Select Committee on End of Life Choices submitted under Legislative Assembly Standing Order 274, Parliament of Western Australia, August 2018, 3.

- Rockhampton boasts a “level five” cancer and palliative care service but has no palliative care physician.
- Pain-relief procedures that are standard in NSW hospitals are not available in Queensland.
- Many at-home packages do not include a nurse.
- Nurses in aged care homes have no palliative care training so patients have to be sent to hospital emergency departments.
- Figures are not kept on staff shortfalls.[14]

19. Do the standards of palliative care and end-of-life care provided in Queensland meet clients’ and the community’s expectations?

They do not. In the context of inadequate resourcing for palliative care, any consideration of euthanasia exposes the Queensland government to the regrettable appearance of using the suffering of the dying to promote a pre-existing ideological commitment to euthanasia.

No responsible government can afford to disregard its budget and the costs of palliative care are obviously considerable. In Canada, the benefits to the national budget of assisting suicide have already been grimly quantified in a 2016 report published in the Canadian Medical Association Journal. Doctor-hastened death, including life-ending drugs, can cost as little as $25 per “patient”. By comparison, particularly in the final month of life, the medical costs of caring for the dying can increase dramatically. This report points out that physician-assisted dying has the advantage of enabling patients to “forgo this resource intensive period.” Even as the authors of this study protest that “neither patients nor physicians should consider costs when making the very personal decision to request, or provide, this intervention,” they announce the results of their gruesome calculations; assisted dying could save the Canadian government as much as $139 million annually.[15]

In the same month this journal published articles on the following subjects:

- “Medical error and medical assistance in dying”;
- “Seniors and self-harm factor in the opioid crisis”;
- “Canada needs twice as many palliative specialists”.

It does not take a cynic to see how these issues are connected. Palliative care is expensive, provision is inadequate, seniors are self-harming under these circumstances and the inexpensive solution – delivering marvellous benefits to the incumbent government whose financial management will surely be applauded by a grateful electorate – is to facilitate euthanasia. It costs less than helping people.

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[14] Op.Cit. Marszalek.

[15] Sharon Kelly, “Doctor-assisted suicide could save Canada up to $139 million each year, Alberta study suggests”, *National Post*, 23 January 2017. Available at: http://nationalpost.com/news/0124-na-assisted-dying; Aaron J. Trachtenberg and Braden Manns, “Cost analysis of medical assistance in dying in Canada”, *Canadian medical Association Journal*, 23 January 2017, p. 189 (doi:10.1503/cmaj.160650)

While financial self-interest, rather than sincere care for the elderly, appears to be driving the pro-euthanasia policy of the Canadian government, it would be regrettable if the Queensland government were to expose itself to suspicion of acting on similar motivation. The parlous state of palliative care provides fertile soil for the unwelcome speculation that this is not entirely disconnected from the advancement of policies that allow for euthanasia.

20. How will demand for palliative and end-of-life services change in Queensland as the population increases and ages, and what changes to the delivery of these services will be needed to meet future demands?

Future needs require a greater availability of palliative care services. It will be necessary to provide for current needs before expanding to future requirements. Evidently there will be a need for more trained palliative care specialists and the placement of palliative care trained nurses in aged care facilities as well as being available to in home aged care services.

21. How can the delivery of palliative care and end-of-life care services in Queensland be improved?

These can be improved by making up the current shortfalls and then continuing to improve availability especially in regional and rural areas.

- Provide home care packages to patients when required and especially before they die.
- Ensure that Regional Queensland has the recommended 8 palliative care specialists rather than the present ONE.
- Ensure that “level five” cancer and palliative care services have a palliative care physician.
- Provide a high standard of pain-relief procedures that are available in NSW hospitals but not available in Queensland.
- Ensure that at-home palliative care packages include a nurse.
- Provide palliative care training to nurses in aged care homes that have no palliative care training so patients do not have to be sent to emergency departments.
- Figures are not currently kept on staff short falls but they should be.[16]

22. What are the particular challenges of delivering palliative and end of life care in regional, rural and remote Queensland?

Availability of palliative care specialists – doctors and nurses – these are severely under resourced or not available at all.

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[16] Ibid. These improvements are extrapolated from the deficits outlined by Dr Greg Parker in his submission to this inquiry.

23. What are the particular challenges of delivering palliative and end of life care for Aboriginal and Torres Strait Islander communities?

The United Nations Declaration on the Rights of Indigenous Peoples, article 24.2 states:

> Indigenous individuals have an equal right to the enjoyment of the highest attainable standard of physical and mental health. States shall take the necessary steps with a view to achieving progressively the full realization of this right.[17]

A critical problem is the poor health care options available to Aboriginal and Torres Strait Islander communities with inferior health outcomes throughout their entire lifecycle. A higher percentage of Aboriginal and Torres Strait Islander babies are of extremely low birthweight, there are more maternal deaths, and Aboriginal and Torres Strait Islanders have a significantly lower life expectation than non-indigenous Australians. They are more likely to develop diabetes and kidney disease than other Australians and much of this can be linked back to lower standards of living and inappropriate diet.[18] This data would suggest that palliative care options need to be available at earlier stages, but there also needs to be a commitment to better whole of life care for indigenous Australians.

Perhaps there are still many lessons to be learned from the death of Gurrumul Yunupingu and the difficulties faced by indigenous people in the health system.[19] For many Indigenous people, treatment requires that they travel large distances and are thereby separated from their communities and support networks. Palliative care nurses should be available to remote communities.

24. What are the key priorities for the future?

Best practice palliative care to be delivered across the entire state.

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[17] As quoted in: http://www.patrickdodson.com.au/15_08_2018bills_restoring_territory_rights_assisted_suicide_legislation_bill_2015_second_reading (Accessed 8 April 2019).

[18] https://healthinfonet.ecu.edu.au/learn/health-facts/overview-aboriginal-torres-strait-islander-health-status/36501/?title=Overview%20of%20Aboriginal%20and%20Torres%20Strait%20Islander%20health%20status%2C%202018 (accessed 8 April 2019).

[19] https://www.abc.net.au/news/2017-07-27/yunupingu-chose-to-leave-dialysis-knowing-he-would-die:-doctor/8749750 (accessed 8 April 2019).

VOLUNTARY ASSISTED DYING

The Issues Paper raises many questions that cannot be answered without implicitly accepting the premise that euthanasia can be legalised "safely". The ACL contends that some deaths through nefarious intervention, lack of good options, indirect or direct pressure, will inevitably result from legalised euthanasia and international examples bear this out. The correct question therefore is not whether euthanasia can be made safe, but rather how many deaths of elderly people are considered acceptable in order to offer the "choice" of euthanasia to those among the wealthy, white, worried well, who, having the privilege of genuine choice, typically lobby for the legalisation of euthanasia out of concern regarding loss of agency in old age.[20] Rather than addressing the specific questions therefore, the remainder of this submission will point to defects in the premise that euthanasia can ever be safely legalised.

EUTHANASIA VERSUS "ASSISTED DYING: NOTES ON THE USE OF LANGUAGE

The Issues Paper, whether intentionally or not, adopts the lexicon of pro-euthanasia lobbyists in describing the activity in prospect as "physician assisted suicide" or "voluntary assisted dying". The use of language is significant, particularly where it is recognised that "political speech and writing are largely the defence of the indefensible."[21]

> An ancient but evergreen practice with controversial political and ethical issues is to manipulate ideas and language, spinning them to serve one's ends... The advocates for physician-assisted suicide make use of a favorite method from the spin tool box, that of obfuscation, defined in dictionaries as an effort to render something unclear, evasive, or confusing. I believe that in recent years, many (though hardly all) advocates of euthanasia and physician-assisted suicide have used organized obfuscation as a political tactic..."[22]

Since linguistic clarity is important to the preservation of distinctions, it is worth noting that euthanasia refers the practice on intentionally acting to kill a person by the administration of drugs.[23] Although it is argued that this is only undertaken a person's voluntary and competent request, internationally, public concern in growing at the numbers of people who are now being euthanised without ever having made such a request.[24]

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[20] Rachel Aviv, "The Death Treatment: when should people with a non-terminal illness be helped to die?", *The New Yorker*, 22 June 2015. (https://www.newyorker.com/magazine/2015/06/22/the-death-treatment).

[21] George Orwell, "Politics and the English Language", London, 1946. http://www.orwell.ru/library/essays/politics/english/e_polit/ (Accessed 11/04/19).

[22] Callahan, Daniel. "Organized Obfuscation: Advocacy for Physician-Assisted Suicide", *Hastings Center Report*, pp. 30–33. (http://mtw160 198.ippl.jhu.edu/article/250758/pdf – accessed 8 April 2019).

[23] https://www.eapcnet.eu/Portals/0/PDFs/PM2015_Euthanasia%281%29.pdf

[24] See, for example, Kenneth Chambaere, Johan Bilsen, Joachim Cohen, Bregje D. Onwuteaka-Philipsen, Freddy Mortier and Luc Deliens, "Physician-assisted deaths under the euthanasia law in Belgium: a population-based survey", *Canadian Medical*

Assisted Suicide (used by anti-euthanasia advocates) or **Assisted Dying** (favoured by pro-euthanasia advocates) refers to situation where a doctor or person "helps a person to terminate their life by providing drugs for self-administration, at that person's voluntary and competent request."[25]

What is being contemplated in Queensland appears to be euthanasia, rather than assisted dying or assisted suicide. The Belgians, who have been practicing euthanasia for years do not attempt to disguise it with inaccurate nomenclature – their report on euthanasia deaths in 2018 is clearly identified as *EUTHANASIE – Chiffres de l'année 2018*.[26]

The argument has been made, for example by the Victorian Premier Daniel Andrews[27], that physician assisted suicide is already happening in Australia and that the legalisation of euthanasia will assist governments to ensure this practice is properly regulated. If the testimony of Lord Laverne, addressing the House of Lords, is to be believed then Andrews is right as to the first point. Laverne claimed that:

> "in Australia, where euthanasia is illegal, the proportion of deaths without consent ...[is] 3.5 per cent."[28]

However, if Australia already has a problem regulating "unofficial" euthanasia, the argument that relaxing the law to allow for greater scrutiny of this practice, is self-defeating. If current legal safe-guards are already failing to protect the vulnerable from being killed against their will in hospitals and hospices – if doctors are already making moral, rather than medical, judgements about the value of different lives – this should signal an environment in which further relaxation of protective legalisation could only increase the dangers for patients.

Euthanasia and assisted suicide are NOT the following things: turning off life support, 'do not resuscitate' requests, stopping treatment, refusing treatment, palliative care. These are all already legally sanctioned and available and do not involve the active and intentional ending of a life.

ELEVATED VULNERABILITY OF ABORIGINALS AND TORRES STRAIT ISLANDERS

Modern, western humanism contends that death must ultimately be a matter for individual freedom of choice. Where people are unable, through incapacity, to complete their own suicide, this gives rise to demands that the state facilitate death. The policies now contemplated are a

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Association Journal, May 17, 2010. (https://euthanasiadebate.org.nz/wp-content/uploads/2012/10/cmaj.091876.full_.pdf - accessed 15/04/19).

[25] Ibid.

[26] Press Release, Commission fédérale de Contrôle et d'Évaluation de l'Euthanasie – CFCEE, Belgium; *EUTHANASIE – Chiffres de l'année 2018;* https://organesdeconcertation.sante.belgique.be/fr/documents/euthanasie-chiffres-de-lannee-2018 (Accessed 2 April 2019).

[27] Legislative Assembly Hansard, Victorian Parliament, 17 October 2017.

[28] House of Lords Hansard, UK Parliament, 6 May 1998, Column 713. Available here: https://publications.parliament.uk/pa/ld199798/ldhansrd/vo980506/text/80506-12.htm

consequence of flawed philosophical foundations that will compel others, including medical professionals who see healing and care as their primary objective, to act against their consciences.

There is another way; a way that entails community and interdependence. It is a way that is understood by our Indigenous communities and which was movingly articulated by Senator Pat Dodson in his opposition to the Restoring Territory Rights Bill on 15 August 2018. To quote from his speech:

> In Yawuru we have three concepts that guide our experience of life. They shape our ways of knowing and understanding and are the collective approach to our existence on this earth and, to that extent, any afterlife that may come. They are: mabu ngarrungu(nil), a strong community—the wellbeing of all is paramount; mabu buru, a strong place and a good country—human behaviour and needs must be balanced in their demands and needs of what creation provides; and mabu liyan, a healthy spirit and good feeling. Individual wellbeing and that of our society not only have to be balanced but be at peace with each other within the context of our existence and experience.
>
> This concept of interconnectedness is one that transcends across many First Nations groups. It is grounded in our understanding that human resilience is based on our relationships with each other and our connectedness with the world around us. The quality of life for individuals and for our communities are intertwined, not limited to the wellbeing of an individual. We are fundamentally responsible for honouring our fellow human beings. We are called to carry responsibilities, to exercise duties and to honour those who are in need, who are ill, who are elderly, who are dependent and those of the next generation to value life with love, respect and responsibility. This is true of family members and unknown individuals. Moving away from such principles and values begins to reshape the value of human beings and our civil society, in my view.
>
> We exist not as solitary individuals; we exist within a family, a community, our cultures and ethos, and in the kinship landscape. I'm a great admirer of those who have cared for loved ones and made personal sacrifices to do so. Not everyone is able to do this, I know, and I do not condemn them for the choices that they make. In the broad sense, we are part of a common humanity. If we give one person the right to make that decision—that is, to assist in committing suicide—we as a whole are affected. If we give one family that right, we as a whole are affected. If we give one state or territory that right, we as a country are affected. If we give one nation the right to determine life, our common humanity is affected. I cannot support this legislation.[29]

It is our Indigenous peoples who, when requiring medical treatment, are likely to be far from their people and their community. This exacerbates pre-existing vulnerabilities relating to depression and despondency and is likely to influence them towards different choices to those they would

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[29] Dodson, Senator Pat; http://www.patrickdodson.com.au/15_08_2018bills_restoring_territory_rights_assisted_suicide_legislation_bill_2015_second_reading (Accessed 9 April 2019).

make if palliative care were available in their communities. The opposition to euthanasia expressed by Senator Dodson is cultural.

This way is not foreign to western civilisation, just in danger of being forgotten. It was a former Labor Prime Minister who remembered it and articulated it as:

> [Euthanasia] constitutes an unacceptable departure in our approach to human existence and the irrevocable sanctity that should govern our understanding of what it means to be human … What matters is the core intention of the law. What matters is the ethical threshold being crossed. What matters is that under Victorian law there will be people whose lives we honour and those we believe are better off dead.
>
> In both practical and moral terms, it is misleading to think allowing people to terminate their life is without consequence for the entire society. Too much of the Victorian debate has been about the details and conditions under which people can be terminated and too little about the golden principles that would be abandoned by our legislature.[30]

Many Indigenous communities are in regional and rural areas of Queensland. Language and literacy problems already contribute to a distrust of healthcare and a reluctance to accept care if it means absence from their communities and support networks. The move towards providing euthanasia is likely

POOR AGED AND PALLIATIVE CARE CREATES VULNERABILITY

The current poor standards in the provision of aged care and palliative care are factors leading to requests for euthanasia due to the pain and demoralisation experienced by the elderly and the terminally ill.

A dying person and their family are extremely vulnerable. In the absence of complete information, particularly information about the possibilities of good palliative care, they make decisions based on the limited options that the Queensland Health Care system makes available to them. In poorly resourced circumstances, families seeing their loved ones going through unnecessary suffering could be forgiven for forming the conclusion that euthanasia is a better option.

THE MERE AVAILABILITY OF EUTHANASIA AS A CHOICE PRODUCES PRESSURE

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[30] Keating, Paul; https://www.smh.com.au/opinion/paul-keating-voluntary-euthanasia-is-a-threshold-moment-for-australia-and-one-we-should-not-cross-20171019-gz412h.html (Accessed 10 April 2019).

Another objection to euthanasia concerns the impossibility of ever entirely comprehending another person's motivation. Advocates for euthanasia argue for the importance of giving effect to 'free choice'. (Presumably, no one who advocates for euthanasia would do so if it meant ending a person's life against their will, in circumstances where their free choice is compromised by other considerations, or where this decision is taken in response to pressure). Free choice can only be said to exist if all other possible motivations to hasten death can be absolutely ruled out. Since no one can fathom the internal processes of another soul, and since this choice cannot be clinically isolated from other complicating considerations which may cloud the purity of that choice and thus compromise the freedom with which it is made, the necessary conditions for purely free decision-making are never achievable in practice.

Pressure to end one's life may be direct or indirect.

Direct pressure

Legislated safeguards offer the vulnerable imperfect protection against overt, direct pressure. Governments can legislate narrow circumstances in which euthanasia is allowable, they can stipulate multiple medical opinions, cooling off periods and guidelines for counselling of the patient, etc. However, even with the best safeguards in an ideal world, no system of protections will ever be entirely impregnable to individuals of ill-will who are motivated to circumvent them. Family and doctors are trusted to act entirely in the best interests of their patients and loved ones. On the other hand, it is well-known that most abuse of the elderly occurs at the hands of family members, typically adult children, and that doctors, however well-meaning, may be subjected to pressure. A 2011 survey of 800 family doctors in the Netherlands found that nearly half had "felt pressured by patients or their relatives" to use euthanasia.[31]

An example of such pressure can be found in the Dutch case referred to by Lord Ashbourne in the House of Lords euthanasia debates, in which an old man was dying of lung cancer:

> His symptoms were controlled, and he asked if he could die at home. When his children were told about his wish, they would not agree to take care of him. Even after repeated discussion, they refused. Instead, they pointed to their father's suffering and the need to finish things quickly in the name of humanity. When the doctor refused, they threatened to sue him. As the patient insisted on going home, a social worker went to investigate. She discovered that the patient's house was empty, and every piece of furniture had been stripped out by the family.[32]

Laws must anticipate human failing. They cannot assume all families, however apparently loving, are entirely free of ulterior motives in hastening the end of elderly relatives. "Inheritance impatience" is a recognised motivating factor for some adult children of older parents in wishing to hasten their death, as is the wish to avoid the expense and burden of caring for them. Whether

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[31] "'One third of doctors have refused a euthanasia request", 7 DutchNews.nl, 29 July, 2011. Available at: http://www.dutchnews.nl/news/archives/2011/07/one_third_of_doctors_have_refu/ (Accessed 9 April 2019)

[32] House of Lords Hansard, UK Parliament, 6 May 1998, Column 723

through nefarious activity or undue pressure to hasten death, the risk of 'involuntary euthanasia' for vulnerable individuals is unavoidably greater where voluntary euthanasia is accepted practice.[33]

These risks cannot be entirely eradicated even by very careful legislation. In 1994, the UK's House of Lords Select Committee on Medical Ethics concluded that it would be:

> virtually impossible to ensure that all acts of euthanasia were truly voluntary and that any liberalisation of the law … could not be abused. We were also concerned that vulnerable people—the elderly, lonely, sick or distressed—would feel pressure, whether real or imagined, to request early death.[34]

More recently, in Haas v. Switzerland, the European Court of Human Rights considered that

> "the risk of abuse inherent in a system which facilitated assisted suicide could not be underestimated."[35]

Were it possible to devise perfect legislative safeguards, it would still be impossible to ensure that the letter of the law would be observed in all cases and that no one would feel pressured to end their lives prematurely. Risk, even from direct pressure, cannot be legislated away.

Indirect pressure

Any discussion of the possibility of pressure being applied for the elderly or terminally-ill to end their lives prematurely must acknowledge the operation of indirect pressure, which occurs merely because euthanasia is an available end-of-life choice. To imagine that the ability to choose death does not impose pressure on the vulnerable is to believe in a world where every individual operates in complete autonomy and can be trusted to make entirely selfish choices, without any consideration for the effects of these decisions on others. Such a world does not exist.

The first principles of social psychology address the fact that we live in community, we make decisions with reference to the common good and for the benefit of those around us all the time. Reduced autonomy is an unavoidable corollary of aging, where dependence on others necessarily increases. If governments could ensure no friend, relative or doctor of an elderly person would ever whisper to them privately that they should consider suicide (and they clearly cannot ensure this), even that would not ensure that the elderly were free from pressure (even if this exists only in their own perceptions) to consider suicide simply because this choice would remove the burden of caring for them from those they love.

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[33] F. Norwood, G. Kimsma, and M. Battin, "Vulnerability and the 'Slippery Slope' at the End-of-life: a qualitative Study of Euthanasia, General Practice and Home Death in the Netherlands", Family Practice, vol. 26, p. 472. 33 Select Committee on Medical Ethics. Report. London: HMSO, 1994. (House of Lords paper 21-I).

[34] Select Committee on Medical Ethics. Report. London: HMSO, 1994. (House of Lords paper 21-I).

[35] Press Release: "Switzerland Cannot be Criticised for Not Having Assisted a Suicide", European Court of Human Rights, Press Release issued by the Registrar of the Court, no. 040, 20th January 2011. https://hudoc.echr.coe.int/eng-press Registrar of the European Court of Human Rights, 2011: 3. (Accessed 2 April 2019).

In the moment that end-of-life choices includes euthanasia, those aspects of care that are perceived as the 'indignities of aging' and the inevitable burden that caring for the aged entails are changed from being inevitable and necessary to being avoidable and the product of 'choice'. The old person who could choose death is now a burden for others through their own selfish choice to stay alive. Such a choice may well be resented by those required to care for them or pay for their care. Circumstances are not difficult to envisage in which such old people come to regard killing themselves as 'the right thing to do'.[36] In 2012 in Oregon, 57% of those requesting death reported 'burden to family and friends' as an end-of-life concern.[37]

If laws are changed to allow voluntary euthanasia, indirect pressure is the inevitable result. No government can legislate safeguards against it. The elderly and terminally ill are only protected from indirect or perceived pressure to choose euthanasia by firm legislation prohibiting assisted dying and by the powers of the government arrayed to prosecute any who break this law. The law cannot be changed to accommodate the wishes of the few without exposing the many to pressure to choose euthanasia.

The risks that legal euthanasia poses to the vulnerable thus come in different forms which include direct pressure and indirect pressure to choose death for the benefit of others or for lack of other good options. The end result of both circumstances is that someone dies when they otherwise would live and the State has contributed to their death by failing to offer sufficient protections. Since death is irreversible, there is no opportunity for injustice to be appealed or victims to be compensated. In such matters of life and death governments must exercise the highest duty of care for all citizens by not enacting legislation that would increase the vulnerability of society's most vulnerable.

There are many groups who are particularly vulnerable to being euthanised. These include the elderly, the disabled and the clinically depressed.

THE ELDERLY ARE ALREADY VULNERABLE AND THEIR RISK IS INCREASED

It is hoped that the Royal Commission into Aged Care will identify ways of improving the welfare of the elderly and examine why, for many, their lives are terrible and what could be done to make them less so. Meanwhile, advocates for the elderly affirm that many elderly people wish for death as a means to escape from abusive situations. Advocacy groups for the elderly have termed these

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[36] Hannah Graham and Jeremy Prichard (October 2013), 'Voluntary Euthanasia and 'Assisted Dying' in Tasmania: A Response to Giddings & McKim', October 2013. http://www.bestcare.com.au/documents/reports/VoluntaryEuthanasia-and-Assisted-Dying-in-Tasmania-A-Response-to-Giddings-and-McKim-Oct2013.pdf 14.

[37] Oregon Public Health Division, Oregon's Death With Dignity Act 2012 [Annual Report Year 15] Oregon Public Health, 2013, Salem, 5. http://www.livinganddyingwell.org.uk/sites/default/files/LDW%20-%20Research%20%20Oregon%20Year%2015.pdf (Accessed 2 April 2019).

"the suicides we choose to ignore". An Australian study investigating patterns of suicide among the elderly (the largest study of its type in the world) was published recently in the International Journal of Geriatric Psychiatry. The study found that, of suicides in the 65+ age bracket:

> nearly 70% ... were male, 66% had a diagnosis of depression and nearly 80% were experiencing one or more major life stresses, such as health deterioration. Around 43% were experiencing isolation and loneliness, and nearly 30% had trouble adjusting to life in a nursing home.[38]

This information should prompt further questions: why are men more susceptible? How can we support men better? What contributes to depression and what can we do about it? How can we help the elderly cope with major life stresses? How can we alleviate isolation and loneliness? While the conversation revolves around euthanasia, even when the answers to some of these questions are known, they still go unaddressed.

The authors of this study also note that 50% of residents in aged care facilities show signs of depression, compared with just 10%–15% of those living in the community. This figure alone contradicts the view that depression is "a natural part of the aging process".[39] Living alone, rather than mental illness, has been found to be a significant predicator of suicide for the elderly.[40] Investigations into the deaths of older people in the Oakden care facility in South Australia revealed conditions which might reasonably cause depression and suicidal ideation in anyone.[41] Why is it then, that every effort is made to avert suicide for those aged 15–29 years, but the same rigor is not applied to alleviating the difficulties that might lead to suicidal ideation for the elderly? The answer can only be discrimination – perhaps unconscious discrimination – against the elderly.[42]

In practice, motivations for choosing to die may be complex. A 2015 survey of patients requesting euthanasia in Oregon revealed the three most significant reasons for this choice concerned a reduction in ability to engage in those activities that made life enjoyable (96%); loss of autonomy (92%) and loss of dignity (75%). By contrast, only 28.7% said they were suffering from 'inadequate

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[38] Briony J. Murphy, Lyndal C. Bugeja, Jennifer L. Pilgrim, Joseph E. Ibrahim, "Suicide among nursing home residents in Australia: A national population-based retrospective analysis of medico-legal death investigation information", International Journal of Geriatric Psychiatry, 5 March 2018. https://doi.org/10.1002/gps.4862 (Accessed 2 April 2019).

[39] Briony Murphy and Joseph Ibrahim, "Too many Australians living in nursing homes take their own lives", The Conversation, 6 March 2018. https://theconversation.com/too-many-australians-living-in-nursinghomes-take-their-own-lives-92112 (Accessed 2 April 2019).

[40] Paul Donoughue, Why are elderly Australians taking their own lives?: searching for answers to 'the suicides we ignore', ABC News, 4 October 2016. http://www.abc.net.au/news/2015-10-08/mental-health-depression-elderlysuicide/6808998 (Accessed 2 April 2019).

[41] Nick Harmsen, "SA Premier 'deeply sorry' after Oakden ICAC reports five individuals for maladministration", ABC News, 28 February 2018. http://www.abc.net.au/news/2018-02-28/icac-report-on-oakden-aged-care-homereleased/9492008 (Accessed 2 April 2019).

[42] Brian Draper, "Elderly men have the highest suicide rate – and ageism stops us from doing something about it", The Conversation, 3 September 2015. https://theconversation.com/elderly-men-have-the-highest-suiciderate-and-ageism-stops-us-from-doing-something-about-it-46923 (Accessed 2 April 2019).

pain control or concern about it'.[43] In jurisdictions that have legalised euthanasia, the State's inability to provide for vulnerable individuals is certainly a contributing factor to the decision in favour of death. Wim Distelmans, Chairman of the Federal Control and Evaluation Commission and staunch proponent of euthanasia, described how doctors in Belgium have adopted increasingly loose interpretations of disease:

> We at the commission are confronted more and more with patients who are tired of dealing with a sum of small ailments—they are what we call 'tired of life.'" Although their suffering derives from social concerns as well as from medical ones, Distelmans said that he still considers their pain to be incurable. "If you ask for euthanasia because you are alone, and you are alone because you don't have family to take care of you, we cannot create family."[44]

Clearly social causes of unhappiness are at least as difficult to treat as medical ones. As it would be repugnant to offer euthanasia in place of medical help, it ought to be repugnant to offer euthanasia in place of social support. A more humane social policy would be directed to alleviating loneliness, rather than simply killing the lonely. Far from being a reason to introduce euthanasia, suicide among the elderly indicates a significant failure in existing levels of support. Until all other possible motivations for choosing death are removed, the choice to suicide cannot be assumed to be the expression of autonomy, or unrestricted free choice. A choice is only a free choice when there are at least two good options.

HOW DO WE TREAT EXISTENTIAL SUFFERING?

As we have seen above, depression is a reality for a large percentage of our elderly. Depression can be treated yet, most jurisdictions which have adopted euthanasia have no mandatory requirements for psychological assessments. Indeed, some of them allow euthanasia *for* depression. In Oregon, depression is supposed to be screened, however, in 2016 less than one in 25 (3.75%) who died under Oregon's euthanasia law were referred by a prescribing doctor for a psychiatric evaluation before the doctor prescribed a lethal substance.[45] It is doubtful that a single visit to a psychologist is sufficient to adequately assess whether a patient requesting assisted suicide was suffering from a condition which impaired their judgement. Only half the psychologists surveyed in a study conducted in Oregon felt they could be confident of an

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[43] *Oregon Death with Dignity Act: 2015 Data Summary*, Oregon Health Authority, 4th February 2016, 6. http://www.worldrtd.net/sites/default/files/newsfiles/Oregon%20report%202015.pdf (Accessed 2 April 2019).

[44] Rachel Aviv, "The Death Treatment: when should people with a non-terminal illness be helped to die?", The New Yorker, 22 June 2015. https://www.newyorker.com/magazine/2015/06/22/the-death-treatment (Accessed 2 April 2019).

[45] Oregon Public Health Division, *Oregon Death with Dignity act: Data Summary 2016.* Table 1, 'Characteristics of end-of-life-care of 1,127 DWDA patients who have died from ingesting a lethal dose of medication as of January, 23, 2016 [sic 2017], by year, Oregon, 1998-2016' 9. https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year19.pdf (Accessed 10 April 2019).

assessment after only one visit.[46]A similar experience is found in the Netherlands where referral for a psychiatric assessment is optional. The rates of psychiatric assessment plummeted from 25% in 1998 to 0% in 2010.[47] Not surprisingly studies show that 50% of patients euthanised in the Netherlands were suffering from depression.[48]

It is obvious to conclude from this that many people are being euthanised while depressed without any efforts to alleviate the depression which may result in reversing the request for assisted suicide.

Typically, where euthanasia is legalised, it is limited only to situations of terminal illnesses. The State of Victoria, for example, requires a diagnosis that the person is likely to die within 6 months. Experience shows, however, that the criteria are invariably expanded over time. The Netherlands, for example, has seen a sharp increase in the number of people choosing to end their own lives due to mental health problems including depression, Borderline Personality Disorder, and trauma caused by sexual abuse. Whereas just two people had themselves euthanised in the country in 2010 due to an "insufferable" mental illness, by 2015 this figure had risen to 56 people. This trend has sparked concern among ethicists.[49]

In January 2018, Aurelia Brouwers, a young Dutch woman, drank poison supplied by a doctor and lay down to die. Euthanasia and doctor-assisted suicide are legal in the Netherlands, so hers was a death sanctioned by the state. But Aurelia Brouwers was not terminally ill - she was allowed to end her life on account of her psychiatric illness.[50] Aurelia had a diagnosis of Borderline Personality Disorder.

Even without legislative permission for euthanasia in Australia, we have seen one case of a 45-year-old man who was not terminally ill, but suffering from depression, suiciding in Australia with the assistance of pro-euthanasia activist Phillip Nitschke.[51] Reducing the legal protections to the vulnerable clearly only increases the risk and directly contradicts all the efforts and messages of suicide prevention groups.

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[46] Ganzini, L. and Fenn, "Attitudes of Oregon Psychologists Toward Physician-Assisted Suicide and the Oregon Death with Dignity Act." World Federation of Right to Die Associations. https://www.worldrtd.net/attitudes-oregon-psychologists-toward-physician-assisted-suicide-and-oregon-death-dignity-act

[47] Leiva, RA, "Death Suffering and Euthanasia", *Canadian Family Physician* 56(6), 528-10. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2902937/ (Accessed 10 April 2019).

[48]White, H. "Dutch Study Shows Patients Requesting Euthanasia Likely Depressed" http://www.euthanasia.com/depression.html (Accessed 10 April 2019)

[49] "Netherlands sees a sharp increase in people choosing euthanasia" *Daily Telegraph*, UK; 11 May 2016. https://www.telegraph.co.uk/news/2016/05/11/netherlands-sees-sharp-increase-in-people-choosing-euthanasia-du/ (Accessed 10 April 2019)

[50] "The troubled 29-year-old helped to die by Dutch doctors" https://www.bbc.com/news/stories-45117163 (Accessed 10 April 2019)

[51] https://www.abc.net.au/news/2014-07-03/nitschke-criticised-over-45yo-mans-suicide/5570162 (Accessed 10 April 2019)

EUTHANASIA EFFECTS THE DISABLED DISPROPORTIONATELY

In her address to the Victorian Parliament, disability rights advocate, Liz Carr pointed out how legalising euthanasia increases the vulnerability of the disabled:

> If there was a non-disabled person at a railway bridge about to jump, what do we do? Do we go up to them and go 'you know what, in the name of autonomy and self-determination, you do this. If this is your choice, you do it." I don't think we do that usually. We usually stop them … We question their mental health. We would see it as a tragedy if it had occurred.
>
> Now, if that person was … disabled … would we act the same? … My betting is a lot of people would not act the same. They would go 'If that person wants to end their life, I understand why because if I was like that, I'd feel the same.' … So then we start to call it about choice … For me, if you even see those two people as different, and those two situations as different, that suggests we do have an unconscious bias and discrimination. So legislation is unsafe already because not everyone starts out as having equal value under the law or in the medical profession or in public perception.[52]

Unavoidably, legalised euthanasia gives the support of law to the proposition that some lives are not worth living.

The Oregon experience at least suggests that suicide as a culturally accepted "value" and legislation permitting "assisted suicide" go together. The culture of suicide, given its imprimatur by the state, confounds the efforts of parents and caregivers. There's something patently contradictory in a state's provision of, on the one hand, a suicide hotline and, on the other, assisted suicide. The depressed and disabled need our care and encouragement.[53]

Agitation to change laws to permit assisted suicide is often motivated by the wealthy, white, worried well and the younger generation, who derive comfort from the knowledge that they can control the end of their lives, and that the process of aging and dying need involve no loss of dignity. A confronting response to this argument has been articulated by the disability rights group Not Dead Yet, when they state what should be obvious, but has somehow been overlooked: "we don't need to die to have dignity". They explain:

> In a society that prizes physical ability and stigmatizes impairments, it's no surprise that previously able-bodied people may tend to equate disability with loss of dignity. This reflects the prevalent but insulting societal judgment that people who deal with incontinence and other losses in bodily function are lacking dignity. People with disabilities

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[52] Liz Carr, Disability advocate, Address to Victorian Parliament.http://www.noeuthanasia.org.au/liz_carr_address_to_victorian_parliament_on_assisted_suicide (Accessed 9 April 2019).

[53] Arthur Goldberg and Shimon Cowen, "The Contagion of Euthanasia and the Corruption of Compassion", Public Discourse, The Witherspoon Institute, 11 September 2017. http://www.thepublicdiscourse.com/2017/09/19983/

> are concerned that these psycho-social disability-related factors have become widely accepted as sufficient justification for assisted suicide.[54]

EUTHANASIA FOR CHILDREN AND "MATURE MINORS"

The issues paper questions the age at which euthanasia might be administered and suggests an age of 18 years. Overseas experience has demonstrated that euthanasia might be administered to children who are terminally ill.

Belgium amended legislation in 2014 to allow minors with terminal illnesses to qualify for euthanasia. Since that time there have been three cases of euthanasia administered to children. The eldest of these was 17. In the Netherlands it is permissible to administer euthanasia to children over the age of 12.[55]

Canada which only legalised euthanasia in 2016 is already considering extending it to children and also to mature minors, who might be able to access euthanasia and have the parents informed after the event has occurred.[56] Or, as Wesley J Smith points out, once euthanasia is available, there is no limit to its application:

> Here's the problem: Once a society widely supports eliminating suffering by eliminating the sufferer and redefines as a "medical treatment" the act whereby doctors kill seriously ill patients, there is no logical argument for limiting euthanasia to adults with legal decision-making capacity. After all, children suffer too, so how can they be logically refused "medical aid in dying" — or MAID, the current euphemism for euthanasia and assisted suicide — only because of their age?[57]

FREEDOM OF CONSCIENCE FOR MEDICAL PRACTIONERS

Conscientious objection is essential to the exercise of freedom of speech and freedom of conscience. Australia is a diverse community and its medical practitioners reflect that diversity. Society and medical practitioners draw on a variety of respected ethical traditions which do not necessarily have the same applications and outcomes. It is important not to narrow the parameters of autonomy of medical practitioners by limiting their free speech and potentially prescribing the manner in which they exercise their professional competence. There are many areas of medicine in which there is no single generally accepted view. Euthanasia is one of them.

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[54] Not Dead Yet, http://notdeadyet.org/disability-rights-toolkit-for-advocacy-against-legalization-of-assisted-suicide (accessed 10 April 2019)

[55] https://www.washingtonpost.com/opinions/children-are-being-euthanized-in-belgium/2018/08/06/9473bac2-9988-11e8-b60b-1c897f17e185_story.html?utm_term=.22bb0ab5514d (accessed 10 April 2019)

[56] https://www.redstate.com/alexparker/2018/10/19/canada-euthanasia-children-parental-consent/ (accessed 10 April 2019)

[57] Smith, WJ; https://www.nationalreview.com/2018/11/canada-euthanasia-assisted-suicide-children/ (accessed 10 April 2019)

The community trusts that doctors will operate within an ethical framework for the best interests of the patient. Mandatory compliance with euthanasia will challenge that relationship by removing the ethical judgment from the doctor and potentially lead to a mechanistic response to the provision of health care.

Importantly, a doctor with a conscientious objection to euthanasia should not be required to refer a patient to a practitioner who does not hold a conscientious objection to euthanasia. In many ethical systems this is considered to be co-operation with an unethical action and therefore a person may not be a conduit to this unethical action occurring. In the case of euthanasia, the objector is opposing the direct killing of another human being (murder) or assisting them to kill themselves (suicide). This can never be condoned.

CONCLUSION

This submission hopes to have identified the dangers that exist in legislating for euthanasia. It shows that, historically, those jurisdictions that have legislated for assisted suicide assure that the most stringent safeguards will be enacted, but inevitably through creeping practice and further liberalisation, those safeguards are subject to continual erosion.

If anything, this only affirms the importance of adhering to the first dictate of the Hypocritic Oath – “first, do no harm” – in considering end-of-life choices. Until positive interventions have been explored, funded and implemented; until an impregnable bulwark against the expansion of euthanasia laws by future governments can be established; until direct pressure and indirect pressure can be absolutely ruled out as motivation for suicide; until we can decide categorically which lives are worth living and which are not; until blue sky can be established between suicide for the terminally ill who want it and suicide for those who think they want it because of illness (even terminal illness), depression or both; until the economic savings of suicide can be shown to play no part in the thinking of governments or families; until palliative care is adequately funded and the benefits fully understood by all Queensland residents; until fear of loss of dignity can be removed as a motivating factor for suicide.

ACL submits that any form of euthanasia, assisted dying, assisted suicide not be introduced in Queensland.

Cancer Council

Submission to the inquiry into aged care, end-of-life and palliative care and voluntary assisted dying

April 2019

About Cancer Council Queensland

One Queenslander will be diagnosed with cancer every 20 minutes. Cancer Council Queensland is dedicated to improving quality of life for people living with cancer, through research, patient care, prevention and early detection.

Our employees, volunteers, and supporters are at the heart of our work – driving our vision for a cancer free future.

We were established in 1961 as the Queensland Cancer Fund, in response to an increasing need for cancer-related services across the state. This year, we are celebrating 57 years of supporting Queenslanders, affected by cancer.

Today, we employ about 200 employees statewide and have more than 1300 registered volunteers. Thousands of Queenslanders donate and volunteer for us each day, helping us to improve cancer control. We have nine offices statewide and operate six accommodation lodges providing regional cancer patients with a home-away-from-home when they access lifesaving treatment services in Queensland's major cities.

We are a member of Cancer Council Australia and work in global affiliation with the Union for International Cancer Control (**UICC**).

About PalAssist

Cancer Council Queensland operates **PalAssist,** a 24-hour accessible online and telephone service that is free[1] for anyone who has a life limiting illness or condition, and/or their families and carers.

Our charter is to provide accurate information, referral advice and compassionate support to those dealing with a life-limiting illness.

PalAssist is operated by a team of nursing and allied health professionals. We understand that every person's journey is different, and offer individualised support and advice to our clients.

The service is funded by Queensland Health, and is here to provide trusted advice, or simply to listen.

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[1] Subject to any costs that may be imposed by a caller's telephone service provider for 1800 number calls.

Executive summary

One Queenslander will be diagnosed with cancer every 20 minutes. Cancer Council Queensland is dedicated to improving quality of life for people living with cancer, through research, patient care, prevention and early detection.

We welcome the opportunity to contribute to this inquiry into aged care, end-of-life and palliative care and voluntary assisted dying (**Inquiry**), being undertaken by the Queensland Parliament's Health, Communities, Disability Services and Domestic and Family Violence Committee (**Committee**).

Our contribution to this Inquiry is based on our experience supporting Queenslanders touched by cancer, and to a lesser degree those with other life limiting conditions.

In respect of aged care, we recommend:

1. The Committee should recommend that myagedcare assessments should meet minimum timeframes where a recipient advises that they are receiving cancer treatment and need to update their plan. This assessment should be implemented in a timely way.
2. Queensland Health should extend educational opportunities and training resources in end-of-life decision making to all caring staff in residential aged care facilities, as part of the implementation of the Statewide strategy for end-of-life care 2015.

In respect of the palliative care system, and particularly informed by the **PalAssist** service we operate, we recommend:

3. Queensland Health engage in a targeted awareness-raising campaign to inform clinical staff about the Optimal Cancer Care Pathways, particularly as they relate to end-of-life care.
4. The Committee should recognise the important role of independent services providing information, practical and psychosocial support, as part of Queensland's palliative care ecosystem.
5. Advance care planning should be investigated to ensure patients' wishes are respected in palliative care and end-of-life treatment.

Cancer Council Queensland does not support, nor do we oppose, assisted dying.

Assisted dying is a complex topic and one which understandably evokes very strong feelings, of both support and opposition, among members of the Queensland community. We respect the rights of individuals to take a position on this very complex issue, however as an organisation which supports all people and all cancers, Cancer Council Queensland takes a neutral stance. While maintaining neutrality, we are cognisant that if assisted dying is legalised in Queensland this will impact on cancer patients and families. In jurisdictions that have legislated for assisted dying in some form, cancer patients comprised the largest group of patients to access some form of assisted dying.[2]

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[2] Ezekiel J. Emanuel, Bregje D. Onwuteaka-Philipsen, John W. Urwin and Joachim Cohen, 'Attitudes and Practices of Euthanasia and Physician-Assisted Suicide in the United States, Canada, and Europe' (2016) 316(1) *Journal of the American Medical Association* 79; *California End of Life Option Act: 2017 Data Report* (California Department of Public Health, 2017). Available at https://www.cdph.ca.gov/Programs/CHSI/Pages/End-of-Life-Option-Act-.aspx

We have invited stakeholders to provide feedback directly to the Health Committee on the issue of voluntary assisted dying.

If the Health Committee is to recommend legislation to allow voluntary assisted dying, any legislation should be compassionate, feasible and contain appropriate safeguards. Assisted dying and palliative care are distinct, and if assisted dying is legalised, palliative care becomes even more important, and the community must have knowledge of, and access to, appropriate palliative care services and choices for end of life care and support. Any proposed legislation should not result in a reduction in palliative care service availability or in the efforts to improve palliative care; nor should it result in a reduction in the focus on, and funding for, the prevention and treatment of cancer.

Contents

Contact: **James Farrell**
General Manager, Advocacy [redacted]
Cancer Council Queensland [redacted]

Aged care

We limit our feedback on the aged care system, to the experiences of Queenslanders who have a life limiting illness or condition (including cancer), and/or their families and carers. In particular, we draw on information from people accessing support from our **PalAssist** service, Cancer Council 13 11 20 and our Metropolitan and Regional Cancer Support teams.

Through those services, our staff receive feedback that the number of aged care beds in Queensland is insufficient. While some regional centres have seen several new facilities built in recent years, the demand still appears to be much higher than supply.

Financially, nursing homes have limited capacity to set the basic daily care fee and income and asset assessed extra fee (as this is set by the government), but individual facilities can set their deposit rates and can calculate additional fees based on the worth they set on a certain room type. Clients have to then assess what is viable, based on their financial circumstances. In our experience this is often a topic of high stress put on uneducated families or older people trying to cope independently

In part, we observe that funding mechanisms can contribute to consumers' (in)ability to access appropriate aged care services. Some nursing home facilities will only admit patients based on their clinical need. If the clinical need is not high enough to fit it the highest earning Aged Care Funding Instrument (**ACFI**) claim, nursing home administration may turn away patients

My Aged Care

State and Federal Governments provide services for older Queenslanders to stay in their homes, with appropriate support. **my**aged*care* helps many older Queenslanders access services at home which can improve their wellbeing and help them stay independent. More information is available at www.myagedcare.gov.au, and the diagram below illustrates the assessment and referral process for older Australians:[3]

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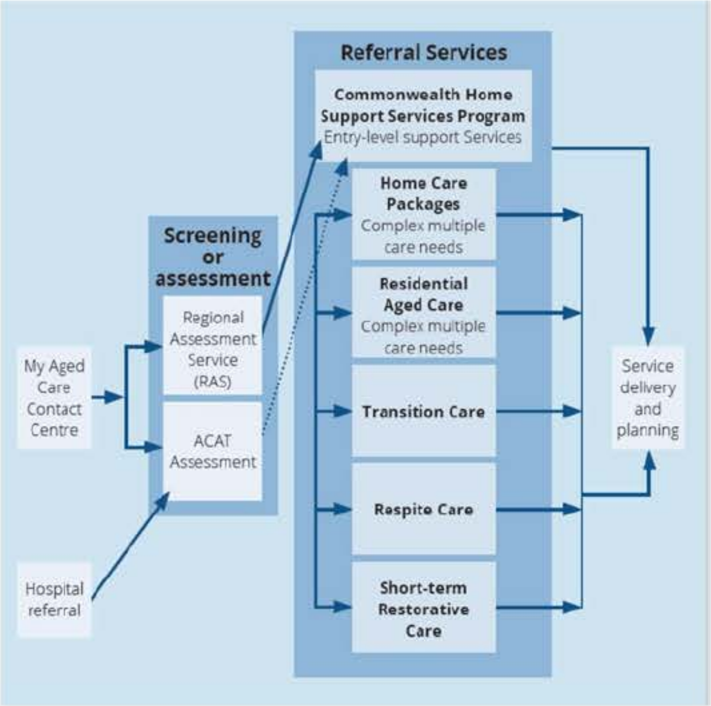
[3] PalliAged, *Tips for Nurses: ACAT Assessment.* Available at https://www.palliaged.com.au/Portals/5/Documents/Practice-Tip_Sheets/ACAT-Assessment-Nurses.pdf



Older Queenslanders tell us that wait times for Aged Care Assessment Team (**ACAT**) assessments in some districts can be over four weeks, sometimes between 8-12 weeks to even be assessed, and wait times to be admitted to a facility can be even longer. Due to these wait times, consumers are left with deciding to go into a home with the first available bed, rather than the home they choose or prefer to live in as there are no available beds.

Tom (not his real name) has a life-limiting illness in the Wide Bay region. He is currently accessing respite in a private nursing facility, as he can't get into a public facility. He can access this service for the cost of his pension for three months, however if he is still alive longer than this period, the cost of a room will be in the vicinity of $300,000 plus the general weekly fees. This has created a significant amount of stress for Tom's family, who are now having to consider what options are available, instead of focussing their time in making memories with their much-loved family member.

These problems are exacerbated for older Queenslanders with cancer and other life limiting conditions. The effects of treatment and/or the condition itself can mean people need additional supports, yet there can be difficulty accessing timely and appropriate assessments (or re-assessments). We are told that additional supports cannot be assessed pre-emptively, even when the impact on a patient is entirely foreseeable. When an older patient receives treatment, they should be able to vary their support services easily and quickly. Assessors should also understand pain management, access to palliative care consultation services and audits of pain management practices.

Recommendation 1:	The Committee should recommend that **my**aged*care* assessments should meet minimum timeframes where a recipient advises that they are receiving cancer treatment and need to update their plan. This assessment should be implemented in a timely way.

Pain and symptom management in residential aged care facilities

Pain management is a frequently reported issue for clients with family members in RACFs. Over half of callers to our PalAssist service in 2018 were carers (13.3%) or family/friends (48.5%), and many of these callers expressed concerns about the pain and suffering of patients.

Many people call PalAssist needing support with nursing homes as they don't feel their family member is being cared for appropriately. They report that some nursing staff are not able to identify palliative care phases or putting palliative care plans in place is a common concern.

Further, almost a quarter of callers (23%) to our PalAssist service in 2018 were general practitioners and health professionals, suggesting additional support is needed to support health professionals. We welcome the September 2018 release of the *A Matter of Care: Australia's aged care workforce strategy,* which identifies 14 strategic actions to help the aged care industry to address the current and future workforce challenges:[4]

1. Creation of a social change campaign to reframe caring and promote the workforce
2. Voluntary industry code of practice
3. Reframing the qualification and skills framework—addressing current and future competencies and skills requirements
4. Defining new career pathways including accreditation
5. Developing cultures of feedback and continuous improvement
6. Establishing a new standard approach to workforce planning and skills mix modelling
7. Implementing new attraction and retention strategies for the workforce
8. Developing a revised workforce relations framework to better reflect the changing nature of work
9. Strengthening the interface between aged care and primary/acute care
10. Improved training and recruitment practices for the Australian Government aged care workforce
11. Establishing a remote accord
12. Establishing an Aged Care Centre for Growth and Translational Research
13. Current and future funding considerations, including staff remuneration
14. Transitioning the existing workforce to new standards

We also hear reports that, in some residential aged care facilities, staffing levels are stretched and that some patients can't access pain or symptom management – and other support services – in a timely way. Cancer Council Queensland doesn't have any direct line of sight into this issue (other than reports from Queenslanders using our services), but expect that other contributors to this inquiry and to the Royal Commission into Aged Care Quality and Safety will be in a position to offer further insights.

Palliative care in residential aged care facilities

PalAssist clients inform us that palliative care delivery in residential aged care facilities (**RACFs**) can be lacking, with differing options for support and education for RACF staff, especially in rural and remote areas. As we noted above, almost a quarter of callers (23%) to our PalAssist service in 2018 were general practitioners and health professionals, and another 13.3% were carers. These figures suggest that additional support is needed to support professionals working in residential aged care facilities.

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[4] Aged Care Workforce Strategy Taskforce, *A matter of care: Australia's aged care workforce strategy*, 2018.

The Australian Institute for Health and Welfare notes that[5]

> [p]alliative care provided in a residential aged care service is regulated under the *Aged Care Act 1997*, within the Quality of Care Principles. Under the schedule of specified care and services, an Approved Provider is responsible for providing access to a qualified practitioner from a palliative care team, and the establishment of a palliative care program including monitoring and managing any side effects for any resident that needs it. In addition, under Schedule 2 – Accreditation Standards, an Approved Provider is responsible for ensuring the comfort and dignity of terminally ill care recipients is maintained.

However, Palliative Care Queensland suggests that '*current workforce requirements for specialist palliative care do not meet those identified by the* Palliative Care Service Development Guidelines *(2018) to deliver quality palliative care.'*[6]

The Queensland Health *Statewide strategy for end-of-life care 2015*[7] identifies four 'service directions'. Relevantly, Service Direction 1 states:[8]

> Knowledge of end-of-life care throughout public health organisations is expanded and includes a comprehensive awareness of the benefits of the planning and delivery of end-of-life care and availability of supporting services/resources within and between health services.

It goes on to state an objective (objective 1.4), that *'Healthcare professionals are knowledgeable and supported in their role in the delivery of end-of-life care (regardless of level of clinical need and/or setting of care).'*[9] It also commits the Department to:[10]

> Prioritise (and consider making mandatory) routine/regular access to educational opportunities and training resources in end-of-life-care decision making for all healthcare professionals including junior medical, nursing and allied workforces.

The Strategy does not specifically note that staff of residential aged care facilities comprise a part of this workforce.

Recommendation 2:	Queensland Health should extend educational opportunities and training resources in end-of-life decision making to allcaring staff in residential aged care facilities, as part of the implementation of the *Statewide strategy for end-of-life care 2015.*

The biggest challenge facing regional, rural and remote Queensland is the limited access to services in their home towns. This can be both a lack of services available to provide the level of care required, or no options suitable to transport patients back to their home towns from major hospitals. This is a particular challenge for Aboriginal and Torres Strait Islanders living outside major regional cities.

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[5] Australian Institute of Health and Welfare (**AIHW**), *Palliative Care Services in Australia* (17 October 2018). Available at https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/palliative-care-in-residential-aged-care

[6] Palliative Care Queensland, *Submission to Queensland Health Review of Palliative Care Services, 2018* (September 2018), 5. Available at https://palliativecareqld.org.au/wp-content/uploads/2018/09/PCQ-submission-for-QHealth-PallC-Services-Review-2018.pdf.

[7] Available online at https://www.health.qld.gov.au/__data/assets/pdf_file/0022/441616/end-of-life-strategy-full.pdf.

[8] Ibid, 4

[9] Ibid, 5.

[10] Ibid, 6.

End-of-life and palliative care

Palliative care and cancer

Cancer patients have a range of options available to them regarding their medical care towards the end of life. These options are dependent on the prevailing circumstances and can include treatment to reduce or maintain tumour size (such as chemotherapy or radiation therapy) delivered by a treating physician (such as a medical oncologist) with support from a multi-disciplinary team. These services are provided in either an inpatient or outpatient hospital setting, depending on the circumstances of the patient.

However, these patients tell us that palliative care and end-of-life care provided is not meeting their needs, particularly for regional and remote Queenslanders. People can have very strong preferences on whether they die at home, in hospital or in hospices however their wishes are often not able to be respected due to the services available.

The biggest challenge facing regional, rural and remote Queensland is the limited access to services in their home towns. This can be both a lack of services available to provide the level of care required, or no options suitable to transport patients back to their home towns from major hospitals.

According to the Australian Institute of Health and Welfare, there were almost 73,900 palliative care-related hospitalisations reported from public acute and private hospitals in Australia in 2015-16, and 48.3% of these hospitalisations involved cancer as the principal diagnosis.[11]

Palliative care for the management and relief of pain and suffering remains the primary medical practice adopted for end of life care and may be provided alongside chemotherapy or radiation therapy if required. Palliative care can be received via public or private inpatient palliative care, community palliative care, consultant palliative care, day hospices, or state-wide palliative care services. These services are often provided concurrently, such as inpatient care to stabilise symptoms with support from community palliative care to ensure optimal transition back home.[12]

Care in these instances is primarily overseen by a palliative care physician with a dedicated and expert support team including palliative care nurse practitioners, nurses, general practitioners, allied health, social workers and personal and spiritual care support.

However, people using our services report that much of the burden falls to family members. Significant numbers of palliative patients have elderly spouses/partners who struggle to manage their daily care as their health declines. Both parties may wish to keep the patient at home and usually continue to do so for as long as possible, placing great strain on the carer, and potentially providing sub-optimal clinical care and symptom management for the patient.

Significant numbers of the public, believe that a referral to Community Palliative Care (**PC**) leads to the full-time presence of a volunteer or professional carer in the home. Many are surprised to learn that the bulk of the patient care will still need to be provided by family or friends. In instances where the patient has a chronic illness that they have been living with for years, or they are frail and aged, but there is no acute illness, Domiciliary Nursing Services may provide the required in-home support and specialist PC Services may not be

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[11] AIHW, above n 5.

[12] Victorian Government Department of Health (2011) *Strengthening palliative care: Policy and strategic directions 2011-2015* http://www.health.vic.gov.au/palliativecare/documents/palcare_policy1114.pdf

required. Enabling care staff (personal carers or registered nurses) to undertake an increased number of visits to the home each day may enable the patient to remain in the home for longer. This would require more human resources but would reduce the cost associated with admission to a Residential Aged Care Facility or hospital.

In some instances, the care for the relief of pain and suffering for a terminally ill cancer patient may be provided by the treating cancer physician who may or may not have undertaken training in palliative medicine. Patients in regional, rural and remote Queensland report limited access to services in their home towns. This can be both a lack of services available to provide the level of care required, or no options suitable to transport patients back to their home towns from major hospitals. These services should not only focus on supporting the dying experience, but on ensuring the person can maximise their engagement in living in the process of dying.[13]

Due to the multidisciplinary nature of cancer care, cancer patients will interact with a range of health professionals throughout their cancer experience. In order to achieve end of life care that comprehensively addresses the needs of terminal cancer patients, it is important for the patient's multidisciplinary treating team to recognise the important role of palliative care and support the earlier integration of palliative care into the person's care team. This recommendation is supported by cancer clinical guidelines, such as the Optimal Cancer Care Pathways (**OCPs**).[14] The OCPs promote early referral to palliative care services, acknowledging that palliative care can improve quality of life and in some instances prolong life. There are also an Optimal Care Pathway for Aboriginal and Torres Strait Islander People that supports the delivery of health services that are culturally safe and responsive.. However, a 2017 survey facilitated by Queensland Health's Central Integrated Regional Cancer Service (**CIRCS**) to measure awareness, knowledge of, accessibility and use of OCPs found that less than one in six respondents were aware of the OCPs before being surveyed.[15]

Recommendation 3: Queensland Health engage in a targeted awareness-raising campaign to inform clinical staff about the OCPs.

Ashby suggests that the work of palliative care can be sub-divided into:[16]

(i) biological aspects: pain and symptom management;
(ii) psychological and spiritual support: for patients, families, friends, and carers, and after death for the bereaved; and
(iii) communication and decision-making.

Yet barriers exist to the early integration of palliative care for cancer patients. Barriers are identified at the patient, clinician and service levels, some of which intersect.

Barriers to early integration of palliative care

Barriers for patients and families

Barriers to early integration of palliative care at the patient level include:

- limited understanding of the care and treatment options available;
- feeling a sense of "giving up" if referral to palliative care services is accepted;

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[13] See further Deirdre Morgan, David Currow, Linda Denehy and Sancia Aranda, 'Living actively in the face of impending death: constantly adjusting to bodily decline at the end-of-life' (2017) 7(20 *BMJ Support Palliat Care* 179.

[14] Queensland Health (2017) *Optimal Care Pathways*. Available at https://www.health.qld.gov.au/circs/html/projects/optimal-cancer-care-pathways

[15] https://www.health.qld.gov.au/__data/assets/pdf_file/0029/647246/Survey-infographic.pdf

[16] Michael Ashby, 'How we die: A view from palliative care' (2016) 16(1) *QUT Law Review* 5, 7.

- patient and/or family preferences to maintain curative treatment; and
- denial of disease state leading to a refusal of referral.[17]

For families and carers, the fear of losing a loved one may also mean referral to palliative care is not considered.

Barriers for clinicians

Australian research suggests that cancer clinicians support early integration of palliative care and consider that patients may benefit from palliative care services whilst still receiving active treatment.[18] However, there are discrepancies between attitudes and practice in respect of early referral to palliative care. In one study of palliative care referral practices, 71% of cancer clinician respondents agreed that early referral is beneficial and 92% agreed that a patient might benefit from palliative care whilst still receiving cancer therapy; however, just one-quarter of respondents referred more than 80% of their patients with advanced cancer to palliative care.[19] The literature suggests a number of common reasons for the reticence in making referrals to palliative care, including:

- cancer clinicians' perceptions of their own ability to manage patient symptoms;[20]
- a sense that referring to palliative care is 'abandoning' the patient;
- lack of awareness about palliative care practice;
- lack of skills, training and experience to recognise when to refer to palliative care;
- uncertain patient prognosis;
- difficulty in discussing end of life care with a patient and family;
- lack of palliative care services to which to refer patients; and
- the absence of physical symptoms in the patient.[21]

Patient and clinician barriers are inextricably linked. For example, if clinicians were more confident in starting discussions with their patients about end of life care, many patients would be provided the opportunity to better understand their end of life care choices.

Service level barriers

In early 2015 Cancer Council Victoria consulted with more than 170 cancer clinicians on priorities for the next Victorian *Cancer Action Plan*. Barriers to early integration of palliative care were discussed as part of these consultations. Barriers at the service level were those most frequently identified by the clinicians consulted.

A key service level barrier identified was insufficient community and consultant palliative care services to meet demand, resulting in patients and families not receiving adequate palliative care upon discharge from hospital. Regional and rural patients are particularly vulnerable to receiving inadequate palliative care due to a lack of services. Compounding these challenges, are the cultural beliefs of Aboriginal and Torres Strait Islander people when the desire is to die on Country and the role of extended family in decision making. Clinicians called for the expansion of a 24-hour, seven-day a week consulting service, and saw particular value in having consultants' positions in acute hospitals to support better

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[17] Anthony Love and Laura Maher Liversage, 'Barriers to accessing palliative care: A review of the literature' (2014) 22(1) *Progress in Palliative Care* 9.

[18] Claire Johnson, Afaf Girgis, Christine Louise Paul and David C Currow (2008) 'Cancer specialists' palliative care referrals practices and perceptions: results of a national survey' (2008) 22(1) *Palliative Medicine* 51.

[19] Ibid.

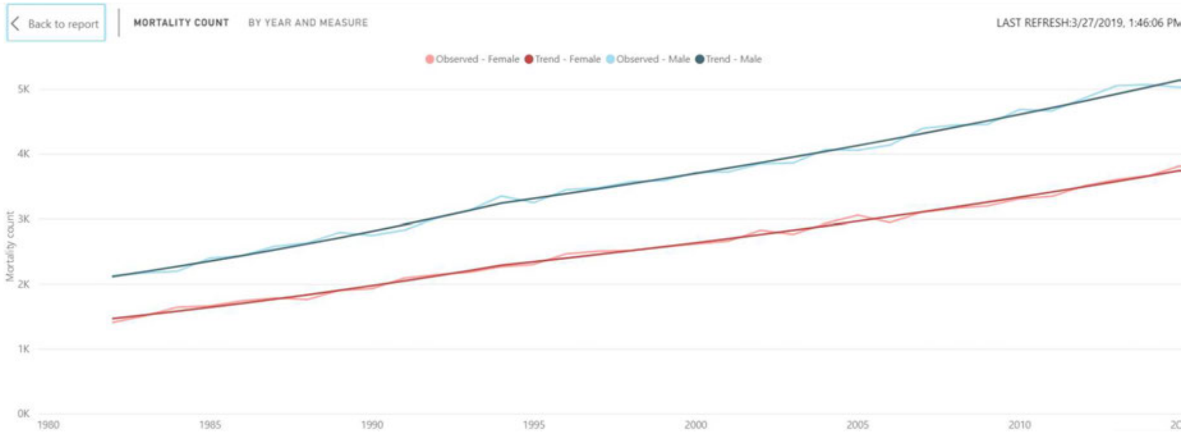
[20] Ibid.

[21] Love and Liversage, above n 17.

integration of palliative care, particularly through attendance at oncology outpatient clinics and at tumour stream multi-disciplinary meetings.

There is a discrepancy between the definition of early referral to palliative care and the current funding model. Clients accessing our services report their frustrations when they have life limiting illnesses and they ‘are not dying quick enough’ to fit the funding criteria.

Given our aging population, the demand for palliative care in Queensland is expected to grow into the future. Despite continued investment in research and improvements to treatment, deaths from cancer are trending upwards, as shown below:[22]



The care pathway of cancer patients can be complex, as patients and their families interact with various clinicians and support services, including palliative care. Inadequate integration of these services can result in delays in access and fragmentation in continuity of care.

Cancer Council Queensland operates **PalAssist**, a service funded by the Queensland Government, to provide support and guidance to Queenslanders with a life limiting illness or condition (and/or their families and carers) to help navigate this complex system.

About PalAssist

Often people have very little idea about what happens when we experience an advanced, life-limiting illness, how care will be coordinated, or how much it will cost. Understandably, this is a daunting time. The registered nurses and health professionals at PalAssist help Queenslanders with:

- Accurate and up-to-date information about palliative care
- Emotional, practical and informational support
- Referral to local services that provide either home care or in-patient facility palliative care for you or your loved one.

PalAssist offers compassionate guidance to help you plan the end-of-life experience that is right for you. We will do all we can to empower you with the information and understanding you need to approach this difficult time on your own terms, with positivity, knowledge and grace.

PalAssist provides service information, referral pathway information and emotional support, mostly via telephone, to families, carers and patients; and some health professionals, between 7am and 7pm, 7 days per week. PalAssist also provides information and support to

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[22] Source: https://cancerqld.org.au/research/queensland-cancer-statistics/queensland-cancer-statistics-online-qcsol/

people via email and webchat, although these are far less common methods of contact with our service.

The PalAssist website is accessible 24/7, with palliative care information and a service directory available online.

Information requested can be in relation to community-based services, outpatient, inpatient, RACFs or hospice. We also receive calls about health system navigation, symptom management, medications, service information, burial assistance and from clients requiring emotional support.

Referral pathways are different in every area across Queensland, and the availability of community services appears to vary greatly between areas.

PalAssist complements our existing 131120 service, available to people to speak to a member of our Cancer Information and Support Team about anything to do with cancer including:

- Emotional support if you or someone you care about has cancer
- How to reduce your risk of cancer
- Questions about early detection
- Cancer diagnosis
- Treatments and their side effects
- Practical support and services that are available for people affected by cancer
- End of life issues

Our health professionals in this team can provide information, and help to clarify medical terms, procedures and treatments. They can also refer callers to Cancer Council Queensland support programs and other community services.

Who we help

In 2018, we aided 721 callers through the PalAssist service.

Most of our clients are family members or carers of people with life limiting conditions, are in metropolitan areas or large provincial areas, are women (74.5% in 2018), are Australian born (53%[23]), and are of non-indigenous status (3.3% of callers in 2018 identified as Aboriginal and/or Torres Strait Islanders).

Approximately 43% of callers in 2018 were calling about someone with cancer, but there were a variety of life-limiting conditions that affected people:

Condition	Number	%
Cancer	313	43%
Neurological	54	7%
Respiratory	31	4%
Cardiac	25	3%
Renal	15	2%
Paediatric	1	0%
Other/undisclosed	282	39%
Total	**721**	**100%**

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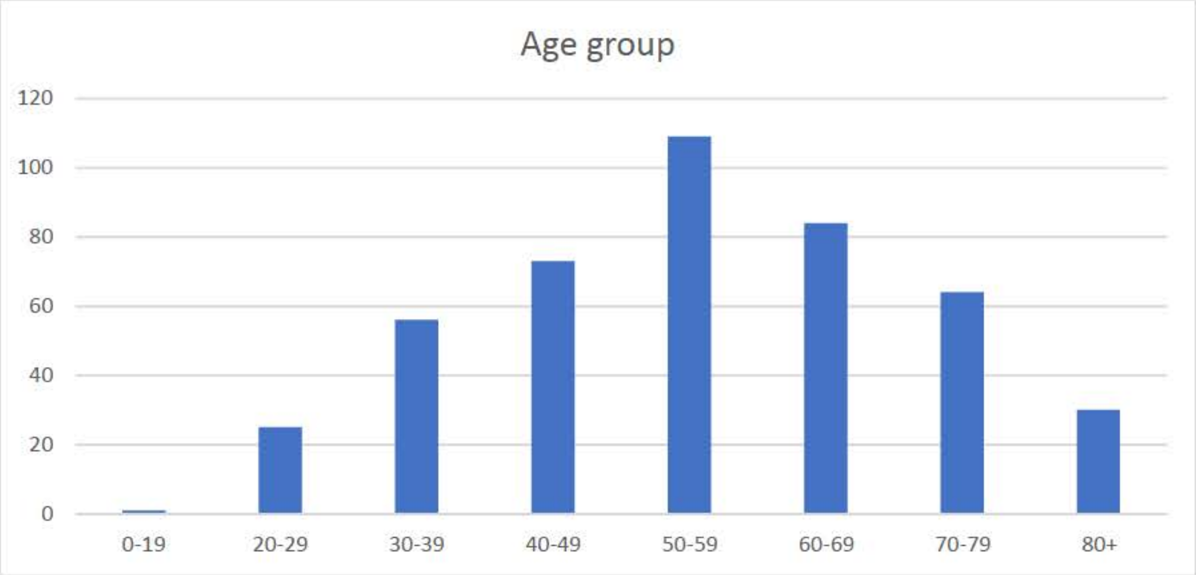
[23] In 2018, we also received calls from clients born in Argentina, Austria, China, Croatia, Denmark, England and other parts of the UK (Scotland, Channel Islands, Isle of Man), Fiji, France, Germany, Hungary, India, Kenya, Netherlands, New Zealand, Philippines, Samoa, Serbia, South Africa, Sweden, Ukraine, United Arab Emirates and the United States.

Only 38% of callers in 2018 reported coming from the greater Brisbane area:

Postcode/region	Number	%
Brisbane	275	38%
Cairns	23	3%
Mackay	8	1%
Maroochydore	60	8%
Rockhampton	22	3%
Southport	74	10%
Toowoomba	24	3%
Townsville	19	3%
Wide Bay/Burnett	57	8%
Interstate[24]	45	6%
Overseas[24]	3	0%
Unknown/other	111	15%
Total	**721**	**100%**

For those callers that identified their age (n=442), there was a real spread across age ranges:



Clearly, there is a continuing need for services like PalAssist, to help Queenslanders to navigate the palliative care system.

Recommendation 4: The Committee should recognise the important role of independent services providing information, practical and psychosocial support, as part of Queensland's palliative care ecosystem.

Advance care planning

Given the experience in other jurisdictions, Cancer Council Queensland expects that this inquiry will need to consider advanced care planning, which allows people to provide some direction about their future care. In Queensland, there are three main types of advance care planning:[25]

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[24] Interstate and overseas callers identified a palliative family member residing in Queensland.

[25] LawRight, *ACP 1 – Planning for future health care - an overview* (July 2017). Available at http://www.legalpediaqld.org.au/index.php/ACP_1_%E2%80%93_Planning_for_future_health_care_-_an_overview.

- **Enduring Power of Attorney:** allows you to name someone to make decisions on your behalf if or when you can no longer do so. That person (referred to as your "attorney") can be authorised to make financial (money) decisions, personal decisions (for example, relating to health care), or both. An attorney appointed for personal matters will become the primary contact if you need medical treatment. People often make an EPA when they make a Will.
- **Advance Health Directive:** This legally binding document tells health care professionals what treatment you would like to receive (or not receive) if you are no longer able to make your wishes clear (e.g. you might be unconscious). While you are still able to speak for yourself, the Advance Health Directive will not be used.
- **Statement of Views:** If a person lacks legal capacity and they have not pre-arranged an EPA or AHD, they may be able to get assistance to prepare a Statement of Views/Choices. Unlike an Advance Health Directive or EPA, this document lacks legal force, but it still may help guide medical and care practitioners in deciding care arrangements. A Statement of Views/Choices is usually prepared by a family member in collaboration with care professionals.

Generally, when our PalAssist team is discussing patients' rights under these instruments with callers, they are told that the legal framework isn't a problem, but sometimes patients' wishes aren't being followed. Strengthening processes to support compliance with patients' wishes is important, and we suggest the Committee investigate the Respecting Choices® program, where

> the advance care plan is used to stimulate discussion between the patient, the next-of-kin and the hospital staff regarding patient end-of-life care. The patient's resulting advance care plan is then placed in a plastic 'green sleeve' in the patient's medical records, ensuring that the document is available and easy to find when an important decision needs to be made and the patient is no longer competent to communicate their wishes.
>
> When the Respecting Choices® program was assessed two years after its implementation in La Crosse, they analysed the impact of the program on all those who had died in the hospital and the community. They found that:
>
> 1. The number of deceased patients who had completed an advanced care plan had increased from 15% to 85%.
> 2. The number of advance care plans available in 'the green sleeve' in patient medical records had increased from 4% to 96%.
> 3. The patient's wishes, as stated in the advance care plan, were followed in 98% of deaths.
> 4. There was a documented improved perception of the quality of care by those aged over 65 in an independent randomised study.
> 5. There was an improved level of comfort felt by appointed medical attorneys with regard to their role…[26]

Again, given our limited line of sight into this experience, we expect other submitters to provide additional information for the Committee's consideration.

Recommendation 5: Advanced care planning should be investigated to ensure patients' wishes are respected in palliative care and end-of-life treatment.

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[26] Meagan-Jane Lee, Melodie Heland, Panayiota Romios, Charin Naksook and William Silvester, 'Respecting Patient Choices: Advance Care Planning to Improve Patient Care at Aus in Health' (2003) 77 *Health Issues* 23. See further Austin Health, *Australian Government Productivity Commission Draft Report on Caring for Older Australians: Submission by the Respecting Patient Choices "Making Health Choices" Steering Committee* (undated), available at https://www.pc.gov.au/inquiries/completed/aged-care/submissions/subdr0803.pdf; Karen M Detering, Andrew D Hancock, Michael C Reade and 'The impact of advance care planning on end of life care in elderly patients: randomised controlled trial' (2010) 340 *BMJ* c1345.

Voluntary assisted dying

Cancer Council Queensland does not support, nor do we oppose, assisted dying.

Assisted dying is a complex topic and one which understandably evokes very strong feelings, of both support and opposition, among members of the Queensland community. We respect the rights of individuals to take a position on this very complex issue, however as an organisation which supports all people and all cancers, Cancer Council Queensland takes a neutral stance. While maintaining neutrality, we are cognisant that if assisted dying is legalised in Queensland this will impact on cancer patients and families. In jurisdictions where Governments have legislated for assisted dying in some form, cancer patients comprised the largest group of patients to access some form of assisted dying.[27]

Experiences from countries that have legalised some form of assisted dying show that the greatest number of people seeking assisted dying have advanced cancer. Cancer Council has outlined the following principles that we believe help ensure that the expectations and needs of the cancer community are considered in law reform for assisted dying.

- Consideration of assisted dying should occur in the broader context of improving end-of-life care. High quality end-of-life care should be available for all Australians regardless of any choices a person may make about assisted dying. This includes equitable availability of palliative care and support for end-of-life decision-making.
- Legislative change for assisted dying must protect vulnerable people, including but not limited to those who have compromised decision-making capacity.
- Public communication about assisted dying must be considered and careful, to ensure compassionate and confidential information and support is available and provided to people considering assisted dying. Any decision to access assisted dying must be fully informed, freely made and respected. Public communication should not position assisted dying as the community's expectation for people with a terminal illness, nor should people with a terminal illness feel pressured to enquire about assisted dying.
- All health practitioners and services must receive education and training to support decision-making at end of life, that includes an understanding of any assisted dying legislation and the processes available to access. This education aims to ensure that people can access the support they need, including support to make assisted dying decisions, and should not depend of the views of the service or practitioner about assisted dying.
- Respect for all health practitioners, regardless of their choice to be involved or not involved in assisted dying, is essential.[28]
- Families of people choosing assisted dying must have the same bereavement support as all families facing the death of a family member.
- Safeguards are an essential part of any assisted dying legislation and include protection of people from coercion, protection of health practitioners involved in assisted dying and prevention of misuse of lethal drugs.
- Assisted dying legislation must include clear reporting obligations and information collection requirements, which will be essential to track the operation of an assisted dying scheme, and to detect and address any negative, unintended effects.

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[27] Ezekiel et al, above n 1.

[28] The need to respect the choices of health practitioners and health services not to participate in assisted dying can be achieved without use of the term 'conscientious objection'.

- Death certification coding should include the capacity to record the death as occurring in the context of an assisted death to aid evaluation.
- An assisted dying scheme requires continuous and adequately resourced monitoring and evaluation.

Assisted dying and palliative care are distinct, and if assisted dying is legalised, palliative care becomes even more important, and the community must have knowledge of, and access to, appropriate palliative care services. Any proposed legislation should not result in a reduction in palliative care or in the efforts to improve palliative care; nor should it result in a reduction in the focus on, and funding for, the prevention and treatment of cancer.

Queensland Parliamentary Inquiry into
AGED CARE, END-OF-LIFE AND PALLIATIVE CARE, AND VOLUNTARY ASSISTED DYING

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15 April 2019

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EXECUTIVE SUMMARY

Responses to the Inquiry's issues for consideration

COTA Queensland believes **older people, their family and community supports play a key role in the delivery of aged and end of life care and support**. It is essential the service providers and health professionals are knowledgeable and respectful of the role of the person's informal support system and ensure user-friendly information and good communication at all times.

COTA Queensland recognises that **the aged care system is maintained by vast numbers of informal and unpaid carers** who provide the majority of care received by older Queenslanders. Support for these carers must be a priority.

COTA Queensland believes that aged care services in Queensland can continue to be improved through a **person and relationship-centred approach** that supports healthy ageing, **wellness in all its forms (physical, mental, social, spiritual) and inclusion.** Services must be **designed around consumers' needs**, not providers' needs. Person-centred care supports services in responding to the **diverse needs** of individual Queenslanders.

COTA Queensland believes that the **aged care system is failing to meet the needs of all Queenslanders:**

- Older Queenslanders express a clear preference for home-based care, with demand currently outstripping supply.
- Waiting times for both residential aged care and home-care packages suggest that current levels of demand are not being met. Waiting times for home-care packages are a particular concern, most notably for higher-level packages.
- Population projections suggest that service availability must rapidly increase simply to maintain current service levels.
- Aged care services are not consistently available across Queensland, with supply in outer regional, rural and remote locations of particular concern.

COTA Queensland believes that **the aged care system is unnecessarily complex.** Many Queenslanders do not understand what services are available. It is likely that many Queenslanders who would be eligible for aged care support do not apply because they do not understand how to navigate the system. The current system places responsibility on consumers to understand what is possible and to complete the necessary applications.

COTA Queensland believes that most Queenslanders are satisfied with the aged care services they receive. However, some pockets of **concern** are evident, particularly about the **quality and safety of services**, the **administration charges** for home-care services, and the **availability of services to meet the needs of diverse or vulnerable groups**. Monitoring and review is required to ensure that standards for **quality, safety and consumer satisfaction are continually improved.**

COTA Queensland believes that **the aged care sector needs to develop the skills of its workforce** to ensure that suitably qualified staff are available to meet the care needs of older Queenslanders. Current concerns relate to staff qualifications and ensuring that appropriately trained staff are available when needed. Longer-term staffing concerns relate to a potential skills shortage, particularly in regional areas. COTA Queensland does not support mandated staffing ratios in residential aged care, but advocates for accepted care standards and published staffing levels.

COTA Queensland argues that **hospitalisations for older people should be minimised**, particularly hospitalisations at the end of life. Unnecessary hospitalisation is a burden on the health system, often with little gain for patients.

COTA Queensland proposes that **aged care services in Queensland should focus on home-based and community-based approaches that capitalise on existing community support and readily available technology.** Communications technology offers great potential for providing equitable, home-based care for older Queenslanders.

COTA Queensland believes that **palliative and end-of-life care services are not meeting the needs of older Queenslanders**. Palliative and end-of-life care is poorly understood and little discussed. Older Queenslanders are frequently asked to make decisions about their end-of-life care at times of stress and ill-health. **Queensland needs to have a community conversation about the role of palliative and end-of-life care. Queenslanders must be encouraged to plan ahead for their end of life.**

COTA Queensland believes that **Queenslanders are ready for a genuine conversation about voluntary assisted dying.** Our research suggests that it is supported by most Queenslanders, provided suitable legal safeguards are in place.

Key Priorities for the Future

1. **Individuals and communities need easy-to-access user-friendly information which enables people to plan ahead and make well-informed decisions.** This information sharing and decision making ideally occurs within communities prior to the need for interaction and negotiation with the health and aged care systems. Facilitated conversations and group discussions assist people in identifying what and who is important for them and can assist in documenting and sharing their wishes and preferences for aged, disability and end-of-life care. COTA Queensland would welcome the opportunity of collaborating with Palliative Care Queensland and older members of the community in co-designing and delivering community-led education and information that supports people to make well-informed decisions through ageing, disability, dying, loss and grief phases of life.

2. **Individuals, carers, family and trusted decision makers want to be involved in decisions that impact their lives and those of their loved ones**. People want to be recognised as partners in the provision of health and aged care, and treated with respect and inclusion in decision making, including in the design and evaluation of services, policies and processes, and information. COTA Queensland assists and advises organisations and government departments to engage with older Queenslanders.

3. **Government responses to aged and end of life care must extend beyond the aged and healthcare systems.** Government support for community services, housing, transport, financial security, information provision and social inclusion are all relevant to supporting adequate care for older Queenslanders. COTA Queensland encourages the Queensland Government to continue to advance their Age-Friendly Strategy and actions, and to ensure that people are engaged and supported in living - and dying - as well as possible, within their communities.

1. INTRODUCTION

COTA Queensland welcomes this opportunity to provide a submission to the Queensland Parliamentary Inquiry into Aged Care, End of Life and Palliative Care, and Voluntary Assisted Dying.

COTA's consultations and engagement with older people, their families and trusted decision makers repeatedly highlight the difference that having access to user-friendly information, helpful relationships, adequate resources and shared decision making can make in negotiating and receiving care and support that is respectful, responsive and dignified.

COTA Queensland promotes and supports individual and community capacity building and strongly urges the Queensland Government to prioritise and adequately resource health promotion programs and activities aimed at:

- Improving the individuals' health and wellbeing through the life course
- Reducing the need for costly health interventions and aged care services delivered in acute care and residential-care settings
- Promoting age-friendly communities that support people to remain active and connected, thereby addressing some of the social and environmental determinants of health.

2. ABOUT COTA QUEENSLAND

The Council on the Ageing (COTA) Queensland was founded in 1957 as the Old People's Welfare Council. For more than 60 years, COTA Queensland has supported older Queenslanders through advocacy and support.

COTA Queensland is a state-based organisation committed to advancing the rights, interests and futures of people as they age. We actively seek input from older Queenslanders, their families, their carers and their organisations on matters that are important to them. We aim to mobilise people, communities and government to create an age-friendly Queensland for all. We advocate for older Queenslanders across many areas, including aged care, health, palliative care, end-of-life care, cost of living, energy, transport, housing and retirement living, and elder abuse. We are the Queensland government's peak seniors' organisation and are currently contracted to manage Seniors Week activities.

COTA Queensland provides peer education, information sessions and resources for older people throughout Queensland. We gather feedback from consumers and the community about their experiences of the aged care system and use this feedback to inform our advocacy and policy discussions. We represent the consumer experience of aged care reforms at state-based and national forums.

COTA Queensland is a member of the COTA Federation, which includes all state and territory COTA organisations. COTA Australia is the national policy organisation representing the COTAs on the National Aged Care Alliance and working at the national level to influence policy and initiatives relevant to older Australians.

COTA Queensland and COTA Australia are actively involved in supporting the Australian Government's reforms in the aged care sector, particularly by enabling older people, carers and community members to be informed and active partners in the reform process.

COTA Queensland's vision is that ageing in Australia is a time of possibility, opportunity and influence. Our Mission is to advance the rights, interests and futures of people as they age.

COTA Queensland is committed to the following values:

1. **Respect** – we respect and value the contribution and lived experience of people as they age and support each person's right to make choices and participate in their community
2. **Diversity** – we value the great diversity that characterises people of all ages and commit to genuine exchange and engagement
3. **Collaboration** – we communicate and work collaboratively with older people, with each other, with our partners and with the Queensland community to achieve our vision and purpose
4. **Integrity** – we operate ethically, openly, honestly and with accountability in all our interactions.

COTA Queensland's strategic goals

1. The lives of people as we age in Queensland will be better
2. Queensland will become an age-friendly state
3. We will be a valued, responsive and sustainable organisation.

COTA Queensland's policy and advocacy

COTA Queensland is committed to removing ageism and age discrimination in all its forms and advancing in practice the full citizenship rights of people as they age. We work with the COTA Federation on national issues such as aged care and retirement incomes. In Queensland our policy priorities are:

- **Cost of living** with a particular emphasis on energy
- **Health** including aged and community care
- **Housing and homelessness**
- **Transport**
- **Work.**

3. GUIDING PRINCIPLES UNDERLYING COTA QUEENSLAND'S VIEWS ABOUT AGEING, AGED CARE, END-OF-LIFE CARE, PALLIATIVE CARE AND VOLUNTARY ASSISTED DYING

COTA Queensland is committed to principles and strategies that support ageing well, dying well and grieving well. These include:

- A wellness approach that sees ageing as a time of possibility, opportunity and active community engagement
- A consumer-focused approach to policy development and implementation that builds social policy around the needs and concerns of citizens
- A person-centred approach that places individuals at the centre of decisions about their care.

3.1 Ageing well

Right around the world, populations are ageing. But while people are living longer than ever before, there is little evidence that those extra years are spent in good health.[1] It is possible that for some, population ageing is adding years lived with disability and chronic disease, rather than years of healthy living.

Ageing well requires a focus on wellness and prevention throughout the life course. Ageing is not simply about the short time before death, but is a process that begins at birth. A focus on healthy ageing recognises that decisions made in early life will influence ageing. It recognises that health is influenced by complex factors – including genetic inheritance, life choices, and the social determinants of health. It recognises that health is dynamic, constantly changing in ways that can be both positive and negative. It recognises that subtle changes in mid-life may be indicators of future care needs.

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[1] WHO, 2017, *10 priorities towards a decade of healthy ageing.*

Healthy ageing and aged care cannot be considered separately from broader issues of health promotion, equality, social inclusion and the social determinants of health.

A traditional view of ageing sees older people as suffering increasing ill-health and frailty. They may be considered as out-of-touch, burdensome or dependent.[2] But this view is outdated and inaccurate. Increasing numbers of older people live active, healthy lives, with no need for formal support. However, ageism remains socially acceptable, strongly institutionalised, largely undetected and largely unchallenged. We live in a society that glorifies youth and turns a blind eye to age discrimination. **The World Health Organization (WHO) argues that ageism remains a powerful barrier to good public policy because it limits the ways problems are framed.**[3]

Discussions on ageing typically assume that chronological age is a valid marker of health and behaviour. This approach is clear in Australian policy making, where age is used as the key criterion for access to aged care support. However, evidence suggests that **chronological age is not a marker for health. Instead, diversity is a hallmark of older age.** Some 80-year-olds have physical and mental capacities similar to that of young people. Others have multiple chronic conditions and require extensive support. **The WHO points out that public policy must be framed to maximise the number of people who experience positive trajectories of ageing.** A comprehensive policy must meet the needs of all older people, at all stages on the health continuum.[4]

In line with the WHO, **COTA Queensland advocates for an approach to health and ageing that considers the life course from a human rights perspective.**[5] We advocate that appropriate care and support include informed choice for consumers and accommodate their preferences for the setting and location of care. We advocate that all people should be treated with dignity and respect, with access to the full range of services available in their communities.

COTA Queensland recognises that the goal of public policy is to ensure the fair distribution of society's resources. This does not require that all people are treated in the same way, but it does require that people are treated fairly. **A human rights focus demands that governments monitor access to services**. It is based on the idea that all people – including all older people – should have opportunities to actively participate in their lives and make informed decisions about their care.

3.2 A global strategy for healthy ageing

Healthy ageing involves prioritising strategies that develop and maintain functional ability to enable wellbeing in older age. In this context, 'functional ability' exists at the intersection between individual capacity and environmental support. For example, functional ability to move about the community will be influenced not only by individual mobility and health status, but also by access to suitable transport. In the same way, functional ability to live independently will be influenced not only by individual self-care skills, but also by the availability of supportive aids.

In 2016, the WHO member states adopted the *WHO Global Strategy and Action Plan on Ageing and Health* as a global response to healthy ageing. The WHO defined 2020–2030 as the decade of healthy ageing, with a series of actions to ensure the decade is a success.

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[2] WHO, 2015, *World report on ageing and health.*

[3] WHO, 2017, *10 priorities towards a decade of healthy ageing.*

[4] WHO, 2015, *World report on ageing and health.*

[5] WHO, 2015, *World report on ageing and health.*

3.3 Queensland's strategy for age-friendly communities

COTA Queensland recognises the Queensland Government's efforts to develop age-friendly communities as outlined in the *2016 Strategic Direction Statement* and subsequent *Action Plan* and *Report Card*.[6] We recognise the efforts made by the Queensland Government to extend age-friendly approaches into policies for housing, financial protection and health through the *Residential Transition for Older Queenslanders* Report, the *Parliamentary Inquiry into the Adequacy of Existing Financial Protections for Queensland's Seniors*, Queensland Health's 10-year strategy *My health, Queensland's future: Advancing health 2026*, and the proposed *Older Person's Statewide Health Policy* and an *Older People's Statewide Health Services Plan*.

We look forward to the planned survey about age-friendly services across Queensland's Hospital and Health Services and the $35 million Integrated Care Innovation Fund to support integrated and coordinated health care pathways, connecting hospitals with community and primary health networks.

COTA Queensland endorses the aims of the *Age-Friendly Strategic Directions Statement*:

- Enable people at all ages to participate in community life
- Ensure that people are free from age-related barriers that prevent participation
- Value the contribution of seniors and help ensure their access to all aspects of life.

We acknowledge the close alignment between the Queensland Government strategy and the WHO's goals for healthy ageing. We recognise the Queensland Government's goals and actions across eight areas: outdoor spaces and buildings, transport, housing, social participation, respect and social inclusion, civic participation and employment, communication and information, and community support and health services. **We particularly endorse the Queensland Government's recognition that healthy ageing is not simply a health issue, but a community-wide concern that extends across government portfolios.**

Of particular relevance is the commitment of the Queensland Government under the *Queensland Housing Strategy* to support housing security for older people through housing assistance and homelessness services, increasing the supply of affordable housing, providing social housing, supporting seniors to enter private residential tenancies, helping seniors to maintain tenancies, and supporting seniors to remain in their own homes. Our research suggests that housing security sits alongside health care as priority issues for older Queenslanders.[7]

COTA Queensland encourages the Queensland Government to continue its work in this area and to ensure that a human rights perspective on healthy ageing is considered in all relevant policy development.

3.4 Person-centred care and current aged care reforms

Person-centred care involves ensuring that people have access to services that respond to their preferences, are coordinated around their individual needs, and are safe, effective, timely, efficient and of acceptable quality.[8] It involves a comprehensive and coordinated approach designed around the needs of the older person, not the needs of care providers. It works to prevent, slow or reverse declines in capacity and, when losses are unavoidable, help people to compensate in ways that maximise functional ability.

COTA Queensland recognises that the Australian aged care system is on a journey towards person-centred care and consumer control. Recent reviews have recommended an improved consumer focus, and reforms are setting the aged care system well on the path to consumer control. In particular, the Tune Review 2017 and

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[6] Queensland Government, 2016, *Strategic directions statement; Action plan*; Queensland Government, 2018, *Age-friendly report card 2017-18*.
[7] COTA Queensland, 2019, *Kitchen table conversations*.
[8] WHO, 2015, *World report on ageing and health*.

the Living Longer Living Better Reforms in 2012-14 (designed in response to the Productivity Commission's 2011 report Caring for Older Australians) resulted in:[9]

- Additional support and care to help older people remain at home
- Additional help for carers to have access to respite and other support
- A gateway to help people find information and navigate the system (My Aged Care,)
- Changes to improve services for those with dementia.

Important recent reforms in the sector include:

- The New Aged Care Quality and Safety Commission (from January 2019) which brings together previously separated functions for complaints handling and accreditation
- New Aged Care Quality Standards (from July 2019) which will have consumer outcomes as central to each standard
- A trial of the Aged Care Navigator system (from January 2019).

These reforms are evidence of a gradual move towards consumer-led, market-based, quality incentivised aged care system that is fully responsive to consumers' needs, choice and capacity to pay. COTA Queensland stands alongside COTA Australia in endorsing these developments at the national level. **We advocate for a system that places individual consumers and their family and friends at the centre of planning and reform.**

The current Royal Commission into Aged Care Quality and Safety and Queensland's Parliamentary Inquiry into Aged Care, End of Life and Palliative Care, and Voluntary Assisted Dying are further putting the spotlight on aged care in Australia. COTA Queensland notes the unique opportunities presented by these reviews and joins COTA Australia's call that ongoing policy reforms must not be delayed by the current enquiries. **COTA Queensland notes that the policy reforms at the national level need to be supported by complementary reforms at the state level.**

COTA Australia has called for five immediate actions to maintain the momentum of reform:[10]

1. More home-care packages to reduce waiting times (estimated 30,000 additional high-level home-care packages needed)
2. Shift control over residential care funding to residents and their families (rather than the current system that allocates 'bed licences' to providers)
3. More information and increased transparency for consumers
4. More funding to build workforce capacity
5. Random, targeted, unannounced inspections in residential care.

There is some evidence that consumer demand is supporting the shift to person-centred care. Consumers expect basic services to be right every time, and they expect support to maintain a reasonable quality of life. Many of today's consumers have, and increasingly into the future will have, more knowledge, more access to choices, increased literacy, wider knowledge of products and services, higher expectations about ageing well, higher expectation of easy access and integrated services, and a preference for personalised services. Ageing well is the expected norm, with older people no longer seeing old age as a synonym for disease and dependency. [11]

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[9] Department of Health, 2017, *Legislated review of aged care*; 2019, *Aged care reform*; Productivity Commission, 2011, *Caring for older Australians.*

[10] COTA Australia, 2018, *Keep fixing Australia's aged care system.*

[11] Macnish et al, 2017, *Future of aged care.*

4. QUEENSLAND'S AGED CARE CONTEXT

4.1 Queensland's ageing population

It is well documented that the Australian population is ageing. The number of older Australians will grow rapidly in coming decades, with clear implications for the supply of aged care services. Queensland is part of this trend, with the population of older Queenslanders set to increase significantly in the next 20 years.

In June 2018, 15.4 per cent of the total Queensland population was aged 65 years and over (768, 121 people). By 2041, the 65 plus age group is predicted to be 21 per cent of Queensland's population (1.5 million people).[12]

Given the population predictions, a 'business as usual' scenario would require a significant increase in the number of aged care places in Queensland in the next 20–25 years with a corresponding increase in all aspects of aged care support.

4.2 Queensland's decentralised population

Queensland is a highly decentralised state, with more than one-third of Queensland's older people living outside major cities. Of those Queenslanders aged 70 years and older, 59 per cent live in major cities and 25 per cent live in inner regional areas. The remaining 16 per cent live in outer regional, remote and very remote areas, where access to services can be limited (see Figure 1).[13]

Outside the major cities, Queensland's older population is clustered in coastal regional communities, which have a high proportion of their total population in older age groups. In 2016, 10 Local Government Areas in Queensland had an older population (65-plus) that was more than 20 per cent of the total population: Tablelands, Hinchinbrook, Bundaberg, Fraser Coast, Gympie, Noosaville, Southern Downs, North Burnett, South Burnett and Flinders. By 2041, almost half of Queensland's Local Government Areas will have at least 20 per cent of their population in the 65-plus age bracket. In 10 Local Government Areas, the population aged 65-plus is expected to be around 30 per cent of the total. [14]

This clustered growth in the older population has important implications for local area planning that extend beyond aged care provision to issues such as health infrastructure and accessibility, housing accessibility, transport infrastructure and employment opportunities. An important aspect of this anticipated growth is the availability of a skilled workforce to meet the needs of the ageing population. Some regions are already experiencing a critical shortage of skilled health care and aged care workers. The statistics suggest this trend is likely to continue.

Queensland does not offer equal access to aged care based on geographical location. As shown in Figure 1, in major Queensland cities, 47.3 per cent of people aged 70 and over have access to aged care in some form. In outer regional areas, this figure is 37.8 per cent and in very remote areas this figure falls to 32.5 per cent.

Health outcomes and life expectancy are poorer in regional and remote areas than in major cities.[15] This means that it is impossible to conclude that Queenslanders living in regional and remote locations have less need for services than their city counterparts. It implies that the current allocation is failing to meet the care needs of older Queenslanders living in rural and remote areas.

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[12] QGSO, 2018, *Population projections.*
[13] AIHW. 2018. *Aged care data snapshot.*
[14] QGSO, 2018, *Population projections.*
[15] AIHW, 2017. *Rural & remote health.*

Figure 1: Queensland Total 70 Years and over population (estimated) by Remoteness Area(a) at 30 June 2018 with Aged Care Participation[16]

Remoteness Area	70 Years & Over Population per cent Share by Area	Residential Care Number of Clients per cent Share by Area	Home Care Number of Clients per cent Share by Area	Transition Care Number of Clients per cent Share by Area	Home Support Number of Clients per cent Share by Area	All Aged Care Number of Clients per cent Share by Area	Percentage 70 years & over popn cohort accessing Aged Care within Area
Major Cities	306,219 59%	21,437 66%	11,406 64%	385 66%	111,555 62%	144,785 63%	47.3%
Inner Regional	131,303 25%	6,740 21%	4,398 25%	143 24%	42,068 24%	53,350 23%	40.6%
Outer Regional	73,067 14%	3,888 12%	1,945 11%	56 10%	21,636 12%	27,525 12%	37.8%
Remote	5,753 1.0%	172 0.53%	41 0.23%	0	2,023 1.1%	2,236 1.0%	38.9%
Very Remote	5,716 1.0%	106 0.3%	137 0.76%	0	1,616 0.90%	1,859 1.0%	32.5%
Total	522,057	31,030	16,746	528	179,006	227,310	43.5%

The Royal Flying Doctor Service notes that poor provision of aged care in the bush leads to older patients being relocated to areas of higher provision. They report that people in remote locations feel they have no option about leaving their communities for aged care, becoming '… socially disconnected from all they knew and loved and forced into exile'. The study found that feelings of aloneness were common, with many participants believing their loved ones died more quickly due to being relocated from their rural and remote communities.[17]

COTA Queensland advocates that a person-centred approach to aged care in a decentralised state requires equity of access, regardless of geography. Policy and planning decisions need to ensure that aged care services do not discriminate on the basis of geographical location. It is likely that communication technology will have an increasing role to play in ensuring equity of access, particularly through remote monitoring and video-conferenced consultations.

4.3 Queensland's Aboriginal and Torres Strait Islander peoples

As part of the effort to Close the Gap in health outcomes between Australia's Indigenous and non-Indigenous populations, Aboriginal and Torres Strait Islander people are entitled to aged care services if needed once they reach 50 years of age. In June 2018, Queensland's Aboriginal and Torres Strait Islander population aged 50 and over was estimated at 32,441.[18]

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[16] AIHW, 2018, *Aged care data snapshot.*

[17] Gardiner, et al., 2018, *Healthy ageing in rural and remote Australia.*

[18] ABS, 2018, *Estimates.*

Aboriginal and Torres Strait Islander people are more likely to live outside major cities than their non-Indigenous counterparts. In June 2018, of the Aboriginal and Torres Strait Islander people aged 50 and above, 28 per cent lived in major cities, 19 per cent lived in inner regional areas, 33 per cent lived in outer regional areas, 7 per cent in remote areas, and 13 per cent in very remote areas.[19]

The problems faced in accessing services in rural and remote locations are greater for Aboriginal and Torres Strait Islander people. Older members of Indigenous communities are often reluctant to leave their country and family to access aged care. The importance of older Indigenous people remaining close to their community is well document. They are likely to see residential facilities as a place where people are sent to die. The need to investigate effective approaches to ageing well in Indigenous communities has been largely ignored.[20]

Given that Indigenous people are more likely to suffer poor health outcomes, and given that services are typically poorer in regional and remote areas, this has important implications for ensuring equity of access to aged care.

In providing aged care services to Aboriginal and Torres Strait Islander people, important issues to consider include:

- The geographical reach of providers
- The availability of Indigenous-specific services and services employing Indigenous health care workers
- The cultural competence of all aged care workers
- Exploring ways to integrate aged care services into other culturally appropriate services.

4.4 Queenslanders with diverse needs and from diverse backgrounds

Queensland's population is increasingly diverse, and aged care strategies need to respond to the community's full diversity. Diversity spans a wide range of concepts including cultural background, disability, sexual preference, mental health, socio-economic status, mental health, education and cognitive impairment. **Some aspects of diversity mean that consumers have high care needs or particular vulnerabilities.**

Diversity presents great opportunities for learning, sharing and richness. But it also presents challenges for ensuring that policies and services respond to people's needs. COTA Queensland believes that policies and services must acknowledge the diversity of the community and be developed to maximise opportunities for inclusion. **We are guided by a human-rights and social justice perspective that advocates for equity, respect and justice for all people, regardless of their background, identity and experience.**

The Aged Care Diversity Framework is an important guiding document for ensuring that aged care services respond fully to the community's diversity.[21] Action Plans have been developed for consumers and service providers to guide and advocate for respectful, safe and appropriate care for people from Aboriginal and Torres Strait Islander (ATSI) and Culturally and Linguistically Diverse (CALD) backgrounds, Lesbian, Gay, Bisexual, Trans and Gender Diverse and Intersex (LGBTI), and soon to be released Action Plan for people experiencing homelessness or are at risk of homelessness.

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[19] AIHW, 2018, *Aged care data snapshot.*

[20] LoGiudice, 2016, *The health of older Aboriginal and Torres Strait Islander peoples.*

[21] Department of Health, 2017, *Aged care diversity framework; 2019, Aged care diversity action plans*

5. CONSUMERS' OPINIONS ABOUT AGED CARE AND RELATED ISSUES

5.1 Consumers' wants and needs

Planning for person-centred care must be based on a sound understanding of the issues and concerns experienced by consumers. A series of recent studies inform our understanding of consumers' wants and needs.

Conversations with the Federal Minister for Mental Health and Ageing
Between August 2011 and February 2012, then Federal Minister for Mental Health and Ageing, Mark Butler, hosted 32 conversations throughout Australia focused on caring for older Australians. Approximately 3,400 people attended these conversations. The Minister spoke about the Productivity Commission's report, *Caring for Older Australians,* and outlined the key reforms proposed. He then had an open discussion with people attending.

Five top messages emerged from those conversations.[22] Older Australians want:

1. Quality services available when and where needed
2. Support in their home as much as possible
3. Simplified and streamlined access to information
4. To obtain services in a seamless way
5. As much control as possible over their death, with access to palliative care at home.

A wide diversity of issues was raised during the conversations, demonstrating that aged care is not the responsibility of a single portfolio nor a single jurisdiction. Aged care planning is relevant for all three levels of government and is relevant across all portfolios. At the Queensland Government level, aged care planning is particularly relevant in the portfolios of health, housing, transport, community services, disability services, justice, emergency services and police.

State of the (older) nation report

In 2018, COTA Australia commissioned a nationally representative survey of Australians aged over 50. The survey sampled 2,562 Australians in a 25-minute survey.[23] The survey revealed:

- **Physical health is by far the strongest measure determining quality of life**
- Women fare better than men when it comes to overall happiness
- Non-working people who rent their home fare significantly worse than others in their age group
- Under-employment is evident: 57 per cent of those aged 50 to 64 are in paid employment, along with 15 per cent of those aged 65-plus; 28 per cent of those want more paid work
- Poor quality of life is more prevalent amongst those who rate their financial position poorly, have a disability, are renting, are unemployed, have children living in the household, are single and are younger; of those stating they have poor quality of life, the highest reasons are physical health, mental health and financial difficulties
- Of those reporting high quality of life, the highest reasons include physical health, mental health, financial situation, living environment, freedom to make choices, independence and family life
- **Indicators of vulnerability include low income, disability, language other than English, bereavement in the past year, being from an Indigenous background, experience of domestic violence in the past year and homeless in the past year**
- Widespread concern (41 per cent) that things are getting worse for older Australians

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[22] COTA Australia, 2012, *Summary report on the conversations on ageing.*
[23] COTA Australia, 2018, *State of the (older) nation report.*

- **Widespread support for assisted dying (84 per cent support), with results highly consistent across the states and territories**.

Kitchen table discussions with Queenslanders
In March 2019, COTA Queensland was part of a collaborative with Palliative Care Queensland, Health Consumers Queensland and Carers Queensland which coordinated 20 conversations with 183 older Queenslanders through the Kitchen Tables Collaborative funded by Queensland Health. The aim of this engagement strategy was to hear about what is important for people who do not usually participate in formal consultations and inquiries, and whose voices are not always heard. Through facilitated conversations discussing issues relevant to them, older Queenslanders reflecting a broad diversity of living arrangements and lived experiences said that:

- Housing is a priority issue; older Queenslanders want to remain in their own homes with the support they need to live, age and die well
- They want access to improved information that will help them to navigate the system and make informed choices
- They want access to quality and timely care and support, with a workforce that is understanding, skilled and sensitive
- They want recognition of the huge contribution made by their family and others in supporting them to live at home, and programs and services which enable these informal carers to also have a quality of life, both now and when/if there caring role finishes
- Voluntary Assisted Dying needs to be discussed and should be an individual choice
- People need to plan ahead with advance care planning and decisions about resuscitation

5.2 Consumers' opinions about home-care packages

The demand for home-based care is growing. Most older people prefer to remain in their own home for as long as possible. Almost 60 per cent of people aged over 70 would rather receive formal care at home than in a residential environment.[24] This desire to remain living in one's own home, or a home-like environment, dominated the preferences for the 183 people who participated in the recent Kitchen Table Discussions engagement with a diverse group of people across Queensland.

Recent reforms have developed a consumer-driven approach to home-care packages, with consumers now able to choose a provider best able to provide their services.

Research by COTA Australia identified that 88 per cent of those receiving a home-care service were satisfied with their care (rating their satisfaction with the service as 7 out of 10 or above).[25] However, of those who had tried to access home-care or aged care services in the past year, 20 per cent reported difficulties in doing so. The difficulties they reported included cost, waiting lists, and lack of suitable services.

In a recent COTA Queensland survey of older Queenslanders, we asked for feedback about home care.[26] Participants said that:

- They receive no independent support once a package is approved, and may find it difficult to locate an appropriate service provider
- Consumers in rural and regional Queensland often lack choice in providers
- Higher-level packages often involve a long waiting period
- Services often use subcontractors, which can increase the cost to the client

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[24] Macnish, et al., 2017, *Future of aged care*; COTA Queensland, 2019, *Kitchen table conversations.*
[25] COTA Australia, 2018, *State of the (older) nation report.*
[26] COTA Queensland, 2018, *Aged-care services survey.*

- Many providers charge high administration costs
- Scheduling of services can be difficult, with scheduling based on the priorities of the service provider not on the needs of the client.

Participants in our survey were generally happy with the home-care services they received. Concerns raised by participants included:

- The staff who visit are excellent, but they're often let down by the provider's administrative team
- Staff are given minimal time to undertake tasks, leaving little or no time for personal interaction
- Cleaning and home maintenance services may be of low quality
- Staff may not be trained to notice signs of physical or cognitive decline (decline would indicate that services need to be reviewed)
- Providers are focused on making money ahead of providing care
- Staff shortages mean that consumers' care provider changes.

5.3 Consumers' opinions about residential care

In 2017-18, the average age on entry into residential care was 82 years for men and 84.5 years for women. The average length of stay was 34.6 months.[27]

In the COTA Queensland 2018 survey of older Queenslanders, the most significant issues raised about residential aged care related to access (waiting times and lack of availability) and health care (staffing, after-hours care and palliative care)..[28]

A 2018 study of consumers' experience in residential aged care found:[29]

- The two questions receiving the lowest responses were: *Do you like the food here* and *If I'm feeling a bit sad or worried there are staff here I can talk to*
- Across all questions, small facilities received higher ratings that medium facilities, and medium facilities received higher ratings than large ones
- Queensland tended to have more large and medium facilities than the other states
- Queensland's satisfaction scores tended to be at the lower end of the mid-range; Queensland's score was second from the bottom on the question *Do you feel safe here* and third from the bottom on *Do staff treat you with respect* and *Do staff follow up when you raise things with them.*

Opinions about aged care staffing

Despite the increased age and frailty of aged care residents, in recent years there has been a decline in the number of skilled health professionals employed in facilities. Registered nurses made up just 14.9 per cent of the workforce in 2016 (down from 21.4 per cent in 2003). Enrolled nurses made up 7.6 percent of the workforce (down from 14.4 per cent) and allied health professionals made up 1.1 per cent (down from 9.3 per cent). In contrast, semi-skilled personal care attendants accounted for 71.5 per cent of the workforce in 2016 (up from 56.5 per cent in 2003). [30]

These statistics are not necessarily any reason for alarm. Researchers recognise there have been substantial improvements to the quality of aged care in Australia.[31] Non-compliance across the sector is low, and the majority of providers consistently deliver good-quality care. However, COTA remains concerned that poor practice may go undetected. As is consistently being reported to the Royal Commission into Quality and Safety

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[27] Department of Health, 2018, *Streamlined consumer assessment discussion paper.*
[28] COTA Queensland. 2018. *Aged-care services survey.*
[29] Wells & Solly, 2018, *Analysis of consumer experience report data.*
[30] ACFA, 2018, *Sixth report.*
[31] COTA Australia 2018, *Submission to the Inquiry.*

in Aged Care, poor-quality care exists and can be traumatic for both residents and their families and friends. Poor care also has an impact on consumer confidence across the sector. Changes in the accreditation process, particularly unannounced visits, will go a long way to address this concern.

There is a widespread concern about staffing in residential aged care, related to the number of staff available, the quality and experience of staff, and the organisational and staff culture they work within. There is a clear need for greater transparency, efficient and effective regulatory processes, and systems to promote the protection of human rights. People need to feel confident that quality of life will not suffer when people go into a residential facility.

For residents in aged care, access to a GP can be an issue. The 2017 AMA Aged Care Survey showed that GPs often discontinue visits to residential facilities because unpaid non-face-to-face time increases, their practices are too busy, the patient rebate is inadequate and the patient rebate doesn't compensate for time lost in the surgery. The AMA proposes that facilities need to improve the availability of experienced nurses and other health professionals, increase funding for medical practitioners to attend aged care facilities, improve access to palliative care services, improve access to mental health services, reduce polypharmacy, and improve access to specialist care.

In our survey of older Queenslanders, participants commented that:[32]

- Residential-care staff are not all trained to the appropriate clinical standard
- Residential-care staff often lack adequate experience
- Residential-care staff may not be adequately qualified to care for the residents suffering from dementia
- Residents can be hospitalised unnecessarily or denied needed pain medication (an example included a terminally ill resident denied pain medication as it could become addictive).

With aged care staffing in the public spotlight, there are questions about whether fixed ratios should be set to ensure minimum numbers of qualified staff. Along with COTA Australia, COTA Queensland argues that fixed, mandated ratios are not the answer to staffing in residential aged care. [33] Mandated ratios cannot, on their own, resolve issues with staff quality and availability. In addition, staff ratios cannot address concerns about organisational culture or ensure that a particular resident will, on any day, receive a guaranteed number of hours of care.

COTA Queensland supports COTA Australia's call for four commitments about staffing in residential aged care: (1) staffing levels that are appropriate for the care needs of residents, (2) the requirement for service providers to publish their staffing levels, (3) for a registered nurse to be on staff at all times, and (4) mechanisms to ensure that qualified medical practitioners are available when required, including after hours.

Complaints and feedback

Aged care facilities may not provide adequate opportunities for residents and their families to submit complaints and feedback. The consumer feedback process included within accreditation reviews may not be sufficient.

COTA Australia notes that consumers often fear retribution if they complain or advocate for their rights.[34] Aged care residents may feel vulnerable because there is a clear power imbalance between residents and providers. In addition, COTA's research suggests that residents and their families frequently don't understand that they are able to give feedback during formal review processes.

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[32] COTA Queensland, 2018, *Aged-care services survey.*

[33] COTA Australia, 2018, *Keep fixing Australia's aged care system.*

[34] COTA, 2018, *Submission to the Inquiry.*

Adequate complaints processes, where feedback and complaints are encouraged as part of normal customer service, need to be implemented in facilities as part of a customer-service culture. The outcomes of these complaints need to be widely shared and discussed as a way of learning how to provide better quality care.

Links to outside activities and care
Once people move into residential care, it's commonly accepted that all their needs will be met by the provider. There's no clear reason why this should be the case and why residents should be cut off from other sectors of the community.

Transfers between aged care and health services are a particular problem area. Aged care services may transfer residents to hospital unnecessarily because of concerns that they will be held responsible for not providing adequate care. Hospitals may fail to communicate adequately with residential care providers when patients are discharged.

5.4 Consumers' opinions about their access to information

Australia's aged care system is complex. From the consumer perspective, this complexity is typically encountered at a time when people are seeking support because advanced age, frailty and poor health mean they are no longer coping with independent living. People applying for aged care may experience physical or cognitive impairment that prevents them from fully investigating the options available. In addition, they are likely to have preconceived ideas about aged care, based on the stories they have heard from friends and in the media.

Consumers need access to impartial, detailed information that helps them make informed decisions about their care needs. In 2016, the Australian Government introduced the My Aged Care system to address this need, offering online and telephone support for consumers.

In our 2018 survey of older Queenslanders, COTA Queensland asked participants to comment on the availability of reliable information.[35] Several participants commented that they have little idea about what services are available and what services are likely to be most suitable for them. They need independent advice to make informed choices between the options.

Participants' responses about accessing information were diverse:

- Some expressed complete satisfaction with My Aged Care and with the range of advice available; many of those who were satisfied said they were confident users of the internet
- Some commented that they did not know where to find information about the options available to them
- Some suggested that My Aged Care lacks detail and questioned its reliability (particularly where it relates to service providers)
- Some questioned whether call-centre staff are trained to work with older people who have hearing problems or other health issues that make talking on the phone difficult
- Some commented that My Aged Care is useful for providing general information, but not for seeking answers to specific questions.

A report by the Aged Care Financing Authority notes that some consumer groups are not aware of My Aged Care. In particular, people from Aboriginal and Torres Strait Islander communities and culturally diverse communities may not know about the system and may need support to navigate the system.[36]

In the 2018-19 budget, the Australian Government allocated funding to improve accessibility of My Aged Care and to trial a system navigator service. The My Aged Care System Navigator Trial, which commenced in January 2019, is testing different types of navigator types: information hubs, community hubs, specialist

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[35] COTA Queensland, 2018, *Aged-care services survey.*
[36] ACFA, 2018, *Sixth report.*

support workers in consumer-focused organisations, and aged care financial information service officers within the Department of Human Services. The navigators are designed to support people to get the best outcome from the aged care system and support them to reach the point where care can begin. COTA Queensland is leading the Wide Bay Community Hub Trial and is working in close coloration with ADA Australia who are leading the Wide Bay Information Hub Trial.

In recent years there has been an emerging industry of user-pays aged care brokers who offer to handle all the paperwork and locate a service provider to meet an individual's needs.

Both the Aged Care Navigator Trials and the emergence of aged care brokers are evidence of the complexity of Australia's aged care system. A person-centred system should not require a navigator to help consumers ensure the system can meet their needs. While COTA Queensland supports the Australian Government's decision to trial system navigators and anticipates the navigators will fill a great community need, we call for ongoing efforts to simplify the system and improve its consumer focus.

A recent Queensland Health initiative offers Nurse Navigators to help ensure patients' treatment is well managed across multiple providers. Nurse Navigators coordinate patient-centred care, create partnerships and improve patient outcomes. They're part of the care team, providing care coordination, liaison between providers and access to information. COTA Queensland calls on the Queensland Government to ensure that all HHS regions have sufficient Nurse Navigators to service the needs of older Queensland and to ensure they have experience in geriatric and palliative care.

It is important to note that older people's information needs extend beyond the need for information about residential aged care and home care. Fewer than 45 per cent of older Queenslanders receive some type of formal care package, and the vast majority of care is provided in the community by family, friends and informal carers. **Consumers and their carers need access to reliable information about the full range of services available to ageing Queenslanders.**

6. AGED CARE IN QUEENSLAND

COTA Australia is the national policy organisation representing the state and territory COTAs at the national level in informing and influencing policy and initiatives relevant to older Australian. COTA Australia is making detailed submissions to the Royal Commission on Aged Care Quality and Safety. However, **there are a number of matters which directly impact on a person's ability to access appropriate and timely aged care, with the potential therefore to have an impact on end of life care.**

6.1 Waiting times

Queenslanders often face extended waiting times between their approval for care and the date their care begins. Even when care eventually begins, it is possible that it isn't at the approved level. Consumers frequently receive a Level 2 service when they have been approved at Level 4 because the number of high-level places is not sufficient.

In Queensland in 2013, the median wait time for entry to residential aged care was close to 50 days. By 2016-17, the wait time had extended to 135 days.[37] The trend to longer wait times appears to be continuing: in 2017-18, the median wait time had increased to 141 days.[38]

Consumers often face an extended wait from the time when an ACAT Assessment is completed to the time when they receive a Home Care Package. The waiting time for access to Level 1 and 2 services has decreased from 108 days in 2015-16 to 85 days in 2017-18. While this drop in wait times must be applauded, it is worth

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[37] AIHW, 2017, *Explore admissions.*

[38] Productivity Commission. 2018. *Report on government services.*

noting that the average waiting time for the most basic level of home support, provided to older people who have been assessed as needing that support at the time of the assessment, still averages almost three months. In addition, the waiting time for higher level services has increased, from 65 days in 2015-16 to 140 days in 2017-18.[39] It is noted that additional home care packages have been released since this reporting period.

In COTA Queensland's 2018 survey of older Queenslanders, many participants expressed concern about lengthy wait times.[40] They felt that not enough packages are available, particularly higher-level packages. One participant noted:

> Mum was not reviewed for about 18 months (plus) after being assessed as a Level 2 'low care' initially, despite requests. After her general condition and dementia deteriorated, it was another year before she was re-assessed as a Level 4 with dementia specific funding…. Getting a written diagnosis was the biggest hurdle.

COTA Queensland recognises that waiting times are linked to Australian Government decisions about ratios and package numbers and the national queue, with the Queensland Government conducting ACAT assessments on the Australian Government's behalf. COTA Queensland calls on the Queensland Government to ensure that ACAT assessments are completed in a timely way with minimal waits. COTA Queensland also calls on the Queensland Government to advocate for Queenslanders to encourage an Australian Government commitment to minimise waiting times and ensure that no Queenslander waits more than three months for a service at the level approved.

6.2 The cost of residential aged care in Queensland

Aged care services are primarily funded by the Australian Government. In 2017-18, the Australian Government spent $3.439 billion in Queensland on aged care programs. The residential component of this was $2.274 billion, and the average annual subsidy per occupied place in Queensland was $66,462.[41]

In 2017-18, approximately 47 per cent of Queensland's residential aged care residents depended on Australian Government subsidies to fund their access to residential care.[42] This is higher than the national average of 43.4 per cent receiving government subsidy.

The Australian Government subsidises residential aged care based through a means test. All aged care users are expected to contribute to the cost of providing their service. The number of subsidised places in Queensland has fallen in recent years.[43] It is possible that consumer demand may have fallen. However, current wait times for care (discussed above) suggest that this is not likely to be the case.

A residential care provider receives up to 85 per cent of an individual's pension as a contribution towards care costs. This means that a person in subsidised residential aged care receives just $207 per fortnight for their living expenses (based on a pension with allowances of $916 per fortnight). While it's clear that residents in aged care have low living expenses because their care needs are provided, it's possible that this low income limits the possibilities available to people in residential aged care, who may find themselves unable to afford simple interactions with their community and simple services such as a telephone.

Low incomes are a concern for many older Queenslanders, which influence their access to care and support outside the aged care sector. Important issues include the cost of health care, transport, housing and related costs such as utilities, and having sufficient spare funds to support active participation in their local community. **Older Queenslanders need equitable access to relevant services, regardless of their capacity to pay.**

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[39] Productivity Commission, 2018, *Report on government services.*
[40] COTA Queensland, 2018, *Aged-case services survey.*
[41] AIHW, 2018, *Aged Care data snapshot*
[42] Productivity Commission, 2018, *Report on government services* (based on Chapter 14, Table 14A.21).
[43] Department of Health, 2018, *Stocktake of places.*

7. OTHER ISSUES RELEVANT TO AGED CARE IN QUEENSLAND

7.1 Access to health care

The World Health Organisation (WHO) notes that health systems in most countries are designed to deal with acute health conditions rather than the more complex, chronic health needs that tend to arise as people age.[44] In addition, **the systems for health care and the systems for long-term aged care tend to operate independently of each other, resulting in poorer health outcomes, inefficient use of health services and cost shifting**.

Queensland is not immune from this global trend. **Queensland is seeing a shift towards health care that is oriented to the long-term management of chronic health conditions and a shift towards person-centred care.** However, our primary health system remains designed to diagnose and solve time-limited health issues. Consumers assume that medical services will provide a quick fix for every problem they face, including the chronic health conditions they experience with age. **The health issues and social needs faced by an ageing population are complex and long term. It is common for older people to see multiple health professionals, often with little communication between them.**[45]

Research suggests that access to **health care is a priority issue for older people.**[46] Consumers want access to reliable, understandable, affordable, quality care that is built around their needs. Consumers want care to be provided in a convenient and suitable location that does not involve extensive travel and long wait times.

Health care is provided in multiple settings and through a combination of state funding, federal funding and user-pays approaches. The **interface between these settings and funding systems is frequently poor, particularly in an environment where an older person is likely to see multiple care providers for a variety of conditions and vulnerabilities.** Information breakdowns may occur, for example, between GPs and hospitals, between specialists and GPs, between allied health providers and GPs, between community care providers and medical practitioners, and between residential-care providers and hospitals. While Nurse Navigators and My Health Record may help to alleviate some concerns in this area, more work needs to be done to develop a fully connected, integrated system.

Home-care packages are often used to support older people's access to health care – including by providing transport and support to get to appointments and visit the pharmacy. It is important to consider whether new technologies may provide opportunities to reduce this type of support, with in-home monitoring, remote consultations and home deliveries from pharmacies freeing up home-care workers to provide more meaningful support to older people.

Improved integration between the health and aged care systems would enable greater continuity of care as well as a more efficient use of resources.

7.2 Housing for older Queenslanders

In COTA Queensland's 2017 survey of older Queenslanders, affordable and appropriate housing emerged as the most important issue that older Queenslanders want the Queensland Government to address.[47] This was closely followed by the housing utility costs of energy and water. Older Queenslanders typically feel that their housing options are limited (it is difficult for them to move) and that housing maintenance absorbs a large portion of their budget.

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[44] WHO, 2015, *World report on ageing and health.*

[45] WHO, 2015, *World report on ageing and health.*

[46] COTA Queensland, 2018, *Aged-care services survey;* COTA Australia, 2018, *State of the (older) nation report.*

[47] COTA Queensland, 2017, *Queensland seniors' views.*

Appropriate, affordable and safe housing is essential to enable people to continue living safely and independently in their own homes and communities. Anxiety is increased when one partner has to enter a Residential Aged Care facility leaving the other uncertain about their own housing tenure. This fear and uncertainty was echoed in the words of a participant in the recent Kitchen Table Discussions engagement: *Will I be homeless if my husband has to go in to a home?*

7.3 Satisfaction with government services

COTA Queensland's 2017 survey of older Queenslanders explored their satisfaction with the services they receive from government.[48]

The results showed that participants were most likely to be satisfied about age-friendly communities (61 per cent), hospital care (61 per cent), community safety and disaster preparedness (60 per cent), community and home support (48 per cent) and local government (45 per cent).

Participants were most likely to be dissatisfied about energy and water costs (71 per cent); infrastructure, planning and development (55 per cent); affordable and appropriate housing (49 per cent); seniors concessions (49 per cent); and public and community transport (48 per cent).

7.4 Elder abuse

The World Health Organisation (WHO) estimates that **one in ten older people experience some form of elder abuse.[49] Those with cognitive impairment and those living in residential aged care may be at particular risk.**

Australia needs a national response to elder abuse. In 2015, almost 40 percent of calls to Seniors Rights Victoria related to elder abuse. In response, the Australian Law Reform Commission has argued that financial abuse should become a reportable incident by aged care providers. The Commission has also called for a serious incidents response scheme for aged care services.[50]

Most elder abuse occurs in the community, between family members. However, as the Royal Commission into Quality and Safety in Aged Care has revealed, elder abuse is a significant concern in aged care services.

COTA Queensland acknowledges the Australian Government's commitment to addressing elder abuse in the 2017-18 budget, with funding to support workforce and consumer responsiveness and funding to support an elder abuse knowledge hub. We call on the Queensland Government to support the Australian Government's proposal for a national register of enduring power of attorney appointments.

7.5 Health promotion

Older people's information needs extend beyond their need for information about aged care. All consumers need access to information about health more broadly and, in particular, **they need access to information that will support them to maintain their health**. This needs to be supported with information about how to remain active in their communities and information about how to meet their basic needs for housing security, income security and transport.

In older age, most of the burden of disease is from non-communicable, chronic disease. Many older people live with multiple long-term conditions. Chronic disease is largely preventable and, as such, chronic disease risk factors are important topics for health promotion targeting people of all ages. Health promotion work needs to start early in life and continue right across the life course.

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[48] COTA Queensland, 2017, *Queensland seniors' views.*
[49] WHO, 2015, *World report on health and ageing.*
[50] COTA Australia, 2018, *Submission to the Inquiry.*

There is growing evidence that key health behaviours, such as engaging in physical activity and maintaining adequate nutrition, may exert powerful influences on the intrinsic capacities of older people. Physical activity increases longevity. Yet, despite clear evidence of the benefits, many people fall short on the guidelines for adequate nutrition and physical activity.[51] Other clear targets for health promotion include alcohol consumption, smoking, drug use and community connectedness.

COTA Queensland calls on the Queensland Government to recognise the long-term value of health promotion and to prioritise health promotion information to Queenslanders of all ages. Consumers need a wide range of materials available, in formats that include print, online, video and audio. Material needs to be provided in multiple languages, including in Auslan. Consumers need tailored information, separate to what is available for health professionals.

COTA Queensland has been delivering peer-led community education for over 20 years on topics including medication management, falls prevention, depression, aged care and enduring powers of attorney. Unfortunately these projects are through one-off funding grants and short-term (frequently 12-18 months maximum) and do not enable long term individual and community capacity building initiatives, sustainability of active partnerships, or efficiencies in terms of costs.

7.6 Disaster preparedness in residential aged care

COTA Queensland has been lobbying over the past five years to strengthen evacuation arrangements for residents in aged care facilities. Current legislation focuses on evacuation in the case of a fire, with providers required to nominate a safe place to which evacuated residents can be moved, typically a car park. Under state emergency legislation there are no specific provisions that relate to residential care facilities.

The Commonwealth Department of Health has guidelines in place that require facilities to maintain quality of care and to have plans in place for emergency events.[52] The guidelines note that state and territory government have primary responsibility for emergency management, and local governments have an important role in planning, preparedness, response and recovery. Providers are expected to assess risk and respond to the advice of local emergency management authorities.

Following Cyclone Debbie, the Office of the Inspector General Emergency Management noted that aged care providers require significant support and encouragement in planning and exercising evacuation.[53] The Inspector General's report noted a lack of consistency across providers, which resulted in varying levels of preparedness. In a 2018 report, Volunteering Queensland called for increased action to safeguard older people during disasters and for Queensland legislation to be strengthened in relation to emergency evacuation requirements for a range of disasters. [54]

COTA Queensland calls on the Queensland Government to implement the recommendations of Volunteering Queensland as part of its current review of the Fire and Emergency Services Act 1990.

8. THE DELIVERY OF PALLIATIVE AND END-OF-LIFE CARE IN QUEENSLAND

In 2017, COTA Australia co-facilitated a report on principles for palliative care and end-of-life care in the residential aged care setting.[55] The report identified eight principles for palliative and end-of-life care in

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[51] WHO, 2015, *World report on health and ageing.*
[52] Department of Health. 2018. *Risk management for emergency events in aged care.*
[53] Office of the IGEM, 2017, *The Cyclone Debbie review.*
[54] Volunteering Queensland, 2018, *Disaster preparedness.*
[55] Palliative Care Australia, et al., 2017, *Principles for palliative and end-of-life care.*

residential aged care to prioritise consumers' needs and wishes, provide care with dignity and respect, involve consumers in planning, support holistic and integrated care, respect consumers' cultural and psychosocial needs, and support families, carers and staff in bereavement. These principles sit alongside the palliative care service development guidelines developed by Palliative Care Australia.[56]

8.1 Palliative care

The WHO defines palliative care as follows:

> Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual. Addressing suffering involves taking care of issues beyond physical symptoms. Palliative care uses a team approach to support patients and their caregivers. This includes addressing practical needs and providing bereavement counselling. It offers a support system to help patients live as actively as possible until death.[57]

Research suggests that approximately 75 per cent of Australians aged over 65 will access aged care services in the 12 months before their death, yet relatively few of these access palliative care. Consumers support the provision of palliative care within the aged care setting, with more than 80 per cent considering it to be important or extremely important.[58]

COTA Queensland has long advocated for increased adoption of palliative care throughout Queensland. Palliative care should be available for all consumers who need it. It should be available in a setting chosen by the consumer and provided in the way most suited to the consumers' needs. COTA Queensland believes that access to palliative care must be broadened.

Palliative care is difficult to access in Queensland. There is a general lack of knowledge about what palliative care is and the benefits it can offer to the patient, family and friends. COTA Queensland understands that the lack of knowledge about good palliative care extends to the medical profession, hospitals and aged care providers. There is a lack of trained medical specialists, GPs, nursing staff and allied health staff in palliative care. **The lack of palliative care options in Queensland is likely to mean that older Queenslanders experience unnecessary pain and suffering in the final stages of their lives**. It also means that **older Queenslanders are likely to be unnecessarily hospitalised near the end of life, when palliative care would be more appropriate.**

Residential aged care facilities are important providers of palliative care, but their palliative-care delivery appears to be highly variable and under-recognised. Addressing the palliative care needs of aged care residents should be part of the core business of residential aged care. When residents are near the end of life, it makes little sense to transfer them to hospital for intervention and treatment. Duckett argues that an appropriate approach to funding would incorporate an allowance for additional palliative care services for residents.[59]

8.2 End-of-life care

A relevant question for end-of-life care is to ask when the end of life occurs. COTA Victoria addressed this question in its submission to the Victorian Voluntary Assisted Dying Bill,[60] and advocated that the definition of end of life should be broadened to include the end of independence and autonomy. A useful way to consider the question is for a medical professional to ask: *Would I be surprised if this person died within the next six*

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[56] Palliative Care Australia, 2018, *Palliative care service development guidelines.*
[57] WHO, 2018, *10 principles for a decade of healthy ageing.*
[58] Palliative Care Australia, 2017, *New survey shows Australians don't plan for the end.*
[59] Duckett, 2018, *Aligning policy objectives and payment design in palliative care.*
[60] COTA Vic, 2017, *Voluntary Assisted Dying Bill submission.*

months? While a precise definition of end of life is difficult, the prognosis of no more than six months to live is useful, and is recognised in other jurisdictions (including Oregon and Washington in the USA).

There has been a significant shift in how Australians die. Today, approximately two-thirds of Australians die when they are old, mostly from chronic diseases and disabilities experienced towards the end of life.[61] Older people who are diagnosed with a terminal illness now have an extended time to contemplate their death and may be overwhelmed by the choices available to them. They may be asked to make choices and decisions about their care without fully understanding the implications of those choices.

In many cases, Australians now have an opportunity to plan for their death and consider what they need to support a good death. However, **many people do not consider nor plan for the end of their lives.** Evidence suggests that, in the last year of life, many people do not receive enough palliative care and many find themselves caught up in interventions and services designed to prolong their lives.[62] The Grattan Institute notes that a good death gives people dignity, choice and support to address their physical, personal, social and spiritual needs.[63]

Most Australians want to die at home, with minimal pain and suffering. However, **only 14 per cent of Australians do die at home, making death in Australia more institutionalised than in the rest of the world**. There is great disparity between what people want and what is happening.[64] People want to know when death is coming. They want time to say goodbye. And they don't want life prolonged pointlessly.

COTA Australia's study of older Australians found that most had done some type of planning for the final stages of their lives:[65] 77 per cent had completed a Will, 38 per cent had enacted an Enduring Power of Attorney, 17 per cent had a funeral plan, and 10 per cent had written an advanced care directive. However, **46 per cent of respondents had not looked at information intended to support their personal planning for the final stage of life.** While respondents in older age brackets were more likely to have considered end-of-life planning, only 16 per cent of those aged 75 and over had completed a formal advanced care plan.

This research suggests that most older Queenslanders do not plan ahead for their end-of-life care. Very few Queenslanders record their wishes in an advance care directive, leaving them vulnerable to having their wishes ignored in the final stages of their lives. If they become unable to express their treatment preferences themselves, these decisions will be made by their family, caregivers, or medical professionals.

A current initiative to respond to this need being developed by ELDAC (End of Life Directions for Aged Care), which is offering grants for community and residential care organisations wishing to develop palliative care and advance care planning activities. ELDAC seeks to help build capacity to provide care for older people nearing the end of life, develop and strengthen linkages between the service and other care providers, and improve initiatives in palliative care.[66]

If consumers are to be supported to make informed decisions about their end-of-life care, they need clear, direct information about their current state of health, treatment options and likely consequences. In particular, they need information about how treatment options are likely to impact on their quality of life.[67] Doctors want to provide their patients with hope and options for prolonging life. This means that end-of-life care and conversations are often delayed, and treatment focuses on prolonging life rather than providing quality of life.[68] **Many people, if given a choice, would choose quality of life over aggressive intervention.**

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[61] Swerissen & Duckett, 2014, *Dying well.*
[62] COTA Vic, 2015, *Inquiry into end-of-life choices submission.*
[63] COTA Vic, 2015, *Inquiry into end-of-life choices submission.*
[64] Swerissen & Duckett, 2014, *Dying well.*
[65] COTA Australia, 2018, *State of the (older) nation report.*
[66] ELDAC, 2019, *Sector engagement.*
[67] COTA Vic, 2017, *Voluntary Assisted Dying Bill submission.*
[68] COTA Vic, 2015, *Inquiry into end-of-life choices submission.*

In 2015, COTA Victoria conducted a series of *Dying to Talk* events to explore people's questions about death and dying.[69] Important themes emerging from the conversations included that people wanted more information about:

- How to start conversations about end-of-life care with their family and doctor
- The process of dying (and particularly addressing their fear of dying)
- Ensuring their wishes and choices are respected
- How to plan for the unknown in drawing up an advance care directive
- How to keep out of hospital and die at home
- What support or services are available for people without family support
- The doctor's role at end of life.

The role of professionals at the end of life needs to be redefined to support the person to die well, according to their own values. This means that medical professionals must communicate the prognosis clearly, communicate the impact of treatment, and not assume that medical intervention should be geared towards prolonging life.

Evidence suggests that **the Queensland community needs to have a conversation about end-of-life care:**

- Aged care workers and medical professionals need more training in end-of-life care to support older people's access to palliative care and supportive end-of-life care that emphasises dignity and individual choice ahead of medical intervention[70]
- Consumers, families and carers need more information about advanced care planning, palliative care and end-of-life care; they need to be encouraged to have conversations early, make informed decisions, and be ready to communicate those decisions to medical staff.
- All Queenslanders need to be more aware of the documents available for end-of-life planning, in particular the advanced care directive.

A human rights approach to healthy aging recognises that older people must be:

- Treated with dignity and respect
- Empowered to make informed decisions about their end-of-life care
- The chief decision makers in their end-of-life care.

Whilst conversations with health professionals are important discussions about a person's end of life wishes need to occur in the community. COTA Queensland recommends a peer-led community education program based on international best practice.

9. VIEWS ON VOLUNTARY ASSISTED DYING

Recent legislative reform in Victoria about voluntary assisted dying provides a rich source of evidence for this Queensland review. The Victorian Legislative Council's Standing Committee outlined the following guiding principles (adapted from the Joint Centre for Bioethics at the University of Toronto), which may be relevant in the Queensland context:[71]

- Valuing human life and the quality of life until death
- Relief from pain and suffering
- The critical role of palliative care

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[69] COTA Vic, 2015, *Inquiry into end-of-life choices submission.*

[70] COTA Australia, 2019, *Pre-budget position statement.*

[71] COTA Vic, 2017, *Voluntary Assisted Dying Bill submission;* Parliament of Victoria, 2016, *Inquiry into end of life choices.*

- Patient-centred care and informed decision making
- Safeguards and protections for people who are vulnerable and for health practitioners
- Equality of access and support for carers and loved ones
- Clear and transparent laws that support end-of-life planning, decision making, and the rights and responsibilities of all involved in end-of-life care.

In COTA Queensland's recent survey of older Queenslanders, we sought their views about whether Queensland should begin a conversation about voluntary assisted dying.[72] Most respondents supported further exploration by the Queensland Parliament. Our research suggests that opinion is divided amongst our cohort in Queensland.

Comments from respondents included:

- I fully believe that the rights of the individual should be observed if they are mentally sound. More needs to be done to ensure legal and medical support is provided to those wishing to take matters into their own hands.
- On religious grounds I would have a problem but can understand it.
- It's a tough choice. I don't really want to die but when I do I want my life immediately beforehand to be decent. If that means I have to kill myself rather than suffer the indignities I have witnessed well I would like to have the option of assisted dying I suppose but it seems a bit Soylent Green to me I am a strong supporter of Voluntary Assisted Dying and hope it is available legally for me when required.
- I disagree because I do not trust the medical system or decisions made by family members. However, if the person is fully able to make their own decisions and are receiving optimal care to minimise pain and discomfort and are not being starved to death, then it is the person's decision. In many instances if the person was given good care and support, they may in fact want to live a bit longer.

COTA Australia's 2018 national survey of older Australians asked participants whether they supported or opposed assisted dying for their state or territory.[73] The majority of participants (84 per cent) indicated that they supported the introduction of assisted dying, provided the right protections and legislation were in place. Just 16 per cent of participants opposed assisted dying. Support was highest amongst those with no religion (95 per cent) and lower among Catholics (74 per cent) and Baptists (53 per cent). Those aged 80-plus were more likely to oppose assisted dying. There was no clear difference in the results of participants from Queensland.

The COTA Australia survey also asked participants whether they would consider assisted dying as an option for themselves if they were suffering from a terminal illness or incurable condition. A large majority (69 per cent) agreed they would consider it. This response rose to 81 per cent among those who supported the legislation and 83 per cent among those with no religion.

A relevant question to voluntary assisted dying is how the condition permitting its use is determined. In Victoria this is called a 'serious and incurable condition'. COTA Victoria argued that individual consumers must be the final decision makers. Only they can assess what is intolerable and unbearable for themselves. The definition of a serious and incurable condition therefore should include that the condition is causing intolerable and unbearable suffering that cannot be relieved in a manner the patient deems tolerable.[74]

Another relevant question to voluntary assisted dying is whether safeguards can be built into the system to ensure the request is voluntary. An agreed process must be defined in legislation. In Victoria, this includes an initial verbal request, followed by a formal written request signed by two independent witnesses, and a final verbal request.[75]

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[72] COTA Queensland, 2018, *Aged-care services survey.*
[73] COTA Australia, 2018, *State of the (older) nation report.*
[74] COTA Vic, 2017, *Voluntary Assisted Dying Bill submission.*
[75] COTA Vic, 2017, *Voluntary Assisted Dying Bill submission.*

Also relevant for voluntary assisted dying is where it would be offered. If voluntary assisted dying is to be approved in Queensland, it must be available in place. Individuals must not be transferred to a new location because they wish to access voluntary assisted dying. In addition, individuals should not be transferred from their hospice or palliative care services because they wish to access voluntary assisted dying.[76]

If voluntary assisted dying were to be approved in Queensland, medical professionals must retain the right to conscientiously object. Queensland may follow the Victorian lead and require medical professionals to refer the patient to an alternative practitioner and require the medical practitioner to communicate this to the patient.

COTA Queensland is unclear whether Queensland's recent Human Rights Bill 2018 will have any impact on the discussion about voluntary assisted dying. For example, Clauses 16 and 17 of the Bill could be used to support a legal case allowing access to assisted dying. Having a person prolong their life against their wishes while suffering pain and suffering could be classed as cruel, inhuman or degrading treatment.

COTA Queensland argues that voluntary assisted dying should be the individual consumer's choice and that appropriate legislative safeguards should be in place to support this.

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[76] COTA Vic, 2017, *Voluntary Assisted Dying Bill submission.*

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Palliative Care
NURSES AUSTRALIA

15 April 2019

The Honourable Mr Aaron Harper
Chair
Health, Communities, Disability Services and Domestic and Family Violence
Prevention Committee
Queensland Parliament
Qld 4000
E: careinquiry@parliament.qld.gov.au

Dear Mr Harper

RE: INQUIRY INTO AGED CARE, END-OF-LIFE AND PALLIATIVE CARE, AND VOLUNTARY ASSISTED DYING

Palliative Care Nurses Australia (PCNA) welcomes the opportunity to contribute to the Inquiry into Aged Care, End of Life and Palliative Care and Voluntary Assisted Dying.

PCNA is a national member based organisation for nurses working with people who are living with and dying from a progressive life limiting illness, and their families. The vision of PCNA is to promote excellence in palliative care nursing for our community, through leadership, representation and professional support. The World Health Organization (2002) definition of palliative care underpins our work.

PCNA has been following the current societal, academic and parliamentary debate in Australia on the topic of legalisation of euthanasia and assisted suicide for people living with a life limiting illness who are experiencing suffering. Euthanasia and physician assisted suicide are currently illegal in all Australian states and territories.

Should you wish to discuss our views further, please feel free to contact our office on 02 8405 7921 to arrange a suitable time.

Yours sincerely

Jane L Phillips

Jane Phillips RN PhD, FACN
President
Palliative Care Nurses Australia Inc.

E: [redacted]

Palliative care in Queensland

There have been several palliative care reviews and scoping studies funded by state government over the last 10 years in efforts to understand palliative care service provision in Queensland and consider future planning. These potentially important pieces of work have not been made publicly available. The information in the reviews and studies is important for all Queenslanders to be able to understand past, current and future palliative care needs and should be made publicly available.

There have been few changes since the most recent inquiry into palliative care in Queensland (2013)[1] and the issues and recommendations from that inquiry remain relevant. Queensland communities continue to be receiving mixed results in the context of provision of high quality end of life care, due to the unequal distribution of specialist palliative care teams throughout the state.

In areas served by specialist palliative care teams, such as Metropolitan Brisbane, Gold Coast, Sunshine Coast, and Townsville, a high standard of end of life care is able to be provided to people who need it. In those areas, excellent holistic care can be offered to patients at end of life and their families, regardless of whether they have complex needs or not. Holistic care includes symptom management, psychosocial care of patients and families, and bereavement care after death for the carers and families.

However, there are regional and remote communities with no access to specialist palliative care services. Clinicians in these communities are required to contact specialist palliative care teams to seek advice. This places a burden on the already stretched specialist teams who are called upon to provide advice with limited knowledge of the person. For patients in these communities, holistic care is often difficult to achieve including the option of choice for place of care. Equitable access to palliative care is a human right and a fundamental component of safe, values-based and high-quality health care.

For urgent palliative care needs out of business hours and outside an acute hospital environment, services are rarely available as there is no routine funding to provide it. Because palliative care is not recognised as an area of service required 24 hours a day, patients with urgent palliative care needs are required to present to emergency departments or call Queensland Ambulance Service (QAS).

There has been huge progress in preventative, curative and rehabilitation health care allowing people to live longer. The consequence of this is that people are living and dying with more complex chronic conditions and co-morbidities that require increasing supports from the health system and the community. Despite this progress, death remains a universal outcome.

Future planning for the delivery of palliative care and end-of-life care services in Queensland

Palliative care nurses have a unique set of skills, knowledge and qualities that enhance the care and support provided to people facing the end of life and to the families and communities that support them. They have extensive knowledge and experience in the management of pain and complex symptoms associated with terminal illness. Palliative care nurses demonstrate leadership in autonomous and collaborative practice, modelling best practice end of life care, and providing mentorship and education to other nurses and health care professionals.

Their specialist skills and abilities are developed through many years of education, interdisciplinary clinical practice and skills development and are informed by the founding philosophies of both palliative care and nursing. Their knowledge of end of life issues often extends the work of the specialist palliative care nurse beyond the bedside to advocating and promoting optimal well-being at the end of life regardless of a patient's geographic location or financial position.

Nurses form the very backbone of any health system. In palliative care, this backbone of nurses needs to be valued with a committed investment of funds for workforce staffing, support and development needs. The current number of FTE nurses will not be adequate to provide quality palliative care for the ageing Queensland population.

Within an already under resourced sector, nurses currently practising in the highly demanding field of palliative care are caring for people with increasingly complex health needs and are themselves facing the prospect of 'burnout', which can leads to workplace injury/illness and overall attrition of the palliative care workforce. This will in turn, lead to poorer care outcomes for palliative care patients and their families. Additionally, there is not only an ageing population, but also an ageing workforce in palliative care.

Framework of care and Future needs

Palliative care in Queensland should align with the National Palliative Care Standards and the Palliative Care Australia Service Development Guidelines (2018)[2] that are achievable in real time. Models of care need to be organised around specialist multidisciplinary services working collaboratively with General Practitioners (GPs) and tailored to meet local needs including access to treatment facilities. Models should focus on early access to palliative care and living well with a life-limiting condition rather than the current focus on terminal phase at end of life which has been brought about by funding limitations.

New models need to incorporate use of technologies to be able to link specialist palliative care clinicians with regional and remote generalist trained health services and clinicians. Models should address the needs of regional Queenslanders whose care requirements may not be met within a single hospital and health service boundary. Focus should be on the person not place of residence.

Workforce

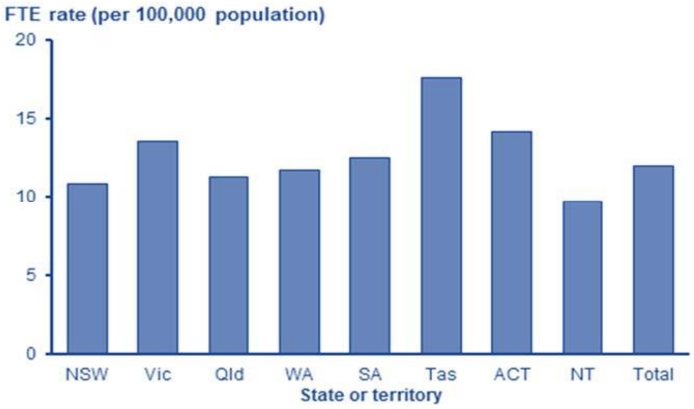
Nursing students and graduates should be exposed to palliative care environments in all settings – acute, community and aged care to properly equip nurses to work in palliative care and promote the field as an attractive career choice.

Palliative and end-of-life care education should be embedded as core components of all post graduate nurse programs in Queensland. This should be accompanied by a structured mentoring program allowing experienced palliative care nurses to provide support for non-specialist palliative care colleagues as support to the future workforce.

Advanced practice nursing roles in palliative care need to be effectively embedded within service models; this includes the training and employment of Nurse Practitioners (NPs) with prescribing authority in aged care and community settings in rural and isolated regions of Queensland.

Whilst we do not have access to Queensland specific palliative care workforce data, recent national data indicates that palliative care nurses made up around 1 in every 90 (1.1%) employed nurses in Australia, with over 3,300 working in Australia in 2015 (1).

Nationally, there were 12.0 FTE palliative care nurses per 100,000 in 2015. The rate of FTE palliative care nurses across the states and territories ranged from 9.7 in the Northern Territory to 17.6 in Tasmania (Figure 1). The average hours worked varied across jurisdictions, ranging from 30.9 hours per week for Western Australia and South Australia to 36.3 hours per week for the Australian Capital Territory (1).



Source: National Health Workforce Data Set 2015.
Source data Palliative care workforce Table Wk.9 (514KB XLS).(1)

Approximately three quarters (73.5%) of FTE palliative care nurses worked mainly in major cities during 2015, with a further 18.4% working in Inner regional areas. Considering differences in population sizes for each remoteness area, the FTE palliative care nurses per 100,000 population was highest for Major cities (12.7 FTE), followed by Inner regional (12.4 FTE) areas, but this drops to 2.3 FTE in remote and very remote areas.

More than 9 in 10 employed palliative care nurses were clinicians (94.5%). About half (51.2%) of all employed palliative care nurses were employed in a hospital setting, followed by community healthcare services (22.7%) and hospices (15.9%).

Aged care

An inevitable consequence of the Australian population ageing is that the aged care workforce has become a major provider of aged-palliative care, which will only increase in coming years. As best practice palliative care demands a skilled response, this has major implications for the configuration of the aged care workforce and for funding the provision of aged and palliative care services.

Community data indicates that while 70% of Australians state that they wish to die at home, currently only 14% achieve their ideal. With this comes the trend for older people to be supported to stay in their own homes for much longer meaning that those requiring admission to a residential aged care facility (RACF) are now frailer, with multiple co-morbidities, requiring more intensive and specialist aged-palliative care and have shorter lengths of stay. The average length of stay in a RACF is currently 34.5 months.[3]

An ongoing investment in community aged care services is required to support the growing number of older people who wish to remain at home. Currently within community aged care services, there is insufficient funding to provide adequate after-hours and weekend services to older people living at home and to support their wish to remain at home until they die.

It is also not possible for all of these older people to be managed by their local specialist palliative care service. The aged care workforce needs to be better prepared to meet the aged-palliative care needs of older people who wish to die at home or within a RACF. To achieve this ideal, the number of RNs will need to grow, especially as the proportion of community aged care RNs has decreased over time. Providing community based aged-palliative care also requires the aged care workforce to have the capabilities to facilitate advance care planning conversations and the pre-requisite communication and grief support skills to support family and unpaid carers, who are integral members of the care team.

People with disabilities are now living long enough to require aged care. This group often has very high care needs and aged care services are not currently equipped or staffed to provide optimum care for this group. The available aged care allied health services are insufficient to meet the needs of this population. The National Disability Insurance Scheme doesn't cover those who because of their disease process can no longer be cared for at home, for example a younger person with a spinal cord compression.

Investing in building the aged care workforce's palliative care capabilities and ensuring that residents have access to timely review by a Nurse Practitioner (NP) or General Practitioner (GP) will help to reduce the number of inappropriate hospital transfers and reduce the pressure on our acute care system.

Voluntary Assisted Dying

Responding to requests for physician assisted suicide

As detailed in our position statement (Appendix 1).

Terminology

Many of the terms used in the question route submitted to PCNA are not universally recognised or accepted medical terms. To ensure that there is a universally understanding of all of the palliative and end-of-life care terms used, PCNA recommends that the committee adopts terms that are widely understood with accepted definition. If this approach is adopted, then:

- 'Palliative starvation" would not be used, as it denotes withholding or refusal of food and fluids with the deliberate intention to cause a person's death. The clinically correct term and concept that is universally understood and accepted as ethical medical care is 'forgoing medically assisted nutrition or hydration'.
- 'Terminal sedation' would also not be used, as it denotes, either inadvertently or deliberately, that sedation is being used with the intent to hasten the patient's death. For these reasons, PCNA does not use or support the use of the term 'terminal sedation'. Sedation that is given in doses and duration that are disproportionate to the symptoms of the dying person with the intention to hasten death is unethical, unlawful and not part of palliative care. This term currently is having a resurgence in jurisdictions where euthanasia is legal, or by proponents of hastened death.[4]
- 'Palliative sedation' would be used, as it has long been recommended by clinical and ethical experts as the preferred and more accurate term to describe the practice of using sedation with the intention to relieve (i.e. palliate) intractable symptoms and distress during dying. [4]

Additional advice on the best end-of-life and/or palliative care terminology to use can be found on the Care Search website funded by the Australian Government (https://www.caresearch.com.au/Caresearch/Default.aspx). Alternatviely PCNA would be happy to advise the Committee on universally recognised terms.

Palliative Care
NURSES AUSTRALIA

PCNA Position Statement: Euthanasia
13 February 2019

APPENDIX 1

Position Statement: Euthanasia and Physician Assisted Suicide

Preamble

With the exception of Victoria, voluntary euthanasia is still illegal in all Australian States and Territories. The recently enacted Victorian Voluntary Assisted Dying legislation will allow voluntary euthanasia (assisted suicide) under strict criteria. This new law which is due to come into effect in July 2019 raises a host of complex ethical and practical challenges that have implications for the nursing care of people with a life-limiting illness.

Background

Palliative Care Nurses Australia Inc. (PCNA) is a national member based organisation for nurses working with people who are living and dying from a life-limiting illness, and their families. Our vision is to promote excellence in palliative care nursing for our community, through leadership, representation and professional support. The World Health Organization (2002) definition of palliative care underpins our clinical practice, research and education endeavours.

Palliative Care Nurses Australia believes that:

- Voluntary Euthanasia is distinct from palliative care;
- Nurses caring for people who are considering voluntary euthanasia or physician assisted suicide have a duty of care to ensure that both they and their families have access to ongoing support and care by:
    - minimising a person's suffering, and maximising their function and access to support and comfort;
    - respecting a person's autonomy to consider euthanasia;
    - protecting vulnerable people by maintaining safeguards; and
    - creating and maintain an environment in which each nurse can adhere to their moral commitments;
- Optimal palliative care nursing involves:
    - advocating for and ensuring all who need it have access to palliative care in accordance with their needs;
    - impeccable assessment and evidence-based management of the physical, psychological, socio-cultural and spiritual needs of the person and their family;
    - discussing and supporting a person's choice to withhold or withdraw treatments where the potential harm outweighs possible benefit, or it is against the person's expressed wishes;
    - considering the complex and multi-dimensional nature of suffering, and acting to prevent and alleviate it where possible using the best available evidence and interdisciplinary advice;
    - respectfully and compassionately acknowledging a person's desire or requests to hasten death in the context of a life limiting illness. This includes seeking to understand the

origins of the request, and acknowledging that for a small proportion of people pain, distress and/or suffering can persist despite the provision of best palliative care;

- responding to a person's request to hasten death in accordance with:
  - the law and one's conscience
  - professional codes of conduct
  - ethical health care principles
  - best available evidence
  - the unique needs of the person and their family;
- fostering informed and respectful communication with patients, their families, other health care professionals and the wider community about death, dying, end of life care, euthanasia and physician assisted suicide.

Definitions

Palliative Care as defined by the World Health Organization (2002) is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care provides relief from pain and other distressing symptoms, and:

- affirms life and regards dying as a normal process;
- intends neither to hasten nor postpone death;
- integrates the psychological and spiritual aspects of patient care;

offers a support system to help patients live as actively as possible until death;

- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness; and
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Euthanasia is a physician (or other person) intentionally killing a person by the administration of drugs, at that person's voluntary and competent request (EAPC, 2015).

Physician Assisted Suicide is a physician intentionally helping a person to terminate their life by providing drugs for self-administration, at that person's voluntary and competent request (EAPC, 2015).

Assisted suicide refers to the practice of a doctor providing a patient with the means to end their life. (Victorian 'Inquiry into choices at end of life' Report, 2016).

Voluntary Euthanasia refers to the medical assistance to die which is administered by a doctor such as through a lethal injection. (Victorian 'Inquiry into choices at end of life' Report, 2016).

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Submission from Dying with Dignity WA to the Queensland Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying (the **Inquiry**)

This submission responds only to the issues for consideration 25 – 38, being those raised by the Inquiry in relation to voluntary assisted dying (**VAD**).

Introduction

Dying with Dignity WA (**DWDWA)** is a charitable incorporated community group that has been working for safe and compassionate legislation for VAD since the early 1980s.

In August 2018 the cross-party committee of the joint select inquiry into end of life choices – the WA equivalent of the Inquiry in Queensland – handed down its recommendations in a report entitled *My Life, My Choice*[1]. These included that more funding should be provided to palliative care to extend its scope and reach, that an increase in the uptake of advance health directives should be promoted, and that VAD should be legislated within a framework that contained well-defined eligibility criteria and safeguards for doctor and patients.

At present a ministerial expert panel appointed by government to guide the development of the legislation is holding statewide consultations. The panel will hand down its recommendations in late June and the legislation is expected to be tabled in Parliament in August. The bill is expected to pass the lower house but the vote will be tight in the upper house of Parliament.

In the meantime DWDWA is campaigning hard for the legislation it has been advocating for 35 years. We hope it will be law by the end of 2019.

25. Should **voluntary assisted dying (VAD) be allowed in Queensland?**

Yes, for these reasons: Australians want change

In the Roy Morgan poll of November 2017, in answer to the question: "If a ***hopelessly ill*** patient with ***no chance of recovering asks for*** a lethal dose, should a doctor be allowed to ***give*** a lethal dose, or not?"

85% of Australians said Yes;
86% of Queenslanders said Yes; and
88% of Western Australians said Yes.
It is time that Members of Parliament across the country represented the will of the people on the issue.

Palliative care is not always enough

Advocates of VAD fully support palliative care, and no doubt the Inquiry in Queensland, as in Western Australia, will make recommendations to extend the funding and reach of palliative care. However, specialists in palliative care agree that it cannot in every case alleviate suffering at the end of life.

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[1] https://bit.ly/2OZdZ6Z

The experience in WA is that this is a critical issue. Many proponents of palliative care are under the misconception that palliative care and VAD are somehow at odds , or in competition, with each other. This is not true. Furthermore, a 2018 report commissioned by Palliative Care Australia found that: "An assessment of the palliative care sectors following the introduction of assisted dying for each of the in-scope jurisdictions provided no evidence to suggest that the palliative care sectors were adversely impacted by the introduction of the legislation. If anything, in jurisdictions where assisted dying is available, the palliative care sector has further advanced."

Self-determination and autonomy are basic human rights

These principles are recognised under Australian law and give people the right to decide their treatment options, even if life-saving options are available and their decisions will lead to death– for instance the right of a Jehovah's Witness to refuse a blood transfusion or a cancer patient to refuse chemotherapy or radiation. Similarly, in every Australian state a person has the right to sign a legally binding directive (in WA called an advance health directive or **AHD**) that is their "voice" even if they have lost decision-making capacity, to refuse treatment, fluids and sustenance in certain circumstances.

No state inquiry has yet been so bold as to recommend that an AHD or equivalent can be used to direct that a person be helped to die if he or she satisfies all the criteria of VAD legislation. In our view, however, if a person completes an AHD with full decision-making capacity, satisfies the other criteria in the legislation and qualifies for access to VAD, and then is prescribed and issued with the relevant lethal drug – and then subsequently loses capacity, the rationale for **not** being able to rely on an AHD is not clear. The reality, probably, is that it is a bridge too far politically, and, like dementia, is just too hard to navigate. We encourage your inquiry to carefully consider ways in which an AHD may, perhaps in limited circumstances only, be permitted to play a role in satisfying medical practitioners of the considered wishes of a patient. We hope that the Ministerial Expert Panel in Western Australia will do likewise in its report.

Compassion

People should have the right to end suffering at the end of their lives.
Some people of faith argue that only God has the right to give life, and only God should have the right to take it away. The reality, however, is that the medical profession frequently intervenes to prolong life in circumstances where a compassionate God would have bestowed on the person the gift of death. Without a VAD law, this occurs in an unregulated and in fact almost invisible way, and this is not desirable.

The palliative care mantra - to neither prolong nor hasten death - can lead to a dying person taking matters into their own hands by refusing treatment and food and dying slowly of starvation or dehydration. Somehow, under the present system, it is acceptable to prolong suffering rather than to assist someone to die peacefully.

Reassurance

For many, just having the comfort of being able to end their lives when the time is right for them is reassuring, and some end up not taking the prescribed drugs. This is very clearly seen in Oregon over the past 21 years.

It is already happening

Although VAD is unlawful in Australia, it already happens "not infrequently"[2] in practice, but without any safeguards for either patient or doctor, and *"without regulation, without support, without transparency or accountability, and from the evidence received, sometimes without consent".*[3] Perhaps no law is ever perfect, but the risks are far greater if there is no law at all.

Within the ambiguity of the existing legal system, patients dying in intolerable pain can only hope to find medical practitioners who are willing to help them die peacefully, as many are not. Dying is our final rite of passage. It should be our choice, endorsed by law, to die in certain prescribed circumstances with the help of our doctors. Medical practitioners with conscientious objections to participating should have the right to opt out. The others should have the right to help us when we need it most.

Suicide prevention

Statistics in Western Australia show that 10% of suicides are by people with a terminal condition who take their own lives, often by violent means and alone for fear of implicating others, because they have no alternative. Often they kill themselves while they are still enjoying their lives, fearing that if they leave it too long they will lose the ability to do so. The recent death of Clive Deverall is a case in point.

The introduction of a VAD law will not encourage suicide in the general community. This is borne out by overseas experience. No "wrong message" is sent, bearing in mind the profound and unique circumstances presented by suffering in the final stages of life.

The laws work

There is a large body of evidence that demonstrates that in overseas jurisdictions that have legalised voluntary assisted dying, these laws work safely and effectively. The number of these jurisdictions is increasing, slowly but surely. The time for this legislation has come.

26. How should VAD be defined in Queensland? What should the definition include or exclude?

DWDWA believes that voluntary assisted dying should include giving the dying person who has satisfied all the relevant criteria under the legislation a choice between:

- self-administration of a lethal drug prescribed and dispensed in accordance with the law; and
- being assisted to die with the help of a medical practitioner.

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[2] http://www.smh.com.au/comment/the-right-to-assisted-death-20130519-2juwp.html. This article summarises the findings of the 2013 Brisbane Roundtable on the inadequacy of existing laws on the issue of VAD in Australia.

[3] Quoted by Andrew Denton from the Victorian Inquiry in his address to the National Press Club (10 August 2016): *The Damage Done: The Price Our Community Pays Without A Law For Assisted Dying.* http://www.gogentleaustralia.org.au/transcript_andrew_denton_s_npc_address

27. N/A

28. If there is to be a VAD scheme, what features should it have?

Eligibility criteria (including age, capacity, residency and condition criteria;

Assessment by two doctors to satisfy themselves independently that the person has satisfied all the relevant criteria, with the ability in their discretion to refer the person for a specialist assessment **only where there is doubt**;

The person dying must make 3 requests, 2 verbal and one written in the presence of an independent witness;

There should be safeguards against coercion, undue influence or duress, and protection for vulnerable groups, including those with disability or mental illness;

The existence of disability and/or mental illness should not of itself qualify any person for access for VAD, and equally should not disqualify anyone who otherwise satisfies all the relevant criteria;

No doctor or health practitioner should be obliged to participate in VAD, but neither should they obstruct or interfere in the process;

The legislation should be clear and not overly bureaucratic, but consistent with the necessary safeguards of proper oversight and medical prudence.

29. Are there aspects of VAD schemes in other jurisdictions that should, or should not, form part of any potential VAD scheme for Queensland, and why?

There is some discussion in the *My Life, My Choice* report about whether there should be a specified time until death, as there is in the Victorian legislation and in many jurisdictions worldwide. The WA Inquiry into end of life choices determined that there should not, for a number of reasons that are perhaps most cogently captured in this quotation from the submission from Doctors for Assisted Dying Choice at para 7.38 of the report:

Severe and intractable symptoms may be experienced for months, and even years, for those with chronic illnesses or neurodegenerative conditions: Prognosis is uncertain in many severely disabling progressive neuro- degenerative terminal conditions. These conditions can cause prolonged severe and progressive suffering for years prior to eventual death. A time-based prognosis may not allow the option of an expedited death to those who need it most.

This clearly explains how specifying an arbitrary time until death may have the unintended consequence of forcing those who are already suffering the most to suffer the longest. For this reason DWDWA does not support a specified time until death criterion.

DWDWA does not believe that there needs to be a 12-month residency requirement as in the Victorian legislation. We accept that it is not desirable that any state become a “death tourism” destination but believe that this is a law that should ultimately be accessible to all Australians.

30. Who should be entitled to access VAD and who should be excluded?

DWDWA supports the eligibility criteria set out on pages 225 and 226 of *My Life, My Choice.*

31. Should the scheme be limited to those aged 18 and over? If so, why?

In our view, yes. 18 is the generally accepted "age of consent", the time at which a child (in the absence of extraordinary circumstances) becomes an adult and can make his or her own life decisions without reference to any other person. VAD is fundamentally about capacity and choice.

Consistent with these criteria, the age of adulthood is appropriate.

32. Under what circumstances should a person be eligible to access VAD?

DWDWA supports the eligibility criteria set out on pp 225 and 226 of *My Life, My Choice,* including that "death must be a reasonably foreseeable outcome of the condition".

We are not persuaded that the *suffering* should be related to the eligible condition, as recommended by the committee of the WA Inquiry. If the person's suffering is "grievous and irremediable" and cannot "be alleviated in a manner acceptable to the person", it does not seem particularly relevant that it be related to the condition, to some other condition, or to a combination of those. We would not object to a requirement that the suffering be related "wholly or in part" to the condition.

33/34. What features should be included in a process to allow a person to legally access VAD/safeguards?

See above. DWDWA supports carefully drafted eligibility criteria and safeguards. We recommend as essential viewing Andrew Denton's address to the Press Club in 2016[4], in particular his discussion of appropriate "gateways" for access to VAD.

35. Should people be provided access to counselling services if they are considering VAD?

Yes

If so, should such counselling be compulsory? Why?

No, it should not be compulsory. Sentient adults are assumed to have decision-making capacity and are entitled to live their lives according to their values and beliefs, so long as they abide by the laws of the country in which they live. They are not obliged to seek counselling in relation to lifechanging decisions, such as getting married or divorced, engaging in extreme sports, or going to war. Deciding to end one's suffering at the end of life is a rational process, and should be the province of the dying person alone, unless they choose counselling voluntarily.

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[4] Quoted by Andrew Denton from the Victorian Inquiry in his address to the National Press Club (10 August 2016): *The Damage Done: The Price Our Community Pays Without A Law For Assisted Dying.* http://www.gogentleaustralia.org.au/transcript_andrew_denton_s_npc_address

36. How could a VAD scheme be designed to minimise the suffering and distress of a person and their loved ones?

With great respect, this may be the wrong question. Having read hundreds of stories of the suffering experienced by both those who stand by helplessly watching the suffering of a loved one dying, and the loved one, with no way out, it seems to us that legalising VAD will by definition minimise the suffering and distress of those people.

37. Should medical practitioners be allowed to hold a conscientious objection against VAD?

Yes. No one should be obliged to participate in VAD, and all should be able to decline to participate for conscientious or for other reasons.

38. If practitioners hold a conscientious objection to VAD, should they be legally required to refer a patient to a practitioner that they know does not hold a conscientious objection or to a service provider that offers such a service?

If a practitioner holds a conscientious objection to VAD, he or she should declare it immediately.

It would be helpful if that person were willing to refer a patient to a doctor and service provider who had no such objection, but making this a legal requirement may not be effective in practice because the second practitioner may also object to facilitating VAD. Any doctor who declines to assist should however be legally obliged to refer the person to a readily available source of information on (for instance) a government website.

It should be legislated that service providers opposed to VAD (eg aged care and palliative care facilities) co-operate to ensure that VAD is not denied to those who choose it and facilitate the transfer to alternative providers who have no such objection. Notorious cases seen in Canada where managers of facilities fail to provide a minimum standard of cooperation and dignity (even leading to a person being taken out of a home on a trolley for assessment in a nearby bus shelter) need to be avoided.

Thank you for considering this submission.
Dying with Dignity WA Inc.
21 April 2019

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VEP VOLUNTARY EUTHANASIA PARTY (NSW)

Submission for the Queensland Parliamentary Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying

Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee

April 2019

Voluntary Euthanasia Party (NSW)

Website: www.vep.org.au/nsw

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Introduction

The *Voluntary Euthanasia Party* (VEP) is a single issue, political party in Australia. It was created in 2013 to try to provide the choice and dignity that current legislation is denying terminally and incurably ill Australians. Although our party hopes to provide a clear political outlet for the overwhelming public support for voluntary assisted dying in Australia, we are more than happy to support any inquiries, or bills, by providing arguments in support of this much-needed law reform.

This submission is provided by the NSW Branch of the VEP. It will not address all three components of the Inquiry but will focus on why voluntary assisted dying should be allowed in Queensland as this is our area of expertise. We will make reference to palliative care and acknowledge its importance; however, will we also provide evidence that voluntary assisted dying (VAD) is urgently needed because palliative care cannot alleviate all pain and suffering at the end of life.

If individuals facing an inevitable death are not given the choice of a peaceful and dignified death at a time of their choosing, we will never remove their fear and these individuals will be unable to make the most of whatever time they have left. As a society, if we do not legalise VAD, we can expect to see an increasing number of people committing suicide, often prematurely and violently, in order to avoid the terrible end stages of their illness.

Members of the VEP believe it is important to create a bill that includes all the necessary safeguards; however, we also believe that any new law should be workable so that the intention of providing choice and dignity for terminally or incurably ill Queenslanders can be achieved and individuals can gain more control over the manner and timing of their deaths.

Like most advocates for voluntary assisted dying, the VEP supports the provision of high quality palliative care; however, even the best palliative care cannot guarantee that some patients won't be forced to endure unrelievable suffering at the end of their illness. For this reason we believe both options should be made available and see no reason why they can't be compatible.

With respect, we would like the Committee to be aware that some submissions from opponents of voluntary assisted dying, during similar inquiries, have included statements based on data that has been misrepresented. We would like to recommend that any reports or data that is referenced in submissions should be independently interpreted and verified.

In this submission we have endeavoured to provide a comprehensive overview of the issues surrounding the legalisation of voluntary assisted dying. We have provided references to recent reports and recent developments in Australia and overseas.

Finally, we appreciate the opportunity to make this submission and as a representative of the *Voluntary Euthanasia Party NSW*, I would be happy to appear before the Inquiry if required.

Ms Shayne Higson
Voluntary Euthanasia Party NSW
State Convenor

Issues for Consideration

25. Should voluntary assisted dying (VAD) be allowed in Queensland? Why/why not?

Like the vast majority of Australians, we believe that if someone is suffering from a terminal or incurable illness, with no hope of recovery, is experiencing unacceptable pain or suffering and has decision-making capacity, they should have the right to request medical assistance to end their life. In other words, we believe they should have the choice to go a little earlier, in order to achieve a peaceful and dignified death surrounded by the people they love.

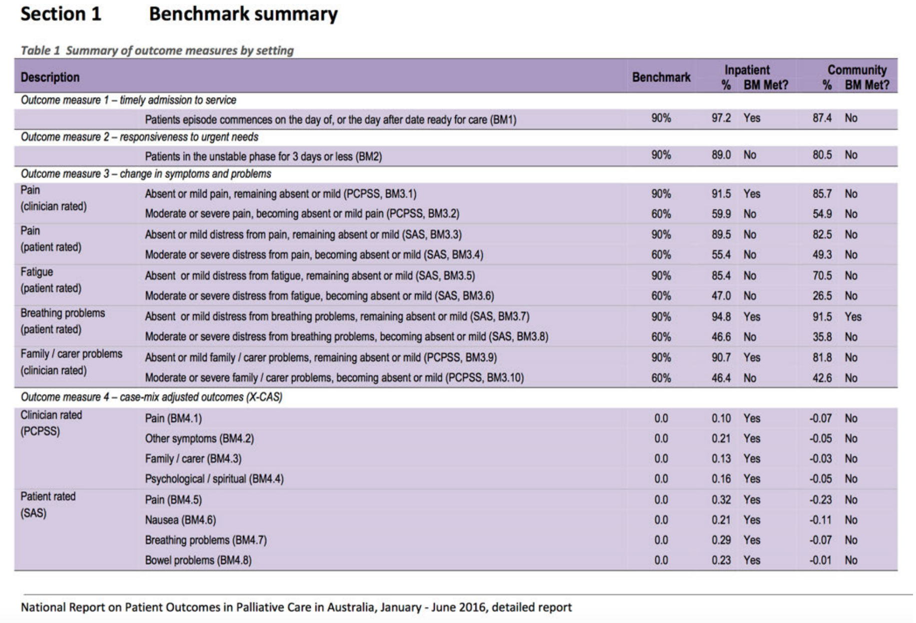
There are many reasons why voluntary assisted dying (VAD) should be legalised in Queensland including:

1) Palliative care cannot always alleviate all suffering.

Australia has one of the best palliative care systems in the world and it has improved significantly over the past 20 years. For the majority of dying Australians, palliative care can relieve the complex mixture of physical, emotional and psychological symptoms; however, it cannot relieve all pain and suffering.

Every year since 2008, data has been collected by palliative care services across Australia. Based on this data we know that a small yet significant percentage of dying patients cannot have their symptoms controlled, even with the best efforts of palliative care.

Two years ago the *Palliative Care Outcomes Collaboration Report 2016* included numerous tables documenting relevant data.[1] Table 1 (below) - 'Benchmark Summary' showed that a realistic goal for 'moderate to severe pain, becoming absent or mild' was only 60% and yet this benchmark was not achieved. The benchmark for 'moderate to severe breathing problems, becoming absent or mild' was also 60%, yet this outcome was only achieved for 46.6% of patients in inpatient services and 35.8% of patients using community palliative care services.



Section 1 Benchmark summary

Table 1 Summary of outcome measures by setting

Description		Benchmark	Inpatient		Community	
			%	BM Met?	%	BM Met?
Outcome measure 1 – timely admission to service						
	Patients episode commences on the day of, or the day after date ready for care (BM1)	90%	97.2	Yes	87.4	No
Outcome measure 2 – responsiveness to urgent needs						
	Patients in the unstable phase for 3 days or less (BM2)	90%	89.0	No	80.5	No
Outcome measure 3 – change in symptoms and problems						
Pain (clinician rated)	Absent or mild pain, remaining absent or mild (PCPSS, BM3.1)	90%	91.5	Yes	85.7	No
	Moderate or severe pain, becoming absent or mild pain (PCPSS, BM3.2)	60%	59.9	No	54.9	No
Pain (patient rated)	Absent or mild distress from pain, remaining absent or mild (SAS, BM3.3)	90%	89.5	No	82.5	No
	Moderate or severe distress from pain, becoming absent or mild (SAS, BM3.4)	60%	55.4	No	49.3	No
Fatigue (patient rated)	Absent or mild distress from fatigue, remaining absent or mild (SAS, BM3.5)	90%	85.4	No	70.5	No
	Moderate or severe distress from fatigue, becoming absent or mild (SAS, BM3.6)	60%	47.0	No	26.5	No
Breathing problems (patient rated)	Absent or mild distress from breathing problems, remaining absent or mild (SAS, BM3.7)	90%	94.8	Yes	91.5	Yes
	Moderate or severe distress from breathing problems, becoming absent or mild (SAS, BM3.8)	60%	46.6	No	35.8	No
Family / carer problems (clinician rated)	Absent or mild family / carer problems, remaining absent or mild (PCPSS, BM3.9)	90%	90.7	Yes	81.8	No
	Moderate or severe family / carer problems, becoming absent or mild (PCPSS, BM3.10)	60%	46.4	No	42.6	No
Outcome measure 4 – case-mix adjusted outcomes (X-CAS)						
Clinician rated (PCPSS)	Pain (BM4.1)	0.0	0.10	Yes	-0.07	No
	Other symptoms (BM4.2)	0.0	0.21	Yes	-0.05	No
	Family / carer (BM4.3)	0.0	0.13	Yes	-0.03	No
	Psychological / spiritual (BM4.4)	0.0	0.16	Yes	-0.05	No
Patient rated (SAS)	Pain (BM4.5)	0.0	0.32	Yes	-0.23	No
	Nausea (BM4.6)	0.0	0.21	Yes	-0.11	No
	Breathing problems (BM4.7)	0.0	0.29	Yes	-0.07	No
	Bowel problems (BM4.8)	0.0	0.23	Yes	-0.01	No

National Report on Patient Outcomes in Palliative Care in Australia, January - June 2016, detailed report

Even if palliative care services reached their benchmarks, there would still be a large number of patients whose pain or suffering was unable to be alleviated.

We had hoped to provide more recent data in our submission; however, the format of the PCOC report has been changed. It no longer includes the tables that identify the numbers of patients whose symptoms cannot be alleviated. The *Palliative Care Outcomes Collaboration Report 2017* stated that 'the euthanasia debate sparked an interest in the data generated by PCOC' and went on to say that 'this data was misrepresented.' [2]

Advocates for voluntary assisted dying have not exaggerated the figures from previous reports. We have always acknowledged that for the majority of dying individuals palliative care can alleviate most distressing symptoms. However, the figures don't lie. There are a number of people who do experience unrelievable symptoms in the weeks, months and sometimes years leading to their deaths. If this were not the case, why would 85% of Australians be calling for voluntary assisted dying laws to be introduced? [3]

In 2013 the *Council on the Aging (COTA)* conducted a survey of people aged 50 years and over. As part of this survey respondents were asked to communicate their views about a range of end of life issues, including palliative care. Just over a quarter (26.3%) of those who knew or had known someone receiving palliative care did not feel that it provided enough comfort towards the end of the person's life. This is a significant proportion and it shows that palliative care should not be the only end-of-life option. [4]

In May 2015, *Palliative Care Australia* (PCA) released data from its own survey. [5] According to the PCA President at that time, Professor Patsy Yates, the survey showed that while almost 70% said they were satisfied or very satisfied with the standard of care, almost a third (31%) were ambivalent about or unhappy with their loved one's care. According to Professor Yates, 'that would translate to about 50,000 Australians each year who feel they did not receive satisfactory care'.

The results from both these surveys demonstrate that despite the best of palliative care, the truth is, there is some suffering that cannot be alleviated.

These surveys do not, of course, capture the opinions of patients and their carers who did NOT participate in palliative care. For many of them, the choice was clearer - make other arrangements, such as DIY suicide or quietly allow a sympathetic doctor to assist them. That means, of course, that the 26% - 31% dissatisfaction rates are likely to be higher in reality.

In their position statements on *Euthanasia and Physician Assisted Suicide,* over the past few years, PCA have stated that 'Euthanasia and physician assisted suicide are not part of palliative care practice'. [6] This has been true because up until recently VAD has not been legal in Australia. However, this position is currently under review and is likely to change since Victoria has passed the *Voluntary Assisted Dying Act 2017* and it comes into effect on 19 June 2019.

In the European countries and American states, where voluntary assisted dying is legal, palliative care and assisted dying are closely intertwined and are certainly not mutually exclusive. [7]

In Belgium, the advocates for legal voluntary euthanasia have been amongst the strongest supporters of palliative care and the two are bound together in legislation and regulations. [8]

In Oregon, where voluntary assisted dying has been legal since 1998, the vast majority of individuals who use that state's dying with dignity legislation are enrolled in hospice care. In 2017, 91% were enrolled in hospice care and 90% of them died at home. [9]

There is no medical specialty that can have all the solutions, for all patients, all of the time. Palliative care is no different, yet this is what many opponents of voluntary assisted dying try to claim. Experienced clinicians know that some patients do not want to be forced into the palliative care pathway, preferring to manage their own death, without the dependency and indignity that the final months or weeks demand. For them, death is not the worst outcome.

2) Offering voluntary assisted dying is compassionate.

Like most Australians, we believe it is cruel and inhumane to force people to endure pointless suffering at the end of their lives and so voluntary assisted dying should be legalised on compassionate grounds.

One of the most vocal organisations to oppose voluntary assisted dying, *The Australian Christian Lobby* (ACL)*,* has in its vision statement that they aim to 'foster a more compassionate, just and moral society', yet they continue to block law reform. [10]

Unfortunately they have a different view on suffering to most. If you access the ACL website you can listen to audio and read articles and comments about voluntary euthanasia. In one report Bioethicist and Palliative Care Specialist, Dr Megan Best said;

> *"You have to look behind the mentality that accepts euthanasia and they just don't think that suffering is something that should be tolerated and they don't see that there is any benefit in someone suffering."*

When asked by the interviewer what the benefits of suffering were, Dr Best went on to say;

> *"For the Church there are lots of benefits to suffering such as strengthening faith and developing perseverance which of course are not going to be at all impressive for the general public."* [11]

Dr Best is probably correct in assuming that the general public would not be impressed because we believe most people would struggle to see any benefit from prolonged suffering.

But the *Australian Christian Lobby* **does not** speak for all Christians. All recent polls show that a significant majority of practicing Christians (between 70% - 88%) support giving a terminally ill patient the choice of a medically assisted death. [12]

An organisation called *Christians Supporting Choice for* Voluntary Assisted Dying was formed in 2009 and its Statement of Belief says:

> *"We are Christians who believe that, as a demonstration of love and compassion, those with a terminal or hopeless illness should have the option of a pain-free, peaceful and dignified death with legal voluntary euthanasia."* [13]

We know that family members and medical staff can be deeply traumatised when someone who is experiencing unrelievable suffering begs for relief when none can be provided. As a compassionate society, we need to offer the choice of voluntary assisted dying to prevent this needless suffering at the end of life.

3) Legalisation of voluntary assisted dying is associated with an improvement in palliative care.

In overseas jurisdictions where voluntary assisted dying has been legalised, there have been improvements in the provision of palliative care. In Oregon, for example, nurses who were asked to rate doctors on their palliative care skills before and five years after the legalisation of voluntary assisted dying, noted significant improvements in care on five of six rated dimensions. The sixth one was unchanged. [14]

Research has also shown that both Belgium and the Netherlands have good palliative care by international standards and are among the countries with the best availability of palliative care in Europe. [15]

In a study (Feb 2015) titled *'Does legal physician-assisted dying impede development of palliative care? The Belgian and Benelux experience',* Chambaere and Bernheim, once again concluded that palliative care had been 'boosted' and 'furthered' in these jurisdictions. [16]

Two key reports related to this question were commissioned by the nation's peak palliative care body, *Palliative Care Australia* itself and released in 2018. The reports examined the international experience and evidence on VAD and concluded that legalising VAD has not been detrimental to the palliative care sector and may, in fact, be beneficial to it. It is not possible to overstate the importance of this conclusion as one of the main arguments raised by opponents of VAD is that it will cause irreparable harm to the delivery of palliative care. [17]

The VEP are confident that there would be plenty of palliative care professionals in Queensland willing to provide the option of voluntary assisted dying if it were legalised, and far from undermining the doctor / patient relationship, we believe it would actually enhance it.

4) Voluntary assisted dying laws work safely and effectively.

There is now a large body of evidence from overseas that demonstrates that voluntary assisted dying laws work safely and effectively. In Europe voluntary assisted dying is legal in Switzerland, the Netherlands, Belgium, Luxemburg and Germany. In America, it is currently legal in eight states - Oregon, Washington, Montana, Vermont, California, Colorado, Hawaii and most recently New Jersey, as well as in Washington DC. It is also legal in the whole of Canada and Colombia.

The *Death with Dignity Act* has operated in Oregon since 1998 and there has been no evidence of abuse over that 21-year period. Former Oregon Governor, Barbara Roberts has said; *"Oregon has proven what happens when you make the law and compassion come together."*

Opponents try to argue that it is impossible to protect the vulnerable and that these laws could be abused but we strongly disagree. All the bills that have been introduced over the past two decades, in the various state parliaments across Australia, have all included stringent safeguards.

Opponents often point to jurisdictions, such as Belgium and the Netherlands, to claim that these laws can be abused; however, what they fail to point out is that the criteria for accessing voluntary assisted dying varies in different jurisdictions.

The *Belgian Act on Euthanasia of May, 28th 2002*, for example, does not require that a patient has a 'terminal illness'. It states:

> *"the patient is in a medically futile condition of constant and unbearable physical or mental suffering that cannot be alleviated, resulting from a serious and incurable disorder caused by illness or accident."* [18]

The same is true for the Netherlands, where their law states that the patient's suffering has to be 'lasting and unbearable'. [19]

Both these European laws include a number of safeguards and, like Oregon, there have been no convictions for abuse of these laws since they were introduced in 2002.

5) Control gives peace of mind, and sometimes that is all that is needed.

Voluntary assisted dying laws provide reassurance to people with terminal or incurable disease that they will not be left to suffer the pain and indignities of a traumatic death. Having control gives peace of mind and as the experience from Oregon has shown, sometimes that is all that is needed. Of the 218 patients for whom *Death With Dignity Act* prescriptions were written during 2017, only 139 (63.8%) ingested the medication. [20]

We have also seen this demonstrated here in Australia. In 2014, Peter Short, a terminally ill Victorian, was able to make the most of the last months of his life because a compassionate doctor, Dr Rodney Syme, had agreed to supply him with the drug Nembutal, if it was required to achieve a peaceful death at the end stage of his oesophageal cancer. Not only did Peter live life to the full without fear, he also used his final year to advocate for voluntary assisted dying law reform. In the end, Peter did not use the Nembutal, however, knowing he had control meant he had a better quality, end-of-life experience than those without that choice. [21]

6) Legalising voluntary assisted dying does not threaten the weak and vulnerable.

Opponents of voluntary euthanasia often muddy the waters with words and concepts that evoke really bad connotations. For example, in a presentation titled *Death Talk*, Professor Margaret Somerville continually referred to the 'killing' and argued that the disabled, the frail, the elderly and even the lonely would be at risk of being euthanised without consent if assisted dying laws were introduced. To support this type of scaremongering, opponents often use wilful misrepresentations of the facts; however, if you investigate the original reports the truth becomes apparent.

Numerous independent audits of existing voluntary assisted dying laws from several jurisdictions have shown them to be safe. The "slippery slope" does not exist. Vulnerable people are less likely to take advantage of voluntary assisted dying.

Rates of assisted dying in Oregon and in the Netherlands showed no evidence of heightened risk for the elderly, women, the uninsured (inapplicable in the Netherlands, where all are insured), people with low educational status, the poor, the physically disabled or chronically ill, minors, people with psychiatric illnesses including depression, or racial or ethnic minorities, compared with background populations. [22]

In Canada the Royal Society of Canada Expert Panel reported: “There is no evidence from the Netherlands supporting the concern that society’s vulnerable would be at increased risk of abuse if a more permissive regime were implemented [in Canada] . . .What has emerged is evidence that the law is capable of managing the decriminalisation of assisted dying”. [23]

Most importantly the two recent Australian parliamentary inquiries into end of life choices found that VAD laws do not pose a risk to the vulnerable and both committees recommended that VAD laws be introduced.

The VEP trusts that your Committee will look carefully at the detail related to the safety and effectiveness of these laws contained in the *Parliament of Victoria’s Inquiry into End of Life Choices Final Report* and the Western Australian Parliament’s *My Life, My Choice, The Report of the Joint Select Committee on End of Life Choices.*

7) Rates of assisted dying without an explicit request go down when VAD is legalised.

Opponents of voluntary assisted dying often try to imply that there is widespread ‘killing of patients without their explicit request’ in countries such as Belgian. However, all the data shows that not only are the rates of ‘life-ending acts without explicit patient request’ continually dropping in Belgium, they are also much lower than in countries without legalised voluntary assisted dying, including New Zealand and Australia. [24 & 25]

Opponents often seize on the reports from Belgium, that quantify the number of ‘life-ending acts without explicit patient request’ trying to imply that these patients are being ‘euthanised’ against their will, when, in fact, ‘these acts predominantly involved the use of opioids’ which are rarely used in euthanasia’.[26] In other words, these acts are the same as those that are carried out in Australian hospitals and nursing homes everyday and are done on compassionate grounds.

8) VAD provides a more humane way to die.

Under current Australian laws there are limited options available for individuals wanting to avoid an unpleasant, painful or undignified death.

Some choose to obtain medication illegally, risking confiscation or prosecution and at significant personal expense. If they are successful in obtaining the drug Nembutal, they then have to die alone for fear that loved ones left behind could be prosecuted for assisting.

Others are so desperate they resort to more violent forms of suicide, which is an absolute tragedy. Traumatic for the individual but also for the others involved - police, paramedics, onlookers and, of course, family and friends.

Even under medical care the proper relief of suffering does not always occur because doctors fear they will be prosecuted for assisting if someone complains.

Even, terminal sedation, that is sometimes possible within a palliative care context, cannot compare to voluntary assisted dying when looking for the safest or most effective way to relieve suffering at the end of life and provide a peaceful and dignified death.

We don't need to imagine what it would be like if a voluntary assisted dying bill was passed into law in Queensland because we have plenty of evidence from overseas.

An article published in Oregon in 2014 told the story of a man named Ben Wald who chose to hasten the end of his life through *Oregon's Death with Dignity Act.* The doctor who prescribed the medication, Dr David Grube said that after practicing for many years, he had seen that in some cases doctors cannot prevent suffering and he said;

> *"In medical ethics, the top value is patient autonomy. The patient should be allowed to choose what they want, not what the doctors want."*

It is worth reading some of the article on Ben Wald's death under the *Death With Dignity Act* to see that there is a more humane way to die. [27] 'There was nothing maudlin about Ben Wald's death at home in Kings Valley.

> *"Once he learned that he was going to be given the choice to end his life, he relaxed," his wife Pam says.*
>
> *Ben and Pam invited 10 of their closest friends, along with the Compassion & Choice volunteers, to join them on the evening of Friday, May 4, 2012.*
>
> *"He was in bed," Pam says. "Prior to taking the medication, he spoke to each of them individually. We sang songs." And one of the friends read a poem.*
>
> *Riggs, the volunteer Compassion & Choices nurse, gave Ben medication to prevent vomiting.*
>
> *Then Riggs mixed the powdery lethal medication — 1,000 milligrams of the barbiturate pentobartibital — with orange juice and handed it to Ben. He drank it himself, as the law requires.*
>
> *"His last words to everyone," Pam says, "were 'Thank you.'"*
>
> *Ben fell asleep within five minutes. Two hours later, as Pam was holding his hands, Riggs tapped her on the shoulder to say that Ben had died.*
>
> *"I'll never forget the experience," Pam says. "Anybody who is at that point in their life has a right to explore this and not be denied the opportunity to take advantage of it.*
>
> *"Making this happen for Ben allowed me to give my husband my last gift of love."* '

9) Many jurisdictions around the world have introduced VAD regimes.

There are now 18 jurisdictions worldwide with legal access to VAD.

Increasing access to legal voluntary assisted dying

By June 2019, more than 200 million people will live in places with some form of legal voluntary assisted dying.

- Switzerland (Criminal Code 1942)
- Netherlands (2002)
- Belgium (2002)
- Luxembourg (2009)
- Colombia (2015 court decision)
- Germany (2015)
- Canada (2016)
  Quebec Province (2014, came into operation Dec 2015)
- US
  Oregon (1997)
  Washington (2009)
  Montana (2010 Court decision)
  Vermont (2013)
  California (2016)
  Colorado (2016)
  Washington DC (2016)
  Hawaii (2018)
  New Jersey (2019)
- Australia
  Victoria (2019)

Australia had the world's first assisted dying law in the Northern Territory (1995) but only four people were able to use it before it was overturned by the Federal *Euthanasia Laws Act 1997*. It took two decades for the next VAD law to pass in an Australian parliament.

10) Australians and others around the world want change.

Repeated polling over 25 years has consistently reported overwhelming support for the legalisation of voluntary assisted dying. According to a 2017 Roy Morgan poll, 85% of Australians are now in favour of voluntary assisted dying. [28]

In June 2015, the well-respected British magazine, *The Economist* asked Ipsos MORI to survey people in 15 countries on whether doctors should be allowed to help patients to die, and if so, how and when. [29] Out of the 15 countries surveyed only Russia and Poland showed minority support. Overall, the survey found strong support across America, Western Europe and Australia for allowing doctors to prescribe lethal drugs to patients with terminal diseases. In 11 out of the 15 countries they surveyed, most people also favoured extending doctor-assisted dying to patients who are in great physical suffering but not close to death. (See graph p. 13).

There are a number of other jurisdictions around the world who, like Queensland, are responding to the overwhelming demand from their communities and are moving towards introducing voluntary assisted dying as a compassionate, end-of-life choice. New Zealand is close to passing their law and Western Australia is likely to introduce their bill in August or September this year.

Do you think it should be legal or not for a doctor to assist a patient aged 18 or over in ending their life, if that is the patient's wish, provided that the patient is terminally ill (where it is believed that they have 6 months or less to live), of sound mind, and expresses a clear desire to end their life?

YOUR ANSWER

Yes, it should be legal

NATIONAL RESULTS

NOTE: This is a completely anonymous questionnaire. No responses are stored.

Source: *The Economist*/Ipsos MORI poll, June 2015

11) The religious beliefs of some should not be imposed on all.

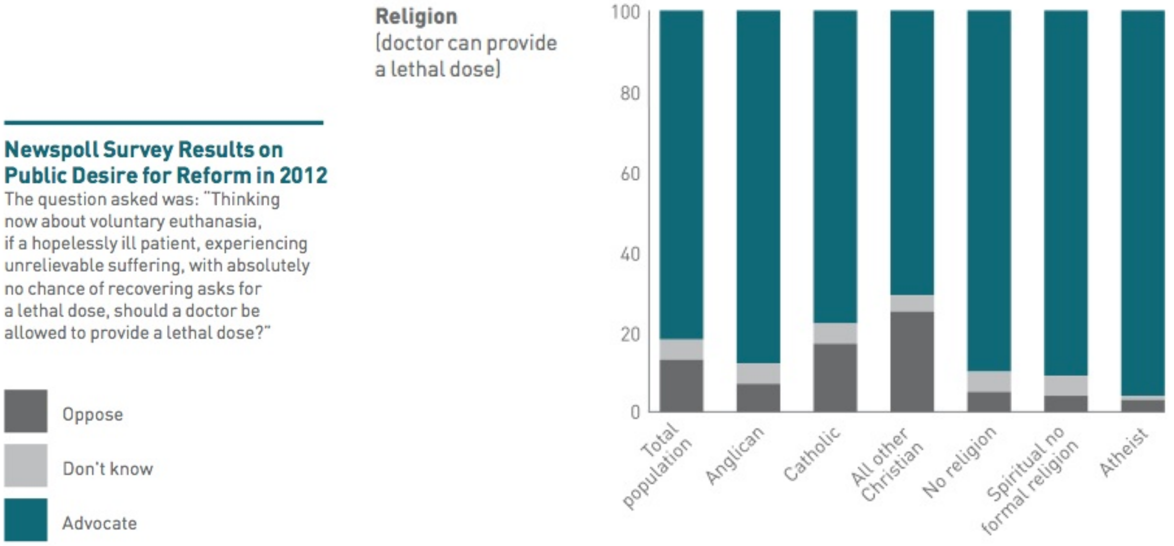
Australia has a diverse faith, and non-faith, community and is increasingly a secular society. Strong opposition to voluntary assisted dying by religious groups, or religious politicians, based on their belief in the sanctity of life, is not a justification for denying choice for those who do not share that belief. To deny voluntary assisted dying for all, on the belief of some, is extremely unfair.

According to the *Australia 21 Report* titled 'The Right To Choose An assisted Death: Time For Legislation? (2013), 'there is now wide acceptance that human life is not an absolute good and that notions of compassion and autonomy can carry greater weight in some circumstance.' [30]

As has been pointed out in previous submissions from the group '*Christians Supporting Choice For Voluntary Assisted Dying',* many Christians are moving away from the more traditional position and are advocating for a more humane approach to voluntary assisted dying. Even high profile religious leaders, such as Archbishop Desmond Tutu and the former Archbishop of Canterbury, Lord Carey, have changed their minds and now support law reform.

Those who fervently reject religious faith should not be exposed to suffering in the expectation of a last minute conversion.

See the Newspoll Survey Results table on p.14 that was included in the *Australia 21 Report*.



Newspoll Survey Results on Public Desire for Reform in 2012

The question asked was: "Thinking now about voluntary euthanasia, if a hopelessly ill patient, experiencing unrelievable suffering, with absolutely no chance of recovering asks for a lethal dose, should a doctor be allowed to provide a lethal dose?"

12) People are suffering now.

Whenever the issue of voluntary assisted dying is discussed in a public forum hundreds, and even thousands, of Australians tell their personal stories of having to watch loved ones die in traumatic circumstances.

During the debate on the *Rights of the Terminally Ill Bill 2013* in NSW in May 2013, *Getup* ran an online survey of its members. A few weeks later they released the results and sent out this email:

> *"We have been overwhelmed by your responses. More than 13,000 GetUp members shared their feelings, thoughts and stories on this deeply personal issue. Of the 13,549 responses, 94% of you voiced support for humane assisted dying legislation provided rigorous safeguards are in place. A huge majority, but those are just the numbers talking.*
>
> *We have spent the last three weeks pouring through your responses. The thoughts and stories you shared were illuminating, confronting, beautiful and they were heartbreaking. Many times, we were moved to tears.*
>
> ***Thank you so much for having the courage to share your stories with us."***

If after reading all these reasons for legalising voluntary assisted dying in Queensland there are members of your committee who still have doubts, please read this comment that was posted on the Channel 7's *Sunrise* Facebook page following an interview they did with Richard Di Natale talking about the *Medical Services (Dying with Dignity) Exposure Draft Bill* in 2014.

They asked whether medically assisted dying should be legalised and Denise Kapernick answered:

> *YES. YES. YES.*
>
> *Anybody who disagrees and considers this murder has obviously not sat there and watched a loved one die a slow, painful and cruel death. They have not seen them cry in pain when the morphine isn't enough. They have not seen them gasp for air as they drown in phlegm. They have not sat and watched as their limbs swell with fluid from being bed-ridden and even cutting their fingernails bringing them to tears. They have not watched as their loved one is reliant on others to spoon feed them, wipe their noses, roll them over to attend to the bed sores, to clean their faeces, to wipe their tears away.*
>
> *They have not watched a once-proud and self-reliant man lose all his dignity and control and become bed-ridden as his body has failed him.*
>
> *It is not murder to give a terminally ill person the option of ending the pain earlier.*
>
> *RIP Dad. Love you always.*
>
> *19 Nov 1939-24 June 2014.* [31]

(NB. Denise Kapernick gave permission for her post to be reproduced in VEP submissions).

…………………………

26. How should VAD be defined in Queensland? What should the definition include or exclude?

The *Voluntary Euthanasia Party (NSW)* supports the definition of VAD used in the Western Australian Parliament's *My Life, My Choice, The Report of the Joint Select Committee on End of Life Choices*, that is:

Voluntary Assisted Dying - The provision for self-administration of lethal medication where an eligible person is physically able to self-administer. In cases where the person is eligible but physically incapable of self-administration, a medical practitioner may administer or provide the medication.

27. If you are a health practitioner, what are your views on having a scheme in Queensland to allow VAD?

One member of the Executive Committee of the Voluntary Euthanasia Party (NSW) is a practising GP in Sydney. Dr David Leaf has been an advocate for VAD for 16 years. He is currently the NSW Convenor of *Doctors for Assisted Dying Choice* and is therefore strongly in favour of allowing VAD in Australia.

The VEP acknowledges that the level of support for VAD from doctors is not as high as support in the wider community; however, in our opinion, evidence from opponents from within the medical profession, should not be given more weight than other submissions. Anecdotal evidence indicates that many Australian doctors are reluctant to express their support for VAD publicly while it is illegal but privately they respect a patient's right to choose the option of VAD if the patient's suffering is unbearable.

During parliamentary debates on previous VAD bills across Australia, the AMA's opposition to VAD has played a key role in blocking the legislation. However, a close examination of the results of their own survey of doctors from 2016 shows that approximately 50% of doctors do support VAD laws so we believe taking a neutral position would have been far more appropriate. [32]

28. If there is to be a VAD scheme, what features should it have?

The *Voluntary Euthanasia Party (NSW)* is made up of members with a range of views in relation to the scope and wording of any proposed voluntary assisted dying legislation. We are reluctant to commit to a fixed position on the detail of any proposed bill, however, we can safely assume that all our members would be united in the belief that any competent adult with a terminal or incurable illness deserves the right to receive assistance to end their lives peacefully, at a time of their choosing.

A VAD scheme should include features such as:

- Specific eligibility criteria;
- Strong and effective safeguards;
- A regulated process to access VAD;
- An option for health professionals to conscientiously object; and
- An independent oversight body to review and regulate the VAD scheme.

29. Are there aspects of VAD schemes in other jurisdictions that should, or should not, form part of any potential VAD scheme for Queensland, and why?

There are a number of aspects of the Victorian VAD scheme that many advocates, including members of the VEP, believe will make it difficult for suffering Victorians to access VAD.

The Victorian legislation limits access to VAD to individuals with a terminal illness with less than six months to live, with the exception of those with a neurodegenerative condition. We believe this will disadvantage some individuals who are suffering and in need of VAD. People with progressive chronic or neurodegenerative diseases may experience intractable suffering for months or years before they die so we believe a specific timeframe should not be included in the Queensland legislation.

The Victorian legislation prohibits doctors initiating a discussion with the patient about the option of VAD. This is a very unusual, supposed safeguard. Usually good medical practice would require a doctor to have open and honest conversations with their patient and inform them of all the treatment options available. We believe this is especially important at the end stage of a person's life and we would not like to see this prohibition in a Queensland VAD law.

Another aspect of the Victorian law that the VEP believes is totally unnecessary is the requirement for the patient to obtain approval from the Health Department for each prescription of lethal medication. Every additional step in what is already a highly safeguarded process for accessing VAD can also become an obstacle and burden for the dying individual. To the best of our knowledge this is not required in any other jurisdiction with legal VAD.

30. Who should be eligible to access VAD and who should be excluded?

In any proposed VAD bill we support a definition of 'illness' that is broad enough to include serious medical conditions and intolerable suffering which may result from serious chronic and neurodegenerative conditions as well as terminal illness. We would prefer the term 'Eligible medical condition' to be used in the Bill. For example:

Eligible medical condition

An eligible medical condition is an incurable and irreversible medical condition, whether caused by illness, disease or injury –

> (a) that would result in the death of a person diagnosed with the medical condition and that is causing persistent and unrelievable suffering for the person that is intolerable for the person; or
>
> (b) that is a progressive medical condition that is causing persistent and unrelievable suffering, for a person diagnosed with the medical condition, that is intolerable for the person –
>
> and that is in the advanced stages with no reasonable prospect of a permanent improvement in the person's medical condition.

Additional eligibility requirements

The VEP (NSW) would support the following additional pre-conditions or eligibility requirements:

- the person is at least 18 years of age;
- the person is an Australian citizen or permanent resident and is normally resident in Queensland;
- the person has decision-making capacity in relation to the request for assistance and the decision to end his or her life has been made freely, voluntarily and after due consideration;
- two medical practitioners have confirmed that the person has an eligible medical condition and has met all other eligibility criteria;
- the second medical practitioner is not a relative or employee of, or a member of the same medical practice as, the first medical practitioner;
- that, in reasonable medical judgement, there is no medical measure acceptable to the person that can reasonably be undertaken in the hope of effecting a cure.

People with mental illness

While some mental illness could be considered to be 'an incurable and irreversible medical condition', and it can cause extreme suffering, it is usually remediable, so therefore it should not be the basis for a request for VAD. However, individuals with mental illness should be given the same legal rights as others. So provided that they have decision-making capacity in relation to the request and they meet the other eligibility requirements people with a mental illness should not be excluded from a VAD scheme.

31. Should the scheme be limited to those aged 18 and over? If so, why? If not, why not?

Based on the difficulties faced over the past two decades in passing VAD laws in Australia and the restrictions that had to be included in order for the Victorian law to pass, the VEP (NSW) believes that our society is not ready to accept that some desperately ill children may also need to access VAD. We therefore recommend that the scheme should be limited to those aged 18 and over.

32. Under what circumstances should a person be eligible to access VAD? Could it be for example, but not limited to, the diagnosis of a terminal illness, pain and suffering that a person considers unbearable or another reason?

See the answer to Q. 30.

33. What features should be included in a process to allow a person to legally access VAD?

- The person seeking VAD should make an initial verbal request to a doctor.
- The person should be assessed by the first doctor in relation to their eligibility. All relevant treatment options should be discussed and the person should be told that their request can be withdrawn at any stage.
- The person should make a second request in writing using a standard template form.
- A second, independent doctor should assess the person to confirm all eligibility criteria are met and provide a written report to the first doctor.
- If either doctor thinks that it is necessary, the person should be referred to a psychiatrist.
- Once both doctors are satisfied that the eligibility criteria has been met the person can make a final oral request.
- Following the final request the first doctor can prescribe the lethal medication and deliver it to the patient.
- The doctor should determine that patient still wants to end his or her life.
- The patient administers the substance to themselves if capable at a time of their choosing or the doctor administers it if the patient is unable to, for example if they are unable to swallow or have a physical disability.
- There should be at least 10 days between the first and final requests unless the person is in the terminal phase of a terminal illness (days to death).
- All stages of the process must be recorded by the first doctor and kept in the patient's record for submission to the independent oversight body.

- There should be adequate measures to safeguard the lethal medication and any unused medication must be returned to the pharmacy.
- The death certificate should report that the death was caused by the patient's underlying disease but also note that it was a voluntary assisted death.
- The death should be reported to the independent oversight body so that annual reports can be prepared and presented and the new law can be monitored.

34. What safeguards would be required to protect vulnerable people from being coerced into accessing such a scheme, and why?

The safeguards have been discussed in the previous questions; however, to recap, the following safeguards are the ones that will ensure vulnerable people will be protected from being coerced.

- Only the suffering individual can make the request for VAD.
- Two doctors have to confirm the strict eligibility criteria.
- If there is any doubt in regard to the decision being made freely, voluntarily and after due consideration, either of the two doctors can request a psychiatric assessment.
- There is a mandatory time that has to elapse between the first and final request.
- In most cases the patient will have to self-administer the lethal medication.
- There is an independent oversight body to review and regulate the VAD scheme.

35. Should people be provided access to counselling services if they are considering VAD? If so, should such counselling be compulsory? Why?

People requesting access to VAD should be offered counselling but it should not be compulsory. The same applies to palliative care. Like other medical treatments, counselling and palliative care should be offered as an option but a person's right to refuse such treatment should be respected.

36. How could a VAD scheme be designed to minimise the suffering and distress of a person and their loved ones?

When considering the detail of any proposed VAD legislation it should always be remembered that individuals who are making such a request are doing so as a last resort. It is likely that they have already endured multiple treatments over many months, or even years. The last thing they need at this time is to face a time-consuming and burdensome, bureaucratic process.

One of the most important aspects of this legislation is its ability to provide a palliative effect for the patient, which will minimise their suffering and distress and also the distress of their loved ones. Once an individual has qualified for VAD they should be allowed to enjoy whatever time they have left with their loved ones.

37. Should medical practitioners be allowed to hold a conscientious objection against VAD? If so, why? If not, why not?

Definitely. We have not heard anyone argue that medical practitioners should be forced to participate in a VAD scheme and it would only cause distress for all concerned if they were.

38. If practitioners hold a conscientious objection to VAD, should they be legally required to refer a patient to a practitioner that they know does not hold a conscientious objection or to a service provider that offer such a service? If so, why? If not, why not?

We believe they should be compelled to refer the patient to a practitioner that they know does not hold a conscientious objection. If VAD is legal, patients need to be able to access this option without facing major obstacles.

Conclusion

The VEP acknowledges that palliative care is, and should be, an important medical service offered to terminally or incurably ill Australians. However, in reality, sometimes the process of dying includes periods of intense and intolerable suffering, which neither medication nor medical staff can control.

The current legal situation leads to enforced suffering, which some have even described as torture. To force a helpless, dying individual to endure pain, discomfort, indignity and fear for days, weeks, months or even years, against their will, is cruel and inhumane and it should no longer be acceptable.

We need healthcare that integrates a peaceful death into the care options available to terminally or incurably ill adults. Doctors need to talk to their patients about end-of-life plans and, most importantly, respect their patients' dying wishes, even if that means providing or allowing a voluntary assisted death.

We believe good laws should reflect the values of society and with a clear majority of Australians in favour of voluntary assisted dying, politicians need to act.

We hope that as a result of this inquiry, a voluntary assisted dying law, with all the necessary safeguards, will be passed in Queensland and that the VAD law will meet the needs and wishes of the individual who has requested access this law.

As indicated earlier, we appreciate the opportunity to make this submission and as a representative of the *Voluntary Euthanasia Party (NSW)*, I would be happy to appear at a public hearing if invited.

Ms Shayne Higson
Voluntary Euthanasia Party (NSW)
State Convenor
Phone: 0403 625 456

Executive Committee of the Voluntary Euthanasia Party (NSW)

Shayne Higson – Convenor

Penny Hackett – Deputy Convenor

Brian Beaumont Owles – Treasurer

Sandi Steep – Party Secretary

Dr David Leaf - Committee Member

Errol Benvie – Committee Member

Julie Hanley - Committee Member

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Aurukun
Shire Council

Growing Respect, Community & Leaders!

26 April 2019

Mr Aaron Harper MP, Chair
Queensland Parliament
Health, Communities, Disability Services and Family Violence Prevention Committee
PARLIAMENT HOUSE QLD 4000

Per Email: careinquiry@parliament.qld.gov.au

Dear Mr Harper

Re: Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying.

Our Council welcomes the opportunity to provide your committee with a brief summary of aged care services provided to residents at Aurukun, from available State and Commonwealth grant programs.

The service provision at Aurukun is coordinated from the 'Chivaree Centre' – a facility owned and managed by the Aurukun Shire Council, with funding agreements with the State Government (QCCP – disability support) and the Commonwealth Government (HCP – Home Care Packages and CCP – Community Care Program). The population of Aurukun is 1,269, with 153 being over the age of 55 (*Australian Bureau of Statistics 2016 Census data*). These statistics are questioned as being reliable and a more accurate population figure is 1450. The Chivaree Centre currently provides services to a total of 42 aged care residents and there are a number of residents awaiting assessments for Home Care Package funding. There are a growing number of clients progressing from low and intermediate care needs to high needs.

.../2

There is no residential aged care facility in Aurukun; with most residents relying on aged care beds at Weipa Hospital. There are 10 dedicated aged care beds at Weipa Hospital, to service the region. On occasion, residents are referred to Weipa Hospital as inpatients and later progress to a residential package so that their high needs are met. There have also been occasion where the individual has requested to return to community to be with family and the local clinic assists with pain medication whilst the individual continues to reside in their family home. There are no inpatient beds at the Aurukun Health Clinic. As Weipa is approximately 2 hrs drive from Aurukun, families transit back and forth to visit the family members who are in residential care. During the 'wet season' the road is closed and the connection with family members does not occur. There is only one flight service from Weipa to Aurukun.

The current challenges facing the provision of services and the sustainability of the service in the long term would include appropriate facilities and infrastructure and also workforce development. If the eligibility age for aged care programs was to be reduced, our community would face considerable challenges in meeting the care needs of this cohort of residents. In addition, there is also uncertainty as to the delivery of disability services under the NDIS program.

The current backlog of assessments for home care packages, places aged persons in a state of limbo as to their care needs. The resources provided to these Assessment Teams needs to be reviewed so that assessments can be completed in a reasonable time and applicants then placed on the national waitlist for funding allocation. As resident health deteriorates, by the time the package is approved, the level of care needs may well have changed.

I look forward to the outcome of your inquiry. If you require any further information in relation to the concerns raised, please contact the Director of Community Services, Mr Alan Neilan on E: [redacted] or [redacted]

Yours faithfully

Bernie McCarthy PSM
Chief Executive Officer

National Seniors
AUSTRALIA

29 April 2019

Committee Secretary
Health Committee
PARLIAMENT HOUSE QLD 4000

Dear Committee Secretary

Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying

National Seniors Australia welcomes the opportunity to make a submission to the *Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying*.

National Seniors is the independent voice of older Australians. Through research and advocacy, we have been active in promoting reforms to improve outcomes for older people for over 40 years.

The issues of aged care, palliative care, end-of-life care and voluntary assisted dying are ones that are top of mind for older Queenslanders. Older people want access to high-quality services, which provide them with dignified support and care in old age.

Attached to this letter are responses to issues raised in the issues paper. These responses have been formulated by the National Seniors Queensland Policy Advisory Group. The Qld Policy Advisory Group is made up of National Seniors members who provide valuable insights into the views of older people in Queensland. All views expressed in this submission are those of the Qld Policy Advisory Group unless stated otherwise.

We hope the committee will carefully consider the input provided by the Queensland Policy Advisory Group as part of the inquiry process.

If you have any questions, please do not hesitate to contact Dr Brendon Radford on [redacted] or [redacted]

Yours sincerely

Vera Somerwil
Qld Policy Advisory Group Chair

National Seniors
AUSTRALIA

Responses to the Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying issues paper

AGED CARE

Issue 1 - Is the aged care system meeting the current needs of older Queenslanders, including those with special needs? Why or why not?

No.

According to evidence presented at the Royal Commission into Aged Care Quality and Safety, the aged care system is not meeting the needs of older people.

National Seniors often hears examples of instances in which the quality of care in aged care facilities in Queensland (and other states and territories) is inadequate. While there are many issues raised by National Seniors members, overall a common element within the feedback was a view that substandard care is, more often than not, a product of staff not having adequate time to attend to the needs of individuals in care. This was especially acute for those who were most frail or with dementia.

National Seniors Queensland Policy Advisory Group believes that young people with disability living in care is an important issue that needs to be addressed. They are being placed in aged care facilities when this should not be happening because there is insufficient accommodation in more appropriate facilities.

Issue 2 - Are the current waiting times for residential and home care places adequately meeting the needs of older Queenslanders?

No.

Waiting times for home care, specifically, are not meeting the needs of older Queenslanders. There are currently 127,000 people who are not receiving the appropriate level of care they need as at 31 December 2018 nationally[1]. Unfortunately, data showing the number of Queenslanders is not readily available.

National Seniors has been calling for a tripling of level 3 and 4 home care packages to eliminate the waiting list for home care[2].

Issue 3 - Do the standards of residential aged care, home care and other care services provided in Queensland meet clients and community's needs of older Queenslanders? Can you give examples.

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[1] Australian Government Department of Health 2019 Home Care Packages Program Data Report 2nd Quarter 2018-19 1 October – 31 December 2018, March 2019 https://www.gen-agedcaredata.gov.au/www_aihwgen/media/Home_care_report/HCP-Data-Report-2018-19-2nd-Qtr.pdf

[2] National Seniors Australia 2019. *Federal Election: Policy priorities of older Australians*. https://nationalseniors.com.au/uploads/ElectionPrioritiesDoc-Web.pdf

No.

It is clear from the need for a royal commission that standards of care are not always being met, particularly in the residential care setting. Despite the existence of quality standards and associated monitoring and accreditation regimes, acceptable standards of care are not being met.

New Aged Care Quality Standards and accreditation regimes will become effective from 1 July 2019.

Under new accreditation rules residential care providers will have to meet new common standards and adhere to a new accreditation regime. This includes a shift to “process” standards, which require providers to have processes to assess individual needs and deliver services in ways that meet these individual needs. It also includes changes to accreditation processes, such as the use of unannounced inspections to evaluate compliance with quality standards.

While the strengthening of standards is welcomed, it remains to be seen if the new standards will improve the quality of care provided to care recipients. Standards alone will not result in high quality care if the resources required to meet the standards are not available.

Issue 4 - How will demand for aged care services change in Queensland as the population increases in and ages, and what changes to the aged care system will be needed to meet future demands for aged care?

Demand for aged care services in Queensland will undoubtedly increase as the population increases and the proportion of older people expands. As the baby boomer cohort ages this will place significant pressure on aged care services and require significant investment in new residential facilities, home care places and home support services.

One of the key challenges facing aged care is the treatment of people with dementia. Rates of diagnosed dementia in aged care facilities is estimated to be around 52 per cent[3]. The significant numbers people with specific needs arising from dementia will pose challenges for the aged care sector in the future. This will have implications for the types of services and levels of support required. Residential care facilities will need to be better equipped to deal with these challenges, so to will the aged care workforce.

Issue 5 - Are there enough residential aged care places (beds) available in aged care facilities, in areas and at the levels of care that are required?

The primary issue with places in residential care is delivering places in locations where demand is required. Seniors tell us they struggle to find a suitable service that is located near family, to enable ongoing support. This is especially difficult for people in rural and remote areas, where some are having to travel significant distances to access residential care, far away from family and community.

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[3] AIHW 2019. Dementia https://www.aihw.gov.au/reports-data/health-conditions-disability-deaths/dementia/overview

Issue 6 - Are there adequate numbers of home care packages available in areas at the levels required?

No.

There were 127,000 people across Australia waiting to receive a package at a level appropriate to their needs as at 31 December 2018. Consumers are waiting more than 12 months to access Level 2, 3 and 4 packages[4], with many being forced to enter residential care or worse, dying, while waiting for higher level packages.

This situation is particularly acute in rural and remote areas where providers are struggling to provide home care services.

Issue 7 - Are there sufficient staff in the aged care sector to meet current and future workloads?

No.

It is likely that the growth in demand for services will lead to significant increase in demands on staffing.

Issue 8 - Is the mix of staff appropriate for different settings within aged care sector?

There are currently no clear guidelines for the mix of staff in aged care.

Residential aged facilities receive extra funding for people with higher needs. Residents who are very frail or suffer dementia, for example, require greater nursing care than a resident with low care needs to support activities of daily living, including feeding, dressing, bathing and toileting. However, there is no requirement to demonstrate that any extra money received for an individual's care be used for their individual care. Providers need only meet the standards of care set out in the quality standards.

Most of this work is carried out by Enrolled Nurses (EN) and Personal Care Assistants (PCA). Registered nurses are responsible for medication, dressings, treatments and documentation.

Registered nurses have responsibility for ensuring that ENs and PCAs carry out their work according to the resident's care plan. In the Queensland's public sector, the Nursing Program uses the Business Planning Framework (BPF) improve application and compliance in aged care.

The National Seniors Queensland PAG has advocated that the Queensland Government introduce nurse-to-resident ratios in public residential aged care facilities to improve safe practice.

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[4] Australian Government Department of Health 2019 Home Care Packages Program Data Report 2nd Quarter 2018-19 1 October – 31 December 2018, March 2019 https://www.gen-agedcaredata.gov.au/www_aihwgen/media/Home_care_report/HCP-Data-Report-2018-19-2nd-Qtr.pdf

The Queensland Government mandated the nursing Guarantee Program and safe nurse to patient ratios in the 2016-17 Queensland Budget[5]. The program has been introduced into medical, surgical and mental health units. Queensland PAG is calling for the program to introduced in public aged facilities in the forthcoming budget (2019-2020). It is hoped the Nursing Guarantee Program will improve safety for the patient and the staff caring for them in Queensland's publicly funded aged care facilities.

It is noted the Victorian Government mandated ratios in health care in 2015 and after a review of all aspects of the program into public hospitals and aged care homes in August 2018[6]

Issue 9 - Do aged care staff receive training that is appropriate and adequate to prepare them for the work?

No.

The increasing frailty of aged care consumers, combined with the increasing incidence of dementia, require that direct care staff have, at the very least, a basic understanding of how to interact with and treat people in these circumstances. National Seniors Australia has been advocating for all direct care staff to have basic dementia training[7].

While registered nurses who complete their nursing degree and specialise in aged care or obtain additional diplomas or degrees in geriatrics or gerontology have knowledge and skills in caring for dementia sufferers, this is not likely the case for many of the PCA's who do much of direct care duties.

Dementia and Alzheimer disease was the second leading cause of death among people aged 75 and over[8]. It essential that people caring for residents who suffer from dementia understand the behaviour associated with this condition and receive training that is appropriate and adequate to prepare them to work in such environments.

Issue 10 - What are the costs to the public health system of caring for elderly people in hospitals whilst they are waiting for residential aged care places to become available?

The current funding model for health and aged care results in circumstances in which residents in aged care facilities end up in the hospital system. A lack of access to primary health care and palliative care services within residential care settings, for example, means that aged care residents are often sent to emergency departments and are admitted to hospital adding a significant cost burden to the health system.

Unfortunately, the disparate and disjointed funding models for health and aged care exacerbate this situation because it encourages cost shifting between aged care and hospital settings.

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[5] Premier and Minister for the Arts, The Honourable Annastascia Palaszczuk and Minister for Health and Minister for Ambulance Services the Honourable Cameron Dick. 2015. 'Nurse- to-patient ratio legislation introduced' Media Statement. 1 December 2015

[6] Australian Nursing and Midwifery Federation (Victorian Branch) 2018. 'Historic hospital staffing laws will be the envy of the world' Media release 21 August 2018.

[7] https://nationalseniors.com.au/uploads/ElectionPrioritiesDoc-Web.pdf

[8] Australian Institute of Health and Welfare 2018. Australia's health 2018. Australia's health series no. 16. AUS 221. Canberra: AIHW

Issue 11 - Are suitable care services being provided within residential aged care and /or aged care providers?

See above

Issue 12 - Is the current aged care system making an appropriate contribution to the health of Queenslanders, within the context of broader health system in Queensland?

National Seniors Qld Policy Advisory Group has no comment.

Issue 13 - How can the delivery of aged care services in Queensland be improved?

With regards to public aged care facilities administered by Queensland Health, National Seniors Queensland PAG supports the introduction of mandated minimum staff-to-resident ratios as per the Nursing Guarantee Program.

More broadly National Seniors Australia supports the implementation of the aged care workforce strategy, mandatory dementia training for all direct care staff, reform of the Aged Care Funding Instrument (ACFI), stronger quality standards and accreditation regime, mandatory quality indicators, increased funding for high level home care packages and increased subsidies for rural and regional service provision among others.

Issue 14 - Are there alternative models for the delivery of aged care services that should be considered for Queensland?

National Seniors Qld Policy Advisory Group would encourage the Queensland Government to review best practice models of the delivery of aged care services, with the view of enhancing productivity and improving quality.

There are examples in Australia and overseas in the Netherlands and Denmark of different service delivery models for clients with dementia. For example, a dementia village is being built in Tasmania for people suffering with dementia. It will have 15 tailored homes, with a supermarket, café and cinema and gardens. This is based on the model used by the De Hogeweyk village in the Netherlands[9].

Issue 15 - How will the model of aged care develop with evolving technology and medical practices?

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[9] Lehman, R. and Bhole, A. 'Dementia village mimicking small-town setting to be built in Tasmania' in *ABC News*. 20 July 2017 https://www.abc.net.au/news/2017-07-19/australian-first-dementia-village-set-to-open-in-tasmania/8724772

Technology will offer aged care with many new opportunities to improve the standard of care, through improved monitoring of the health and wellbeing of care recipients, increased efficiencies in the delivery of services to consumers and means of supporting the workforce to administer care.

Technology will not replace the need for competent staff to perform day-to-day care activities but it will augment their work, hopefully increasing efficiency and quality of care.

Issue 16 - What are the key priorities for the future?

- **Evidence gathering and data collection** Ensure there is adequate information about existing services, preferences of consumers and population demands to inform service planning.
- **Home care** Facilitating increased access to home care will reduce pressure on residential care and provide consumers with the type of care that is most preferred.
- **Standards and quality** Strengthen quality standards and accreditation processes and processes to enable consumers to understand and compare quality.
- **Workforce** Implementation of national workforce strategy to ensure there are adequate workers available is required.
- **Care models** Alternate care models are needed which are more receptive to the specific needs of individuals yet retain cost efficiencies to challenge existing models of care.

END OF LIFE AND PALLIATIVE CARE

Issue 17 - What are the palliative care services offered in Queensland?

National Seniors Qld Policy Advisory Group has no comment.

Issue 18 - Are palliative care and end-of-life care services meeting the current needs of Queenslanders? Why or why not?

No.

The existence of high-quality palliative care is of significant concern for all Australians. All people should have the right to die with dignity, free of pain and distress, in the setting of their choosing. The issue of pain management is clearly one factor that is of significant concern for patients, family and carers. Studies have found that poor pain management is one of several key factors that inhibit patients from achieving their preferred place of death[10]. Patients are often transferred from home to hospital, for example, because pain is not able to be managed effectively causing significant distress.

National Seniors Australia believes that individuals should be able to choose their palliative care setting knowing that the quality of the care provided will be generally equal regardless of the setting they choose. If this is not possible, then they need to know explicitly that there are differences in outcomes within different settings and why these differences occur before they choose a setting[11].

Palliative care services should be provided in a way that meets the unique needs of individuals. This requires a diverse range of practitioners and models of care within the service setting, which are not currently provided. While large urban areas have a greater capacity to offer choice when compared to areas with small and dispersed populations, all people should have access to appropriate, high quality specialist palliative care services regardless of where they live.

It is unlikely that palliative and end-of life care services are meeting the needs of Queenslanders, however this will differ on a case-by-case basis. It is distressing to hear stories from seniors who claim that they have had to wait for weeks to receive appropriate services or the quality of services are not adequate.

Services do not appear to be well integrated with hospital and health services in Queensland. This has been recognised by the Queensland Compassionate Communities, an independent advisory group.

A first step in improving these services can be achieved by gathering information about the preferences of people about palliative and end-of-life care services. This could be achieved if advance care planning instruments were more broadly used and if individual preferences within advance care planning instruments

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[10] Damanhuri, G. 2014. ‘What factors influence the terminally ill patient referred to the hospital specialist palliative care team in a NHS hospital, not achieving their preferred place of death? A critical evaluation." in *BMJ supportive & palliative care.* 4, 1. http://spcare.bmj.com/content/4/Suppl_1/A54.3.short

[11] National Seniors Australia 2017. *Submission to the inquiry into the increased application of competition, contestability and informed user choice to human services.* Brisbane: National Seniors Australia

were captured at a community level. This would assist in determining likely demand for specific service types. These insights could be combined with existing health and demographic data to plan for the delivery of appropriate levels of service to meet the diverse needs of a community.

Issue 19 - Do the standards of palliative care and end-of-life care provided in Queensland meet clients' and the community's expectations?

No comment.

Issue 20 - How will demand for palliative and end-of-life services change in Queensland as the population increases and ages, and what changes to the delivery of these services will be needed to meet future demands?

The population of Queensland is expected to increase from 4.8 million in 2016 to 9.5 million in 2066. The proportion aged 65 years and older will increase from 14.7 per cent of the population to between 23.8 and 25.8 per cent over this period[12]. The significant increase in the number and proportion of older people over time will have significant impacts on palliative and end-of-life care services. The need for specialist palliative and end-of-life care services will undoubtedly increase.

Given that home-based services are not currently meeting demand it will be crucial that government takes urgent steps to realign services to meet these demands in the future. Along these lines it is essential that workforce planning occurs to ensure there are adequate palliative care nurses, allied health and other appropriate staff available to serve the needs of care recipients.

The Queensland Government should adopt an integrated palliative care service delivery plan (incorporating specialist palliative care, general palliative care and public health approaches to palliative care) such as has been suggested by Palliative Care Queensland[13].

Issue 21- How can the delivery of palliative care and end-of-life care services in Queensland be improved?

By promoting best practice service delivery models. This can only be achieved through objective analysis of existing service delivery models to ensure that only best practice models are promoted.

Issue 22 - What are the particular challenges of delivering palliative and end of life care in regional, rural and remote Queensland?

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[12] Queensland Government Statistician's Office 2019. *Queensland Government population projections, 2018 edition: Queensland* http://www.qgso.qld.gov.au/products/reports/qld-govt-pop-proj/qld-govt-pop-proj-2018-edn.pdf

[13] Palliative Care Queensland 2018. *Submission to Queensland Health Review of Palliative Care Services* September 2018 https://palliativecareqld.org.au/wp-content/uploads/2018/09/PCQ-submission-for-QHealth-PallC-Services-Review-2018.pdf

Service delivery in regional, rural and remote areas of Queensland is of concern to seniors. Seniors have difficulties accessing aged care services in regional, rural and remote areas.

The ongoing challenge is the tyranny of distance. It is difficult to deliver palliative and end-of-life care services to people living in regional, rural and remote Queensland who choose to remain at home to receive palliative care services. Similarly, the tyranny of distance makes it difficult for carers, family and friends to support people receiving these services in hospital settings.

Issue 23 - What are the particular challenges of delivering palliative and end of life care for Aboriginal and Torres Strait Islander communities?

National Seniors Qld Policy Advisory Group has no comment (Aboriginal and Torres Strait Islander representatives are best places to comment here)

Issue 24- What are the key priorities for the future?

- **Evidence gathering and data collection** Ensure there is adequate information about existing services, preferences of consumers and population demands to inform service planning (this should include understanding of service gaps for specific population groups).
- **Best practice models** Analyse and promote best practice models to ensure that only services achieving quality outcomes continue to deliver services in Queensland.
- **Workforce planning** Ensure the right number of the right people with the right skills in the right locations with the right support (including for specific population groups).

VOLUNTARY ASSISTED DYING

Issue 25 - Should voluntary assisted dying (VAD) be allowed in Queensland? Why/why not?

National Seniors Australia conducted a broad advocacy survey of its members and supporters in 2017. As part of this survey, respondents were asked the following question - "Do you support legislating to allow medically assisted dying?".

Nationally, 5,619 people responded to the question, of which

- 3,738 or 66.5 per cent answered "Yes",
- 965 or 17.2 per cent answered "No" and
- 916 or 16.3 per cent answered "Unsure".

Of those who responded to the question - "Do you support legislating to allow medically assisted dying?" – 2414 indicated they lived in Queensland. The results for Queensland were largely the same as nationally:

- 66.5 per cent answered "Yes"
- 17.3 per cent answered "No" and
- 16.2 per cent answered "Unsure".

The response appears to reflect broader community feelings about this matter.

Any moves to introduce voluntary assisted dying in Queensland, should be subject to appropriate legal protections to ensure that the rights of the vulnerable are protected.

Issue 26 - How should VAD be defined in Queensland? What should the definition include or exclude?

National Seniors Qld Policy Advisory Group believes that the following eligibility criteria should be considered in any definition.

Voluntary assisted dying be made available to people who have an appropriate legal direction document in place regarding their future end-of-life care and who suffer one or more of the following:

- Terminal illness
- Incurable, irreversible, progressive chronic illness, e.g. Dementia and Alzheimer's diseases, that seriously affect the dignity and quality of life of the sufferer.
- Intractable and unbearable pain from a condition that is incurable and with no chance of improvement
- Unbearable mental and physical distress
- Indignity through becoming totally and permanently dependant on others to be able to perform normal, everyday functions

Issue 27 - If you are a health practitioner, what are your views on having a scheme in Queensland to allow VAD?

Not relevant

Issue 28 - If there is to be a VAD scheme, what features should it have?

Please refer to our answer to Issue 29 below.

Issue 29 - Are there aspects of VAD schemes in other jurisdictions that should, or should not, form part of any potential VAD scheme for Queensland, and why?

National Seniors Qld Policy Advisory Group believes legislation should not differ dramatically between states and territories to ensure national consistency as best as practical.

National Seniors Qld Policy Advisory Group believes that the Victorian legislation is generally fit-for-purpose with appropriate safeguards. However, the Victorian legislation has one significant deficiency in that it requires a prognosis that the illness or disease will cause death within 12 months. Qld PAG believe there should not be any such timeframe stipulated before a person can access voluntary assisted dying.

Issue 30 - Who should be eligible to access VAD and who should be excluded?

Please refer to our answer to Issue 26 above.

Issue 31 - Should the scheme be limited to those aged 18 and over? If so, why? If not, why not?

Please refer to our answer to Issue 26 above.

Issue 32 - Under what circumstances should a person be eligible to access VAD? Could it be for example, but not limited to, the diagnosis of a terminal illness, pain and suffering that a person considers unbearable or another reason?

Please refer to our answer to Issue 26 above.

Issue 33 - What features should be included in a process to allow a person to legally access VAD?

National Seniors Qld Policy Advisory Group believes the VAD procedure should be able to be performed at any reasonable location chosen by the person, including at their own home.

Issue 34 - What safeguards would be required to protect vulnerable people from being coerced into accessing such a scheme, and why?

National Seniors Qld Policy Advisory Group believes the following options be considered as options which could provide safeguards against coercion:

- A requirement that those wishing to legally access VAD have first prepared a “living will” or advanced care directive, at a time when the person is of sound mind and competent to draft, understand and sign the document, that includes the authority of the nominated Power of Attorney to undertake the wishes of the person if they are no longer able to communicate for themselves.
- Confirmation by two medical professionals that the person meets any criteria laid down in the VAD legislation.
- A case conference involving the person, if they are competent to participate, their treating general practitioner or specialist doctor, plus the next of kin and/or appointed agent to verify the VAD is in accordance with the person’s wishes as evidenced by document/s they have signed.
- A review committee consisting of a mix of medical and lay representatives who have a responsibility to review submissions made by the person, their medical professional/s or their appointed agent in support of the VAD request to ensure the VAD Law requirements have been met. The committee should be required to endorse the decision within 14 days of the criteria being met.

Issue 35 - Should people be provided access to counselling services if they are considering VAD? If so, should such counselling be compulsory? Why?

National Seniors Qld Policy Advisory Group believes that counselling services should be available but not compulsory.

Issue 36 - How could a VAD scheme be designed to minimise the suffering and distress of a person and their loved ones?

National Seniors Qld Policy Advisory Group believes some fundamental features could be included within the VAD design to minimise the suffering and distress of an eligible person or their loved ones.

These include:

- Upholding the dignity of the person requesting access to the VAD scheme should be paramount throughout the process.
- A decision to proceed with VAD must be able to be made in a timely manner to limit a person’s suffering.
- Access to the Queensland VAD scheme should be available to all Australian residents until similar schemes are made available to all Australian residents.
- The VAD procedure should be kept as simple as possible.

Issue 37 - Should medical practitioners be allowed to hold a conscientious objection against VAD? If so, why? If not, why not?

National Seniors Qld Policy Advisory Group believes anyone holding a conscientious objection to VAD should not be forced to participate in the scheme against their will, including medical practitioners.

Issue 38 - If practitioners hold a conscientious objection to VAD, should they be legally required to refer a patient to a practitioner that they know does not hold a conscientious objection or to a service provider that offer such a service? If so, why? If not, why not?

National Seniors Qld Policy Advisory Group believes the Queensland Government could provide a register of general practitioners who are willing to participate in the VAD scheme if an individual practitioner held a conscientious objection to VAD.

Other comments

Protecting the vulnerable against any possible abuse by persons seeking to take advantage of the VAD scheme.

The introduction of VAD has the potential to endanger vulnerable people at the hands of individuals who might stand to benefit from an eligible person being coerced to access the VAD scheme. Special attention must be paid to the protection of the vulnerable by those who are responsible for the proper conduct of the VAD scheme. National Seniors Qld Policy Advisory Group have suggested several safeguards (see Issue 34 above), which could be applied to increase protections. The Committee should give this issue comprehensive consideration.

Interaction of palliative care and VAD.

It can be argued that world class palliative care, incorporating physical, mental, social, psychological and spiritual support, reduces or even removes the need to VAD. However, National Seniors Qld Policy Advisory Group believes palliative care and VAD are not the same thing and should exist in a complimentary way so that the service most suitable to the individual be provided.

Religious / cultural objections to VAD

There is a proportion of the community who will object to the introduction of VAD on religious or cultural grounds. These objections should be seriously considered by the committee.

Community education

As with all significant and contentious legislative changes, success or failure will depend on ongoing community acceptance and ownership over this change. National Seniors Qld Policy Advisory Group believes an ongoing public education campaign is required to ensure the law is clearly understood and accepted.

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Committee Secretary
Health Committee
Parliament House,
BRISBANE QLD 4000

Re: Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying

Summary

The Australian Family Association appreciates the opportunity to make a submission to the inquiry into aspects of aged care and palliative care, as well as the proposal to legalise so-called voluntary assisted dying in Queensland.

The Australian Family Association has been in existence for almost 40 years. We provide a forum and a vehicle for those individuals and organisations in the community concerned with the strengthening and support of the natural family. We are a voluntary, ecumenical and non-party-political organisation.

We will confine our submission to end-of-life and palliative care and doctor-assisted dying and euthanasia.

Our submission recommends:

1. That funding for palliative care in Queensland be boosted substantially and services significantly expanded so that all terminally ill patients can receive the end of life care to which they are entitled as a fundamental human right.
2. That the Queensland Government educate the public about palliative care and its ability to ease the dying process in relieving pain and caring not only for patients but also for their families.
3. That the current laws that make doctor-assisted suicide and euthanasia criminal offences in Queensland be retained.

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1. Introduction

The campaign to legalise doctor-assisted suicide and euthanasia in Queensland is based on lies and fear.

Euthanasia advocates give the false impression that terminally ill patients have to suffer excruciating pain and dreadful agony.

This is simply not the case with the advanced health care available today in Australia.

2. The Correct Use of Language: What is Doctor-Assisted Suicide and Euthanasia?

As George Orwell said, “political language has to consist largely of euphemism, question-begging and sheer cloudy vagueness”. Indeed, the goal of much political speech and writing, wrote Orwell, “is to make lies sound truthful and murder respectable.”[1]

The misnomer “voluntary assisted dying” hides what doctor-assisted suicide and euthanasia really are.

Doctor-assisted suicide is intentional killing by doctors providing poison for the patient to take, while euthanasia is a lethal injection administered by doctors. Both are acts that intentionally and directly cause a patient’s death.

So “voluntary assisted dying” (VAD for short) is a misleading description because both assisted suicide and euthanasia are in fact killing.

The true form of assisted dying is palliative care, and the euthanasia lobby is trying confuse the public by muddying the waters.

There is a crucial difference between hastening or inducing a patient’s death and letting nature take its course. The first is homicide, and the second is natural death.

Euthanasia cannot be considered to be part of health care, and is certainly not part of palliative care.

As the Health Committee heard in evidence from Dr Phillip Good, of the Queensland Specialist Palliative Care Services Medical Directors’ Group, at the public hearing on 5 April, “palliative care is a healthcare service”, while “VAD is a societal issue…People do not access VAD overseas for symptom control issues; they access VAD for societal issues… like fear of the future, loss of independence… loss of autonomy.”

3. Palliative Care – a fundamental human right for all towards the end of life

The definition of palliative care by the World Health Organisation (WHO) is:

Palliative care is an approach that improves the quality of life of patients **and their families** facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (emphasis added).

Palliative care:
- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;

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[1] Politics and the English Language, essay published in April 1946. www.orwell.ru/library/essays/politics/english/e_polit

- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Palliative care is delivered by teams of specialist doctors and nurses, as well as accredited GPs, aided by psychiatrists, psychologists, physiotherapists, counsellors, social workers and chaplains.

Depending on the disease, oncologists, neurosurgeons and respiratory physicians may be consulted.

Other allied health professionals who may be part of the team include: dietitians, music therapists, occupational therapists, orthotists and prosthetists, pharmacists, podiatrists and pastoral care workers.

Palliative care is delivered in hospices, hospitals, aged care facilities and at patients' homes.

The founder of the palliative care movement, Dame Cicely Saunders, a nurse who became an eminent doctor, researcher, medical administrator, fundraiser and publicist, opened the first modern hospice, St Christopher's, in London in 1967. She knew that care for the dying was not simply a matter of managing patients' pain, so she developed a theory of "total pain" which encompassed its emotional, social and spiritual elements.

"The whole experience for a patient includes anxiety, depression and fear: concern for the family who will become bereaved; and often a need to find some meaning in the situation, some deeper reality in which to trust," she said.[2]

The loudest voices in today's debates over euthanasia are often its champions, doctors whose credentials include public defiance of the law by killing depressed and lonely patients. But in the long run, it will probably be the softer and more humane voice of **Dame Cicely Saunders** who helped thousands to a peaceful death: **"You matter because you are you, and you matter to the last moment of your life.**"[3]

In 1990, WHO's expert committee report, *Cancer Pain Relief and Palliative Care,* stated: "… with the development of modern methods of palliative care, legalisation of voluntary euthanasia is unnecessary. Now that a practicable alternative to death in pain exists, there should be concentrated efforts to implement programs of palliative care, rather than a yielding to pressure for legal euthanasia."[4]

It should be pointed out that palliative care has made great advances since 1990. Yet it is still under-utilised, largely because of the lack of resources caused by government underfunding and sometimes ignorance by medical professionals who should know better but persist with active measures to extend life rather than focussing on relieving symptoms.

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[2] Michael Cook, *The Great Human Dignity Heist: How bioethicists are trashing the foundations of Western civilisation (Connor Court Publishing, 2017), p.57.*

[3] Ibid, p. 61

[4] WHO, *Cancer Pain Relief and Palliative Care*: report of a WHO expert committee (Geneva: World Health Organisation, 1990): WHO Technical Report Series 804, p. 11

An Australian palliative care expert, Dr Brian Pollard, wrote in 1994: "In medical practice, it is *never* necessary to kill a person to relieve physical pain."[5]

In 1999, two American ethicists pointed out: "Physicians have at their disposal today the means to adequately control the pain of virtually every patient who is terminally ill… Hospices specialise in the art of pain control, particularly for the terminally ill. Far too many people die in hospitals, pursuing aggressive care, when they could be spending their last days with their pain under control, their depression (from being terminally ill) being treated, and not subject to expensive and burdensome aggressive medical technology."[6]

It is the stories of these cases that we hear from those traumatised by these experiences crying out for euthanasia, unaware or dismissive of the much better alternative end of life care that palliative care offers, if properly resourced.

We note the written submission to the Health Committee from the Qld Specialist Palliative Care Services Medical Group, which states on Page 3: "Death is a universal health outcome. Equitable access to comprehensive palliative care, therefore, must be recognised as a fundamental human right and an essential component of value-based safe and high-quality health care for all. It cannot and should not be considered an optional extra of any health service."

The submission stated that "the total funded full time equivalent (FTE) palliative medicine specialist positions in Queensland are 38.4 FTE positions while the required FTE positions equate to 92.94 FTE positions".

This indicates that funding for palliative care in Queensland needs to be more than doubled.

In oral evidence on 5 April, Dr Peter Whan, told the Committee that he was the only palliative care specialist for the Central Queensland Health and Hospital Services, in a population of 400,000 people over 200,000 square miles, when the guidelines say there should be 8 such specialists. We understand that he has since retired, so presumably there is now not even one palliative care specialist assigned to central Queensland.

Dr Andrew Broadbent, the palliative care specialist for the Gold Coast HHS, gave an example to the Committee of a teenage patient with cancer who could not be treated with complex pain relief in Queensland who had to go to Lismore in NSW to access the necessary treatment.

This under-resourcing of palliative care by the Queensland Government is a disgrace. Steps need to be put in place now to remedy this scandalous situation. We call on the Committee to deliver to the Government an interim report calling for immediate adoption of the resourcing, training and funding recommendations made by Palliative Care Queensland.

To quote Dr Phillip Good in oral evidence to the Committee: "Our viewpoint is that, until you have an equitable, world class palliative care system across the state, it seems premature to introduce a pathway that some people may choose to go down when they have not had good access to good symptom control."

In other words, Parliament must not introduce euthanasia laws in Queensland, at least while palliative care services are so patchy and hard to access. And this situation will take years to fix because of the training that needs to be done to boost the numbers of specialist doctors and nurses, as well as putting in place the necessary supporting structures.

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[5] Brian Pollard, *The Challenge of Euthanasia* (Sydney: Little Hills Press, 1994), p. 174

[6] Scott B. Rae and Paul M. Cox, *Bioethics: A Christian Approach to a Pluralistic Age* (Grand Rapids, Michigan: William B. Eerdmans, 1999), p.246.

Otherwise, the message you would be giving the public is this: Your Government will help you kill yourself, but won't provide you the care you need to relieve your suffering.

This deficit in adequate funding of palliative care services is not limited to Queensland.

We have been informed by Palliative Care Victoria there is still a $65 million shortfall in annual funding for palliative care services in that state, despite three specific recommendations in the Parliament of Victoria Inquiry into End of Life Choices Report in June 2016 to increase support and funding.[7]

In fact, there has been a 4% decline in real terms in recurrent funding of palliative care services in Victoria since 2014-15.

Consequently, Palliative Care Victoria has informed us that it estimates that each year 10,000 terminally ill patients who need palliative care die without receiving it. This is absolutely scandalous.

Yet the Victorian Government is just about to introduce its system of legalised killing in public hospitals in June this year.

We understand that thousands of Queenslanders are in a similar situation – dying each year with unnecessary pain and suffering because they do not have access to palliative care.

Some final points we wish to make about palliative care:

It is entirely ethical, completely legal and best medical practice for a doctor to do whatever it takes to relieve a patient's pain, even if it has the unintended but possible effect of hastening death.

In the very rare cases when physical pain cannot be managed adequately, palliative care specialists can use a form of light sedation to keep the dying patient comfortable, whether to allow a brief "time out" at peaks of pain, or to manage terminal symptoms.

This is called palliative sedation, or terminal sedation because in the rare instances it is required it typically occurs in the last weeks or days of a patient's life.

We note that the euthanasia lobby tries to confuse the issue and demonise this perfectly legitimate technique by suggesting that there are no safeguards around it.

This is utter nonsense, and again is a tactic to confuse the public and muddy the waters.

There does not have to be any safeguards around a practice which only seeks to relieve a patient's pain, unlike euthanasia for which all the safeguards in the world are useless in preventing wrongful deaths.

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4. True Dignity

Euthanasia presumes that a life can lose its worth, but all human life has worth and dignity and is to be cherished.

This does not mean that the dying process should be prolonged, but that we should care for each member of the human family with love, and commit to ensuring they receive the best palliative care possible.

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[7] Recommendations 1, 5 and 16

There is nothing dignified about killing another human being, even out of misguided compassion.

There is dignity in relieving pain and keeping patients comfortable in order to allow a natural and peaceful death at their appointed time.

The phrase "dying with dignity" has been hijacked by the euthanasia lobby to put across the idea that each of us should be entitled to decide how and when we die, as if an unexpected death that comes from accident or illness rather than own choice, is automatically lacking in dignity.

According to Dr Margaret Somerville, Professor of Bioethics at Notre Dame University in Sydney, euthanasia advocates "see dignity as an extrinsic characteristic that can be lost with an individual's loss of autonomy, independence and control".[8]

The euthanasia lobby argues that providing assistance to suicide is a means of restoring control and thereby safeguarding the dignity of the individual.

However, this view cannot be correct, as the dictionary definition of dignity – "the quality of being worthy or honorable" - surely must be able to be applied to those who are living with disability and infirmity, not just those who are healthy and able-bodied.

As Peter Kurti, a senior research fellow at the Centre for Independent Studies and Adjunct Associate Professor in the School of Law at Notre Dame University in Sydney, has observed: "Dignity in the face of death is a possibility for everyone as they die; it is something that depends on the character and bearing of the individual who is dying."[9]

It is important to affirm that the human conditions of vulnerability, weakness and infirmity do not rob any person of the dignity he or she possesses.

4. True compassion

One of the most common arguments for euthanasia is that it is the compassionate thing to do. After all, we put animals down to get them out of their misery, so why not do the same thing we human beings.

The most obvious point to make is that we are not animals, so we should not be treated as animals.

As Norman Geisler and Frank Turek write: "Since we believe human life has a higher value than that of animals, we do not treat humans like laboratory rats. Moreover, people don't lose their value when they lose their health. People are valuable because of their humanity, not because they lack an infirmity."

The editor of *CultureWatch*, Bill Muehlenberg, observes: "It is a very strange kind of compassion which says that the way to relieve suffering is to kill the sufferer. We should be concentrating on removing the suffering, not the sufferer. This is why the many advances in palliative care and the treatment of pain are so important: it really is quite unnecessary to argue for the legalised killing of patients, even it is done in the name of compassion."[10]

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[8] Margaret Somerville, *Death Talk: The Case Against Euthanasia and Physician-Assisted Suicide*, 2nd edition, (Montreal: McGill-Queens University Press, 2014), xxviii.

[9] Peter Kurti, *Euthanasia: Putting the Culture to Death?* Connor Court Publishing, 2018

[10] Bill Muehlenberg, *The Challenge of Euthanasia*, CultureWatch Books , 2016

As John Ling writes: “The truly compassionate person seeks to heal and restore, and bring hope and justice to the situation. The falsely compassionate euthanasiast just wants to end it all, and move on. True compassion and euthanasia do not mix. [11]

Let’s be honest about this. When people say “I can’t stand to see Aunt Mary suffer”, they are really saying that they cannot stand their own suffering. They want the patient to be euthanised so that their own suffering can come to an end.

In other words, the concern is not so much to put the patient out of his or her misery as it is to put us out of our misery. We do not like what we see or feel; so we want the patient to no longer be around so that our own bad feelings can quickly disappear.

A much better option would be for grieving family members to be helped by palliative care teams to achieve peace and understanding, insofar as that is possible.

5. Personal autonomy not an argument for doctor-assisted suicide or euthanasia

Peter Kurti, in his book Euthanasia: Putting the Culture to Death, asks: “If an individual really does seek to act with autonomy… why is such an effort directed to harnessing the power of the state to enable [its] exercise?

“Advocates for legalisation of assisted suicide are actually creating a dependence on the state for doing the very thing that an individual is already free to do – that is, to commit suicide.

“Perhaps what advocates really seek is not a commitment by the state to the principle of autonomy, but approval in advance of individual acts of suicide…

“A further important point, frequently overlooked, is that an appeal to autonomy in support of legalising assisted suicide is inconsistent with the restrictions placed on its availability…

“If individual autonomy really is a ground for obtaining assistance in dying, all requests from competent individuals ought to be honoured regardless of life expectation.”[12]

American bioethicist Daniel Callaghan wrote: “The idea that we can waive our right to life, and then give to another power to take that life, requires a justification yet to be provided by anyone. Consenting adult killing, like consenting adult slavery or degradation, is a strange route to human dignity.”[13]

Assisted suicide is “a mutual, social decision between two people, the one to be killed and the other to do the killing… [and] a complicit society to make it acceptable”[14] with at least one individual “who remains behind to struggle with issues of responsibility, morality, grief and remorse”.[15]

Kurti further comments: “Liberal societies have long sought to limit the circumstances in which one person can take the life of another and have based the limits on a fundamental respect for human life.” Examples include laws regarding self-defence and the ban on capital punishment.

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[11] John R. Ling, *The Edge of Life: Dying, Death and Euthanasia* (London: Day One Publications, 2002), p.124.

[12] Kurti, *Euthanasia: Putting the Culture to Death*? op.cit. p.26, 28.

[13] Daniel Callaghan, When Self-Determination Runs Amok, Hastings Center Report, (March-April 1992).

[14] Ibid.

[15] Robert D. Orr, David L. Schiedermayer and David B. Biebel, *More Life and Death Decisions* (Grand Rapids, Michigan: Baker Books, 1990), p.66.

"Yet at the same time these legal restraints are broadly welcomed and accepted, advocates of assisted suicide are seeking to waive the principle of the inviolability of human life and to sanction a new category of killing in which the medical profession is specifically and actively involved."[16]

It is true to say that "no man is an island". Every death by intentional self-harm has a profound impact on others. Such a death often causes great emotional trauma among friends and relatives.

The abolition of the criminal offense of attempting to commit suicide did not confer a legal right to do so, nor did it signify the state's approval of suicide.

If doctor-assisted suicide were to be legalised, it would send the dangerous message that "some lives are not worth living", which would totally undermine the efficacy of suicide prevention programs when we already have one of the highest suicide rates in the world. Suicide is the leading cause of death for Australians aged between 15 and 44. It is estimated there are 63,500 suicide attempts each year in Australia.

As bioethicist Mark Blocher puts it, "Expanding personal freedom to include assisted suicide undermines another right – to remain alive without having to justify one's existence."[17]

Moreover, many requests for doctor-assisted suicide "are not truly autonomous but [often] result from depression and inadequate palliative care."[18]

Also, an argument for the right to suicide is a very strange argument indeed. A person seeks to use his autonomy to end his autonomy. As Leon Kass points out, "In the name of choice, people claim the right to choose to cease being choosing beings."[19]

Or as Arthur Dyck asks, "How can suicide be considered a right, when the freedom to undertake it puts an end to all possibilities to act, to freedom and life, and hence is an act that abolishes these basic rights?"[20] So much for choice and autonomy.

And J.P. Moreland says, "suicide is also a self-refuting act, for it is an act of freedom that destroys future acts of freedom: it is an affirmation of being that negates being."[21]

Everyone agrees that if terminally ill patients were given futile and burdensome life-saving intervention, this would not be in their best interests as it would prolong the dying process.

In any case, this should never happen, as competent adults have the legal right to refuse medical treatment, put their wishes in binding Advance Health Directives and/or give Enduring Powers of Attorney to their family or trusted friends to decide on their behalf if they are unable to do so.

6. There are NO effective safeguards in assisted suicide and euthanasia laws

In any assisted suicide or euthanasia regime, there can be no effective safeguards to prevent wrongful deaths.

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[16] Kurti, *Euthanasia: Putting the Culture to Death*? op.cit. p.34

[17] Mark Blocher, *The Right to Die? Caring Alternatives to Euthanasia* (Chicago: Moody Press, 1999), p. 173

[18] John Keown, *Euthanasia, Ethics and Public Policy: An Argument Against Legalisation* (Cambridge: Cambridge University Press, 2002), p. 57.

[19] Leon Kass, "Death with dignity and the sanctity of life" in Michael M. Uhlmann, ed., *Last Rights? Assisted Suicide and Euthanasia Debated* (Grand Rapids, Michigan: William B. Eerdmans, 1998), pp. 199- 222, p. 201.

[20] Arthur Dyck, *Life's Worth: The Case Against Assisted Suicide* (Grand Rapids, Michigan: William B. Eerdmans, 2002), p. 54.

[21] J. P. Moreland, "The morality of suicide", in Timothy J. Demy and Gary P. Stewart, eds. *Suicide: A Christian Response: Crucial Considerations for Choosing Life* (Grand Rapids, Michigan: Kregel, 1998) pp 182 -197, p. 192.

Australian bioethicist Michael Cook says that in Belgium safeguards are meant to be hurdled. A report published in 2012 by the Brussels-based European Institute of Bioethics claimed that euthanasia is being “trivialised” and that the law is being monitored by a toothless watchdog. After 10 years of legalised euthanasia and about 5,500 cases, not one had ever been referred to the police.

Dr Wim Distelmans, a euthanasia practitioner himself and the chairman of Belgium’s Federal Control and Evaluation Commission, which checks euthanasia paperwork to check that doctors observe regulations, said: “If you ask for euthanasia because you are alone, and you are alone because you don’t have family to take care of you, we cannot create family.”

In other words, comments Michael Cook, people who live in a crumbing social network are on their own. “Belgian doctors will do their best to kill them, but not to find a solution to their loneliness.”[22]

A careful examination of the evidence from those jurisdictions that have laws permitting either assisted suicide or euthanasia shows that at least eleven categories of people would be at risk of wrongful deaths.

Some proponents of legalising assisted suicide or euthanasia admit that it is the case that wrongful deaths will occur.

Dr Henry Marsh, a noted British neurosurgeon and champion of assisted suicide, famously said: “Even if a few grannies are bullied into committing suicide, isn’t that a price worth paying so that all these other people can die with dignity?”

This is the question that anyone considering this issue needs to ask.

The proper tests for a law permitting assisted suicide or euthanasia are the ones that are usually applied to any proposal to reintroduce capital punishment:

“Can we craft a law that will ensure there will not be even one wrongful death?”

“Can we ensure that any deaths under this law are humane – that it is both rapid and peaceful?”

Attached as an **Appendix** to this submission is a 44 page report detailing **Eleven Categories of Wrongful Deaths by Assisted Suicide or Euthanasia** produced by the Australian Care Alliance.

Certainly, the Victorian assisted suicide law which comes into operation in June, touted as having the strongest safeguards in the world, is seriously deficient in at least two aspects:

1. The law does not require a patient requesting doctor-assisted suicide to have a prior consultation with a palliative care specialist to determine whether his or her symptoms could be improved; and
2. The law does not require a patient requesting doctor-assisted suicide to have a prior consultation with a psychiatrist to determine whether he or she is competent and whether his or her depression should be treated.

7. Consequences – the slippery slope

If the principle of individual autonomy is given precedence above all else and accepted as the justification for assisted suicide, it is difficult to see how, in time, the preferences of the individual could be contained by regulation, no matter how rigorous.[23]

This is also true in respect to the ideology of doctors, as can be seen in the Netherlands and Belgium.

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[22] Michael Cook, *The Great Human Dignity Heist*, op.cit. pp. 27 & 30.

[23] Kurti, *Euthanasia: Putting the Culture to Death*? op.cit. p.52

Dr Theo Boer, senior lecturer in ethics at the University of Utrecht in the Netherlands and a member of one of the five Dutch regional review committees on euthanasia from 2005 to 2014, was a former euthanasia supporter, but in 2014 he warned UK politicians not to open the door to assisted suicide:

"I used to be a supporter of the Dutch law. But now, with 12 years' experience, I take a very different view. At the very least, wait for an honest and intellectually satisfying analysis of the reasons behind the explosive increase in the numbers. Is it because the law should have had better safeguards?

"Or is because the mere existence of such a law is an invitation to see assisted suicide and euthanasia as a normality instead of a last resort? Before those questions are answered, don't go there. Once the genie is out of the bottle, it is not likely to ever go back in again."[24]

In 2004, Groningen Academic Hospital has asked the Dutch government to approve protocols for involuntary euthanasia for killing deformed and terminally ill children – after admitting that it had already done this four times in the past year.

The Dutch Medical Society, the KNMG, in the same year released a lengthy report in support of voluntary euthanasia for existential rather than for medical reasons. The chairman of the committee, Dr Jos Dijkhuis, argued that "suffering is too often linked to illness" and that a person who simply cannot bear to live any longer and whose outlooks on the future is hopeless is "suffering from life".

None of this was really a surprise. Dutch doctors have been killing their patients upon request for years with the connivance of the government, even before the practice was legalised in 2002. Immediately thereafter came reports that many doctors were killing patients outside of the agreed guidelines because there was too much red tape. Broadening the ambit of euthanasia to include children under 12 who cannot give informed consent and people whom no medicine can cure because they are not sick is a natural development. Dementia is already deemed a valid reason for euthanasia.[25]

Demand for euthanasia is rising sharply in the Netherlands, with figures showing an 8 per cent increase in euthanasia and assisted suicide in 2017. This has prompted a stark warning from Dr Boer:

"Supply has created demand. We're getting used to euthanasia. We're no longer speaking about the exceptional situations that the law as created for, but a gradual process towards organised death. A border is being crossed between individual empathy and societal acceptance. A culture of euthanasia undermines our capacity to deal with suffering, and that is very bad for society."[26]

Research in Belgium in 2010 reported in the *Canadian Medical Association Journal* found that almost half of Belgian nurses have admitted to killing patients without their consent. The authors stated: "The nurses in our study operated beyond the legal margins of their profession."

In 2011, an article in a Canadian research journal *Current Oncology* noted: "In Belgium, the rate of involuntary and non-voluntary euthanasia deaths (that is, without explicit consent) is 3 times higher than it is in the Netherlands. ("Involuntary euthanasia" refers to a situation in which a person possesses the capacity but has not provided consent, and "non-voluntary euthanasia", to situation in which a person is unable to provide consent for reasons such as severe dementia or coma). "A recent study found that in the Flemish part of Belgium, 66 of 208 cases of "euthanasia" (32%) occurred in the absence of request or consent."[27]

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[24] Muehlenberg, *The Challenge of Euthanasia*, op. cit. p. 25

[25] Michael Cook, *The Great Human Dignity Heist*, op.cit. pp. 15 & 16.

[26] Theo A. Boer, "Recurring themes in the debate about euthanasia and assisted suicide", *Journal of Religious Ethics*, (2007), 35.5:529-555.

[27] Jose Pereira, "Legalising euthanasia or assisted suicide: the illusion of safeguards and controls, *Current Oncology* (Toronto), Vol. 18, no. 2, 2011, pp. 38-43, p.39

In 2015, a study published in the *Journal of Medical Ethics* found that about one in every 60 deaths of patients under the care of a general practitioner in Belgium involved someone who had not asked for euthanasia. A report in the *Daily Mail* put it this way:

"Thousands of elderly people have been killed by their own GPs without ever asking to die under Belgium's euthanasia laws, an academic report said yesterday. It said that around one in every 60 deaths of patients under GP care involves someone who has not requested euthanasia. Half of the patients killed without giving their consent were over the age of 80, the study found, and two-thirds of them were in hospital and were not suffering from a terminal disease such as cancer.

"In about four out of five of the cases, the death was not discussed with patients subjected to 'involuntary euthanasia' because they were either in a coma, they were diagnosed with dementia, or because doctors decided it would not be in their best interests to discuss the matter with them.

"Very often doctors would not inform the families of plans to lethally inject a relation because they considered it a medical decision to be made by themselves alone."[28]

In 2010, also in Belgium, a 37-year-old woman, who was depressed because of a break-up with her boyfriend, was also allowed to be put down. Once again, no terminal conditions, no uncontrollable physical anguish - just a woman grieving over a broken relationship, something that happens millions of times. Even the family who was with her have questioned how easy all this was.

On Christmas Eve 2009, Tine, who was 37 at the time, announced her intention to pursue euthanasia, following a split from her boyfriend. She was killed by lethal injection on 24 April 2010, with her parents and her sisters Lotte and Sophie by her side. In an interview with Terzake, a Flemish current affairs television program, Lotte and Sophie expressed their dismay at the attitude doctors took toward Tine's request. The law requires that two doctors and a psychologist evaluate a person's request for euthanasia. In Belgium, euthanasia on the grounds of "unbearable suffering" is permitted.

In this case, the doctors decided that Tine's break-up was a reasonable justification for her wanting to end her life. The two sisters felt that very little effort was made to persuade Tine to live. Not only did the three doctors fail to communicate with each other, but they failed to offer treatment for Tine's diagnosed autism. One doctor described Tine's death as "a lethal injection administered to a favorite pet to end its suffering." A Flemish psychiatrist. Joris Vandenberghe, commented: "This is really very worrying. The bar for euthanasia should be higher."[29]

Here is incontrovertible evidence of the slippery slope which euthanasia advocates deny exists. Belgium legalized euthanasia for adults in 2002, and then early in 2014 it passed a law to allow euthanasia for children. From an ABC News report:

"Belgium has become the first country to allow euthanasia for terminally ill children of any age, after its lower house of parliament passed new 'right-to-die' legislation. The law passed with a large majority of 86-44, with 12 abstaining. Under the extension to the existing euthanasia law, all age restrictions will now be removed on the right to die. It goes beyond Dutch legislation that set a minimum age of 12 for children judged mature enough to decide to end their lives.

"Opinion polls suggest around 75 per cent of the Belgium population support the move. Adult euthanasia became legal in the country in 2002."[30]

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[28] Steve Doughty, "Belgium GPs killing patients who have not asked to die'; Report says thousands have been killed despite not asking the doctor", *Daily Mail* (UK), June 12, 2015. www.dailymail.co.uk/news/article-3120835/Belgian-GPs-killing-patients-not-asked-die-Report-says-thousands-killed-despite-not-asking-doctor.html

[29] Anon., "Belgian woman euthanised after heartbreak", Christian Concern (UK), February 11, 2016. www.christianconcern.com/our-concerns/end-of-life/belgian-woman-euthanised-after-heartbreak

[30] Barbara Miller, "Euthanasia law: Belgium passes legislation giving terminally ill children the right to die", ABC News Feb 14, 2014. www,abc.net.au/news/2014-02-14/Belgium-child-euthanasia-law/5259314

So children too young to be married, to drive, to vote, to buy alcohol or cigarettes, to get a tattoo, can request to be killed.

Between January 2016 and December 2017, lethal injections were given to three children in Belgium. The children were aged 17, 11, and 9 – the latter two being the first cases of euthanasia administered to a child under the age of 12.

Belgian doctors have now taken the step from providing assistance with suicide for the terminally ill, to killing deliberately a person whose life is simply deemed not worth living – and they are the first (as far as we know) to have killed children.

Esteem for the value of human life, together with a humane commitment to the duty of showing compassion to the weak and alleviating the suffering of the vulnerable, are foundational moral components of our society. Changing the law to permit the killing of another person, for whatever reason, is an act of enormous moral significance. Once introduced, such a change will erode other moral principles as the justification for killing in one set of circumstances becomes, in time, the justification for killing in another.[31]

8. Consequences – the doctor-patient relationship

The first duty of the medical profession is to do no harm.

This is why **the Australian Medical Association, along with the World Medical Association, is opposed to the legalisation of euthanasia and instead supports palliative care, which is the true form of assisted dying**. This focuses on relieving pain and keeping patients comfortable in order to allow a natural and dignified death at their appointed time.

Good medical practice is all about facilitating natural death with dignity and peace. Doctors should kill the pain, not the patient. There is no dignity in killing.

The motive of compassion can never justify extending the role of doctors beyond caring, curing, and healing to include the act of killing.

Such an intentional act must be distinguished from prescription of a course of treatment intended to be of benefit to the patient – such as for the relief of great pain – but which may turn out to be lethal. It must also be distinguished from the decision to stop medical intervention and to allow nature to take its course, especially if this is a course of action requested by the patient.

In making a medical decision to alleviate pain or withdraw treatment, the doctor does not intend to kill the patient, even though death may follow because of that decision. This is very different from a decision to end the life of the patient and to make the patient dead.

The decision to kill a patient surely contradicts the fundamental tenets of medicine, for "to bring nothingness is incompatible with serving wholeness", as Leon Kass has noted. "One cannot heal – or comfort – by making nil. The healer cannot annihilate if he is truly to heal."

If the law permits doctors to express mercy by acts of mercy killing, the relationship of trust between doctor and patient is bound to be harmed. Once doctors are licensed to kill, there is a real danger that a patient's trust in the authenticity of a doctor's professional commitment to her well-being will be undermined.

Damage to the relationship between doctor and patient also would damage the standing of the profession of medicine; this, in turn, will inflict damage on the wider society.

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[31] Kurti, *Euthanasia: Putting the Culture to Death*? op.cit. pp. 54, 55.

Great harm will be caused to the capacity of medicine for maintaining this consensus if the practice of doctor-assisted suicide – that is, to be clear, the practice of permitting physicians intentionally to kill patients – was to be made legal.

As Professor Margaret Somerville has remarked: “It is a very important part of the art of medicine to sense and respect the mystery of life and death, to hold this mystery in trust, and to hand it on to future generations – especially future generations of physicians. We need to consider deeply whether legalising euthanasia would threaten this art, this trust, and this legacy.”

The danger is that instead of viewing death as the inevitable end to life, medicine now views death as a form of failure of treatment. But human finitude is neither a moral nor medical failure; it is the boundary beyond which we cannot see, but beyond which we must pass.[32]

As English medical ethicist John Wyatt expresses it, “There would also be the psychological effect on doctors who have broken deep human intuitions and cultural taboos against the intentional taking of human life. Would doctors and other staff be brutalised by the experience? Would the doctor who has just committed euthanasia fight as hard as she might have done to save the life of her next patient? What are the psychological consequences for carers, when the overriding duty of care is transformed into a duty to kill?”

The final word goes to Professor Margaret Somerville again: “Doctors’ absolute repugnance to killing people is necessary to maintaining people’s and society’s trust in them. It would be very difficult to communicate to doctors a repugnance to killing in a context of legalized euthanasia. Harm to medicine also harms society. We need to protect the institution of medicine not just for its own sake, but also because it is a very important value-creating, value-carrying and values-consensus-forming institution, especially in a secular society.”[33]

9. Consequences - Right to die, duty to kill

Canadian writer Monique David put it this way: “Currently, there is much confusion; many accept euthanasia because they do not want their lives to be maintained artificially nor to become victims of excessive treatment. However, these practices can be legitimately refused by the patient or their family through the ethical perspective of the right to die within the limits of natural death.

“Euthanasia and assisted suicide advocates claim something else: the right to terminate life at the moment and in the way that the individual chooses – or that someone chooses for them. Therefore **we should not use these terms to refer to the right to die (because this right is intrinsic), but rather to the right to be killed. This desire, expressed as a personal right, demands the intervention of a third party and a legal system that authorises it. In other words, euthanasia and assisted suicide imply that doctors become agents of death** and that society legally recognizes a criminal act to be lawful; or even more pernicious a medical act.”[34]

As there are no rights without corresponding duties, an officially-sanctioned right must be backed up by the legally-enforced means to ensure those rights can be carried out. Thus if society goes down the path of legalised euthanasia, this right to die will lead to its necessary corollary, the duty to kill.

In fact, once legalised, it is possible that doctors may one day face lawsuits if they violate someone’s rights by not killing them. As commentator John Leo puts it, “Imagine doctors purchasing malpractice insurance that covers ‘denial of death’ suits. That day may not be far away.”[35]

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[32] Kurti, *Euthanasia: Putting the Culture to Death*? op.cit. pp. 58 - 60.

[33] Muehlenberg, *The Challenge of Euthanasia*, op. cit. pp. 6, 7.

[34] Monique David, “Solidarity in suffering”, MercatorNet (Sydney), September 16, 2010. www.mercatornet.com/articles/view/solidarity_in_suffering/

[35] Cited in Keith A. Fournier and William D. Watkins, In Defense of Life: Taking a Stand Against the Culture of Death (Colorado Springs, Colorado: NavPress, 1996), p.54.

As ethicist Germain Grisez writes, “The legalisation of euthanasia would not merely permit the practice for those who felt morally free or morally bound to engage in it. Euthanasia, if legal, would become an ordinary medical operation. Physicians would be expected to perform it, nurses to participate in it, hospitals to permit it, and private health plans and Medicare to pay for it.” [36]

For all the talk about choice, freedom to choose and giving people options, the legal and social legitimisation for assisted suicide would effectively eliminate one position, namely, staying alive without having to justify one’s existence. With legalised euthanasia, the burden will be upon people to justify being alive – we will have to prove that we ought to be allowed to live!

Others have said the same. In 1984, the then Colorado Governor Richard Lamm said, “Elderly people who are terminally ill have a duty to die and get out of the way.” Or remember the comments made here in Australia by the then Governor-General Bill Hayden who, thinking of his own advancement in years, spoke of “unproductive burdens” of which we need to be “disencumbered” via euthanasia.”

Would Hayden set up a test whereby we determine who is an unproductive burden? Will people be forced to give written evidence as to why they should be allowed to remain alive? After all, in a world of scarcity, such proposals are not all that far off.

If assisted suicide were ever permitted to become a legitimate and legal part of medical practice, in the end it would be less about “choice” than about profits in the health care system and cutting the costs of health care to government and families. The drugs for assisted suicide only cost about $35 to $40, while it might cost $35,000 to $40,000 (or more) to treat the patient properly. The math is compelling, and contains a warning we dare not ignore.

Euthanasia and assisted suicide doesn’t give you ownership of your life. It takes life away, sometimes even without your consent. The answer is not to come up with better safeguards, as the right-to-die advocates suggest. It is logically impossible to come up with solid safeguards when they are subjectively determined in the first place. It will only take time for someone else to challenge them as a violation of their “right to die”.[37]

10. The most vulnerable will be at risk

Legalised euthanasia would put pressure on people for a number of other reasons. For example, family members who may gain from a person’s Will may wish to speed along the death of someone in the family. And the most vulnerable will be on the defensive. The entire class of the elderly, terminally ill and disabled people “would be forced to justify their own continued existence”, and this is at the most vulnerable time in their lives.

Because more important than any individual’s “right to die” is the right of all of us to be free from any pressure to die – and by that we mean the slightest, tiniest, most minuscule suggestion that the world or their loved ones might get along easier without them. If you legalise euthanasia, if you institutionalise the concept that people should be weighing up the pros and cons of their own existence, that pressure is inevitably going to follow.

People battling serious diseases or just the onset of time may start to feel selfish for doing so, when in fact the will to live is the most fundamental and decent desire within all of us. It drives our quest for peace, for democracy and for true progress.

It is very easy to slip into moral deception in a discussion of euthanasia … Euthanasia opens up the opportunities at this early stage of the game for almost inconceivable fraud, deception, and deceit.

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[36] Germain Grisez, Suicide and euthanasia, in Dennis J. Horan and David Mall, eds *Death, Dying and Euthanasia* (Frederick, Maryland: University Publications of America, 1977), pp 742 – 817, p. 799.

[37] Muehlenberg, *The Challenge of Euthanasia*, op. cit. pp. 6, 7.

Think of burdensome elderly people, whose rapid demise could be looked upon as a financial blessing for their family. Think of the temptation to hasten a legacy. Think of how easy, when there are ulterior motives, to emphasise the ending from suffering and anxiety that comes with painless death.

No group is more justifiably concerned about legalisation (of euthanasia) than people with disabilities. When people with disabilities become depressed and suicidal, their condition is mistakenly viewed as the inevitable and untreatable result of their disability.

Diane Coleman says that the “widespread public image of severe disability as a fate worse than death is not exactly a surprise to the disability community”. She goes on to say: “Disability rights advocates have fought against these negative stereotypes of disability for decades in the effort to achieve basic civil rights protections.”

If we declare that everyone has a right to die, then how can we say only certain people can be euthanised? In an age fixated on rights, and on equal rights for all, anyone can demand, and receive, the same treatment. The Royal Dutch Medical Association has said that teenagers and children should have the right to choose to be killed, even without parental consent. As one commentator has put it, “Once the fundamental human ‘right’ to euthanasia is created, that right must be and is being extended to all who claim fundamental humanity.”

People who are depressed and suicidal need help and counselling, and should not be told that there is an easy way out. Many of these individuals suffer such issues only temporarily, and can often move beyond them. This is all the more reason to keep euthanasia illegal.

Australian doctor Karen Hitchcock explains:

“Any attempt to make death easy will inevitably expose those in the community who are vulnerable to untimely deaths, to feeling worthless and burdensome. No panel of doctors or booklet of rules, no ream of checks and balances, can prevent this invisible coercion based on new social norms. It is clinicians on the front line who see this invisible coercion in action: patients apologising for taking up beds, for being a burden, for finding themselves disgusting and so wishing they could die.

I can understand why killing might be framed as a humane response to your diminished function, physical suffering and mental anguish. But our responsibility is to help make your life bearable. I hope for a society with the values and the resources to allow us to say, “Don’t be scared. We will attend to you, ease your pain, witness your anguish. No, we will not kill you.”

The UK House of Lords Select Committee on Medical Ethics in 1994, was chaired by Lord Walton, who was the patron of the Voluntary Euthanasia Society, yet after visiting the Netherlands and seeing first-hand the abuses there, it unanimously arrived at this position:

“Ultimately we concluded that none of the arguments we heard were sufficient to weaken society’s prohibition of intentional killing, which is the cornerstone of law and social relationships. Individual cases cannot establish the foundation of a policy which would have such serious and widespread repercussions.”

The Select Committee's main concern was about the injustice euthanasia would cause if it were legalised. The Committee stated:

“It would be next to impossible to ensure that all acts of euthanasia were truly voluntary. We are concerned that vulnerable people - the elderly, lonely, sick or distressed - would feel pressure, whether real or imagined, to request early death. We believe that the message which society sends to vulnerable and disadvantaged people should not, however obliquely, encourage them to seek death, but should assure them of our care and support in life."

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This is the crux of the matter. A kind, caring, compassionate society cannot abandon the vulnerable elderly to the risk of coercion, and pressure, “real or imagined” to do the right thing and request to be killed because they do not want to be a burden on their family.

With the best quality palliative care, euthanasia and doctor-assisted suicide would be totally unnecessary. So let the Government fund an upgraded and expanded palliative care service so Queenslanders get the care they deserve, and ensure that we all continue to value human life. As Leo Alexander stated, the crimes against humanity in World War II “started from small beginnings”.

“The beginnings at first were merely a subtle shift in emphasis in the basic attitude of physicians. It started with the acceptance of the attitude, basic in the euthanasia movement, that there is such a thing as a life not worthy to be lived.”

RECOMMENDATIONS

1. That the Queensland Government take urgent action to boost funding substantially and significantly expand the services of palliative care in Queensland, so that all terminally ill patients can receive the end-of-life care to which they are entitled as a fundamental human right.

2. That the Queensland Government educate the public about palliative care and its ability to ease the dying process in relieving pain and caring not only for patients but also for their families.

3. That the current laws that make doctor-assisted suicide and euthanasia criminal offences in Queensland be retained.

We request an opportunity to present oral evidence to the Committee at a public hearing.

Sincerely,

Alan G Baker

Alan Baker
[redacted]

Committee member,
On behalf of the Queensland Branch of the Australian Family Association

Phone [redacted]

ELEVEN CATEGORIES OF WRONGFUL DEATHS BY ASSISTED SUICIDE OR EUTHANASIA

byRichard Egan

for the Australian Care Alliance

Contents

INTRODUCTION

A careful examination of the evidence from those jurisdictions that have laws permitting either assisted suicide or euthanasia shows that at least eleven categories of people would be at risk of wrongful deaths.

Some proponents of legalising assisted suicide or euthanasia admit that it is the case that wrongful deaths will occur.

Henry Marsh, a noted British neurosurgeon and champion of assisted suicide, famously said,

“Even if a few grannies are bullied into committing suicide, isn’t that a price worth paying so that all these other people can die with dignity?”

This is the question that anyone considering this issue needs to ask.

The proper tests for a law permitting assisted suicide or euthanasia are the ones that are usually applied to any proposal to reintroduce capital punishment:

“Can we craft a law that will ensure there will not be even one wrongful death?”

"Can we ensure that any deaths under this law are humane - that is both rapid and peaceful?"

Both simple logic and the available evidence show that neither of these outcomes are achievable.

This publication is kept up to date and is readily available online for consultation or downloading at:

https://www.australiancarealliance.org.au/flawed_experiments

Australian
CareAlliance
“Care and Compassion: Opposing Assisted Suicide.”

Richard Egan is a researcher who has studied euthanasia and assisted suicide since 1987.

This version updated to26 March 2019

WRONGFUL DEATHS BY ASSISTED SUICIDE OR EUTHANASIA

A WRONG DIAGNOSIS

If a person dies by assisted suicide or euthanasia following **a mistaken diagnosis that the person has a terminal illness** then that is a wrongful death – with no remedy.

[redacted]

It was only after the family of retired Italian magistrate Pietro D'Amico, aged 62, insisted on an autopsy that he was found not to have a terminal illness at all, despite being given such a diagnosis by both Italian and Swiss doctors prior to undergoing assisted suicide in Switzerland.[1]

According to evidence given by Dr Stephen Child, Chair of the New Zealand Medical Association to the New Zealand parliamentary inquiry into the practice of euthanasia:

"*On diagnosis, 10 to 15 per cent of autopsies show that the diagnosis was incorrect. Three per cent of diagnoses of cancer are incorrect*".

Dr Child said this scope for error was too large, when weighed against the outcome. "*This is an irreversible decision in which the consequences are final.*"[2]

Ten per cent of cases in Australia are misdiagnosed according to Peter McClennan, chief executive at Best Doctors.[3]

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[1] https://www.thelocal.ch/20130711/assisted-suicide-in-question-after-botched-diagnosis

[2] http://www.stuff.co.nz/national/politics/84252580/euthanasia-toofinal-when-the-risk-of-error-is-to-great--doctors

[3] https://amp.afr.com/business/insurance/insurance-companies/mlc-life-to-expand-best-doctors-service-20170827-gy4zfk

An August 2018 report on Missouri resident Pasquale Michael Fatino, aged 52, who is suing three doctors at his former primary care clinic for a misdiagnosis of terminal cancer that caused him and his family unnecessary pain and suffering last year, illustrates that such mistakes do happen.[4]

Simply having two doctors diagnose that a person has a terminal illness is an illusory safeguard. There is no remedy for a wrongful death by assisted suicide based on misdiagnosis.

How many wrongful deaths from assisted suicide following misdiagnosis of a terminal illness are too many?

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[4] https://www.kansascity.com/news/business/health-care/article216764080.html

WRONGFUL DEATHS BY ASSISTED SUICIDE OR EUTHANASIA

A WRONG PROGNOSIS

If a person dies by assisted suicide or euthanasia **after being told in error that they have less than six months to live when they may have many years of life ahead of them** then that is a wrongful death – with no remedy.

Medical literature on errors and uncertainty in prognosis

A survey of the medical literature on prognosis indicates that **an accurate prognosis is notoriously difficult to make**.

A study on the accuracy of prognoses in oncology found that "*discrimination between patients who would survive for one year and those who would not was very poor*".[5]

Another paper describes doctors' ability at predicting survival at 1 year as "*only slightly better than a random guess*".[6]

Australia's *National Consensus Statement: essential elements for safe and high-quality end-of-life care* wisely observes: (on page 17)

> *Predicting prognosis and the timing of dying can be difficult. For some patients, it may be difficult to distinguish clinical deterioration that is reversible from deterioration that is irreversible and part of the normal dying process. In such cases, it may be appropriate to consider a trial of treatment for a defined period to assess reversibility of a patient's deterioration.*[7]

One recent study of prognostic accuracy for brain cancer found that:

> *All physicians had individual patient survival predictions that were incorrect by as much as 12-18 months, and 14 of 18 physicians had individual predictions that were in error by more than 18 months. Of the 2700 predictions, 1226 (45%) were off by more than 6 months and 488 (18%) were off by more than 12 months.*" Of particular relevance to the use of a prognosis of expected death to grant access to assisted suicide is the finding that "*In this study all physicians were unable to accurately*

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[5] https://www.sciencedirect.com/science/article/pii/S0895435696003162

[6] http://journals.plos.org/plosone/article?id=10.1371/journal.pone.0161407

[7] https://www.safetyandquality.gov.au/wp-content/uploads/2015/05/National-Consensus-Statement-Essential-Elements-forsafe-high-quality-end-of-life-care.pdf

> *predict longer term survivors. Despite valuable clinical data and predictive scoring techniques, brain and systemic management often led to patient survivals well beyond estimated survivals.*[8]

A study published in 2000 in the British Medical Journal found that physicians only made accurate (within 33% margin either way) prognoses in 20% of cases for terminally ill patients.

Significantly for the use of a prognosis in allowing access to assisted suicide or euthanasia is the finding that in 17% of cases physicians were overly pessimistic in their prognosis by more than 33% and out by a factor of 2 in 11.3% of cases.[9]

In other words, perhaps **more than one in ten people given a prognosis of 12 months to live may live for 2 years or more**.

Evidence from Oregon and Washington

Evidence from the states of Oregon and Washington, where assisted suicide is legal, demonstrates conclusively that physicians make significant errors in determining a prognosis of less than six months to live in the context of a request to access assisted suicide.

Oregon's *Death With Dignity Act* provides that before prescribing a lethal substance a doctor must first determine whether a person has a "terminal disease". This is defined by section 127.800 (12) of the Oregon Revised Statute to mean "*an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment, produce death within six months*".

In 2018 one person ingested lethal medication 807 days (2 years 2 ½ months) after the initial request for the lethal prescription was made. The longest duration between initial request and ingestion recorded is 1009 days (that is 2 years and 9 months).[10] Evidently in these cases the prognosis was wildly inaccurate.

Washington State's *Death With Dignity Act*, based on Oregon's, came into operation on 9 March 2009.

Although this Act specifies that only persons with "*six months or less to live*" may request lethal doses of medication from a physician, the data shows that in each year

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[8] https://www.ncbi.nlm.nih.gov/pubmed/24160479

[9] http://www.bmj.com/content/bmj/320/7233/469.full.pdf

[10] Oregon Public Health Division, *Oregon Death With Dignity Act: 2018 Data Summary, Table 1,* p.13 https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year21.pdf

between 5% and 17% of those who die after requesting a lethal dose do so more than 25 weeks later with one person in 2012 dying nearly 3 years (150 weeks) later, one person in 2015 dying nearly two years later (95 weeks), one person in 2016 dying more than two years (112 weeks) later and one person in 2017 dying 1 year and 7 months later (81 weeks).[11]

Evidently in each of these cases the prognosis was wildly inaccurate.

And of course **we will never know how long many of those who take the lethal dose within the 6 month period might have lived** if they hadn't been given assisted suicide.

[redacted]

The example of Jeanette Hall, who is still alive today after commencing the process of seeking assisted suicide in Oregon in 2000, illustrates the danger of making assisted suicide available to people when first diagnosed with a terminal illness. Thankfully for Jeanette her doctor refused to collaborate in assisting her suicide and helped her find hope – and effective treatment – instead.[12]

There is always a better way than the counsel of despair offered by proponents of assisted suicide.

How many wrongful deaths from assisted suicide following a mistaken prognosis are too many?

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[11] https://www.doh.wa.gov/YouandYourFamily/IllnessandDisease/DeathwithDignityAct/DeathwithDignityData

[12] https://www.dailysignal.com/2015/05/18/assisted-suicide-how-one-woman-chose-to-die-then-survived/

WRONGFUL DEATHS BY ASSISTED SUICIDE OR EUTHANASIA

UNAWARE OF AVAILABLE TREATMENT

Will patients suffer wrongful deaths?

Some assisted suicide or euthanasia laws purport to provide an additional safeguard by requiring at least one doctor with relevant specialist experience to assess the person and inform them of all relevant information about the person's condition.

However, despite such provisions the evidence from jurisdictions which have legalised assisted suicide or euthanasia shows that **some people miss out on treatment that could have helped them and instead suffer a wrongful death** by assisted suicide or euthanasia.

Northern Territory

The *Rights of the Terminally Ill Act 1995* (the ROTI Act) was in operation in the Northern Territory from 1 July 1996 until it was suppressed by the Commonwealth's *Euthanasia Laws Act 1997* on 27 March 1997.

During the nine month period in which the ROTI Act was in effect and under its provisions, four people were assisted to terminate their lives by Dr Philip Nitschke.

Case studies on these four deaths have been published.[13] The principal author of this paper is Professor David Kissane, who is a consultant psychiatrist and professor of palliative medicine. Philip Nitschke is a co-author of the paper.

The case studies examine how the conditions required by the ROTI Act were met. Cases numbered 3, 4, 5 and 6 in this paper refer to those cases which ended with the person's life being terminated with the assistance of Dr Philip Nitschke.

The ROTI Act provided that a "*medical practitioner who receives a request*" may, if certain conditions are met, "*assist the patient to terminate the patient's life*".

The conditions to be met included that a second "*medical practitioner who holds prescribed qualifications, or has prescribed experience, in the treatment of the terminal illness from which the patient is suffering*" has examined the patient and has confirmed

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[13] http://www.healthprofessionalssayno.info/uploads/1/0/9/2/109258189/seven_deaths_in_darwin_case_studies_unde.pdf

"*(A) the first medical practitioner's opinion as to the existence and seriousness of the illness; (B) that the patient is likely to die as a result of the illness; and (C) the first medical practitioner's prognosis*" (Section 7(1)(c)(i) and (iii)).

In case 4, there was no consensus that the person was terminally ill. The person was diagnosed with mycosis fungoides. "*One oncologist gave the patient's prognosis as 9 months, but a dermatologist and a local oncologist judged that she was not terminally ill. Other practitioners declined to give an opinion. In the end an orthopaedic surgeon certified that the ROTI provisions for terminal illness had been complied with.*"

In case 3 the patient may have benefited from radiotherapy or strontium but neither of these was available in the Northern Territory.

In case 5, the patient had an obstruction and was clinically jaundiced. The ROTI Act required Dr Nitschke as a "*medical practitioner who receives a request*" to have "*informed the patient of the nature of the illness and its likely course, and the medical treatment, including palliative care, counselling and psychiatric support and extraordinary measures for keeping the patient alive, that might be available to the patient.*" However, Kissane reports that "*when questioned about options like stenting for obstructive jaundice or the management of bowel obstruction*" Dr Nitschke "*acknowledged limited experience, not having been involved in the care for the dying before becoming involved with the ROTI Act.*"

This raises doubts as to whether the patient in this case – who was reported by Dr Nitschke to exhibit "*indecisiveness*" over a two month period about whether or not to request euthanasia – would still have done so if he had been given better symptomatic relief for the jaundice and obstruction.

Netherlands

The review committees in the Netherlands are required to consider whether all the conditions of the euthanasia law have been met in each case. The law there requires assessment by a relevant specialist before a person is euthanased.

In case 15 of the 2011 annual report the Regional Euthanasia Review Committees conclude that the attending physician failed to achieve an accurate diagnosis of the woman's back pain and only prescribed limited pain relief medication. Consequently it could not be said that the woman's pain was definitively unrelievable. Of course the woman can get no relief from this finding of error on the part of the doctor who failed her and then euthanased her as she is already dead by euthanasia.[14]

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[14] http://www.euthanasiecommissie.nl/Images/RTE.JV2011.ENGELS.DEF_tcm52-33587.PDF

The same lack of remedy applies to the two cases of people with dementia who were euthanased in 2012 in relation to which the Review Committees found "*not to have been handled with due care*".[15]

In Case 2015-01 the Review Committee found a lack of due care before euthanasia was carried out on a woman with a history of stomach pains from an undiagnosed cause, who was reluctant to be examined by a geriatrician. No further action was taken on this case.[16]

Conclusion

No legal framework permitting assisted suicide or euthanasia has yet been established which effectively ensures that all persons being killed or helped to commit suicide are accurately diagnosed and properly informed about all treatment options available for their condition.

People are being killed or helped to commit suicide who could have benefited from treatment

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[15] http://www.euthanasiecommissie.nl/Images/JV.RTE2012.engelsDEF2_tcm52-39100.pdf

[16] https://www.nvve.nl/files/8414/6166/0719/RTE_jaarverslag2015DEF.pdf

WRONGFUL DEATHS BY ASSISTED SUICIDE OR EUTHANASIA

NO ACCESS TO PALLIATIVE CARE

Is assisted suicide needed to deal with physical pain?

There is a telling disconnect between the focus of assisted suicide and euthanasia laws **when they are being proposed** and **after they have been implemented**.

During the proposal phase the focus is almost universally on an alleged group of hard cases, few in number, who, it is said, are suffering unbearable physical pain or other physical symptoms that cannot be relieved by even the best palliative care. This claim is based largely on anecdotal evidence, often from earlier decades before recent improvements in palliative care.

- Proponents of assisted suicide laws falsely claim it is needed to relieve physical pain in a small number of hard cases
- Palliative care experts say that pain can be alleviated, including by the use of palliative sedation in some cases
- Physical pain is not among the main reasons people in Oregon give for seeking assisted suicide; loss of autonomy and being a burden on others are more common concerns
- Ian Haines is a medical oncologist who has changed his mind on euthanasia due to recent developments in palliative care
- The Australian Pain Management Association says legalising assisted suicide "*may lead to government having an opportunity for people to end their life with the help of another person rather than investing in early pain management support and the medical treatment and community support that people need in order to have a 'good death' and die with dignity*"

Assisted suicide for pain management?

After implementation it becomes clearer that the real focus is on autonomy – an alleged right to assistance to die at a time of one's own choosing for any reason.

Proposals to legalise assisted suicide for a select group of people often include a criterion such as "*suffering from a serious and incurable condition which is causing enduring and unbearable suffering that cannot be relieved in a manner the patient deems tolerable*".

Proponents often claim that palliative care cannot relieve all pain.

For example the Victorian parliamentary committee report *End of Life Choices* falsely claimed (p. 206) that palliative care specialists gave evidence that "*not all pain can be alleviated*".[17] Footnote 809 references "*Palliative Care Victoria, Submission, pp. 14–15*". This is most misleading as what that submission actually states is that in the rare cases when all other methods of palliation for pain and other symptoms fail, palliative sedation therapy is available to provide adequate relief of suffering.[18]

Palliative Care Victoria: pain can be alleviated

The Palliative Care Victoria submission relevantly states:

Achieving the effective management of pain and other symptoms is a high priority in the care of people with a life limiting illness and people who are dying. Where these symptoms are not readily alleviated by general health and care services, a referral to access the specialised expertise of palliative care services should be made. In most cases, specialist palliative care teams are able to address the person's physical pain and other symptoms and to respond to their psycho-social, emotional, spiritual and cultural needs so that they are able to live and die well with dignity. However, a small minority of patients experience refractory symptoms such as agitated delirium, difficulties breathing, pain and convulsions.

Refractory symptoms are defined as:

"pain or other symptoms for which all possible treatment has failed, or it is estimated that no methods are available for palliation within the time frame and the risk-benefit ratio that the patient can tolerate."

A patient with refractory (unrelieved) distress "must have received skilled multidimensional management directed at the physical, psychological and existential dimensions of the symptom before a symptom is considered refractory." Prudent application of palliative sedation therapy may be used in the care of selected palliative care patients with otherwise refractory distress.

[T]he level of sedation used should be the lowest necessary to provide adequate relief of suffering: "The doses of medications should be increased or reduced gradually to a level at which suffering is palliated with a minimum suppression of the consciousness levels and undesirable effects, with documentation of the reason for changes and response to such manoeuvres." Only under exceptional circumstances is deep and continuous sedation required from initiation of palliative sedation therapy.

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[17] http://www.parliament.vic.gov.au/images/stories/committees/SCLSI/EOL_Report/LSIC_58-05_Text_WEB.pdf

[18] http://www.parliament.vic.gov.au/images/stories/committees/lsic/Submissions/Submission_236_-_Palliative_Care_Victoria.pdf

Having misleadingly claimed that palliative care experts concede that pain and other physical symptoms cannot be alleviated and that therefore some Victorians are faced with unavoidably painful deaths the End of Life Choices majority report then niftily substituted **a purely subjective notion of suffering** for that of objective pain and other physical symptoms.

Assisted suicide in Oregon: *not* for pain

"*Enduring and unbearable suffering*" is a phrase capable of including the prime reasons given by the 1275 people who have died under Oregon's assisted suicide law:

- A steady loss of autonomy (90.9%)
- Less able to engage in activities making life enjoyable (89.5%)
- Loss of dignity (75.7%)
- Loss of control of bodily functions, such as incontinence and vomiting (45.7%)
- Physical or emotional burden on family, friends, or caregivers (43.7%) .[19]

Only 327 out of 1275 people (25.8%) mentioned inadequate pain control or concern about it. Earlier annual reports noted that "*Patients discussing concern about inadequate pain control with their physicians were not necessarily experiencing pain.*"[20]

In 2017 just over one in five (21%) mentioned concern about inadequate pain control but more than half (55.25%) cited concerns about being a burden on others as a reason for seeking assisted suicide.[21]

Ian Haines: a change of mind on euthanasia

[redacted]

Associate Professor Ian Haines, MBBS is a medical oncologist and palliative medicine specialist. He comments:

As an oncologist with 35 years' full-time experience, I have seen palliative care reach the point where the terminally ill can die with equal or more dignity than euthanasia will provide. It is now very effective and increasingly available for two of the three possible ways of dying, outside of sudden unexpected death, which are advanced cancer and chronic relapsing and

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[19] https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year20.pdf

[20] http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year6.pdf

[21] https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year20.pdf

remitting organ-specific disease such as heart or lung failure.

Palliative care is also available for people with chronic progressive cognitive diseases such as dementia. This is the fourth way of dying and perhaps the most feared of all.

Like Andrew Denton and others who have observed unbearable suffering in loved ones and the terrible failures of modern medicine in the past, I had once believed that euthanasia was the only humane solution.

I no longer believe that.

If the Victorian government legalises assisted dying for people suffering from serious and incurable conditions, it will be the wrong choice. It is not necessary and, as outlined in the minority report to government, it will inevitably increase the pressure, both stated and perceived, for some chronically ill patients to move on and stop being a burden.[22]

Australian Pain Management Association

The Australian Pain Management Association is concerned legalising assisted suicide "*may lead to government having an opportunity for people to end their life with the help of another person rather than investing in early pain management support and the medical treatment and community support that people need in order to have a 'good death' and die with dignity*".

"*Australia has achieved a high level of expertise in pain and palliative medicine including well-coordinated multidisciplinary care. However, this needs to be delivered across the health care system, particularly at home or in residential aged care facilities. Less than optimal analgesia and symptom control are major obstacles to quality end-of-life care.*

"[E]ndorsing such a Bill [may] let health services off the hook from providing the best and widest pain management services."[23]

Conclusion

No case for legalising assisted suicide can properly be made on the basis that this is the only possible response to people facing unrelievable pain.

Every Australian deserves access to gold standard palliative care which can alleviate pain, including using palliative sedation as a last resort.

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[22] http://www.theage.com.au/comment/i-believed-that-euthanasia-was-the-only-humane-solution-i-no-longer-believe-that-20161118-gss921.html

[23] https://www.painmanagement.org.au/

WRONGFUL DEATHS BY ASSISTED SUICIDE OR EUTHANASIA

DENIED FUNDING FOR MEDICAL TREATMENT

People who are denied funding for medical treatment by medical insurers or the public health system but are offered funding for assisted suicide or euthanasia, as has happened in Oregon, California and Canada are at risk of wrongful deaths either by being denied needed treatment or bullied into agreeing to assisted suicide.

Oregon

In Oregon, of those who died from ingesting a lethal dose of medication in 2017, more than one in twenty (5.6%) mentioned the "*financial implications of treatment*" as a consideration.[24] While this percentage is relatively small it is appalling that since 1998 forty seven (47) Oregonians have died from a lethal prescription after expressing concerns about the financial implications of treatment.

In two notorious cases, those of Barbara Wagner[25] and Randy Stroup,[26] the Oregon Health Plan informed a patient by letter that the particular cancer treatment recommended by their physicians was not covered by the Plan but that the cost of a lethal prescription to end their life would be covered.

[redacted]

The news from Barbara Wagner's doctor was bad, but the rejection letter from her insurance company was crushing.

The 64-year-old Oregon woman, whose lung cancer had been in remission, learned the disease had returned and would likely kill her. Her last hope was a $4,000-a-month drug that her doctor prescribed for her, but the insurance company refused to pay*.*

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[24] http://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year20.pdf

[25] https://abcnews.go.com/Health/story?id=5517492

[26] http://www.foxnews.com/story/2008/07/28/oregon-offers-terminal-patients-doctor-assisted-suicide-instead-medical-care.html

What the Oregon Health Plan did agree to cover were drugs for a physician-assisted death. Those drugs would cost about $50.

"It was horrible," Barbara Wagner explains "I got a letter in the mail that basically said if you want to take the pills, we will help you get that from the doctor and we will stand there and watch you die. But we won't give you the medication to live."[27]

[redacted]

Since the spread of his prostate cancer, 53-year-old Randy Stroup of Dexter, Oregon, has been in a fight for his life. Uninsured and unable to pay for expensive chemotherapy, he applied to Oregon's state-run health plan for help.

Lane Individual Practice Association (LIPA), which administers the Oregon Health Plan in Lane County, responded to Stroup's request with a letter saying **the state would not cover Stroup's pricey treatment, but would pay for the cost of physician-assisted suicide***.*

"It dropped my chin to the floor," Stroup said. "[How could they] not pay for medication that would help my life, and yet offer to pay to end my life?"[28]

California

[redacted]

Stephanie Packer, a wife and mother of four who was diagnosed with a terminal form of scleroderma, said her insurance company initially indicated it would pay for her to switch to a different chemotherapy drug at the recommendation of her doctors.

But shortly after California's End of Life Option Act, which authorizes physicians to diagnose a life-ending dose of medication to patients with a prognosis of six months or less to live, went into effect, Ms. Packer's insurance company had a change of heart.

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[27] https://www.youtube.com/watch?v=erzYKNrsx_I

[28] https://www.youtube.com/watch?v=fKOT3oujULI

“And when the law was passed, it was a week later I received a letter in the mail saying they were going to deny coverage for the chemotherapy that we were asking for,” Ms. Packer said.

She said she called her insurance company to find out why her coverage had been denied. On the call, she also asked whether suicide pills were covered under her plan.

“And she says, ‘Yes, we do provide that to our patients, and you would only have to pay $1.20 for the medication,’” Ms. Packer said.

Ms. Packer said her doctors have appealed the insurance company’s decision twice, to no avail. She said **the assisted-suicide law creates an incentive for insurance companies to deny terminally ill patients coverage**.[29]

[redacted]

Dr Brian Callister, associate professor of internal medicine at the University of Nevada, said he tried to transfer two patients to California and Oregon for procedures not performed at his hospital. Representatives from two different insurance companies denied those transfer requests by phone, he said.

The patients were not terminal, but “would have become terminal without the procedures.”

And in both cases, the insurance medical director said to me, "Brian, we’re not going to cover that procedure or the transfer, but would you consider assisted suicide?’ ”

The phone calls took place last year within the span of a month, Dr. Callister said. He said he did nothing to prompt the suggestion in either case.[30]

Canada

[redacted]

Roger Foley, who has a crippling brain disease, has been seeking support to live at home. He is currently in an Ontario hospital that is threatening to start charging him $1,800 a day. The hospital has told Roger that his other option is euthanasia or assisted suicide under Canada’s medical assistance in dying law.[31]

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[29] https://www.youtube.com/watch?v=1NoNthOhMd4

[30] https://youtu.be/JzafMM9QCAg

[31] https://www.australiancarealliance.org.au/canada_assisted_suicide_not_assisted_living

WRONGFUL DEATHS BY ASSISTED SUICIDE OR EUTHANASIA

MENTALLY ILL AT RISK

- People with a mental illness are at risk of wrongful death under any law authorising assisted suicide or euthanasia.
- In the Netherlands and Belgium mental illness is seen as a condition for which euthanasia or assisted suicide is increasingly considered to be an appropriate response.
- In Oregon and Washington State where the laws provide for *optional referral* for psychiatric assessment the evidence shows that the gatekeeping medical practitioners very seldom refer and that this results in persons with *treatable clinical depression* being wrongfully assisted to commit suicide.
- In the Northern Territory, where euthanasia was legal from July 1996-March 1997, and compulsory screening by a psychiatrist was required, there was a failure to adequately identify depression, demoralization or other psychiatric issues which may have been treatable in all four cases of persons killed under that regime.

Belgium

Belgium offers assisted suicide or euthanasia for persons suffering with depression or other mental illnesses.

A total of 201 people with psychiatric disorders were killed by euthanasia in Belgium between 2014 and 2017 including for mood disorders such as depression, bipolar disorder (73 cases); organic mental disorders, including dementia and Alzheimer's (60 cases); personality and behavioural disorders (23 cases); neurotic disorders, and disorders related to stressors including posttraumatic stress disorder (16 cases); schizophrenia and psychotic disorders (11 cases); organic mental disorders, including autism (10 cases) and complex cases involving a combination of several categories (8 cases).

Of these 201 cases there were 25 cases of people under 40 being killed by euthanasia. In relation to these troubled young people the Commission observes:

> *In the group of patients under 40, it is mainly personality and behavioral disorders. All these patients have been treated for many years, both outpatient and residential. There has always been talk of intractable suffering. For this type of disorder, serious psychological trauma at a very young age has been*

> *mentioned several times, such as domestic violence, psychological neglect or sexual abuse.*[32]

Belgium is treating the victims of child abuse by domestic violence, neglect and sexual abuse by killing them.

US psychiatrist Dr Mark Komrad explains how profoundly the law on euthanasia has affected the practice of psychiatry in Belgium:

The criteria for euthanasia— a condition that is "insufferable and untreatable"— has called into existence a new category for the mentally ill who have those characteristics. As in the US, the notion of [a] truly "untreatable" condition in psychiatry really didn't exist in the Benelux countries, until their legislatures conjured that category into legal existence, thinking of the terminal somatic conditions with which physician administered euthanasia originally began. Once this category opened to "psychological suffering" it became a beckoning space which influenced how psychiatrists and their patients began to see some cases.[33]

Netherlands

Euthanasia is legally permitted in the Netherlands for dementia patients and for persons with depression or other mental health issues in the complete absence of any physical illness or suffering.

In 2017 there were 83 notifications of euthanasia or assisted suicide involving patients with psychiatric disorders. There were 166 notifications involving dementia. All these cases were in the absence of any other condition justifying euthanasia. Three of the dementia cases of euthanasia were performed on the basis of an advanced directive rather than a contemporary request by the person who was euthanased.[34]

Psychiatric conditions for which euthanasia was performed in 2015 included personality disorder with posttraumatic stress disorder and self-mutilation; and obsessive compulsive disorder.[35]

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[32] https://organesdeconcertation.sante.belgique.be/sites/default/files/documents/8_rapport-euthanasie_2016-2017-fr.pdf

[33] http://www.psychiatrictimes.com/couch-crisis/psychiatrist-visits-belgium-epicenter-psychiatric-euthanasia

[34] https://www.euthanasiecommissie.nl/actueel/nieuws/2018/maart/7/vijftien-jaar-euthanasiewet-belangrijkste-cijfers-2017

[35] https://www.nvve.nl/files/8414/6166/0719/RTE_jaarverslag2015DEF.pdf

Oregon

Oregon's *Death With Dignity Act*, which has been operative since 1997, provides for medical practitioners to provide prescriptions for lethal medications to be taken later by the person for whom the lethal dose is prescribed.

Research by Linda Ganzini et al. found that "*Among terminally ill Oregonians who participated in our study and received a prescription for a lethal drug, one in six had clinical depression*".[36]

Depression is supposed to be screened for under the Act. However, of the 1275 people who have died by ingesting lethal dose prescribed under the Act only 62 (4.9%) were first referred for psychiatric evaluation.[37]

This means **as many as 150 people with depression may have been helped to commit suicide** without any such referral.

In 2011 Dr. Charles J. Bentz of the Division of General Medicine and Geriatrics at Oregon Health & Sciences University explained that Oregon's physician-assisted suicide law is not working well. He cited the example of a 76-year-old patient he referred to a cancer specialist for evaluation and therapy. The patient was a keen hiker and as he underwent therapy, he became depressed partly because he was less able to engage in hiking.

He expressed a wish for assisted suicide to the cancer specialist, who rather than making any effort to deal with the patient's depression, proceeded to act on this request by asking Dr Bentz to be the second concurring physician to the patient's request.

When Dr Bentz declined and proposed that instead the patient's depression should be addressed the cancer specialist simply found a more compliant doctor for a second opinion.

Two weeks later the patient was dead from a lethal overdose prescribed under the Act.

Dr Bentz concludes;

"*In most jurisdictions, suicidal ideation is interpreted as a cry for help. In Oregon, the only help my patient got was a lethal prescription intended to kill him.*" He urges other jurisdictions "*Don't make Oregon's mistake*."[38]

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[36] http://www.bmj.com/highwire/filestream/384131/field_highwire_article_pdf/0.pdf

[37] https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year20.pdf

Northern Territory

The *Rights of the Terminally Ill Act 1995* (the ROTI Act) was in operation in the Northern Territory from 1 July 1996 until it was suppressed by the Commonwealth's *Euthanasia Laws Act 1997* on 27 March 1997.

During the nine month period in which the ROTI Act was in effect and under its provisions, four people were assisted to terminate their lives by Dr Philip Nitschke.

Case studies on these four deaths have been published.[39] The principal author of this paper is Professor David Kissane, who is a consultant psychiatrist and professor of palliative medicine. Philip Nitschke is a co-author of the paper.

The case studies examine how the conditions required by the ROTI Act were met. Cases numbered 3, 4, 5 and 6 in this paper refer to those cases which ended with the person's life being terminated with the assistance of Dr Philip Nitschke.

From the case histories, it is apparent that cases 3 and 4 each had depressive symptoms.

In case 3, the patient had received "*counselling and anti-depressant medication for several years*". He spoke of feeling sometimes so suicidal that "*if he had a gun he would have used it*". He had outbursts in which he would "*yell and scream, as intolerant as hell*" and he "*wept frequently*".

Neither the patient's adult sons nor the members of the community palliative care team who were caring for him were told he was being assessed for euthanasia. "*A psychiatrist from another state certified that no treatable clinical depression was present.*"

In case 4, "*the psychiatrist noted that the patient showed reduced reactivity to her surroundings, lowered mood, hopelessness, resignation about her future, and a desire to die. He judged her depression consistent with her medical condition, adding that side-effects of her antidepressant medication, dozepin, may limit further increase in dose.*"

Kissane comments that "*case 4 was receiving treatment for depression, but no consideration was given to the efficacy of dose, change of medication, or psychotherapeutic management.*" While Dr Nitschke "*judged this patient as unlikely to respond to further treatment*", Kissane, comments that "*nonetheless, continued psychiatric care seemed warranted – a psychiatrist can have an active therapeutic role in ameliorating suffering rather than being used only as a gatekeeper to euthanasia*'.

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[38] http://blogs.theprovince.com/2011/12/05/province-letters-icbc-egypt-assisted-suicide-oregon-christmas-pre-marital-sex/

[39] http://www.healthprofessionalssayno.info/uploads/1/0/9/2/109258189/seven_deaths_in_darwin_case_studies_unde.pdf

In case 6 a key factor seemed to be the patient's distress at "*having witnessed*" the death of her sister who also had breast cancer, "*particularly the indignity of double incontinence*". She "*feared she would die in a similar manner*". She "*was also concerned about being a burden to her children, although her daughters were trained nurses*".

Kissane noted that "*fatigue, frailty, depression and other symptoms*" – not pain – were the prominent concerns of those who received euthanasia. He observed that "*palliative care facilities were underdeveloped in the Northern Territory, and patients in our study needed palliative care… There is a need to respond creatively to social isolation, and to treat actively all symptoms with early and skilled palliative care.*"

Further concerns are raised by the report on case 5. Dr Nitschke reported that "*on this occasion the psychiatrist phoned within 20 min, saying that this case was straightforward*". This assessment took place on the day on which euthanasia was planned. This case involved an elderly, unmarried man who had migrated from England and had no relatives in Australia. Dr Nitschke recalled "*his sadness over the man's loneliness and isolation as he administered euthanasia*". Dr Nitschke has since revealed in testimony to a Senate committee, that he personally paid for this psychiatric consultation and that it in fact took less than 20 minutes.[40]

Dr David Kissane, comments on the issue of demoralisation:

Review of these patients' stories highlighted for me the importance of demoralization as a significant mental state influencing the choices these patients made. They described the pointlessness of their lives, a loss of any worthwhile hope and meaning.

Their thoughts followed a typical pattern of thinking that appeared to be based on pessimism, sometimes exaggeration of their circumstances, all-or-nothing thinking in which only extremes could be thought about, negative self-labelling and they perceived themselves to be trapped in this predicament. Often socially isolated, their hopelessness led to a desire to die, sometimes as a harbinger of depression, but not always with development of a clinical depressive disorder. It is likely that the mental state of demoralization influenced their judgement, narrowing their perspective of available options and choices. Furthermore, demoralized patients may not make a truly informed decision in giving medical consent.

Demoralization syndrome … is an important diagnosis to be made and actively treated during advanced cancer. It is recognised by the core phenomenology of hopelessness or meaninglessness about life. The prognostic language within oncology that designates 'there is no cure' is one potential cause of demoralization in these patients, a cause that can be avoided by more sensitive medical communication with the seriously ill. While truth telling is needed, hope must also be sustained so that life may be lived out as fully as possible. Patients with advanced cancer can be guided to focus on 'being' rather than 'doing', savouring the experiential moment of the present, so that purpose and meaning are preserved through inherent regard for the dignity of the person. Active treatment of

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[40] https://www.aph.gov.au/~/media/wopapub/senate/senate/commttee/S10740_pdf.ashx

a demoralized state by hospice services would involve counselling and a range of complementary therapies, use of community volunteers and family supports, all designed to counter isolation and restore meaning.[41]

Conclusion

There is no model from any jurisdiction that has legalised assisted suicide and/or euthanasia for adequately ensuring that no person who is assisted to commit suicide or killed directly by euthanasia is suffering from treatable clinical depression or other forms of mental illness that may affect the capacity to form a competent, settled, determination to die by assisted suicide or euthanasia.

Jurisdictions, like Oregon, that provide for optional referral for psychiatric assessment manifestly fail to identify all cases of clinical depression.

The only jurisdiction which has required a psychiatric assessment for each case of euthanasia was the Northern Territory. However, this system signally failed to adequately identify depression, demoralization or other psychiatric issues which may have been treatable in all four cases of persons killed by former doctor Philip Nitschke under the Rights of the Terminally Ill Act 1995 (NT).

Compulsory referral to a psychiatrist, who may have never seen the person before, for a single brief assessment of whether the person's decision making capacity about assisted suicide or euthanasia is affected by depression or other psychiatric factors is clearly an inadequate safeguard and will not make assisted suicide "safe".

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[41] https://www.aph.gov.au/~/media/wopapub/senate/committee/legcon_ctte/completed_inquiries/2008_10/terminally_ill/submissions/sub589_pdf.ashx

WRONGFUL DEATHS BY ASSISTED SUICIDE OR EUTHANASIA

BETTER OFF DEAD

Are the disabled at risk of wrongful death from an assisted suicide law?

- In the Netherlands and Belgium disability – both physical and intellectual – is accepted as a reason to euthanase a person.
- In Oregon the **five main reasons** given for requesting assisted suicide **all relate to disability** issues.
- People with disabilities are often seen in our society as "*better off dead*".
- Depression is less likely to be diagnosed and treated in a person with disability.
- The boundary between physical disability and terminal illness is fuzzy, not clear.

Netherlands and Belgium

A 2018 paper examines nine case reports on euthanasia in the Netherlands between 2012 and 2016 of people with an intellectual disability or an autism spectrum disorder.[42]

The case reports make for chilling reading, illustrating how once euthanasia becomes normalised in a society it becomes the go-to, accepted, "*final solution*" for "*difficult*" patients.

A man in his 60s with Asperger's, described as "*an utterly lonely man whose life had been a failure*", was euthanased because he was "horrified at moving into sheltered accommodation". Although he had been diagnosed with "*severe and probably chronic depression with a persistent death wish*" another psychiatrist, after seeing him just once, certified that he was free of depression in order to facilitate his euthanasia.

Another man in his 30s, also with Asperger's, was euthanased based on his distress at "*his continuous yearning for meaningful relationships and his repeated frustrations in this area, because of his inability to deal adequately with closeness and social contacts*".

A third case was of an intellectually disabled woman in her 60s who was euthanased for tinnitus despite a finding that:

the patient had indeed gone through many treatments in the past, but also, that often the wrong treatments had been instigated. It had also become clear to the physician that the patient often wanted to abandon the treatments, and that the treating

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[42] https://bmcmedethics.biomedcentral.com/articles/10.1186/s12910-018-0257-6

practitioners had not encouraged her to try and persevere with these treatment(s) a bit longer.

In Case 2016-44 the Netherlands Review Committees approved the action of a doctor who euthanased a man aged between 80 and 90 years of age on the sole ground of having progressive loss of vision due to macular degeneration with his lack of capacity to read being accepted as unbearable and hopeless suffering.[43]

In Belgium, in December 2012 identical twin brothers were euthanased on the grounds of their psychological distress at learning they were both going blind. The brothers were reportedly distressed that they would not be able to see each other.[44]

Commenting on this case, Dr. Marc Maurer, President of the [US] National Federation of the Blind,[45] said:

"*This disturbing news from Belgium is a stark example of the common, and in this case tragic, misunderstanding of disability and its consequences. Adjustment to any disability is difficult, and deaf-blind people face their own particular challenges, but from at least the time of Helen Keller it has been known that these challenges can be met, and the technology and services available today have vastly improved prospects for the deaf-blind and others with disabilities. That these men wanted to die is tragic; that the state sanctioned and aided their suicide is frightening.*"[46]

Disability issues accepted as leading reasons for assisted suicide: "You would be better off dead!"

Assisted suicide proposals usually would require two doctors to agree to a person's request for a prescription for a lethal dose to be used to end the person's life. To do so the doctors essentially need to agree that the person would "be better off dead" or at least that it is reasonable for a person in that position to consider that he or she would be better off dead.

The five main reasons given for requesting assisted suicide in Oregon in 2017 are **not primarily to do with pain (only 21%)** but rather with concerns about decreasing ability to participate in activities that made life enjoyable (88.1%), loss of autonomy (87.4%), loss of dignity (67.1%), physical or emotional burden on family, friends, or caregivers (55.2%)

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[43] https://www.euthanasiecommissie.nl/binaries/euthanasiecommissie/documenten/jaarverslagen/2016/april/12/jaarverslag-2016/RTE_jaarverslag2016.pdf

[44] http://www.telegraph.co.uk/news/worldnews/europe/belgium/9798778/Belgian-identical-twins-in-unique-mercy-killing.html

[45] http://www.facebook.com/NationalFederationoftheBlind

[46] https://nfb.org/national-federation-blind-comments-belgian-euthanasia-deaf-men-losing-sight

and the loss of control of bodily functions, such as incontinence and vomiting (37.1%) .[47] **These are all disability issues.**

Any assisted suicide proposal that includes a subjective notion of suffering as part of the eligibility criteria would allow assisted suicide for a similar set of concerns.

This set of concerns reflects the day to day realities of life for many people living with disabilities of various kinds.

If we legalise assisted suicide for incontinence, a loss of ability to engage in one's favourite hobby, a need to have other's take care of your physical needs, a loss of mobility and so forth what is the take home message for those who live with these challenges every day?

Are we saying they would also be better off dead?

Stella Young

The late Stella Young, comedian, writer and disability activist, wrote on the implications of legalising assisted suicide for people living with disabilities:

[redacted]

As a disabled person, I'm accustomed to conversations about quality of life and dignity. Specifically, I'm accustomed to assuring people that my life is worth living. I'm short statured, a wheelchair user, and I frequently have bone fractures. All the visual cues that make me 'the other' are front and centre.

People make all sorts of assumptions about the quality of my life and my levels of independence. They're almost always wrong.

*I've lost count of the number of times I've been told, "I just don't think I could live like you," or "I wouldn't have the courage in your situation," or, **my favourite one to overhear (and I've overheard it more than once), "You'd just bloody top yourself, wouldn't you?"**. What we as a society think we know about what it means to live as a disabled person comes from cultural representations of disability seen through a nondisabled lens. And we, as people with disability, rarely get to tell our own stories.*

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[47] https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year20.pdf

Also, social attitudes towards disabled people come from a medical profession that takes a deficit view of disability. This is my major concern with legalising assisted death; that it will give doctors more control over our lives. As a disabled person who has had a lot to do with the medical profession, I can tell you that this is the space in which I've experienced some of the very worst disability prejudice and discrimination. Doctors might know about our biology, but it doesn't mean they know about our lives.

Media reports on assisted dying feed these misconceptions. ABC News reported this week on the case of Barbara Harling, a Queensland woman with motor neurone disease who said that she would consider moving to Tasmania if the Voluntary Assisted Dying Bill had passed. Harling is quoted as saying: "Well, let's put it this way. I can use my left hand, my right hand is just about useless. If I can't use my left hand to wipe my bottom, then I can do nothing else for myself. That means someone has to do everything for me. I couldn't bear to live like that."

The thing is, a lot of people do live like that. I know many, many people who depend on personal assistants for all of their daily living tasks, some of them requiring 24 hour care. ***Having to rely on someone else to wipe your bum may not be something anyone aspires to, but I'm quite sure it's never killed anyone.***

Perhaps our discomfort with this kind of thing is why we don't hear the counter view in reports about assisted dying. Often we hear supporters of euthanasia and assisted suicide talk about wanting to avoid the pain and suffering that often comes with imminent death. But more often, we hear stories like Barbara Harling's, which are more about wanting to avoid a loss of autonomy and independence. [48]

Screening for depression and coercion

Proposals for assisted suicide offer require assessing doctors to screen for depression or other mental health conditions that may be affecting the person's decision making capacity. Similarly the assessing doctors are supposed to determine that the request is voluntary and not the result of coercion.

Doctors are less likely to identify depression in people with disability, simply by assuming that it is normal for a person with disability to show signs of depression such as sadness and lack of hope.

Doctors may also easily miss the particular vulnerability of a person living with disability to overt or subtle coercion from family or caregivers who reinforce a feeling that the person is a burden, "*too much trouble*", "*life is too hard*" and so forth.

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[48] http://www.abc.net.au/rampup/articles/2013/10/18/3872088.htm

Terminal condition or disability?

Proposals for assisted suicide may suggest making assisted suicide available to people with a specified length of time to live, such as six or twelve months or use some vaguer term such as where death is reasonably foreseen.

However, such proposals generally indicate that the prognosis should take account of which treatments are "acceptable to the person". On this basis various condition that are not in themselves terminal may be considered as terminal for the purpose of offering assisted suicide if the person decides to forego an effective, available treatment for whatever reason.

This approach poses a severe risk to people following an initial acquisition or diagnosis of a condition that may involve a considerable level of disability.

Marilyn Golden writes :

Research overwhelmingly shows that people with new disabilities frequently go through initial despondency and suicidal feelings, but later adapt well and find great satisfaction in our lives.

However, the adaptation usually takes considerably longer than the mere fifteen-day waiting period [generally] required by assisted suicide proposals. People with new diagnoses of terminal illness appear to go through similar stages. In that early period before one learns the truth about how good one's quality of life can be, it would be all too easy, if assisted suicide is legal, to make the final choice, one that is irrevocable.

Dr. Richard Radtke, a well-known retired academic oceanographer in Hawaii, provides one such example. Dr. Radtke has had a very disabling form of muscular sclerosis for over 25 years. In the period after his diagnosis, doctors often classified him as terminally ill. He experienced severe depression for two years. Had assisted suicide been legal, he acknowledges that he would have chosen it and died long ago. Today, still with an extremely limiting disability, he has retired from a successful academic career, is a happily married father, remains the president of a charitable foundation, and is grateful for the length and varied experiences of his life.

How many such individuals is our society prepared to sacrifice as the collateral damage from the legalization of assisted suicide? [49]

Conclusion

Legalising assisted suicide poses a direct threat to the lives of some people with disabilities who may be assessed as eligible to request it. Doctors are more likely to agree that they are "*better off dead*" and to miss signs of depression or coercion.

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[49] https://dredf.org/public-policy/assisted-suicide/why-assisted-suicide-must-not-be-legalized/

Legalising assisted suicide for being a burden, incontinence and loss of ability to enjoy activities trivialises issues faced daily by persons living with disability and demeans their courage in facing the challenges of life.

WRONGFUL DEATHS BY ASSISTED SUICIDE OR EUTHANASIA

BULLYING OR COERCION

Can we rule out coercion if we legalise assisted suicide?

- Assisted suicide and euthanasia laws usually require that a request be voluntary and free of coercion. To be truly voluntary a request would need to be not just free of overt coercion but also **free from undue influence, subtle pressures and familial or societal expectations**.
- A regime in which assisted suicide is made legal and in which the decision to ask for assisted suicide is positively affirmed as a wise choice in itself creates a framework in which a person with low self-esteem or who is more susceptible to the influence of others may well express a request for assisted suicide that the person would otherwise never have considered.
- Elder abuse, including from adult children with "***inheritance impatience***" is a growing problem in Australia. This makes legalising assisting suicide unsafe for the elderly.
- Evidence from jurisdictions that have legalised assisted suicide or euthanasia shows that coercion, including the feeling of **being a burden on others, is a real problem.**
- Some supporters of assisted suicide **don't care if some people are bullied into killing themselves** under an assisted suicide law.

Oregon and Washington

The data from Oregon shows that in 2018 more one out of two (54.16%) people who died after taking prescribed lethal medication cited concerns about being a "*Burden on family, friends/caregivers*" as a reason for the request.[50]

In a further 14.9% of cases (nearly one in seven cases) the attending physician reported not knowing if the person who requested lethal medication and subsequently died after

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[50] Oregon Public Health Division, *Oregon Death With Dignity Act: 2018 Data Summary, Table 1,* p.12 https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year21.pdf

ingesting had a concern about physical or emotional burden on family, friends or caregivers.[51]

ORS 127.815 sets out as the very first responsibility of an attending physician under the Death With Dignity Act a duty to "*Make the initial determination of whether a patient has a terminal disease, is capable, and has made the request voluntarily*"

How can a physician come to a firm conclusion that a person is voluntarily requesting lethal medication in order to end their lives without exploring whether or not the person is motivated by a concern about the physical or emotional burden on family, friends or caregivers.

Surely such a discussion is necessary to exclude any possibility that the person is making the request under duress, subject to coercion or undue influence from a family member or caregiver.

Additionally, in the absence of such a discussion there may be a missed opportunity to relieve the person's concern about being a burden by arranging respite for family caregivers or additional care or support.

If the 14.9% of cases where the attending physician does not even bother exploring this issue with a person before writing a prescription for lethal medication are added to the 54.2% of cases in 2018 where the attending physician reports knowing that the person had a concern about the physical or emotional burden on family, friends or caregivers then in nearly seven out of ten cases (69.1%) concern about being a burden is or maybe a factor in a request for lethal medication.

The data from Washington[52] shows that in 2017 more than half (56%) of those who died from prescribed lethal drugs cited concerns about being a "*Burden on family, friends/caregivers*" as a reason for the request.

Does the concern about being a burden originate from the person or is it generated by subtle or not so subtle messages from family, friends and caregivers - including physicians - who find the person to be a burden or a nuisance or just taking too long to die?

Elder law expert Margaret Dore comments:

In both Washington and Oregon, the official reporting forms include a check-the-box question with seven possible "concerns" that contributed to the lethal dose request. These concerns include the patient's feeling that he was a "burden."

The prescribing doctor is instructed: "Please check 'yes,' 'no,' or 'don't know' depending on whether or not you believe that a concern contributed to the request."

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[51] https://assets.nationbuilder.com/australiancarealliance/pages/96/attachments/original/1552018763/Oregon_-_Twenty_one_years_of_assisted_suicide.pdf?1552018763

[52] https://www.doh.wa.gov/Portals/1/Documents/Pubs/422-109-DeathWithDignityAct2017.pdf

In other states, a person being described as a "burden" is a warning sign of abuse.

For example, Sarah Scott of Idaho Adult Protection Services describes the following "warning sign":

"Suspect behavior by the caregiver . . . [d]escribes the vulnerable adult as a burden or nuisance."

The recommendation is that when such "warning signs" exist, a report should be made to law enforcement and/or to the local adult protective services provider.

Washington and Oregon, by contrast, instruct its doctors to check a "burden" box. Washington and Oregon promote the idea that its citizens are burdens, which justifies the prescription of lethal drugs to kill them. Washington's and Oregon's Acts do not promote patient "control," but officially sanctioned abuse of vulnerable adults.[53]

Belgium

Claire-Marie Le Huu-Etchecopar is a French nurse who has worked in Belgium since 2008. She has written about her experience with euthanasia in Belgium.

She describes the actions of the friends of a patient:

> *Those close to her are locked in the emotion of seeing their friend disabled. They cannot bear to see her different. Any other solution than euthanasia seems unimaginable to them. In a small notebook where they leave her messages while she's sleeping, the question of euthanasia is on every page. You can read words such as:*
>
> > *Do not forget your euthanasia, it is your right, you have to ask the doctors or they'll never do it for you…* [54]

Elder abuse

Undue influence is increasingly being seen as a relevant factor in the financial abuse of elders.

Seniors Rights Victoria provides a useful summary of case law and best practice on undue influence in the financial abuse of elders.[55]

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[53] http://scholarship.law.marquette.edu/elders/vol11/iss2/8

[54] http://alexschadenberg.blogspot.com.au/2014/05/lifting-veil-on-euthanasia-what-really.html

[55] https://assetsforcare.seniorsrights.org.au/relationship-breaks-down/equity/undue-influence-unconscionable-dealing/

It is clear from this summary that undue influence can easily be missed and may be difficult to identify. Of course, the courts can apply the remedy of recission if it is established. In the case of assisted suicide a failure to spot undue influence before writing a prescription for a lethal dose will be incapable of remedy once the lethal dose is ingested.

A recent parliamentary report on Elder Abuse in New South Wales also referenced the failure of professionals to identify undue influence and so unwittingly facilitate elder abuse.[56]

It cites the Council on the Ageing NSW as observing that the *NSW Interagency policy on preventing and responding to abuse of older people:*

> *does not address the more common cases where elder abuse is perpetrated by a family member or carer 'in an environment of isolation, dependence and undue influence*. (para 5.13 on p. 54)

The report also notes that:

> *Capacity Australia observed that financial abuse is often fueled by ignorance and family conflict, as well as 'inheritance impatience'. It further noted that undue influence by one family member over another is commonly facilitated by legal professionals because of their failure to detect when an older person is struggling to manage their financial affairs, that is, when they lack financial capacity*. (para 6.6 on p. 80)

As long ago as 1885 in what is still cited in Australian law as the leading case on undue influence, Sir James Hannen described some of the kinds of subtle coercion that a frail, elderly or ill person may be subjected to that could be hard for any outside person to detect.

The coercion may of course be of different kinds, it may be in the grossest form, such as actual confinement or violence, or a person in the last days or hours of life may have become so weak and feeble, that a very little pressure will be sufficient to bring about the desired result, and it may even be that ***the mere talking to him at that stage of illness and pressing something upon him may so fatigue the brain, that the sick person may be induced, for quietness' sake, to do anything.*** *This would equally be coercion, though not actual violence.* [57]

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[56] https://www.parliament.nsw.gov.au/committees/DBAssets/InquiryReport/ReportAcrobat/6063/Report%252044%2520-%2520Elder%2520abuse%2520in%2520New%2520South%2520Wales.pdf

[57] https://swarb.co.uk/wingrove-v-wingrove-1885/

If a few grannies are bullied …

Dr Henry Marsh, a British neurosurgeon and proponent of legalising assisted suicide and euthanasia, has acknowledged the possibility of coercion and elder abuse leading to wrongful deaths under such a law but he simply doesn't care:

"Even if a few grannies get bullied into [suicide], isn't that the price worth paying for all the people who could die with dignity?"[58]

Conclusion

It is clear from this evidence that simply requiring a physician to tick a box stating the person requesting assisted suicide is doing so voluntarily is no guarantee that the physician has the competence or has undertaken the extensive and careful inquiries necessary to establish that the person is not subject to undue influence or subtle pressure (albeit unwittingly) from family, friends or society to request assisted suicide so as not to burden others.

No jurisdiction that has legalised assisted suicide has even made any serious effort to establish a genuinely safe framework in this regard. Indeed no such framework is possible.

Any law permitting assisted suicide or euthanasia will inevitably result in wrongful deaths from coercion.

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[58] https://www.medscape.com/viewarticle/879187

WRONGFUL DEATHS BY ASSISTED SUICIDE OR EUTHANASIA

SOCIAL CONTAGION OF SUICIDE

Does legalising assisted suicide affect the suicide rate?

- Legalising assisted suicide for some Australians undermines the commitment to **suicide prevention for all** Australians
- Legalising assisted suicide has been shown to lead to **an increase** in the overall rate of suicides of 6.3% and of the elderly (65 years and older) by 14.5%
- This is outcome is predictable because of the well-known **Werther effect of suicide contagion whenever suicide is presented in a positive light** as a romantic or rational act
- The families of those who commit suicide under an assisted suicide law suffer high rates of posttraumatic stress disorder

Should suicide prevention strategies include all Australians?

Proposals to legalise assisted suicide or euthanasia for a select group of people, such as the terminally ill, necessarily imply that society agrees such people may be better off dead and supports their suicide as a legitimate, rational choice to be facilitated rather than prevented.

The question arises as to how publicly and openly offering assistance to commit suicide to one group of Australians fits with the public policy goal, widely shared across the whole community, to reduce the incidence of suicide?

Does legalising assisted suicide reduce the suicide rate as claimed?

Proponents of assisted suicide have claimed that providing the elderly, terminally ill with a legal lethal dose of drugs to facilitate assisted suicide will reduce the incidence of other forms of suicide among this group and, because, it is claimed, many of those for whom the lethal dose is prescribed may never take it, actually decrease the overall suicide rate.

This hypothesis has been subjected to careful scrutiny in an important study by David Albert Jones and David Paton comparing trends in suicide rates in those states of the United States which have legalised assisted suicide compared to those which have not.[59]

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[59] https://pdfs.semanticscholar.org/6df3/55333ceecc41b361da6dc996d90a17b96e9c.pdf

The study, which controlled for various socio-economic factors, unobservable state- and year effects, and state-specific linear trends, found that legalizing assisted suicide was associated with a 6.3% increase in total suicides (i.e. including assisted suicides).

This effect was significantly larger in the over 65 year old age group with a massive 14.5% increase in total suicides.

The introduction of legalised assisted suicide was not associated with a reduction in non-assisted suicide rates, nor with an increase in the mean age of non-assisted suicide.

The conclusion is that assisted suicide either does not inhibit (nor acts as an alternative to) non-assisted suicide, or that it acts in this way in some individuals but is associated with an increased inclination to suicide in other individuals.

The latter suggestion would be consistent with the well known Werther effect of suicide contagion.[60]

Effect on families

Suicide is a distressing event that disrupts the lives of families, friends and communities who are bereaved.

Like any other suicide, assisted suicide can profoundly affect surviving family members and friends.

A recent study found that about 20% of family members or friends who witnessed an assisted suicide in Switzerland, where assisted suicide is legal, subsequently suffered from full (13%) post-traumatic stress disorder or subthreshold (6.5%) post-traumatic stress disorder.[61]

Conclusion

Proposals to promote assisted suicide for some people runs an unacceptable risk of undermining efforts to prevent suicide for all other members of the community and of increasing the trauma suffered by families, friends and communities due to the suicide of loved ones.

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[60] http://journals.sagepub.com/doi/abs/10.1080/00048670701266680

[61] https://linkinghub.elsevier.com/retrieve/pii/S0924933810002683

WRONGFUL DEATHS BY ASSISTED SUICIDE OR EUTHANASIA

KILLED WITHOUT REQUEST (OR WHILE RESISTING)

Those who are killed **without any request** by doctors who have grown used to the practice of ending their patients' lives are clearly wrongful deaths. In some cases a doctor has performed euthanasia even where a person resisted.

Netherlands

In 2015 there were 431 cases of euthanasia without explicit request, representing 6.06% (or more than one out of sixteen) of all euthanasia deaths.[62]

More than 1 in 200 (0.52%) of all deaths (other than sudden and expected deaths) of 17-65 year olds in the Netherlands are caused intentionally by euthanasia without an explicit request from the person being killed.

In Case 2016-85 the Review Committees found that a doctor had not acted with due diligence in administering euthanasia to a woman with Alzheimer's disease. The woman had made a general reference in a living will to wanting euthanasia at the "right time". At the time the doctor euthanased her she was incompetent to voluntarily request it.

The doctor put medication in her coffee to reduce her consciousness deliberately so as to avoid her resisting being given drugs. Nonetheless she physically struggled against the administration of an intravenous lethal injection. She was physically restrained by family members while the doctor completed the administration of the lethal drugs.[63]

On 13 June 2018 the Regional Disciplinary Court for Healthcare in The Hague considered a complaint against the doctor brought by the Inspectorate for Health Care and Youth. The decision was published on 24 July 2018.[64]

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[62] https://opendata.cbs.nl/statline/#/CBS/en/dataset/81655ENG/table?ts=1525401083207

[63] https://www.euthanasiecommissie.nl/binaries/euthanasiecommissie/documenten/jaarverslagen/2016/april/12/jaarverslag-2016/RTE_jaarverslag2016.pdf

[64] https://www.tuchtcollege-gezondheidszorg.nl/binaries/tuchtcolleges-gezondheidszorg/documenten/publicaties/documentatie-procedures/uitspraken/uitspraken-van-persberichten/beslissing-euthanasie-bij-dementie/2018-033bes.pdf

The Court found that the written declaration of intent was not sufficiently clear to justify euthanasia in this case. It also found that the doctor should have tried to discuss the execution of euthanasia with the patient beforehand.

> *In view of the irreversibility of termination of life and the ethical aspects connected with the deliberate ending of the life of a fellow human being, a written euthanasia declaration must be unambiguous, not needing any further interpretation.*

The Court did not completely ruled out that ambiguities in a written declaration of intent could be removed (even in the case of a demented patient) if a patient is later unambiguous, consistent and tenacious (verbally or non-verbally) in his statements about wanting death. However, with this patient this was not the case because she sometimes said she wanted to die and sometimes not.

Despite its finding that the doctor had seriously breached the requirements for euthanasia it only imposed a reprimand on the doctor.

On 9 November 2018 it was announced that a criminal investigation into this case by the Board of Public Prosecutors had concluded and that the doctor would be prosecuted.[65]

This is the first time that the Dutch Public Prosecution Service (OM) will prosecute a doctor for euthanasia since the introduction of the Act on Termination of Life on Request and Assisted Suicide in 2002.

> *After extensive investigation, the public prosecutor came to the conclusion that the nursing home doctor had not acted in accordance with the legal standards. The public prosecutor considers it important* **that the court assesses whether the doctor was entitled to rely on the living will completed by the woman***. In addition, the OM reproaches the physician that she assumed that the woman still wanted to die without verifying this with the woman. Although the woman had regularly stated that she wanted to die, on other occasions she had said that she did not to want to die. In the opinion of the OM,* **the doctor should have checked with the woman whether she still had a death wish by discussing this with her***. The fact that she had become demented does not alter this, because according to the Public Prosecution, the law also requires the doctor to verify the euthanasia request in such a situation.* **These two legal questions on the termination of life of people suffering from dementia justify the submission of this case to the criminal court judge.**

It is not yet known when the case will be heard by the District Court of The Hague.

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[65] https://www.om.nl/vaste-onderdelen/zoeken/@104443/nursing-home-doctor/

WRONGFUL DEATHS BY ASSISTED SUICIDE OR EUTHANASIA

NOT A RAPID OR PEACEFUL DEATH

The case for legalising assisted suicide and euthanasia **simplistically assumes** that once legalised such deaths will be both rapid and peaceful. However, this is not the case. As a recent article in the journal *Anaesthesia* found:

Complications related to assisted dying methods were found to include difficulty in swallowing the prescribed dose (≤9%), a relatively high incidence of vomiting (≤10%), prolongation of death (by as much as seven days in ≤4%), and failure to induce coma, where patients re-awoke and even sat up (≤1.3%).

This raises a concern that some deaths may be inhumane.

Netherlands

Technical problems, complications and problems with completion in the administration of lethal drugs for euthanasia have been reported from the Netherlands.

Technical problems occurred in 5% of cases. The most common technical problems were difficulty finding a vein in which to inject the drug and difficulty administering an oral medication.

Complications occurred in 3% of cases of euthanasia, including spasm or myoclonus (muscular twitching), cyanosis (blue colouring of the skin), nausea or vomiting, tachycardia (rapid heartbeat), excessive production of mucus, hiccups, perspiration, and extreme gasping. In one case the patient's eyes remained open, and in another case, the patient sat up.

In 10% of cases the person took longer than expected to die (median 3 hours) with one person taking up to 7 days.

From 2016 to July 2018 the Board of Procurators General reported on 11 cases of euthanasia with serious breach of protocols by the doctor, including a failed assisted suicide because the doctor ordered the wrong drug; seven cases of the muscle relaxant being administered when the person was not in a full coma and therefore potentially causing pain; and three cases where a first attempt at euthanasia failed and the doctor had to leave the person to get a second batch of lethal drugs.

Oregon

In Oregon in 2018 nearly four out of ten (39.28%) of all deaths by ingesting a lethal dose involved a cocktail in which morphine sulfate was the main lethal substance.

This experimental lethal cocktail does not always result in a swift and peaceful death.

In 2018 one in nine (11.11%) of those for whom information about the circumstances of their deaths is available either had difficulty ingesting or regurgitated the lethal dose or had other complications. Two people had seizures in 2017.

The interval from ingestion of lethal drugs to unconsciousness has been as long as four hours (in 2017).

The time from ingestion to death has been as long as 104 hours (4 days and 8 hours). One person in 2018 took 14 hours to die.

A total of 8 people have regained consciousness after taking the supposedly lethal dose, including one person in 2018.

In 2005, "One patient became unconscious 25 minutes after ingestion, then regained consciousness 65 hours later. This person did not obtain a subsequent prescription, and died 14 days later of the underlying illness (17 days after ingesting the medication).

This patient was lumberjack David Prueitt who, after ingesting the prescribed barbiturates spent three days in a deep coma, then suddenly woke up, asking his wife *"Honey, what the hell happened? Why am I not dead?"*

David survived for another 14 days before dying naturally from his cancer.

Since 2005 seven other people have regained consciousness after ingesting the lethal medication.

"*In 2010, two patients regained consciousness after ingesting medications. One patient regained consciousness 88 hours after ingesting the medication, subsequently dying from underlying illness three months later. The other patient regained consciousness within 24 hours, subsequently dying from underlying illness five days following ingestion.*

In 2011, two patients regained consciousness after ingesting the medication. One of the patients very briefly regained consciousness after ingesting the prescribed medication and died from underlying illness about 30 hours later. The other patient regained consciousness approximately 14 hours after ingesting the medication and died from underlying illness about 38 hours later."

In 2012 "*one patient ingested the medication but regained consciousness before dying of underlying illness … The patient regained consciousness two days following ingestion, but remained minimally responsive and died six days following ingestion*".

In 2017 "*one patient ingested the medication but regained consciousness before dying from the underlying illness*".

In 2018 one person regained consciousness after ingesting the prescribed substance and later died of the underlying illness.

Two of the cases of regaining consciousness occurred after using DDMP2 – the latest experimental lethal cocktail being used by pro-assisted suicide doctors.

Washington

In 2017 one person took 6 hours to lose consciousness after ingesting the lethal dose and one person took 35 hours to die after ingesting the lethal dose. In 2016 one person took 11 hours to lose consciousness after ingesting the lethal dose. In 2015 one person took 72 hours (3 days) to die after ingesting the dose. In 2013 one person took 3 hours to lose consciousness after ingesting the lethal dose and one person took 41 hours (1 day and 17 hours) to die after ingesting the dose. In 2009 two people awakened after initially losing consciousness. In 2014 one person suffered seizures after ingesting the lethal medication.

At least 18 patients have regurgitated the lethal medication. Seven of these cases occurred in 2016 alone.

This may be related to the use of new experimental cocktails of lethal drugs being used since the price of the previously used drugs, secobarbital and pentobarbital (Nembutal), escalated.

The first of the new cocktails is a mix of phenobarbital, chloral hydrate and morphine sulfate. It was prescribed in 88 cases in 2015 and 106 cases in 2016 but no longer prescribed in 2017 no doubt due to the fact that it was found to be very caustic and to cause a profound burning in the throat.

The second experimental cocktail includes morphine sulfate, propranolol, diazepam, digoxin and a buffer suspension. It was used in 4 cases in 2015, 53 cases in 2016 and 130 cases (66%) in 2017.

DDMP2

The latest attempt at an experimental lethal cocktail aimed at delivering a rapid and peaceful death is a failure.

The 2018 Data Summary from Oregon reports on 43 cases of (attempted or completed) assisted suicide using DDMP2 where the results were observed and recorded.

12 people out of 43 (27.9%) died between 13 and 59 minutes of ingesting the lethal cocktail.

19 people (44.18%) died between 1 and 6 hours of ingesting the lethal cocktail.

10 people (23.2%) or almost one out of four people took between 6 and 21 hours to die after ingesting the lethal cocktail.

2 people (4.65%) regained consciousness and did not die after ingesting the (supposedly) lethal cocktail.