LEGISLATIVE COUNCIL

The Honourable Greg Donnelly MLC

12th April 2019

The Chair
Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee
Parliament House
George Street
BRISBANE QLD 4000

Dear Chair,

RE: Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying

My name is Greg Donnelly and I am a member of the New South Wales Legislative Council. As the Committee may be aware, in late 2017 the New South Wales Legislative Council debated a bill that provided for physician-assisted suicide and euthanasia. The bill was titled the *Voluntary Assisted Dying Bill 2017*. The following link will take you to the webpage relating to the bill https://www.parliament.nsw.gov.au/bills/Pages/bill-details.aspx?pk=3422. The bill was debated, voted on and defeated.

As you would expect both MLCs and MLAs received a significant number of submissions and letters from organisations and constituents expressing serious concerns regarding the proposed legislation and calling on both Houses to unanimously oppose the bill. With respect to the submissions and letters, they dealt with both the broader concerns relating to physician-assisted suicide and euthanasia legislation as well as particular deficiencies and shortcomings regarding the bill that was before the Parliament.

In terms of this inquiry, what I thought may be useful to the Committee would be to provide it with a selection of documents outlining various concerns about the proposed legislation in New South Wales. Even though some of the comments related specifically to the particular bill being considered in this state before the Legislative Council, I believe the vast majority of reflections and considerations are directly relevant to the Queensland inquiry. For ease of reference, I have placed the documents under particular subject headings. They are as follows:

Elder Abuse

1. General Purpose Standing Committee No. 2 *Elder Abuse in New South Wales* Report No. 44 dated 24th June 2016 https://www.parliament.nsw.gov.au/committees/DBAssets/InquiryReport/ReportAcrobat/6063/Report%2044%20-%20Elder%20abuse%20in%20New%20South%20Wales.pdf;
2. Australian Law Reform Commission *Elder Abuse – A National Legal Response* Final Report dated May 2017 https://www.alrc.gov.au/sites/default/files/pdfs/publications/elder_abuse_131_final_report_31_may_2017.pdf;

NSW Parliament
Macquarie Street
Sydney NSW 2000
Australia

[redacted]

3. Newspaper articles:
    a. "Financial Abuse of Parents Growing" by Sue Williams –Sun Herald dated 27th August 2017 https://www.domain.com.au/news/financial-abuse-of-elderly-parents-on-the-rise-as-housing-becomes-more-unaffordable-20170827-gy33zq/;
    b. "Australian Dream Becomes Nightmare for the Elderly" by Graham Hill –The Sydney Morning Herald dated 30th August 2017 (attachment two); and
    c. "Loved Ones Pose Biggest Threat to Old People's Assets" by Caroline Overington – The Weekend Australian dated 9th-10th September 2017 http://www.theaustralian.com.au/news/inquirer/loved-ones-pose-biggest-threat-to-old-peoples-assets/news-story/966cfe0e6dfdf43044b5049ffd3638a1.

Suicide Prevention

1. NSW Parliamentary Research Service e-brief 03/2017 dated July 2017 https://www.parliament.nsw.gov.au/researchpapers/Documents/Suicide%20prevention.pdf.

New South Wales Auditor-General's Report – *Planning and Evaluating Palliative Care Services in NSW*

1. The New South Wales Auditor-General released on 17th August 2017 an important report titled *Planning and evaluating palliative care services in NSW.* The following link will take you to the report https://www.audit.nsw.gov.au/our-work/reports/planning-and-evaluating-palliative-care-services-in-nsw.

Submissions and Commentary on Proposed NSW Legislation

1. Submission by the Royal Australasian College of Physicians regarding the Draft *Voluntary Assisted Dying Bill 2017* dated July 2017 (N.B. the submission relates to the NSW draft bill) https://www.racp.edu.au/docs/default-source/advocacy-library/pa-racp-submission-nsw-vad-bill-submission.pdf;
2. Submission by the St Vincent's Health Australia regarding the Draft *Voluntary Assisted Dying Bill 2017* dated 14th July 2017 (N.B. the submission relates to the NSW draft bill) http://www.healthprofessionalssayno.info/uploads/1/0/9/2/109258189/svha_nsw_voluntary_assisted_dying_bill_submission_final.pdf; and
3. Analysis of the *Voluntary Assisted Dying Bill 2017* by State Member for Ku-ring –gai, Alister Henskens SC MP (attachment three).

Media Articles

1. "So Much to Lose if we Allow Voluntary Assisted Dying" by John Watkins – The Sydney Morning Herald dated 14th August 2017 http://www.smh.com.au/comment/so-much-to-lose-if-we-allow-voluntary-assisted-dying-20170814-gxvivj.html.
2. "Why I'll Be Voting "No" to Assisted Dying Bill" by Walt Secord - The Sydney Morning Herald dated 2nd September 2017 http://www.smh.com.au/comment/why-ill-be-voting-no-to-the-voluntary-assisted-dying-bill-2017-20170830-gy70p3.html;
3. "Euthanasia: Definition Matters" by Paul Russell – The Spectator Australia dated 4th September 2017 https://www.spectator.com.au/2017/09/euthanasia-words-matter/;
4. "Legalising Assisted Dying Would be a Failure of Collective Human Memory and Imagination" by Margaret Somerville – The Guardian Australia dated 20th September 2017

https://www.theguardian.com/commentisfree/2017/sep/20/legalising-assisted-dying-would-be-a-failure-of-collective-human-memory-and-imagination;

5. "New York Courts Rule Against "Aid in Dying" and Warn of its Dangers" by Richard M. Doerflinger – The Public Discourse dated 29th September 2017 http://www.thepublicdiscourse.com/2017/09/20144/; and
6. "Paul Keating: Voluntary Euthanasia is a Threshold Moment for Australia, and One we Should Not Cross" by Paul Keating – The Sydney Morning Herald dated 19th October 2017 http://www.smh.com.au/comment/paul-keating-voluntary-euthanasia-is-a-threshold-moment-for-australia-and-one-we-should-not-cross-20171019-gz412h.html.

Academic and Journal Articles

1. "Unaddressed Issues in The Australian Euthanasia Debate" by Margaret Somerville dated 13th March 2017 (attachment four); and
2. "Ethics and the Legalization of Physician-Assisted Suicide: An American College of Physicians Position Paper" by Lois Snyder Sulmasy, JD et. al. – published in the Annals of Internal Medicine dated 19th September 2017 http://annals.org/aim/article/2654458/ethics-legalization-physician-assisted-suicide-american-college-physicians-position-paper.

Helpful Websites

There are two particular websites that provide reputable information relating to physician-assisted suicide and euthanasia. The following links will take you to them:

1. **HOPE: Preventing Euthanasia & Assisted Suicide** - http://www.noeuthanasia.org.au/; and
2. **Euthanasia Prevention Coalition** - https://www.epcc.ca/.

[redacted]

[redacted]

Other Material

1. Statement by Professor Theo Boer dated 16th July 2014 urging legislators to not support physician-assisted suicide and euthanasia legislation (attachment thirty);
2. "*Euthanasia and physician-assisted suicide:focus on the data*" by Ezekiel Emanuel – Medical Journal of Australia dated 1st May 2017 (attachment thirty one);
3. "*Real care, love and compassion – the alternative to euthanasia*" by Australian Catholic Bishops Conference https://www.catholic.org.au/euthanasia-pamphlets/1647-real-care-love-and-compassion-the-alternative-to-euthanasia-dl/file;
4. Report of the Health Committee to the New Zealand House of Representatives dated August 2017 https://www.parliament.nz/resource/en-NZ/SCR_74759/4d68a2f2e98ef91d75c1a179fe6dd1ec1b66cd24;
5. Research Note titled "*The Gendered Risks of Euthanasia and Assisted Suicide*" and Fact Sheet by Women's Forum Australia dated October 2017 (attachment thirty two); and
6. Letter from the Institute for Ethics & Society, The University of Notre Dame, Australia dated 19th October 2017 (attachment thirty three).

Finally, attachment thirty four is a copy of an article written by Professor John Keown from Georgetown University in the USA titled *"Voluntary Assisted Dying" in Australia: The Victorian Parliamentary Committee's Tenuous Case for Legalization*. It appeard in Issues in Law & Medicine, Volume 33, Number 1, 2018.

If you would like me to answer any questions or provide oral evidence at a hearing that may be scheduled as part of the inquiry, do not hesitate to contact me on [redacted] or by email on [redacted]

Yours sincerely,

G.G. dll

Greg Donnelly MLC
Parliament of New South Wales

MON 04 SEPTEMBER 2017

Elder financial abuse

Executive Summary
August 2017

Australian dream becomes nightmare for the elderly

Sydney Morning Herald, Sydney, General News, Graham Hill 30 Aug 2017

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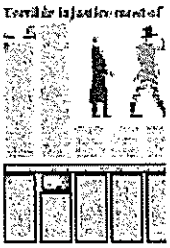

Soaring house prices are fuelling rising levels of elder abuse in Australia.

This wickedness can, however, be addressed if there is the political and public will to put a stronger legal safety net under vulnerable elderly people.

Growing numbers of older people are being pressured by adult children to guarantee enormous loans.

Legal aid commissions regularly deal with elderly parents who have gone guarantor without understanding they will be legally liable for the debt if the borrower defaults. This problem will only worsen unless we require lenders to ensure older Australians have independent legal and financial advice before these individuals offer their home to secure a loan or agree to be guarantor. As well, there should be a "cooling off" period within which guarantors can withdraw from the arrangement.

The pressure on older people can be immense. Adult children sometimes deny access to grandchildren if an elderly parent does not agree to be a guarantor or provide funds for a home deposit.

Legal Aid family law divisions regularly provide advice to grandparents about gaining access to grandchildren. All too often, we hear of conversations that go like this: "Mum, if we can't get funds to complete our deposit, and get a guarantor for our loan, we'll have to move interstate. The other option is that we move in with you. Your place is too big for you since dad died."

The boom in property prices has resulted in a spike in the numbers of adult children taking over an elderly parent's home and refusing to move out. Vulnerable parents are unable to free themselves of an abusive son or daughter who insists on living rent-free. This is often compounded by physical or emotional abuse. One woman in her 80s was repeatedly beaten by her 45-year-old son who rejected her pleas for him to move out. He had access to his frail mother's bank accounts, restricted her social activities and allowed her only a small amount of her pension.

At times, rising house prices result in an adult child persuading an elderly parent to sell up and buy a home with them. Problems arise when the relationship between parent and child breaks down and cohabitation can no longer continue.

Legal aid commissions have come across many cases where the older person thought they were jointly purchasing the new property but it turned out they were not registered on the title.

Legal assistance is vital to empower vulnerable older Australians and to reduce elder abuse.

However, court action isn't always the solution where families are involved. It can be costly, long and emotionally painful. There is another choice though; across Australia, legal aid commissions are quietly resolving thousands of high-conflict family law disputes involving separated couples who disagree about the living arrangements for children. Legal aid commissions run these family dispute resolution mediation services to enable separated couples to resolve their differences, with the assistance of a lawyer, outside a courtroom. These services have an 80 per cent success rate in settling disputes. Many people affected by civil law elder abuse disputes would benefit if legal aid commissions were funded to extend this service to them. It would

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enable civil disputes involving family members to be resolved outside court, through a process that can be much swifter and less painful than courtroom litigation.

Australians are living to unprecedented ages at a time when their adult children and adult grandchildren face unprecedented housing prices. I must stress that financial abuse is not the only form of abuse affecting older Australians. Mistreatment includes physical, psychological or sexual harm.

However, financial abuse is becoming more prevalent and this emerging issue requires a vigorous response from the community.

In recent times Australia has risen to the challenge of addressing the scourge of domestic violence.

The issue of elder abuse requires a commitment of similar proportions.

Dr Graham Hill is the chairman of National Legal Aid, the body representing legal aid commissions in all states and territories.

Download print article

Audience

93,403 CIRCULATION

Analysis of the Voluntary Assisted Dying Bill 2017
By Alister Henskens SC MP

EXECUTIVE SUMMARY OF THIS PAPER

A. Everybody brings to this debate their own personal history including various family, life, humanistic, spiritual, religious and other perspectives. This paper is not intended to debate those issues or change minds on them. It is merely intended to consider legal issues arising out of the proposed Bill and to report a number of other matters relevant to the operation of the Bill which I have investigated.

B. This paper contains:
   1. This executive summary;
   2. Then the detailed paper which has:
      a. An introduction – at page 12;
      b. An explanation of the paper's methodology and the nature of the investigations undertaken – at page 13;
      c. A summary of the provisions of the Bill which will explain how assisted dying would operate in practice – at page16;
      d. Observations on the nature of expert evidence including medical evidence in court proceedings – at page 24;
      e. A detailed analysis and critique of the Bill – at page 27;
      f. A discussion of some other relevant matters – at page 48;

C. The paper's major findings are that:

<u>This Bill creates Confusion not Clarity</u>

1. This Bill is the first piece of legislation (to my knowledge) since the abolition of capital punishment which allows for a person to intentionally end the life of another person (or aid and abet that act) without any legal punishment or sanction.

2. There is a strong public interest that any legislation that results in the lawful ending of a person's life is clear to follow, well drafted, without legal ambiguity and protective of any vulnerable persons.
3. Unfortunately, this Bill is not well drafted, is confusing to follow, has critical definitions left out and has many other shortcomings.
4. For example, the most important person, other than the patient, under the Bill is the primary medical practitioner, who is in charge of making relevant inquiries and who ultimately assists the patient to die.
5. A primary medical practitioner is described in clause 9 as a "registered medical practitioner."
6. There is no definition in the Bill of what is a "registered medical practitioner."
7. A person will answer the description under the Bill if they are registered as a medical practitioner anywhere in the world and such a person could therefore legally assist people to die.
8. The Bill does not include any period of practice or experience to be a "registered medical practitioner."
9. There are other examples given in the paper of similar shortcomings.

Medical Opinions Are Required that Cannot be Given

10. For the purpose of my investigation, I consulted doctors (without knowing their attitude to euthanasia) with specialities granted a role under this Bill.
11. The Bill requires medical practitioners to give a number of medical opinions that they tell me that they are not medically qualified to make.
12. Central to a patient's right to physician-assisted suicide under the Bill is that a person must have a terminal illness with only 12 months to live.
13. The medical advice that I have received is that, in most if not all cases, it is impossible to accurately predict a terminal patient's likely date of death more than about 2 – 3 weeks from the patient's actual death.
14. The central plank of the Bill, that a person can be accurately assessed to have 12 months or similar to live, is a medical fallacy in almost all cases.
15. A former Senator of the Parliament of the Netherlands told me that the Dutch did not include a criterion of the period to the time of death under their euthanasia legislation because their medical advice was the same as mine -

that no long term accurate prediction beyond a few weeks from death can be made as to how long a person has to live.

16. At a higher professional leadership level than I consulted, the Federal AMA's considered opinion is against physician- assisted suicide, which is also the American College of Physicians' position.

Psychiatric Assessment is Inadequate

17. The exposure draft of the Bill required a psychiatrist or psychologist to give an opinion on whether the patient requesting to die was of sound mind and whether the decision making capacity of the patient had been adversely affected by his or her state of mind. These requirements have been taken out of the Bill that was the subject of the second reading speech and replaced with the requirement that the patient only has to have decision- making capacity.
18. A professor of psychiatry has advised me that, under the current Bill, a patient can have a psychiatric condition (e.g. depression) causing the patient to ask his doctor to die and which, if not present, might have had the consequence that the patient did not proceed – but the expert psychiatrist or psychologist is not required to test for or report on any psychiatric motivation to die.
19. This has a cumulative impact because, under Clause 18(1)(c) of the Bill, the illness giving rise to the right to assisted death can be terminal because the patient has unreasonably (perhaps due to a mental disease like depression) refused treatment that can cure the illness.
20. A person with a terminal illness is likely to experience 5 stages of grief by reason of being told that they have a terminal illness.
21. The patient's 5 stages of grief are likely to be of 6 – 9 months duration.
22. A decision to end a patient's life during the 5 stages of grief could be changed at the end of that period into a decision to continue to want to live when the grief has resolved.
23. For example, in another area of medical concern, many paraplegic and quadriplegics wish to end their life during these 5 phases of grief but go on to want to live and in fact have very satisfying lives.

24. The Bill also requires the psychiatrist or psychologist to report on whether the patient's decision to request physician-assisted suicide has been made freely, voluntarily and after due consideration. Again, my expert advice is that a psychiatrist would be no better than any other person (including a lawyer) in determining whether there has been family coercion or the like upon the patient making the decision to die.
25. But the assessment of the psychiatrist/psychologist, which they have no particular professional expertise to make, is the only measure in the Bill designed to detect possible duress or coercion upon the patient from family members or others.
26. This taken with other matters developed in the paper has caused me to arrive at the conclusion that there is not adequate protection under the Bill for vulnerable people who are subjected to actual duress or coercion.
27. Even if psychiatrists and psychologists were requested under the Bill (which they are not) to ascertain whether a person who wants to die is doing so as the actions of somebody of a sound mind, they would have only a limited basis for doing so – medical orthodoxy is that suicidal ideation is the consequence of a mental illness, not a rational choice without the presence of a mental illness.
28. Rather than reducing the number of cancer patients from suiciding, there is research cited by the American College of Physicians that jurisdictions with the availability of euthanasia have seen a 6% increase in total suicides.
29. Whilst we can only speculate on why this is the case, it is possible that people that are suicidal are more comfortable to take their own life because the state has sanctioned physician-assisted suicide.
30. We need to know more about why the suicide levels have increased with the availability of euthanasia.

Consent and Duress

31. The idea that somebody may want to encourage a relative to end their life when they do not really want to may seem fanciful to many people who have a loving family and a good relationship with their relatives.

32. My experience as a legal practitioner has shown me that, in some families, family members can be shamelessly and aggressively motivated by the prospect of an inheritance.
33. Furthermore, since becoming an MP, I have been reliably informed of the incidence of elder abuse in our community. Even in a relatively affluent electorate like Ku-ring-gai, I have been told (by people working in our community with seniors), that there are elderly people eating cat or dog food while living in multi-million dollar homes because of family control over their finances or an absence of family financial support.
34. It may be uncomfortable to confront but, taking into account credible accounts of elder abuse in our community, this Bill could motivate greedy relatives to put pressure on a family member patient to end their life earlier than the patient wants.
35. The obligation on a psychiatric or psychological assessment under this Bill to determine whether a "patient's decision to request the assistance to die has been made freely, voluntarily and after due consideration"(i.e. free from duress by greedy relatives) is not capable of a scientific assessment by a psychiatrist or psychologist and so will therefore have a significant margin of error.
36. Further, under the Bill, the primary or secondary medical practitioners, treating doctors or nurses can be aware that a patient who has requested to die is being subjected to actual duress from a relative or other third party but those medical professionals have no obligation under the Bill to report those matters to anyone (including the psychiatrist or psychologist making an assessment under the Bill).
37. As a consequence, the patient can be legally assisted to die by the primary medical practitioner without there being a truly voluntary request by the patient.
38. Attention needs to be directed in this context as to what would provide certainty that all vulnerable patients are without any coercion by a family member or other close person.
39. What is clear is that the protections in the Bill with regard to the voluntary nature of the patient's actions are wholly inadequate and almost non-existent.

40. If passed, there will be instances of death under this Bill where there has been a request to die by the patient under duress which will in law mean there has been a state-sanctioned murder.
41. As the main witness to this abuse has died, any action against the wrong doer/s is unlikely.

Court Review is an Illusive Protection

42. Included in the Bill is a right for family members to have a court review of the process prior to death.
43. But this is not a right in reality.
44. It is impossible to bring a court case to protect a relative, whom you know has been subjected to duress by another family member, if you do not know that they have requested to end their life under the Bill.
45. There is no obligation on a patient or anyone else to inform close family members that the patient/ relative has requested to die under this Bill.
46. Therefore, the first occasion that some people may find out that their spouse, parent, child, brother or sister has requested to die under the Bill may be after they have medically had their life ended.
47. Furthermore, the grounds for any legal challenge to a request for an assisted death are limited in scope and do not include grounds at common law such as duress, oppression, undue influence or unconscionable conduct.

Other Vulnerable Patients

48. The decision-making capacity definition means that patients with an intellectual disability may be able to have physician assisted suicide under the Bill.

Objectivity of the Medical Opinions under the Bill

49. None of the medical practitioners doing assessments under the Bill is required to be the patient's treating doctor. Each can be a pro-euthanasia, hired-gun doctor negating the intended independent medical practitioner protections in

the Bill. There is no necessity that in practice there will be balanced medical assessments under this proposed law.

50. Unlike adversarial court proceedings where an expert opinion can be tested by cross examination, a partisan expert opinion under this Bill can stand untested as an essential and important criterion upon which somebody may die.

51. Further, given the time involved and the magnitude of the issues involved that the medical assessments include, the voluntary participation of a patient's treating medical practitioners to perform the obligations imposed upon them under the Bill is questionable – but those treating doctors are probably the best able and most independent persons to determine the issues arising under the Bill.

Very Late In The Terminal Illness

52. The process under the Bill takes a minimum of 9 days from the first request to die until death.

53. I strongly doubt that many, if any, patients with a terminal illness will go through the process under the Bill, including 3 costly medical examinations and reports (unlikely to be covered by Medicare or private medical insurance), to reduce the end of their life from 14-21 days by about 5 to 12 days.

54. Concerns about this Bill need to be weighed against this meagre 5 to 12 day maximum benefit that will apply to most, if not all, patients where proper medical assessments of when they are likely to die are made.

No Pain Needed to be Able to Die

55. I Clause 9(2)(e) of the Bill requires that the patient is experiencing severe pain or suffering or incapacity to an extent unacceptable to the patient. The test is wholly subjective without any objective medical verification. It also allows for deaths where there is not any severe pain but only a "physical incapacity" or an unspecified other "suffering" that is not the same as "severe pain". Presumably, that is psychological suffering.

56. Under Clause 18 (1)(c) of the Bill, even if medical treatment can provide proper relief from severe pain, suffering or physical incapacity, the fact that they can all be resolved does not prevent a doctor from still being able to assist the patient to die if there is no "cure" for the terminal illness through medical measures acceptable to the patient. This is of great concern, having regard to any concerns about a patient being encouraged by their family or friends to die.
57. The Bill is sufficiently broad in its terms that it effectively allows any terminally ill patient (who can secure two doctors to say they have less than 12 months to live and a psychiatrist to say the patient understands the medical advice they are being given) to end their life regardless of their actual level of pain because they only have to claim that their "suffering" is unacceptable to them. Is this an Improvement on the Status Quo?

58. The Bill will probably create, in some cases of an unknown number, a new kind of psychological suffering for:
    a. some patients who are subjected to coercion to end their life early; and
    b. family members who may be asked to, and do reluctantly, give the patient relative their moral support, to end the patient's life.
59. All legislation can have unintended consequences. There is no empirical evidence that this Bill will not create more distress and problems than it is trying to solve.
60. Post-Traumatic Stress Disorder (**PTSD**) is a potential unintended consequence for those involved in the termination of life, including doctors and family members.
61. There seems to be a conflict of medical opinions on the benefits of palliative care. Some doctors say that all palliative care is effective and others that it is not in all cases. The professional advice I have received is that those who receive modern palliative care but do not respond to it are small in number.

Many Patients With No Benefit

62. Patients who are in chronic pain or who have a very low quality of life but do not have a terminal illness are not able to die under this proposed legislation. These include :
    (a) patients suffering from Alzheimer's and like diseases;
    (b) those with painful rheumatoid arthritis;
    (c) cardiac cripples; or
    (d) those who do not have mental capacity at the time that a medical opinion can first be given as to the likely time to their death.
63. If this Bill is passed, it is reasonable to assume that persons advocating on behalf of these types of patients excluded under the Bill will then advocate for their right to physician-assisted suicide because this Bill has at its heart the notion that there is a justification for state-sanctioned suicide. This has in fact occurred in the Netherlands, where the number of patients using euthanasia has increased over time to now be 4.6% of all deaths in that country or more than 6000 people every year.
64. Given these international trends, there should be no assumption this legislation will necessarily be only limited in its use, thus emphasising the need for care to ensure the legislation is as good as it can be.

No Requirement for a Humane Manner of Death

65. The Bill provides that a doctor may prescribe, prepare or give only an authorised substance for a patient to die.
66. The authorised substance is to be specified by regulation.
67. There is no obligation under the Bill for the manner of death to be humane, painless and without distress.
68. A doctor may only administer the authorised substance if the patient is "physically incapable of self-administration." Otherwise, the patient has to take the life ending medication themselves and not necessarily under any medical supervision.
69. The Bill currently precludes the much more proficient method of euthanasia, which is that a doctor injects a drug to put the patient to sleep and then a

further drug is injected to end the patient's life. I understand that this is the process in the Netherlands.

Poor Penalty Provisions and Deterrent of Unconscionable Conduct

70. Clause 14 of the Bill, which is designed to deter interested persons from financially benefiting from their position of power under the Bill, contains no penalties for any transgressions or any requirement to repay any ill-gotten gains.
71. The intent of Clauses 15 and 16 is to deter improper conduct with regard to the assistance to die and have maximum penalties of only 4 years in gaol. This falls well short of the maximum of life imprisonment for conspiracy to murder to obtain a financial advantage or the maximum 10 years imprisonment for fraud.

Jurisdiction Shopping Cost Drain

72. A person living in another State of the Commonwealth can move after they have been diagnosed with a terminal illness and become ordinarily resident in NSW.
73. They are free to avail themselves of medical services in order to have the possibility of using the provisions of this Bill.
74. The Bill could operate as an incentive to put more demand upon NSW medical services.

Under 25s Not Covered

75. Eighteen years of age is the age of legal maturity but this Bill says that people of that age cannot make the decision to die.
76. Other protections could instead be put in place for those who are 18 – 25 years of age.

The Bill's Operation in Practice

77. The AMA does not support this Bill.
78. Doctors feel reluctant to become a person who facilitates death rather than saves lives.
79. There will have to be a significant cultural shift in the medical profession for the Bill to operate properly in practice, especially when the medical profession is being asked to perform a number of tasks which are not medical in nature.

THE PAPER IN DETAIL

Introduction

1. The Voluntary Assisted Dying Bill 2017 is co-sponsored by a cross party group consisting of Alex Greenwich MLA, Trevor Khan MLC, Lee Evans MLA, Mehreen Faruqi MLC and Lynda Voltz MLC. The Coalition and Labor parties have been granted a conscience vote on the Bill.

2. Everybody brings to this debate their own personal history including various family, life, humanistic, spiritual, religious and other perspectives. This paper is not intended to debate those issues or change minds on them. It is merely intended to consider legal issues arising out of the proposed Bill and to report a number of other matters relevant to the operation of the Bill which I have investigated. I have interviewed many different medical practitioners because we do not, to my knowledge, currently have any member of the medical profession elected to the NSW Parliament. This was essential because the proposed legislation has a central role for doctors and assumes that they are able to give certain opinions and will co-operate with the implementation of this proposed legislation.

3. This paper contains:

    a. an explanation of the paper's methodology and the nature of the investigations undertaken;

    b. a summary of the provisions of the Bill which will explain how assisted dying would operate in practice;

    c. observations on the nature of expert evidence including medical evidence in court proceedings;

    d. a detailed analysis and critique of the Bill; and

e. a discussion of other relevant matters.

Methodology

4. Under our current laws, it is permissible for a patient to refuse medical treatment that has the effect of keeping the patient alive. For example, a patient who has a kidney condition requiring dialysis can refuse, lawfully, to have any dialysis treatment and that patient will certainly die within 14 days. The patient cannot be forced to take food intravenously or dialysis treatment that would keep the patient alive. Similarly, a patient dependent upon other machines to keep them alive can request that machinery be turned off and a medical practitioner can lawfully follow that instruction, knowing that the effect will be to end the life of the patient.

5. Under the current law, administering morphine to a patient to treat their pain, which may have the medical effect of shortening the patient's life, is a lawful step that can be taken by a doctor.[1] Refusal of treatment which has a by-product of shortening life, is sometimes called passive euthanasia and is legal. What cannot be performed now by a medical doctor is active euthanasia meaning, any steps to administer or supply a drug with the sole intention of causing or facilitating death. These may seem to involve very fine distinctions but the legal line is understood and applied day in and day out by the medical profession under our current laws.

6. The proposed legislation gives a central role to the medical profession. After the exposure draft was released and well before any publicity about the legislation, I embarked from mid-March 2017 upon a number of interviews (face-to-face where possible) with several members of the medical profession. These interviews were arranged in a deliberate fashion. Medical practitioners were sought out on the basis of their area of expertise and geographical

[1] It should be noted that during the seminars at Parliament House on 20 and 21 September 2017, it was contended by several palliative care physicians that pain relieve such as morphine does not shorten a patient's life.

convenience without knowing where they stood on the issue of euthanasia or assisted dying. As the proposed Bill had not yet achieved much, if any, publicity at the time that I conducted most of my interviews, it was not possible that the matters that I was informed of by the doctors were influenced by the more recent public discussion that has taken place. At a convenient time during an interview, I asked the doctor to give me their opinion on whether they supported euthanasia or assisted dying. As it turned out, a majority of the medical practitioners that I consulted did not support assisting patients to die. This would appear to reflect the current position of their professional body, the Australian Medical Association. The types of doctors consulted included (in order of consulting them):

(a) a medical oncologist;

(b) a clinical and laboratory haematologist;

(c) a palliative care specialist;

(d) a neurological specialist;

(e) a practising psychiatrist;

(f) a pain specialist;

(g) a Professor of Psychiatry who participates in clinical practice and research into mood disorders;

(h) a general practitioner with an elderly cohort of patients;

(i) a joint palliative care and pain management physician specialising in the treatment of cancer patients; and

(j) a retired palliative care specialist.

7. In order to inform myself as to the euthanasia legislation of the Netherlands and how it operates in practice, through the kind assistance of the Australian Ambassador to The Hague, I was able to be introduced to and to speak over the telephone with:

   (a) Mr Jacob Kohnstamm, a lawyer and the National Co-ordinating Chairman of the Assessment Committee under the Dutch euthanasia legislation. Mr Kohnstamm was also a member of the Dutch Senate when their euthanasia legislation was passed;

   (b) Dr Gerrit Kimsma, a Dutch general practitioner experienced in the practice of euthanasia, who is also a lecturer in medical ethics at the Radboud University, Nijmegen; and

   (c) Mr Eric van Wijlick, who is the euthanasia contact at the Royal Netherlands Medical Association.

   All of these gentlemen from the Netherlands are strong advocates for the euthanasia law and believe that it operates well in their country.

8. The Royal Netherlands Medical Association gave me a number of documents in English explaining the current Dutch system which I will refer to further below.

9. I also had a one-on-one meeting with two board members of the advocacy group Dying with Dignity, who shared with me various written material and with whom I discussed some of the issues raised by this paper.

10. I would like to thank the people that I have consulted for giving me their valuable time and answering my questions. I take full responsibility for any misunderstandings I have arising out of our conversations. The views in this paper are my own and not of these individuals.

11. Although I had a conflicting engagement, David Garnsey of my office, who is a very experienced and highly qualified lawyer, attended the presentation (arranged by the Dying with Dignity group at Parliament House) by Dr Leigh Dolin, the Past President of the Oregon Medical Association, on the manner in which assisted dying operates in the USA state of Oregon. David has provided me with a report of the presentation and a copy of his notes made during the presentation.

12. David Garnsey and I also attended the seminar at Parliament House on 21 September and David attended the seminar at Parliament House on 20 September 2017 on the topic of assisted dying.

13. I have also taken note of the material that has been sent to all MPs by various groups this year.

Summary of the Proposed Bill

14. The following summary is provided of the important provisions in the Bill for the purposes of explaining its proposed operation. Because the structure of the Bill is confusing, I have tried to explain the sequential operation of the process under the Bill as clearly as I can.

15. A patient may request a registered medical practitioner, who is not a close relative of the patient, for assistance to end the patient's life if five criteria are satisfied: [2]

(a) the patient is 25 years of age ;

(b) the patient is an Australian citizen or a permanent resident of Australia, and is ordinarily resident in NSW;

[2] Clause 9

(c) the patient is suffering from an illness which, in the reasonable medical judgement of a medical practitioner, will result in the death of the patient within 12 months (defined as a "terminal illness" under clause 4 of the Bill);

(d) the registered medical practitioner has informed the patient that the patient is suffering from a terminal illness (as defined) ; and

(e) the patient is experiencing severe pain, suffering or physical incapacity to an extent unacceptable to the patient.

16. A patient may rescind a request for assistance to voluntarily end the patient's life at any time and in any manner.[3]

17. If the Clause 9 requirements are met and the patient has not rescinded his or her request for assistance to end their life, then the medical practitioner who is to assist the patient to end the patient's life (called the **primary medical practitioner**) must undertake a number of further steps under Part 4 (Clauses 17-23) of the Bill before the primary medical practitioner can assist in ending the life of the patient. These further steps include:

(a) the primary medical practitioner must examine the patient;[4]

(b) another registered medical practitioner eligible to conduct an examination (called the **secondary medical practitioner**) must independently also examine the patient;[5]

(c) the second medical practitioner must be qualified in a relevant speciality to provide the diagnosis or treatment of the terminal illness in respect of which the patient is suffering;[6] and

[3] Clause 10
[4] Clause 17(1)
[5] Clause 17(1)
[6] Clause 17(3)(a)

(d) there are provisions which attempt to keep a separation of association and therefore a degree of independence between the primary and secondary medical practitioners but these are limited to defined family, employment and commercial relationships.[7]

18. Before the patient can be assisted to die, the primary medical practitioner must form the opinion that:[8]

(a) the patient is suffering from an illness which will, in his or her reasonable medical judgement, result in the death of the patient within 12 months;

(b) the illness is causing the patient severe pain, suffering or incapacity to an extent unacceptable to the patient; and

(c) there is no medical measure acceptable to the patient that can reasonably be undertaken in the hope of effecting a cure.[9]

19. The secondary medical practitioner must prepare a written opinion agreeing with the three opinions of the primary medical practitioner in relation to the patient, set out in the previous paragraph of this paper.[10]

20. After the primary and secondary medical practitioners have independently examined the patient, the primary medical practitioner must inform the patient in writing of information relating to:

(a) the nature of the illness and its likely course;

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[7] Clause 17(2), 17 (3)(b) – (c) and clause 8
[8] Clause 18(1)
[9] In the exposure draft of the Bill there were two other conditions which have now been deleted from the Bill, namely that the medical practitioner also formed the view that:
(a) Any medical treatment reasonably available to the patient is confined to the relief of pain or suffering; and
(b) The patient has considered the possible implications of the patient's assisted death for the spouse or de facto partner or family of the patient.
[10] Clause 18(2)

(b) the medical treatment, including palliative care, counselling and psychiatric support and measures for keeping the patient alive, that might be available to the patient;

(c) the consequences of the administration to the patient of an authorised substance, including the risk and possible adverse consequences of the administration not resulting in the death of the patient; and

(d) the right of the patient to rescind a request for assistance.[11]

21. The primary medical practitioner must also offer to refer the patient to a palliative care specialist – the patient is not required to accept the offer.[12]

22. The patient, after receiving that information and the offer of referral, must tell the primary medical practitioner if they still wish to have the doctor's assistance to terminate their life.[13]

23. The patient must next be examined and assessed by an independent qualified psychiatrist or an independent qualified psychologist[14] who, after an examination of the patient, must provide a written report[15] to the primary and secondary medical practitioners, by including the expression of an opinion as to whether[16]:

(a) the patient has decision-making capacity in relation to the request for assistance; and

(b) the patient's decision to request the assistance to die has been made freely, voluntarily and after due consideration.[17]

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[11] Clause 19 (1)
[12] Clause 19(3)
[13] Clause 19(4)
[14] Clause 20 (1)
[15] Clause 20(3)
[16] Clause 20(4)
[17] The exposure draft has been changed. It previously also required that:
(a) the patient be of sound mind; and

24. Decision-making capacity under the Bill is defined in relation to a request for assistance as a patient having the capacity to:[18]

(a) understand the facts relevant to the patient's illness and condition; and

(b) understand the medical treatment and other options available to the patient; and

(c) assess the consequences of the patient's decision to request the assistance and understand the impact of those consequences on the patient, and

(d) communicate the patient's decision (whether by speaking, sign language or any other means).

25. The primary medical practitioner must provide the secondary medical practitioner and the psychiatrist or psychologist, prior to their examinations, with any prior reports given to that primary medical practitioner which has rejected a request for assistance under the Bill.[19]

26. After all of these steps have been taken and not earlier than seven days[20] after making the initial request to the primary doctor for assistance, the patient must then sign a declaration of their consent to be assisted to die[21] or, if the patient is physically unable to sign the request certificate, make an audio-visual record of:

(a) the patient reading aloud the patient's declaration on the request certificate; or

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(b) the patient's decision making capacity was not adversely affected by his or her state of mind.

[18] Clause 7
[19] Clause 21
[20] Clause 22(4)
[21] In the form set out in Schedule 1 of the Bill under clause 22(1)

(b) any other person reading the declaration aloud with the apparent agreement of the patient, if the patient is unable to read the declaration aloud. [22]

27. It is a requirement that the primary medical practitioner be present during the signing of the request certificate or the making of an audio-visual request and both the primary and secondary medical practitioners must sign the request certificate in the presence of the patient.[23] There is also a requirement that an interpreter (if any) signs the request certificate.[24]

28. There is a cooling-off period in so far as the primary medical practitioner cannot provide assistance to a patient to end their life until 48 hours after the request certificate was completed[25].

29. If all these matters are complied with, then the primary medical practitioner may either:

(a) assist the patient to end the patient's life; or

(b) for any reason and at any time, refuse to provide that assistance.[26] It is clear that there is no obligation on any person to be a primary or secondary medical practitioner for the purposes of the Bill.[27]

30. It is made clear that the primary medical practitioner should be guided by general medical standards and any regulations with regard to the substances given by the primary medical practitioner to end the patient's life.[28]

31. There are various integrity provisions which prevent the primary or secondary medical practitioners, psychiatrists/psychologists, interpreters or close

[22] Clause 22(3)
[23] Clause 22(5)-(7)
[24] Clause 22(8)
[25] Clause 12
[26] Clause 11 (1) and (2)
[27] Clause 11(3)
[28] Clauses 6 and 13

relatives of any of those people from obtaining any financial advantage from an assisted dying.[29]

32. Close relatives of the patient may apply to the Supreme Court claiming that the request certificate is not an effective request certificate for the purposes of the Act.[30]

33. There is no duty upon any health care facility operator, health care provider or other person to participate in any steps under the Act.[31]

34. The Bill provides protection from liability in that:

(a) persons acting in good faith by participating in the lawful provision of assistance under the Act, incur no civil or criminal liability;

(b) dealing in any way with an unused authorised substance[32] , is not deemed to be participating in the provision of assistance[33]; and

(c) a lawful assisted death is not to be regarded as a suicide for the purposes of section 31C of the *Crimes Act 1900*.[34]

35. Wills, contracts or other agreements of any person are void if they purport to impact on whether a person may make or rescind a request for assistance, or provide assistance, under the Act.[35] A request to die does not have any impact upon liabilities under other contracts.[36]

36. A death with assistance under the Act must be reported to the Coroner and to the Voluntary Assisted Death Review Board and medical records retained.[37]

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[29] Clauses 14-16
[30] Clause 24. A close relative is defined in clause 3 as being a parent, guardian or child of the person or a brother, sister, half or step brothers or sisters, spouse or de facto partner of the patient.
[31] Clause 28(1)
[32] As defined in Clause 29(5)
[33] Other than by destroying or possessing it for that purpose under section 29(3)(f)
[34] Clause 29 (7)
[35] Clause 30 (1)
[36] Clause 30(2)
[37] Clauses 31-34

37. The Bill establishes a Voluntary Assisted Death Review Board and sets out its functions.[38] The Board will review each assisted death under the Act and will also monitor the scheme, refer any breaches to the relevant authorities, conduct research, make recommendations to improve the operation of the law and report to Parliament and to the public. The Board will consist of 7 members including:

(a) A Chairperson appointed by the Minister;

(b) The State Coroner or a nominee of the State Coroner;

(c) a representative of the NSW Board of the Medical Board of Australia;

(d) a representative of the NSW AMA or The Royal Australasian College of Physicians;

(e) a representative of The Royal Australian and NZ College of Psychiatrists or Australian Clinical Psychology Association Ltd;

(f) a representative of Palliative Care NSW Inc;

(g) a person who, in the opinion of the Minister, has relevant expertise in law.

38. Breaches of clauses 15 or 16 are the only indictable offences created by the Bill.[39]

39. A Ministerial review of the Act is to take place after 5 years with a report to Parliament by 6 years after its commencement.[40]

40. As already noted, the above is an explanation of the legislation by attempting to put the sequence of each step involved in a request for assisted dying in a chronological order. The draft Bill does not do that and its current

[38] Part 8 and Schedule 2 of the Bill
[39] Clause 46
[40] Clause 47

organisation will be confusing as a consequence to those who have to operate under it if it is passed into law. The Parliamentary drafting could be greatly improved to promote accessibility to the provisions of the Bill and to ensure that there are not errors in process in practice.

Observations on the Nature of Expert Evidence

41. Court proceedings have traditionally had a healthy scepticism with regard to expert (sometimes called opinion) evidence. The reason is that expert evidence presents opinions as if they are a fact. The most dramatic illustration of the unreliability of this sort of evidence was in the Lindy Chamberlain prosecution.

42. In that case, a Scotland Yard "expert" scientist gave an opinion that there was foetal blood underneath the dashboard of the Chamberlain's vehicle. In fact, the so called "foetal blood" was a rust suppressant. The evidence that foetal blood was present in the vehicle was critical to a jury finding Lindy Chamberlain to be guilty of the murder of her daughter. The inconsistency between the foetal blood opinion and the rust opinion escaped the full exhaustion of Court appeal rights to the High Court of Australia and was not exposed until a Royal Commission was held into the soundness of the conviction for murder. After the foetal blood opinion was declared to be wrong by the Royal Commission, Lindy Chamberlain was pardoned and freed from goal.

43. Wherever expert opinion is frequently used in the legal system, camps of experts seem to develop. There are experts who are renowned to be "pro plaintiff" or "pro prosecution" and experts who are renowned to be "pro defendant". These camps tend to develop in areas where there are repetitive types of the same kind of litigation involving experts. This is probably because experts can make a living out of conducting the sorts of cases that they give evidence in by being retained regularly by one side or the other (the same could also be said of lawyers). The areas of litigation of this kind which immediately come to mind include planning experts, financial experts giving

opinions as to loss of future income, business valuation experts, economic experts in competition law cases, land valuation experts, psychiatric experts as to criminal insanity and medical experts in personal injury cases.

44. In personal injury litigation there are well-known medical practitioners who are considered to be "pro plaintiff" and medical practitioners who are believed to be "pro insurance company". In the famous High Court of Australia decision on apprehended bias of *Vakouta v Kelly* (1989) 167 CLR 568, a judge at first instance referred to three insurance company doctors in the case as the "unholy trinity". The judge was found to have created a reasonable apprehension that he had pre-judged the evidence of the doctors and should have disqualified himself.

45. Notwithstanding the Judge's comments giving rise to a reasonable apprehension of bias, his comments reflected a widely held view within the legal profession at the time, which was that expert medical opinions in personal injury litigation were not independent and could be influenced by the self-interest of the party seeking it. Unlike adversarial court proceedings where an expert opinion is to be tested by cross examination, a partisan expert opinion under this Bill will stand untested as an essential and important criterion upon which somebody may die.

46. Generally speaking, medical opinions given by "treating doctors" tend to be more unguarded than evidence given by full-time professional forensic medical expert witnesses. That is because the treating doctor does not necessarily understand the full forensic consequence of expressing views in a certain way. These treating doctors also often see giving medical evidence as a burden upon their usual medical practice and are not necessarily giving evidence in such a way as to attract future opportunities to give expert evidence to a court.

47. However, by reason of the doctor/patient relationship, treating doctors, to my observation, can in some cases be unreliable for other reasons, including that they are consciously or sub-consciously influenced by their pre-existing

relationship and try to help their patient rather than be wholly objective. These are important matters in the context of the Bill because there is nothing within the provisions of the proposed legislation which require the primary medical practitioner to be either the patient's treating doctor or randomly selected. This is a major departure from the Dutch legislation where the request for euthanasia is made to the patient's treating doctor.

48. Furthermore, I was informed that a request for euthanasia under the Dutch system is the most unwelcome request that a medical practitioner can receive. That is because the medical practitioner is required to go through a number of stringent administrative steps to fulfil the request of the patient. Under Dutch law, the doctor ends up being referred to a criminal prosecutor if there are any failings in the process.

49. If the Bill does not specify that the primary medical practitioner must be the patient's treating doctor (unless the treating doctor has a conscientious objection) then I fear that an industry of specialist medical (and probably pro assisting dying) hired guns will emerge, similar to what has occurred in the area of personal injuries (and other expert-heavy types of) litigation. This will mean that the Bill, which assumes the occurrence of even-handed medical opinions, will probably not achieve its objective in practice.

50. When discussing several of the medical issues, a number of specialists commented that it would be undesirable to have "technical amateurs" deciding some of the medical issues that can arise under the Bill. A panel approved by the Health Minister, in consultation with the AMA, relevant College or other peak professional body, of doctors willing to perform the role of objective medical assessor and give a genuine even-handed objective opinion would be an improvement to the Bill, with members of the panel operating as at least one of the medical practitioners and probably as the psychiatrist/psychologist expert in all cases.

51. While discussing expert evidence, it is important to note that the legal definition of an expert under Section 79 of the *Evidence Act* is a person who is

able to express an opinion because they have specialised knowledge based on the person's training, study or experience. This is important to keep in mind because, when I later discuss other provisions of the legislation, it will become apparent that there is not a specialised knowledge, on my advice, based on training, study or experience for some of the medical opinions that are sought to be provided pursuant to the Bill.

Commentary on the Provisions of the Bill

Clause 9 of the Bill (see paragraph 15 above) – Eligibility and the Request to Die

52. As will have already been observed, the Bill gives a central role to the primary medical practitioner. The primary and secondary medical practitioners do not have to be the treating doctors of the patient. Further, no qualifications are set out for the primary medical practitioner under Clauses 3 and 9, other than the practitioner is not a close relative of the patient (as defined in Clause 9) and is a "registered medical practitioner."

53. Who falls under the description of a registered medical practitioner under the Bill is not easy to determine. There is no actual definition of a "registered medical practitioner" in the Bill. A confusing reverse definition is possible in that the definition under clause 5(2) of a "designated health practitioner" includes a registered medical practitioner under the Health Practitioner Regulation National Law. However, even if this operates as a reverse definition of a "registered medical practitioner", there is no definition in the Bill of what is meant by "the Health Practitioner Regulation National Law." .

54. A loose definition of this kind for the person with a central role under the Bill is highly unsatisfactory. It allows for the possibility of "registered medical practitioners" from foreign jurisdictions with dubious qualifications to be lawfully ending people's lives under this Bill. On the most probable available construction of the Bill, a registered medical practitioner, trained and registered in any jurisdiction (even if with much lower standards than NSW), could be lawfully ending lives in NSW if the legislation is passed.

55. Given the central role of "medical practitioners" under the Bill, it is highly damaging to the integrity of the Bill that such a basic concept does not have a proper definition. Furthermore, to properly perform the functions of a medical practitioner under the Bill, a doctor should, at the very least, have a current Australian medical provider number with a certain level of practical experience, such as practical experience of no less than a period of 7 years in duration.

56. The Bill uses the terminology that a person must be suffering from a terminal illness as a necessary criterion for the availability for assisted dying. Most would commonly understand that to be an illness which at some time may kill you. However, under Clause 3 (1) of the Bill, a terminal illness is defined as an illness which will, in a reasonable medical judgement result in the death of a patient within 12 months. This gives rise to several questions. Firstly, what is the standard of proof that a doctor needs to apply in forming this opinion? Is it just a 50.01% probability of death in 12 months, beyond reasonable doubt or what might be called a scientific certainty of death in 12 months? The Bill is silent on the criteria to be applied. This is important because when I asked doctors how often it is possible to predict when a terminally ill patient is 12 months from death, they said rarely, if ever.

57. The consistent advice that I have received is that predictions as to life expectancy do not conform to an opinion to the standard of a medical certainty and would not conform to the standard of evidence required for a court proceedings. One doctor described the time to death as only "a best guess." For most terminal illnesses, it is not possible to predict the time of death more than about 2 or 3 weeks in advance of when a person actually dies. At this point the patient starts to exhibit certain changes, physically, emotionally and physiologically that start to point to an impending death. Also, for many terminal illnesses, there are different treatment options and it is usually only when these are exhausted that the patient is not actively treated and is put on a "best supportive care" plan, which is palliative only. Medical science has, by and large, not been directed towards the accurate prediction

of when people will die, which the Bill assumes can take place. Instead, medical science is fundamentally focussed upon keeping people alive for as long as possible.

58. The psychiatric advice that I have received is that most mental health is treatable and would not fall into the definition of a terminal illness. However, it may be an added protection for those with mental ill-health for them to be expressly excluded from the definition of a terminal illness under the Bill.

59. In the case of cancer, in respect of which about 80 percent of the deaths by euthanasia in the Netherlands take place, I am told that it is possible only to predict about 2 or 3 weeks in advance of death when a person is likely to die. That has a profound importance for this Bill. If a person is so advanced in their illness that they only have 2 or 3 weeks to live before they can avail themselves of assisted dying, are they likely to wish to go through the many bureaucratic steps in the Bill already described in order to shorten their life by only a small number of days? The minimum period of time between the first request of a doctor to assist the patient to die and actual death under the Bill is 9 days (putting together the 7 days under Clause 22 and the 2 days cooling off period under Clause 12 of the Bill).

60. I strongly doubt if many people will bother to go through the 9 day steps of the Bill with three costly medical examinations when it is unlikely to be available until their illness is so advanced that they only reduce their life by about 5 to 12 days. It is unlikely that most people will be able to or want to use this legislation in practice.

61. I was informed that, with motor neuron disease, the medium time from diagnosis to death is 18-24 months. This is, one half live longer and one half-lives shorter than that time. I was also informed that t some recent research suggests that, depending upon how quickly the disease progresses between the initial early stages, it may be possible to statistically express an opinion at a point in time that a person has about 12 months to live under that terminal condition. However, it would seem that this is still not a medical certainty and

has the same problems of prediction already mentioned. With motor neuron disease, patients are fully conscious and feel distress. There may be other relatively rare diseases beyond the 14 -21 day accurate prediction of death but on the advice I have taken they appear to be few in number.

62. This practical problem with the Bill is largely a problem of medical science. The haematologist told me that, 6 months from death, it is impossible to tell if a lymphoma patient will survive, as many do, or die. In Oregon, the 6 month (rather than 12 month) from death criterion before there can be an assisted death is unlikely to change the operation of the Bill in practice. The Dutch legislation has no time specified before death but that would be something that would change the nature of the proposed legislation entirely because people who are in pain or suffering, or with a physical disability but without a terminal illness would then also be able to die. This could include paraplegics still coming to terms with their dramatically altered life, people with painful chronic cardiac conditions or other medical conditions resulting in pain which are not terminal.

63. Another aspect of medical science which is problematic for the 12 months from death criterion is the dynamic nature of medical research. New cures and treatments for chronic or terminal conditions are discovered from time to time. Under the legislation, people may die in circumstances where, if their life was allowed to follow normal treatment, the terminal illness may have become treatable. HIV AIDS is a good example where a certain death sentence in the 1980s became changed at a point in time in the 1990s to a manageable non-fatal disease upon the discovery of new drugs.

64. Another criterion for assisted dying under Clause 9 of the Bill is that, because of the terminal illness, the patient is experiencing severe pain, suffering or incapacity to an extent unacceptable to the patient. It is not clear whether the suffering or physical incapacity has to be severe like the pain or merely that the terminally ill patient has the most minor physical incapacity from the illness. The suffering could be completely psychological grief treatable by the medical profession. I think most supporters of some form of euthanasia want

it for unbearable pain and not for it to be available because of what might be fear of the unknown or limited physical incapacity. With regard to the severe pain, or suffering or physical incapacity, it is wholly subjective. Whilst different people appear to have different tolerances for pain (and why one person's tolerance for pain is greater than another person's is not completely understood), making it a subjective test means that there is no requirement for a doctor to also objectively satisfy themselves that any severe pain complained of is probably actually occurring.

65. This effectively means that if it was possible to predict death 12 months in advance, and the patient was not actually suffering pain but merely informed a doctor that they were suffering pain or some other kind of "suffering" or physical incapacity which was intolerable to them, the patient would (if the other requirements existed) be entitled to assisted dying under the Bill. This is particularly relevant to the psychological trauma caused by a person finding out that they have been diagnosed with, say, cancer. I was told that there are 5 stages of grief which can take from 6 – 9 months. This has important consequences for the 12 month from death criterion. Somebody within one of the 5 stages of grief may want assisted dying at that time but when they finish going through all of the stages of grief, would not want to do so. The psychiatric advice was that it would be undesirable to assess someone as they may set in motion a process that they feel they cannot change.

66. I was told that it is believed medically that the same receptors to the brain which convey physical pain also convey psychological pain. It is therefore possible that the unacceptable pain being suffered by the patient is of a psychological rather than physical kind. The importance of that distinction is that psychological pain could be the consequence of grief having regard to a diagnosis of a terminal illness, which will probably occur as part of the ordinary grieving process. It is also a pain which may be capable of treatment. Therefore, the provision could be improved by the availability of assisted dying by a requirement that it is limited to instances of pain and the pain is physical in its origin and medically verifiable as a probability.

67. The final requirement under Clause 9 of the proposed Bill is that the patient must be at least 25 years of age, an Australian citizen, or a permanent resident of Australia and ordinarily resident in New South Wales. The requirement of ordinary residence in New South Wales is desirable because it will prevent jurisdiction hopping within Australia for terminally ill patients. However, the clause does not specify for how long a person must be ordinarily resident in NSW before coming under the Act.

68. At common law, someone is ordinarily resident in a jurisdiction merely because they have decided to permanently reside there. It is possible that, unless a person has been ordinarily resident in NSW for a qualifying period, upon a diagnosis for terminal illness, people from jurisdictions without any form of euthanasia may come to NSW. They could become a further burden on the hospital and medical system of NSW because they feel that at some time during the course of their illness they may wish to avail themselves of the assisted dying legislation. There should be some protective provisions within the legislation to stop jurisdiction hopping of this kind.

69. The 25 year old age limitation is interesting. Although it is no doubt to protect against people who are not sufficiently mature enough to make a wise decision, it is highly anomalous that somebody can vote from the age of 18, become a Member of the Federal or State Parliament (like Wyatt Roy did at the age of 20), from the age of 18 years die in a war defending this country or be a primary medical practitioner under the age of 25 that assists the patient to die but none of those persons can be a patient and make a decision as to whether they wish to avail themselves of the provisions of the proposed Bill until the age of 25 years. I would suggest that a preferable position would be to have some extra physiological testing between say the age of 18 and 25, like under the Dutch legislation (where the doctors are required to apply particular attention to the decisional competence when people who are between the age of 12-18 who want to die), or court or other scrutiny to ensure that the patient is properly exercising their decision.

70. As already identified, in the exposure draft of the Bill there were two other conditions to be satisfied before a patient could avail themselves of assisted dying, which have now been deleted from the Bill. In the exposure draft, the primary medical practitioner also had to form the view that:

    a. any medical treatment reasonably available to the patient was confined to the relief of pain or suffering; and

    b. the patient had considered the possible implications of the patient's assisted death for the spouse or de facto partner or family of the patient.

71. This means that, under the Bill, a person can legally be assisted to die, even if medical treatment could cure the illness. Under clause 18(1)(c) it is clear that, if a cure is unacceptable to the patient, no matter how reasonable, the patient can have access under the Bill to physician assisted suicide.

72. Furthermore, there is no requirement for the patient to consider the impact upon the patient's family members or discuss with close family members the assisted death. The absence of such a provision highlights my concerns about the adequacy of the right to seek court review of the request to die under Part 5 of the Bill when relatives may have no knowledge of the existence of the request.

73. It would seem to me that at least some people with intellectual disabilities may have "decision-making capacity" under clause 7 and be able to request to die under this Bill. This is not an issue that I have discussed expressly with the medical practitioners, but the ability of patients with intellectual disabilities, and the possibility of pressure to be placed upon them, to request to die is a significant concern. . There are particular issues with regard to the vulnerabilities of this group in our community that does not appear to have been taken into account under the Bill.

Clauses 5 and 6 of the Bill – How the Assistance to Die is Given

74. Under Clauses 5 and 6 of the Bill, the primary medical practitioner assists or provides assistance to end a patient's life if he or she prescribes, prepares or administers to the patient an "authorised substance" or gives an authorised substance to the patient for self-administration. Substances which are authorised will be prescribed by regulation. There is therefore no detail within the Bill as to the sorts of medical substances and manner of death that will occur under the legislation. This is important because the medical practitioners to whom I spoke were not (unsurprisingly) aware of the "best" way in which to kill a person.

75. It could be that, having regard to the analysis above, the manner of death may be as painful and as uncomfortable as the likely only few days of living left to most patients if they were to die under normal circumstances and receive palliative care. There needs to be a medical discussion of what ways a person can humanely and painlessly die and to ensure that the Bill has a broad obligation within it that death must be humane and painless as the method of dying specified by regulation. The Bill provides that a doctor may only administer the authorised substance if the patient is "physically incapable of self-administration." The Bill currently precludes the much more proficient method of euthanasia, which is that a doctor administers a drug to put the patient to sleep and then a further drug is given at that point to end the patient's life. I understand that this is the process in the Netherlands.

Clause 10 – Rescission of the Request to Die

76. A right to rescind a request can be made at any time and the rescission must be notified to the primary medical practitioner. However, there are no provisions dealing with the recovery of the script or any fatal medications supplied under the request. In Oregon, 35% of people who go through the assisted dying process do not go ahead and use the medication to die. That could mean that there are significant amounts of deadly medication in the community, raising safely concerns.

77. A closer medical supervision of the administration of the medication could be desirable.

Clauses 14 – 16, 29 and 46 of the Bill (see paragraphs 31, 34 and 38 above) – Improper Advantages or Conduct

78. Clause 14 of the Bill specifies that the primary medical practitioner, secondary medical practitioner, independent qualified psychiatrist/psychologist, interpreter (if any) or close relative (if assisting the person to die) or associate of those persons must not obtain a financial advantage from assisting a person to die. This provision is designed to stop any of these people individually or collectively conspiring to benefit from a death governed by the Bill. However, there is no penalty specified in the Bill if they were to obtain a financial advantage from the assisted dying. Nor is there any provision which requires them to pay back to the estate of the deceased person (as a debt due) any financial advantage which they have obtained.

79. By contrast, under Clause 15 of the Bill, any person giving or promising any financial or other advantage or threatening to cause a disadvantage to any primary medical practitioner or other person for assisting or refusing to assist the death or primary medical practitioner accepting any financial advantage for assisting to end a patient's life is liable to a penalty which includes a maximum imprisonment for 4 years. The secondary medical practitioner, independent psychiatrist/psychologist or interpreter or close relative of those persons could receive a financial advantage under Clause 14 without any penalty whatsoever. Under Clause 16 of the Bill, a person can also receive a maximum penalty of 4 years imprisonment for procuring the signing or witnessing of a request certificate under the Act by deception or improper influence, which is an indictable offence under Clause 46. The anomaly with regard to Clause 14, where the obligations can be breached without any penalty, should be rectified.

80. The maximum 4 years imprisonment for these offences appears to be very light. Penalties for like offences such as conspiracy to murder somebody in order to obtain a financial advantage, currently range from a maximum of imprisonment for life down to lesser sentences if the offence is fraud (10 years imprisonment) or larceny (5 years imprisonment) under sections 19A, 117 and 192E of the Crimes Act 1900 (NSW).

81. Clause 29 of the Bill is so broadly drafted that it could be used in a defence to any offences under Clauses 14 – 16. Clause 25 (1) should be redrafted to be clear it is subject to Clauses 14 – 16 of the Bill.

Clause 17 of the Bill (see paragraph 17 above) – Examination of the Patient

82. Under Clause 17 (3), the qualifications of the secondary medical practitioner are set out. All that is required is that the secondary medical practitioner be registered under the Health Practitioner Regulation National Law in a speciality in the medical profession that is relevant to the diagnosis or treatment of the terminal illness in respect of which the patient is suffering and that the secondary medical practitioner is not closely related to the primary medical practitioner by reason of employment, family relationship or membership of the same medical practice. The Health Practitioner Regulation National Law is not defined in the Bill. Again, there is no requirement that the secondary medical practitioner has any period of registration in the relevant specialty or any particular skills with regard to the terminal illness in question.

83. The primary and secondary medical practitioners could nonetheless be very close friends or perhaps share a similar philosophy on assisted dying. This is different to the Dutch system where there is a panel of people (not specialists necessarily and they can be general practitioners) who are available to be the secondary medical adviser under its legislation and the primary medical practitioner does not choose the second medical practitioner. In the Netherlands, the secondary medical adviser is supplied from a panel operated by the Royal Dutch Medical Association and is usually a person not well

known to the primary medical practitioner. I think a random selection by a person other than the primary medical practitioner is highly desirable so that there is a true independent check and balance in the system and there is not a pool of like-minded medical practitioners giving the medical opinions.

84. Furthermore, it has been pointed out to me by a number of the medical practitioners that there are significant sub-specialties within each area of specialisation in the medical profession. It has been suggested that it would be more desirable than the mechanism under the proposed Bill to allow for a panel of well-regarded experts, who have practised for a long period within a speciality, to provide a secondary medical opinion. The relevant medical College may devise a mechanism to select the panel of secondary medical specialist opinion-givers with relevant expertise to the terminal illness of the patient. The panel specialist may also have to be prepared to travel from time to time into regional areas in order to examine patients under the proposed Bill.

Clause 18 of the Bill (see paragraph 18 above) – Opinion of Medical Practitioners

85. The primary medical practitioner must form an opinion under the Bill that the patient has less than 12 months to live due to the terminal illness (see comments above), the illness is causing severe pain, suffering or physical incapacity to an extent unacceptable to the patient (see comments above) and that there is no medical measure acceptable to the patient that can be reasonably undertaken in the hope of effecting a cure.

86. The idea that there is not a medical cure acceptable to the patient is a wholly subjective test. The use of "reasonably be undertaken" gives a misleading impression because there is no obligation on the patient to act reasonably. The way clause 18(1)(c) is drafted, a patient can unreasonably reject reasonable measures to cure the terminal illness.

87. Significantly, the absence of any medical measures of any assistance only needs to be with regard to the terminal illness i.e. the absence of a "cure" under clause 18(1)(c). Even if medical science can provide proper relief from severe pain, suffering or physical incapacity, the fact that they can be resolved does not prevent a patient from still being able to be assisted to die under the legislation. This is of great concern having regard to any concerns about a patient being encouraged by their family or friends to die.

88. It is not clear whether the obligation upon the primary medical practitioner to form an opinion as to the Clause 18 criteria must be provided in writing to the patient as part of the written report to the patient under clause 19(1) of the Bill.

89. The "second medical practitioner", like the primary medical practitioner, must form an opinion as to the same matters. It is required that the second medical practitioner provide his or her opinion on these matters in writing. Again, the same concerns as to the matters raised with regard to the primary medical practitioner would apply equally to the secondary medical practitioner except that the secondary medical practitioner may have some greater medical knowledge of the terminal illness and its implications.

Clause 19 of the Bill (see paragraph 20 above) – Information by the Primary Medical Practitioner to the Patient

90. Under Clause 19 (1) of the Bill, the primary medical practitioner must, after examining the patient, provide information in writing to the patient informing the patient of the nature of the illness and its likely course and of matters relevant to the medical treatment, including palliative care, counselling and psychiatrist support and the measures for keeping the patient alive that might be available. It is probably appropriate for a general practitioner to play this role given that there may be a number of different areas of speciality that are necessary to have input into the provision of a report of this kind. As a matter of drafting, the Clause should require "all relevant" information of the kind specified to be provided to the patient. In addition to the matters set out in Clause 19 (1) (a) - (e), it is desirable that the primary medical practitioner also

puts in writing the doctor's opinions required to have been formed under Clause 18(1)(a)-(c).

Clause 20 of the Bill (see paragraph 23 above) – Examination by the Psychiatrist/ Psychologist

91. Under Clause 20 of the Bill, either a qualified psychiatrist or a qualified psychologist must provide an expert opinion on whether the patient has decision-making capacity and the patient's decision to request the assistance has been made freely and voluntarily and after due consideration.

92. It has been suggested to me that is not appropriate for a psychologist to provide such opinions because psychologists are not qualified medical doctors and therefore not able to understand the physical aspects of the terminal illness and its impact upon the mind of the patient.

93. When I put to a psychiatrist that psychiatry was largely focused on preventing people with mood disorders from killing themselves as a consequence of their mental illness rather than ascertaining whether a sound person could reasonably want to kill themselves, it was conceded that there was no training, study or experience (being the legal definition of expert knowledge) that psychiatrists hold as to whether a person was sufficiently sane to want to kill themselves.

94. The exposure draft of the Bill required a psychiatrist or psychologist to give an opinion on whether the patient requesting to die was of sound mind and whether the decision making capacity of the patient had been adversely affected by his or her state of mind. These requirements have been taken out of the Bill that was the subject of the second reading speech and replaced with the requirement that the patient only has to have decision- making capacity.

95. A professor of psychiatry has advised me that, under the current Bill, a patient can have a psychiatric condition (eg. depression) causing the patient to ask

his doctor to die and which, if not present, might have had the consequence that the patient did not proceed – but the expert psychiatrist or psychologist is not required to test for or report on any psychiatric motivation to die.

96. This has a cumulative impact because, under Clause 18(1)(c) of the Bill, the illness giving rise to the right to assisted death can be terminal because the patient has unreasonably (perhaps due to a mental disease like depression) refused treatment that can cure the illness.

97. Therefore, the psychiatrist or psychologist is being asked to express opinions on whether "the patient has decision –making capacity" to want to kill themselves when they have no relevant expertise to do that. They are not required to report on whether the patient is subject to grief and may arrive at a decision that they do not wish to die if they were given more time.

98. An aspect of the psychiatrist or psychologist's opinion under Clause 20(4)(b) of the Bill is whether the patient's decision to request assistance to die has been made "freely, voluntarily and after due consideration". The area of possible coercion of a patient is an area which concerns me greatly.

99. A recent survey of 1,000 Australians undertaken by Slater and Gordon Lawyers reported in the Sydney Morning Herald on 20 August 2017 showed that 26% of people who are in Gen Y expect to be able to buy their first home because of an inheritance from their parents, with almost ¼ of those people coming from NSW.

100. It is readily apparent within some family dynamics, that jostling takes place between siblings or other close relatives (or even people who have endeared themselves to a wealthy person) with regard to who will inherit parts of the estate of a person who will soon be deceased. These issues can become magnified in circumstances of family break-down or remarriage. In the succession cases that I have been briefed in as a barrister in private practice, complex family dynamics were very apparent.

101. Under the Bill, it is only the psychiatrist or psychologist who is responsible for determining when the patient is acting voluntarily. Even if the primary or secondary medical practitioners were aware, or saw evidence, of actual coercion of the patient by third parties, they are not required to report it under Clause 18 of the Bill or inform the psychiatrist or psychologist, nor would it prevent any medical practitioner from lawfully assisting the patient to die. I put to a psychiatrist that a specialist psychiatrist could not really ascertain whether there was express or implied pressure being brought to bear by family relatives upon a patient's decision to end their life.

102. In answer it was conceded that there is no area of expertise unique to psychiatry to do so and that lawyers or social workers could determine the presence or absence of any duress just as well. It was also conceded that, in order to properly determine whether that kind of pressure did or did not exist in relation to a patient could require multiple consultations with the patient and also probably interviews with close family members or other relevant people. However, the Bill assumes that a psychiatrist/psychologist, probably in one examination with the patient, can determine the free-will of a patient. If the psychiatrist under the Bill conducts multiple consultations of multiple people, the minimum period from the request to die until the actual death referred to above (9 days) will become even longer and the cost to the patient higher. But there is no guarantee that any actual duress by the family members upon the patient to die will be uncovered by the psychiatrist even with multiple interviews.

103. When I have voiced this concern about patient coercion with the Dutch participants in their system, they point to the fact that, under the Dutch medical system, it is impossible for a patient to ever go to hospital unless they have registered with a general practitioner. Therefore, within the Dutch system there is embedded a structural long-term relationship between the patient and a general practitioner, or at least the same GP practice. In the Netherlands the general practitioner is the person who performs the euthanasia.

104. Therefore, in the Netherlands, the person who is giving an opinion or making an assessment about the free-will of the patient's request for euthanasia, it is argued, has probably observed the patient through the progress of the disease, has some familiarity with the family dynamics operating in respect of the patient and can make a decision as to whether there is a sudden desire to be assisted to die. None of the provisions of the proposed Bill suggest that any in depth assessment of the voluntary nature of the request for assisted dying will occur through a single consultation with a psychiatrist, who will probably have no prior history with the patient, nor can the psychiatrists even be given a family history by the referring primary medical practitioner because that practitioner does not necessarily have any history with the patient.

105. Under the Dutch legislation, if the treating general practitioner has a conscientious objection to euthanasia, they are obliged to assist and provide all clinical notes to the substitute doctor who will be assessing the patient who has requested euthanasia. As discussed in relation to Clause 28 of the Bill, inadequate facilitative provisions are made in the Bill with regard to the various laws applying to patient privacy and confidentiality and the fact that professional notes and other documents on the doctor's file are probably legally owned by the doctor and not the patient.

Clause 21 – Provision of Information to Examining Doctors

106. There is a limited attempt to stop a patient shopping around for medical opinions after they have been assessed as not satisfying the prerequisites of the Bill.[41] It requires only that the primary medical practitioner provide to any secondary medical practitioner or the psychiatrist/psychologist copies of previous reports given by other practitioners to him or her. The protection can be easily avoided by the patient going to a new primary medical practitioner who will then be relieved from the obligation under clause 21. In order to properly protect patients, there should be a requirement that any rejection of a request for assisted dying be notified to a central body and there be an

[41] Clause 21

obligation under the Bill on all primary medical practitioners to consult with them as to earlier requests to die by the patient.

Clause 22 (see paragraphs 26-27 above) – The Request Certificate

107. One of the ways under the Bill that a patient may give a request certificate for assisted dying, is to make an audio-visual request. Under Clause 22 (3)(b), if the patient is unable to read the declaration aloud, any other person reading it aloud can do so with the apparent agreement of the patient.

108. It is what constitutes an "apparent" agreement of the patient which should be of some concern. If a patient is unable to read a declaration aloud and is unable to sign a patient declaration, it is difficult to understand how the psychiatric assessment under Clause 20 has taken place. If this is intended to cover situations of blind people then there could be no reason to be concerned. However, it is not so limited and is sufficiently broadly drafted that the consent protections would seem to be rendered nugatory. The primary medical practitioner and his or her reliability is paramount because, under the Bill, the primary medical practitioner must be present when any "apparent agreement" of the patient is given.

Clause 23 - Interpreters

109. Courts of law generally only accept persons as translators if they have a certification under the National Accreditation Authority for Translators and Interpreters (NAATI). The Bill does not require people to have such certification in the language of the patient (if not English). It merely requires that "an interpreter holds a professional qualification for interpreters described by the regulations (if any)". If the regulation does not specify any qualification there is no quality control and integrity under the Bill verifying that the consent or advice given is properly understood by the patient The clause should be changed to require NAATI accreditation or other acceptable qualification prescribed by the regulations (if any).

Part 5 – Review of Request for Assistance (See paragraph 32 above)

110. Under Clauses 24-27 of the Bill, close relatives of the patient may apply to the Supreme Court seeking an order that a request certificate is not effective. The primary medical practitioner and the patient must be a party to any such application along with the applicant relative. The Supreme Court may, on its own initiative or on the application of a close relative, decide to join as a party to proceedings any person who, in the opinion of the Court, should be a party to the proceedings.

111. Clause 24 is very prescriptive as to the matters of non-compliance under the Act which may give rise to an order by the Supreme Court that the request certificate is not effective. Rather than confining the criteria for review of the request certificate to the matters set out in Clause 24 (2)(a)-(c), it would be preferable for the court to have a broad discretion to give relief whenever a request certificate relating to the patient is not an effective request certificate for reasons including, but not confined to, paragraphs (a)-(c) of Clause 24(2). That would enable the common law to operate with regard to matters such as duress, oppression, undue influence or unconscionable conduct, none of which are, but should all be, specified under Clause 24 (2) as grounds of Court relief. There may be other irregularities within the process prescribed by the Bill that are not set out in Clause 24 (2)(a)-(c) which may make it undesirable for the request certificate to be effective in all of the circumstances of a particular case.

112. There is also a fundamental problem with the nature of the right sought to be given by Clause 24 of the Bill. There is no requirement under the Bill to notify close relatives that a request to die has been made by the patient. Therefore, if the close relative does not know such a request has been made, they can hardly review the situation and make an application to a Court to suggest coercion, duress or any other irregularity in the process. In my view, there should be a requirement to notify close relatives in the Bill.

113. It is anomalous that, under the *Succession Act*, all sorts of close relatives need to be notified with regard to any challenge to a will and a proposed re-adjustment of property distribution under a deceased estate. The sort of eligible persons under Section 57 of the *Succession Act* with regard to a Family Provision Act action gives a guide to the sort of persons that could have an interest in the fact that a request certificate has been made under the Bill.

Clause 30 (see paragraph 35 above) – Effect on Wills and Contracts

114. The intent of Clause 30 is not entirely clear. Clause 30 (1) of the Bill effectively specifies that any attempts to contract out of the right to assisted dying or to penalise someone within a will for the fact that they have engaged in assisted dying are invalid. The provisions of Clause 30 (1) of the Bill are contrary to the freedom of other people to take an attitude of their liking to whether someone should engage in voluntary assisted dying or not. People should have the ability to express their opinion in a will or contract about assisted dying, just as the proponents of the Bill wish to express their opinion via the Bill on the subject. At the moment, this is a legislative barrier to freedom of choice if that choice is inconsistent with the right to die under the Bill. Clause 30(1) is unduly proscriptive by denying people who take a contrary view to the Bill to express that in the will they make or the contracts they wish to enter into. This intolerant position should be rejected and the sub clause deleted from the Bill.

115. Clause 30 (2) of the Bill appears to be directed towards assisted dying not being an exclusion or limitation under an insurance policy but it is broader than that and should be confined only to insurance policies. At the moment, Clause 30 (2) is drafted sufficiently broadly that it applies to all contracts of any kind and again is an attack on the freedom of contract generally.

Part 7 Records and Reporting of Death

116. Clause 31 of the Bill specifies the sorts of records that the primary medical practitioner must keep. An anomaly is that the written report required by Clause 19 (1) is not referred to in Clause 31. Also, Clause 31 is consistent with the concern expressed earlier that the matters under Clause 18(1) required to be put in writing by the secondary medical practitioner under Clause 18(2) are not required to be put in writing by the first medical practitioner and given to the patient.

117. Under Clause 32 of the Bill, any assisted death is a reportable death under the Coroners Act. That means that a Coroner could investigate the circumstances of the death if the Coroner chose to do so. Whilst this may be appropriate in obviously suspicious cases, the Coroner already has a busy caseload and it is unlikely the Coroner will investigate many cases.

Part 8 Review Board

118. The Voluntary Assisted Death Review Board (**Review Board**) was not part of the exposure draft of the Bill.

119. The Bill has one of the 7 members of the Review Board as the State Coroner or his/her nominee.[42] As every assisted death is a reportable death to the Coroner under clause 32 of the Bill, there is the ability for there to be a conflict of interest if the State Coroner sits on the Review Board.

120. In the Dutch legislation, there are only three members of their Review Board, having expertise in law, medicine and ethics with one of them being the Chairperson. I would suggest that the Bill is amended so that, in place of Clause (2)(a) and (g), the Minister has the power to appoint a Chairperson

[42] Clause 35(2)(b)

and up to two other appointees in order to ensure that there are at least two members of the Review Board with expertise in each of law and ethics.

121. Clause 39 of the Bill allows for the Review Board to require information and/or records relating to the assisted death. There appears to be no ability to orally examine witnesses and, as there is not express abrogation of the right to claim a privilege against self-incrimination, any review could be highly limited in its scope. How clause 39 interacts with the privilege against self-incrimination should be explained.

122. Rather than having such a large number of medical representatives on the Review Board, it would be preferable to have one representative from the AMA and an ad hoc specialist member in the area of terminal illness sit on the Review Board for each different kind of patient who has been assisted to die.. A mode of appointment of the ad hoc specialist would have to be devised but presumably that could be done in consultation with the relevant College.

Clause 46 – Nature of Proceedings for Offences

123. Clause 46 (2) provides that only Sections 15 or 16 of the Act should be dealt with on indictment. In the event that Clause 14 also becomes an offence provision, as I have suggested, it should be added to this clause.

Clause 47 – Review of Act

124. A review of the Act will not be undertaken until 5 years' time with a report within a year thereafter. Given that this is new legislation, involving the State sanctioned death of our citizens, that period would appear to be too long. An investigation being undertaken after 3 years of operation with a report within 6 months of that time is appropriate.

Other Relevant Matters

Position of Australian Medical Association and The Doctor Patient relationship

125. The Bill has, as its central players assisting a patient to die, the primary and secondary medical practitioners and the psychiatrist/psychologist. Other than the patient, each of the other players is eligible to be a member of the AMA. In correspondence exchanged between Mr Greg Donnelly MLC and Dr Michael Gannon, the AMA Federal President, that was copied to all MLAs and MLCs on 5 and 6 October 2017, the official AMA position was set out and it is not to support the Bill. Dr Gannon attached the AMA Position Statement and a copy of his speech on 23 August 2017 to the National Press Club.

126. Further, the American College of Physicians in its paper "Ethics and the Legalization (sic) of Physician Assisted Suicide"[43] also does not support euthanasia and raises a number of concerns. These include the impact upon the professional relationship of a doctor turning from the patient's unambiguous champion of life to a mixed role where the doctor both saves and assists to end life. As a barrister and solicitor, I experienced 27 years of being in a position of professional trust. In situations of emotional stress and confusion, clients place a great deal of trust in their professional advisers. But the professional relationship can begin where the client is sceptical of the professional advisor until true trust is earned.

127. In the times where big decisions have to be made based upon professional advice, the relationship of trust is critical and can be highly influential. In a legal adviser/ client relationship, there is never a leave pass to throw a case. Under our current medical system there is never a leave pass to do other than save lives unless, after informed consent, the patient or authorised family member states that treatment is not wanted. Doctors are often people who have strong opinions and a strong belief in the correctness of their decisions. There is a legitimate concern that some doctors could use their influence to advance opinions unrelated to their medical training under this Bill and in

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certain circumstances try to influence people to end their lives, even if that is not really the patient's preferred choice.

128. The American College of Physicians also raises important social justice issues about euthanasia. They are concerned that people can be made to feel they are a burden and that the patient seeks euthanasia for that reason. This has some support in the Dutch experience. Dr Kimsma informed me that most of his euthanasia patients did so, not from pain or a terminal disease but because they felt that they had grown old and lost the dignity of their lives. This is consistent with the concerns of the American College.

129. The American College of Physicians Paper also notes that, in jurisdictions where there is physician-assisted suicide, rather than total suicides reducing, (contrary to the justification that this Bill will reduce terminal patients who currently kill themselves) the availability of euthanasia has seen a 6% increase in total suicides. This may also reflect that legislation of this kind could convey to some people that suicide is acceptable if the State sanctions it, which is contrary to a raft of government suicide prevention programs in recent years.

Concerns of Doctors

130. Many of these concerns are held by the local doctors that I consulted. On a number of occasions, I have had discussions with doctors about the changing nature of trust between patient and doctor that would result from a doctor being not just the maintainer of life but also under the Bill becoming an ender of life. The implications for trust between doctor and patient and the standing of the medical profession was also a matter of concern to some medical practitioners.

131. Many doctors expressed to me a concern about this law being a thin edge of the wedge. They are concerned that a right to die can become a duty to die. Furthermore, patients without a terminal illness who have chronic pain will ask for the right to die. The concern was that, whilst initially a law designed to hasten people's death who are already certain to die, the law could devolve

over time to apply to people without chronic pain or terminal illness, as in the Netherlands where people who are suffering simply wish to die are able to do so.

132. This concern about the legislation would appear to have some justification, having regard to what I was told of the operation in practice of the Dutch legislation. Doctor Kimsma advised me that many of his patients were not 2-3 weeks from death but had decided to use euthanasia because they felt that they had lost their dignity of life by reason of becoming incontinent, immobile or otherwise unhappy with the situation that they were in.

133. Great psychiatric skill, I was advised, is required to ascertain whether the request to die is being generated by a depressive mood or a grief reaction from being told that a person has a terminal illness. Not all psychiatrists are skilled in these diseases nor are all psychologists. Medical training will not assist with the detection of coercion or pressure upon patients to request to end their lives.

Adequacy of Palliative Care

134. There is necessarily a relationship between palliative care and the need for assisted dying. The large boost in palliative care funding in the last budget has expanded the availability of better pain management across the State. Family anecdotes as to poor pain management in the death of a loved one many years ago may no longer be relevant to the current environment.

135. In determining the need for this legislation, I tried to get a feel for the number of patients who, when palliative care was available, did not respond to treatment.

136. One of the physicians told me that he had between 2000-2500 cancer patients per year. Less than 1/1000 patients were unable to have adequate pain management. The patients whose pain management was not adequate, were patients with what he described as "existential pain." Due to cultural or

belief system issues, the patients appeared to want to feel pain. With the use of psychologists or social workers, these patients were able to receive better treatment. The physician also informed me that new and improved approaches to palliative care were allowing fewer drugs (and therefore fewer side effects) and a better quality of life for terminally ill patients.

137. In the course of investigating this paper, I have taken the opportunity at public meetings or Party meetings to ask people to share with me their views on euthanasia. My impression is many people, at a high level of abstract thought, support euthanasia. But that support is without necessarily having considered many of the issues raised in this paper. Indeed, many have said to me that they supported it before having reservations, after discussing some of my practical concerns, about how such a law would operate. Many support euthanasia because they would like to have it as an option should they be dying a painful death – they would like euthanasia as a fall back option.

138. The people who feel most strongly about euthanasia from my discussions are a small minority of people. This is supported by the 2016 Senate results in NSW where the Voluntary Euthanasia Party received less votes then the Australian Motoring Enthusiasts Party, the Jacquie Lambie Party, the Cyclists Party, Drug Law Reform and half of the votes of the Australian Sex Party or Animal Justice Party and about 1/10th the vote of the Christian Democratic Party or Pauline Hanson's One National Party. Usually those who feel strongly about euthanasia have explained they have formed their opinions as a result of having a close family relative or friends who have had an unpleasant death. When recounting their own personal experience, people have frequently become very emotional. A relatively high proportion of these people have communicated to me that the person who was dying requested that they kill the patient and it is clear that there is a feeling of guilt that they did not comply with that request or, even if not asked to kill the patient, they nevertheless are guilty that they were suffering. It is understandable that to have a request made of them to kill a patient would be highly traumatic.

139. One of the palliative care specialists whom I consulted and who has worked in the area for 22 years gave me an account of a patient who was a friend of the specialist and died in circumstances where the pain management was good and the patient's family and friends were around the patient when she died. The specialist met a mutual friend about a week afterwards who expressed sorrow at the terrible circumstances in which the friend passed away.

140. This story raised the question of whether the psychological grief experienced by surviving relatives and friends may not be unknowingly transferred onto the dying relative or friend.

141. However, under our current system, doctors report very few requests from patients to die. Their experience is that the overwhelming majority of people want to cling onto life rather than to die early.

Modified Scheme?

142. As already discussed, the legislation will allow a terminally ill patient to end their life in circumstances where they are not undergoing any pain. Better legislation could be drafted which is tailored to particular circumstances surrounding particular diseases e.g. for motor neurone disease or chronic cardiac pain and the like in certain circumstances a patient could request to die even if it is not known when they will die; cancer patients could have assisted dying when they cease treatment and go into "comfort only" assistance if they are in physical pain and the patient was not responding to palliative care. The Bill would appear to be trying to do too much in a general fashion and, without sufficient medical focus, making it then inadequate for everybody.

Coercion

143. It would seem to me generally that there is a tension between crafting protections against vulnerable patients being coerced (by third parties) into

believing that they should kill themselves under the Bill and the speed with which it may be reasonable for them to want to die if in pain. This may be a tension which may never properly be resolved. The doctors tell me that very few people now ask them to die prematurely. It could be that it is undesirable to help the small number of people who would wish to end their life prematurely because it would create a new class of disadvantaged persons, namely patients with terminal illnesses who are vulnerable to being coerced into killing themselves.

144. The law has various protections against coercion, when a person is forced to, for example, enter into a contract, however, when the circumstances of duress no longer exist, the person the subject of coercion can seek relief from the legal relationships created because of the coercion. If a patient is assisted to die by coercion, there is no capacity to "bring back" the dead patient. This is a great dilemma with regard to assisted dying or euthanasia.

Cost

145. At a practical level, it is also necessary to raise the question of cost under the Bill. The Bill assumes that there will be multiple medical consultations. Only wealthy patients will be able to afford the professional fees involved in retaining the medical specialists, even under the Bill in its current form. Furthermore, the State government will have to divert funds from existing medical services to set up the Review Board. Also, if physician-assisted suicide is allowed by this Bill, and it becomes 4.6% of all deaths as in the Netherlands, many doctors are going to be tied up in the performance of the requirements of the Bill and not treating patients who are ill. These costs are part of the societal cost benefit analysis which needs to be considered before changing the status quo.

146. Furthermore, one of the doctors raised with me the time and cost and exposure to criminal prosecution which would be incurred by doctors who participate as the primary medical practitioner in assisted dying under the Bill. The doctor expressed the view that many doctors would be reluctant to be involved.

UNADDRESSED ISSUES IN THE AUSTRALIAN EUTHANASIA DEBATE

Margaret Somerville

INTRODUCTION

I have researched and written on euthanasia and physician-assisted suicide for four decades while holding academic appointments in both the Faculty of Law and the Faculty of Medicine at McGill University in Montreal. In a series of decisions, which I believe future generations of Canadians will seriously regret, Canada has recently legalized these interventions. I have just left McGill and Montreal to take a position as Professor of Bioethics in the School of Medicine at The University of Notre Dame Australia in Sydney and find myself immediately involved in the same debate about legalizing euthanasia and doctor-assisted suicide as we had in Canada.

As part of my involvement in these activities, I have written seven short articles focused on different aspects of the debate. They are gathered together below.

The first warns that the impact of legalized euthanasia, especially its risks and harms to vulnerable people, cannot be properly judged in isolation from the total social milieu in which it would be practised and looks at its dangers in a "post-truth" society in which the abuse of elderly people is endemic.

The second examines the unsupportable claim of pro-euthanasia supporters that the evidence from jurisdictions which have legalized euthanasia and/or physician-assisted suicide shows that legalizing these interventions does not open up any "slippery slopes".

The third reports on the strategy of pro-euthanasia activists seeking to eliminate opposition to the legalization of euthanasia by labelling opposition as just a religious stance and arguing that religion and values based on religion have no place in the public square.

The fourth explores the importance of stories in forming our shared values and the impact of "good death" stories and "bad death" ones on the stances we take in the euthanasia debate. It relates a case where providing euthanasia

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was a "bad death" story, in contrast to the usual "good death" stories associated with its provision by pro-euthanasia advocates.

The fifth describes a recent experience I had as an invited panellist on a Q&A session on "Voluntary Assisted Dying", held as part of Australian Medical Association Victoria Congress 2017. I experienced it as a serious suppression by pro-euthanasia advocates of my freedom of speech as a person who opposes the legalization of euthanasia. Legislators, in particular, need to be very aware of this danger in deciding for or against legalizing euthanasia.

The sixth looks at what we could learn of importance to the decision about legalizing euthanasia from the indigenous wisdom of looking back seven generations to consult human memory (history) and looking forward seven generations through imagination. If it is legalized and becomes the norm governing death, how will our great-great-grandchildren die? Will we have left to future generations a world in which no reasonable person would want to live?

And the seventh looks at the wider and deeper impacts of legalizing euthanasia beyond simply legalizing the intentional infliction of death and proposes that they include damage to important existential human experiences and our ability to find meaning in life.

Together these articles identify some of the unaddressed issues in the euthanasia debate. That they are unaddressed is not accidental. They are avoided by pro-euthanasia advocates because exploring them establishes the case against legalizing euthanasia.

The strongest case for legalizing euthanasia is made at the level of the individual, seriously suffering, terminally ill person, who is competent, gives informed consent and asks for euthanasia. The pro-euthanasia argument is that it is cruel to deny that request and kindness demands that it be honoured. The wider and deeper concerns and consequences that such honouring raises and results in, respectively, establish the case against legalizing euthanasia. I identify some of these concerns and consequences, which it is essential lawmakers take into account in deciding whether or not to legalize euthanasia.

Finally, just to be clear, as there is a great deal of confusion about the definition of euthanasia and doctor-assisted suicide, euthanasia is a doctor administering a substance to a person with the intention of killing the person, physician-assisted suicide is a doctor prescribing medication with the intention

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that the person should use it to commit suicide. Justified withholding or withdrawal of life-support treatment or the provision of fully adequate necessary pain management, even if that could shorten life, are not euthanasia or assisted suicide.

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i) POST-TRUTH, EUTHANASIA AND ELDER ABUSE: CONNECTING THE STORIES IN THE NEWS

Exploring the connections that can be made among three very recent stories in the news, which at first glance seem unrelated, can provide important insights and warnings. These stories are that "post-truth" is the Oxford English Dictionary's word of the year. That the Victorian Government will introduce an "assisted dying" bill in the second half of 2017 which, if passed, would legalize physician-assisted suicide and, in exceptional cases, euthanasia. And that the Australian Law Reform Commission has just released a discussion paper which documents elder abuse in Australia and seeks ways to prevent it.

a) "Post-truth"

Here's how Wikipedia describes "post-truth" in relation to politics: "Post-truth politics (also called post-factual politics) is a political culture in which debate is framed largely by appeals to emotion disconnected from the details of policy, and by the repeated assertion of talking points to which factual rebuttals are ignored. Post-truth differs from traditional contesting and falsifying of truth by rendering it [truth] of "secondary" importance." Or, one could add, of little or no importance at all.

In contemporary societies we increasingly use the prefix "post": post-industrial; post-modern; post-feminist; post-religious; and so on, and now post-truth. We know what we were, we know we are no longer that, but we don't yet know what we now are or are becoming.

Words are the tools of both truth and lies, so words matter. Nowhere is this truer than in the euthanasia debate.

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b) The euthanasia debate

Word changes can be subtle and nuanced. So, for instance, when, as has happened in promoting the legalization of euthanasia and physician-assisted suicide, more words are used to describe something that already had a name – euthanasia has become "physician assisted dying" and even the word death is dropped - we should know that we are being manipulated and something is being concealed. That something is the intentional infliction of death.

The strongest case for the legalization of euthanasia is made at the level of the suffering identified individual who wants to die when and how they choose. Pro-euthanasia activist Andrew Denton makes the case for legalizing euthanasia in this way in describing his father's death. We feel compassion for his father and Mr. Denton, himself, for the suffering they both endured and our hearts rightly go out to them.

In a post-truth society feelings matter more than facts, the heart rules the head. So the facts about the larger impact of legalizing euthanasia – what it will mean for healthcare institutions, professions and professionals; how it will damage foundational societal values, such as respect for human life in general and the prohibition on intentionally killing another human being, except to save life; the impact in the future of normalizing euthanasia; and so on - are ignored or even denied.

Even hard factual evidence is rejected: In Canada the courts accepted the pro-euthanasia claim that in the Netherlands and Belgium, where euthanasia is legal, there was no "logical slippery slope" (the situations and persons eligible for euthanasia expand rapidly and very substantially once it is legalized) or "practical slippery slope" (euthanasia is carried out in breach of the law, especially on vulnerable people), when the evidence is clearly otherwise, as has been recognized by the Irish Supreme Court and most recently the Supreme Court of South Africa.

We can question whether the current "progressive values" stance of giving priority to respect for individual autonomy over upholding values, such as respect for life, needed to protect the common good, means that we have become a narcissistic society, one focussed just on individuals' claims, and that the denial of facts which would cause us to reject those claims is a "narcissistic unawareness".

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I hasten to add here that I am not denying the importance of feelings - they are one of the central ways of "human knowing" - but facts are, at the least, equally important, not least because good facts are essential for good ethics and good ethics is essential for good law.

And so to the third story where facts are needed and serious concerns raised about the abuse of one group of vulnerable people, namely, the elderly.

c) Elder abuse

Here's a 12th December 2016 ABC website headline: "*Elder abuse inquiry calls for power of attorney changes to stop children ripping parents off*".

The post continues: "A national register of enduring powers of attorney should be established to prevent greedy children from using the document as a "licence to steal" from their elderly parents, the Australian Law Reform Commission (ALRC) says", referring to an ALRC discussion paper which is part of its inquiry into elder abuse, which includes elderly persons being victims of financial fraud. The paper notes "the potential for pressure and coercion in setting up the instruments [the powers of attorney appointing children to act on their parent's behalf]" and that "early inheritance syndrome" is on the rise.

> "With Australians living longer than ever before, the ALRC inquiry heard many examples of children who were impatient to get their hands on their parents' money and tried to claim their inheritance before they were entitled to it.
>
> This is often described as "early inheritance syndrome".
>
> "It's as if the current generation wants it now and somehow they justify that it's okay to take mum or dad's money right now," said Aged and Disability Advocacy Australia CEO, Geoff Rowe."

There are no concrete statistics on the prevalence of elder abuse in Australia, but a 2016 research report to the Australian Government Attorney-General's Department states that

> "at the international level, the WHO (2015) recently reported that estimated prevalence rates of elder abuse in high- or middle-income countries ranged from 2% to 14% … and that the perpetrators are likely to be related to the victim… [and] one study suggests that neglect could be as high as 20% among women in the older age group (Australian Longitudinal Study on Women's Health

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> [ALSWH], 2014). Older women are significantly more likely to be victims than older men, and most abuse is intergenerational (i.e., involving abuse of parents by adult children), with sons being perpetrators to a greater extent than daughters."

d) Combined effect

So consider in a "post-truth" society the combined effect in relation to elderly persons of "pressure and coercion", "early inheritance syndrome", abusers' self-justification of the abuse, 2% to 14% of elderly persons being victims of abuse, abusers being relatives, and women being more at risk than men, in the context of legalized euthanasia. At the very least, we should have second thoughts about whether legalization is a good idea.

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ii) DENIAL OF "SCOPE CREEP" AND ABUSE IN EUTHANASIA: LOGICAL AND PRACTICAL SLIPPERY SLOPES

For a long time, it's puzzled me how proponents of the legalization of euthanasia can confidently claim, as they do, that in the Netherlands and Belgium, the two jurisdictions with the longest experience of legalized euthanasia, there have been no slippery slopes, when the evidence is clearly otherwise.

a) Definitions

The "logical slippery slope" occurs when the legalization of euthanasia for a very limited group of people in very limited circumstances is expanded to include more people in more situations. This has been described as "scope creep".

The "practical slippery slope" occurs when euthanasia is carried out in breach of the legal requirements as to either who may have access or the situations in which they must find themselves for euthanasia to be permissible.

b) Logical slippery slope

The logical slippery slope is inevitable once euthanasia is legalized and becomes common place, as we can see in what has happened in the Benelux

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countries. It's been rapidly expanded to more and more people in more and more situations. This is entirely foreseeable and to be expected. As we become familiar with interventions which we once regarded as unethical, our moral intuitions and ethical "yuck" factor responses become blunted and we move from rejection to neutrality, often even to approval of the action involved.

Legalizing euthanasia means that the rule that we must not intentionally kill another human being – this line in the sand which we must not cross, this most ancient ethical and legal barrier – is breached, indeed annihilated, and beyond it there is no other obvious stopping line which we must not violate, perhaps not even that euthanasia is only acceptable with the consent of the person on whom death is inflicted. People with Alzheimer's disease and other dementias have been euthanized in the Netherlands and Belgium.

Anti-euthanasia adherents believe that the prohibition on intentional killing of another human being is a line we must not cross, not only, because intentional killing is inherently wrong, but also, because, as British moral philosopher Dame Mary Warnock has put it, "you cannot successfully block a slippery slope except by a fixed and invariable obstacle", in the case of euthanasia, the rule that we must not intentionally kill.

There could also be a further explanation for the denial of a logical slippery slope by pro-euthanasia advocates, such as Oxford University bioethicist Professor Julian Savulesco and Andrew Denton in his address to the National Press Club, screened on ABC TV and iView, which is less obvious at first glance. This is that no potential slippery slope exists.

The basis for the pro-euthanasia case is that we must have respect for an individual's autonomy – their right to self-determination - including with regard to a decision that they prefer death to continued life and want help in terminating their life. Once that rationale is accepted and applied in its fullest sense, it's difficult to justify restrictions on access to euthanasia. Consequently, the diminishment or repeal of existing restrictions is not recognized as a slippery slope, rather, it's seen simply as more fully implementing respect for individual autonomy and the right to self-determination - the rationale used to justify euthanasia in the first place.

Consequently, it should not be surprising that the Dutch are now considering a special form of access to intentionally inflicted death for those who believe they have a "completed life", which they do not want to call or

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treat as euthanasia, although it involves the same type of death-inflicting intervention. The movement to legalize such an intervention started with a petition to the Dutch Parliament that those who were "over seventy and tired of life" should be able to have assistance in terminating their lives. The age requirement can be questioned as being inconsistent with the right to self-determination rationale for allowing the intentional infliction of death and it's been reported that debate has begun in the Dutch media on eliminating it.

c) Practical slippery slope

Pro-euthanasia advocates' denial of a practical slippery slope – administration of euthanasia other than in compliance with the law – despite clear evidence to the contrary, might also be able to be explained on a related basis. If one believes there should be more or less open access to euthanasia, then legal requirements are annoying impediments and their breach is a trivial matter and as the old saying goes "de minimis non curat lex" – the law does not concern itself with trifles.

Another element in this denial might be acceptance of the "non-deprivation justification" of euthanasia, which was considered approvingly by Canadian courts in ruling that an absolute prohibition of euthanasia was unconstitutional. The rationale of this argument is that a person's quality of life can be so bad, that the bad in continuing to live outweighs any good experienced in doing so, such that nothing good is lost if one is euthanized – there is no deprivation of anything worthwhile or valuable - indeed death can be seen as a benefit.

A breach of the law which is seen as trivial and as conferring a benefit is unlikely to be characterized as an abuse by those supporting euthanasia and so, like the logical slippery slope, the practical slippery slope is defined out of existence.

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iii) EVICTING RELIGIOUS VOICES FROM THE PUBLIC SQUARE IS ANTIDEMOCRATIC AND DISCRIMINATORY

a) "Label as religious and dismiss" strategy

The Australian reports "Denton tells church to get out of euthanasia debate" (August 11, 2016) and the ABC website that "Andrew Denton has

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lashed out at a 'subterranean Catholic force' of politicians and businessmen who he claims continue to thwart attempts to allow legally assisted voluntary euthanasia in Australia."

This is the "label as religious – in particular, Roman Catholic - and dismiss" strategy of pro-euthanasia advocates. It's applied to both clergy and members of the public with religious beliefs. The strategy is founded on the argument that religious beliefs are unacceptable as an informing principle for values decisions other than purely personal ones, especially those decisions relevant to public and social policy, and, consequently, religious people's voices should be excluded from the public square.

It's a strategy used to avoid addressing the arguments or views of people with religious beliefs, whether or not their arguments and views are religiously based: They *and their arguments* are dismissed simply on the basis of having a religious affiliation. The assumption underlying this strategy and purportedly justifying it is that people who have religious beliefs are puppets of their Church - unthinking, uncritical automatons.

People like Mr. Denton, who use this strategy, overlook that everyone has a belief system. For example, secularism and atheism are belief systems, yet their adherents are not automatically dismissed for being such and should not be, because in a democratic society everyone has a right to a voice in the public square. To silence people because they are religious is anti-democratic and discrimination, just as silencing atheists and secularists would be.

If Mr. Denton has good arguments against his Catholic opponents' positions he should present them and show why these Catholics' arguments should not prevail, instead of trying to suppress them. Indeed, his efforts to do the latter raises the issue of whether he believes his arguments will fail if they are competently challenged.

b) Emotions and moral intuitions matter

The euthanasia debate involves ethical decision-making, therefore, not only reason, but also other human ways of knowing, such as "examined emotions" and intuition, especially moral intuition, play an important role. A wise axiom in applied ethics is that "we ignore our feelings at our ethical peril." That is not to say we should act just on the basis of our emotional reactions, but that we must carefully examine these reactions and take them into account in ethical decision making.

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We must react with compassion and care for people who are suffering from horrible illnesses, but our reaction should be to kill the pain and suffering, not the person with the pain and suffering.

Humans have an innate reluctance to killing another human being and rightly recoil from doing so. Indeed, in the past, soldiers have been psychologically deprogrammed in order to be able to kill an enemy soldier at close quarters. So might we need to be more concerned about the ethics of doctors willing to inflict death, than the ethics of those who refuse to do so for reasons of conscience or religious belief?

A case in point has arisen in Canada where euthanasia has recently become legal. Pro-euthanasia advocates are trying to force doctors with conscientious or religious objections to euthanasia to participate in it, which is clearly unethical and wrong. We should keep in mind that a doctor's good conscience is a patient's last protection.

c) Words matter

Our choice of language is important and influential with regard to emotional and intuitive responses. For instance, Mr. Denton's use of the word "subterranean" in describing "a Catholic force" brings to mind secret, dark, nefarious forces and conspiratorial activity.

Pro-euthanasia advocates such as Mr. Denton speak in the neutral terminology of "assisted death" (we all want medical assistance when we are dying). They assiduously avoid the language of doctors inflicting death on their patients or, even more graphically, being allowed to kill them, as these latter descriptions rightly raise many people's moral and ethical concerns about this practice.

Very recently, Mr. Denton announced the launch of a pro-euthanasia lobby group called "Go Gentle Australia". It sounds like a catchline in an advertisement for Kleenex or toilet paper.

d) Seeking meaning in suffering

Mr. Denton had a traumatic experience with his father's death and is seeking to have some good – his perception of what is good - come out of that. He wants to make sure that others will benefit from the suffering his father endured by trying to ensure that they do not experience the same suffering. In

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short, he wants to give his father's suffering meaning. Seeking meaning, especially in suffering, is innate to being human.

However, euthanasia will seriously harm our capacity to find meaning in the face of death, not promote it. It converts the mystery of death to the problem of death and offers a quick-fix technological solution to the problem, a lethal injection.

In contrast, making available fully adequate access to high quality palliative care for every Australian who needs it will help people to find meaning in the last days of life until death occurs naturally.

I note here that seeking good for others out of a traumatic medical event, such as Mr. Denton and his father experienced, is a very common reaction of people who themselves or their child, spouse or parent have been the victim of medical malpractice. Failure to take all reasonable steps to relieve the pain and suffering, especially of terminally ill people, is medical malpractice and, as is recognized in the Declaration of Montreal 2010, a breach of fundamental human rights.

I also note that the case Mr. Denton describes in his submission to The New Zealand Parliamentary Health Select Committee of the dying woman, who was in excruciating pain but refused pain management until a certain pre-determined time represents a gross violation of ethical medical practice, unprofessional conduct, medical malpractice (actionable negligence) and possibly criminal negligence. (See the Declaration of Montreal on pain management, which has been affirmed by the World Health Organization and the World Medical Association, which represents 9 million doctors worldwide.) This patient needed competent palliative care, not a lethal injection.

e) Identifying wider and deeper issues

The strongest case for legalizing doctor-assisted suicide and euthanasia is the one Mr. Denton makes, that is, the relief of the suffering of individual competent adults who want and consent to this. But, in deciding as a society whether to legalize doctor-assisted suicide and euthanasia, we must look beyond what an individual might want and consider far wider issues.

Importantly, these include:

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- the impact of euthanasia on fragile or vulnerable people – those who are old or live with disabilities, or even just perceive themselves as a burden on their families;
- the impact on suicide prevention of the normalization of suicide as an acceptable response to suffering; and
- what it means for society and our shared values to move from caring for those unable to care for themselves to killing them.

What would be the impact on important values, such as respect for human life, in general, in society? Respect for life must be upheld at both the individual and the general societal level.

If fully adequate palliative care is not available, what would it mean that we are saying "we will not care for you but we will kill you"? Religion used to carry the value of respect for life for society as a whole, but in a secular society, such as Australia, the institutions of law and medicine carry this value. How would their capacity to do this be affected by society changing the law to allow the infliction of death and permitting doctors to do that?

f) Outcome in practice of legalizing euthanasia

Finally, what would the practical reality be if euthanasia were legalized in Australia? Most advocates of euthanasia propose there's no danger in legalizing it because it will be rarely used and only in extreme circumstances. Mr. Denton is reported as saying that "less than 4 percent of deaths in The Netherlands were as a result of assisted death", seemingly, and quite astonishingly, as demonstrating that this is a rare outcome. But if the same rate applied in Australia as in The Netherlands, using the lower more accurate figure of 3.6 percent, there would be around 5000 euthanasia deaths each year. Are we prepared to allow that? Can we live with it?

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iv) THE IMPORTANCE OF STORIES IN THE EUTHANASIA DEBATE

a) Making the pro- and anti-euthanasia cases

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The pro-euthanasia case is compact and quick and easy to make: It focuses on a terminally ill, seriously suffering, competent adult who gives informed consent to euthanasia and bases its claims to prevail on the obligation to respect that person's right to autonomy, self-determination and dignity.

The case against euthanasia is more complex and time-consuming to establish. It requires placing euthanasia in a much wider context that takes into account, among many other considerations, what its impact would be, not only in the present, but also in the future, and what protection of both vulnerable people and society demands.

b) Clash of values

Euthanasia involves a clash of two important values: respect for individual autonomy and respect for life. Pro euthanasia advocates give priority to autonomy; anti-euthanasia proponents to respect for life.

Respect for life is not just a religious value as pro-euthanasia advocates argue. All societies in which reasonable people would want to live must uphold respect for life and at two levels: Respect for every individual human life and respect for life in society in general. Even if legalizing euthanasia were viewed as not contravening the former, it seriously harms the latter.

Both the pro- and anti- euthanasia sides in the euthanasia debate are trying to persuade the public to affirm their stance. So how are they presenting their cases to the public?

c) Shared "death stories"

We form and support or reject the shared values on which we found our society, in part, by creating stories that we tell each other and buy into, in order to create the glue that binds us together as a community.

The pro-euthanasia case relies on "bad natural death" stories - stories of the extreme suffering of some terminally ill people who die a natural death - and characterizes and promotes euthanasia as an essential-to-provide kindness and its prohibition as cruelty.

Anti-euthanasia advocates often counter these stories with "good natural death" ones of people dying naturally and peacefully, in the presence of those they love, feeling that they have had a completed life. ("Good death" stories do not assume that death can be good, but rather that the process of dying a natural death can be "good" or "bad" and that we can to a large extent

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influence which of these it is by the physical, psychological and spiritual care that we provide to the dying person.)

But there are also some "bad euthanasia death" stories, which support arguments against legalizing euthanasia. One, by journalist Guilia Crouch, was posted on the Mailonline on 28th January 2017. (http://www.dailymail.co.uk/news/article-4166098/Female-Dutch-doctor-drugged-patient-s-coffee.html-) It gives an account of the following facts:

Last month, a Dutch Regional Euthanasia Review Committee reported on a case brought before it: The woman patient had dementia. A woman doctor put a sedative in her coffee as a prelude to euthanizing her. The doctor said she didn't tell her of the sedative or her plans for euthanasia, "because she did not want to cause her [patient] extra distress". In deciding to euthanize her patient, the doctor was relying on a phrase in the patient's declaration in her will that she could consider euthanasia "when I myself find it the right time".

While being injected with the lethal drug, the woman woke up. She struggled and the only way the doctor could continue with the injection was by asking the woman's family to help to restrain her, while she continued with the injection. The woman's case notes recorded that she had said several times during the previous days, "I don't want to die".

The review committee concluded that the doctor "had crossed the line" by secretly giving the sedative and not stopping the injection when the woman resisted and had too broadly interpreted the woman's declaration, but that the doctor had acted in "good faith" and should not be punished.

However, the chair of the review committee wants the case brought to court to create a precedent to enable other doctors to lethally inject people with dementia, without fear of legal repercussions.

d) So what can we learn from this story?

Even if we believe that euthanasia is not inherently wrong, its risks and harms to vulnerable people – those with disabilities, the elderly and the fragile - outweigh any benefits.

I have written previously, about the Australian Law Reform Commission's research on elder abuse - between 4 and 14 percent of old people are abused most often by a close relative. It's hard to imagine a more extreme form of

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abuse than helping a doctor to euthanize an elderly relative by restraining the "loved one" who doesn't want to die.

The Commission was concerned in particular about "early inheritance syndrome", where a person, usually a child of the old person, obtains a power of attorney and uses the financial assets of their parent for themselves.

Many people worry about the cost of residential care for their elderly relatives and heirs see "their" inheritance, to which they feel entitled, dissipating. Many old people say they would rather be dead than go into a nursing home. Imagine adding euthanasia to this situation – it would certainly be a lethal cocktail.

e) Moral hazards

Euthanasia is, what is called in ethics, a moral hazard – that is, it opens up possibilities of breaches of ethics, such as I've just described.

A response might be that the moral hazard risk of euthanasia can be avoided if only assisted suicide is legalized. But it too is a moral hazard. Research shows that high on the list of reasons people want to die is that they feel that they are a burden on loved ones and there is an ever present danger of coercion.

There is also a broader moral hazard from assisted suicide: the general suicide rate has increased in jurisdictions that have legalized assisted suicide. (http://sma.org/southern-medical-journal/article/how-does-legalization-of-physician-assisted-suicide-affect-rates-of-suicide/; http://alexschadenberg.blogspot.ca/2016/03/rushing-toward-death-euthanasia-in.html) This is not surprising: state sanctioned assisted suicide endorses suicide as an appropriate response to suffering and suicide is contagious. Suicide is also the leading cause of death in young adults. This is a serious and major public health concern, which legalizing assisted suicide would only magnify.

How could this Dutch doctor have done what she did? That same question has been pondered over and over again in relation to the Nazi doctors.

It's a result of a process of incremental desensitization of the doctor to what is involved: namely, killing her patient.

This desensitization results from multiple factors: Placing the "white coat" of medicine on euthanasia carries with it messages of the ethical validity of

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euthanasia and its kindness. The language used to describe euthanasia is massaged and euphemized. The doctor is blinded by a conviction that this is best for the patient and she's only doing good for her. The doctor has no conscious recognition that this is not medical treatment and that she is acting contrary to medicine's healing mandate and beyond the proper goals of medicine.

The doctor's equanimity may, however, be only on the surface. At a deeper level of the psyche, carrying out euthanasia may have harmful impact on healthcare professionals. Doctors in the Netherlands and Canada are opting out because they are suffering mental trauma, including PTSD, from providing it. Some Canadian doctors who placed their names on a list of doctors willing to provide euthanasia withdrew their names after undertaking their first case saying it was too traumatic for them and they never wanted to do it again. (http://alexschadenberg.blogspot.com.au/2017/02/canadian-doctors-are-struggling-with.html?utm_source=EPC+Contacts&utm_campaign=b51a17a348-EMAIL_CAMPAIGN_2017_02_15&utm_medium=email&utm_term=0_d113c154ac-b51a17a348-157716225)

This too is not surprising: Doctors are trained to heal and save life wherever possible, not to intentionally take life. And all mentally healthy human beings have a powerful instinct against killing another human being.

We must never ignore the heart wrenching pleas of both those who are suffering and those who love them and want the loved one's suffering ended. But we must kill the pain and suffering, not the person with the pain and suffering.

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v) SHUTTING UP BY SHOUTING DOWN: THE SUPRESSION OF ANTI-EUTHANASIA STORIES: RESPECTING BOTH SIDES FREEDOM OF SPEECH IN THE EUTHANASIA DEBATE

a) The context

Very recently, I was a participant in a Q&A panel on "Voluntary Assisted Dying" at the Australian Medical Association Victoria Congress 2017. I was

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pleased to have been invited and hopeful that there would be a balanced discussion, but also somewhat concerned that might not be realized in practice, given the membership of the panel.

The panel participants included the well-known advocate of the legalization of doctor-assisted suicide Andrew Denton and the leader of the Greens, Senator Richard Di Natale, who also supports its legalization in certain circumstances.

Unfortunately, my concerns materialized.

b) The events

First, my participation in the discussion was limited in several ways. Shortly before the event, the chair telephoned to tell me that the question of whether or not legalizing doctor assisted suicide or euthanasia was a good or bad idea, ethical or unethical, was not open for discussion.

She explained that the only topic to be discussed was the conditions which should apply for access to assisted suicide and how it should be regulated. In short, the panel was based on an assumption that legalizing assisted suicide was inevitable in Victoria, even though legislation has not yet been tabled in the Victorian Parliament, let alone debated or enacted. This assumption is a pro-assisted suicide/euthanasia strategy as it leads people to believe there is no point in discussing views opposing legalization.

Legislative bodies only regulate conduct that they and the community consider to be ethical under certain conditions and they regulate to set out those conditions. We prohibit conduct we believe to be inherently unethical, as those who oppose euthanasia believe it to be. Consequently, discussing regulation affirms the ethical acceptability of assisted suicide and euthanasia.

On more than one occasion, I was told by the chair that I had been invited as a lawyer and not an ethicist, despite the fact that the latter has been my main professional role for forty years. Given this proviso, it was not unexpected that the questions addressed to me from the chair were purely legal ones; for instance, I was asked to define mental capacity and dignity. This gave me speaking time and an appearance of fair time allocation among panellists, without my necessarily being able to address the anti-assisted

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suicide/euthanasia arguments I wanted to propose, but I took the opportunity to present briefly some of them.

A theme developed by the panellists who agreed with legalizing assisted suicide was that being absolute on the issue of its legalization is “not helpful” and that the voices in the public square debate should be those of reasonable people who were not absolutists. This, in fact, amounts to another pro-euthanasia strategy, because if one is not against the legalization of assisted suicide or euthanasia, one is necessarily for it in some form. While some people might be uncertain where they stand, and many people say they are, there is no entirely neutral position.

At the beginning of the event, the chair told the audience that they should text questions to her and that she would collate and present them; those who did not have an iPhone were told they should raise their hand and ask the question in person. She added that if the questioner spoke for too long or was presenting commentary or policy, rather than a question, the audience could shout “No, no, no!” and she would cut off the person.

It seems reasonable to assume this invitation was offered only in relation to an audience member asking a question. But when I prefaced an intervention by saying that I wanted to describe a case of euthanasia that showed its risks and harms, the chair interjected and said “No stories please”, and a substantial percentage of the audience immediately joined in to shut me down, shouting, “No, no, no, no stories”.

In forty years of giving speeches on average around twenty five to thirty times a year, I have never encountered such an incident. Moreover, bear in mind that I was an invited guest speaker sought out by the AMA to be a Q&A panellist at the congress and the audience were all, or almost all, medical doctors.

This behaviour does not fulfil the requirements of respectful discussion. Indeed, it is designed to stifle, rather than facilitate, debate on an important social and medical issue, and I felt intimidated.

A positive aspect of the panel was that Andrew Denton - one of the very few people present who was not a medical doctor - did behave respectfully with regard to my anti-euthanasia arguments and towards me. And a positive and important message, delivered by the gerontologist and psychiatrist on the panel, was that we shouldn’t even be talking of legalizing euthanasia until we

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have fully adequate palliative care available to all who need and want it, which is far from the case at present in Australia.

In summary, I experienced this panel as involving silencing and intimidation and a failure to respect freedom of speech.

c) Self-censorship

Many people with traditional or conservative values, especially young people, when they encounter such experiences respond by self-censoring. They tell me, privately, that they share some of the values I present, but would never say so publicly for fear of being ridiculed or shamed or, even, not being employed or promoted. The same is true of many conservative politicians who fear losing votes.

Indeed, I had initially decided not to publish this article for fear that I and the case against doctor-assisted suicide and euthanasia would be discredited by being characterized as extreme and summarily dismissed. But then I realized that I, too, was falling prey to self-censorship.

We should also always keep in mind in the euthanasia debate that whether we are pro- or anti- legalizing doctor-assisted suicide and euthanasia, we have a common goal of relieving suffering. Where we disagree is the limits on the means we may use to do this. As I've written elsewhere, I believe we should kill the pain and suffering, not the person with the pain and suffering.

d) The wider consequences

The vignette that I describe has wide moral and ethical implications in relation to the quality and character of public debate, which is essential to a healthy democracy and maintaining a society in which reasonable people would want to live.

Perhaps one of the most disturbing aspects of this event is that it was an Australian Medical Association Victoria congress and, as I've noted already, almost everyone present, whether as speakers or in the audience, was a medical doctor. In secular, democratic, pluralist, multi-cultural societies like Australia, medicine is a major values-creating and values-carrying institution for society as a whole, because it is one of the few institutions to which we all personally relate. That means it must be open to taking into account the full range of people's commitments and values systems.

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We need to ask whether, in the organization and conduct of this doctor assisted suicide-euthanasia panel, the AMA Victoria lived up to its responsibilities in this regard.

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vi) LESSONS FROM INDIGENOUS WISDOM IN THE EUTHANASIA DEBATE

a) Looking to the past and the future in deciding about legalizing euthanasia

Some time ago, I was a member of an ethics committee set up as part of the Nuclear Waste Management Organization established by the Canadian Government to advise it on how it should deal with the complex issue of the disposal of nuclear waste.

At the first meeting of the committee, the chairperson asked us each to introduce ourselves and to make some brief remarks relevant to the disposal issue.

George Erasmus, who was the national chief of the Assembly of First Nations from 1985 to 1991, was a committee member. When it came to his turn, after a long moment of silence, George said softly, "Well if it had been up to us, we would never have been in this position, because we would never have allowed the technology that results in nuclear waste. We would have looked back seven generations for lessons from our ancestors and looked forward seven generations to its risks and harms to future generations and decided against its use."

George's words came to mind as wise advice for those of us engaging in the legalization of euthanasia debate currently raging in Australia. They struck me as especially *a propos* in light of the fact that Aboriginal and Torres Strait Island and First Nations communities in Australia and Canada, respectively, are, in my anecdotal experience, uniformly and adamantly opposed to euthanasia. What might these indigenous communities be perceiving that pro-euthanasia advocates are not?

Looking back seven generations is to consult history or, as John Ralston Saul evocatively calls it, "human memory".

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Since the time of Hippocrates 2,400 years ago, medicine has a history of the absolute prohibition of physicians intentionally killing their patients. Why now do some people want to abandon this foundational value guiding the practice of medicine?

We have always been faced with death and suffering and have never seen euthanasia as ethically acceptable medical treatment or, indeed, as medical treatment. Why then, when there is so much more we can do to relieve suffering, might our society suddenly think it is a good idea to allow doctors to inflict death? The contributing factors are multiple and complex, but at base the cause is a sole focus on upholding the individual's absolute right to autonomy and "choice", to the exclusion of other balancing considerations that should be taken into account.

b) The need to protect individuals AND the common good

These other considerations include what approach is needed to protect the common good, that is, the well-being of the community as a whole, not just the wishes and claims of an individual person, important as these are. The cultures of indigenous peoples are more cognisant of this need to protect the community and attuned to it, which could be one reason they reject euthanasia.

Pro-euthanasia advocates adamantly reject that the history of the Nazi horrors has anything to teach us and scorn anyone who dares to suggest that, when judiciously examined, it might provide insights and warnings. It's true that we will not see a Holocaust resulting from the legalization of euthanasia, but some of the origins of the Holocaust - in German doctors' involvement in small, allegedly well-motivated and compassionate medical acts and the justifications used to validate these acts - carry serious warnings that deserve attention in the current debate.

In using their imaginations to look forward seven generations in order to be warned of future harms and risks to their descendants, indigenous communities are again seeking to protect not only individuals, but also the community. How a person dies, when death is caused by euthanasia, affects not only that person, but also unavoidably affects others and the community, and not just in the present but also in the future.

To summarize, the strongest case for legalizing euthanasia is based in radical individualism and "presentism". It focuses on a suffering, competent

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adult individual who asks for and gives informed consent to euthanasia to the exclusion of the impact on the community of allowing euthanasia, and ignores what we could learn from considering it in the context of both the past and the future.

c) Questions we must address

So in deciding about legalizing euthanasia we should learn an important lesson from indigenous wisdom and ask ourselves questions which include: How do we *not want* our great-great-grandchildren to die? What must we *not do* now if we are to leave to future generations a society in which reasonable people would want to live? Would an Australian society in which euthanasia had become a norm be such a society?

In thinking about that last question, further realities can be brought to light. If, as Andrew Denton claims, Australia will have the same rate of deaths by euthanasia as the Netherlands and Belgium, around 4 percent of all deaths, that will result in around 6000 euthanasia deaths annually, which would make euthanasia the sixth leading cause of death in Australia. It would fall between respiratory diseases and diabetes on the Australian Bureau of Statistics "Causes of Death 2015" list, and there would be 25 percent more deaths by euthanasia than from diabetes, five times the number of deaths from road accidents (1200 per annum) and twice the number of deaths from suicide (3000 per annum). Could Australians accept that?

The population of the Victorian town of Lakes Entrance is just under 6000. Would they be comfortable with wiping out with euthanasia each year the same number of people who presently live in that town?

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vii) THE FLIGHT FROM MYSTERY: CHOICE, CONTROL AND FINDING MEANING AT THE END OF LIFE: THE CHALLENGE OF EUTHANASIA

a) "Choice, change and control"

People who espouse "progressive values", who include those advocating for the legalization of euthanasia, adopt a mantra of "choice, change and control".

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Choice maximizes respect for individual autonomy which is the preeminent value of “progressivists”. Choice also allows change to be implemented and “progressivists”, often naïvely, simply assume that change is always for the better. And power to change can give one a power to control or at least an illusion that one is in control.

Why only an illusion? There are some things that we cannot control, or indeed change, no matter how much we might like to be able to do so. Death is one of them.

It’s an innate human characteristic to search for meaning and we do that whether or not we are religious. The questions the vast majority of us ask, “Who am I?” “Why am I here?”, manifest and articulate our search for meaning. Many of us recognize that there is a mystery at the centre of our responses to those questions, which are asked most powerfully in seeking meaning in relation to death. Consequently, death involves a mystery which we must accommodate. We can do that in various ways.

Euthanasia seeks to take control over death. It does so, as I’ve noted previously, by converting the mystery of death to the problem of death and offering a technological solution to that problem, namely a lethal injection. In doing so, it destroys the mystery of death and, thereby, the possibility of finding meaning in the presence of death.

I want to make clear that I am not promoting religion here, although that is one way, and was until the post-modern era the most common way, to find meaning, in particular in death. Rather, I am proposing that all of us need to be able to find meaning, if we are not to become nihilists and lead a life of despair. Today, many people find meaning in life by devoting themselves to a worthy cause that benefits others, including future generations, but that doesn’t help them to find meaning in death.

What I am proposing is that one of the serious harms of legalizing euthanasia is the intangible one of serious damage to our capacity to find meaning in death, which might be a requirement for finding meaning in life, in general. This might be caused, at least in part, by euthanasia’s impact of trivializing death.

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b) The importance of shared stories, intimacy and leaving a legacy

We hear many stories of "bad deaths" told in support of legalizing euthanasia. Our hearts rightly go out to the people involved and we recognize that their motives of relief of suffering are good. But if we do not want to set in motion a much wider range of harms that legalizing euthanasia unavoidably causes, I propose that we must kill the pain and suffering, not the person with the pain and suffering. This makes it imperative that fully adequate palliative care, including pain management, be readily available to all who need it.

We should also balance the stories of "bad deaths" with those of "good deaths" – or perhaps it's better phrased as deaths from which otherwise unavailable "goods" flow, not only to the dying person, but also, to many others. These include conversations that would never have taken place, reconciliations with family and long lost friends, and joys such as holding a first grandchild. French psychoanalyst Marie de Hennezel, who has cared for many dying people including President Francois Mitterand, describes this time and its possibilities as "intimate death".

When we are dying, the vast majority of us also want to be remembered, to leave a legacy of our presence on this planet, and as Canadian psychiatrist Dr. Harvey Max Chochinov and his co-researchers have shown, we can help people to do this through a structured psychotherapeutic intervention which they call "dignity therapy". This is an alternative to seeing euthanasia as necessary to respect a dying person's dignity, a frequent justification of legalizing euthanasia.

c) Managing terror of death

Social psychologists propose that not just individuals, but also societies have a psyche and that both can experience terror. When we have a strong free-floating fear of something, for example, death, we seek to take control of it to reduce our fear and anxiety. The social psychologists speak of responding with "terror management devices" or "terror reduction mechanisms". I believe euthanasia can be seen as such a device or mechanism for managing the fear of death. We can't avoid death, but euthanasia allows those who seek it to get death before it gets them.

As individuals and a society we hide death away by euphemising the word. It is almost "politically unacceptable" to use "death", "died" or "dead" in

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relation to a person's "passing". We hide from our fears, which hinders our own preparation for death. We could also see euthanasia as limiting the capacity of a dying person to help to prepare others for a "good death" by showing them what used to be called "ars moriendi" (t*he art of dying*). We have lost "death literacy".

d) Need for a deeper and broader societal conversation

Our conversation about whether it's a good or bad idea to legalize euthanasia needs to be much broader and deeper than it is at present. It's not sufficient just to focus on an individual suffering person who wants death inflicted, much as we must have the most sincere compassion for them and ensure that everything possible, other than killing them, is done to relieve their suffering.

Euthanasia raises profound issues about how we find meaning in life; its impact on law and medicine, the two institutions in a secular society which carry the value of respect for life for society as a whole; and its impact on one of our foundational values as a society, namely, that we must never intentionally kill another human being, except to save human life. Such considerations and many more must be taken into account in our decision making about legalizing euthanasia, if we are to act wisely and ethically. At present, the debate is very superficial and narrow and reduces one of the most solemn moments of life to a mere contractual undertaking.

CONCLUSION

Legalizing euthanasia would be a seismic shift in Australia's foundational societal value of respect for human life. It is different-in-kind not just different-in-degree from medical interventions we currently regard as ethical and legal. It is not, as pro-euthanasia adherents argue, just another small step along a path we've already taken in respecting refusals of treatment even if that results in death and requiring fully adequate pain management to be offered to patients. Euthanasia rebrands killing as kindness, which is very dangerous.

In deciding whether to legalize euthanasia we should keep in mind the axiom that "nowhere are human rights more threatened than when we act purporting to do only good", as that sole focus on doing good blinds us to the unavoidable risks and harms also present.

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'ASSISTED DYING: DON'T GO THERE'

Professor Theo Boer

16th July 2014

In 2001 The Netherlands was the first country in the world to legalise euthanasia and, along with it, assisted suicide. Various 'safeguards' were put in place to show who should qualify and doctors acting in accordance with these 'safeguards' would not be prosecuted. Because each case is unique, five regional review committees were installed to assess every case and to decide whether it complied with the law. For five years after the law became effective, such physician-induced deaths remained level - and even fell in some years. In 2007 I wrote that 'there doesn't need to be a slippery slope when it comes to euthanasia. A good euthanasia law, in combination with the euthanasia review procedure, provides the warrants for a stable and relatively low number of euthanasia.' Most of my colleagues drew the same conclusion.

But we were wrong - terribly wrong, in fact. In hindsight, the stabilisation in the numbers was just a temporary pause. Beginning in 2008, the numbers of these deaths show an increase of 15% annually, year after year. The annual report of the committees for 2012 recorded 4,188 cases (compared with 1,882 in 2002). 2013 saw a continuation of this trend and I expect the 6,000 line to be crossed this year or the next. Euthanasia is on the way to become a 'default' mode of dying for cancer patients.

Alongside this escalation other developments have taken place. Under the name 'End of Life Clinic,' the Dutch Right to Die Society NVVE founded a network of travelling euthanizing doctors. Whereas the law presupposes (but does not require) an established doctor-patient relationship, in which death might be the end of a period of treatment and interaction, doctors of the End of Life Clinic have only two options: administer life-ending drugs or send the patient away. On average, these physicians see a patient three times before administering drugs to end their life. Hundreds of cases were conducted by the End of Life Clinic. The NVVE shows no signs of being satisfied even with these developments. They will not rest until a lethal pill is made available to anyone over 70 years who wishes to die. Some slopes truly are slippery.

Other developments include a shift in the type of patients who receive these 'treatments'. Whereas in the first years after 2002 hardly any patients with psychiatric illnesses or dementia appear in reports, these numbers are now

sharply on the rise. Cases have been reported in which a large part of the suffering of those given euthanasia or assisted suicide consisted in being aged, lonely or bereaved. Some of these patients could have lived for years or decades.

Whereas the law sees assisted suicide and euthanasia as an exception, public opinion is shifting towards considering them rights, with corresponding duties on doctors to act. A law that is now in the making obliges doctors who refuse to administer euthanasia to refer their patients to a 'willing' colleague. Pressure on doctors to conform to patients' (or in some cases relatives') wishes can be intense. Pressure from relatives, in combination with a patient's concern for their wellbeing, is in some cases an important factor behind a euthanasia request. Not even the Review Committees, despite hard and conscientious work, have been able to halt these developments.

I used to be a supporter of the Dutch law. But now, with twelve years of 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 it 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.

Theo Boer has been a Member of a Regional Review Committee since 2005. For the Dutch Government, five such committees assess whether a euthanasia case was conducted in accordance with the Law. In the past nine years, Prof. Boer has reviewed almost 4,000 euthanasia cases. The views expressed here represent his views as a professional ethicist, not of any institution.

Euthanasia and physician-assisted suicide: focus on the data

We should aim at improving the care of dying patients

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Modern debates about legalising euthanasia and physician-assisted suicide (PAS) in Great Britain and the United States began in the late 19th century.[1] Legislation was periodically proposed only to be defeated until, in 1942, Switzerland decriminalised assistance in suicide for cases when there were no "selfish motives".[2] In 2002, euthanasia was legalised in the Netherlands and Belgium, then in Luxembourg in 2009, and most recently, in 2015 in Colombia and in 2016 in Canada.[3] PAS, but not euthanasia, has been legalised in five US states. In Oregon, PAS was legalised by popular referendum in 1997. In addition, in 2009, Washington State legalised PAS by referendum and Montana by court ruling; Vermont in 2013 and California in 2015 also legalised PAS by legislation.[4]

Debates about legalisation of euthanasia and PAS continue in a number of countries and states. On both sides, there are many claims and counterclaims that may not cohere with our empirical understanding. To ensure evidence-based discussions and policy formulation, it is important to consider three major points regarding the practices of euthanasia and PAS.

First, euthanasia and PAS are rarely used, even in countries where these interventions are legal and have been used for more than a decade.[5] Since the 1980s, euthanasia and PAS were permitted and not prosecuted in the Netherlands if certain safeguards were followed, and they were finally legalised in 2002. Yet, according to the latest data from 2010, dying patients have requested euthanasia in only about 6.7% of all deaths.[5] In a similar manner, in Belgium, only 6% of all deaths have a request for euthanasia or PAS.[6] However, not all requests are honoured; in the Netherlands, just 45% of requests are granted, and in Belgium this rate rises to 77%.[5-7]

Moreover, few deaths are caused by euthanasia or PAS. The most recent study from 2014 suggests that in the Netherlands 3.8% of deaths are by euthanasia or PAS, most of which — about 92% of the 3.8% — are by euthanasia, and in Belgium, only 4.6% of all deaths are by these interventions.[5] After 17 years of legalisation, in Oregon in 2014, only 0.3% of all deaths occurred by PAS,[7] and in Washington State only 0.24% of deaths were by PAS.[8]

Not only are these interventions rarely requested, they are predominantly used by patients with cancer. Even though cancer accounts for less than 25% of deaths in high income countries, about 75% of all euthanasia and PAS cases occur in patients who have cancer.[3-6] Few occur in patients with neuro-degenerative diseases, such as amyotrophic lateral sclerosis.[3-6]

These data mean that the claim that legalising euthanasia and PAS will help solve the problem of poor end-of-life

care is erroneous. Euthanasia and PAS do not solve the problem of inadequate symptom management or improving palliative care. These interventions are for the 1% not the 99% of dying patients. We still need to deal with the problem that confronts most dying patients: how to get optimal symptom relief, and how to avoid the hospital and stay at home in the final weeks. Legalising euthanasia and PAS is really a sideshow in end-of-life care — championed by the few for the few, extensively covered by the media, but not targeted to improve the care for most dying patients who still suffer.

Second, pain is not the primary reason why people seek euthanasia or PAS. It is commonly thought that patients in excruciating and unremitting pain would want these interventions. Many healthy people believe that pain would be the reason why they may want them; however, evidence suggests otherwise. Patients who request and receive euthanasia or PAS infrequently experience pain; similarly, few patients in pain actually want euthanasia or PAS. Two decades ago, research with patients who had cancer or HIV showed that those who were interested in euthanasia or PAS were not those experiencing pain.[9] This has been confirmed multiple times; for instance, the data from the state of Oregon in the US, which has followed patients who have requested and used PAS for 17 years now, show that fewer than 33% of patients are experiencing — or fearing — inadequate pain control.[5] Even in Australia, when for a brief moment seven patients were given euthanasia in the Northern Territory, none had uncontrolled pain.[10]

If not pain, then what motivates patients to request euthanasia and PAS? Depression, hopelessness, being tired of life, loss of control and loss of dignity. These reasons are psychological — they are clearly not physical pain — and are not relieved by increasing the dose of morphine, but by antidepressants and therapy. In the states of Oregon and Washington, the reasons for wanting PAS were: 90% of patients reported loss of autonomy, 90% were less able to engage in activities that make life enjoyable and 70% declared loss of

dignity[5,6] — depression and hopelessness are not listed and are not included in the reporting list. Likewise, in the Netherlands, the main legal requirement is "extreme physical or mental suffering," and patients' reasons are classified in this manner, making it hard to know whether the reasons are physical symptoms of depression. However, when researchers from the Netherlands — who were convinced that the main rationale was pain — interviewed patients who requested euthanasia, they found that few of the ones using euthanasia were experiencing pain, but most were depressed.[11]

The importance of psychological suffering as patients' rationale for requesting euthanasia and PAS indicates that these interventions are less like palliative care and more like traditional suicide condoned and assisted by the medical community. The main drivers of traditional suicide are psychological problems. Despite the importance of psychological suffering as the main motivator, few physicians in the jurisdictions where euthanasia and PAS are legal receive psychiatric consultation. Indeed, in the states of Oregon and Washington, less than 4% of patients who had PAS had a psychiatric consultation.[5-7] In Belgium, where an independent physician needs to be consulted for non-terminal cases, in 42–78% of cases that physician is a psychiatrist. Since psychological reasons dominate, one would think that requiring psychiatric evaluation would be a reasonable safeguard before providing euthanasia or PAS. Therefore, we need to think very differently about what drives people to want euthanasia. The picture most people have of patients who are writhing in uncontrolled pain despite morphine is simply wrong.

Third, many people believe euthanasia and PAS are flawless, quick and painless. This belief is common but mistaken. No medical procedure — even simple ones like blood draws — is flawless; every medical procedure has problems and complications. Euthanasia and PAS are no exceptions. According to a study in the Netherlands from 2000, 5.5% of all cases of euthanasia and PAS had a technical problem and 3.7% had a complication. An additional 6.9% of cases had problems with completing euthanasia or PAS. Technical problems, including difficulty finding a vein and administering oral medications, occurred in 4.5% of euthanasia cases and in 9.8% of PAS cases. Moreover, 3.7% of euthanasia cases and 8.8% of PAS cases had complications, such as nausea, vomiting and muscle spasms. Overall, an additional 1.1% of patients who had euthanasia or PAS did not die but awoke from coma.[12] The data suggest that the common view of euthanasia and PAS as quick, flawless, and painless ways to die is unrealistic.

When considering this evidence, the case for legalising euthanasia and PAS looks less compelling. They will not improve the care of many dying patients, they are not helping people in pain and enduring inadequately treated physical symptoms, and are far from quick and flawless. What is then the great impetus to legalise interventions to end lives for a small minority of patients who are depressed, worried about losing autonomy and being tired of life?

We should end the focus on the media frenzy about euthanasia and PAS as if it were the panacea to improving end-of-life care. Instead, we need to focus on improving the care of most of the patients who are dying and need optimal symptom management at home.

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WOMEN'S FORUM AUSTRALIA
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RESEARCH NOTE, Oct 2017: The Gendered Risks of Euthanasia and Assisted Suicide*

Background

The question of whether or not to legalise euthanasia and assisted suicide is again being debated in Australia, specifically in the states of Victoria and New South Wales where bills were tabled on 20 and 21 September 2017, respectively. Despite the continuing debate around the globe, only a handful of jurisdictions have legalised the practices. In keeping with this trend, South Australia rejected a euthanasia bill in November last year.

What are Euthanasia and Assisted Suicide?

'Euthanasia' is the intentional killing of a patient, whereas 'assisted suicide' is suicide effected with the assistance of another, both with the intention to relieve suffering. They may be accomplished by active steps, usually the administration of a lethal drug, or passively, for example by deliberately withholding treatment.

Euthanasia and assisted suicide are distinct from a situation where extraordinary or disproportionate means of sustaining a patient's life are withheld or rejected (i.e. high risk surgery for a patient dying of cancer). In this situation the intention is to reject or withdraw the burdensome treatment, not to kill the patient.

Euthanasia and assisted suicide are similarly distinct from a situation where a patient is given medication in order to alleviate their suffering, even if this *risks* hastening their death. Here the intention is to *alleviate the patient's suffering* via the medication, not to *kill* them via the medication.

General Concerns around Instituting Euthanasia and Assisted Suicide as Standard Medical Practices

- The **normalisation of suicide** and what facilitating it in some instances but not others says about the different value society places on certain lives.
- The **risk of coercion or pressure** from partners, other family members, health professionals and the patient themselves if they have come to feel like a burden on others.
- The **risk of non-voluntary euthanasia**, when euthanasia is performed on a person who does not have the capacity to make the decision themselves, and **involuntary euthanasia**, when euthanasia is performed against a person's will. Both have occurred in jurisdictions where euthanasia is legalised (Cohen-Almagor, 2003).
- The **future expansion of the conditions for eligibility** as demonstrated overseas (aka 'bracket creep'). Laws that once required a patient to have a terminal illness and to be over a certain age now allow euthanasia and assisted suicide for certain minors, psychosocial conditions, disability, and for those who are simply tired of life.
- The **fallibility of medical diagnoses/prognoses** and the potential for a person's life to be mistakenly ended based on inaccurate medical information.
- The **diminished capacity of patients** who are facing terminal illness and experiencing severe suffering and the question of whether or not they are able to give truly informed consent to their lives being ended.
- The potential **adverse impact on palliative care development** when it is less burdensome, both economically and socially, to end a patient's life.
- The ability of physicians to end the lives of their patients **fundamentally changes the nature of the physician-patient relationship** from one of healing and pledging to "do no harm" to one where physicians may take their patients' lives. This may damage the relationship of trust and care between physicians and their patients and ultimately undermine the integrity of the medical profession.

* Much of this research note is based on an article by Dr Katrina George titled, 'A Woman's Choice? The Gendered Risks of Voluntary Euthanasia and Physician-Assisted Suicide'. Dr George was a former director of Women's Forum Australia.

Why Women May be Uniquely Vulnerable to Euthanasia and Assisted Suicide Laws

There is a growing body of feminist academic literature that raises concerns about the rights and wellbeing of women and the impact that sex and gender may have on decisions regarding the end of life (see Wolf, 1996; Raymond, 1999; Canetto & Hollenshead, 2000; Parks, 2000; Platt, 2000; Allen, 2002; George, 2007; Callahan, 2015). Gender responsive healthcare is important and if there is the potential for gendered risks in legalising euthanasia and assisted suicide, then this requires public acknowledgement and further empirical research (Graham & Prichard, 2013: 17). Some possible gendered risks of euthanasia and assisted suicide include:

1. **Women tend to live longer than men** and are thus more likely to develop diseases and disabling conditions that motivate the desire for euthanasia and assisted suicide. They will also be more likely to experience the discrimination and abuse faced by the elderly in our society, which could be a further motivating factor in the request for euthanasia and assisted suicide. The Australian Law Reform Commission's report on elder abuse recognised that women are significantly more likely to be victims than men and that neglect of older women could be as high as 20% (ALRC, 2017: 37).

2. **Women are also more likely to experience the death of a partner or spouse** due to their relative longevity, and to be deprived of this support and companionship in older age. A 2013 Australian study found that living alone is an important predictor of suicide in older adults (De Leo, 2013). A 2016 American study found that loneliness was a key motivation behind euthanasia and assisted suicide requests of patients with "psychiatric" disorders in the Netherlands (Kim, 2016: 362). 70% of the cases reviewed were women and 76% were 50 years or older (Kim, 2016: 362). One women in her 70s "without health problems" said she experienced life without her husband who had died one year earlier, as a "living hell" and "meaningless" (Kim, 2016: 364).

3. **Women have less economic resources when they are older** (Herald Sun, 2017), the time when decisions about euthanasia and assisted suicide are most likely to occur. This entrenched economic disadvantage limits their options for care and means they are more likely to face other adversities such as homelessness, being unable to leave violent relationships due to financial insecurity and the general struggles associated with financial hardship, all of which could influence a decision for euthanasia or assisted suicide. Women also receive less care assistance from family members than men and are more likely to have to pay for assistance even if their spouse or partner is still around (Roscoe, 2001: 444). Such economic disadvantage disproportionately affects women and there is evidence that it does influence requests for euthanasia and assisted suicide (Emmanuel, 1998: 510).

4. **Women are arguably more self-sacrificial and less assertive than men,** whether by nature, socialisation or simply in terms of society's ideals about femininity (Callahan, 2015: 112; George, 2007: 18-22). They may thus be more likely to decide for euthanasia and assisted suicide to spare their loved ones the burden of caring for them, or to be persuaded that their life is unworthy of other's care and their family's resources. There is evidence that the fear of being a burden influences some patients in their decisions for euthanasia and assisted suicide (George, 2007: 21). In a study of assisted suicides where the majority of cases were women, the fear of being a burden was a prominent reason for deciding for death (Canetto & Hollenshead, 2000). The ethic of self-sacrifice was summed up by a friend of one of the suicides who said: "She felt it was a gift to her family, sparing them the burden of taking care of her" (Canetto & Hollenshead, 2000: 180).

5. **Women demonstrate a stronger preference for more structured, passive methods of suicide, with significant physician participation** (George, 2007: 7), and it is clear that increasing numbers of women decide to die when offered the more passive options of euthanasia and assisted suicide (George, 2007: 25). The rate of assisted death by women in the Netherlands, Oregon and elsewhere is nearly four times that of the usual female self-inflicted suicide rate (George, 2007: 25). One explanation for this might be that decisions for euthanasia and assisted suicide fit in with cultural expectations of women as passive and compliant, and play out gender expectations of subordination and dominance in a profession where physicians are still predominantly male (George, 2007: 23-27). One study has warned that the structure and passivity of euthanasia and assisted suicide "will create a sense of obligation on the part of a woman, especially one who subscribes to stereotypic sex roles to complete a physician-assisted death towards which she may be initially ambivalent" (Kaplan, 2002: 42).

6. **Women are more likely to attempt suicide than men as they are more prone to psychological problems such as depression** (The Guardian, 2015). Men are more likely to die by suicide due to the fact that they often use more violent methods such as hanging or suffocation, whereas women tend to use nonviolent means, such as overdosing (The Guardian, 2015). However, if euthanasia and assisted suicide are enshrined into law, women's preference for more passive methods of suicide coupled with their higher tendency to attempt suicide could have a harmful compounding effect on women's decisions to die. This may already be evident in the 2016 American study reviewing euthanasia and assisted suicide cases of patients with psychiatric disorders in the Netherlands, in which 70% of the cases reviewed were women (Kim, 2016).

7. **Female euthanasia and assisted suicide need to be considered within the context of pervasive male violence against women, particularly against intimates** (George, 2007: 15). Research indicates striking similarities between the broader patterns of male violence against women and at least one form of assisted death: 'mercy killing' (George, 2007: 15). There is a higher incidence of female mercy killings, mostly by men, who are most often the woman's partner, often without consent from the female victims (George, 2007: 15-18). Mercy killing reflects gendered patterns of violence in that the incidence and demographics of mercy killing match those of male violence against women generally (George, 2007: 18). It is also characterised by the same themes of domination, possessiveness and control which characterise other killings of women by men (George, 2007: 18). The prevalence of violence against women in Australia (particularly intimate partner violence) is concerning, with at least one woman a week being killed by a partner or former partner, and one in three Australian women having experienced physical violence since the age of 15 (Our Watch). Thus, before legalising euthanasia and assisted suicide, it is vital that we understand the dynamics at work and whether the dynamics underlying other forms of gendered violence and unbalanced power relationships that result in the deaths of women, may sometimes also underlie female euthanasia and assisted suicide (Wolf, 1996: 284-285).

8. **Women's historical and ongoing experience of power imbalance and gender domination could 'play out' in a clinical relationship** and influence their decision for euthanasia and assisted suicide (George, 2007: 25). The medical profession is traditionally paternalistic and still predominantly male, and a male physician's cooperation with a woman's request for euthanasia or assisted suicide could reflect entrenched sexism and gender roles (George, 2007: 25). Similarly, women's preferences for more structured, passive deaths at the hands of their (more often than not) male physicians could be an indication of gender dynamics at play (George, 2007: 27). One example of possible gender dynamics at play in the clinical relationship is in a study of euthanasia and assisted suicide in the United States (Meier, 1998: 1195). Relative to men, women died in circumstances where their requests were less likely to be explicit, less likely to be at their personal request and more likely to be initiated by family members or partners (George, 2007: 6).

9. **The majority of high profile euthanasia and assisted suicide cases are female** (George, 2007: 1, 25). Given the persistence of gender stereotypes and inequality, this raises the question of whether women are being used to portray euthanasia and assisted suicide because it "seems right" that women would passively and compliantly sacrifice themselves to prevent being a burden on their loved ones (whether consciously or not). It also raises concerns as to what kind of influence such media portrayal could have on women's decisions to request euthanasia and assisted suicide, and whether such depictions of women could be self-fulfilling.

10. **Autonomy and choice is often the principal argument used for euthanasia and assisted suicide but these insights challenge the presumption that women who decide for euthanasia and assisted suicide are always exercising autonomy** (George, 2007: 18). Biological factors, structural inequalities, disparities in power, social and economic disadvantage and cultural stereotypes that may underlie the decisions of some women are gender distinctive and challenge the rhetoric of choice (George, 2007: 2, 8). Even if there were no greater incidence of women deciding for euthanasia and assisted suicide, the reasons for their decisions could suggest a lack of autonomy (George, 2007: 2). By legitimising and increasing access to methods of suicide which appeal to women, the risk is that for some women a legalised regime will compound oppressive socio-cultural influences and facilitate the last of many non-choices (George, 2007: 33).

Further Information

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WOMEN'S FORUM
THINK•ACT•MAKE A DIFFERENCE

FACT SHEET: The Gendered Risks of Euthanasia and Assisted Suicide

1. **Women tend to live longer than men** and are thus more likely to develop diseases and disabling conditions, or to experience elder abuse and discrimination, both of which could motivate the desire for euthanasia and assisted suicide. In terms of elder abuse, women are significantly more likely to be victims than men.

2. **Women are also more likely to experience the death of a partner or spouse** due to their relative longevity, and to be deprived of this support and companionship in older age. Studies have found that loneliness is an important predictor of suicide and a key motivation behind euthanasia and assisted suicide requests.

3. **Women have less economic resources when they are older,** the time when decisions about euthanasia and assisted suicide are most likely to occur. This entrenched economic disadvantage limits their options for care and means they are more likely to face other financially-related adversities, all of which could influence a decision for euthanasia or assisted suicide. Women are also more likely to have to pay for care than men.

4. **Women are arguably more self-sacrificial and less assertive than men** and may thus be more likely to decide for euthanasia and assisted suicide to spare their loved ones the burden of caring for them, or to be persuaded that their life is unworthy of other's care and their family's resources. There is evidence that the fear of being a burden influences some patients in their decisions for euthanasia and assisted suicide.

5. **Women demonstrate a stronger preference for more structured, passive methods of suicide, with significant physician participation** and it is clear that increasing numbers of women decide to die when offered the more passive options of euthanasia and assisted suicide.

6. **Women are more likely to attempt suicide than men as they are more prone to psychological problems such as depression.** If euthanasia and assisted suicide are legalised, this, coupled with women's preference for more passive methods of suicide could have a harmful compounding effect on women's decisions to die.

7. **Female euthanasia and assisted suicide need to be considered within the context of pervasive male violence against women, particularly against intimates.** Research indicates striking similarities between the broader patterns of male violence against women and at least one form of assisted death: 'mercy killing'. There are more female mercy killings, mostly by men, who are most often the woman's partner, and they are characterised by the same themes of domination, possessiveness and control as other gender-based violence.

8. **Women's historical and ongoing experience of power imbalance and gender domination could 'play out' in a clinical relationship** (where the medical profession is traditionally paternalistic and still predominantly male) and influence their decision for euthanasia and assisted suicide.

9. **The majority of high profile euthanasia and assisted suicide cases are female.** Given the persistence of gender stereotypes and inequality, this raises concerns as to why this is the case and what kind of impact the media coverage of such cases has on women's decisions for euthanasia and assisted suicide.

10. **These insights challenge the presumption that women who decide for euthanasia and assisted suicide are always exercising autonomy.** A legalised regime could in fact compound oppressive socio-cultural influences and facilitate the last of many non-choices for some women.

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Queensland Parliamentary Inquiry Submission

Aged care, end-of-life, palliative care and voluntary assisted dying

HammondCare
Champion Life

About HammondCare

Established in the 1930s, HammondCare is an independent Christian charity specialising in dementia care, palliative care, rehabilitation and older persons' mental health services. HammondCare is acknowledged as Australia's leading dementia-specific service provider and is dedicated to research and supporting people who are financially disadvantaged. HammondCare's mission is to improve quality of life for people in need, regardless of their circumstances.

HammondCare provides community care to more than 4,500 people throughout Australia's eastern seaboard. Our HammondCare At Home services provide care for older people, people living with dementia, palliative care patients, and respite and counselling for carers. We currently operate 1,363 residential aged care places across in NSW and Victoria and provide specialist inpatient and community palliative care and supportive care services in NSW. We also provide Special Care Programs for people displaying severe behavioural and psychological symptoms of dementia. On any given day, HammondCare's Dementia Centre is recognised in Australia and internationally for its high quality research, consultancy, training and conferences in the area of best-practice dementia care.

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Aged Care

Meeting the needs of older Queenslanders and raising standards: more dementia specific services

The prevalence of dementia in Queensland, like the rest of Australia, is projected to increase significantly (Nichols, Vollset and Murray, 2018). One projection estimates that the number of Queenslanders living with dementia will have increased by 342% between 2012 and 2050 (Alzheimer's Australia 2011). Even though a recent study has highlighted a decrease in the incidence of dementia within Australia due to effective national public health measures, it is well established that Australia's population is ageing and the decline in dementia rates are likely to be short lived (Harrison et al., 2019). Therefore, better ways of supporting people with dementia remain an integral factor for consideration in quality aged care provision in Queensland.

Improving service provider knowledge and understanding of dementia across the board will certainly improve the support and care available to clients and residents living with dementia. However, the needs of people with dementia vary greatly and it is unreasonable to expect that all services can adequately serve all people living with dementia. HammondCare therefore supports specialisation among aged care providers to better service the individual profiles of people living with dementia.

In order to better serve the growing needs of Queenslanders living with dementia and meet future demands for aged care, HammondCare calls for an increase in the number of aged care services specialising in the needs of people with dementia. Dementia-specific home care services promote choice, independence and social inclusion for people living with dementia, while purpose built residential care facilities foster greater resident autonomy and quality of life (Dyer et al., 2018). HammondCare's experience of specialisation demonstrates that a clear focus enables services to develop expertise and models of care better aimed at responding to the individual needs of people living with dementia. We are mindful of the important role the physical and social environment can play in supporting dignity, maximising independence and promoting feelings of comfort and security in our residents. As such, HammondCare's residential care services proudly champion an evidence informed domestic model of care (Afendulis et al. 2016; Ausserhofer et al. 2006; Dyer et al. 2018).

The creation of a familiar and more understandable environment is at the core of HammondCare's approach to increasing people's control, comfort and confidence. Our dementia-specific aged care homes are made up of a series of small cottages that use multiple consistent cues to orientate the resident, have easy access to safe outdoor spaces and scope for personalisation. Community connection is encouraged through welcoming entries, views to the world outside and integrated community amenities. Unwanted stimuli are purposefully removed and safety features remain unobtrusive. Clear articulation of both the form and function of rooms, gardens and other spaces supports residents recognising possible activities and being confident that they are in the right room for a particular usage. Food preparation and distribution always occurs in the domestic

kitchen of each cottage by multi-skilled care workers and willing residents. Engaging residents in normal daily activities such as cooking helps to maintain skills, independence and purpose.

Residents and their family members are shown to rate the overall quality of care in domestic models significantly higher in comparison to more traditional models of institutionalised residential care (Dyer et al., 2018). Furthermore, 73% of residents living in these facilities are shown to have lower emergency presentations; hospitalisations are associated with poor health outcomes for residents and incur higher costs to governments (Dyer et al., 2018). The cottage model of care for people living with dementia is an evidence-based model for residential aged care delivery in Queensland with the potential to generate significant savings to the state government.

However, increasing the supply of dementia specific home and residential care services alone will not succeed in meeting the goal most older Australians living with dementia have: to remain living at home for as long as possible. HammondCare supports additional funding for cottage respite services, a model consistently favoured by care recipients and their carers that is well suited to providing tailored care to individuals living with dementia (Carers Australia 2018; Poulos and Birch 2016). Cottage respite provides overnight respite care out of converted family homes in the community or cottage-style facilities on state government land, offering flexible services within a more familiar and home-like environment. This small-scale and highly adaptable care setting is particularly well suited to people living with dementia. HammondCare's experience with cottage respite has been overwhelmingly positive; the service suits many carers who prefer to have one or two nights of respite more regularly instead of blocks, and is commonly used multiple times by the same consumers, promoting continuity of care and relationships of trust.

Access to services and current wait times

The current My Aged Care (MAC) interface has caused ongoing difficulties for many prospective home care clients. Many Queensland clients and their family members who have received support from HammondCare have been affected by this. One particular case outlines this struggle, whereby an elderly man living at home with dementia was approved for a Level 3/4 Home Care Package (HCP) in 2015. At the time, the individual was accessing services but required a more coordinated approach to fulfil his care needs. Upon commencement of the National Prioritisation Scheme in February 2017, the client failed to enter the queue as his carer had difficulty comprehending the system. HammondCare was first introduced to this particular client when he was admitted to hospital for a dementia related incident. We made multiple phone calls to MAC on his behalf, requesting the client be placed on the queue. The MAC representative eventually identified a 'glitch' in the system that could not be easily rectified, meaning the case had to be escalated to more senior personnel. Three home visits and advocacy phone calls were required before the client was able to be placed on the queue. This story is remarkably common; care recipient testimonies from the Royal Commission suggests many aged care consumers are not computer literate and have trouble navigating the MAC online portal. As Senior Counsel for the Royal Commission, Dr Timothy McEvoy bluntly stated, 'My Aged Care is failing the very people who need to access it the most' (McEvoy, 2019).

Compounding the problems clients face interacting with MAC is the shortage of home care packages, particularly Levels 3 and 4. Quarterly data released by the Australian Department of Health (DoH) suggest an individual approved for a Level 4 HCP can expect to wait 12-plus months for their package (DoH, 2019). In practice, wait times are often longer. The DoH recently told a hearing of the Aged Care Royal Commission that these clients can actually expect to wait 22 months (DoH, 2019). HammondCare is well aware of the disparity between published estimations and actual waiting times. One Brisbane client was forced to wait 1,019 days (33 months) for a Level 4 package, receiving an interim Level 3 package more than a year (389 days) after first being approved for an HCP. Despite both timeframes indisputably not "meeting the needs of older Queenslanders", such anecdotes remain unfortunately familiar in an era of Consumer-Directed Care (CDC). Since the implementation of the queue in 2017, waitlists for Australians seeking an HCP have been steadily growing.

In order to reduce the queue and improve overall waiting times for home care consumers HammondCare offers the following solutions:

- Establish more home care packages, particularly higher Level (3 and 4 packages). One way to achieve this is to enable parked offline residential aged care licences to be converted to home care packages on a temporary basis, favouring high level packages (Tune Report Recommendation #6: That the government further increase access to high level home care packages to better reflect current demand by allowing for the temporary allocation of a home care package where there is a residential care place that is not being used).
- Reduce the period of time that consumers have to choose a provider and establish an agreement with them from 56 days (eight weeks) to 28 days (four weeks). Confident and capable consumers who have already been in the queue will have had sufficient opportunities to research and compare different providers.
- Like superannuation, clients who are unable to choose a service should instead be allocated a default provider. If a consumer has opted to engage a provider on their own but fails to activate their referral code within a set time period, then MAC should issue a public broadcast referral to all providers that provide home care packages in the consumer's location. This will activate a 'pull through' for those consumers who are at risk of missing out on the care they need, stopping them from falling through the gaps. However, consumers should maintain the option to change providers at any time. Utilising public broadcasts to pull clients through the system, along with a shorter choice period and a streamlined ability to change providers will ensure that no client falls through the gaps while continuing to uphold choice and helping to shorten the queue.

Appropriate staffing

Maintaining an appropriate and effective staffing mix is an integral component of quality care provision within the aged care sector. HammondCare's domestic cottage environment works best with a multi-skilled workforce structure; care workers are the 'eyes and ears' of the facility, while Registered Nurses are clinical leaders, teachers and enablers. Rigid staff ratios stifle such innovative models and evidence is inconclusive as to whether such ratios directly improve quality and safety outcomes for residents (COTA 2018, 28-30). However, literature does indicate that staff

characteristics such as turnover, staffing levels, worker stability and agency staff should be addressed simultaneously to improve the quality of care being delivered in residential care facilities (Castle and Engberg, 2007). Consequently, HammondCare maintains the view that the appropriateness of staffing levels should be assessed in the context of the service's philosophy, objectives and resident need.

The introduction of a minimum total care hours per resident per day could form part of the solution to improving transparency and information for aged care consumers. However, this minimum should be developed in accordance with the care needs of defined resident groups, and would not on its own 'solve' the problem of poor quality care.

HammondCare offers all residents and their families the opportunity to take part in a bi-annual 'Partnering in Care' survey that assesses multiple indicators of satisfaction across service practices and outcomes. Findings from the survey result in client-driven measures of quality being recognised and measured. The 2016 and 2018 surveys highlighted an ongoing theme of consumers valuing staff consistency, which is well supported by literature (Castle and Engberg 2007; Gnanamanickam et al 2018). HammondCare has acted on this evidence, prioritising continuity of care by reducing reliance on agency staff in all of our services.

Inadequate and poor-quality training, particularly in dementia care, has been a recurring theme in the Royal Commission into Aged Care Quality and Safety. HammondCare understands the need for better alignment of funded programs to support the development of the aged care workforce. The Queensland and Federal Government must maintain budgeted funding in the forward estimates for targeted aged care and dementia education initiatives. Additionally, a greater focus on recruiting prospective employees on the basis of attitude and character rather than solely qualifications and experience will further improve the quality of staff across the aged care sector.

To be effective, any dementia education program aimed at aged care staff should have the following:

- Clear strategic outcomes to measure program performance;
- Alignment between the education provided to direct care workers and the education provided to managers and team leaders;
- Interactive on-the-job learning through workplace trainers and buddy mentorship;
- And, a blended learning approach incorporating online and face-to-face delivery.

In order to provide meaningful career progression to people working in aged care, it is necessary to provide opportunities for employees of all levels and qualifications to specialise their skills. Not everyone can progress their career in a conventional sense, through promotion, but all care staff should be given the opportunity to develop skills and participate in education that enables them to have a specific focus in their work. This specialisation enables staff to support their colleagues and be a source of knowledge within their team, leading to improved job satisfaction and wellbeing at work. This approach to career progression is particularly effective through innovative models of care.

End-of-Life and Palliative Care

Palliative care in Queensland

It is HammondCare's position that all Queenslanders, like all Australians, should have access to palliative care when they require it. This goal should be an urgent priority for the Queensland Parliament. Estimates vary on the number of people who need palliative care. According to Palliative Care Australia specialist palliative care services should support 90 per cent of cancer patients and half of non-cancer patients, through assessment, ongoing consultation or direct care (PCA 2003). More recent research (Murtagh et al. 2014) suggests that between 69 per cent and 82 per cent of people who die in high income countries like Australia are likely to need palliative care. Given that approximately 31,500 people died in Queensland in 2017 (ABS 201, it can reasonably be assumed that around 22,000 to 26,000 Queenslanders require palliative care every year. Given this, it is clear that significant investment is needed to increase the provision of palliative care services throughout Queensland.

It is equally important to consider the setting where palliative care services are delivered, bearing in mind that many people will require palliative care and support in a range of settings.

Historically, death was an event that occurred within the home, rarely with a doctor in attendance (Kellehear 2007). Advances in medicine throughout the 20th century saw the development of evidence-based curative treatments that were both effective and accessible. The concentration of clinical knowledge and sophisticated medical technology made hospitals the place for treatment – but also for death. Today only 14 per cent of Australians die at home, a percentage that is less than half that of similar countries such as Ireland, France, the USA and New Zealand (Broad et al. 2013). Of the remaining deaths in Australia, 50 per cent occur in hospitals and 35 per cent die in residential aged care homes (Swerrisen and Duckett 2014). This is despite the fact that multiple surveys show that between 60 and 70 per cent of Australians would prefer to die at home.

HammondCare recognises the need for more specialist inpatient palliative care beds in Queensland. At the same time, there are also great opportunities to improve the quality of life for dying Queenslanders and to generate significant savings by assisting more people to receive palliative care and support in non-hospital settings.

Supporting more people to die at home

In order to support more people to die at home, a HammondCare consortium (including Sacred Heart Health Services and Calvary Healthcare Sydney) has been providing the Palliative Care Home Support Program (PCHSP) in seven Local Health Districts (LHDs) of New South Wales (four of which were in rural areas) since October 2013. Funded by the NSW Ministry of Health, the PCHSP was designed to supplement existing community palliative care services by providing specially trained

community care workers[1] to support patients and their families who wished to die at home or remain at home for as long as possible.

The PCHSP provides packages of up to 48 hours of flexibly delivered palliative care home support to palliative care patients who are referred by attending clinicians, hospital palliative care teams or community palliative care teams. These packages can be provided for a continuous period of time or in smaller blocks, according to the preferences of patients and their families. A second package of care can be made available to patients and families if needed.

In 2016, HammondCare undertook a qualitative and quantitative evaluation of the PCHSP to evaluate the outcomes, potential reach and cost effectiveness of the program (Poulos 2016). The evaluation demonstrated that the PCHSP had been successful in supporting dying people and their families who wish to receive end of life care in their own homes.

The key findings from the evaluation included that:

- Between the program's inception in 2013 and the evaluation in 2016, the HammondCare consortium's PCHSP had supported 1,295 patients (including seven paediatric patients) and their families with end of life care in their homes.
- Nearly three quarters (73 per cent) of patients on the program had died at home, which compares very favourably with the Grattan Institute findings that 70 per cent of people wish to die at home but only 14 per cent currently do.
- The PCHSP had provided full coverage across the three metropolitan LHDs and throughout more than 267 towns across the four rural LHDs.
- 586 community care workers had been trained across the seven LHDs.
- The most significant growth in activity over the 12 months prior to the evaluation had occurred in rural LHDs.
- The PCHSP was being delivered at around a third of the cost of substitutable inpatient palliative care.[2] (In 2015-16, the PCHSP had an average cost per patient of $3,454 compared to a price of $10,393 for substitutable inpatient care by similar phase.)
- Families found the support of specially trained community care workers very beneficial and, in some instances, crucial for enabling end of life care in the home.
- Compared to other community palliative care programs participating in the Palliative Care Outcomes Collaboration (PCOC), the PCHSP had a much higher home death rate.

The PCHSP has continued to support people throughout the seven NSW LHDs. Between October 2013 and February 2019, it had supported nearly 3,600 dying patients and their families, of whom 73 per cent died at home in accordance with their wishes. Through the program, more than 1,000 care workers have received targeted training in palliative supportive care for people and their families at the end of life. Published in October 2017, a peer reviewed evaluation of the programme

[1] The education program used was adapted from Hospice New Zealand's 2011 Program *Fundamentals of Palliative Care*. The adapted HammondCare training program became known as the *Fundamentals of End of Life Care*.
[2] This calculation only considers the cost of the provision of the PCHSP. It does not take into account the cost of existing local community palliative care and primary care services that may have been provided to a patient while in receipt of the PCHSP.

showed that family carers who had used the PCHSP found it had succeeded in enabling choice, providing practical assistance and offering emotional support and reassurance (Poulos et al. 2017). The study found that the program had supported people to realise their desire to die at home, achieving satisfactory outcomes for most patients and their families.

As all of this evidence demonstrates, the PCHSP has succeeded in helping patients and families to achieve their wishes in both metropolitan and rural settings. At the same time, it has demonstrated that the flexible delivery of in-home support at the end of life by trained community care workers is both effective and cost-effective. Based on these findings, there is a compelling case for similar models to be adopted in Queensland.

Supporting more people to have good end of life care in residential aged care

Just over a third of all deaths in Australia occur in aged care homes. Yet too often, residential aged care services are not well set up to provide palliative and end of life care. Studies from North America (Temkin-Greener et al. 2013; Menec et al. 2009) indicate that around a fifth of nursing home residents die in hospital. In Australia, at least 14 per cent of aged care resident deaths occur during an admission to an acute hospital. While some aged care residents may require hospital care at the time of death, many of these admissions may be unnecessary.

Unfortunately, residential aged care has not been widely recognised as a site for palliative and end-of-life care in Australia. Improving end of life care in nursing homes requires increased and upskilled staff and better coordinated primary care, along with access to specialist palliative care expertise and round-the-clock access to controlled medications.

HammondCare operates a dedicated specialist palliative care suite within one of its existing residential aged care homes in Sydney's southwest. The Lavender Suite supports up to nine aged care residents who have been diagnosed with a life limiting disease and have an estimated prognosis of less than 12 months (and often for significantly much less than that). It is designed to meet residents' physical, psychological, social and spiritual needs in a flexible and personalised manner. Families and carers are also supported through a 24/7 visitation policy, a fold-up bed provided in residents' rooms for overnight stays, as well as emotional and bereavement support.

The Lavender Suite operates as an integrated health and aged care service and utilises a multi-disciplinary approach to care. It benefits from close links with HammondCare's inpatient palliative care unit at the nearby Braeside Hospital, the HammondCare Learning & Research Centre in palliative care and the South West Sydney Local Health District palliative care team, which provides a 24-hour palliative care telephone advisory service. The suite has an in-house pharmacy licence to access emergency palliative medications (including opiates), and staff also have direct access to other HammondCare resources including a pain management specialist. Weekly case conferences held within the Lavender Suite are attended by a palliative care specialist and a registrar from Braeside Hospital, local GPs and relevant specialists. The suite also benefits from a higher than normal staff-to-resident ratio.

An internal evaluation of the Lavender Suite identified positive feedback from staff, residents and their families. This included high levels of satisfaction with quality of care, flexibility of care, flexible visiting hours and the responsive communication of staff. HammondCare believes this demonstrates the advantages of providing palliative care in a tailored residential aged care setting.

There are additional costs of running the Lavender Palliative Care Suite compared to a normal residential aged care unit that come from providing:

- Regular input from a palliative care specialist.
- Regular allied health input.
- Additional medical and pharmaceutical expenses.
- A dedicated nurse working in nine-bed the suite 24 hours a day, 7 days a week
- An additional care worker rostered on every day in the morning and afternoon shifts.

HammondCare chooses to bear these additional costs because we believe the Lavender Suite's unique approach offers a positive model for the provision of palliative care within an aged care setting. While the costs of operating the suite are higher than other aged care services, they are significantly lower than the costs of providing care in an inpatient palliative care unit, hospice or acute hospital setting. At the same time, the suite avoids the disruption of taking an older person away from their 'home' and admitting them to an unfamiliar hospital setting, with all the risks that move entails. For this reason, HammondCare believes the Lavender Suite serves as a positive example for policy makers of what can be achieved. We believe this model could be expanded in NSW and adopted around Australia with top-up funding provided by state and territory governments.

Voluntary Assisted Dying

Definitions

As the Issues paper acknowledges, there is no consensus around the definition of assisted dying or voluntary assisted dying. HammondCare prefers not to use these terms as we believe other terms, such as physician assisted suicide and euthanasia are clearer terms for the practices proposed in this paper.

We choose to adopt the European Association for Palliative Care (EAPC) White Paper definitions. For these terms. The EAPC defines euthanasia as "a physician (or other person) intentionally killing a person by the administration of drugs, at that person's voluntary and competent request" (Radbruch et al. 2015, 5). This differs from physician-assisted suicide (PAS), which occurs when a physician supplies lethal drugs for the patient to administer themselves.

Physician-assisted suicide (PAS) is defined by the EAPC White Paper as "a physician intentionally helping a person to terminate his or her life by providing drugs for self-administration, at that person's voluntary and competent request" (Radbruch et al. 2015, 5).

It is important to understand that turning off life-support machines or discontinuing life-sustaining treatment is not euthanasia. When this happens a patient dies because of their underlying illness, not because of a lethal drug they take themselves (PAS) or are given by a physician (euthanasia). Some people label this form of dying 'passive euthanasia'. Following the EAPC White Paper we find this term to be unhelpful and inappropriate as: "euthanasia is active by definition, and so 'passive euthanasia' is a contradiction in terms (an oxymoron)" (Radbruch et al. 2015, 5). A more appropriate way to describe this then, is "allowing a natural death".

Reasons why physician-assisted suicide and euthanasia should not be legalised

HammondCare does not believe that physician assisted suicide or euthanasia should be allowed in Queensland. The following eight points outline the reasons for our opposition to these practices.

1. Such a change would undermine the value that we as a community place on human life

By assisting people to end their life, our society would be sending the message that some lives are not worth living. Such a change in attitude could place pressure on vulnerable people including older people and those living with dementia and disability.

2. Legislated safeguards cannot detect coercion behind closed doors

The safeguards outlined in existing laws permitting physician assisted suicide and euthanasia are not able to detect psychological pressure from family members and others with vested interests.

This is particularly concerning for potentially vulnerable groups such as older people, given that more than one in 10 older people experience psychological abuse in any given year (Yon Y et al. 2017).

3. Legislated safeguards around mental health disorders and decision making capacity are severely limited

The existing and proposed legislated safeguards to protect people with mental disorders and impaired decision making capacity require referral for assessment from a psychiatrist or other specialist. In jurisdictions where this requirement is optional, it is rarely used; where it is mandatory, significant concerns remain about the assessment of capacity and the presence of mental illness in people with a terminal illness (MacLeod 2012).

4. Legislated safeguards have been progressively diluted and removed in other jurisdictions

Laws allowing physician-assisted suicide and euthanasia in the Netherlands and Belgium were initially intended only for people with terminal illnesses but have now been broadened to include people with psychiatric conditions, dementia, depression and old age. In Belgium and the Netherlands, physician-assisted suicide and euthanasia were originally restricted to people aged 18 and over but they can now be accessed by people under the age of 18 (Radbruch 2015).

5. People from vulnerable population groups are increasingly receiving assistance to end their lives where safeguards have been removed

In the Netherlands, for example, 141 people living with dementia were euthanased in 2016 (compared with just 41 in 2012), including some people with advanced dementia. A further 244 people were euthanased due to a range of "ailments associated with old age" and 60 people were euthanased as a result of psychiatric disorders (EIB 2017).

6. Such legislation could negatively impact the relationship between doctors and patients

If, as well as promoting quality of life, medical practitioners also began to assist with suicide and euthanasia, there is a valid and widely held concern that this would undermine the trust between other patients and their doctors (McLachlan 2010). The Australian Medical Association (AMA 2016) and the Australian and New Zealand Society of Palliative Medicine (ANZPSM 2017) do not support physician-assisted suicide or euthanasia.

7. There is widespread evidence of a negative impact on doctors who take part in assisted suicide and euthanasia

In the Netherlands, many physicians have found performing euthanasia to be a "drastic and sometimes even traumatic event" (van Marwik et al. 2017). In other jurisdictions doctors who have participated in physician-assisted suicide and euthanasia have reported that this subsequently affected their ability to practice medicine (MacLeod et al. 2012).

8. Such a change has been linked to reductions in the use of palliative care

Allowing physician-assisted suicide and euthanasia without a requirement to engage with palliative care has led to a devaluing of these services. The utilisation rates of hospice and palliative care services in US states where physician-assisted suicide was legalised have reduced compared to other states where the practice remains illegal (Ballentine 2016).

Greater investment in palliative care

Instead, HammondCare supports greater investment in high quality palliative care[3] that improves quality of life of people and families facing life-threatening illness by:

- Providing relief from pain and other distressing symptoms that result in suffering.
- Affirming life and regarding dying as a normal process.
- Seeking neither to hasten nor postpone death.
- Integrating psychological and spiritual aspects of care.
- Offering a support system to help people live as actively as possible until death.
- Supporting the family to cope during the person's illness and in their own bereavement.
- Using a team approach to address the needs of patients and their families, including bereavement counselling, if indicated.
- Enhancing quality of life.

Conscientious objection and the requirement to refer

Should the Queensland parliament decide to legalise physician-assisted suicide and euthanasia, HammondCare strongly supports the right of all medical practitioners to have a conscientious objection to participating. This is the case in Victoria, where information for health practitioners in anticipation of the introduction of that state's voluntary assisted dying regime clearly states that health practitioners can refuse to provide information about or participate in physician-assisted suicide or euthanasia on the grounds of conscience (DHHS 2019).

HammondCare also believes that health services and providers of health services should have the right to object on the basis of conscience. This also is the approach adopted in Victoria, where The Victorian Department of Health and Human Services' information website states that a health service may choose not to participate in voluntary assisted dying if it does not align with its organisational values (DHHS 2019).

Those medical practitioners and health services that hold a conscientious objection to voluntary assisted dying, where it is legalised, should not be required to refer a patient to a practitioner who does not hold a conscientious objection. Forcing professionals and organisations to make such a referral would undermine their right to object and cause them to act in a way that goes against their own conscience. Again, this approach has been adopted in Victoria, where neither health practitioners nor health services are under any obligation to refer for voluntary assisted dying although they must not "inhibit a person's access to treatment" (DHHS 2019).

[3] Based on the WHO definition of palliative care: http://www.who.int/hiv/topics/palliative/PalliativeCare/en/

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Assisted dying regimes

Briefing note for the Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying

Health, Communities, Disability Services & Domestic & Family Violence Prevention Committee of the Queensland Parliament, April 2019

Introduction

A small but growing number of jurisdictions now permit euthanasia and/or assisted suicide. This briefing note discusses the how the law was changed in those jurisdictions, outlines the regulatory regimes, and summarises the empirical evidence of the practice of euthanasia and assisted suicide (defined in box 1).

How the law was changed to permit assisted dying

The Netherlands

In the Netherlands, euthanasia and assisted suicide were effectively legalised through the use of the defence of necessity in prosecutions of (primarily) doctors. The defence is available when the doctor faced a conflict between his or her duties to preserve life and relieve suffering. The courts held that only doctors can face such a conflict of duties because only doctors have a professional duty to relieve suffering: lay-persons (who include relatives) and nurses do not. Over some thirty years, the courts developed this duty-based defence of necessity in euthanasia cases, placing conditions on the defence, including: an express and earnest request; unbearable and hopeless suffering; consultation; careful termination of life; record-keeping; and reporting. These conditions became known as *requirements of due care* or *careful practice*. The Dutch legislature eventually codified the parameters of the defence in the Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001, which lists six *due care criteria* which must be met in cases of euthanasia and assisted suicide (see box 2). The judicially-developed necessity defence is still applied to cases involving incompetent persons, particularly neonates.

Belgium

Unlike in the Netherlands, there had been few criminal prosecutions in euthanasia cases prior to its legalisation in Belgium, so legal change had to come from outside the judiciary. The 1980s and 1990s witnessed a series of unsuccessful legislative moves to allow euthanasia. After a change of government and intense legislative debate, the Law on Euthanasia was passed in 2002. It allows only doctors to perform euthanasia. Assisted suicide is not explicitly covered, although Belgium's oversight body, the Federal Euthanasia Control and Evaluation Commission (FECEC) has accepted cases of assisted suicide as falling under the law.[1]

Luxembourg

The Law on Euthanasia and Assisted Suicide came into force in Luxembourg in 2009 after a heated political and public debate. The law is closely based on the Belgian law, although it does specifically permit assisted suicide as well as euthanasia.

Box 1. Definitions

- *Euthanasia*: an intervention undertaken with the intention of ending a life to relieve suffering. In the Dutch and Belgian contexts, the term *euthanasia* refers only to the termination of life upon request.
  Some common (and often confusing) modifiers of *euthanasia* are:
  active: a deliberate intervention to end life
  passive: withdrawal/withholding of life-sustaining treatment
  voluntary: at the request of the person killed
  involuntary: in the absence of a request by the person killed, although that person is competent
  non-voluntary: in the absence of a request by the person killed, when that person is not competent and has not made an advance request for euthanasia
- *Assisted suicide*: any act which intentionally helps another person to commit suicide, for example by providing him or her with the means to do so. In the Netherlands, *assisted suicide* is often included in the term *euthanasia*. Legal regimes often permit only *physician-assisted suicide* which is commonly referred to as PAS.
- *Assisted dying*: (voluntary active) euthanasia and assisted suicide. (Though sometimes used as a synonym only for *assisted suicide*.)

Switzerland

In Switzerland, it is a criminal offence to assist a suicide only where the assister has a selfish motive. This provision in the Penal Code has not changed since 1942. When it was originally drafted in 1918, "the attitudes of the Swiss public were shaped by suicides motivated by honour and romance, which were considered to be valid motives. Motives related to health were not an important concern, and the involvement of a physician was not needed."[2] Euthanasia is not permitted in Switzerland, although as in many other European jurisdictions, the separate offence of murder at the victim's request carries a lower minimum sentence than murder.

Oregon, Washington, Colorado, California, Vermont, District of Columbia, New Jersey, USA ("Oregon-model states")

Many US states allow legislation to be enacted if a majority votes for an initiative placed on the ballot following a petition signed by a minimum number of voters. Following two narrowly unsuccessful attempts to permit physician-assisted suicide by ballot initiative in Washington and California, Oregon voters passed the first Death with Dignity Act in 1994 by a majority of 52%. The Act permits the provision of a prescription for lethal medication to be self-administered by the patient. The Act was controversial from the moment the ballot measure was passed, and there were a number of ultimately unsuccessful legal challenges to it. Washington state voters passed an

almost identical Act in 2008, as did Colorado voters in 2016. In 2013, 2015 and 2016 respectively, Vermont and California state legislators and District of Columbia council members passed statutes very similar to the Oregon Act, all of which are now in force. The Vermont Act was amended in 2015 to remove certain sunset clauses which would have changed the regulatory framework after three years from a regime modelled on Oregon to a professional practice standard. This would have permitted PAS on the basis of a valid request from a terminally ill patient, without requirements for consultation with a second physician, psychiatric evaluation, or waiting periods. The Oregon-model regime will now continue. The New Jersey legislature passed an Oregon-model Act in March, 2019.

Colombia

In 1997, the Colombian Constitutional Court ruled that a physician should not be prosecuted for ending life at the repeated request of a terminally ill patient who is suffering unbearably because the physician's action "is justified". The Court called on Congress to establish a regulatory regime to vindicate the fundamental right to die with dignity. Although a number of Bills were introduced, no progress was made in Congress on this issue. In 2014, the Constitutional Court reviewed the case of a terminally ill patient who had repeatedly and unsuccessfully sought euthanasia. The Court ordered the Ministry of Health immediately to issue a directive to health care providers requiring them to set up local expert committees to respond to requests for euthanasia. A national expert committee collaborated in the writing of the resulting Resolution which came into force in 2015.

Canada & Québec

In 2014, the provincial legislature of Québec passed *An Act Respecting End of Life Care* which came into force on 10 December 2015 and legalised euthanasia ("medical aid in dying") for patients at the end of life. In February 2015 in *Carter*, the Supreme Court of Canada struck down the criminal prohibition on assisted suicide found in the federal *Criminal Code* on the grounds that it infringes the rights of competent adult patients with a grievous and irremediable medical condition causing enduring and intolerable suffering who consent to an assisted death.[3] The Court granted a one year suspension of the declaration of invalidity to give the Parliament of Canada the opportunity to craft a regulatory regime. The suspension was subsequently extended by four months; during the extension individuals were permitted to access assisted dying by making a court application.[4] Just after the expiry of the extension in June 2016, the Parliament of Canada enacted a statute amending the *Criminal Code* to permit medical assistance in dying, which is defined as "(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."

Features of assisted dying regimes

This section outlines and compares the features of the main legal regimes permitting assisted dying: those in the Netherlands, Belgium, Luxembourg, Oregon (the model for the 6 additional US jurisdictions), Colombia, Québec and Canada.

The requesting person's condition and experience of suffering

The legal requirements relating to the requesting person's condition and experience of suffering vary widely across these jurisdictions. It is notable that despite this variation, over 70% of all reported cases of euthanasia or physician-assisted suicide involve cancer patients.[5]

In the Netherlands, the "attending physician . . . must have been satisfied that the patient's suffering was unbearable, and that there was no prospect of improvement". The patient's suffering need not be related to a terminal illness and is not limited to physical suffering such as pain. It can include, for example, the "fear of future deterioration".[6] A related due care criterion (see box 2) is that there must be "no reasonable alternative in light of the patient's situation". In cases where the source of the suffering is a physiological disorder, the patient's reasonable decision to refuse a realistic treatment possibility (whether curative or palliative) which might ease his or her suffering does not stand in the way of a request for euthanasia based on that suffering.

In Belgium, the "patient [must be] 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". The patient's suffering need not be limited to physical suffering such as pain. As in the Netherlands, there is no requirement that the patient be suffering from a terminal illness, although additional procedural requirements are imposed if the patient is "clearly not expected to die in the near future". Again there must be "no reasonable alternative" to euthanasia. However, euthanasia is permissible only if the disorder is incurable, so a patient's reasonable refusal of potentially curative treatment will generally prevent access to euthanasia;[7] the reasonable refusal of a palliative treatment possibility will not have this effect.[8] In recent years, the FECEC has accepted the possibility that refusal of a potentially curative treatment with particularly serious side-effects could be reasonable and would not, therefore, prevent access to euthanasia.[9]

The Netherlands permits assisted suicide in cases where the source of the patient's suffering is a psychiatric rather than a physiological disorder. In such cases, the patient may not reject "a realistic alternative to relieve the suffering",[10] although "patients are not obliged to undergo every conceivable form of treatment."[11] In Belgium, the permissibility of euthanasia in psychiatric cases was initially unclear, but such cases are now accepted by the FECEC.[12]

The Oregon-model states, Colombia and Québec all require the diagnosis of a terminal illness; the Canadian requirement is less clear. In Oregon, the patient must be suffering from a terminal disease, defined as "an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment, produce death within six months". In Colombia, the patient must be in the terminal phase of an illness or serious pathology, which is progressive, incurable and irreversible, with death predicted in the relatively short term. Similarly in Québec, the patient must be at the "end of life". The Act requires that the patient "suffer from a serious and incurable illness; be in an advanced state of irreversible decline in capability; and experience constant and unbearable physical or psychological suffering which cannot be relieved in a manner the patient deems tolerable." The Canadian Act requires that the patient have a "grievous and irremediable medical condition" for which there are four criteria: (1) a serious and incurable illness, disease or disability; (2) an advanced state of irreversible decline in capability; (3) that illness, disease or disability or that state of decline must cause the patient enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable; and (4) their natural death must have 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.

The request

In the Netherlands, the patient's request must be "voluntary and carefully considered". The patient must be competent to make such a request.

In Belgium, the patient must be "legally competent". The request must be both "completely voluntary" and "not the result of any external pressure". The doctor must inform the patient about "his health condition and life expectancy" and "the possible therapeutic and palliative courses of action and their consequences".

In Oregon, the competence, voluntariness and information requirements are set out in some detail. The patient must have "the ability to make and communicate health care decisions to health care providers, including communication through persons familiar with the patient's manner of communicating if those persons are available." Two witnesses must attest that the patient is acting voluntarily and is not being coerced to sign the request. The patient must make an "informed decision ... that is based on an appreciation of the relevant facts and after being fully informed by the attending physician of: (a) his or her medical diagnosis; (b) his or her prognosis; (c) the potential risks associated with taking the medication to be prescribed; (d) the probable result of taking the medication to be prescribed; (e) the feasible alternatives, including, but not limited to, comfort care, hospice care and pain control."

In Colombia, the request must be free, informed and unequivocal. In Québec, the patient must have capacity, be informed and be acting freely. In Canada, the person must be an adult with capacity who has made a voluntary and informed request for assistance in dying.

The requesting person's age

The Dutch law applies both to adults and to patients under the age of majority (18). A patient between the ages of 16 and 18 who is "capable of making a reasonable appraisal of his own interests" may request euthanasia or assisted suicide. The parent(s) or guardian does not have a veto, but must be consulted. Patients aged between 12 and 16 must pass the same test of capacity. In addition, the consent of the parent(s) or guardian is required.

In Belgium, euthanasia was originally legal only for patients over the age of 18 and for minors over the age of 15 who have been legally emancipated by a judicial decision. In 2014, the Belgian Act was amended to include minors with the capacity of discernment, although this group of minors must be suffering from a terminal illness in order to access euthanasia. An additional consultation with a child psychiatrist or psychologist is required to verify capacity. The consent of the minor's legal representatives (usually the parents) is also needed.

In Colombia, a 2018 Resolution permits euthanasia for children from the age of 6 at their competent, informed and voluntary request. Below the age of 14, parental consent is required. Between the ages of 6 and 12, a psychiatric evaluation is required to ensure the child has attained (i) exceptional neuro-cognitive and psychological development, and (ii) the level of understanding of the concept of death (as irreversible and inexorable) expected of adolescents aged 12 and over.[13]

The Oregon, Luxembourg, Québecois and Canadian laws apply only to patients over the age of 18.

Consultation and referral

All of the regimes require another physician (or nurse practitioner in Canada) to confirm the fulfilment of the legal requirements. A number of additional functions may be served by a consultation requirement, including quality control; avoidance of idiosyncratic judgments; provision of information to the attending physician; and enabling effective retrospective scrutiny of actions and decisions.[14]

> Box 2. The Dutch due care criteria
>
> The due care criteria are set out in section 2(1) of the 2001 Act. "The attending physician must:
>
> a. be satisfied that the patient has made a voluntary and carefully considered request;
> b. be satisfied that the patient's suffering was unbearable, and that there was no prospect of improvement;
> c. have informed the patient about his situation and his prospects;
> d. have come to the conclusion, together with the patient, that there is no reasonable alternative in the light of the patient's situation;
> e. have consulted at least one other, independent physician, who must have seen the patient and given a written opinion on the due care criteria referred to in a. to d. above; and
> f. have terminated the patient's life or provided assistance with suicide with due medical care and attention."

In the Netherlands, the independent physician must see the patient and give a written opinion on the extent to which the due care criteria are met (see box 2). The consultation requirements are more stringent if the patient's suffering is due to a psychiatric disorder.[15] The state-funded programme Support & Consultation on Euthanasia in the Netherlands (SCEN) trains physicians to be consultants and to provide support and advice for doctors treating patients at the end of life. The "vast majority" of reported euthanasia cases involve a SCEN consultant.[16]

In Belgium, the consulting physician must examine the patient and the medical record and ensure that the suffering requirement has been met. Moreover, if the patient "is clearly not expected to die in the near future", there is a mandatory additional consultation with either a psychiatrist or relevant specialist (and a waiting period of at least one month). Although a consultation with a palliative care expert is not legally required, many Catholic hospitals in Flanders impose such a *palliative filter* in addition to the statutory criteria.[17]

In Oregon, the attending physician must refer the patient to "a consulting physician for medical confirmation of the diagnosis, and for determination that the patient is capable and acting voluntarily." Further, a counselling referral must be made if either the attending or consulting physician suspects that the patient "may be suffering from a psychiatric or psychological disorder, or depression causing impaired judgment". PAS is allowed only if the counsellor determines that the patient is not suffering from such a condition.

In Québec, the consulting physician was originally required to be independent of both the attending physician and the patient. This was interpreted as meaning that the consulting physician could not be involved in the patient's care. This requirement has now been re-interpreted by the Commission on End of Life Care (CELC), so that the consulting physician may have a treating (but not a personal) relationship with the patient.[18]

The person providing assistance

In the Netherlands, the courts originally required that the person who providing euthanasia was the patient's *treating* physician.[19] The current requirement focuses more closely on its purpose: the doctor must know the patient sufficiently well to be able to assess whether the due care criteria are met (see box 2).[20]

The Belgian Act requires that the physician have "several conversations with the patient spread out over a reasonable period of time" in order to be certain of the persistence of the patient's suffering and the enduring character of the request. The Dutch purpose-focused argument (that in order to assess whether the due care criteria are met, the doctor must have some familiarity with the patient) might also be applied in Belgian euthanasia cases. However, the legislative history makes clear that the patient should be able to bypass his or her attending physician if so desired – from which one might infer that there is no requirement for a pre-existing physician-patient relationship.[21]

In 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". The evidence suggests that many patients who sought assisted suicide had to ask more than one physician before finding one who was willing to provide a prescription. Over the first three years of operation of the Oregon law, only 41% of patients received their prescription from the first physician asked.[22] This suggests that in many cases there was no longstanding or pre-existing physician-patient relationship.[23] The median duration of that relationship in Oregon over the first ten years was 11 weeks. The range was between 0 and 1440 weeks.[24] Commentators opposed to the Oregon law have raised the possibility that a patient refused PAS by one physician on the grounds of failing to meet one of the statutory criteria may obtain the prescription from a more accommodating physician.[25]

The laws in Belgium, the Oregon-model states, Québec and Canada contain conscientious objection provisions. Although there is no such provision in the Dutch law, it is nonetheless clear that "no doctor has any obligation to accede to a request [for euthanasia], however well-founded."[26] The Royal Dutch Medical Association (KNMG) has reiterated this position, stating that "physicians are not under any obligation to assist in euthanasia. Physicians who have fundamental objections to euthanasia and assisted suicide must be respected in their views."[27]

Reporting and scrutiny

Termination of life on request and assisted suicide remain criminal offences in the Netherlands. The defences inserted into the Penal Code by the Act require the doctor to report the case as euthanasia or assisted suicide to the municipal pathologist, who then passes the file to the relevant Regional Euthanasia Review Committee (RERC). If the RERC finds that the doctor did not act in accordance with the due care criteria (see box 2), the case is referred to the Public Prosecution Service. 105 cases were referred between 1999 and 2017 (0.17% of reported cases).[28] The first prosecution to be brought following these referrals was recently announced in a case involving an advance request from a patient with dementia.[29] Lack of, or inadequate, consultation is the most significant reason for referral. Consultation may be considered inadequate if the doctor consulted is insufficiently independent from the attending doctor, or the consultation takes place too early or too late. Problems with the way in which euthanasia is carried out are the second-most significant reason for referral. In recent years, most of these cases involve concerns about the dosage of the coma-inducing sedative administered prior to the muscle relaxant which causes death and the need to ascertain the depth of the patient's coma before administering the muscle relaxant.[30]

Compliance with the Belgian law is monitored by the FECEC, to which all cases of euthanasia must be reported. Only one case has been reported to the prosecutorial authorities by the FECEC (in late 2015; 0.008% of reported cases). It is not yet known on what grounds the referral was made. (The biannual report covering this period does not describe this case in any detail.[31] Concerns have been raised in the media about the patient's underlying medical condition, the consultation requirement for cases where the patient is not expected to die in the near future, and the waiting period for such cases.[32]) A separate criminal investigation is currently proceeding in a case instigated by the family of a young woman diagnosed with autism, which the FECEC did not refer to the prosecutorial authorities.[33]

Compliance with the Luxembourgeois law is monitored by the National Commission of Control and Evaluation (NCCE) which reports biannually. From 2009 to 2016 there were 52 reported cases. No cases have been referred to the prosecutorial or medical authorities.[34]

In Oregon, the physician must report each prescription written under the Act to the Oregon Department of Human Services (ODHS), and report each death resulting from the ingestion of the prescribed medication. A total of 24 physicians were referred by the ODHS to the Board of Medical Examiners between 1998 and 2018 for non-compliance with the provisions of the Oregon Act (1.96% of all reported deaths under the Act). Non-compliance with the Oregon Act identified by the ODHS has been almost exclusively of a clerical nature, the most common items being incomplete or late physician reporting forms or incomplete witness forms.[35] In relation to the other Oregon-model states, there is no evidence to suggest that non-compliance with the Washington, California or Vermont Acts is reported to the state medical authorities.

In Colombia, the Resolution requires requests for euthanasia to be approved by a special three-person multi-disciplinary hospital-based committee comprising a specialist in the patient's condition (not the treating physician), a lawyer, and a psychiatrist or clinical psychologist. The committee also bears responsibility for ensuring that euthanasia is provided within strict time-limits, and for accompanying the patient and their family members. A retrospective reporting requirement is also imposed. No reports have been published. Informal data suggests the cumbersome procedure is little used.[36]

Between 10 December 2015 and 31 March 2018, the Québec CELC received 1493 reports of medical aid in dying. At the time of publication of the third annual report, the CELC had examined 1443 of these and reached decisions on 1374. In 62 cases (4.9%, down from 6.6% in the previous period) the CELC found that one of the legal requirements had not been met. In 29 of these 62 cases, the consultant physician was not professionally independent of the patient (ie was treating the patient). As previously noted, this interpretation of the independent consultation requirement has since been abandoned. Leaving out these cases, the referral rate would be 2.4%. All of these cases were referred to the professional regulatory body.[37] In Canada, a monitoring system was implemented by regulations in 2018.[38] Interim official data indicate that at least 3714 cases were reported across Canada between June 2016 (after the federal legislation came into force) and December 2017.[39]

Empirical evidence

What is known about the effectiveness of safeguards?

An extensive body of empirical evidence exists relating to the safeguards and criteria outlined above, and how they operate in permissive regimes, with the most detail available in the Netherlands, Belgium, Oregon and Switzerland.[40] The evidence from these jurisdictions suggests that the legal criteria that apply to an individual's request for assisted dying are well respected: individuals who receive assisted dying do so on the basis of valid requests; third parties who assist individuals to die do not act unlawfully.[41]

What is known about reporting?

Evidence of the effectiveness of the reporting requirement and the scrutiny of reported cases in the Netherlands, Belgium, Oregon and Switzerland is less consistent. There is no data on the reporting rate in Oregon. The reporting rate within the right to die organisations in Switzerland may be 100%. The reporting rate in the Netherlands rose when the RERCs were inserted as a buffer between physicians and the authorities, although the Swiss experience suggests that a buffer may not be needed to encourage reporting if the process leading up to the assistance comprises several layers of administration involving a number of different actors coupled with few legal requirements.[42] The reporting rate is significantly higher (81% in 2015) in the Netherlands than in Belgium (53% in 2007) where legalisation occurred more recently.[43] The reporting rate has risen over time in the Netherlands; it is not yet known whether this is the case in post-legalisation Belgium. "The major reason for failure to report [a case as euthanasia] is that the physician does not regard the course of action as a life-terminating act".[44] These unreported cases frequently involve the use of non-typical drugs to cause death (morphine rather than barbiturates and/or muscle relaxants which are typically used in euthanasia cases) and/or a very short life expectancy.[45] The number of *estimated* deaths from euthanasia includes such cases, as it does not rely on doctors' labelling of their own practice. Since almost all cases involving typical euthanasia drugs are reported,[46] this inconsistent labelling now likely accounts for almost all unreported cases. This thesis is supported by anonymous data collected from physicians which indicates that consistently close to 100% of the acts termed *by physicians* as euthanasia and assisted suicide were reported.[47]

What is known about vulnerable groups?

In 2007, researchers examined data from the Netherlands and Oregon in order to see if members of vulnerable groups were more likely to receive assistance in dying (either euthanasia or PAS). They examined the frequency of such assistance in ten groups of potentially vulnerable patients, defined by gender, age, ethnicity, educational and socio-economic status, illness and disability. They found "no evidence of heightened risk ... with the sole exception of people with AIDS." It should be noted though that the lack of Oregon data on pre-existing disabilities weakens the force of this conclusion with respect to disability.[48] The researchers concluded that "the available data ... shows that people who died with a physician's assistance were more likely to be members of groups enjoying comparative social, economic, educational, professional and other privileges."[49]

What is known about the frequency of end of life decisions?

Many of the empirical claims made about the practice of euthanasia and PAS under existing legal regimes misrepresent the data, take it out of context or neglect important comparisons with jurisdictions where these practices are prohibited.[50] Chart 1 shows the percentage of all deaths in specific years that were cases of euthanasia (EUT), PAS or termination of life without request (TLWR). It combines data from a number of different anonymous prevalence surveys of doctors.[51] All surveys were based on one originally designed by Dutch researchers.[52] The relatively broad and overlapping confidence intervals suggest that fine comparisons should not be made between countries with the lowest percentages. As indicated, some comparisons are from different years. Although similar, the surveys are not identical. The percentage of deaths in which an end of life decision (ELD) is made varies across jurisdictions.

This evidence does not support the argument that there is a slippery slope between the legalisation of euthanasia (termination of life on request) and termination of life without request (TLWR).[53] The rates of TLWR vary. The evidence suggests that TLWR takes place in both permissive and non-permissive jurisdictions, with some of the highest rates in non-permissive jurisdictions (eg Australia in 1997), although rates of TLWR in some permissive jurisdictions are higher than in some non-permissive jurisdictions. TLWR occurs more frequently than euthanasia in all countries that have been surveyed except the Netherlands and Belgium.[54] Rates of TLWR have decreased since legalisation in the permissive jurisdictions of the Netherlands and Belgium.[55]

Chart 1. Rates of euthanasia (EUT), PAS and termination of life without request (TLWR)

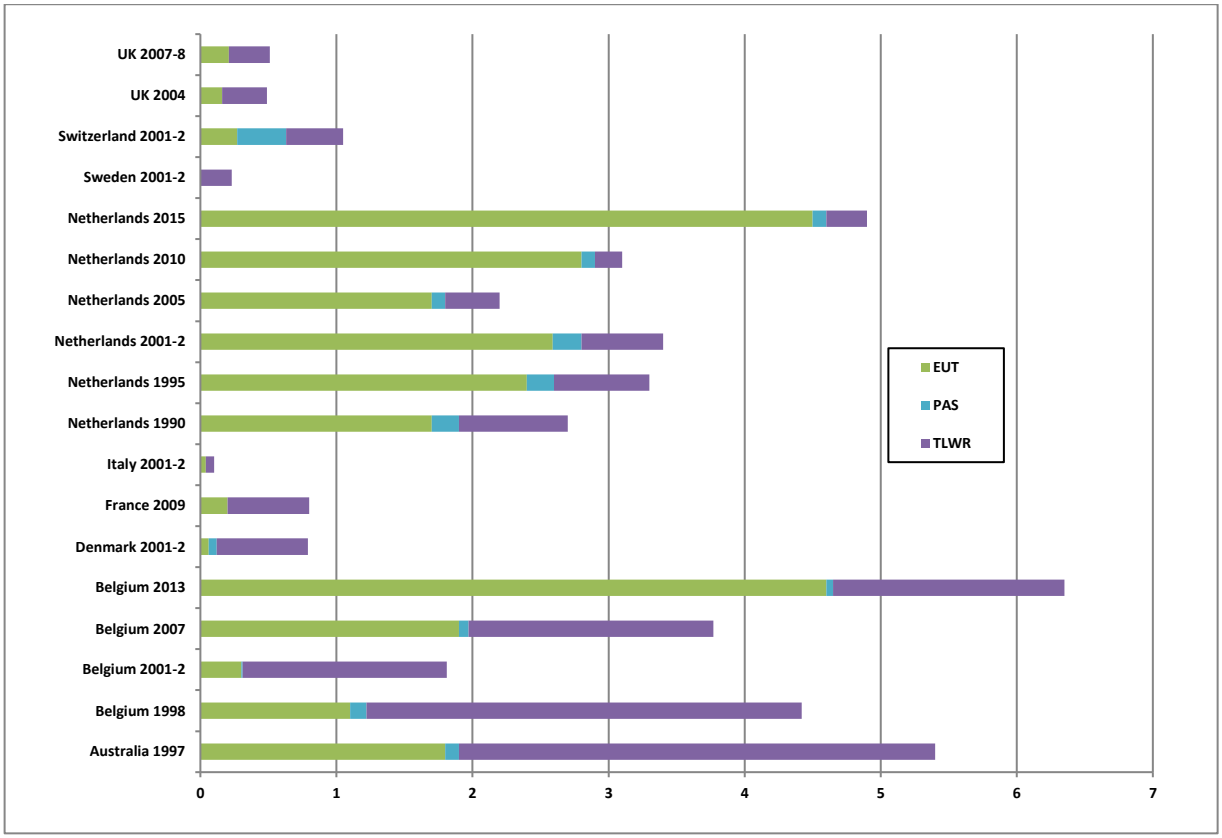
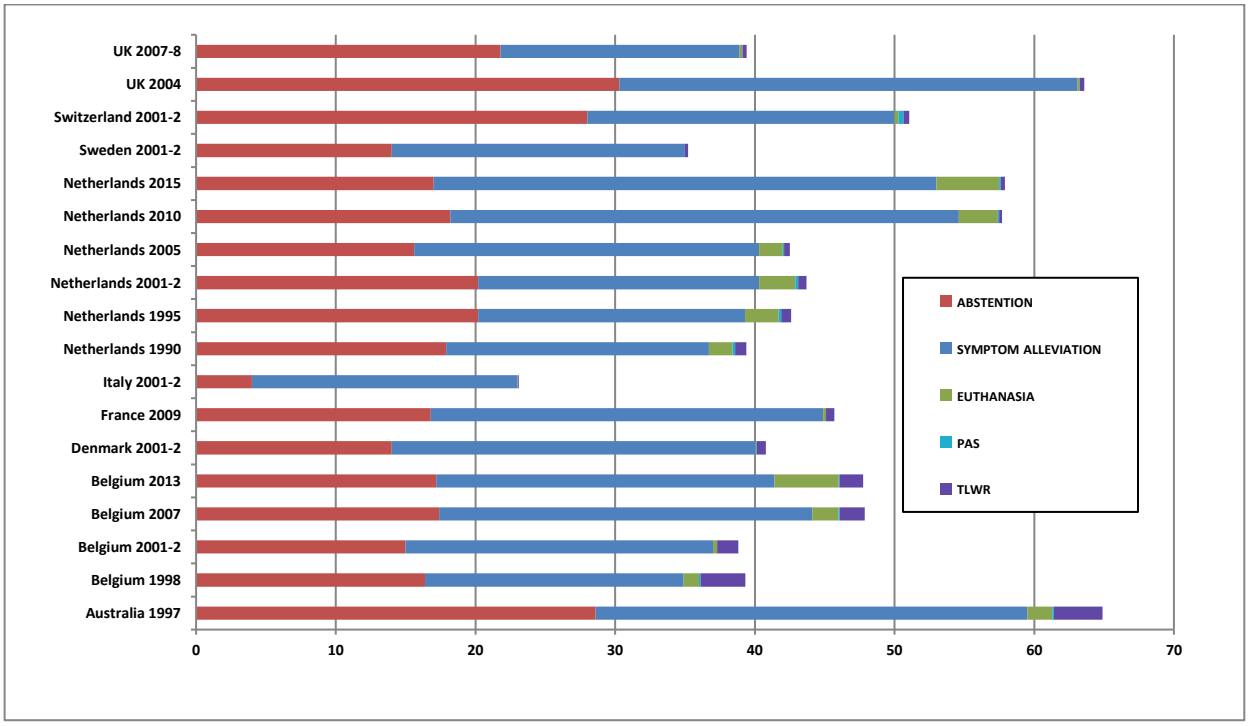


Chart 2: Rates of end of life decisions (percentage of all deaths)

Chart 2 compares the types of ELDs in the jurisdictions in which the original Dutch survey has been carried out. In addition to euthanasia (EUT), PAS and termination of life without request (TLWR), two much larger categories are included: *abstention* (withdrawing or withholding life-sustaining treatment) and *alleviation of symptoms* taking into account possible or probable hastening of death. In all countries, EUT, PAS and TLWR are relatively rare.



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EXPERIENCE

King's College London (KCL) Dickson Poon School of Law: Professor of Law (2007-present); Co-Director of Centre of Medical Law & Ethics (2013-present); Reader (2005-2007); Lecturer (1995-2005); Impact Lead. Vice-Chair, KCL Research Ethics Committee (2004-2015; Member 2002-2015). Programme Director, MA in Medical Ethics & Law. Awards for teaching excellence & extraordinary contribution to the College community.

Supreme Court of Canada: Law Clerk to Mr. Justice Frank Iacobucci (1992-1993)

ASSISTED DYING PUBLICATIONS

Book

Lewis P. *Assisted Dying and Legal Change*. Oxford: Oxford University Press 2007:217pp

'this book is likely to have broad appeal, across disciplines and across borders. It is a well composed, tightly written, thoughtful work which is at the same time both analytical and searching. . . . The book usefully builds on the existing literature by making new connections, drawing inferences and venturing suggestions. The author poses novel questions and pushes the boundaries of understanding in an effort to find answers to the different approaches to legal change in different jurisdictions. In doing so, the book unquestionably augments the body of existing literature internationally on the subject of assisted dying and lays a foundation for more informed and reflective analysis of legal change in the area of assisted dying in future scholarship.' (Otlowski M. *Med Law Rev* 2008;**16**:314-19)

'This is a well argued and scholarly book that provides the reader with a clear overview of international variations in the law covering assisted dying, and a compelling argument for understanding national contexts before generalising from one nation's experience to that of another. I can recommend this book strongly to sociologists who want to understand the role played by the law in this issue.' (Seale C. *Med Sociology Online* 2008;**3**:36-37)

'In sum, informed philosophical readers of this well researched and clearly written book … may learn the valuable lesson that making [the case for and against the permissibility of euthanasia and assisted dying] is not enough if one wants to have the law changed. They may also learn that ethical arguments may not respect jurisdictional boundaries, but effective strategies of reform need to do so.' (Archard D. *Phil Q* 2011;**61**:215-216)

'The terse style and dense nature of the study requires close reading but it will reward abundantly with a remarkably creative legal approach to the topic of assisted dying. The depth of literature that is woven into the analysis will provide a wonderful resource for students and scholars in the field. And the contribution of the analysis for public policy discourse will set a benchmark for years to come.' (Magill G. *Heythrop J* 2012;**53**:862-863)

Selected Assisted Dying Articles, Chapters and Memoranda

Lewis P. Should assisted dying require the consent of a High Court judge? *Forthcoming* 2019

Lewis P. *Assisted Dying Regimes*. Invited written evidence submitted to the Oireachtas Committee on Justice, November 2017, published in Houses of the Oireachtas Joint Committee on Justice & Equality, Report on the Right to Die With Dignity, June 2018, 32/JAE/18, 74-80

Lewis P. Response to Consultation on draft Voluntary Assisted Dying Bill (New South Wales), submitted July 2017

Lewis P & Black I. Adherence to the Request Criterion in Jurisdictions Where Assisted Dying Is Lawful? A Review of the Criteria and Evidence in the Netherlands, Belgium, Oregon, and Switzerland. *J Law Med Ethics* 2013;**41**(4):885-898

Lewis P. Response to Consultation Paper, *Voluntary Assisted Dying: A Proposal for Tasmania*, submitted March 2013

Lewis P & Black I. Reporting and scrutiny of reported cases in four jurisdictions where assisted dying is lawful: a review of the evidence in the Netherlands, Belgium, Oregon and Switzerland. *Med Law Int'l* 2013;**13**:221-239

Lewis P. The failure of the defence of necessity as a mechanism of legal change on assisted dying in the common law world. In Baker D and Horder J, eds. *The Sanctity of Life and the Criminal Law: The Legacy of Glanville Williams*. Cambridge: CUP 2012:274-295

Lewis P. The Limits of Autonomy: Law at the End of Life in England and Wales. In: Negri S, ed. *Self-Determination, Dignity and End-of-Life Care. Regulating Advance Directives in International and Comparative Perspective*. Amsterdam: Brill 2012:221-48

'This essay raises some very powerful and timely concerns relating to current UK policy.' (Dyal M. *Med Law Rev* 2012;**20**:650-655)

Lewis P & Black I. Commissioned Briefing Paper. *The effectiveness of legal safeguards in jurisdictions that allow assisted dying*. Commission on Assisted Dying. 2012

Brownsword R, **Lewis P** & Richardson G. Commissioned Briefing Paper, *Prospective Legal Immunity and Assistance with Dying*, Commission on Assisted Dying, 2011

Lewis P. Informal Legal Change on Assisted Suicide: The Policy for Prosecutors. *Legal Studies* 2011;**31**(1):119-34

Lewis P. Commissioned Briefing Paper, *Assisted Dying Regimes*, End of Life Assistance (Scotland) Bill Committee, 2010, ELA080

Lewis P. Out of Focus: the DPP's final guidance on assisted suicide prosecutions. *Solicitors J* 2010;**154**(9):10-11

Lewis P. The Director of Public Prosecutions' Interim Policy for Prosecutors in Respect of Cases of Assisted Suicide: A Response to the Consultation, 2009

Lewis P. Unfinished business: The DPP's interim guidance on assisted suicide prosecutions. *Solicitors J* 2009;**153**(37):11

Lewis P. Assisted dying after *Purdy*. *Solicitors J* 2009;**153**(31):6

Lewis P. Euthanasia in Belgium Five Years After Legalisation. *Eur J Health Law* 2009;**16**:125-138

Lewis P. England and Wales. In: Griffiths J, Weyers H, Adams M. *Euthanasia and Law in Europe*. Oxford: Hart 2008:349-70

Lewis P. The Empirical Slippery Slope from Voluntary to Non-voluntary Euthanasia. *J Law Med Ethics* 2007;**35**:197-210

Lewis P. Evidence & Memorandum, *Assisted Dying for the Terminally Ill Bill*: A Comparison with the Netherlands, Belgium & Oregon. In: House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill, *Evidence*. HL Paper 86-II: 2005:27-46

Lewis P. The evolution of assisted dying in France: A third way?. *Med Law Rev* 2005;**13**:44-72

Lewis P. Rights Discourse and Assisted Suicide. *Am J Law & Med* 2001;**27**:45-99

Lewis P. The Dutch Experience of Euthanasia. *J Law Soc* 1998;**25**:636-49

Professor Penney Lewis

IMPACT

Case Study

Lewis P. Assisted dying: legal change, the slippery slope and regulatory safeguards (submitted to Research Excellence Framework (REF) 2014)

Summary: 'Whether assisted dying should be legalised is often treated as an ethical question transcending national boundaries and legal systems. Work in this field is dominated by partisan exhortation by proponents or opponents of legalisation. Professor Lewis's comparative research on legal change on assisted dying highlights the central importance of the choice of legal route in shaping regulatory regimes, evaluates the impact of legalisation on non-voluntary euthanasia (the 'slippery slope' argument) and assesses the effectiveness of regulation in permissive jurisdictions. Her critique of the unsatisfactory legal position in the UK coupled with expert interventions, have shaped and informed policy debate, and directly influenced the campaign to legalise assisted suicide and on-going judicial challenges to the current position. Elsewhere, her work has directly contributed to legal change in Canada and a Bill in Australia.'

Feedback from the sub-panel, REF 2014: 'The case studies were regarded as effective in demonstrating a clear thread between high-quality underlying research, pathways to impact through widespread dissemination, and concrete effects of the research, which were well documented. The sub-panel judged the case stud[y] on the law on assisted dying … to have demonstrated outstanding impact in terms of [its] reach and significance.'

Evidence & Affidavits

Public evidence before the Oireachtas [Irish Parliament] Joint Committee on Justice & Equality on the right to die with dignity, November 2017

Expert witness report on law & application of the law in relation to assisted dying in the Netherlands, Belgium, Luxembourg, Switzerland, Germany, Oregon, Washington, Vermont, California, Colorado, Montana, the District of Columbia, Colombia, Québec, & Canada, *R. (Omid T.) v. Secretary of State for Justice* [2017] EWHC 3181 (Admin), 29 September 2017

Addendum to Expert witness report on law & application of the law in relation to assisted dying, updating report on the Netherlands, Luxembourg, Oregon, Québec, & Canada, & adding Germany & the District of Columbia, *R. (Noel Conway) v. Secretary of State for Justice* [2017] EWHC 640 (Admin); [2017] EWCA Civ 275; [2017] EWHC 2447 (Admin); [2018] EWCA Civ 16, 9 June 2017

Expert witness report on law & application of the law in relation to assisted dying in the Netherlands, Belgium, Luxembourg, Switzerland, Oregon, Washington, Vermont, California, Colorado, Montana, Colombia, Québec, & Canada, *R. (Noel Conway) v. Secretary of State for Justice* [2017] EWHC 640 Admin; [2017] EWCA Civ 275; [2017] EWHC 2447 (Admin); [2018] EWCA Civ 16, 15 December 2016

Affidavit as expert witness on law & application of the law in relation to assisted dying in the Netherlands, Belgium, Luxembourg, Switzerland, England & Wales, Oregon & Washington state, *Carter v AG Canada & AGBC* [2012] BCSC 886, 31 August 2011, confirmed in [2015] SCC 5

Public evidence before the Commission on Assisted Dying, 25 May 2011

Public evidence before the End of Life Assistance (Scotland) Bill Committee, 7 September 2010, *Official Report*, 7 September 2010, Cols. 13-30

Evidence in private before the End of Life Assistance (Scotland) Bill Committee, June 2010

Public evidence before the House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill, 14 September 2004, House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill, *Evidence*, HL Paper 86-II, 2005, pp.32-46

OTHER RELATED PROFESSIONAL ACTIVITIES

Member, St Christopher's Hospice Clinical Ethics Committee (since 2003); Member, Human Tissue Authority (since 2016); Member, UK Donation Ethics Committee (2010-2016).

Invited conference papers & research seminars on assisted dying in Japan, France, Italy, Netherlands, US, Canada, the Institute of Advanced Legal Studies, universities across the UK; conference papers given in Australia, France, Netherlands, US, across the UK.

Media Appearances on assisted dying include Al Jazeera, BBC Newsnight, BBC World, BBC News, BBC Four, Channel 4 News, Sky News, Radio France International, *Times*, *International Herald Tribune*, *New York Times*, *Washington Post*, *Boston Globe*, *Huffington Post*, *La Presse* (Canada), CBC Radio (Canada), *Toronto Star*, *Sydney Morning Herald*, *Brisbane Times*, *Daily Telegraph (Australia)*, *New Zealand Herald*.

Research grants for work on assisted dying received from British Academy, Arts and Humanities Research Council, Institute of Advanced Legal Studies, Fondation Brocher (Switzerland), Social Sciences & Humanities Research Council of Canada.

LANGUAGES

Fluent French (classified as bilingual by Federal Government of Canada), Conversational Spanish (university level), Conversational Italian (A-level 2003 (A grade)), Advanced Dutch (funded by KCL Staff Bursary & KCL School of Law), Intermediate Brazilian Portuguese, Elementary Japanese.

FURTHER INFORMATION

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Queensland Aged Care, Palliative Care and End of Life Care Inquiry

Submission: **Preparing the Way and Australian Doula College**
Contacts: Harpreet Kalsi – [redacted] – [redacted]
Helen Callanan – [redacted] [redacted]

This submission was developed in partnership with Preparing the Way, the Australian Doula College and a core group of End of Life Doulas (EOLDs) in Queensland. This group includes qualified registered nurses, aged care workers, art therapists, educators, occupational therapists, dementia care workers, counsellors, Public Health Network staff and health promotion and policy specialists. The goal of our submission is to raise awareness regarding the vital contribution End of Life Doulas make to palliative and end of life care. We focused our submission on questions most relevant to our work and our experience. Responses consist primarily of direct quotes from End of Life Doulas, their thoughts and views based on their experiences.

Initially, the role of End of Life Doulas is outlined to provide the panel with an understanding of our role and work. We are in the process of finalising an End of Life Doula Model of Care which can be provided as an attachment (if required) to illustrate alternative models for providing care. As the document is lengthy, we have summarised the sections of the model associated with aspects of the Aged Care, Palliative Care and End of Life Inquiry in this submission.

The questions addressed in this submission focus on aged care and palliative care and are as follows:

1. The Role of End of Life Doulas – Background

1.1 Who are End of Life Doulas?

2. Aged Care – Questions Explored:

2.1 Is the aged care system meeting the current needs of older Queenslanders, including people with special needs? Why or why not?
2.2 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?
2.3 Are suitable health care services being provided within residential aged care settings and/or aged care providers?
2.4 How can the delivery of aged care services in Queensland be improved?
2.5 Are there alternative models for the delivery of aged care services that should be considered for Queensland?

3. Palliative Care – Questions Explored:

3.1 Are palliative care and end of life care services meeting the current needs of Queenslanders? Why or why not?
3.2 Do the standards of palliative care and end of life care provided in Queensland meet the clients' and the community's expectations?
3.3 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?
3.4 How can the delivery of palliative care and end of life care services in Queensland be improved?
3.5 What are the specific challenges of delivering palliative and end of life care in regional, rural and remote Queensland?

3.6 What are the specific challenges of delivering palliative and end of life care to Aboriginal and Torres Strait Islander communities?
3.7 What are the key priorities for the future?

Note: Individual End of Life Doulas have in some instances, stated their view of voluntary assisted dying in our survey. As an organisation, we do not advocate one way or the other.

1. The Role of End of Life Doulas (EOLDs) – Background

The palliative care environment is facing urgent challenges, some which can be bridged with the increasing visibility and vital role of End of Life Doulas in end of life care. At the same time, we are witnessing community mobilisation and rapid growth of individuals and communities who are working to 'do dying and death better'. What is currently missing is serious reference and in-depth understanding of the present and future roles of EOLDs in end of life care. EOLDs can and do provide an authentic continuity of care model across the entire spectrum of life. For example, an EOLD can provide education, information and support to clients who are living well with no diagnosis by assisting them to complete their end of life plans, Advance Care Directive 'Statement of Choices' and then, when the time comes, on through diagnosis, treatment, palliative care, active dying, death, after death care, funeral and bereavement.

The visibility of End of Life Doulas in Australia has increased in recent years. There are groups of committed and skilled professionals who have organised themselves to provide professional training and professional end of life support to clients, carers and families. What we are currently seeing in the organisation and integration of End of Life Doulas is similar to the decades of work that took place prior to the formal establishment of the Australian Doula College in relation to Birth Doulas in 2007. There are also similarities in the barriers experienced in integrating formally into an environment that is largely viewed as the domain of clinical and medical practice.

1.1 Who are End of Life Doulas?

End of Life Doulas (EOLDs) are non-medical professionals who, in aim and practice, complement those in medical/clinical practice and service provision. EOLDs take a holistic approach to health and wellbeing of individuals and families. They take into consideration the physical health, mental health, emotional health as well as the community networks, social connection, spiritual connection, cultural connection and connection to 'home' (or land) – not just of the dying person but of the significant others around them. EOLDs take a whole of life view of health and see death as part of the circle of life, not something to be avoided and denied.[1]

End of Life Doulas work within and across any and all end of life settings – the home, community aged care, hospice, palliative care units (both community-based and hospital based) and hospitals. Their aim is to provide ongoing support and ensure that clients, carers, family members and those who care about them are informed and equipped with the support, skills and knowledge necessary to make informed choices about their end of life journey. We work in partnership with primary care services and other end of life organisations.

[1] Aboriginal Health Strategy 1989 and Aboriginal Health and Medical Research Council http://www.ahmrc.org.au/index.php?option=com_content&view=article&id=35&Itemid=37

End of Life Doulas provide non-medical support and work to achieve all other aspects of holistic palliative care elements identified by the World Health Organisation (aside from clinical management). The EOL Doula will:[2]

- affirm life and regard dying as a normal process;
- intend neither to hasten or postpone death;
- integrate the psychological, social and spiritual aspects of patient care;
- offer a support system to help people at end of life live as actively as possible until death;
- offer a support system to help the carer/family effectively manage the illness and bereavement;
- use a team approach to address the needs of patients and their families, including bereavement support and / or counselling, if indicated and
- enhance quality of life.

Additionally, EOLDs can identify pain and potential medical issues and alert clinicians for evaluation and management.

'…the action that Doulas are involved in is an important part of prevention, harm reduction and early intervention. Doulas are at the heart of early intervention and harm reduction and on the other side of the public health spectrum doulas promote health and wellbeing, so it's not all about the bad things that go on in dying and grieving and care giving but it's also about promoting the positive side.

There are two key areas of activity for End of Life Doulas in Australia: one is a strengthened public health education and Doula training and mentoring and the other one is publicly profiling the good work and the civic work that Doulas do so that we can be part of the 'broad church' of end of life care and, in the future, the most important part of it.' Alan Kellehear.

2. Aged Care Response

The following section outlines the responses from End of Life Doulas to questions most relevant to our work.

2.1 Is the aged care system meeting the current needs of older Queenslanders, including those people with special needs? Why or why not?

End of Life Doulas who responded to this question all stated that from their experience the current aged care system is failing to meet the needs of older Queenslanders, including those with special needs. Staffing shortages, a lack of skilled and trained staff, a 'cookie cutter approach' and a gap in compassionate and respectful care were the key reasons provided. Individual responses are as follows:

No. Care is not tailored to the client. The trauma of forced separation from loved ones is callously handled. Options are limited. Most options are too expensive. There is a big gap in care/placement for what used to be low or hostel care, this was caused by the government reducing funding to aged care providers.

Staying at home is not always an option. Queenslander homes are not 'elderly friendly' and social isolation is a serious issue. There are insufficient rental properties for the elderly in a safe, supportive

[2] https://www.who.int/cancer/palliative/definition/en/

environment. The documentation and hurdles elderly must deal with are overwhelming and inappropriate at a time of severe stress.

Residential respite for carers of special needs people is practically non-existent in Qld. That a person can't be admitted without a GP is understandable, but this leaves many aged care facilities with empty beds due to lack of GPs. There is not enough understanding of what model of care Indigenous people require. More appropriate documentation requirements for funding and supporting the remote and indigenous sector of our population is needed.' - End of Life Doula A

No. Care providers do not have enough time to provide quality care. There are too few carers for too many residents. - End of Life Doula B

I have just started volunteering in a nursing home. There never seems to be enough staff to go around. Some patients are unable to feed themselves, it can seem they have food just sitting there. Residents needing to go to the toilet have to wait until a staff member can assist them... - End of Life Doula C

Aged care services Australia wide should have registered nurses: patient-to-staff ratios are insufficient for adequate care. We should need to rely on non-nursing staff to care for the majority of our vulnerable elder population who require clinical and nursing care.
More money should be spent on nutritious food.
An Advance Care Directive/ MPOA/ FPOA should be a legal requirement to enter aged care with State Trustee appointed where there is no family/NOK – End of Life Doula D

No - there are lots of lonely, socially isolated older people, and there are limited options to those who choose to stay at home. A lack of adequate resourcing is evident along with a lack of suitably trained staff, not just medical staff. - End of Life Doula E

We are all going to need more facilities across Australia and good carers trained properly and they need to be better paid to stay in the job as so many are casuals. End of Life Doula F

No. There are too many instances where our aged and those with special needs are not being treated with respect. Their basic human needs are not being met, and the system is very understaffed, both nursing and other care. - End of Life Doula G

My Aged Care is a nightmare for the elderly to navigate (and for those of us who attempt to help them). It is labour intensive, complicated and inefficient. Frankly, it is insulting. There needs to be a ***simple*** *system focused solely on palliative care to which the response time is immediate*. End of Life Doula K

2.2 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?

Serious concern about how our current system will struggle to meet the present and increasing demands of an ageing population and how it will fail many older Queenslanders if serious structural changes are not made was identified by all respondents. Investment in streamlining administrative processes for accessing care, ensuring more affordable and quality options of care (including greater options of care and adequate numbers of suitable trained staff, increasing education and awareness of planning for aged care were all raised as areas where changes need to be made to meet the future demands of aged care. Individual responses are as follows:

I don't think the system will be able to cope, a multifaceted approach is needed. Cultural change regarding sharing the responsibility in caring for aged and vulnerable e.g. Compassionate Communities approach, has been proven to be cost effective and have positive benefits to all involved. We also need effective resourcing for aged care. Investment alone may not fix the problem, but we need to change the way things are done by making sure staff are exceptionally well trained and the system includes family, friends and the community. Sharing the responsibility and having adequate community support is necessary. - End of Life Doula A

Unless federal funding increases for the middle to low socio-economic population, the hospitals will be more stressed than they are now. The wealthy will have a selection of upmarket – user pays aged care villages or have the funds to stay at home with extra services and home alterations. Better education of the Baby Boomers now of what their future will look like and what they need to get in lace now! Medical assessments, financial assessments and legal requirements need to be streamlined and preferably in one aged care document and department not three maybe four if you include QCAT for aged who have lost capacity. Grassroots community accommodation, mixing age groups as done in Europe – creating that extended Family, that isn't necessarily actual blood relatives should be options for care that are invested in. - End of Life Doula B

Unless the government steps up and increases the funding to aged care providers substantially, there will be many more mistreated senior citizens. - End of Life Doula C

Higher ratio of staff to residents needs to be a priority. Greater options will be expected. - End of Life Doula D

Obviously, the need will increase. Forward planning is necessary, and we need to make RACFs more appealing. - End of Life Doula E

Increased numbers expected. Need to consider other innovative ways to deliver services. - End of Life Doula F

Changes: Increased service options to include in-home care and end of life choices that are choices of those with life limiting conditions. - End of Life Doula G

Better training, secure job contracts for carers and much better management. - End of Life Doula H

Demand is bound to increase and for many the absence of family geographically close will mean that some will need to rely on the government or other paid systems for support. - End of Life Doula I

Small community homes – located in the heart of the community – geared towards aged care and end of life care are easier to manage, more person-centred and more likely to attract community participation. - End of Life Doula K

2.3 Are suitable health care services being provided within residential aged care settings and/or aged care providers?

All but two respondents stated they do not believe suitable health care services are being provided within residential aged care settings. Insufficient staffing ratios, a lack of trained allied health specialists such as physiotherapists, dieticians, trained spiritual care providers were all identified as

lacking. Two respondents felt that care was being provided reasonably given the resource constraints of aged care facilities. Individual responses are as follows:

Not as good as before the Federal government severely cut funding –the result of which is that the elderly pay a horrible price. Most aged care settings are an extension of hospital and are modelled on nursing not person care. They are becoming more End of Life Palliative facilities. Once again, if you're wealthy you're ok. If we look at a person staying at home and being cared for by family, there is no need or requirement for one of the family to be an RN or even EN, or for family to provide 24-hour RN service at home. I don't see why an aged care facility should either. Double standards and waste of nursing staff training, particularly with a world shortage of nurses. More than adequate allied health services and lifestyle support provided. The shortage of GPs in most regional and remote areas is of more concern. - End of Life Doula A

No, holistic care is not being provided. There needs to be more access to physios, podiatrists, dieticians, spiritual care etc. - End of Life Doula D

No - they need specialists in end of life care who have both the time and scope in their role to provide quality non-medical end of life care. Patient/staff ratio needs to be mandated. - End of Life Doula E

Meals are not nutritious and lack variety. - End of Life Doula F

No, there are poorly trained RNs. Doctors not specialised in elderly care. It takes too long to communicate changes in resident's wellness. - End of Life Doula G

They do their best with the funding they receive. - End of Life Doula H

Yes, but I don't believe there are enough service providers for that care to be delivered in a timely and compassionate manner. - End of Life Doula I

No. It seems that the bigger the facility, the less person-centred they are. The small community facilities, while greatly understaffed and overworked, at least have the support of families and community members. Carers should receive specific palliative care training, given permanent positions and be paid higher wages.

Aged care residents' and palliative care patients' physical, medical and spiritual needs should be addressed sooner rather than later. The waiting times I have witnessed are cruel.
The lack of palliative care training among the majority of health professionals needs to be addressed urgently. - End of Life Doula K

2.4 How can the delivery of aged care services in Queensland be improved?

All respondents stated funding is a major element that needs to be drastically increased to improve the quality of aged care provision in Queensland. Respondents also stated that alternative models of aged care that are not so costly need to be explored, and public education for the need to plan and what options are available commenced early on, along with a focus on increasing in-home support and services. Individual responses are as follows:

Reinstate the funding to provide palliative care, equipping staff to provide palliative care. Sharing the responsibility of care equipping and educating families / community to be actively involved. Enlist the services of End of Life Doulas. - End of Life Doula A

Funding and education. Looking at alternate models of aged care that are not so costly. That might attract providers to invest. More support to carers, so that there is less emotional and long-term physical damage. More residential respite or service providers funded to have support works live in for periods of time or as in England, later hours. My mother in law is 102 and lives alone in London in a council flat. Besides the allied health staff that come nearly daily, support staff to take her to appointments, she has specific support staff come in at 9am to check that she is up, dressed, had her breakfast, discussed day's activities. In the afternoon social support person for an hour or so. The 10pm another support person comes in to help her to bed and to see she is ok for the night. Just wonderful for her but she likes being on her own, this doesn't suit everyone. - End of Life Doula B

More funding, better training, public education. - End of Life Doula C

Higher staff ratio to resident numbers adjusted again to a higher level for those requiring full nursing care. - End of Life Doula D

Increase in quality, broad, home care services. Where care in a facility is necessary ensure patient/staff ratios allow for quality care. - End of Life Doula F

Improved staffing education numbers and communication skills. Improve the currently poor coordination of care. - End of Life Doula G

Transient staff. No one knows the residents. No one is accountable. Issues are handed over to next shift. - End of Life Doula H

Government funding support needs to increase, much better training from the top down need to occur along with better staffing ratios. The addition of allied and alternative health and wellbeing support. - End of Life Doula I

Make it more community-based. Provide public education that normalises death; implement aged care and palliative care volunteer care training programs. – End of Life Doula K

2.5 Are there alternative models for the delivery of aged care services that should be considered for Queensland?

All respondents agreed that there are alternative models for aged care delivery that should be considered. The Compassionate Communities model along with international examples of in-home support from students who have their rent heavily discounted, if not free, for living with older people and providing support should all be investigated further and trialled. The role End of Life Doulas can contribute to closing existing gaps in coordination of care, psychosocial support, education and planning should be seriously explored. We have provided details of the End of Life Doula model of care and what our principles are in providing aged and end of life care in Appendix 1 and Appendix 2. Individual responses are as follows:

Increase the use of Doulas in the system and compassionate communities. I believe we all have a role to play (not just the government and health professionals) but I also think that often families and communities can struggle to co-ordinate services during times they are also trying to manage their own emotions and care needs. - End of Life Doula H

- *Yes, compassionate community model sharing the responsibility, increase in-home supports.*
- *There are already alternative models in Queensland, but they are expensive, which excludes the majority of the population. Serviced apartments, villages that allow couples to stay 0together. I Love New Direction Care in Caboolture.*
- *Hospice. The use of End of Life Doulas/Deathwalkers/Death Midwives*
- *End of Life Doulas could assist with the non-medical requirements together with other support services.*
- *Dementia-specific villages like the new one in Tasmania.*
- *Yes, have End of Life Doulas provide the non-medical aspects of care to the dying.*
- *End of life practices starting early in aged care. End of Life Doulas to provide non-medical support roles for both family and residents.*
- *Small aged care and palliative care 'home-like' community facilities in the heart of the community.*

Refer to Appendix 1 and 2 for a detailed explanation of a model of care End of Life Doulas provide and how we fit in a palliative care framework.

3. Palliative Care Response

3.1 Are palliative care and end of life care services meeting the current needs of Queenslanders? Why or why not?

All but one respondent believed that palliative and end of life care services are not meeting the current needs of Queenslanders. The main barriers identified were:

- a lack of shared responsibility and focus on the medical model rather than holistic care including a focus on psychosocial and emotional wellbeing;
- insufficient facilities, staffing and training levels to provide the care that's needed with an increasing population that requires palliative and end of life care and
- a lack of community and health professional knowledge of palliative and end of life services including when and how to access existing services.

Specific responses include:

…no mention of cultural change and shared responsibility that needs to occur, it seemed to be very biased towards the medical, hence limits people's choice. - End of Life Doula A

Some amazing places and services around but there are not enough of high-quality holistic services available, we need more. - End of Life Doula B

No. Not enough funding or training for either. - End of Life Doula C

I believe discussions on advanced care directives, care for end of life could be improved greatly. - End of Life Doula D

Higher medical and assistance for basics such as toileting, feeding are basic requirements to maintain dignity and care is needed. - End of Life Doula E

No, staff/family/GPs need more education about what palliative care is i.e. it is about living life well and being supported in the final weeks and days. - End of Life Doula F

No - the care is very medically-oriented and palliative/end of life support should encompass emotional, practical, planning to die, and spiritual care aspects. - End of Life Doula G

They are not. They are accessed too late in most cases. Often, because it is a weekend and nothing was done earlier they end up dying in emergency rooms. - End of Life Doula H

With the increasing number of patients, we need more staff to cope with the demand. - End of Life Doula I

Yes, AND I think that Queenslanders could use more education on what those services are and when they can be accessed. - End of Life Doula J

3.2 Do the standards of palliative care and end of life care provided in Queensland meet clients' and the community's expectations?

All but two respondents believed that the standards of palliative and end of life care services provided in Queensland are not meeting the current needs of Queenslanders. The main barriers identified were a lack of understanding of standards and best practice in palliative and end of life care by clients, carers and family members. Much of the community think they will be able to access hospice care. In reality, there are not enough services, staff or beds. Respondents stated that from their experience most people do not understand or plan for end of life or palliative care, and so their expectations cannot be adequately met. As End of Life Doulas, most of our clients want a pain free and peaceful death, without sufficient planning, resources, services, understanding of options and standards and support expectations are often not met. Individual responses are as follows:

My mother died in Qld on the Sunshine Coast I was amazed at the number of independent hospice services that were available. So much better then in WA. We found each service we contacted to be excellent. Each service we encountered and worked with were NFP. We didn't encounter and weren't offered any state-based services. At times, when she was admitted to hospital her treatment was not palliative but medically focused which caused complications that were distressing to her and the family. - End of Life Doula A

Not really, it's too disjointed, there is no single point or person of continuity during this incredibly stressful time. Community knowledge about their rights and options is nearly non-existent. - End of Life Doula B

I think much more discussion needs to occur around this. If higher nursing ratios are met, residents could comfortably remain in their home to die, whether that be a residential facility or their own home rather than being transferred to a hospital, highly technical environment which is thereto maintain life. Support for End of Life Doulas to help bridge the gap between the medical assistance provided by pal care and providing practical, spiritual and emotional support to an individual and/or family/support people. As the baby boomers start to hit this demographic a much higher choice and availability of standards will be expected. The current residents were/are still the demographic who do as the experts (Drs etc) tell them. Following generations will not accept these conditions and lack of choices. - End of Life Doula C

No there are gaps and choices are limited. - End of Life Doula E

Yes, I believe so. - End of Life Doula H

There are exemplary palliative care facilities and professionals in Queensland. Unfortunately, they are understaffed, underpaid and overworked and those at end of life are often not made aware of their services until the very end. Because Western medicine still sees death as a failure, costly, painful and ineffective medical interventions are carried during many patients' last year of life totalling on average $100,000. If given the option, I reckon that given the chance, the majority of these patients would opt for palliative care, thereby saving themselves and their families untold physical and emotional agony and saving the government health services millions of dollars. End of Life Doula K

3.3 **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?**

All respondents agreed that demand for palliative and end of life care support will drastically increase with an ageing population. Innovative community support and activation will be needed to support people to have a 'good' death. Shared responsibility, investment and training for in-home support, an increase in facilities and hospices and innovation in supporting vulnerable groups and populations such as Aboriginal and Torres Strait Islanders, remote, CALD and LGBTI all need to be focused on. End of Life Doulas are and continue to play a pivotal role in meeting needs for holistic support and coordination of care to support peoples' wishes, most of whom prefer to die at home. Individual responses are as follows:

Shared responsibility, cultural change e.g. where possible the community becoming involved. A focus on improving dying and death literacy and growing the communities' understanding and acceptance of the inevitability of death, in essence the community reclaiming dying and death and for it not to be seen as a medical event. - End of Life Doula A

EOLDs, assisted dying option and support groups. - End of Life Doula B

More funding, more training, more community education. - End of Life Doula C

Services that are not cost prohibitive need to be offered in the home. - End of Life Doula D

More facilities will need to be built and more information needs to be given to the population about care in the home possibilities and making that happen re staffing and utilities being available. - End of Life Doula E

I feel that we could do more to meet the needs of those in remote and rural settings. Perhaps a palliative care bus that travels to these areas to provide care and also to work as a touch point for families to identify gaps in care. - End of Life Doula F

Palliative care needs are going to increase greatly during the next few decades. Public education campaigns – which can be led by EOLDs – will ensure that people become familiar sooner rather than later about the options available to them and be encouraged to plan ahead. Effective community education programs would go a long way towards smoothing the way. End of Life Doula K

3.4 How can the delivery of palliative care and end of life care services in Queensland be improved?

Respondents stated that community education, increased funding of services and increased training to better equip staff and increase numbers of end of life and palliative care workers is imperative to the improvement of palliative and end of life care in Queensland. Alternative options to support

people to die at home rather than in hospitals was also voiced as a key improvement to be made. Again, integrating the role of End of Life Doulas in palliative and end of life care can minimise the gaps that exist in providing coordinated holistic care that is urgently needed. As previously noted, to see the support we provide as End of Life Doulas and how we fit in a palliative care and end of life care framework refer to Appendix 1 and Appendix 2. Individual responses are as follows:

Education of all stakeholders as to the appropriate model and benchmark. - End of Life Doula A

More funding, more training, more community education, more use of non-medical end of life professionals (doulas etc.) - End of Life Doula B

Greater number of options will be required. People will want more informed choices, more support especially in the spiritual aspects but not so much from a formal religious association. Greater options to remain in own home to die. - End of Life Doula C

Educate family and GPs. Have enough INREACH services and community palliative care that can go in and support staff. Offer affordable palliative care further education and promote free online education through services such as Carereach. - End of Life Doula D

Broaden outside of the medical model. End of life does not need to be medicalised. Bring end of life care back into the home and family unit, if people wish. Educate and debunk some myths about end of life care. - End of Life Doula E

More staff being available to talk and listen freely, going out into the community to make people aware of all options available. - End of Life Doula F

Community-based public education! End of Life Doulas are the ideal ones for the job. End of Life Doula K

3.5 What are the particular challenges of delivering palliative and end of life care in regional, rural and remote Queensland?

All respondents stated that access and sufficient staffing and service providers were identified as the major barriers to delivering palliative and end of life care in regional and remote Queensland. The reliance of telecommunication support such are Telehealth cannot be a constant 'get out of jail card' – although Telehealth is enormously beneficial when it works, there continues to be significant segments of the population that cannot access this service in remote areas of Queensland who require alternative options to be tabled, and not put in the 'too hard basket.'

Access to palliative care staff. - End of Life Doula A

Everything. Distance. Cultural. Lack of resources. Communication infrastructure so inadequate. Consulting approach not directive service provision. - End of Life Doula B

Lack of adequate supplies, access to palliative care service providers, equipment, volunteers. - End of Life Doula C

Lack of general support, isolation, potential funding. In my own instance I am the only person training in End of Life Doula care and there are only two training in Cairns. - End of Life Doula D

Distance, remote communities, lack of resources. - End of Life Doula E

Lack of choice, appropriately skilled care providers (not just medical). - End of Life Doula F

Not enough staff, red tape and change hold people back. - End of Life Doula G

Access to services. Isolation. Absence of community support. - End of Life Doula H

Lack of palliative care training for ALL health professionals. The fact the death and dying are no longer accepted as normal stages of life. They are in the hands of the 'professionals' not the community. End of Life Doula K

3.6 What are the particular challenges of delivering palliative and end of life care for Aboriginal and Torres Strait Islander communities?

Lack of consultation with Aboriginal and Torres Strait islander people. - End of Life Doula A

A culture of not trusting Aboriginal and Torres Strait people to know what's best for them. Isolation, cultural, financial. - End of Life Doula B

Lack of adequate supplies, access to palliative care service providers, equipment, volunteers and community education. - End of Life Doula C

Lack of cultural awareness may be an issue. Currently studying some modules on this, will be interesting to be able to apply and learn about this in the end of life aspect. Not enough experience to state if this is a definite issue. - End of Life Doula D

Higher mortality rates amongst this population. Reluctance for these populations to access. - End of Life Doula E

Cultural beliefs likely impacting on choices. - End of Life Doula F

Lack of cultural understanding and awareness. Limited training options. - End of Life Doula G

Beliefs, acceptance to change or being allowed to enter these groups with respect and trust from the community. - End of Life Doula H

Programs such as Program of Experience in the Palliative Approach (PEPA) should be much more widely publicised and implemented in areas inhabited by Aboriginals and Torres Straits Islanders. PEPA training for health care providers and end of life professionals in these areas should be mandatory. - End of Life Doula K

3.7 What are the key priorities for the future?

Respondents agreed that the key priorities for the future centred around ensuring shared responsibility for finding solutions and closing the many gaps that are evident in end of life and palliative care. An urgent increase in raising awareness and education of end of life literacy is needed, along with providing new accessible and affordable models of in-home care and support to help people die well and home. We note that there is a great deal of wonderful activity around trying to increase death literacy and end of life planning, the lack of funding to reach the entire population through a mass campaign has not been achieved and may assist to ensure that the good work that is being done actually reaches the intended populations.

Shared responsibility. Improving the communities' death literacy commune-based services education of all stakeholders as to what is available – choices and benchmarks. - End of Life Doula A

Funding, more carers, better training, volunteers, community education. - End of Life Doula B

Higher staff ratios, greater options for remaining at home as places will not cope with numbers, higher awareness /education around dying. Support for those roles that could be a vital nonmedical link in continuous care (physically, emotionally, spiritual and practical care). - End of Life Doula C

Empowering people to take control of their future. It should start earlier rather than later in life. - End of Life Doula D

Promote palliative care as life affirming not life ending, normalise dying and death and make palliative care more accessible to all. - End of Life Doula E

Quality in-home end of life care options staff/patient ratios increase in home care options when preferred. - End of Life Doula F

Making everyone aware that change has to occur as the population ages. - End of Life Doula G

Finding and providing models of care that are network-centred and not just patient-centred. Putting the respect and dignity for patients first and foremost. - End of Life Doula H

Empowering communities to take back death and dying. Community-based public education which can be delivered by your friendly local End of Life Doula! - End of Life Doula K

Conclusion

There is substantial evidence regarding the burden of unmet need for palliative and end of life care. As the population ages and an increasing number of people approach or reach the end of their life, a significant burden on communities, social, aged and health care services to provide appropriate levels of support and care will occur.[3]

...a shift in culture is needed to focus more on managing long-term illness in palliative care, rather than on curing illness. This will require a change in health investment and planning as the traditional model of acute hospital care will need to be augmented by different service environments, including home-based palliative care, respite and short stay care, nursing home care and hospice care... While this transition will be costly, there is evidence of the comparatively lower cost of providing community-based care as opposed to acute care, and the potential to reduce acute hospital stays and avoid unplanned emergency room visits. (Economist Intelligence Unit 2015).

The Economist Intelligence Unit identified a range of elements that can improve the quality of end of life care. These included:

- increasing access to home and community-based palliative care;
- providing support for the families and voluntary workers who can extend access to care and
- encouraging more open conversations about death and dying.

[3] National Palliative Care Strategy 2018:20

End of Life Doulas provide services in all these areas and can make a significant contribution to providing better end of life experiences for clients, carers and family members. Together, in partnership with primary, specialist and community support, we can holistically and appropriately care for people approaching the end of their life.

Appendix 1

Where EOLDs 'fit' in an integrated palliative care framework

The Commonwealth Senate Community Affairs Reference Committee reviewed the Australian palliative care system in 2012. One key recommendation from the review was '…an increase in the capacity to support palliative care in the home and other community settings (for example, aged care facilities) and to reduce the demand on transfers to the hospital system.'[4] It is well known that in the next 25 years the number of Australians who die each year will double; 60–70% of Australians would prefer to die at home and yet only 14% cent do, and 54% of people die in hospitals and 32% in residential care.[5]As noted by Dr Julian Abdel, 'If we take a public health approach it is possible to improve the experience of dying for families, communities and ultimately the person with a terminal illness.'[6]

Dr Abel conducted a project in Frome, a small English community of 30,000 people. The project focussed on identifying vulnerable patients, mapping their networks, building community capacity to support people at the end of life through community development and implementing the Compassionate City Charter more broadly. He found that the community of Frome experienced a 30% reduction in all emergency admissions to hospital admissions, compared to the rest of Somerset, resulting in savings of $3.25 million AUD per annum in Frome alone. If these savings were made in a population as large as Australia, this could result in savings of $2.6 billion per annum.[7]

The role of building, activating and coordinating community can result in saving costs associated with unnecessary hospital admissions and taking pressure off the system and also allow more people and those around them to accomplish their wish of dying at home. Further, 'many stakeholders who participated in the inquiry (2012) described the palliative care system as fragmented and identified this fragmentation as a barrier for patients and families accessing the services they need' (Urbis 2016:25).

The points above demonstrate that we require a fundamental change in the current system and processes of delivering palliative care. We propose that in order to reform the current fragmented system – which is currently unable to support the many people who wish to die at home or in community settings – the End of Life Doula, in many instances, can work effectively in partnership with primary health services, specialist palliative care services and other health and wellbeing supports to ensure that people at end of life are able to die in the location of their choice. As previously mentioned, EOLDs can and do provide continuity of care from pre-diagnosis through diagnosis, treatment, palliative care, active dying, death, after death care, funeral and bereavement.

[4] https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Completed_inquiries/2010-13/palliativecare/report/index

[5] Gratten Insitute Dying Well Report 2014

[6] Compassionate Communities Communique 2017 p2

[7] Ibid p20

In creating a strong and effective national palliative care strategy to close existing gaps and build on the existing level of care provided, Urbis (2016:3) recommended the following:

- Ensure the supply of well-trained medical, nursing and other health professionals.
- Improve consistency of access and quality across the country. 'Identifying tangible and practical activities to support jurisdictions and educational institutions to address workforce shortages and capacity issues would be useful,' (Urbis 2016:5).
- Increase the appropriateness of services to respond to the specific needs of sectors of the population (e.g. indigenous and culturally and linguistically diverse) and, critically:
- 'The importance of increasing the public comfort with thoughtful and considered discussion about death and dying.' (Urbis 2016:4).

Drawing upon existing frameworks and models, reviewing recommendations of previous reviews and evaluations, and in line with the Palliative Care Service Development Guidelines (Palliative Care Australia), our model of care places people living with life limiting illnesses, their families and carers at the centre of the model.

It is well understood that carers and families often provide the lion's share of support for the person with a life-limiting illness. When the core support person or people are not supported sufficiently, we see an increase in hospitalisation and a breakdown in the support system.[8] With the increase of an ageing population across the country and in the community, there is an untapped resource that can be integrated into care plans for people approaching end of their life, their families and carers. The impact End of Life Doulas can have in bridging existing gaps and providing social, emotional and wellbeing support as well as advocacy cannot be underestimated.

1.2 Categories of Connection

Two broad categories of connection have been identified as essential components of holistic care within which End of Life Doulas work across the palliative care spectrum:

- With and within community
- Between agencies, services and organisations

With and Within Community

'A strong connection with the community is undeniably important for helping to facilitate a relationship between the client, the service and the community and has additional benefits.'[9] End of Life Doulas work predominantly with and within the community. We provide a non-threatening, simple entry point to discuss and plan end of life care. Our role in increasing public thought, discussion and planning on end of life is significant.

Soft entry options

Soft entry options are points to introduce clients to in informal environments in their own communities rather than expecting families to seek out specific services to support palliative care and other end of life care support. Soft entry options can significantly increase the knowledge and uptake of end of life care literacy and support and improve connections between services needed to provide a range of access options for people with a life limiting illness to access.

Providing opportunities

Although knowledge of and connections to end of life services exist within communities to varying degrees, there is capacity for End of Life Doulas to bridge connections for individuals and families who do not have such linkages. End of Life Doulas are able to assist in providing opportunities and

[8] Gratten Insitute Dying Well Report 2014

[9] (MHC Journey of Wellbeing p.6)

developing community connections to better enable communities to respond to their specific concerns.

How do we Focus on Soft-Entry Options?

- ✓ Have an open-door policy and welcome engagement from community members.
- ✓ Encourage self-referral.
- ✓ Facilitate, coordinate and / or help deliver community care at end of life events, information sessions, death cafés etc (improve EOL literacy and support).
- ✓ Encourage completion of ACDs prior to illness and aging.

How do we Focus on Providing Opportunities?

- ✓ Facilitate the establishment of support networks for communities in providing care at end of life awareness, literacy and connections
- ✓ Provide a venue or opportunity for connections to develop and strengthen
- ✓ As awareness and connection between communities grow, we support individuals and the community to participate in care at end of life events and initiatives

The importance of raising awareness of end of life care support and creating opportunities for connection by End of Life Doulas cannot be underestimated. As identified by Urbis, 'the need for public awareness and understanding of the process of death and dying continues to be identified as a barrier for managing pain and symptoms for many people at the end of life.'[10]

Between Services, Agencies and Organisations

Movement between different services, agencies and organisations working in the area of end of life care will have a profound impact on a client, career and families experience.[11] The existence of strong connections between services provide for better quality of care for clients, carers and families. End of Life Doulas can assist in fostering greater collaboration and act as intermediaries between clients, families and services. Through fostering greater collaboration, transitions between services and home or community-based care can be strengthened.

Collaboration

'Collaboration between services is the most effective way to extend limited resources within a region and ensure that all services are working together to deliver a consistent, holistic and supportive model of care.' [12]

How do we Focus on Collaboration?

- ✓ Regular meetings between care givers (often family) and when authority has been given, meeting with other support services to coordinate care, identify and bridge gaps
- ✓ High level meetings between peak bodies and national, state EOLD representatives
- ✓ Shared template for care
- ✓ Develop MOU between Australian Doula College and key national and state services (e.g. Palliative Care Australia and State / Territory affiliates)

[10]Urbis 2016:4

[11] Mental Health Commission Journey of Wellbeing 2017

[12] Ibid

Improving Transitions

'Improving the connection and communication between services helps to manage some of the identified risks associated with the transition between services.'[13] This includes waiting periods, slow response from referred services, repeating case information and emotional stress with delay in care. EOLDs are a consistent point of contact and connection who 'know' the whole story and can assist with sharing information with permission when necessary.

How do we Focus on Improving Iransitions?

- ✓ Discuss and review needs with client and family and suggest requesting referral to any identified services which can improve the quality of care for the client and family.
- ✓ Follow up on referrals to make sure that a client's care has been appropriately transferred.
- ✓ Support families to develop a list of regional resources that can benefit them.
- ✓ Encourage early/self-referral to palliative care to develop relationships and trust.

Supporting the Social and Emotional Wellbeing of Clients and Families

As End of Life Doulas our key role is to support the social, emotional, psychosocial and spiritual wellbeing of clients. We do this by:

- providing continuity of care while services generally drop in and out of the care journey. We listen and meet the needs of clients, supporting them for as long as they want. We work pre-diagnosis to support and encourage people to think and plan for their end of life, we then continue to work from diagnosis through to death and bereavement;
- providing 24/7 support and ensure a back-up EOLD is always available. If a client is admitted to hospital in the middle of the night or awakens afraid early in the morning, we can be there;
- coordinate communication strategies and processes between family, friends and, if requested, with supporting services and organisations and
- identifying people's wishes, then look at and discuss what their best- and worst-case scenarios might be. We then work with them to create plans for what they would like to do if things do not go the way they wish– plans B and C.

Critically, we support people to die at home. It takes at least sixteen support people (from the informal network – this does NOT include medical/nursing/allied clinical staff known as 'formal' network) to successful assist someone to die at home.[14]

We identify and can coordinate these people and provide ongoing support and care to the client and their family. Being an End of Life Doula is about prioritising networked-centred care – a team approach. Solely focusing on the dying person does not help provide the best possible care as the carers are usually carrying majority of the burden. When the carer burns out, in the majority of cases, the person who is dying is no longer able to die at home. People at end of life spend only 5% of their time with their doctors at end of life. End of Life Doulas can be with them 100% of the time.

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[13] ibid

[14]Horsfall, D; Yardley, A; Leonard, R.J; Noonan, K; Rosenberg, J.P. (2015) End of Life at Home: Co-creating an ecology of care. Research report, Western Sydney University.

[15]Professor Alan Kellehear – https://vimeo.com/275086030

We provide support to the carers and the family and are able to monitor everyone to ensure early intervention is available for depression and anxiety, new symptoms, a change in the trajectory of the illness and during bereavement. As one End of Life Doula noted, *'When everyone goes home and drops off, a Doula is still there providing authentic continuity of care'*

In terms of psychosocial support EOLDs also:

- work to prevent social isolation by being present and coordinating companion support. If none is available, we can be there to prevent social isolation and assist with home support and outings;
- provide support during the grieving process before and after bereavement for the client and their family;
- educate carers and family members about the importance of self-care and create opportunities for respite, e.g. we actively participate and support self-care and relieve the carer burden, and
- support and assist the client identify and fulfil their needs, from social to practical. If relevant, an EOLD can act as a 'team manager', coordinating care and support for the dying person and provide support for families and friends.

How do we Support the Social, Emotional, Psychosocial and Spiritual Wellbeing of Clients, Carers and Families?

- ✓ Undertake comprehensive needs assessment of person living with their illness, their caregivers and family members and identify skills, resources and gaps in care.

- ✓ Collaborate with caregivers/family to create an agreed plan for the support, services and care the EOLD will provide.

- ✓ Establish communication and referral pathways and processes with primary care services and other specialist services that may be required to meet patient needs.

- ✓ Support families to work with their grief by creating rituals around space. For example, taking some time when they are caring for a loved one to read a poem, or gently rub their feet, talk about particular photos or memories they shared. Creating a dedicated time to connect with their dying loved one in a gentle and unique way to create positive memories of the death journey.

- ✓ Encourage the creation of legacy documents – biographies, videos, tape recordings, artwork, poetry etc.

The family and carers are often exhausted, overwhelmed and may be confused about how best to support the dying person and themselves. EOLDs can act as a lighthouse, looking at the needs and situation with a broader perspective and coordinating priorities and care. '…not everyone is able to receive the palliative care they need to live well. Many experience various barriers in accessing and choosing the care they wish to receive, including geographical, cultural, language, and other barriers.'[15]

[15] National Palliative Care Strategy 2018:16

PRINCIPLES OF THE EOLD MODEL OF CARE

The following principles illustrate our statements of intent as End of Life Doulas and members of the Australian Doula College and who have trained with Preparing the Way.
The principles apply to every aspect of End of Life Doula care.

EMPOWERMENT	CHOICES	CONNECTION
'Having strong relationships within communities empowers individuals to take control of their own social and emotional wellbeing. The relationship further empowers the community to set the standard of the services they want and need.' (Mental Health Commission – Journey of Wellbeing 2016).	The importance of choice is at the heart of providing client-centred care at end of life. Too frequently clients do not know and /or are not asked what their end of life choices or wishes are. This is due to a lack of end of life literacy across communities and health professionals. Further, often clients are not deeply listened to, or there is a lack of advocacy to meet the choices and wishes of clients and their families. It is well documented that individuals who feel listened to and that their choices are being implemented have much better EOL outcomes.	Providing connection between the array of existing information, processes and pathways clients and families need to navigate to understand and receive holistic end of life care is central to the role of EOLDs. A key role of EOLDs is to assist in identifying and finding solutions to fill the gaps in clients' end of life care through community, health service and specialist connections. This is especially important given that palliative care service provision in Australia has been described as fragmented and disjointed (Urbis 2016).
'We educate, support and guide families to learn about the choices available for end of life care and to help them understand how these options will (or won't) work for the family. Ultimately, we want the family to decide what is right for them, for the person dying and for the network of family and friends who support them'. Nikki Lloyd	'We give clients and families their power back while they are still alive. This is incredibly important given that their control and capacity is either diminishing or being taken away as the illness or ageing progress.' - Helen Callanan	'Doulas provide authentic continuity of care across all of sectors of end of life.' - Helen Callanan

Appendix 2

Case Studies:

Case Study 1: Nikki Lloyd, End of Life Doula Brisbane

Last year, I spent time with a client in his 30s who was fit and healthy. We put together an end of life plan so that if anything happened unexpectedly, his family could carry out his wishes. This man is married with three young children and he owns and manages his own accounting business.

I saw him late July 2018 and learned that his mum died after a 30-year journey with cancer. The family had almost become accustomed to the cycle of 'mum has another cancer – the doctors will fix her for now – mum is fine'.

The medical profession had reached the point where curative care was not an option and comfort care was the priority.

I asked him how that was for him and he said, 'After talking to you I strongly recalled two things: The first was to find out what was important to my mum in her final days and also what would I need to do to say goodbye with no regrets.'

'So how did that turn out?' I asked.

- The family held a living wake with all his mum's siblings and cousins. Some of the family were uncomfortable with the idea of going to a party to say goodbye but my client talked with them about their chance to do so and not have to live with the regret of not seeing her that one last time.
- Every day he told his mum one thing he was grateful for that he learned from her. He wanted his mum to know (beyond any doubt) that she had made a positive impact on his life and was leaving a legacy.
- He told her he loved her every day.
- He (and his sister) took their children over to spend time with her and recorded the stories they shared and took lots of photos of them all together. This created not just beautiful memories but also gave the children a chance to view the death process as just another part of life.
- They laughed and cried and just held each other. Their presence with each other was something they had not had for many years since growing up and having 'busy' lives.
- They had an amazing funeral service which he felt was a true reflection of his mum's life.
- All the extended family spoke about how beautiful the service was and how much 'personality' it had.

He told me 'thanks to the time I spent with you, I feel like I was more present with my mum during her last few weeks and my grief feels easier'.

Case study 2: Dr Catherine McBride

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Dr Catherine McBride, a GP who trained as a doula, says the role is vital.

My first contact with an End of Life Doula was during the slow, inevitable decline of my father's experience with Alzheimer's disease. Helen was there to support me. Part of it was about allowing me to recognise the precious gift of being my dad's loving daughter, aware of his needs as life slowly passed away from him. I was also able to deal with the needs of my family to ensure they could spend time with him. He had a peaceful death, quietly in the nursing home, just the way he wanted to.

As a family, we were all content. Then, within six weeks, my best friend was in palliative care with metastatic breast cancer. She was 55. This diagnosis and her transfer to palliative care came as a shock — to her and her family, and to me too. A group of us women, her friends, nurtured her for nine full days. We fed her, watered her, massaged her, and gave her every bit of loving we could imagine. In the background of all of this was Helen on the end of the phone, checking to see how it was all going. She knew immediately where I was at emotionally. By the end of the nine days, she could recognise just by the tone of my voice the upcoming time when my friend would pass away. It is close now, she said to me. And it was. It was that very night. Having experienced her ability as an End of Life Doula, I was aware of the deficits in my medical education when it came to death and dying. I had only been introduced to Dr Elisabeth Kübler-Ross, the psychiatrist who developed the theory of the five stages of grief. I had not been educated in any way to support those who were caring for the dying. So, I elected to do a one-day doula workshop called 'Preparing the Way'. For the first time, I was exposed to my own mortality, and to confronting the fears I had been harbouring about my own passing.

I came to realise that I had received very little education in how to raise this same topic with my own family — or even with my patients for that matter — in a direct and practical manner, with compassion and patience for their needs. It was a taboo conversation. I also came to learn of the great need we have to 'deinstitutionalise' death, not to hide it behind walls — the walls of hospitals or aged-care facilities. The sad fact is we do not have the services to cope with the number of deaths expected over the next 20 years. We need community resources to undertake this huge burden. As far as I'm concerned, End of Life Doulas should be encouraged as an essential aspect of palliative care. It would assist in the transition of knowledge and education back into the community to allow death to be part of our lives.

Case Study 3: Helen Callanan – supporting clients in coming to terms with their dying

I was called in to work with a client in the palliative care unit of a large Melbourne hospital – he believed that he was going to experience a spontaneous healing and walk out of there. Needless to say, his family were struggling as they could not express their love, fears, loss, grief for fear of 'betraying' his hope.

I was asked to come in and see if I could make a difference to the family and to him. After a number of conversations, he realised his perception that to die was a 'failure' and that he would be letting his family down, so he had a 'never say die' attitude. When he could see, with my spiritual support, that his body would be what died – not his 'being', that his life and legacy would still live on in a form

– he relaxed and was able to be with his family and he proceeded to heal his relationships, enter into loving communication with his family and he died five days later with a smile on his face.

The NUM of the palliative care unit talked of it being miraculous the turnaround in the family dynamic and in the client – it had been all so dark and sombre but by the time he died it was uplifted. The End of Life Doula was asked if they could come and do more work there by the NUM.

Case Study 4: Belinda Brooks, providing the tools and support to prepare for the end of life you want

Belinda, an End of Life Doula, has been supporting Ree in her home for 18 months following a cancer diagnosis. Belinda was contacted by Ree's daughter Simone, who sought guidance about how to support her parents when she felt 'helpless' about what to do to help her parents 'feel better'.

Some community gathering and initial planning were undertaken, Belinda provided support to record a variety of questions Ree and the family wanted to be able to ask the oncologist, in order to make the best decisions for treatment. Ree decided she was not 'sick enough' to complete an advanced care directive.

After six months resisting specific planning, Ree spoke to Belinda about feeling 'powerless'. Ree is an incredibly strong woman who has always held a position of authority in her home, her community and in her professional life. She spoke of experiencing medical professionals and family members making decisions on her behalf when her brain was working 'perfectly well' even if her body was not. Belinda reintroduced the idea of completing an advanced care directive, as a way Ree could have a voice in her treatment and care even when she could no longer physically communicate.

The ACD was completed with key family members who were likely to be in the position of making decisions, her partner and her children. Several medical treatment options caused quite a heated debate, making it clear to all that they had different agendas regarding Ree's care (such as wanting mum here for as long as possible, whatever it took, to Ree being very clear she wanted no further medical intervention). Through facilitated discussion, Ree was clearly able to articulate her desires and why she wanted decisions to be made in the manner of her choosing. Belinda not only recorded her medical preferences, but also her deepest values and desires when it came to preferences for where, who would be with her, and her idea of a 'dignified' death, which included lots of plants, or at least photographs of plants.

Her documents were signed off by both her GP and her palliative care specialist. Following this process, Ree advised she felt far more 'in control' of her choices, and her family had a better understanding of why Ree wanted to make them herself for as long as she was able.

Her palliative specialist stated that this values approach to advanced care planning had caused the doctor to start a new discussion with Ree, and completely re-evaluated the treatment plan, realising it was not in alignment with Ree's desires.

Referrals were made for legal planning, undertaken with a solicitor, and a financial planner was called in who was able to save the family approximately $20,000 by simply withdrawing her superannuation prior to her death instead of her husband waiting to receive it after she dies.

The palliative care team are very collaborative in their approach and Ree is well supported in her pain management, although as she is approaching her last few weeks of life, this is getting more difficult. Other professionals that Belinda has sought support from call in from time to time.

Some days Belinda simply wheels Ree into the garden and they sit companionably in silence. Some days Ree ponders what happens when she breathes her last. Belinda asks a few gentle questions to assist Ree to order her thoughts and holds space for the not knowing. Some days Ree decides she just wants to try and eat a crumb of cake.

Other days Ree feels up to hopping on a mobility scooter and causing havoc around town. She even wrote her own eulogy and found a supplier of plant seeds as she wanted each person who attends her funeral to be given a packet of her favourite flowers, Forget Me Nots.

In all aspects of service, the Doula is ultimately a 'space holder' and an end of life empowerment educator, be that for the client, their carers and family members, or for the professional team including aged care and palliative care who are providing treatment.

A Doula works to provide a peaceful, safe, nurturing space (whether in an aged care space, hospital or a home) for the person approaching death, as well as those around them by doing all we can to ensure that the person who is dying has all their physical, mental, emotional and spiritual needs met. A Doula does this by being a resource: providing options, explaining what is happening and what one might expect, giving support, listening and caring.

Case Study 5: Regional and remote care

I was working with a man who lived in regional NSW and had a diagnosis of non-Hodgkin's lymphoma, then went into remission then myelodysplastic syndrome (MDS) developed. He came to Melbourne for some treatment then was at home. He was in and out of regional hospitals then to his local town to the single palliative care bed they had there. The End of Life Doula based in Melbourne was in contact with family, talking to medical teams about management of his care and where it would happen. I researched options for home supports and resources, aids and funding, and so on. I worked to support the family and the team of people they had assisting him. The work with over phone, Skype and in person and I was present with the family the last two days of vigil before death, and then supported the family after death into the funeral planning.

Case Study 6: Sydney - coordinating support and after death body care

An example is Pat, a woman diagnosed with stage IV lung cancer and brain tumours with an acute four-month prognosis. Pat had one of the most difficult deaths I have ever seen, even though she was in a palliative care unit in a large outer Sydney hospital. Seven days and nights of what looked torturous agony, restlessness, agitation, some deep dark battle within her being. Heavily sedated, heavy pain medication loads, staff struggling to hold her when she was determined to 'get out' of her body, bed and being. It was agony for all involved. Her family, friends all wanted to make a difference. The staff valiantly doing all they could but with only two staff across sixteen beds with four actively dying people and needs of all the others they struggled.

So, myself and another Doula who Pat had engaged were the ones there, supporting her family and friends, witnessing and holding the space for Pat, creating a roster so Pat was never alone as we knew she was frightened of that – she had wanted to die at home but with her reduced breathing capacity and lung issues it just wasn't working for her and those around her.

We briefed those coming on to be with Pat and debriefed those coming off their 'shift', we soothed, tag teamed, we kept the staff informed and asked for their help when we really had to have it and only then – they expressed their gratitude and relief that we were there for her as they just couldn't be given everything else happening on the ward.

After seven long days and nights, Pat finally died, her body exhausted, looking tortured and twisted and strained. We bathed her, gently held and soothed her dead body as it slowly released its tension, the transformation was extraordinary. Her god-daughter, who had been with her at her time of death, didn't want to see her again and I encouraged her to as she looked so very different. She reluctantly allowed me to lead her into Pat's room to her bed side and stood with her mouth open as she saw Pat now looking so very at peace, relaxed and beautiful. It was so healing for her and all those who had witnessed Pat's last week to spend those hours with her at the hospital after her death.

The palliative care nurses again expressed their gratitude and their regret for not being more. We knew that they did absolutely everything they could within the deep constraints of staffing, patient needs and demands and their own capacity.

Case Study 7: Gently persuading the GP and RN facility manager in a remote community aged care facility to consider the palliative care option

Bob had a brain injury following a near-fatal fall from the roof. He lived in a small nursing home for seven years during which he also developed bladder cancer and other life-threatening diseases. Periodically, he would be transported from the island nursing home where he lived, to the mainland for a blood transfusion whenever he appeared to be going downhill because this procedure 'pepped him up for a while'. His adult children believed that this was the best solution, even though they knew he was dying, unable to communicate, obviously in great pain and more often unconscious than not. Prior to the latest decision to send him for a pep-up session, it was obvious to me that Bob was on his way out and that subjecting him to the transportation and hospital stay would be greatly unfair to him.

I asked the GP and the RN facility manager if I could ring my friend who was head of the palliative care unit on the mainland to have a chat to Bob's kids to let them know what the options were at this stage. The GP stared at me for a few seconds and said, 'Yes, you are absolutely right. It's time for a referral to palliative care.' Whew.

The next morning the local PC team was on the doorstep of the nursing home, options were explained to the children, who opted for immediate palliative care and Bob died peacefully a few days later.

An aside: During a staff meeting where I spoke of PEPA palliative care training available to the nursing home carers, the RN manager of the facility said, 'But we only have one or two residents in palliative care!' One of the long-time carers responded, 'No, they are ALL palliative. None of them are getting out of here alive.' While initially shocked by this response, the RN facility manager quickly realised that this was indeed true and approached her job from thereon in from a completely different angle.

The Honourable Mr Aaron Harper
Chair
Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee
Queensland Parliament Qld 4000

Dear Mr Harper,

Inquiry into aged care, end of life and palliative care and voluntary assisted dying

Our thanks to the committee for the opportunity to provide input into the Inquiry. The views communicated within this submission are our own, as active members of Compassionate Communities Sunshine Coast. Citizens drawn together by our experiences of death, dying and grieving, focusing on place-based, community-led, community development. To activate communities by facilitating safe accessible discussions and together, to find innovate ideas and actions to address issues that are of increasing importance to the local community including; ageing, death and dying, social isolation and loneliness.

Yours sincerely,

Gillian Hall
Lead
Compassionate Communities Sunshine Coast

On behalf of:
Julie Priddle, Christine Elcoate, Meera Allen, Susan Paynter and Marc Bright

Introduction

Working with what's strong in our communities, rather than what's wrong.

Compassionate Communities Sunshine Coast was successful in joining the National Compassionate Communities Practice Forum (NCCF) in 2018, the only community in Queensland. This practice forum is part of an acclaimed international movement called *Compassionate Communities* which has seen the transformation of end of life care in communities in the UK and Canada.

The National Compassionate Communities Practice Forum (NCCF) is an initiative of The GroundSwell Project, inspired by a vision that when someone is dying, caring or grieving, we all know what to do.

The cohort of eight communities is supported to initiate a community development approach to this movement in their area and Western Sydney University is researching the experience of each community group.

The work of Compassionate Communities Sunshine Coast aims to build community capacity to develop, implement and sustain their own solutions to local health, community and social care. To network and align with partners with similar values.

At our launch on 31 October 2018, an analysis of a Community Network Mapping exercise revealed there is a fragmentation of community and health services and organisations in our region with weak or no relationships. Further, community members are spectators, unsure how they can contribute, perhaps viewing their role as 'consumers', passive recipients of services rather than active citizens wanting to be included in solutions about issues that directly impact their lives.

We bring people together every month and also participate in community events. In addition, we are hosting three community engagement, raising awareness, call to action events in 2019. We advocate to all levels of government on behalf of our communities and recently participated in the Sunshine Coast Cemetery Plan Review. We are demonstrating there is a community need by the number of attendees and motivated participants creating innovate ideas, that people want to get together and share their story, and their unique gifts, strengths, skills and ideas to do things differently.

We are pleased to share that the National Compassionate Communities Practice Forum has just been invited to present a symposium at the 6th Public Health Palliative Care International Conference (PHPCI) taking place in October 2019 which will see the work of Gillian Hall and Compassionate Communities Sunshine Coast along with the other seven groups showcased to an international crowd.

Defining the Problem

As Australia faces an ageing population which is set to double by 2050, the end of life sector requires collaborative action. It is imperative that the sector builds capacity for a public health approach to palliative care. Compassionate Communities and Compassionate Cities are emerging as an international strategy for implementing a public health palliative care approach to end of life. However, there is insufficient research on how these concepts might be operationalised, especially in the Australian context (NCCF).

A city is not merely a place to work and access services but equally a place to enjoy support in the safety and protection of each other's company, in schools, workplaces, places of worship and recreation, in cultural forums and social networks anywhere within the city's influence, even to the end of our days.
Compassionate City Charter[1], Professor Allan Kellehear

'In a compassionate community it is everyone's responsibility to care for each other during times of crisis and loss, and not simply the task of health professionals.'
Bonnie Tompkins, National Lead Compassionate Communities, Canada

- Our population is changing[2], and we need to prepare; prevention is better than cure and there are social and economic benefits.
- Unsustainable; demands are being placed on services for earlier and wider access[3].
- Increasing recognition of the importance of social factors[4].

The Sunshine Coast population is growing rapidly when measured against other regions. It is anticipated that the Sunshine Coast population will grow by approximately 200,000 individuals to about 518,000 by 2041.
The Coasts population is ageing with a significant increase in individuals aged 65 years or older. About 1 in 4 persons will be 65 years or older by 2041[5].

- Summary for Sunshine Coast Local Government Area (LGA): 6,512 elderly individuals are living alone.
- High proportion of elderly persons in Caloundra-Kings Beach (27.7%) and Golden Beach Pelican Waters (27.4%) within the Sunshine Coast LGA.
- Stakeholders noted an unmet need in the ageing community, in terms of respite care, and dementia care[6].

Time for Action

The experience of death and dying is not limited to a few but is something that will impact every one of us, so how then do we reshape our society to be a more compassionate place for those who are dying, those who are caring and those who are grieving (NCCF 2018).

The time is now with the Australian Government showing renewed interest in a public health approach to palliative care as a viable strategy to match the rising needs in the population. In 2018, eleven Primary Health Networks were funded to deliver Compassionate Communities initiatives and the Department of Health commissioned a report on the feasibility of Compassionate Communities which was published in July 2018. This report confirmed that a Compassionate Communities model is indeed a feasible way of implementing a public health approach to end of life in Australia[7].

In our region, Central Queensland, Wide Bay, Sunshine Coast PHN (Primary Health Network) received funding to implement the pilot Measure.

Several PHNs receiving funding from the GCfAHPC (Great Choice at Home Palliative Care Measure) measure are engaging with the Compassionate Communities framework. The framework has begun to be implemented in Victoria and Tasmania and aims to explore the role local government can perform in engaging local community organisations and individuals in providing support to people nearing the end of their lives[8].

Recommendations:

1. Central Queensland, Wide Bay, Sunshine Coast PHN (Primary Health Network) work with Compassionate Communities Sunshine Coast to explore the role local government can perform in engaging local community organisations and individuals in providing support to people nearing the end of their lives.

   That the State Government and Central Queensland, Wide Bay, Sunshine Coast PHN (Primary Health Network) jointly, commit funding to Compassionate Communities Sunshine Coast to support this community capacity building initiative.

2. To address the growing need to build community capacity and research the Compassionate Communities model in an Australian context.

   That the State Government provide resources for a pilot project on the Sunshine Coast, where research is undertaken to do a cost-benefit analysis of community development, demonstrating its effectiveness.

   This will provide clear direction for community groups and service providers to align their activities and services to achieve the social vision of a Compassionate Community and strengthen the government's strategic direction, 'Queensland: an age friendly community' and implementing a collaborative public health approach to end of life in Australia.

   To develop a measurement framework that aligns to social justice and human rights principles.

3. Use this data to review the outcomes of the project and to lobby Treasury for additional investment needed to truly ensure the social policy aims are met.

   Apply the research findings to implement additional community development projects that align with the aims of Compassionate Communities and the government's strategic direction, implementing a collaborative public health approach to end of life in Australia.

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7. National Compassionate Communities Practice Forum 2018, *Media Brief October 2018*.

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Heath Professionals Say No!

April 14, 2019

The Chair
Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee
Parliament House
George Street
BRISBANE QLD 4000

Re: Queensland enquiry into Aged care, End-of-Life and Palliative Care and Voluntary Assisted Dying.

I am writing on behalf of over 700 health care professionals Australia wide concerned about the implications and effects of introducing euthanasia and physician assisted suicide to Australia on its citizens and to healthcare. Approximately 40 health professionals from Queensland are signatories to this submission. We welcome this opportunity to contribute our experience and evidence to this inquiry to voice our concerns and inform government in decisions and what is needed for appropriate care.

We hold this type of legislation is a most serious threat to the wellbeing and safe care of people with terminal illness, mental health problems and to those with severe, chronic and disabling conditions, who may feel they have become a burden to others, and not that it should be part of health care agendas in provision of services to these individuals.

We also hold that Government focus should be on the compassionate and equitable provision of Social Services, Health Care and Palliative Care toward maintaining and protecting the dignity and lives of those with illness, age or disablement. There is still much to be done to address social, medical, palliative care and mental health service inequity in our society, especially so in regional Australia.

We hope to constructively contribute positively to your enquiry and welcome contact with you to assist with any further information or clarification you would require for our comments and opinions.

Yours sincerely,

Anthony Herbert

Dr Anthony Herbert MBBS(Qld), FRACP, FAChPM, B Med Sci

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Adjunct Associate Professor, Faculty of Health, Queensland University of Technology

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Heath Professionals Say No!
www.healthprofessionalssayno.info

RE: Queensland Parliament Inquiry into Aged Care, End-of-Life and Palliative Care and Voluntary Assisted Dying

The Chair
Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee
Parliament House
George Street
BRISBANE QLD 4000

Thank you for this opportunity to respond to the above inquiry. We note that this inquiry covers several unrelated matters, namely aged care and palliative care on the one hand, and euthanasia and assisted dying on the other. This submission will briefly address aged care and palliative care, but focus on the topic of voluntary assisted dying, or as we prefer to phrase it, euthanasia and assisted suicide (EPAS). We represent a network of over 700 health professionals including Palliative Care Physicians, Oncologists, Geriatricians, Rehabilitation Specialists, Psychiatrists, General Practitioners and Allied Health Workers who work with and care for people with palliative, aged, mental health needs and disabilities. Please find our responses to the issues for consideration below.

AGED CARE

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?

We are aware of patients not receiving their required medication due to the absence of a registered nurse on the staff of residential aged care facilities at the time they are required. It is essential that there be a registered nurse at all times available in aged care facilities to receive their prescribed medication, and any emergency medication (such as pain medication) as required. Furthermore, we are aware of aged care facilities who do not allow palliative care teams onto their premises to see patients, and/or doctors who do not prescribe the treatments recommended by the palliative care team. All of these practices result in inferior care for patients/clients. Staff ratios may also present a problem for adequate care during times of illness. Issues include:

1. Many residents do have not had adequate or appropriate advance care and goals of care planning done at a primary level for individual residents due to lack of expertise/knowledge /time/understanding of how to do so in a just and meaningful way to facilitate appropriate levels of care prior or to avert a un-necessary hospital admissions/re-admission.
2. Reasons for some to many of the admissions/readmissions to hospitals include:
   - Conflicts in dealing with models of care in RACF between frail aged and dying or complex patients with increased palliative need
   - Most nursing done by junior nursing staff as only mode of promotion for senior nurses is though the management ladder
   - Therefore a need for recurrent and ongoing education to all RACF, including RNs, care, staff, GP (medical) and allied health around these patients, and adequate educator role for this to occur with expert input
   - ACFI funding model provides some money for end of life care, but not for more complex or longer-lived palliative care/aged residents, and nursing/carer ratios, especially after hours, cannot provide the medicinal and personal care required for these patients and their relatives along side other residents.
   - There are limited and diminishing numbers of GPs with experience or knowledge of Palliative care (and also poor incentives here through appropriate item numbers) due to the time taken for these patients.
   - There can increased distress from families feeling their loved ones' needs may be better met in hospital, especially in a diverse multicultural or indigenous population who have fears around "not being heard or valued" in a culturally appropriate way
   - There is limited ability/availability of RACF outreach teams to respond to RACF requests for assistance with deteriorating residents also due partly to limited Palliative care experience or lack of integration with Palliative Care services.
   - When Ambulance paramedics are called, they may feel unable to leave residents in place of care due to issues above already outlined, especially after hours.
3. Even for patients known to Palliative Care, lack of more an extensive and integrated resourced model between Aged care and Palliative care, results in breakdown of plans, continuity and responsiveness for these residents.

PALLIATIVE CARE

18. Are palliative care and end-of-life care services meeting the current needs of Queenslanders? Why or why not?

Universal access to palliative care is still not available in Queensland. See comments above about lack of access for people in aged care facilities. Palliative Care Australia has identified other demographics which lead to reduced access to palliative care services; low income, non-urban location, acute care settings and nursing homes, ethnic or indigenous background, very old or very young age, and non-cancer diagnosis. More government

funding is needed to fill the gap. See https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/02/PalliativeCare-Service-Delivery-2018_web-1.pdf for findings and information for guidelines of what is needed to deliver adequate palliative care and associated considerations across various care settings.

VOLUNTARY ASSISTED DYING

25. Should voluntary assisted dying (VAD) be allowed in Queensland? Why/why not?

We strongly recommend against allowing EPAS in Queensland. As healthcare workers, we are aware of much misunderstanding about what is, and what is not, EPAS. We're told that 85% Australians are in favour of a change in the law to allow euthanasia and assisted suicide (based on a poll using a limited and leading question around suffering without alternative approach), but perhaps less well known is that the majority of doctors (those who are expected to actually do the deed) are against euthanasia, and the size of the majority increases as their work is more involved with the dying. All palliative care organisations around the world are against it as is, as well as the Australian Medical Association, and the American College of Physicians and the World Medical Association. These **position statements** and many others are all visible at for your consideration: http://www.healthprofessionalssayno.info/resources.html

So our question is this: Why are we having this debate now, at a time when we have more medical cures than ever before in human history? The timing suggests it is not a failure of *medicine* that has prompted this debate. We believe that this is a societal issue, fear of dying and desire of control over death, which should not be resolved by falsely legitimising the killing of patients by doctors and by claiming the EPAS is a form of healthcare. Moreover, there are many reasons why we oppose the legalisation of EPAS based on the experience in overseas jurisdictions where it is legal. These should make politicians hesitate to introduce laws allowing EPAS into Queensland's Parliament.

Importantly so, despite reported public support for this socio-political agenda, it is rarely discussed that this support is not found this support is weak among groups who express concerns about being pressured to die (i.e. older adults, people with disabilities, people with less education, women, indigenous and racial and ethnic minorities).

For a clear, thorough and authoritative and objective recent review of evidence in discerning whether euthanasia and physician-assisted suicide are clinically necessary or desirable, we strongly recommend the recently published paper for the International Association of Hospice and Palliative Care, written by Professor Roger Woodruff, oncologist and palliative physician, Victoria. https://hospicecare.com/policy-and-ethics/ethical-issues/essays-and-articles-on-ethics-in-palliative-care/euthanasia-and-physician-assisted-suicide-are-they-clinically-necessary/

a. Mistreatment of distressed patients

Research in Canadian palliative care patients has demonstrated that when patients expressed their fears at the end of life it was often misinterpreted by healthcare providers as a request for euthanasia when it was really intended to be a cry for help.(1) When a patient says they wish they were dead, it doesn't necessarily mean they are asking you to kill them. We all have bad days. This research also found that patient desires are known to fluctuate over time, including desires for hastened death and that depression was a common finding (up to 60%) in many.(2) These patients need support, not a referral for EPAS, as recommended in the current VAD training for Victorian doctors.

Palliative care literature shows requests to hasten death are uncommon after referral to specialist palliative care services (1-2%). This number reduces significantly further when problems and symptoms are addressed. It has also been shown that a patient's desire to die is often due to a sense of burden on others and lower family cohesion, and also more likely to persist when managed by a doctor who is not trained psychologically or in palliative care to deal with end of life suffering and sense of hopelessness. (3)

b. Abuses of the law

Australian lawmakers have looked to the Oregon USA model of legislation as a basis for legislation, and many promoters of EPAS have claimed that it has operated without problems for many years. However, the lack of official evidence of problems does not reflect the absence of problems, as the official reporting system does not allow for the reporting of problems.(4) Dr Katrina Hedberg, of the Oregon Department of Human Services, has reported: "We are not given the resources to investigate [assisted-suicide cases] and not only do we not have the resources to do it, but we do not have any legal authority to insert ourselves."(5) Nonetheless, there are many documented examples of abuse. For example:

- Kate Cheney, 85, died of assisted suicide under Oregon's law even though she had early dementia. Her personal physician declined to provide the lethal prescription. Her managed-care provider found another physician to prescribe a lethal dose of drugs. When counseling to determine her capacity was sought, a psychiatrist concluded that she was not eligible for assisted suicide since she was not explicitly seeking it, and her daughter seemed to be coaching her to do so. Nevertheless, Kate Cheney soon received and used the lethal drugs.(6)
- Michael Freeland, age 64, had a 43-year history of acute depression and suicide attempts. Yet, when Freeland and his daughter went to see a doctor about arranging a legal assisted suicide, the physician said he didn't think that a psychiatric consultation was "necessary."(7) Oregon's statistics for the last four years show that only 2% of patients were referred for a psychological evaluation or counseling before receiving their prescriptions for lethal drugs.(8)
- Patrick Matheny received his assisted suicide prescription by Federal Express. He couldn't take the drugs by himself so his brother-in-law helped. Commenting on the Matheny case, Dr. Hedberg of Oregon DHS said that "we do not know exactly how he helped this person swallow, whether it was putting a feed tube down or whatever,

but he was not prosecuted ...." The state's official annual report on assisted suicide deaths did not take note of this violation of the Oregon law.(9)

- The first known assisted-suicide death under the Oregon law was that of a woman in her mid-eighties who had been battling breast cancer for twenty-two years. Initially, two doctors, including her own physician who believed that her request was due to depression, had refused to prescribe the lethal drugs. Compassion & Choices—then operating under the name Compassion in Dying—became involved in the case and referred the woman to a doctor willing to write the prescription.(10)

c. Mental illness

The incidence of depression in cancer patients has been measured as high as 45%. One study found that up to 80% of depressed patients in palliative care were untreated. (10) Research has also shown that the majority of these cases were missed diagnoses rather than treatment-resistant depression, with treatment effective 6-8 weeks after commencing anti-depressants. (Hart 2012) Desire for hastened death is a symptom of depression. Several studies have shown that treatment of depression increases patient interest in living. In any other group, a request for death would alert a doctor for urgent psychiatric review: why is this group of patients being treated differently? (12)

d. Risks of increasing the suicide rate

The Centre for Rural & Remote Mental Health published a report on Suicide and Suicide prevention in Rural Areas of Australia in 2017.(13) It found that is every state of Australia, the rate of suicide in those who lived outside capital cities is higher than that for residents that live within them, and the rate has risen much higher in rural areas over the period 2011-2015. The rate is much higher amongst Aboriginal and Torres Strait Islander People (11%), and the majority of suicides among this population occur outside of capital cities. A study of male suicides in Queensland found that the appropriateness and effectiveness of health services which rural men are accessing needs to be improved to reduce rural suicide. Legalisation of VAD sends a message to the population that hastening death is a legitimate way to deal with suffering in life. Life in the country is becoming harder for many reasons, and it needs to be considered by the Committee whether legalising VAD will impact suicide rates in Queensland.

In the jurisdictions where EPAS is legal, non-assisted suicide rates have also increased, for example in Oregon USA, it was found that legalising EPAS was associated with an increased rate of total suicides relative to other states and no decrease in non-assisted suicides. The authors concluded: 'This suggests either that PAS 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.'(14)

Here lies the real agenda:

In every state in Australia, the rate of suicide among those who live outside the greater capital cities is higher than that for residents that live within them, and the rate has risen much higher in rural areas over the period 2011-2015.....If we are to reduce rural suicides ***in the long term****, we need to work out how to address the social determinants of health, using strategies based on knowledge about these determinants as they apply to individual rural locations. .....****If we are to reduce rural suicides right now*** *we need to start reducing the gap in access to and use of*

evidence-based medical and psychological treatments for those who are experiencing mental distress: **Centre for Rural and Remote Health NSW** Suicide and Suicide Prevention in Rural Areas of Australia

e. Risk of coercion

The model of legislation which Australian parliaments are currently examining involved prescription of lethal medical which a patient is expected to consume at home without supervision. It was stated that in Washington State only 10% of those who were given prescriptions ultimately took them. Further as stated before, the experience of psychiatry and palliative care is that desire to die fluctuates and in the majority diminishes with appropriate care, or if someone changed their minds for other reasons, often relational to what is occurring in their personal life. This would indicate that many of those given prescriptions may change their minds and not want to die, but there is no oversight here. How will medication safety and coercion be policed in such cases? See also comments on elder abuse, below.

f. Complications of EPAS

Contrary to proponents' claims, legalizing assisted suicide does not guarantee patients a quick and peaceful death. Previous experience in jurisdictions where EPAS is legal has suggested that complications occur regularly. (15-17)

Consider the case in Oregon USA.

- Speaking at Portland Community College, pro-assisted-suicide lawyer Cynthia Barrett described one botched assisted suicide. "The man was at home. There was no doctor there," she said. "After he took it [the lethal dose], he began to have some physical symptoms. The symptoms were hard for his wife to handle. Well, she called 911." He was taken to a local Portland hospital and revived.(19)
- David Prueitt took his prescribed lethal overdose in the presence of his family and members of the assisted-suicide advocacy group Compassion & Choices (formerly the Hemlock Society). After being unconscious for 65 hours, he awoke. His family leaked the failed assisted suicide to the media. Oregon DHS issued a release saying it "has no authority to investigate individual Death with Dignity cases." (20)

Legislation in Victoria is reputed to be more stringent than above, however, the oversight committee consists of a panel with lack of expertise and scope to review prescriptions given, and if given, the falsification of health records and death certificates allowed to indicate an underlying disease and not the cause or means of death, also eroding the power of the Coroner's office to investigate potential coercion, abuse or complications (not to mention the recording of accurate data for health epidemiology). As in Oregon, Canada, Belgium, and the Netherlands, abuses and complications will remain grossly under reported and unable to be managed.

g. Disability perspective

The late **Stella Young**, comedian, writer and disability activist, wrote on the implications of legalising VAD for people living with disabilities:

'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 center.
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 [redacted] 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.
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 on the case of Barbara Harling, a Queensland woman with motor neurone disease who said that she would consider moving states when a 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 often, we hear stories like Barbara Harling's, which are more about wanting to avoid a loss of autonomy and independence.' (21)

We also refer you to testament given at the time of public enquiry into VAD Legislation in Victoria. See **disability advocates Sam Connor**, **Kelly Cox** and **Liz Carr** at this link discuss their experiences and views: http://www.healthprofessionalssayno.info/links.html

h. Risks to Indigenous Australians

The Committee will be aware that there is a life expectancy gap between Aboriginal and non-Aboriginal Australians throughout Australia, including Queensland. People in the state are dying of preventable diseases and injuries in their 50s, 40s, and even 30s. Considering that we as a country are dedicated to closing this embarrassing life expectancy gap between Aboriginal Australians and other Australians, introducing euthanasia would be very contradictory and frankly immoral.

If VAD were to be legalised, then care would need to be taken to ensure that some of the most marginalised residents of the state, who have some of the worst health outcomes,

should understand what exactly the legislation is about. There is no word for euthanasia in Aboriginal languages.

Not only do many Aboriginal Queenslanders have very poor health outcomes, but many also have limited comprehension of English. As health care professionals, we often have great difficulties in communicating with Aboriginal patients, despite our best efforts, and have seen Aboriginal patients receiving sub-optimal care due to language barriers. Our patients with terminal and non-terminal illnesses often find their conditions unbearable because we frequently have great difficulty in explaining the complexities of conditions and their treatment to patients whose first or even second language is not English; Aboriginal interpreters exist, but the demand for them far exceeds their supply. Therefore, introducing the possibility of a doctor being able to kill a patient will further confuse patients and the trust between patient and doctor will be even harder to build and maintain. This will further dampen efforts to close the gap in life expectancy between Aboriginal and non-Aboriginal Australians.

If VAD were legalised, then the great efforts that we now expend in persuading our patients to accept treatment in order to alleviate their suffering and prolong their lives could be redirected to educate them about the benefits of asking for an early death instead of accepting expensive medical care, especially in a setting of rising health care expenditure. Indeed, over the years, we have evidence for this from colleagues working in the Northern Territory of Aboriginal patients being fearful of palliative care, or even of intramuscular injections, because of the legalisation of euthanasia in the Northern Territory almost two decades ago.

"*...I do not think it is an exaggeration to say we are in times of terror for our country...I have worked doing locums in Alice and Darwin and going to remote Aboriginal communities with the Palliative Care Service Top End. For Aboriginal and Torres Strait Islander people, if legislation goes through in the Territory, (probable domino effect from Victoria), people will understandably be more afraid than ever of accessing what they call 'white fella medicine', especially Palliative Care. And so many are dying so young.*" Dr Helen-Anne Manion OAM, Palliative Care Physician and Director Co-founder *DYING AT HOME PROGRAM.*

We trust that you would agree that it is wrong that these vulnerable and marginalised Aboriginal Queenslanders who are already dying too young should be enabled to die even younger. Instead, resources are desperately needed to educate them about preventing and managing, the diseases they are dying from prematurely.

As spoken by indigenous **Senator Patrick Dodson** during considerations for the Rights of the Territories Bill, "*Regardless of how you feel about the topic itself, can we be certain that we can craft a regime that will actually provide adequate protections to people, particularly those in the most vulnerable of circumstances?"*

For the sake of the health and well-being of marginalised Queenslanders with poor health outcomes, especially Aboriginal Queenslanders, we suggest resources be directed to enabling Aboriginal Queenslanders with poor health status to live longer and healthier lives, including the provision of adequate health education and treatment that might reduce the

unbearable hopeless suffering that increasing numbers of Aboriginal Queenslanders are enduring.

i. Euthanasia is not medical care

We reject the notion that EPAS constitutes a form of medical care. Doctors are taught to care for the vulnerable and not to intentionally shorten life. By introducing EPAS as a procedure which is carried out by doctors in healthcare institutions, it is given a veneer of medical legitimacy which it does not deserve. If the Australian public insist on this practice being legalised, we suggest it be removed from the healthcare setting and not contaminate the environment of care and compassion which should be found there. The fact that the Victorian working party charged with implementation of that state's EPAS legislation will have to train doctors demonstrates clearly that it is not within the doctor's skill set. Like capital punishment in the USA, others should be trained for a practice in conflicts with medical ethical guidelines that have existed for millennia. The power imbalance of the therapeutic relationship cannot be underestimated, as discussed and evidenced earlier in this paper, in forming the views and actions of patients. Those involved in the care of those at the end of their lives, the vulnerable and marginalised should not be involved as agents or facilitators of a non-therapeutic socio-legal phenomena.

"*Neither palliative care nor medicine can eradicate total suffering; similarly, politicians and lawyers do not have such power. There may be an illusion of a medical solution to alleviate suffering, but the real answers lie in how we connect and support each other as a society, as health care providers, and as professionals entrusted to care for people who are dying and their families."* A/Prof Leeroy William, Palliative Medicine Physician, Eastern Health, Victoria. https://onlinelibrary.wiley.com/doi/abs/10.5694/mja17.01217

Nor should it be implied that EPAS/VAD is part of palliative care or expected to be an extension of palliative care. There are many who already do not seek palliative care for their needs due to media and general misconceptions or misinformation around what constitutes palliative care and its implications. By even implying that EPAS/VAD is part of palliative care would create further misunderstanding and fear of those truly vulnerable and in need of care. Lastly, in a multicultural society with migrants from areas of injustice, persecution, war, torture and power imbalances, fear of the actions of those with authority within medical and healthcare systems cannot be underestimated, preventing those with palliative needs to come forward for assitance.

Such legislation for ***the argument for autonomy of a few to be managed within healthcare actually infringes upon the autonomy of those vulnerable in ambiguous health care and legal systems,*** and this infringement extends to those with disabilities and mental illness, as well as the aged.

j. Harm to physicians

In jurisdictions where EPAS is legal, physicians who carry out assisted suicide have reported a negative impact from the act. In an American study, of 38 oncologists who reported participating in EPAS, nearly a quarter regretted their actions, and another 16% reported

that the emotional burden of performing EPAS adversely affected their medical practice. Doctors were not trained for this task and have not asked for this role. If VAD is legalised, doctors should have nothing to do with it, so the role of healer is not confused. Shortly after legislative introduction in Ontario, over 200 doctors who initially had supported the enactment of legislation in Canada have removed themselves from the "Medical Assistance In Dying" Register, due to the effect of their experience into the reality of what their actions involved. There is a great and stark incongruence here in the role of the physician in the therapeutic relationship.

k. Inadequate Palliative Care

The most recent data from the Australian Institute of Health and Welfare states that in 2016, there was an insufficient 226 specialist palliative medicine physicians across all Australia. We are gravely concerned about the potentially dangerous impact this legislation would have, undermining the medical profession and devaluing palliative care. Palliative care must be resourced as a priority and provision made for all Queenslanders to experience a positive end of life. Those living with terminal illness require some of the greatest levels of support. Should we not be investing our efforts into enhancing and innovating palliative care to ensure it? We believe that until all Queenslanders have access to palliative care, it is immoral to even consider legalizing EPAS. We refer again to the Palliative Care Australia Workforce Strategy, mentioned above.

l. Elder abuse

Elder abuse is a recognised problem in Queensland, as evidenced by the advertising of the Elder Abuse Helpline on the Queensland Government website. (20) The NSW Government released a report on Elder Abuse in 2016. The Committee found evidence that elder abuse is a significant and growing problem in our community. Financial abuse emerged during the inquiry as a substantial problem demanding urgent action on the part of government. The report refers to claims that the law as its stands provides insufficient safeguards against financial abuse, that it does not treat many forms of financial abuse as criminal, and indeed, that the law itself is significant enabler of abuse. A need for increased awareness of financial abuse was noted. See the **Report into Elder Abuse** here:
https://www.parliament.nsw.gov.au/lcdocs/inquiries/2387/Report%2044%20-%20Elder%20abuse%20in%20New%20South%20Wales.pdf &
https://www.parliament.nsw.gov.au/lcdocs/inquiries/2387/summary%20of%20recommendations.pdf

In June 2017, the Australian Government Attorney-General's Department launched the Australian Law Reform Commission's (ALRC) report on elder abuse: **Elder Abuse – A National Legal Response**: http://www.attorneygeneral.gov.au/Media/Pages/National-Plan-to-address-elder-abuse.aspx

It also found that elderly persons are victims of financial fraud. It recommended that a national register of enduring powers of attorney be established to prevent greedy children from using the document as a "license to steal" from their elderly parents.

The paper notes that “the potential for pressure and coercion in setting up the instruments” [the powers of attorney appointing children to act on their parent’s behalf] and that “early inheritance syndrome” is on the rise. “With Australians living longer than ever before, the ALRC inquiry heard many examples of children who were impatient to get their hands on their parents' money and tried to claim their inheritance before they were entitled to it.”

While the exact prevalence of elder abuse is not established in Queensland, the ALRC reported that “at the international level, the WHO (2015) recently reported that estimated prevalence rates of elder abuse in high- or middle-income countries ranged from 2% to 14% … and that the perpetrators are likely to be related to the victim…[and] one study suggests that neglect could be as high as 20% among women in the older age group (Australian Longitudinal Study on Women’s Health, 2014). Older women are significantly more likely to be victims than older men, and most abuse is inter-generational (i.e., involving abuse of parents by adult children), with sons likely to be perpetrators at a greater extent than daughters.” The report is accessible here: https://www.alrc.gov.au/sites/default/files/pdfs/publications/elder_abuse_131_final_report_31_may_2017.pdf

What has this got to do with euthanasia? A portrayal of the mixed motives of family support of euthanasia was the topic of the winning short film in this year’s Tropfest Festival; ‘The Mother Situation http://mobile.abc.net.au/news/2017-02-12/tropfest-matt-daytakes-top-honours-forthe-mother-situation/8263168?pfmredir=sm This also exemplifies concerns around inadequacy of safeguards one a means to be killed is issued vulnerable individuals who may change their views over time, as is a common experience.

26. How should VAD be defined in Queensland? What should the definition include or exclude?

There are many scenarios in the end-of-life situation which are ethically challenging. These include the cessation of life-supporting therapy, symptom control which may reduce the consciousness of the patient, and limitation of nutrition and hydration. Each deserves to be considered individually in ethical terms, as different facts need to be considered for each practice. We believe, therefore, a narrow definition of euthanasia and assisted suicide should be used, so it is not confused in practice or in ethical terms, with other end-of-life decision-making issues. We oppose the use of the definition ‘voluntary assisted dying’ for several reasons. Firstly, the term ‘voluntary’ in this instance suggests that ‘involuntary’ and/or ‘nonvoluntary’ assisted dying exists. However, such acts with intention to kill would normally constitute murder, and should be named as such. As suggested in the Issues Paper, the tactics of those promoting laws allowing EPAS have tried to suppress use of the term ‘suicide’ in an attempt to increase support for this practice, rather than to clarify its meaning. In such debates, changing recognised terms such as euthanasia and physician assisted suicide or using other terms in advocacy for "voluntary assisted dying" laws, including “medical assistance in dying”, is evasive and renders the reality of such acts and their application unclear and confusing, particularly for the general public’s and members’

of parliament interpretation. The also imply the person who is being killed is actively dying, which they are not. Further they create misunderstanding of what constitutes good and best practice end of life care in the dying, as practiced by palliative care. We believe that any terminology that reduces transparency or creates illusion or confusion in debate is to be avoided; a practice where one is given the means to kill oneself is, therefore, more accurately termed as a form of 'suicide' than 'dying', which is much broader in meaning.

Killing of patients by another, such as a doctor, would be murder or manslaughter if no legal provision were available to allow them to avoid prosecution. For decades such provisions across the world have been termed 'euthanasia' and we see no need to change this terminology. 'Medical aid in dying' as used in Quebec is an attempt to give the act legitimacy by conflating it with other medical procedures. 'Medical assistance in dying' is similar. We need to keep our definitions clear so we all know what we're talking about. The term euthanasia comes from the Greek – it means 'good death'. However, this is not particularly helpful as both sides claim the advantage of bringing about a good death, and indeed, the question of what constitutes a good death is at the heart of the euthanasia debate.

We would all like to see people in our communities dying with dignity and without suffering. The question is, how do we go about achieving this?

First of all, we need to be clear on what euthanasia is not a medical treatment. Euthanasia is sometimes confused with cessation of treatment which aims to prolong life. In life-threatening illness, treatment initially aimed at cure may become futile (no longer working), or so burdensome (such as due to distressing side-effects) that any benefit from the treatment is no longer worthwhile. At this point the treatment may be no longer prolonging life so much as prolonging the process of dying. At this time a decision may be made to stop, or not to start, such a treatment. This practice is not euthanasia because the intention is not to kill the patient, but to allow the underlying disease to take its course. Full supportive care will remain in place so the patient is kept comfortable and family supported through this time.

In the same way, taking someone off life support is not euthanasia. It's not flicking the switch that kills the patient, it's the underlying disease that does it, that's why they were on life support in the first place.

We are aware of media reports that claim that palliative care services starve patients to death. This is a simple misunderstanding of the changes in physiology that occur at the end of life, the anorexia-cachexia syndrome, where patients not only lose their appetite, but will not put on weight regardless of what they eat.

Another situation which if often confused with euthanasia is adequate symptom control in the terminally ill. Very occasionally in the terminal stages of disease the distressing nature of a patient's symptoms may require the careful sedation of the patient, while seeking to preserve their dignity. It is not euthanasia because the intention is not to kill the patient, but to alleviate their distressing symptoms.

Some people would call this practice of symptom control *passive* euthanasia because of a myth in the community that use of morphine shortens the life of the patient. They argue that if we already practice *that* type of euthanasia, there is no reason not to practice the *other* type of euthanasia, using lethal injection, which they call *active* euthanasia. You see the problem in this terminology. We therefore suggest that the terms 'active' and 'passive' euthanasia be avoided.

Philosophers have spent a lot of time talking about the principle of double effect in order to justify analgesia use at the end of life, but it really isn't necessary. It's all based on a myth – that morphine kills the patient. This myth been around for years, and we don't seem to be able to squash it. It makes people scared to use what is an excellent treatment for pain. But in fact **morphine in therapeutic doses does not shorten life**. Indeed, it may actually prolong it. An Australian study (21) showed increased survival of palliative care patients on high doses of morphine, likely due to a less stressful and better symptomatically controlled dying process for those individuals.

Stopping futile and burdensome treatment and maintaining adequate symptom control are good medical practices at the end of life and should be encouraged in clinically appropriate situations. They should not be confused with practises aimed at killing patients.

We define euthanasia as 'An act where a doctor intentionally ends the life of a person by the administration of drugs, at that person's voluntary and competent request, for reasons of compassion'. The key points to note are that it is an intentional act by a doctor, motivated by compassion. It is a decision made voluntarily by the patient, with no coercion involved, and they are mentally competent at the time. We prefer to keep the definition narrow, so we can evaluate each end of life scenario individually.

We define physician assisted suicide as 'The situation where a doctor intentionally helps a person to commit suicide by providing drugs for self-administration, at that person's voluntary and competent request'. The doctor is thus distanced from the act, but morally it is no different to euthanasia as the motivation, intention and outcome are the same – therefore in this submission, the terms are used interchangeably.

We commend these definitions to the committee.
https://gimmun.gimptuj.si/2017/files/Euthanasia.pdf - WHO definitions

On the issue of defining **choices around dying,** it is interesting to note that *The Parliament of Victoria Inquiry into End of Life Choices*, made **fourty-nine (49) recommendations** toward the adequate care of those approaching the end of their lives. The recommendations included addressing societal stressors, resource and health system issues, the greater need for Palliative Care provision and respite, as well as inadequacies around support of vulnerable individuals and their families/carers**. We find it incongruous that is in this State the last of the recommendations was being addressed first.** Until the other 48 recommendations are addressed adequately, those seeking euthanasia or physician assisted suicide, may actually be so because they may feel they have limited or **no other choice** presented to them. Presenting legislation for euthanasia and physician assisted suicide as one of choice also misleads the public and those who govern around the role of healthcare

for the dying and the social agendas needing to be addressed to provide appropriate dignified care.

27. If you are a health practitioner, what are your views on having a scheme in Queensland to allow VAD?

As outlined above, we oppose the introduction of VAD in Queensland. If laws allowing EPAS were to be approved, we strongly suggest that it have nothing to do with the practice of medicine. This is not a novel idea. Euthanasia is practised in Switzerland by non-physicians. Capital punishment, a process similar to euthanasia, is practised in USA by non-physicians. This will allow the practice of killing patients to be separated from medical practice, which since ancient times has contained ethical prohibitions against harming patients, and for which doctors are not trained. The government could set up clinics with staff trained to assess clients and hand out drugs without the complication of involving the medical fraternity.

Particularly in view of the fact that laws for EPAS are being promoted as a right to autonomy, or the right to decide the timing and manner of one's death, it is recommended that medical practitioners be separated from EPAS. Individual doctors would of course be eligible to train as VAD practitioners if they wish, but not within the framework of healthcare.

Safety issues are still paramount even in these settings, especially in terms of coercion, depression, agendas involved in decision making and provision of best practice care.

28. If there is to be a VAD scheme, what features should it have?

As outlined above, we oppose the introduction of VAD in Queensland and do not believe it is possible to construct legislation which would adequately protect our patients. If VAD is legalised it should be separated from healthcare and not involve doctors. Please refer to the recommended recently published paper for the International Association of Hospice and Palliative Care, written by Professor Roger Woodruff, oncologist and palliative physician, Victoria, for this most up-to-date, expert, authoritative and comprehensive review on this exact topic area: https://hospicecare.com/policy-and-ethics/ethical-issues/essays-and-articles-on-ethics-in-palliative-care/euthanasia-and-physician-assisted-suicide-are-they-clinically-necessary/ No system will have features able to mitigate risk. Safeguards are only an illusion of such, as evidence has proven time and again.

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?

It is the experience in other jurisdictions, as outlined above, that make us believe that it is not possible to construct legislation which would adequately protect our patients. If VAD is

legalised it should be separated from healthcare and not involve doctors. We have given references and links and outlined this in other sections of our submission. See above.

30. Who should be eligible to access VAD and who should be excluded?

See rationale and arguments and rationale presented in other sections.

31. Should the scheme be limited to those aged 18 and over? If so, why? If not, why not?

As outlined above, we oppose the introduction of VAD in Queensland and do not believe it is possible to construct legislation which would adequately protect our patients. In particular we do not believe that adolescents cannot have the experience to develop the breadth of intellectual, psychosocial and spiritual development required to deal with the existential questions from life to which suffering and dying belong. There is a large variability in the development between individuals. There are no standard routes to develop from child to adult and there is no fixed developmental speed, and there are also male and female differences in this. The minimal developmental levels reflecting full capacity to judge the situation and the full weight of the request for, and consequences of, euthanasia are rarely if ever reached during the teenage years. Further, we know from adolescent and young adult psychology studies action in this group may be driven by peer influence and impulse. The qualities provide great concerns in the face of legislation even for those up to the age of 25.

Furthermore, it is evident that the influence from those surrounding children and adolescents is strong and cannot be neglected. When faced with difficult medical decisions, minors will inevitably be dependent on the strong and evident authority of their parents, thereby diminishing their own autonomy in the decision-making process. Influence can exist through unspoken signals of pain and distress. Minors will try to take responsibility and look for methods to alleviate the suffering in his surroundings for which he is the cause. The opportunity to request euthanasia may be perceived by a minor in this situation as a chance, or even an obligation, to relieve this suffering. It is impossible to assess these influences in an objective way and to weight them at the time when a minor requests euthanasia.(22)

This group is also particularly vulnerable to suicide from mental illness, and particularly so in regional and indigenous populations, and in particularly so in men. Again psychological and mental health strategies, and earlier detection and management of illnesses and their psychosocial context are what need to be addressed here.

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?

As outlined above, we oppose the introduction of VAD in Queensland and do not believe it is possible to construct legislation that would adequately protect our patients. International experience proves that safeguards do not prevent scope-creep, suicidal practices or abuses. We have grave concerns around re-defining criminal law, the definition of suffering, safe

guard provision and postulated regulation. Overseas experience has demonstrated repeatedly that original changes to the law have been gradually extended or changed, that regulation and reporting is often inadequate, and that definitions of concepts including "suffering", are so arbitrary, that there can be no significant evidence to demonstrate that safe-guards would work or be able to be used without bias. Specific concerns include the issues of extension of legal re-definition of what activity is decriminalised, consent, medical practice and process complexities. As such practices represent a seismic shift in how a society views individual lives, the potential harms and impacts to patients, carers/families and clinicians are also great.

Resultant will be the extension of injustices and how our society views what life is worth living. In the 2016 New Zealand Parliamentary Commission into legislative introduction in that country, **Simon O'Connor**, the Chairman of the Health Select Committee reported, *"It is very difficult to see how there could be sufficient safeguards to actually protect vulnerable people in New Zealand. And that's been the experience overseas as well, it probably comes down to the simple question of 'how many errors would Parliament be willing to accept in this space'?"*

33. What features should be included in a process to allow a person to legally access VAD?

As outlined above, we oppose the introduction of VAD in Queensland and do not believe it is possible to construct legislation which would adequately protect our patients.

34.What safeguards would be required to protect vulnerable people from being coerced into accessing such a scheme, and why?

We believe it is the obligation of government to protect its most vulnerable citizens. As outlined above, we oppose the introduction of VAD in Queensland because we do not believe it is possible to construct legislation that would adequately protect our patients. Please see arguments above, and the comments of the Chairman of the New Zealand Health Select Committee above.

35.Should people be provided access to counselling services if they are considering VAD? If so, should such counselling be compulsory? Why?

As outlined above, we oppose the introduction of VAD in Queensland and do not believe it is possible to construct legislation that would adequately protect our patients. These patients should instead be referred to best practice referral pathways and appropriate healthcare professionals able to assist and accompany them in their care.

36.How could a VAD scheme be designed to minimise the suffering and distress of a person and their loved ones?

Palliative care, appropriate care and service provision for the elderly, those with disabilities and earlier detection and support of those with depression and marginalised social needs, and assistance for carers, **not VAD**, are the best way to minimise the suffering and distress

of our citizens. In the context of VAD laws, considering such legislation as a way of relieving the suffering and distress of loved ones suggests the needs of family and not the patient may be considered as justification of use of such a law (as it is in some forms of euthanasia legislation in The Netherlands) and is to be deplored.

From **Michael Ferguson,** the Tasmanian Health Minister, on the 23rd of May 2017,
"I ask those promoting this bill to be truly frank and honest in their descriptions, and for those listening to the debate today, if or when you hear those euphemisms, you need to remind yourself that the real words, however distasteful they are, are mercy killing and assisted suicide by a doctor……. Such a bill lacks adequate safeguards……A prime responsibility of a parliament is to pass laws that are for the good of the common people. When considered from a social perspective the parliament creates laws to protect the vulnerable people in our society. I wish a parliament could end suffering for anyone, for everyone, by passing a law. That is a fantasy, an impossible and false hope, albeit a compassionate aspiration, but a totally tragic building of false hope."

37. Should medical practitioners be allowed to hold a conscientious objection against VAD ? If so, why? If not, why not?

If VAD is legalised it should be separated from healthcare and not involve doctors. Medicine is an inescapably ethical practice and patients do not have the right to overrule the autonomy of the medical practitioner to act in accordance to their own beliefs or professional and expert understanding of best practice medicine. It is not in the interests of Queensland society to have medical practitioners who are comfortable to treat their patients in ways they personally believe are wrong. It is also an abnormal situation to expect a doctor who provides or understands what constitutes best evidenced practice for such patients, to have to conscientiously object to not refer for euthanasia and assisted-suicide practices, which have no good evidence in safety, where there cannot exist adequate oversight of coercion, and where there is gross under-reporting of complications, as well as unaddressed needs.

For those with a greater professional and ethical understanding of what is being presented here, it is an absurdity to expect someone to refer or counsel their patient toward such a dangerous and inadequate poor substitute social practice, in the name of "autonomy". *Respect of autonomy* is one of the four moral principles in healthcare and medicine, and needs to be *balanced* against the others (beneficence, non-maleficence & justice) in relation the effects of the autonomous action and not be positioned above *common welfare***.** *Assertion of one's autonomy* in itself is *not a basis for a healthcare intervention,* especially in the face of a socio-legal agenda, not due to the failure of health care or medicine.

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?

If VAD is legalised it should be separated from healthcare and not involve doctors.

Some of our members would construe referral of a patient for VAD as being complicit in facilitating VAD and therefore against their conscience. We do not believe that the patient has a right to force a medical practitioner to act against their conscience. Furthermore, it is not in the interests of the Queensland public to encourage medical practitioners to act against their conscience when it comes to patient care. The Medical Board of Australia recognises the right of medical practitioners to decline to personally provide or participate in care to which they morally object (Good Medical Practice 2.4.7).(24)

Further, such laws or change to code of conduct would create a further silencing of legitimate debate around the controversial topic area in society in medicine, and pose a further risk to the vulnerable in our society. It should be noted that over 30 jurisdictions around the world have rescinded or rejected proposed legalisation within the last 4 years, and that such practices are only actually legal in a very small number or jurisdictions. Of importance it should be noted in the last month a major Bill in Mexico expected to be introduced was defeated due to the legitimate arguments of those disabilities groups and psychiatrists around safety concerns, mental health issues and the effect of public perception of what life may be then be considered worth living.

Our question to the Queensland Government is; Why would the Queensland Government want such a controversial and inherently unsafe legislation to exist for its citizens, and then even consider coercion of doctors and healthcare to accept it with absolute co-operation at this time, and in the process deviate attention away from what is truly required and evidenced to be so for its citizens' in need, instead?

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14 Apr 2019

Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying

Queensland Parliamentary Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee

E: careinquiry@parliament.qld.gov.au

Re: Submission to Inquiry - by Pro-Life Victoria Inc.

Dear Committee members,

On behalf of Pro-Life Victoria, please accept the following submission.

We have found in our experience in Victoria, high quality palliative care is being provided in some parts of Victoria but this is far from universal. Even in larger cities, a significant portion of the city population are not gaining access to high quality palliative care. Outside of the cities, people are at a disadvantage when it comes to providing the best possible care. The distances involved provide a greater challenge to the provision of quality care. Therefore there is considerably more work to be done before it can be claimed that the provision of care and support is adequate. This situation undoubtedly is particularly relevant in Queensland. As long as there is room to improve access to high quality care, the offer of assisted suicide represents an abrogation of responsibility.

Federal Minister for Health, Hon Ken Wyatt has spoken out in this context indicating that 40% of people in aged care do not receive any visitors. Mr Wyatt said “When I talk to people in aged care, I find so many who crave simple touch, a hug, the warmth of palms clasped together, or a soothing hand on their shoulder.” The Queensland Government should offer them better than providing them with a lethal substance to kill themselves.

Palliative care provides enormous benefits to many people in their final days and months. All Australians deserve a concerted effort to extend the provision of high quality palliative care as much as possible.

Just as good palliative care practitioners see a request for euthanasia first as a cry for help, we need our members of Parliament to inform themselves sufficiently on calls for euthanasia to see that we must improve the provision of high quality palliative care. This is not to suggest that pain and suffering can always be averted but there is room to generate a substantial improvement in end of life care. It is the appropriate response to substantial evidence that this committee will receive indicating that for some Queenslanders, poor outcomes have been experienced in terms of the quality of end of life care.

The existing power of Medical Attorney plays an important role for many in end of life decision making. Greater promotion of this has potential to improve end of life choices. This also needs attention.

Overseas Experience

The British have long led the world in developing palliative care programs which draw on the latest advances in pain relief, providing the best possible support for patients facing despair and depression. The British Parliament recently overwhelmingly rejected euthanasia.

The Netherlands and Belgium have led the world and continue to expand their euthanasia programs. Legalised euthanasia and assisted suicide have initially been limited to certain categories of people or scenarios with many supposed safeguards. The safeguards soon become mere guidelines sometimes respected only when convenient – wrongful deaths occur. The categories of people affected are also expanded.

In practice, there is an inevitability for quality care to be undermined and for subtle coercion to be exercised. Palliative care lags and understandably the need is not as compelling. For those who are vulnerable and at some risk of thinking that they are 'a burden on society' or who are at risk of being influenced towards this, there is a very negative impact just from the message or awareness that our society has a new option - 'assistance in dying (assisted suicide)'.

Pro-Life Victoria shares the concerns presented in a submission prepared by The Linacre Centre for Healthcare Ethics for the House of Lords Select committee on the Assisted Dying for the Terminally Ill Bill (Sept 2004). We believe the submission contains vital information that is particularly relevant to this Inquiry.

Therefore the resume and conclusions reached by The Linacre Centre for Healthcare Ethics are presented here in Attachment 1.

An evaluation of outcomes of legalising euthanasia in the Netherlands formed a major part of the Linacre Centre submission. It is also extracted from the submission and included here as Attachment 2.

Pro-Life Victoria requests that the Committee peruse the information in these two attachments.

Impact on Vulnerable Patients

The availability of this option will adversely impact the state of mind and thinking of large numbers of vulnerable patients. Specialists in the care of the terminally ill have expressed the view that a request for euthanasia should be viewed as a cry for help. In future, when people present in hospitals they would be presented with 'options' that will have an impact completely at odds with the supportive care that should be offered.

The availability of this option will impact the manner in which people with disabilities are viewed by society and the manner in which people who become seriously disabled due to accidents come to terms with their lives.

How will the practice of medicine be affected by the delivery of the proposed assisted dying option? We are deeply concerned about the institutional and cultural change that will follow from the proposed changes in law. In hospital environments, there are often significant difficulties in co-ordination and communication between multi-disciplinary team members. Availability of beds, financial pressures and time constraints are also factors that need to be considered in thinking about how the priorities and focus of health professionals will be affected. The Victorian Premier, Daniel Andrews early in the Victorian debate expressed concerns himself with assisted dying proposals referring to the financial pressures on the health system.

The potential for family members to have differing interests than those of patients makes abuse of assisted dying an inevitable outcome. This may flow with people making value judgements on the lives of others from their own ill-prepared perspectives. The vulnerable patients in need of supportive care will be influenced by those around them. Our culture itself will shift away from supportive care

Experience With Legislative Change For Euthanasia

Federalism is such that the issue of euthanasia has been tested carefully many times by various State governments. Governments all around Australia have carefully considered and ultimately rejected the prospect of legalising euthanasia. After some very extensive and thorough inquiries, legislators have recognised that the laudable practice of withholding overly burdensome treatment can be maintained without resorting to the homicidal intent which characterises euthanasia.

The 1995 Northern Territory legislation was thoroughly discredited by the assessment of the Federal Parliament and also by a review of its operation that appeared in the *Medical Journal of Australia* in 1998 (*Kissane DW, Street A, Nitschke P. Seven deaths in Darwin: case studies under the rights of the Terminally Ill Act Northern Territory, Australia. Lancet 1998; 352: p1097-1102*).

As detailed in the abovementioned review, the Northern Territory legislation proved to be poorly drafted and open to abuse during its period of operation in 1995-96. Its intended safeguards against abuse and protection of the innocent and vulnerable very quickly proved inadequate.

The Northern Territory legislation was correctly viewed as requiring that the Federal Parliament protect Australians from its consequences.

Victorian Government's Inquiry into end-of-life choices and assisted suicide consultation process

Paragraph 2c of the Terms of Reference refer specifically to the Victorian Government's Inquiry into end-of-life choices. Concerns with the Victorian process were expressed very well by former Victorian Attorney-General, Robert Clark in his article first published in

the Spectator on 7 December 2017. We share his concerns. [redacted]

Concluding Comments

The legalisation of euthanasia is frequently promoted emotionally on the basis of the most difficult cases but particularly on this issue, hard cases would make bad law. The legalisation of euthanasia would increasingly encourage the elderly to see themselves as a burden. Euthanasia would destroy both life and dignity in more ways than is commonly appreciated.

The best palliative care physicians see a request for euthanasia as invariably being a cry for help. Terminally ill patients commonly face higher risk of depression and this is more often the case if their medical treatment and pain relief is in need of improvement.

As long as there is room to improve access to high quality care, the offer of assisted suicide represents an abrogation of responsibility.

Inquiries into these issues have presented many positive recommendations such as the promotion of palliative care. The emphasis of palliative care techniques is to control pain and distressing emotional symptoms when medical treatment of a curative nature is no longer of any avail and the terminal stage has been reached.

It would be helpful if the current inquiry could also add its support for initiatives to improve the care of the terminally ill and to emphasise that a request for euthanasia should always be an indicator that requires a further effort to ensure that the best medical possible care is being provided.

Yours faithfully

Denise Cameron
President
Pro-Life Victoria
[redacted]

Peter Beriman
Vice President
Pro-Life Victoria
[redacted]

Attachment 1

Resume and Conclusions (Extracts) of Submission to the House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill

on behalf of

The Linacre Centre for Healthcare Ethics

September 2004

Resume

Euthanasia is standardly defended by reference to one or both of two considerations: autonomy and welfare. Either consideration can lead to much more widespread euthanasia than defenders of its legalisation had originally envisaged.

If euthanasia is about patient choice, why should the patient need to be terminally - or physically - ill to receive it?

If euthanasia is about benefiting the patient, why should patients who cannot request it be deprived of this benefit?

Thus we see in the Netherlands an extension of euthanasia to those who are mentally ill or 'tired of life', and also to significant numbers of patients who have not consented to it – including patients who could have consented but in fact have not.

In this submission, we argue that respect for the patient's life is part of respect for the patient's human dignity, and that palliative care, not euthanasia, is the morally appropriate response to terminal suffering. The law should continue to uphold human dignity and equality by prohibiting homicide/assisted suicide for disabled and able-bodied alike. Suicidal people should not be confirmed in their own estimate of their lives' value; instead, they should be supported and protected, whatever their physical condition.

Conclusion

To conclude: a doctor's willingness to kill some patients – whether because this is their 'choice' and/or because the doctor thinks their lives have no value - undermines a commitment to the patient's true welfare which is basic to medicine.

Voluntary euthanasia is not a 'private' choice: it very much affects (among other things) the character of doctors, and their treatment of other patients. Once legalized, euthanasia would become a 'quick fix' for disposing of 'difficult' patients in response to the demands they make on care.

Medicine would be robbed of the incentive to find genuinely compassionate solutions to the difficulties presented by such patients. The kind of humane impulses which have sustained the development of hospice medicine and care would be undermined, because too many would think euthanasia a cheaper and less personally demanding solution.[1]

Doctors would be mistrusted by patients, who would die in an atmosphere of suspicion. Many patients would be killed without request, even if this remained illegal.

The suicidal would be confirmed in their estimate of their lives' value, while the non-suicidal would be, at least, disheartened by the public view of lives such as theirs. For all these reasons, it is vitally important that society continue to value the lives of all its members, including those who, in pain or distress, do not see their own lives as worthwhile. Euthanasia betrays the suicidal by accepting their own view of their lives: suicidal people, whatever their physical condition, need protection and support.

Attachment 2

(Extracts) of Submission to the House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill

on behalf of

The Linacre Centre for Healthcare Ethics

The Netherlands

The position of euthanasia advocates who stress both 'autonomy' and 'welfare' considerations is inherently unstable. There is not just a 'logical' but a 'practical' instability: either consideration can lead in practice to much more widespread euthanasia than was originally envisaged in official guidelines. Thus in the Netherlands we see both an extension of euthanasia to those who are mentally ill or 'tired of life'[2] and its extension to those who are unable to consent, such as infants and young children.[3] Indeed, there is now official toleration of non-voluntary euthanasia, in that (for example) euthanasia of children is required to be reported. In 2001, 100 out of 1088 deaths of babies under one year of age involved the giving of drugs with the explicit purpose of ending life.[4]

Three major Government-ordered studies of euthanasia and other end-of-life decisions have been carried out in the Netherlands, where euthanasia was accommodated for many years by court decisions before being legalized by statute. These studies show a far from reassuring picture with regard to observance of guidelines, including the requirement that

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[2] With regard to grounds for euthanasia, 3% of doctors say that they have themselves assisted suicides of people 'tired of life' who did not have any serious somatic or psychiatric ailment (G. van der Wal, A. van der Heide, B.D. Onwuteaka-Philipsen & P.J. van der Maas, *Medische Besluitvorming aan het einde van het leven: De prektijk en de toetsing procedure [Medical Decisionmaking at the End of Life: The Practice and the Review and Verification Procedure*] (Utrecht, 2003), p.104, Table 10.2). 29% of doctors consider this an acceptable motive for assisted suicide (*Ibid*, p.107).

[3] In Belgium, too, where euthanasia has recently been legalized, a member of the Belgian House of Representatives, Madame Avontroot, claims that many cases of non-voluntary euthanasia are performed, without even the family's consent, and that the number of cases registered after a year (203) is far below the real number (see the electronic briefing of the Institut Européen de Bioéthique *Quality of Life – Spécial Belgique* January-June 2004, p.8). The president of a commission evaluating the law on euthanasia, Dr Distelmans, recently called for the law to be extended to minors and those with degenerative conditions such as Alzheimers who had made an advance request (*Ibid*, p.2).

[4] Van der Wal, van der Heide *et al*., p.121.

the patient give consent.[5] In the studies, the term 'euthanasia' is used in the official Dutch sense of 'active voluntary euthanasia'; moreover, not all deliberate life-terminating acts - let alone deliberate life-terminating omissions – are classed as 'euthanasia', 'assisted suicide' or 'life terminating acts without request'. To arrive at a more realistic, though still conservative, figure for euthanasia in the Netherlands, it is necessary to count all acts – and if possible, omissions[6] – on the part of doctors which are chosen with the 'explicit intention' (or 'explicit purpose') of ending life. These figures are available for 1990 and 1995; however, the data for 2001 make it impossible to determine the exact level of (for example) non-voluntary active killing, since doctors who gave intentional overdoses of painkillers with the intention of hastening death were not asked, as in previous years, if the patient had consented.

4. 1 Compliance with guidelines

When we read that 900 patients were deliberately killed without their request in 1995 (a figure which rose to 980 in 2001) we should remember that this figure, alarming as it is, does not include 1,537 cases where palliative drugs were given with the explicit, unrequested aim of hastening death.[7] If we include this group of cases, it becomes clear that more than a third of those actively killed were killed non-voluntarily. Even excluding this group of cases of active non-voluntary euthanasia, one in five of those actively killed were killed without their request.[8] If we turn to euthanasia by omission, there were as

[5] For an in-depth analysis of the first two studies, together with much other useful material, see J. Keown, *Euthanasia, Ethics and Public Policy* (Cambridge, 2002). For a summary statement of striking results of these studies which come into view when the terminological ambiguities are clarified, see J. Finnis, 'Euthanasia, Morality, and the Law', *Loyola University of Los Angeles Law Review* 1998, Vol.31, pp.1123-45 at pp.1125-8.

[6] As John Keown comments on the 1995 study, 'A note to the relevant questions [on withholding/withdrawing treatment with the explicit intention/purpose of hastening death] states that an intention to "hasten the end of life" could also be understood as an intention "not to prolong life". This creates an unfortunate ambiguity … An intention not to prolong life is not the same as an intention to end it. In many of these cases doctors may have intended to withhold/withdraw treatment not to end the patient's life, but because the treatment was futile or too burdensome' (*op cit*., pp. 129-130).

[7] P.J. van der Maas *et al.*, 'Euthanasia, Physician-Assisted Suicide, and Other Medical Practices Involving the End of Life in the Netherlands', *New England Journal of Medicine* 1996, Vol. 355, p.1704.

[8] Keown, *op.cit.*, p.128. The larger figure includes assisted suicide.

many as 18,000 such cases in 1995,[9] of which 14,200 – a substantial majority - were without the patient's request. It is worth noting that by no means all the patients killed without request, whether by act or by omission, were incompetent at the time.[10]

4. 1. 1 Reporting

It is often said that euthanasia will be better controlled where it can be freely reported.[11] In fact the Dutch experience shows widespread underreporting, in addition to widespread disregard of other guidelines. About half the cases of 'euthanasia' and 'assisted suicide' revealed by the 2001 survey went unreported, as did 99% of cases of termination of life without the patient's request, 100% of cases of intentional lethal overdose of painkillers (whether requested or unrequested), and a huge majority of cases where the patient killed was a child.[12]

This is in line with earlier research, which found that between 15% and 20% of doctors said they would not report their euthanasia cases under any circumstances, and that 20% of doctors' most recent unreported cases involved ending life without consent. [13] Such cases, both the 1990 and 1995 studies revealed, were virtually never reported.[14] Even

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[9] See note 8.

[10] Indeed, of those killed without their request, between 25% and 40% (depending on the series studied) were capable of making a request, but did not do so. See Finnis, *op. cit.*, at p. 1126; Loes Pijnenborg *et al*., 'Life-Terminating Acts Without Explicit Request', *Lancet* 1993, Vol. 341, pp.1165, 1197; The New York State Task Force on Life and the Law, *When Death is Sought: Assisted Suicide and Euthanasia in the Medical Context* (1994), p.134 n. 31; J. Keown, 'Euthanasia in the Netherlands: Sliding Down the Slippery Slope', in J. Keown (ed.), *Euthanasia Examined: Ethical, Clinical and Legal Perspectives* (Cambridge, 1995), at p. 292 n. 104.

[11] A comparative study of six European countries (A.van der Heide *et al*., 'End-of-life decision-making in six European countries: descriptive study', *Lancet* June 17, 2003, published online at http://image.thelancet.com/extras/03art3298web.pdf) shows a high rate of euthanasia in the Netherlands, and a relatively high, if not the highest, rate of non-voluntary life termination. (It is worth stressing that not all cases of active non-voluntary killing – much less non-voluntary killing by omission – will be included in these figures.)

[12] R. Fenigsen, 'Dutch Euthanasia: The New Government Ordered Study', *Issues in Law and Medicine* 2004, Vol. 20, No. 1, p.77. It is striking to note that in 3% of these cases, the baby was euthanised without the consent or knowledge of the parents (Van der Wal, van der Heide *et al*., Table 12.2) and that similarly in three cases older children were euthanised without the request of either the child or the parents (Table 13.2).

[13] Van der Wal *et al*., 'Evaluation of the Notification Procedure for Physician-Assisted Death in the Netherlands', *New England Journal of Medicine* 1996, Vol. 335, p.1708.

[14] H.Hendin, 'The Dutch Experience', *Issues in Law and Medicine* 2002, Vol. 17, No. 3, p.230.

where euthanasia takes place 'with consent', there is a real possibility of pressure being brought to bear by doctors and/or relatives. It is startling to note that more than 50% of doctors surveyed thought it appropriate to suggest euthanasia to patients.[15]

As one researcher comments, 'When, as the 1990 and 1995 studies document, 59% of Dutch physicians do not report their cases of assisted suicide and euthanasia, when more than 50% feel free to suggest euthanasia to their patients, and when 25% admit to ending patients' lives without the patient's consent, it is clear that terminally ill patients are not adequately protected.'[16] Most striking of all, in both the 1995 study[17] and the 2001 study,[18] the authors suggest that it is the *patient* who is responsible for avoiding

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[15] P.J.van der Maas, J.J.M.van Delden and L. Pijnenborg, *Euthanasia and Other Medical Decisions Concerning the End of Life* (1992), pp.101-2.
[16] Hendin, *op.cit.*, p.234.
[17] G. van der Wal and P.J. van der Maas, 'Euthanasie en andere medische beslissingen rond het levenseinde: De Praktijk en de Meldingsprocedure [Euthanasia and Other Medical Decisions Concerning the End of Life: The Practice and the Notification Procedure] (The Hague, 1996), p.237.
[18] Van der Wal, van der Heide *et al*., p.201.

Submission by the Guild of Saint Luke(Federation of Catholic Medical Associations, Queensland) Regarding the Inquiry into Aged Care, End-Of-Life and Palliative Care and Voluntary Assisted Dying.

Dr Terrence Kent, President(Qld)

Voluntary assisted dying should NEVER be allowed in Queensland.

Australian Society is indeed a prosperous society. We pride ourselves on our democratic ways, with freedom not experienced elsewhere. We have wealth and we care for all. We care for sick people. We care for the sick whether they are young, old, poor, or disabled. It is the Australian and Queensland way. This is how it should be. In the same way, we must look after our dying. It is our duty to do so.

It is important that those who are suffering and struggling are valued no matter what their level of 'productivity'. In fact, those whose lives are weakened or diminished deserve special respect. They must not feel that they are a burden on society, their families, on the hospitals, nor the health care system. Never ever should they be made to feel afraid of their future.

Palliative care, the care of the dying, is an important component of our health care system. In our technologically advanced world, palliative care is sophisticated and deals with all symptoms. Palliative care controls pain and can control psychological symptoms. It is critical that funds and resources be allocated to enable proper, comprehensive palliative care. If there is a patchwork system of care, then palliative care becomes inadequate and people can suffer.

The care of the aged, as well as palliative care, are thus noble and essential components of modern medicine. However, voluntary assisted dying is not noble. Voluntary assisted dying should NEVER be considered when discussing aged and palliative care. The two entities are incongruous. Aged and palliative care seeks to find answers, while euthanasia ends the search to truly help.

Voluntary euthanasia is morally unacceptable. In his encyclical the Gospel of Life (Evangelium Vitae), Pope St John Paul II states:

> "I confirm that euthanasia is a grave violation of the law of God, since it is the deliberate and morally unacceptable killing of a human person." [1]

Whatever name is given to voluntary assisted dying, it is still the taking of a life. Euthanasia is not mercy killing or any other manufactured use of words. Euthanasia should NEVER be allowed in Queensland, as it is killing, and the taking of life is definitely outlawed in Queensland. Putting a bureaucratic name to the act, still makes it the taking of life. Surely, Queenslanders want better than this.

Rejection of voluntary assisted dying does not mean that patients must accept all treatment that is burdensome or excessive. Patients and their families are even today in Queensland rejecting futile or unnecessary treatments. Today, patients and their families have the choice to reject treatments that will not make them well, but will only prolong suffering. This system does not have to change. Patients should be able to reject burdensome treatments. They are surely not calling for euthanasia.

According to bio-ethicist Nicholas Tonti-Filippini, reasons for rejecting voluntary assisted dying, what he aptly called physician assisted suicide include

1. It undermines the trust in patient-doctor relationships. Patients become suspicious of their doctors
2. It changes the role of the doctor from a healer to someone who takes life. A situation that has been maintained since Hippocrates first took his famous oath over 2500 years ago.
3. It puts at risk the fate and wellbeing of our most vulnerable and dependent patients. Patients who may feel that they are a burden on others.

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[1]Pope John Paul II Evangelium Vitae, (1995) p 125

4. It endangers the respect and value that society places on human life. This applies not only to those nearing the end of their lives but also to those who are sick, disabled and vulnerable.[2]

It is true that in countries where it has been permitted, voluntary assisted dying has been widened. This has happened in the Netherlands and in Belgium. It has been extended in the Netherlands to children and infants, those who are incompetent and mentally ill patients. This WILL happen. Do not be fooled. Queensland does not want VAD, Queensland does not want euthanasia, Queensland does not killing that today is rightly considered both murder and suicide.

[2] Tonti-Filippini, Nicholas About Bioethics Volume 2:Caring For People Who Are Sick Or Dying. 2012. p 102

The Uniting Church in Australia
QUEENSLAND SYNOD

Moderator
Rev David Baker

11 April 2019

Mr Rob Hansen
Committee Secretary
Health, Communities, Disability Services, Domestic and
Family Violence Prevention Committee
Parliament House
George Street
BRISBANE QLD 4000

Dear Mr Hansen

The Uniting Church in Australia Queensland Synod welcomes the opportunity to provide feedback to the Health, Communities, Disability Services, Domestic and Family Violence Prevention Committee's (the Committee) inquiry into aged care, end-of-life and palliative care, and voluntary assisted dying.

These are all important topics for the community to consider and we commend the Parliament for its willingness to examine these challenging issues. As this inquiry covers areas relevant to the Uniting Church and its service delivery agencies UnitingCare and Wesley Mission Queensland, we are making a response that brings together our views and experiences.

Whether voluntary assisted dying should be legalised in Queensland is a significant question for the community to consider. The Uniting Church in Australia Queensland Synod's position is that voluntary assisted dying presents substantial moral problems and we are opposed to it being legalised in Queensland.

The Uniting Church supports however, the critical importance of high quality, well-resourced, and accessible palliative and end-of-life care that responds to the physical, psycho-social and spiritual needs of people at the end-of-life.

The attached submission provides detailed comment in response to the Committee's Issues Paper. Our comments on voluntary assisted dying reflect the theological tradition of the Church and also include definitions and comment on safeguards should it be legalised.

Our comments on the status of aged care, end-of-life and palliative care in Queensland reflect the experience of UnitingCare and Wesley Mission Queensland, who provide hospital, aged care, and palliative care services. Our response also includes commentary from Hummingbird House, Queensland's only specialist palliative care service for children.

The Queensland Synod, UnitingCare and Wesley Mission Queensland would welcome future opportunities to discuss this submission in person as well as looking at opportunities to work with

The Uniting Church in Australia
QUEENSLAND SYNOD

government to improve outcomes for older Queenslanders and people at the end-of-life. Should you require any further information, you can contact me on [redacted]

Yours sincerely,

Rev. David Baker
Moderator, Uniting Church in Australia Queensland Synod

Supported by:

Craig Barke
CEO, UnitingCare

Geoff Batkin
CEO, Wesley Mission Queensland

The Uniting Church in Australia
QUEENSLAND SYNOD

Submission to the Queensland Parliamentary Inquiry into Aged Care, End-of-Life and Palliative Care, and Voluntary Assisted Dying

Supported by:

UnitingCare

wesley mission QUEENSLAND

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Summary

The Uniting Church in Australia Queensland Synod welcomes the opportunity to provide feedback to the Health, Communities, Disability Services, Domestic and Family Violence Prevention Committee's (the Committee) inquiry into aged care, end-of-life and palliative care, and voluntary assisted dying.

Whether voluntary assisted dying should be legalised in Queensland is a significant moral and ethical question and our comments on this are led by the Uniting Church. Our comments on the status of aged care, end-of-life and palliative care in Queensland reflect the experience of UnitingCare and Wesley Mission Queensland, who provide hospital, aged care, and palliative care services. Providing these services is a reflection of the Church's mission to work with older people and advocate for their rights to access the care they need.

Aged Care

All older people are of value and should enjoy life in all its fullness as they age. The importance of living a meaningful life does not diminish as people's physical and cognitive health declines and the end-of-life approaches.

Older Australians expect safe, consistent and high quality care that they can easily access when they need it. Many of the measures needed to improve older people's access to aged care are managed by the Commonwealth. However, the Queensland Government still has an important role to play in improving older people's access to aged care, particularly at the interface with the health system.

The needs of older people are best served by a health and aged care system that is person-centred and integrated. Where health and medical services are available and accessible, information is shared, systems talk to each other, partnerships are commonplace, complex needs are understood and addressed holistically, and multidisciplinary approaches are the norm.

Older Queenslanders are entitled to access the same services from the general health care system as the rest of the population. However, they frequently miss out due to assumptions that aged care funding can effectively provide a full range of health services. Aged care is not funded to provide acute health services and this inequity for older people must be addressed by the Queensland Government as a matter of urgency.

Palliative and end-of-life care

We believe people should have access to high quality palliative care and support in the location of their choice. We support the Productivity Commission's finding that there is a mismatch between where people prefer to die and what support is available. In particular we note research showing 70 percent of people would prefer to die at home, but are unable to[1]. However, through our practical experience we also know that people's preferences for place

[1] Productivity Commission. 2017. *Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services*. Report No. 82. Canberra. Chapter 3: End-of-life care in Australia.

of care and place of death vary and change over time. While some may prefer to die at home, others will prefer a hospice or hospital setting.

All of our services offering palliative and end-of-life care in Queensland are struggling to meet demand. To meet people's needs, our health, aged, and community care systems need to be appropriately resourced and flexible so people are placed at the centre of care and are able to get support in the setting of their choice. More work needs to be done so people wishing to die at home have the care they need, but we must also maintain and build on options for people who prefer a hospice or hospital setting. Doing this will help make sure people are offered dignity, choice and respect as they approach the end of their lives.

Voluntary assisted dying

The Uniting Church in Australia Queensland Synod's position is that voluntary assisted dying presents substantial moral problems and we are opposed to it being legalised in Queensland.

The Uniting Church supports the following:

- The critical importance of high quality, well-resourced and accessible palliative and end-of-life care that responds to the physical, psycho-social and spiritual needs of people at the end-of-life. There is strong concern about the provision of these services especially in regional and remote Queensland;
- Having a well-resourced and flexible system of palliative and end-of-life care that consistently meets people's needs and preferences for care; and
- If legalised, provisions for conscientious objection for both individuals and organisations be included in any legislation for voluntary assisted dying in Queensland.

While we do not support voluntary assisted dying, if it is legalised, the Uniting Church is committed to offering a compassionate and pastoral response to people and families who choose this path.

Recommendations

Aged Care

Recommendation 1

The Queensland Government commit to:

- Boosting navigator roles within existing health and community services who work with older people and their families. This will support people to access aged care;
- Greater partnering between the health and non-government sector on aged care issues. This should involve continuing positive conversations and work from statewide meetings; and
- Building a client journey across sectors and facilitating a person-centred approach across the government and non-government services involved in older people's lives.

Recommendation 2

The Queensland Government acknowledge aged care funding constraints limit the role the sector can play in cross subsidising services to meet the health needs of older people and avoid hospitalisation.

Recommendation 3

The Queensland Government partners with the aged care sector to develop and implement a strategy to improve the interface between hospitals and aged care to meet the health needs of older people. Actions to improve health responses to older Queenslanders should include:

- A shared commitment and action between health and aged care providers to meet older people's needs in a holistic and person-centred way. This should be supported by a clear partnership approach, formal delivery arrangements, and appropriate investment for health related services. These should include hospital avoidance, hospital in the home, transition care and palliative care services;
- A focus on wellness and reablement while at hospital to assist people retain fitness and stay as independent as long as possible;
- Greater availability of hospital in the home and transition care services, which can assist people to move out of hospital more quickly;.
- Resources within hospitals for rapid assessment of older people living in residential aged care to avoid hospital ramping or admission if it is not needed. For example, the Geriatric Outreach Assessment Service and the CARE-PACT program;
- Specialist mental health and dementia services that provide outreach to older people in the community and residential aged care. This should include a focus on practice excellence and providing education and training to people working in both health and aged care;
- Ensuring that a diagnosis of dementia does not lead to older people's mental health needs going unaddressed;
- Better information sharing, including access to discharge summaries and exploring a shared client record by linking My Health Record and My Aged Care with shared access to both systems;

- Additional training for registered nurses to provide some sub-acute care. However, this must be done in partnership with hospitals; and
- Building a understanding of the role of private hospitals in the system.

Palliative and end-of-life care

Recommendation 4

The Queensland Government produce financial models for funding new community-based hospices that draw upon public, private or mixed funding models.

Recommendation 5

The Queensland Government provide consistent funding levels for nurse practitioners in specialist palliative care responses.

Recommendation 6

Queensland Health and Hospital and Health Services partner with community-based providers, and in the absence of an individualised funding model, invest in them to deliver palliative care services to the community.

Recommendation 7

Any government delivered or funded specialist palliative care services be adequately resourced to identify and respond to people's spiritual needs, particularly in the context of bereavement care for both adults and children.

Voluntary assisted dying

Recommendation 8

That voluntary assisted dying not be legalised in Queensland.

Recommendation 9

The following definitions are adopted by the Committee:

Term	Definition	Other Common Terms
Physician assisted dying	A doctor or other person provides drugs, at the request of a person with decision making capacity, which a person can take themselves to intentionally end their life.	**Physician assisted suicide** **Voluntary assisted suicide**
	A doctor or other person intentionally hastens death, at the request of a person with decision making capacity, by administering a substance to end their life.	**Euthanasia** **Active voluntary euthanasia** **Voluntary euthanasia**
Ending a life without explicit request	A doctor or another person administers a medication or performs another action to intentionally end life, either without a mentally competent person's request or the person is non-competent and unable to make a request.	**Non-voluntary euthanasia** **Involuntary euthanasia**

Term	Definition	Other Common Terms
Withdrawal of treatments	Withholding or withdrawing overly burdensome medical treatment from a person because of medical futility, non-beneficial care, or at the request of a competent person or a person without decision making capacity's surrogate decision maker. The intention of this is not to hasten death, but to provide comfort care.	**Refusal of treatment** **Limiting of life-sustaining treatments**
Providing pain medication to relieve suffering	Doctors provide pain medication to people with the intention to relieve their suffering. Depending on a person's condition, this may hasten death, but the primary purpose is to provide comfort and relieve suffering.	
Advanced health directive	A written instruction, describing the medical care a person wants if they become unable to make or communicate their own health care decisions. The laws governing these vary between States and Territories and can be complex.	
Palliative care	Palliative care is an approach that improves the quality of life of patients and their families facing a life threatening illness. Relief and prevention of suffering occurs through early identification and thorough assessment and treatment of pain and other physical, psychosocial and spiritual concerns.	

Recommendation 10

If voluntary assisted dying is legalised, the conscientious objection provisions in the Victorian scheme, including capacity for organisations to conscientiously object, should be adopted.

> '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;
>
> (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.'
>
> (*Voluntary Assisted Dying Act (Vic) 2017,* Section 7)

1. Introduction

The Uniting Church in Australia Queensland Synod welcomes the opportunity to provide feedback to the Health, Communities, Disability Services, Domestic and Family Violence Prevention Committee's (the Committee) inquiry into aged care, end-of-life and palliative care, and voluntary assisted dying. These are all important topics for the community to consider and we commend the Government for its willingness to examine these challenging issues. As this inquiry covers areas relevant to the Uniting Church and its service delivery agencies UnitingCare and Wesley Mission Queensland, we are making a response that brings our views and experiences together in one combined submission.

Whether voluntary assisted dying should be legalised in Queensland is a significant moral and ethical question for the community to consider, and our comments on this are led by The Uniting Church in Australia Queensland Synod. Our comments on the status of aged care, end-of-life and palliative care in Queensland reflect the experience of UnitingCare and Wesley Mission Queensland, who provide hospital, aged care, and palliative care services. Providing these services is a reflection of the Church's mission to work with older people and advocate for their rights to access the care they need.

Our comments on aged care are focused on areas where we see the Queensland Government as having a key role in improving outcomes for older people. Our comments on palliative and end-of-life care reflect our agencies' extensive experience delivering these services in hospitals, specialist hospices such as Hummingbird House, residential aged care and in the community.

2. About The Uniting Church in Australia Queensland Synod

The Uniting Church is committed to working towards a society characterised by love, compassion, justice, inclusion and reconciliation so that all people, at every stage of life, can experience 'life in all its fullness' (John 10:10). Our faith calls us to the preferential care for the most marginalised in society. Moreover, the Christian vision for a flourishing society includes valuing and promoting the compassionate service and love of the most vulnerable in society based on the sanctity of all life. The experience of sickness, pain and suffering, especially at the end-of-life, is a vulnerable and fragile experience. As the Church, we are called to participate in and witness to God's mission of compassionate care for the sick, the dying, the poor in spirit, people with a disability, the aged, and those who are experiencing brokenness and forsakenness.

2.1. About UnitingCare

UnitingCare Queensland is committed to delivering quality health, aged care, disability and community services as one of the largest charities in Australia.

As a part of the Uniting Church, we provide person-centred care and support services to thousands of people every day of the year enabling our clients to live their best possible lives whatever their circumstances.

2.1.1. Blue Care

For more than 65 years Blue Care has been committed to empowering individuals to live life their way. Today our people make more than three million visits to Queenslanders each year, providing the same holistic care, service and companionship that has been our hallmark since our establishment.

Blue Care puts customers and their loved ones first, and this focus on individuals has helped us become one of Queensland largest and most trusted providers of in-home care, residential aged care and independent and supported retirement living. We provide services from Thursday Island to Coolangatta and as far west as Mt Isa and Charleville. Through all of our services, we provide care to more than 75,000 people a year.

Our service model, Blue Care 'Tailor Made', represents our approach to care and service delivery. It guides the way we work with people as they choose and direct their services that support and respond to their individual needs and goals.

In 2017-18, Blue Care provided 13,017 funded hours of palliative care services to 1,024 people. These services were provided in community and residential aged care settings across Queensland and were funded by a variety of sources, including contracted services on behalf of Queensland Hospital and Health Services, such as the Wynnum-Manly Palliative Care Unit. We also provide palliative support to many of the people we serve every year.

We have invested in building clinical capability and multidisciplinary models to offer people positive end-of-life experiences. We are also committed to research and evidence-based practice and were the first community-based provider in Australia to report through the Palliative Care Outcomes Collaboration program.

2.1.2. UnitingCare Hospitals

UnitingCare is one of the largest private hospital groups in Queensland and provides a comprehensive range of private medical services. We operate a palliative care unit at The Wesley Hospital in Brisbane and a smaller inpatient service at St Andrew's War Memorial Hospital.

The Wesley Palliative Care Service is a multidisciplinary, holistic and inclusive service which values the human spirit in overcoming the burden of advanced incurable illness, regardless of the underlying cause. This unit has 17 beds and is supported by a team of medical specialists and registrars, experienced palliative nursing staff, dieticians, physiotherapists, occupational therapists, nurse counsellors and chaplains.

The care type provided by the unit is acute and is at the interface of acute care and the transition to a palliative care approach. The Wesley Hospital provides a small, private outpatient clinic of 6 hours per week to provide specialist support for Wesley patients in the community. The palliative care service also supervises the inpatient service at our St Andrew's War Memorial Hospital in Spring Hill, Brisbane.

2.2. About Wesley Mission Queensland

Wesley Mission Queensland was established in 1907 to provide nursing care to homeless people in Brisbane and was the first provider of residential aged care in Queensland (based at Wheller Gardens in Chermside, which was established in 1936).

Wesley Mission Queensland's core purpose is to walk alongside people in need; offering care and compassion and promoting choice, independence and community wellbeing.

As at 30 June 2018, Wesley Mission Queensland cared for 946 people in residential care and 421 people through home care packages. In the 2017-18 financial year, we supported over 100,000 people with care services - 25,000 older people and 75,000 children, young people and families.

Wesley Mission Queensland also provides two hospice services; Hopewell Hospice on the Gold Coast and Queensland's only children's hospice, Hummingbird House. Hopewell Hospice is an 8 bed private facility, which provides end-of-life care to approximately 150 people a year.

2.2.1. Hummingbird House

Hummingbird House is a 9 bed facility with 8 guest-in-care suites and one purpose-built suite for after death care, based in Chermside. The service is accredited under the National Safety and Quality Health Service Standards and is a licensed private healthcare facility. It is the only paediatric palliative care hospice facility in Queensland, the third in Australia, and is operated by Wesley Mission Queensland.

Within the Clinical Skills Capability Framework, 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.

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) specialist short stay breaks (e.g. respite); and

e) step down transition care.

Hummingbird House is also licensed to provide specialist nursing, allied health, and family support service input in a child's home care.

Further information on the Hummingbird House model of care is available in **Appendix I.**

3. Aged Care

All older people are of value and should enjoy life in all its fullness, with dignity, as they age. The importance of living a meaningful life does not diminish as people's physical and cognitive health declines and the end-of-life approaches. Older people consistently tell us they want care that:

- provides assistance to be all they can be;
- addresses and connects body, mind and spirit;
- offers the right level of care at the right time; and
- creates nurture and belonging in a home-like environment with a good lifestyle[2].

UnitingCare and Wesley Mission Queensland have a long history of working with Older Australians and advocating for their rights to access the care they need. We have contributed to and provided evidence for a number of aged care reviews and reform processes and our views on many issues form part of the public record. We are also participating openly and transparently with the Royal Commission into Aged Care Quality and Safety (the Royal Commission), which we welcome and are hopeful will contribute to improving the quality, safety, and accessibly of aged care services for all older Australians. In responding to the Committee's issues paper we have chosen to focus on the aspects of the aged care system we believe the Queensland Government has an important role to play in improving outcomes for older people.

3.1. Previous reviews and reforms

As the Committee conducts its inquiry and considers previous reviews and system changes in aged care, we suggest they be guided by the findings from the following reports:

- Legislative Review of Aged Care, 2017 (Tune review);
- Review of the National Aged Care Quality Regulatory Processes, 2018 (Carnell Paterson review); and
- Aged Care Workforce Strategy, 2018 (Pollaers review).

We also support the Committee's intention to participate in and be informed by the progress of the Royal Commission.

3.2. Our involvement in aged care

Our aged care services have grown out of advocacy for and service with older Australians. The worth and dignity of every person was fundamental to why the Church responded to the health and care needs of older people. Seeing the need in the community, the Church could not watch without acting. In 1936, Wesley Mission Queensland was the first provider of residential aged care in Queensland. In 1953, the first Blue Nurse went house to house by foot, tram, bicycle or borrowed car, serving older people with professional care and compassion.

[2] UnitingCare Queensland. *Blue Care Tailor Made*; *A Matter of Care Australia's Aged Care Workforce Strategy*, Aged Care Workforce Strategy Taskforce, June 2018

Today, UnitingCare and Wesley Mission Queensland are still working with older people and empowering them to live life in its fullness. We are driven by our mission to do everything we can to make sure people have access to quality care that meets their needs. This means our services are often found in locations others won't go and our voice is heard advocating for changes to the aged care system to improve outcomes for older people.

We became involved in aged care because of need in the community, and while older people's needs are changing, they have not gone away. We do not believe the aged care system is fundamentally broken, but parts of it are. Our vision for aged care, of what good care looks like, guides our thinking and advocacy for how we can fix it.

3.3. Vision for the aged care system

Meaningful ageing experiences for Australians are supported by an aged care system that puts people in the centre and builds on their strengths and capabilities. A good system empowers older people, families, care staff, volunteers and the broader community to live and work together in communities where they experience connectedness, joy and hope. This allows older people to have a valued place in the community, recognising past contributions, maintaining and generating connections and living valued roles.

Achieving this requires a system that is:

- Easy to access—flexible, clear and fair
- Trusted—regulated well and quality-focused
- Skilled—staff are compassionate, supported and trained
- Sustainable—health and wellness needs are resourced

We believe all elements of the aged care system should be underpinned by the principles of respect, connectedness, compassion, integrity and choice.

3.4. Accessing the aged care system

The following section responds to questions 1, 2, 4, 5 and 6 in the Committee's issues paper.

Older Australians expect safe, consistent and high quality care that they can easily access when they need it. The processes for getting aged care need to be quick and they need to be fair.

For the aged care system to be accessible and give people assurance their needs will be met, care must start from each person. When care starts with the person and their needs, access to health, social, emotional and spiritual support will be facilitated. Achieving this for all older Queenslanders depends on different factors impacting service availability, such as resourcing, workforce, geography and local relationships with the health system.

3.4.1. Issues impacting access to aged care

Many older people and their families find My Aged Care confusing to navigate and can delay accessing services until a crisis point is reached. Brokerage services can be expensive and difficult to find, and the navigator functions within My Aged Care do not always meet people's needs. Service providers are well placed to support people to navigate the system to get quicker access to services, but there is limited funding for navigator services.

Research commissioned by UnitingCare Australia shows that the number of aged care assessments undertaken over the past four years has not increased at the same rate as the growth of demand. This puts older people at risk of accelerated health deterioration and can limit their capacity to age in their own home. This increases their need for acute health interventions and can lead to premature entry into residential care.

The waitlists for home care package funding, particularly at the higher levels are well known[3]. Research commissioned by UnitingCare Australia shows that there are over 121,000 older people currently on waiting lists for home care packages they are assessed as being eligible for, and waiting times can be over 12 months. It is widely acknowledged that some people are accessing lower level packages while waiting but this does not meet their needs. We note that additional packages have been announced by the Commonwealth in the MYEFO and the 2019-20 Federal Budget, but these are unlikely to have a big impact on the overall waitlist.

A lack of shared vision for positive aging and different priorities across health and other care systems limits access to care that keeps people in the centre. Tensions between different care paradigms also occur when seeking a coordinated approach across systems to meet people's needs. This is demonstrated very clearly in the interface between the health and aged care system, where competing service perspectives, priorities and pressures often lead to older people falling through the cracks. Issues relating to the interface between health and aged care are discussed further in section 3.7.

3.4.2. Options for improving access to aged care

Many of the measures needed to improve older people's access to aged care are managed by the Commonwealth. However, the Queensland Government still has a role to play in improving older people's access aged care.

Recommendation 1

The Queensland Government commits to:

- Boosting navigator roles within existing health and community services who work with older people and their families.
- Greater partnering between the health and non-government sector on aged care issues. This should involve continuing positive conversations and work from statewide meetings.
- Building a client journey across sectors and facilitating a person-centred approach across the government and non-government services involved in older people's lives.

[3] Royal Commission into Aged Care Quality and Safety. (2019). *Navigating the maze: An overview of the Australia's current aged care system*. Available at: https://agedcare.royalcommission.gov.au/publications/Documents/background-paper-1.pdf

3.5. Strengthening trust in the aged care system

The following section responds to question 3 in the Committee's issues paper.

The evidence being heard by the Royal Commission is demonstrating that Australia's aged care system is not always meeting the community's expectations, with a number of examples being provided by consumers and families.

We are strong advocates for reasonable and accountable regulation of the aged care industry to protect the rights and safety of older people, and to ensure the quality and accessibility of services across geographical locations. Good regulation and accountability of aged care is vital for strengthening the public's trust in aged care. We support the new Single Aged Care Quality Standards, which have a greater focus on consumer engagement. We believe the regulation of aged care should continue being led by the Commonwealth.

3.6. Growing a skilled aged care workforce

The following section responds to questions 7 and 9 in the Committee's issues paper.

We believe older people have the right to individualised care and we work to make sure people are supported by the right care staff, at the right time, in the right culture and service type. Unfortunately, we are subject to a range of external factors that limit our ability to manage our workforce as effectively as possible and achieve our care goals.

3.6.1. Issues impacting the aged care workforce

The aged care workforce currently employs more than 366,000 people across Australia and will need to grow to include nearly one million direct care workers by 2050[4]. We are currently experiencing workforce challenges in aged care and without intervention expect these to worsen in coming years.

We are experiencing increasing complexity of need among care recipients, which requires us to increase the skills of our workforce and have them working in contemporary ways with good access to best practice and real time information. This is particularly important to meet the needs of people living with dementia and dual diagnoses of mental health issues. Responding to people with complex needs requires a highly skilled workforce and a range of staff in a multidisciplinary model.

We currently require a minimum Certificate III qualification for people to work in our aged care services. However, vocational training courses vary and additional on the job training can be required. We also need to provide additional training and support for staff to deliver care according to service models. We regularly provide staff with training and ongoing professional development opportunities to ensure people have the right skills. We do this through face-to-face and digital delivery methods. While face-to-face training is recognised as the best practice delivery mode, this is a very expensive model in remote areas. Other delivery modes, such as videoconferencing, can be good alternatives, but can be limited by connectivity issues in many remote communities. All workforce training and support must be provided within existing resources, which are frequently under pressure.

[4] *A Matter of Care Australia's Aged Care Workforce Strategy*, Aged Care Workforce Strategy Taskforce, June 2018

We experience a number of specific workforce challenges in rural and remote communities. The workforce in small communities can be very dependent on a sole supplier model. For example, a carer living in a small town can deliver great service to the older people of that community. However, if they leave there may be no one to take their role. Service provision may also rely on a worker who lives a lengthy distance away, making the provision of that service financially unviable for a provider. Workers are predominantly looking for full time, or close-to full time work. Irregular casual employment does not suit the workforce in these areas; decreasing the ability of providers to have any flexibility within its workforce.

Very remote services are reliant on a proportion of (or in some cases all) staff being fly-in, fly-out (FIFO). In addition to the dislocation from their own homes, staff are then required to stay in the very small and often unfamiliar communities they are working in, severely impacting their ability to have downtime when they are off-duty.

3.6.2. Options to grow a skilled aged care workforce

A clear, government-supported whole-of-industry workforce strategy is required to manage growth and meet people's needs. The Pollaers Report describes a range of systemic issues and options to address current and future skills, recruitment and retention needs as well as career pathways, and developing cultures of feedback and continuous improvement. The report also contains findings on the role of current and future funding of aged care and its impact on staff remuneration (Strategic Action 13). This includes a finding that personal care workers and nurses in aged care are being under-rewarded by about 15 percent. The report highlights that an important part of addressing this is to examine areas of revenue shortfall, explore an industry productivity agenda, and have a broader conversation around who pays for care[5]. We support this report and encourage its implementation.

3.7. Improving how the health and aged care systems work together to meet Queenslander's needs

The following section responds to questions 10, 11 and 12 in the Committee's issues paper.

The health system plays a fundamental role in meeting the needs of older Queenslanders. The needs of older people are best served by a health and aged care system that is person-centred and integrated. Where health and medical services are available and accessible, information is shared, systems talk to each other, partnerships are commonplace, complex needs are understood and addressed holistically, and multidisciplinary approaches are the norm.

Unfortunately older people often experience difficulties accessing appropriate and timely health care across a range of health and lifestyle related needs[6]. Funding models contribute to silos across service systems and there is limited funding for collaboration and coordination. The lack of integration between the health and aged care systems can lead to increased hospital attendance and admissions, escalation of health concerns where there is not early intervention, and end-of-life journeys that are more difficult than they need to be.

The Queensland Government has an opportunity to lead an innovative response to address gaps at the health and aged care interface.

[5] *A matter of care: Australia's Aged Care Workforce Strategy*. 2014. pp. 88 – 95.
[6] *Ibid.* p. 7

3.7.1. Issues impacting the interface between health and aged care

In our experience, hospitals can be reluctant to accept admissions of older people due to anticipated extended lengths of stay. Older people can have longer lengths of stay in hospital while awaiting Aged Care Assessment Team assessments, residential aged care bed availability or the implementation of home supports to enable a safe and supported return home.

Treatment provided in hospitals generally focuses on acute issues, rather than considering the holistic and complex needs of older people. There is also a limited focus on wellness and re-ablement while a person is in hospital. A consequence of this is that older people often lose conditioning and ability, even during short hospital stays, impacting their wellbeing when they return to the community. The reason for this is care approaches are often siloed by organisation or profession and funding models do not support a multidisciplinary approach or provide adequate support for a re-ablement focus.

Involvement of aged care services in hospital discharge planning is limited and there is often a lack of good handover when a person transitions back to residential aged care or community services. There is no funding for this transition.

During hospital discharge planning, there is often an assumption that because there are nurses within the aged care system it will accept responsibility for providing and funding the ongoing health service needs of older people. Residential aged care services are not funded at the same level or in the same way as hospitals and consequently do not have the same level of specialised care staff regularly available. Residential aged care has an average cost of $254 per day[7], compared to an average cost of $2,000 per day in acute hospitals[8]. Research has also found that 45.1 percent of residential aged care facilities recorded a negative operating result for the 2018 financial year[9]. These resourcing levels have a number of implications when considering how funding levels impact care availability and how people transition between hospital and aged care. In the community, programs such as home care packages and the Commonwealth Home Support Program often end up sponsoring health needs by default.

Access to hospitals for older people in the aged care system can also be difficult due to geography and transport needs. People often have limited knowledge of patient transport services and rely on the aged care system for transport - and sometimes accompaniment - for medical appointments at hospitals. Funding in aged care does not support staff engaging in this activity.

[7] Aged Care Financing Authority. 2018. *Sixth report on the Funding and Financing of the Aged Care Sector*. Available at: agedcare.health.gov.au/reform/aged-care-financing-authority/2018-acfa-annual-report-on-funding-and-financing-of-the-aged-care-sector

[8] Independent Hospital Pricing Authority. 2018. *National Hospital Cost Data Collection Cost Report: Round 20 Financial Year 2015-16*. Available at: ihpa.gov.au/sites/g/files/net4186/f/publications/nhcdc_cost_report_round_20_financial_year_2015-16_0.pdf

[9] StuartBrown. 2018. *Aged Care Financial Performance Survey: Sector Report 2018 Financial Year*. Available at: stewartbrown.com.au/news-articles/26-aged-care/166-june-2018-aged-care-sector-reports-released

3.7.1.1. Mental health and behavioural support

The transition to aged care is a significant life stage change and requires attention to people's mental health. Yet access to state-based mental health services for older people is limited. Access to private psychologists and social workers to support older people is also limited by the availability of Medicare funding.

There can also be confusion around service pathways for people who have mental health issues and dementia. This can create problems around ensuring adequate and appropriate services and increases complexity of how care is managed. We have experienced that when someone receives a diagnosis of dementia, access to other mental health treatments and supports can reduce. This is inequitable and needs to be addressed.

We find the current system is also not flexible enough to respond well to older people who have aggressive behaviour. The safety of staff and other people in residential care facilities or the community must be paramount. However there may also need to be a therapeutic response to the person who is aggressive and it may require mental health expertise and interventions, additional training and hours for workers to assist in managing the condition and keeping people safe.

3.7.2. Options to improve the interface between health and aged care

Older Queenslanders are entitled to access the same services from the general health care system as the rest of the population. However, they frequently miss out due to assumptions that aged care funding can effectively provide a full range of health services. Aged care is not funded to provide acute health services and this inequity for older people must be addressed by the Queensland Government as a matter of urgency.

Strong commitment and action by all parties across the health and aged care systems to meet the needs of older people in a person-centred and consumer-directed way would create greater incentives for a common purpose. This will give better outcomes for older people and reduce the burden on hospitals if unnecessary admissions can be avoided. There is an opportunity for the Queensland Government to take a leadership approach to this work.

If properly resourced and supported with supplementary funding and capability by the broader health care system, aged care services have the skills, capacity and opportunity to reduce costly hospital admissions through both avoidance of hospital admissions and shortened lengths of stay. We support a least restrictive approach of 'right service, right time, right staff member' across the health and aged care systems. Providing this support at the interface between the hospital and the home is achieved is possible, and was demonstrated by Blue Care's Hospital in the Home program.

Case Study – Hospital In The Home

In 2014, Blue Care commenced delivery of the Hospital in the Home (HITH) Service for patients at a number of Queensland Health Hospital and Health Services. Since that time, more than 6,500 care recipients, of all ages, have received part of their hospital treatment at home with a HITH package of care. Without this service, these patients would have otherwise been in a hospital bed and treated as an inpatient in hospital. As part of this service, treatment is provided in a location of the patient's choice, mostly in their own home, or in a residential aged care facility.

The average age of people using Blue Care HITH is 57.3 years old and the median age is 56.4 years. The youngest person was 11 and the oldest 111 years old. Since 2014, 38% of Blue Care HITH patients were over the age of 65.

In 2016, the Blue Care HITH services achieved full accreditation under the National Safety and Quality Health Service Standards, including 6 'met with merits'. We were one of the first non-hospital based HITH to achieve accreditation under the National Standards and are currently accredited until May 2019.

Outcomes

The HITH is aimed at being a cost effective and safe alternative to in-hospital care and since its introduction in 2014, the service has saved more than 28,000 in hospital bed days.

We have found people generally prefer to be home and most patients (96%) are either very satisfied or satisfied receiving their hospital care at home. Following review, it was concluded that most patients would recommend this service to their family or friends.

There is great potential to expand these services into residential aged care with appropriate funding.

Recommendation 2

The Queensland Government acknowledge aged care funding constraints limit the role the sector can play in cross subsidising services to meet the health needs of older people and avoid hospitalisation.

Recommendation 3

The Queensland Government partner with the aged care sector to develop and implement a strategy to improve the interface between hospitals and aged care to meet the health needs of older people.

Actions to improve health responses to older Queenslanders should include:

- Shared commitment and action between health and aged care to meet older people's needs in a holistic and person-centred way. This should be supported by a clear partnership approach, formal delivery arrangements, and appropriate investment for health related services. These should include hospital avoidance, hospital in the home, transition care and palliative care services.
- A focus on wellness and reablement while at hospital to assist people retain fitness and stay as independent as long as possible.
- Greater availability of hospital in the home and transition care services, which can assist people to move out of hospital more quickly.
- Resources within hospitals for rapid assessment of older people living in residential aged care to avoid hospital ramping or admission if it is not needed. For example, the Geriatric Outreach Assessment Service and the CARE-PACT program.
- Ensuring that a diagnosis of dementia does not lead to older people's mental health needs going unaddressed by providing specialist mental health and dementia outreach services for older people in the community and residential aged care. This should include a focus on practice excellence and providing education and training to people working in both health and aged care.
- Additional training for registered nurses to provide some sub-acute care. However, this must be done in partnership with hospitals.
- Better information sharing, including access to discharge summaries and exploring a shared client record by linking My Health Record and My Aged Care with shared access to both systems.
- Building an understanding of the role of private hospitals in the system.

3.8. Using technology in aged care

This section responds to question 15 in the Committee's issues paper.

There is a significant opportunity to use technology to support person-centred care and continue improving outcomes for older people into the future. We support a contemporary approach to using technology to enhance service quality and advocate for changes to service delivery models to embrace technology use. This must be supported by strong workforce planning and support to introduce new models.

Blue Care has participated in a number of pilots using technology to improve care delivery, which have included telehealth, video conferencing and assistive technologies. All of these pilots produced positive outcomes for clients and led to some minor changes to our care model. Through this experience we have found that, while pilots of single devices and systems allow some improvements to be made, a broader adoption of integrated care technology and engagement with clients and team members at a whole of organisation level offers the greatest opportunity to improve outcomes for older people. Technology and innovation grants could support these kinds of projects to be implemented more broadly and achieve a greater impact.

There are opportunities to use technology to better support information sharing across health and aged care services. Access to a single client record that shares admission, discharge summaries and reports is critical to person-centred multidisciplinary care. The lack of a reliable single client record with consistent access for all stakeholders remains an ongoing barrier.

4. Palliative and end-of-life care

We believe all people should have access to high quality palliative care and support in the location of their choice. We support the Productivity Commission's finding that there is a mismatch between where people prefer to die and what support is available. In particular we note research showing 70 percent of people would prefer to die at home, but are unable to[10]. However, through our practice experience we also know that people's preferences for place of care and place of death vary and change over time. While some may prefer to die at home, others will prefer a hospice or hospital setting.

Ultimately, our health, aged, and community care systems need to be appropriately resourced and flexible so people are placed at the centre of care and are able to get support in the setting of their choice. This requires discussions about disease trajectory and people's needs and wishes to happen early. More work needs to be done so people wishing to die at home have the care they need, but we must also maintain and build on options for people who prefer a hospice or hospital setting. Doing this will help make sure people are offered dignity, choice and respect as they approach the end of their lives.

4.1. Current service delivery and meeting future demand

The following section presents information on use and demand of UnitingCare and Wesley Mission Queensland's palliative care services, responding to questions 17 to 20 in the Committee's issues paper.

4.1.1. Hospital inpatient specialist palliative care

Our inpatient palliative care service at The Wesley Hospital has approximately 800 admissions a year and has 15 to 35 patients at any given time. The inpatient unit at St Andrew's War Memorial Hospital is smaller and has between 2 and 10 patients at any given time. We take admissions from across Queensland and northern New South Wales with many people returning to regional centres or smaller towns on discharge.

Our patient numbers have grown at a rate of about 7 to10 percent a year over the last 10 years. This growth rate is now easing off at about 2 to 3 percent per year and we anticipate growth to continue at this rate over the next few years. We estimate about 30 percent of our patients will die in the hospital unit, with the rest being discharged to community or residential aged care.

Our inpatient palliative care services are only just able to meet patient demand at this time. Our hospitals do not provide direct community palliative care. This is done by referral to Queensland Health services or private providers such as Blue Care. Finding appropriate community care for our patients in the greater Brisbane area is difficult due to the level of funding received by community services, which limits their care offerings.

[10] Productivity Commission. 2017. *Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services*. Report No. 82. Canberra. Chapter 3: End-of-life care in Australia.

4.1.1.1. Responding to current and future demand

Private health insurers are starting to support community palliative care for their members. We believe better liaison or contractual arrangements with private funds would lead to better community palliative care and reduced admissions to both private and public hospitals. However, this approach will only meet the needs of people with private health insurance. In Queensland, 41.6 percent of people currently have private hospital cover and 48 percent have general treatment cover. These rates have been declining in recent years[11]. This highlights an ongoing role for the Queensland Government to fund or deliver palliative care services.

At a federal level, improvements in Medicare funding for GP home visits and new palliative care billing items would significantly improve in-community GP support and engagement with patients. This work could also be supported with additional state-funded community-based nursing and allied health support.

4.1.2. Specialist palliative care for children

Since opening in 2016, Hummingbird House has been actively involved with the care and support of over 200 families from across Queensland, with an average bed occupancy rate of 95%.

Funding constraints have limited capacity to 5 - 6 of the 8 guest-in-care overnight beds, with focus primarily on symptom management, extreme carer fatigue, and care at the end-of-life. Despite Hummingbird House having a state-wide remit, the majority of families who access our services are local to the south-east corner of Queensland.

In April 2017, Hummingbird House 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 family have been welcomed into the service by the team. This has seen families spend time with their newborn in a home-like environment, use the backyard and other areas to create memories and spend time together as a family, including with their pets.

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, with the mean score is 2-3 days (3 outliers of 9, 14 & 26 days)
- Average stay after the child's death if the child's death occurred at Hummingbird House – 3.75 days
- Average stay after the child's death if admitted after death - 4.15 days

[11] Australian Prudential Regulation Authority. 2019. *Private Health Insurance Membership and Coverage Statistics December 2018*. Available at: apra.gov.au/publications/private-health-insurance-membership-and-coverage

Based on the experiences of the other two Australian children's hospices, it was estimated that we would see around 15 deaths per year. Since opening in 2016, we have had the privilege of providing care at end-of-life for over 70 children, and supporting families (to December 31 2018). These have been either at Hummingbird House or in the community where we are the lead service for the family's bereavement and grief support.

4.1.2.1. Responding to current and future demand

There is an opportunity to increase children'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 inter-disciplinary 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, such as 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 Hummingbird House is clearly challenging, let alone supporting those who are not at risk of dying within the next 12 months.

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 an admission to an acute care facility. This results in marked increase in carer fatigue. This is evident in the marked change 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 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 tele-heath 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.

4.1.2.2. Client and community 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 is often a reluctance to enter into the conversation on a community level. 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, hope and wishes around their child's end-of-life and after death care.

When the child is approaching death, the option exists for them to be at home, in hospital or in a hospice, according to the family's wishes. This is in line with the principle of right service in the right place at the right time for children. It is preferable for children to be looked after in the hospital closest to their home and this can be achieved with support of health professionals and families locally. However, this is not always achievable for children with very complex needs.

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 a life–limiting condition, 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 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 Queensland Children's Hospital Paediatric Palliative Care Service team, will see an increase in resources and skills available to communities. A 'compassionate communities' 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.

4.1.3. Hospice Care

Hopewell Hospice is an 8 bed service located on the Gold Coast, funded primarily through private health funds with some state government funding and fundraising income to support uninsured residents. The service is usually at 80% occupancy, which is expected to continue. However, there is growing demand for hospice services from people who do not have private health insurance.

To support community-based services on the Gold Coast, Hopewell Hospice also offers a 24 hour overnight respite service to assist with the clients who wish to die at home. This is a

self-funded program, which is recognised as valuable by clients, non-government organisations and the Health and Hospital Service. However, external funding remains difficult to secure.

4.1.4. Community-based services – including residential aged care

Blue Care and Wesley Mission Queensland offer a range of multidisciplinary services in the community, including specialist nurse practitioners, clinical nurses, personal carers, allied health and pastoral care staff. When a person needs palliative care, we seek to provide it within our existing resources or where we are specifically funded to do so.

In a collaborative partnership with the Metro South Hospital and Health Service Palliative Care Service, Blue Care currently delivers the Wynnum-Manly Palliative Care Unit. This service delivers specialised palliative care services in the Wynnum-Manly area, strengthens our connections and contributes to people living in the local community. The service also builds on Blue Care's experience as a leading provider in person centred palliative care services.

This unit is the first of its kind operating within a residential service that is well known and established within the Wynnum area. The unit provides acute and hospice level care to people who are palliating from within the local community. This partnership involves the Blue Care providing the property and staff to operate the unit, with Metro South providing the clinical and medical support, governance and funding. This is truly a collaborative project with a model that is proving to be effective with very high patient and family satisfaction.

Blue Care also runs a 24 hour community based service with clinical nurses on call across the state to support clients and respond to acute symptom management should there be a need.

Currently, we are struggling to meet demand for services due to inconsistent and complex funding models across jurisdictions and a lack of appropriate resourcing within the system to meet people's needs in the community.

4.1.4.1. Residential aged care settings

Residential aged care services are not funded at the same level as hospitals and consequently do not have the same level of specialised care staff regularly available. As discussed by the Productivity Commission, funding for palliative care under the Aged Care Funding Instrument can only be accessed in the last week or days of a person's life[12]. In many cases, it is not viable to do a reassessment to access this funding and care is often provided without additional funds.

In the absence of additional funding, Blue Care and Wesley Mission Queensland provides support for residents through existing resources and by partnering and working closely with Queensland Health funded specialist palliative care teams. However, we can only do this when resources allow and where external funding is available for services in a particular area.

[12] Productivity Commission. 2017.

4.1.4.2. Responding to current and future demand

We are currently unable to meet demand for palliative care in some parts of Queensland due to inconsistent service models, funding gaps and changes to tendering arrangements.

Inconsistent service models

The current funding model supplying specialist palliative care services in Queensland distributes funding to Hospital and Health Services, who then direct how this is used. While this decentralised approach has benefits in addressing local need, it has also led to inconsistencies in how funding is directed to people's care in different parts of the state. For example, some Hospital and Health Service regions only focus support on the final six weeks of life, while others take a longer-term approach to providing care from the point of diagnosis. The latter approach is consistent with best practice in palliative care. This leads to inequitable service access across the state and within the South East corner.

Funding gaps

Funding gaps regularly arise when specialist palliative care models are focused into short timeframes at the end-of-life and have limited funding for allied health and other ancillary support. This leads to unmet needs that are also not met by other community support systems, such as the Commonwealth Home Support Program, which take a basic needs approach. In some instances there can be a heavy reliance on alternative programs when eligibility for services is stretched. In many cases, clients have to pay for their services, which can financially stretch families at the time of bereavement.

Current community-based aged care and disability funding does not generally cover palliative care as it is designed to improve capability and wellbeing for people to remain in community. People with terminal conditions do benefit from this approach, but need more support as their disease progresses. Despite this, these programs are frequently used to bridge the funding gap so people get the support they need. This is problematic if people are not already receiving Commonwealth care packages or funding, as applying for these often involves significant wait times for assessment and approvals (see section 3.4). This approach is not sustainable and this funding gap must be addressed to meet both current and future demand.

Tendering palliative care services

Blue Care is contracted by a number of Hospital and Health Services to provide specialist palliative care services. Tendering these services to not-for-profit organisations is a positive step towards providing responsive, holistic and cost effective community-based services. This is especially the case when community-based services already operate in local communities and have existing relationships with people who have palliative conditions. In these cases, resourcing agencies to respond creates strong continuity of care. The Queensland Government regularly tenders health and community services to non-government organisations, however there can be a lack of understanding of the value of this relationship within Queensland Health. Blue Care has previously experienced a sudden change in these arrangements, which has created a range of issues and distress for families in the Brisbane region. This included people struggling to access services due to delays from the My Aged Care process, frustrations with eligibility, and people continually being reassessed at multiple points within the system.

We believe there is significant value to be gained by Queensland Health when contracting specialist palliative care services to organisations such as Blue Care and Wesley Mission Queensland. When funded appropriately, community-based programs can operate flexibly to respond to people in their setting of choice, provide high quality care, and deliver comparable outcomes to publically funded services. Community-based services also operate more cost effectively than government services. However, it is important that tendering processes value the contributions of community organisations and have strong transition mechanisms in place if contracts change.

4.2. Improving experiences for people and families

The following section responds to question 21 of the Committee's issues paper.

While there are a range of challenges impacting people's experiences across the palliative care system, the most common issue to be addressed to improve experience is lack of funding and resources to meet current and future demand. Addressing funding and resourcing issues should be a primary consideration of State and Commonwealth governments as each has a responsibility for different aspects of palliative care.

4.2.1. Specialist palliative care for children

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 child and family centred care 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.

A major shortfall currently exists in the provision of a state-wide children's palliative care 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 Paediatric Palliative Care Service, 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.

4.3. Challenges in regional and remote communities

The following section responds to question 22 of the Committee's issues paper.

Outside of South East Queensland and major regional cities people have limited access to specialist palliative care. This is can be a problem when a patient returns home with a modest life expectancy, months, but may require specialised medications to manage pain or other symptoms. However, end-of-life care can be done very well with the support of a well-

educated community nursing team and a capable GP. This is supported by technology, such as teleconferencing, which allows services to attend to remote clients.

4.3.1. Providing palliative care for children

The total land mass of Queensland covers 22.5 percent of the Australian continent, an area of 1,730,648km^2. The other two children's hospices are in Victoria (with an area of 227,594 km²), and New South Wales (with an area of 809,444 km^2) respectively. 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. Key geographical areas such as central, northern and western Queensland would be well suited to a Hummingbird House presence both within the local regional health facility and community support organisations. Consideration around what this looks like is part of an ongoing project developing the model of care for the state-wide arm of Hummingbird House. This would see a more community-focussed responsive service for families who live outside metropolitan areas.

As stated previously, Hummingbird House has a state-wide remit. In order for Hummingbird House to meet the needs of Queensland families across approx. 1.8 million square kilometres a hub-and-spoke design is used. 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 use and develop capacity within existing networks, rather than unnecessary duplication of service.

Hummingbird House 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 effective, 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.

4.4. Challenges delivering services to Aboriginal and Torres Strait Islander Communities

The following section responds to question 23 of the Committee's issues paper.

4.4.1. Providing palliative care for children

Hummingbird House has provided care for babies, children, and young people who identify as Aboriginal and Torres Strait Islander, 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 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 Hummingbird House is asked to provide with regards to children. Although the 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 Hummingbird House is increasing awareness of our service within regional, rural, and remote Aboriginal and Torres Strait Islander communities. Currently, we are working with local advisory groups to enhance and refine our model of care, which will see us liaising with key stakeholders to understand 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 our services. Hummingbird House would welcome an opportunity to rectify the current dearth of research knowledge around this area.

4.5. Priorities for the future

The following section responds to question 24 of the Committee's issues paper.

Providing high quality palliative care services focused on dignity, choice and respect must be the primary goal when responding to future demand for palliative care services.

4.5.1. Providing care in people's settings of choice

High quality specialist palliative care and support should be available to people regardless of their location and should offer choice wherever possible.

We support the Productivity Commission's recommendation that State and Territory governments increase availability of community-based palliative care so people with a preference to die at home are able to do so[13], whether that home is in the community or a residential facility.

We consider people in aged care as having the same right to access state based health services as all other Queenslanders. While it is often considered aged care funding will cover people's palliative support needs, this is not the case and the State needs to address access for this client group. Residential aged care facilities are very willing to work in partnership to develop sustainable service and funding arrangements.

Technology to support care should be a part of any future models.

[13] Productivity Commission. 2017.

4.5.2. Growing the availability of hospice care

Consideration must be given to increasing the availability of hospice care. This could be funded privately, publicly, or jointly. Hospices provide a safe, well-resourced place of care which meets the needs of people who do not have family or carers, whose carers cannot support them, and those who prefer someone else to care for them.

Emerging contemporary residential care models based on household or cottage approaches may also be able to support hospice-type arrangements. In these models, smaller areas can be allocated according to people's needs and services are often close to their local community. These should also be considered in assessments for meeting future need.

Recommendation 4

The Queensland Government produce financial models for funding new community-based hospices that draw upon public, private or mixed funding models.

4.5.3. Providing care for children

Hummingbird House identifies research, funding, increasing complexity of needs and care after death as key priorities for the future.

Understanding impact - subjective wellbeing

Hummingbird House is a community palliative care service. As such, the care we provide is not limited to "in-house" 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' – Hummingbird House 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 in a UK setting from 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 Hummingbird House, and we are committed to documenting this through published research.

We are beginning to work in partnership with the Health Economist to develop a tool that can measure the efficacy of the work we do with families and children. An overall measure of subjective well-being 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 Hummingbird House services throughout the time a child and family engages with us. This allows the overall quality of care to be determined and valued according to its direct effect on families' lives.

Subjective wellbeing has a demonstrated effect on outcomes at all stages of the treatment experience and improved health and quality outcomes are shown to consistently enhance subjective wellbeing. Furthermore, subjective wellbeing 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 regard to service creation and funding. It was initially anticipated that Hummingbird House would cost $3.2 million to operate, however our current operating cost for 5/6 beds 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 our services since Hummingbird House 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 fundraise $2.4 million every year, to operate as a free service to Queensland families. It is vital to the forward planning of our service delivery that there is certainty around funding that ensures we can meet our potential and remit.

However, Hummingbird House 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 under development. These coupled with a strong community base from which to draw support and philanthropy will combine to comprise the necessary funds to operate Hummingbird House.

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 Hummingbird House will be eligible for funding packages to support the various services we offer. This will see Hummingbird House moving to having two 'NDIS-funded' beds available for families to book as part of their care packages. Respite packages can be delivered either in-home or within Hummingbird House. Only children who meet our eligibility criteria can access care packages Hummingbird House. This will see us having a stream of income derived from NDIS.

As we are a private licensed health care facility, we have 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 Hummingbird House, and some allied health services are also eligible for Medicare rebate. As we do not undertake procedures, Medicare funding is limited to a finite list of item numbers.

Second tier default benefit is a safety net for Hummingbird House as we have demonstrated compliance with a range of quality and service criteria. This is in place until a contract is in place 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 differently than we thought it would?

Whilst the service Hummingbird House provides bears some resemblance to the service that was originally conceptualised and funded, we have a different model of care to the other children's hospices in Australia. Hummingbird House 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 things we have experienced, which were not anticipated in the first 3 years of operations include:

- Guests have increasing acuity, often being transferred directly from paediatric or neonatal intensive care units;
- 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 Neonatal Intensive Care 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 Queensland Children's Hospital 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 Clinical Skills and Capability Framework; and
- Approximately 25 percent[14] of Hummingbird House 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 the Department's guardianship or in foster care.

Learnings

Business as imagined saw Hummingbird House 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, the team delivers a higher level of complex care than either of the other two children's hospices in Australia, particularly in the area of care after death. This is in part because Hummingbird House has strong links with Queensland Children's Hospital.

[14] 2016 – 2018 Hummingbird House admission data

Hummingbird House 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 we work with, as these guests are likely to die within hours, days or weeks of referral. Other guests are referred to Hummingbird House as we can provide expert care for children with complex needs in their homes or onsite.

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 Hummingbird House to deliver this care but at a more manageable cost. In addition, a Family Support Manager guides and leads staff in providing apt, culturally appropriate and holistic care after death to children and families.

Care after death is emerging as a specialty for Hummingbird House. 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 on-hand support.

4.5.4. The role of nurse practitioners in specialist palliative care

In responding to trends in aged care, we have been supporting our staff to build their palliative care skills and regularly work with state-funded specialist palliative care teams. We have also begun introducing nurse practitioners to our care teams, who have advanced clinical skills in palliative care and can work with GPs to manage complex symptoms and support client and family wishes for ongoing care. Nurse practitioners can also work across community and residential services.

As Blue Care were trialling the nurse practitioner in our home service team, they wrote more than 200 scripts for 75 percent of clients and placed 9 pathology orders. This saved clients 92 visits to their GP and reduced waiting times for scripts from GPs. Two family members also provided feedback that because our nurse practitioner was able to visit at short notice in a crisis, they have not called an ambulance. Almost 80 percent of people reviewed by the nurse practitioner were supported to die at home rather than in hospital.

We believe that consistent funding models supporting an increased role for nurse practitioners in palliative care teams is a significant opportunity to improve care for end-of-life care for people in residential aged care settings.

Recommendation 5

The Queensland Government provide consistent funding levels for nurse practitioners in specialist palliative care responses.

4.5.5. Removing time limits in community palliative care services

Time-limited funding of specialist palliative care services creates gaps across the whole system. To meet future demand, funding for expanded early intervention, community-based, multidisciplinary specialist teams must be considered. This should include guidelines to ensure each Hospital and Health Service region provides access to care following people's diagnosis and removes reliance on Commonwealth programs not designed to meet these needs.

4.5.6. Exploring an individualised funding approach

There is scope to consider an individualised funding model when examining different funding models for palliative care. This approach would be consistent with consumer-directed care approaches in the broader aged care and disability sectors, and would allow people to access care from qualified providers in settings of their choice.

4.5.7. Expanding the role of community-based providers

Blue Care, Wesley Mission Queensland and other community-based palliative care providers have built a strong reputation for delivering high quality care. The Queensland Government has a long history of contracting services to not-for-profit services which are responsive to their local communities, can provide continuity of care, and have strong governance and accountability frameworks. In this context, expanding the role of community-based providers develops a model of working together and resourcing support so people have access to excellent palliative care in their place of choice.

Recommendation 6

Queensland Health and Hospital and Health Services partner with community-based providers, and in the absence of an individualised funding model, invest in them to deliver palliative care services to the community.

4.5.8. Integrating spiritual and pastoral care into palliative care

Spiritual and pastoral care is fundamental to the delivery of high quality person centred care. Whether a person affiliates with a religious tradition or not, they have spiritual care needs. We believe an approach that incorporates spiritual care holistically into our teams and services will deliver the best outcomes for the people and communities we work with.

We define spiritual care as responding to the fundamental human need for meaning, purpose and deep relationships. These relationships include those with other people, self, those with creation, with the sacred or God. Spiritual care is offered to every person regardless of beliefs. It may include faith-specific support, exploring questions of meaning and purpose, enhancing relationships, reconciliation and healing, finding meaning and purpose in life stories, rites, rituals, mindfulness, meditation or prayer to enable people to experience life in all its fullness.

Research increasingly demonstrates the importance of spiritual and pastoral care in health and aged care settings. This type of care plays a role in reducing distress and enhancing a person's ability to cope with illness and positively respond to changing life circumstances.[15] Care that values spiritual elements such as faith, hope, meaning making, compassion and connections has been shown to promote health and quality of life.

[15] Boero, M.E., Caviglia, M. L., Monteverdi, R., Braida, V., Fabello, M., & Zorzella, L. M. 2005. 'Spirituality of Health Workers: A Descriptive Study.' *International Journal of Nursing Studies* 42:8: 915-921.; Carr, T. 2008. 'Mapping the Processes and Qualities of Spiritual Nursing Care.' *Qualitative Health Research* 18:5: 686-700.

> Illnesses are deeply meaningful events within people's lives, events that often challenge people to think about their lives quite differently. Spirituality sits at the heart of such experiences. A person's spirituality, whether religious or non-religious, provides belief structures and ways of coping through which people begin to rebuild and make sense of their lives in times of trauma and distress.[16]

An important part of spiritual and pastoral care in palliative care is working towards dying well. Dying well is about working through issues of the meaning of life, legacy, restoring relationships, and preparing emotionally and spiritually to be at peace with dying. This is important for people as well as their caregivers and families. The importance of spiritual care at the end-of-life is reflected by its inclusion in the *National Consensus Statement: Essential Elements for Safe and High-Quality End-of-Life Care*, developed by the Australian Commission on Safety and Quality in Health Care[17].

Recommendation 7

Any government delivered or funded specialist palliative care services be adequately resourced to identify and respond to people's spiritual needs, particularly in the context of bereavement care for both adults and children.

[16] Swinton, J. In Cobb M (Ed). 2015. *The Hospital Chaplain's Handbook*. Norwich: Canterbury Press.
[17] Australian Commission on Safety and Quality in Health Care. 2015. *National Consensus Statement: essential elements for safe and high-quality end-of-life care*. Sydney: ACSQHC.

5. Voluntary assisted dying

5.1. Legalising voluntary assisted dying

The following section responds to question 25 of the Committee's issues paper.

The Uniting Church in Australia Queensland Synod's position is that voluntary assisted dying presents substantial moral problems and we are opposed to it being legalised in Queensland.

From the perspective of the Uniting Church, the key question for voluntary assisted dying is around balancing individual autonomy and social consequences. Our view is that in the case of voluntary assisted dying, the social consequences outweigh individual autonomy. There is a serious risk that the adoption of voluntary assisted dying in Queensland will diminish the sanctity of life. There is also the threat that voluntary assisted dying will place undue pressure on medical practitioners to participate in these acts, which goes against their belief of 'do no harm'. Ultimately, the impact to the core foundation of society from intentionally ending a life and devaluing the sanctity of life, presents too much of a risk for this to be allowed in Queensland.

The Uniting Church supports the following:

- The critical importance of high quality, well-resourced and accessible palliative and end-of-life care that responds to the physical, psycho-social and spiritual needs of people at the end-of-life. There is strong concern about the provision of these services especially in regional and remote Queensland (see Section 4).
- Having a well-resourced and flexible system of palliative and end-of-life care that consistently meets people's needs and preferences for care.
- If legalised, provisions for conscientious objection for both individuals and organisations be included in any legislation developed for voluntary assisted dying in Queensland.

While we do not support voluntary assisted dying, if it is legislated the Uniting Church is committed to offering a compassionate and pastoral response to people and families who choose this path.

Recommendation 8

That voluntary assisted dying not be legalised in Queensland

5.1.1. Theological rationale

We are committed to working towards a society characterised by love, compassion, justice, inclusion and reconciliation so that all people, at every stage of life, can experience 'life in all its fullness' (John 10.10). In our life as the Christian community, we seek to witness to and advocate for the sanctity of all life. Christianity is a life-affirming faith; meaning that all life has intrinsic dignity, worth and value. The promotion of the good in society requires that the sanctity of life is upheld, respected and not diminished in any way. The 'good' in society is measured and promoted by the way this value is maintained and especially the way it is

expressed in our treatment of the most vulnerable in society. This is all potentially undermined if voluntary assisted dying is allowed in Queensland.

The Christian faith understands human beings as made in the image of God, and this is understood to mean that we are fundamentally relational, i.e. we are made for community. Any decision an individual makes has the potential to impact upon other people, the shape of community and ultimately the broader society. No person is 'an island', rather, we are inextricably related to each other. It is critical that we balance individual decision making and responsibility within the context of a wider set of relationships and the larger societal implications. Voluntary assisted dying is not simply an individual matter but impacts upon the wider society. The interest of an individual cannot be neatly separated from the interest of the whole society, or indeed the interests of their family, friends and community. Arguments for voluntary assisted dying based on individual rights must be examined in light of the social impacts of these decisions.

In a society shaped by this understanding of our humanity, it is critical that the sick, suffering and dying do not feel as if they are a 'burden' to others or to the broader society. From a Christian perspective, the compassionate service of the aged, sick, suffering and vulnerable is a great gift and privilege. As we love and serve others, we are witnessing to the image of God revealed in Jesus Christ. This ultimately should be understood as enabling the full expression of our humanity, rather than as a burden placed upon us. However, the feeling of 'burden' is often experienced by people as they age and need care. Data from Oregon tells us that fear of being a burden is one motivating factor for people to seek voluntary assisted dying[18]. This is the risk of allowing voluntary assisted dying in Queensland. Regardless of the safeguards put in place, we fear that vulnerable people may be subtly pressured into feeling that they are a burden to their family or the wider society and see voluntary assisted dying as a way of removing this 'burden'. It is also very difficult to ensure the 'voluntary' nature of any decision given the multiple complex factors in a person's decision making process to end their life.

The Uniting Church understands that human dignity stems from the belief that we are created by God. Locating human dignity in our 'createdness' means our worth is intrinsic and our dignity is underwritten by a reality that is untouched by the circumstances of our lives. This idea critiques the human impulse to associate lesser or greater dignity with particular circumstances i.e. an extrinsic sense of worth. Our understanding of what 'dying with dignity' means is grounded in this account of human dignity. We reject the notion that voluntary assisted dying means 'dying with dignity' and see the alternative to be high quality end-of-life and palliative care.

The Uniting Church is committed to offering a compassionate and pastoral response to people at the end-of-life. Part of the Christian faith is that all people deserve compassionate care, and this is especially important in their sickness, disability, suffering and end-of-life. Sickness, suffering and death is a human reality. Yet it is important to acknowledge that there are circumstances in which we can understand the call to 'end life' and to 'end this suffering'. We are called to accompany people compassionately in these circumstances and to relieve suffering as far as possible. Why am I suffering? Where is God in our suffering? These are profound questions for those who are in the midst of pain and suffering. We must

[18] Public Health Division Centre for Health Statistics. 2018. *Oregon Death with Dignity Act 2017 Data Summary*: Oregon Health Authority.

avoid neat and simple answers to questions like these. Moreover, these should not be dismissed by us and we should not judge this cry of lament.

Compassionate care is about remaining with people, in both lament and hope. It is critical that we do not devalue a human life as not worth living because of external circumstances, while doing all that we can to alleviate suffering and to offer physical, psycho-social and spiritual support. An understanding of compassion as solely concerned with the relief of suffering is premised on the utilitarian pursuit of optimal happiness. Whereas a Christian account of the good is more comprehensive than the absence of pain and suffering in the present, and includes a hope in eternal life, a belief that God will sustain us in the midst of difficult life circumstances and a vision for a flourishing society in which all people experience life in all its fullness.

5.2. Defining voluntary assisted dying

The following section responds to question 26 of the Committee's issues paper.

Terminology for voluntary assisted dying has changed over time and varies across the world. Terms are often based on what is defined in legislation, which also reflects the terms in use when voluntary assisted dying was debated in communities.

The term 'euthanasia' has become complicated with many permutations including voluntary active, involuntary active, voluntary passive and involuntary passive. It can be difficult to be precise on which form of euthanasia is being discussed and what this means. It also has strong emotional and ethical connotations and this can reduce engagement with the complicated human experiences around the end-of-life.

The phrase 'physician assisted suicide' is also not recommended. Using the language of 'suicide' can also obscure the complicated human experiences around the end-of-life. It also has the risk of triggering unhelpful conversations that could be distressing to some people.

The language that is mostly used in Australia, at this time, is 'voluntary assisted dying'. In Australia, the debate tends to be focused on the ending of a life, either by a doctor or the person themselves, with the consent of the person who has decision making capacity. We are concerned about the potential for people to be coerced in their decision making and about the nature of 'voluntary' around this issue. For this reason, we suggest the use of the term 'physician assisted dying'.

Recommendation 9

The following definitions are adopted by the Committee:

Term	Definition	Other Common Terms
Physician assisted dying	A doctor or other person provides drugs, at the request of a person with decision making capacity, which a person can take themselves to intentionally end their life.	**Voluntary assisted suicide**
	A doctor or other person intentionally hastens death, at the request of a person with decision making capacity, by administering a substance to end their life.	**Euthanasia** **Active voluntary euthanasia** **Voluntary euthanasia**
Ending a life without explicit request	A doctor or another person administers a medication or performs another action to intentionally end life, either without a mentally competent person's request or the person is non-competent and unable to make a request.	**Non-voluntary euthanasia** **Involuntary euthanasia**
Withdrawal of treatments	Withholding or withdrawing overly burdensome medical treatment from a person because of medical futility, non-beneficial care, or at the request of a competent person or a person without decision making capacity's surrogate decision maker. The intention of this is not to hasten death, but to provide comfort care.	**Refusal of treatment** **Limiting of life-sustaining treatments**
Providing pain medication to relieve suffering	Doctors provide pain medication to people with the intention to relieve their suffering. Depending on a person's condition, this may hasten death, but the primary purpose is to provide comfort and relieve suffering.	
Advanced health directive	A written instruction, describing the medical care a person wants if they become unable to make or communicate their own health care decisions. The laws governing these vary between States and Territories and can be complex.	
Palliative care	Palliative care is an approach that improves the quality of life of patients and their families facing a life threatening illness. Relief and prevention of suffering occurs through early identification and thorough assessment and treatment of pain and other physical, psychosocial and spiritual concerns.	

5.3. Impacts of voluntary assisted dying on health practitioners and the workforce

The following section responds to question 27 of the Committee's issues paper.

While we cannot comment on behalf of specific professions, our agencies' experience in delivering health, aged care and palliative care services highlights a number of concerns for professionals who work on the frontline caring for people who are dying:

- The views of health, nursing, allied health, and chaplaincy practitioners vary.
- Legalisation of voluntary assisted dying could create significant ethical conflict for medical staff who are trained to focus on treatment and preserving life.
- Staff may feel conflicted between their personal values and their need and desire to treat and care for a person who chooses to access voluntary assisted dying.
- The potential psychological and emotional impact on medical practitioners who perform voluntary assisted dying, and any other care staff who may be present and how these will be managed.

5.4. Features of a voluntary assisted dying scheme if legalised

While the Synod does not support the legalisation of voluntary assisted dying, if legislation were to be introduced in Queensland we strongly recommend it include the following provisions around eligibility, safeguards and conscientious objection.

5.4.1. Eligibility

The following section responds to questions 30, 31 and 32 in the Committee's issues paper.

To access voluntary assisted dying, we recommend a person must:

- Be aged 18 years or more.
- Have decision-making capacity at ***all stages*** of the process.
- Be diagnosed with a disease, illness or medical condition that is:
    - incurable.
    - advanced, progressive and is expected to cause death within weeks or months, not exceeding 6 months.
    - physical pain that is unrelievable and considered intolerable for the person and that cannot be relieved from high quality palliative care.
- Persons should not be eligible to access voluntary assisted dying only because they are diagnosed with a mental illness or a disability.

The scheme should be limited to those aged over 18 who have decision making capacity. This is consistent with the law regarding children and end-of-life decision making as it currently stands in Australia. Current law identifies a child is a person below 18 years of age in every State and Territory except South Australia, which allows young people from 16 years of age to make decisions about their medical treatment as an adult. This is also consistent with the broader social view of adult decision making capacity.

5.4.2. Safeguards

The following section responds to questions 28, 29, 33 and 34 of the Committee's issues paper

Any legislation relating to voluntary assisted dying must include the following safeguards:

- A person must have decision making capacity at ***all stages*** of the process.
- Psychiatric or relevant specialist assessment should be used to verify a person's decision-making capacity and ensure their choice is voluntary.
- The application process includes verification from two medical practitioners.
- A counselling service, as part of a multidisciplinary team, should be a compulsory part of the assessment process.
- The length of time for the application process allows people to have as many opportunities to consider their decision, receive palliative care and process the complex array of emotions and grief experienced by the individual, and their families and friends. This could include a minimum of two weeks, between completing the application process to access voluntary assisted dying, and the final administering or prescribing of the relevant substance.
- Registered health practitioners, other health care staff, and organisations can conscientiously object to participate in voluntary assisted dying.
- Organisations can conscientiously object to performing voluntary assisted dying.
- Workforce planning, including resources for additional workplace support to manage the psychological impact of voluntary assisted dying on health and care staff.
- Universal access to palliative care, especially in regional and remote areas of Queensland.

5.4.2.1. Drawing from the Victorian legislation

Any legislation relating to voluntary assisted dying in Queensland should draw from the Victorian legislation and what is learnt as it is implemented. The Victorian scheme is comprehensive and could be explored, modified and built upon. The Application and Review Process and the features of the process for the first assessment and the information given to the person is helpful. This includes the following important features:

> (1) 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 the following matters—
>
> (a) the person's diagnosis and prognosis;
>
> (b) the treatment options available to the person and the likely outcomes of that treatment;
>
> (c) palliative care options available to the person and the likely outcomes of that care;
>
> (d) the potential risks of taking a poison or controlled substance or a drug of dependence likely to be prescribed under this Act for the purposes of causing the person's death;
>
> (e) that the expected outcome of taking a poison or controlled substance or a drug of dependence referred to in paragraph (d) is death;

(f) that the person may decide at any time not to continue the request and assessment process.

(*Voluntary Assisted Dying Act (Vic) 2017,* Section 19)

Research from overseas schemes indicates that decision making regarding voluntary assisted dying is complex and includes a range of factors other than the experience of physical pain[19]. It is therefore important to broaden any medical or physical assessment tool to include psycho-social and spiritual considerations. Moreover, the Victorian assessment process could be strengthened by including compulsory counselling to explore holistic considerations for the person and a psychiatric or other specialist verification of the 'voluntary' nature a person's decision to access voluntary assisted dying.

Another aspect of the Victorian scheme that is worthy of consideration is the Voluntary Assisted Dying Review Board. This Board has the following functions:

(a) to monitor matters related to voluntary assisted dying;

(b) to review the exercise of any function or power under this Act;

(c) to provide reports to each House of the Parliament on the operation of this Act and any recommendations for the improvement of voluntary assisted dying;

(d) to promote compliance with the requirements of this Act by the provision of information in respect of voluntary assisted dying to registered health practitioners and members of the community;

(e) to refer any issue identified by the Board in relation to voluntary assisted dying that is relevant to the following persons or bodies—

(i) the Chief Commissioner of Police;

(ii) the Registrar;

(iii) the Secretary.

(*Voluntary Assisted Dying Act (Vic) 2017,* Section 93)

The representatives of the Board could be enhanced by the inclusion of a broad range of stakeholders including cultural and religious representation to ensure that the Board monitors the broad range of issues around voluntary assisted dying. The terms of the Board could be expanded to include psycho-social and spiritual considerations.

Finally, the conscientious objection provisions in the Victorian scheme are also worthy of consideration. It could be strengthened with provision for organisation's to conscientiously objection.

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;

(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;

[19] Hendry M, Pasterfield D, Lewis R, Carter B, Hodgson D, Wilkinson C. Why do we want the right to die? A systematic review of the international literature on the views of patients, carers and the public on assisted dying. *Palliative Medicine.* 2012;27(1):13-26.

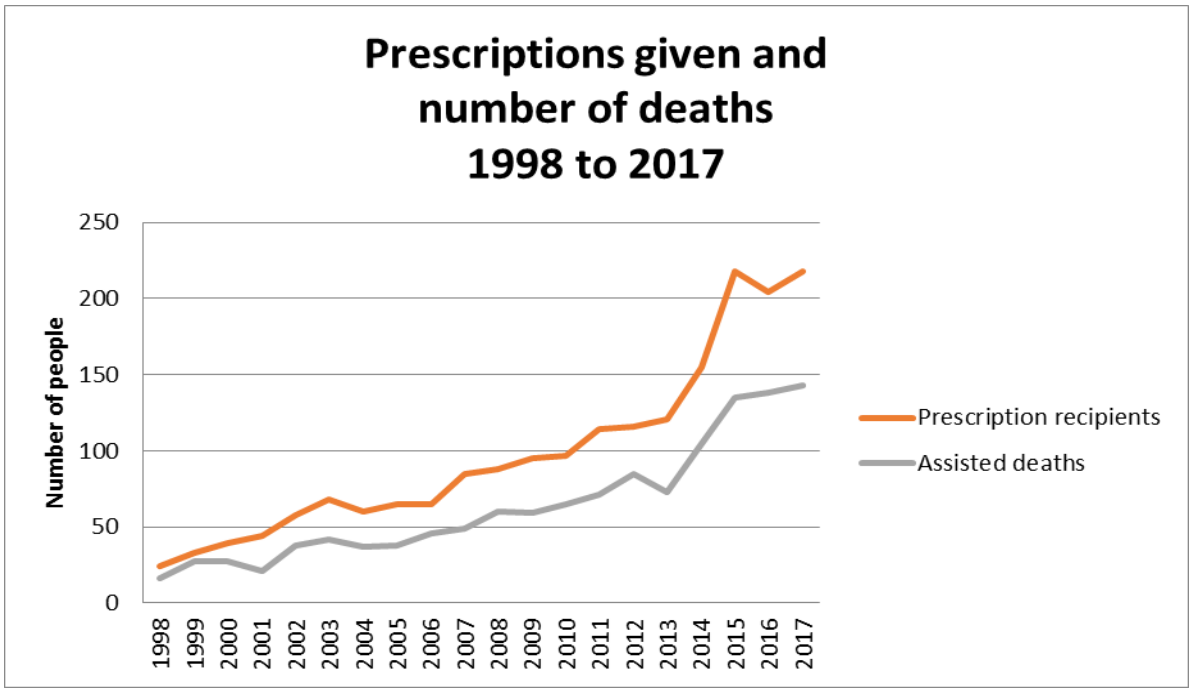
(f) to dispense a prescription for a voluntary assisted dying substance.'

(*Voluntary Assisted Dying Act (Vic) 2017,* Section 7)

5.4.3. Access to counselling services to provide psychosocial and spiritual support

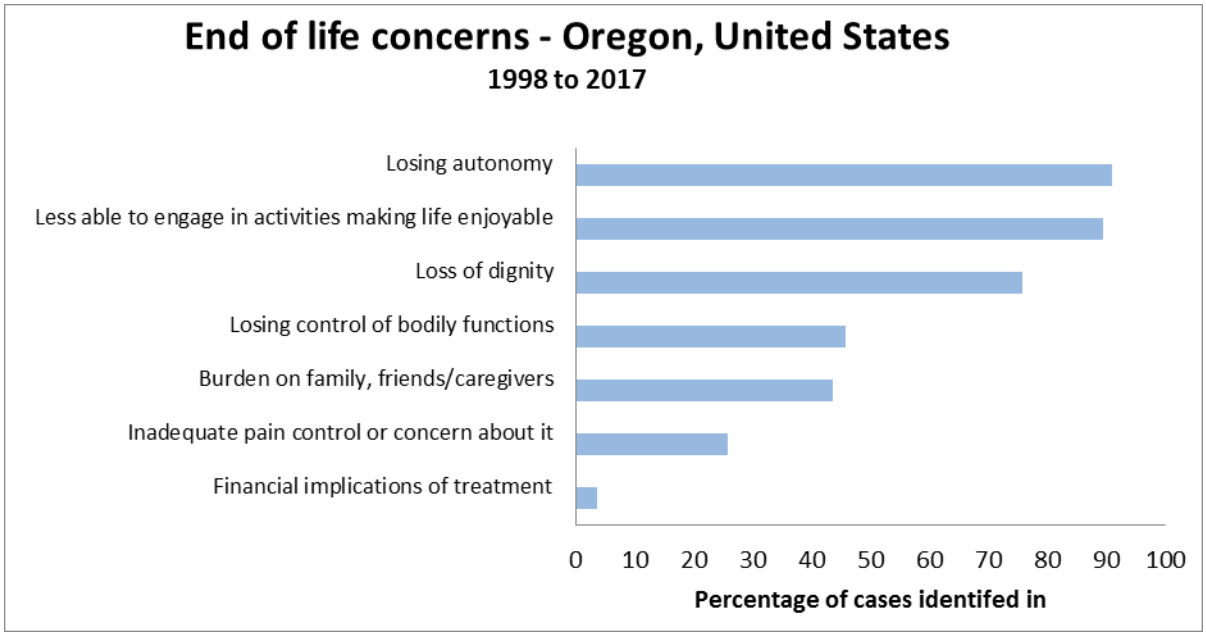
The following section responds to questions 35 and 36 of the Committee's Issues Paper.

Research indicates that the reasons for a person choosing to access voluntary assisted dying are multifaceted and complex, and not simply about physical pain[20] [21]. There is also a significant gap between those who are prescribed the relevant substance for voluntary assisted dying and those who try to take it.



Source: Oregon Health Authority 2018[22]

[20] Emanuel EJ, Onwuteaka-Philipsen BD, Urwin JW, Cohen J. Attitudes and practices of euthanasia and physician-assisted suicide in the United States, Canada and Europe. *JAMA.* 2016;316(1):79-90.
[21] Hendry M et al. (2012).
[22] Public Health Division Centre for Health Statistics. *Oregon Death with Dignity Act 2017 Data Summary*: Oregon Health Authority; 2018.



Source: Oregon Health Authority 2018[23]

A counselling service should be a compulsory part of the assessment process exploring a range of motivations and issues associated with the decision to access voluntary assisted dying and its consequences. This service could also embed a variety of support processes, delivered by a multidisciplinary team, which responds to the physical, psycho-social and spiritual needs of people, families and staff.

Creating adequate time between completing the application process to access voluntary assisted dying and the final administering or prescribing of the relevant substance is also important to support the person, family and friends through the ending of life process.

Having options around the locations where voluntary assisted dying can occur would also respect the choices of the person accessing voluntary assisted dying as well as their social, cultural, religious, and spiritual backgrounds.

5.4.4. Conscientious objection

The following section responds to questions 37 and 38 of the Committee's Issues Paper.

Conscientious objection is critical for both individuals and organisations based on their values, mission and beliefs. Voluntary assisted dying is a matter of conscience and no person should be forced to participate in ending a life.

Performing voluntary assisted dying is not a medical emergency circumstance that would result in harm if immediate action is not undertaken. Given the gravity of the act, the potential conflicts arising within personal and professional ethics, and the potential for psychological impacts on staff involved, it is important people can conscientiously object based on their beliefs and values.

[23] Ibid.

Recommendation 10

If voluntary assisted dying is legalised, the conscientious objection provisions in the Victorian scheme, including capacity for organisations to conscientiously object, should be adopted.

> '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;
>
> (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.'
>
> (*Voluntary Assisted Dying Act (Vic) 2017,* Section 7)

If a practitioner holds a conscientious objection to voluntary assisted dying, they should not be legally required to refer a patient on.

We are aware of the potential problem of limited access to medical practitioners in rural and remote Queensland. This could also be a problem for those who hold a conscientious objection but have no other local medical practitioners to refer to who does not also hold an objection to voluntary assisted dying. However, compulsory referral has the potential to place an individual in conflict with their conscience regarding voluntary assisted dying. There is no medical emergency that would result in immediate harm if voluntary assisted dying is not administered urgently. Respecting the beliefs and values of a medical practitioner to not be involved in any way with voluntary assisted dying, including the referral process, is a fundamental right that needs to be protected.

If voluntary assisted dying is legalised in Queensland, we believe it should be the responsibility of the State Government to ensure the community is well-informed and can access voluntary assisted dying if they choose.

6. Conclusion

The Uniting Church in Australia Queensland Synod has welcomed the opportunity to contribute to the community discussions around these important topics, and thank the Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee for the opportunity to do so.

The Synod, UnitingCare and Wesley Mission Queensland would welcome future opportunities to discuss this submission in person as well as looking at opportunities to work with government to improve outcomes for older Queenslanders and people at the end-of-life.

7. Appendix I – Hummingbird House Model of Care

Aims of Hummingbird House

Hummingbird House (HH) exists to complement other services that support children with a life limiting condition and their families, contributing to the comprehensive provision of state wide paediatric palliative care. We also aim to significantly enhance the holistic wellbeing of children living with a life limiting condition and their families. The initial services provided at Hummingbird House focus on improving access to specialist respite care, enhancing symptom management and increasing choices for families in relation to end-of-life care within the facility based at Chermside.

Through collaboration and an evolving and responsive model of family-focused, child-centred 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; through developing caring, supportive and long-lasting relationships.

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.

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 family-focussed, child-centred care means that a significant investment is made into the time staff spend assessing and managing family needs, and understanding their hopes and wishes. Hummingbird House has always promoted care of the entire family as opposed to just the child.

This model of care ensures that the family is constructed as a whole. Whoever is important to the child is important to HH. This extends into the area of care after death too. 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 make meaning, ritual and ceremony around their child's 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 stay 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 predominate 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-focussed, 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 who all 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, in the context of limited possibility of staff having previous exposure to the field. Therefore HH performance criteria do not align with

those typically adopted by hospitals which focus on intensive treatment and cure, rather its focus is on quality of a life. 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 come from a variety of sources including the child's lead clinician, PPSC, other paediatric specialties, GPs, allied health care workers and families. Referrals can be made by anyone involved in the care of the child - medical professionals, social workers, case workers or the family themselves.

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 be 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
- Symptom Management
- End-of-life Care
- After Death Care

12 April 2018

The Honourable Mr Aaron Harper
Chair
Health, Communities, Disability Services and Domestic and
Family Violence and Prevention Committee
Queensland Parliament QLD 4000

Dear Mr Harper

Queensland inquiry into aged care, end-of-life and palliative care and voluntary assisted dying

I am very pleased to offer this inquiry submission as Chief Executive Officer of The Karuna Hospice Service Ltd.

Karuna is a registered charity providing no cost, in-home palliative care services to help terminally ill people live well and die peacefully. Our broader aim is to transform the way we as a community consider and experience death, understand what palliative care is and how it can in fact, transform lives.

Many families within the Karuna community have openly expressed to me how profoundly moved they were by the holistic palliative care we offered to support their loved ones. Palliative care made their sons, daughters, husbands, wives and parent's death a peaceful and life affirming experience for them.

One recent example is the young mother of two primary school aged children in our care for approximately four weeks before dying peacefully of a cancer related illness, at home with her children and husband by her side. Karuna provided no-cost specialist palliative nursing on call, twenty four hours a day, and seven days a week. As we offer a holistic service, Karuna also supported the family with:

- Counselling for both parents and specialist paediatric counselling for the children.
- Spiritual care for the parents.
- A chance to use the time they had to prepare a biography for the family and children.

Ongoing grief and bereavement counselling will be provided to the family. The children can also attend the Karuna Kids Bereavement program.

I have attached a number of testimonials that speak to the magnitude of palliative care as an end-of-life option.

Karuna recommends the inquiry take into careful consideration the role and benefits of palliative care in end-of-life planning, under all circumstances.

Karuna welcomes this inquiry and would be very pleased to give further evidence at a public hearing.

Yours sincerely

Tracey Porst
Chief Executive Officer
Phone: [redacted]
Email: [redacted]

LIVING WELL AND DYING PEACEFULLY

Words by Cory Taylor

I often think how different my life would be if I didn't have a terminal illness. I'd be making plans, travelling, starting new writing projects, imagining that I had unlimited time to do everything I want to do. And all the time I'd be pushing away the thought of death, as healthy people can, imagining it is something that happens to other people.

When you have a mortal illness this way of thinking is no longer very useful. You have to recalibrate. You have to adjust to the knowledge that your time is limited. In my experience this means choosing whether or not to accept dying as a fact of life, the price we pay for the amazing gift of living. I often tell people how relieved I was when my treatment options ran out and I could stop pretending there was a cure for my disease. This was the point at which I knew for sure my life was ending. It was also the point at which I found Karuna.

At first I was simply grateful to have found people I could talk to about dying well. One's biggest fear of course is pain, so I was reassured by my conversations with the nurses at Karuna about pain relief, and about all of the other medical issues that might lie ahead of me. I was also relieved to hear that Karuna was committed to keeping me at home, visiting me at home, assisting me and my family to live a normal life for as long as possible, and, ideally, making it possible for me to die at home.

Then, as my knowledge of Karuna deepened, I realised that a deeper philosophy was at work in the organization,

that it was not just a question of caring for me as a patient, it was a commitment to honouring my life as a whole, as well as the lives of those I love. One of the best illustrations of this commitment is Karuna's biography programme.

Every Wednesday for over three months I met with a trained volunteer biographer, Susan Addison. Susan would record me telling the story of my life. She would guide me in the telling by asking thoughtful questions. She would then go home and transcribe her recordings so that eventually they could be compiled into a printed document, complete with photographs. The biography is there now, for my family to have after I'm gone. It is a great comfort to me to know that they have this record of my tale, but beyond that, it was a true blessing to be listened to for all those weeks, with such respect and attentiveness.

There are many other ways in which Karuna has helped me to live well in these past few months. I have met with Karuna volunteers, of all kinds; all of them committed to assisting me, both practically and spiritually, to be the person I am right to the end. Without Karuna, I would not have been able to write my third book, a memoir about dying, due for release in May. The fact that I was able to concentrate and work on the book, free of anxiety and despair, is a testament to the power of the Karuna philosophy, which is to embrace mortality as a means of celebrating life.

Please help to make sure that others can receive the precious care that my family is receiving by contributing to this tax appeal.

WRAPPED IN THE ARMS OF KARUNA

by Loody Stewart

Just over a year ago, my 26-year-old son Charles was told he would have little more than 24 hours to live. Family and friends gathered at the hospital to send him off with love. But true to his courageous spirit and infinite humour, Charles woke the next morning, turned to us and declared "anyone would think I was going to die".

We counted our blessings but knew he didn't have long. Shortly after, our six month journey with Karuna began. Charles was born with Cystic Fibrosis and had spent his life in and out of hospital, but his spirit was indomitable.

He didn't just want to survive his last few months, he wanted to truly live surrounded by his beloved pooch Shadow, his friends and his family. Karuna empowered him to do this.

Being wrapped in the arms of Karuna was akin to a young child being cuddled by a loving parent. That feeling of calm, of being secure in the face of adversity. When our Karuna nurse Millie first arrived she said, "we laugh, we cry and we give great hugs".

As a young boy, my Charles enjoyed a very physical life. He was an incredible sportsman, excelling in every sport he set his sights on. When he left school he completed an apprenticeship, travelled, established a marine business and was a self taught pyrotechnics expert. Charles was adventurous, independent, passionate and a loyal friend. Karuna allowed him to be himself right to the end.

Our first meeting with Karuna was in March 2016. There was a chill in the morning air, heralding not only a change of seasons but a massive change for our family as we were told he had less than a month to live.

Our house is a haven for young men. Charles had his dream car in the driveway, he had his pyrotechnics in the garage, his dog by his side and he had his mates. A month passed and he was still driving up to Mt Coot-tha in his beloved Mercedes. Two months passed and he was setting off fireworks in the backyard. State of Origin came and went with Charles and his twin Toby cheering on Queensland.

The seasons changed and a tsunami of friends flowed in and out of the house. Five months went by and his devoted Baptist pastors John and Nick were by his side playing guitar, taking song requests. It was so calm.

Having Charles at home meant we could walk this journey with family and friends - Sunday roasts, long lunches, his dog at his bedside, praying and sharing funny stories.

Charles required specialist care that is most often delivered in a hospital setting. Medicines needed to be administered, syringe drivers needed to be changed, and Charles and our family supported. Charles could not have had this precious time without the holistic palliative care provided by Karuna at home.

Our Karuna nurses Millie and Cora would tend lovingly to all his medical needs as well as liaising with all of Charles' medical practitioners. They became important family members, knowing how to comfort me when I felt overwhelmed and supporting close family and friends. Karuna volunteers would come and go, doing the washing, ironing, tidying and staying at home with Charles when I needed some air. I was able to focus entirely on Charles.

When Charles was born I was overjoyed to be able to care for my baby. With Karuna's support I was again able to be a mother to my baby as his 27 year journey came to an end. Charles' last 24 hours were incredibly special. Charles hosted his last supper - Thai takeaway - with his closest friends and family. It was such a beautiful journey and one we could not have taken together without Karuna.

GRANDPA HAS 'THE CANCE'

Graham and Jeanette Ferguson's four-year-old granddaughter Emily is talking about her most beloved bear Fergus.

"He has 'The Cance' like Grandpa, and he is very skinny so make sure you don't hug him too tight because you will hurt his bones."

Emily attaches a mask to Fergus' head so that he doesn't get any germs because "germs can make him dead". Emily has been regularly role playing 'The Cance' since her mum Karina and Dad Tim broke the news that her Grandpa was sick. Emily is one of nine beautiful Ferguson grandchildren, ranging in age from four to twenty-one.

"Keanna, Jay, Luke, Amelia, Sam, Georgia, Alex, Jack and Emily, half of them call me 'Paga' and the others call me Grandpa. We see them all the time, we're very lucky," says Graham.

The upstairs of their two story home at Albany Creek is set up to house their four children (Lee, Ricky, Tarcia and Karina), their partners (Jenni, Jazzy, Tim 1 and Tim 2) and their grandchildren whenever they wish to stay.

They are all looking forward to spending Christmas together – it will be their last with Graham.

"My family is the most important thing in my life, there's nothing better than having my grandchildren climb up on the couch next to me to watch TV. It's the little things, "says Graham.

Graham was 63 when he was diagnosed with kidney cancer in February 2015. In a rare complication, a tumour was discovered in his heart a year later and tumours were subsequently found in his brain. He is now being cared for at home by Karuna.

"It was a total shock, we were all devastated, there were no signs," says Jeanette. "We are a very close knit family and this has been a real shock for us all. We used to think that this kind of thing only happened to other people, but now we are the other people."

Graham continued to work for 12 months after his cancer diagnosis but for the past 18 months he's relished the time at home, the serenity of the bushland behind their house and the comfort of being able to have family and friends come and go.

"One of the positives of this disease has been stepping away from work. I feel lucky to have had this time - family holidays, days at the beach, out for coffee with my girls."

"I couldn't have had this time without Karuna."

Jeanette says Karuna has been a life-line for her and their family. "Knowing that we have nurses on call and counsellors to go to is a relief. We don't have to worry about getting Graham to the hospital in the middle of the night, we know that we can call Karuna and a nurse will be here."

"It's a wonderful service, we feel very blessed."

To the wonderful palliative care team,

[redacted]12 months ago, my husband [redacted] connect with your team to help us manage [redacted] pain. Palliative care was a new concept to us. [redacted]t was 30, we had a baby girl jus[redacted]ne.

Despite our time with your service being brief, you offered exceptional care, gentle words, thorough explanations and a solid foundation to lean on when we were feeling unbalanced.

[redacted] was an incredible human, and one who lived until the end. He led by example and I have been overwhelmed by the support and the sharing of stories of how the man I loved the most in the world touch others by the very way we faced each day. He inspired so many.

One of his qualities was humility. He never sought the limelight, or expected praise for his efforts. Each year, he organised a charity golf day to raise money for the Cancer Council. This year, we split the proceeds between the Cancer Council and Karuna. It was important for me to show my appreciation for the work you have done to support our family, and acknowledge that I have a very strong village around me, carrying me through this darkness. I am all too aware, that there are others that are not so lucky.

I want you to accept this donation as a gesture of my thanks and to hope that you can continue to do the work that you have done so well.

Kind regards,

[redacted]

Karuna Hospice Services,
P.O. Box 2020
Windsor QLD 4030

[redacted]
Everton Park Q. 4053
21st February, 2012.

Dear Nurses and special people,,

I would like to take this opportunity to thank you sincerely for the care you have shown [redacted] *over these last few months. You all helped make* [redacted] *last few months as comfortable as possible.*

It was always [redacted] *wish to slip quietly from this world in his sleep and this he did at 15 minutes to 12 on the evening of the* [redacted]. *We thank you all so very much for your loving care of* [redacted] *and support for me during this difficult time.*

[redacted] *was finding it very difficult with that big fat leg as it was so heavy and made it really difficult for him to move around and he also found it hard to accept the fact that he couldn't be down stairs doing the things he loved. As he was unable to get out and about we decided to bring the action to him and we were able to have lovely get togethers with our friends with him the centre of attention which as you can imagine he loved. His sense of humour never really left him.*

[redacted] *had set himself three goals. The first was to enjoy Christmas which he did and then to see the New Year and the third was to see his* [redacted] *Birthday.* [redacted] *enjoyed all three and then decided he had had enough and was ready to go.*

We really appreciated the visits from the lovely Nurses and support staff from Karuna and were also very grateful for the home visits from Dr. [redacted]. *I was able to manage the medication with your help and his shoulder settled down and was not giving him too much trouble.*
Our friend [redacted] *visited and bought his magic silk slide sheet. Together with your nurses* [redacted] *helped prepare us over those last few days as to what was likely to happen.*

When Dr [redacted] *visited on the 18th and said it was time to call anyone who* [redacted] *needed to say goodbye to I really hadn't grasped the fact that the end would happen as soon as it did even though* [redacted] *told me that if he had made up his mind to go it would happen sooner. The nurses had told me that it would become much easier when* [redacted] *was in bed full time and I can remember wondering how that could possibly be but it was certainly true. That syringe driver certainly made a great difference.*

On the Thursday morning of his passing [redacted] *was like an angel when he appeared at the door.* [redacted] *said that* [redacted] *was in a coma and then he noticed that his knee cap was mottled. He told me that was a very significant sign and that his circulation was beginning to shut down.* [redacted] *decided to play some of his Scottish music and we could hardly believe it when we saw his foot under the sheet moving in time to the music.*

That evening when we tucked him in for the last time the mottling was covering his legs all the way up his thighs. We lowered the hospital bed to the same level as my bed and

pushed both beds together. I was able to hold his hand. I noticed his breathing change and then a little while later it changed again. His breathing had changed into more like little puffs. This lasted for some time and then he missed a few puffs. I put my hand on his chest and there was still movement and the breathing started again. This happend a couple of times and then he was still and there was no movement so I knew he had slipped away and got his wish

We would like to say a special thankyou to [redacted] *your Biographers who have given of their time so generously. This is a fantastic service and I am sure* [redacted] *really appreciated being able to tell his story and I think it has helped me so much in the grieving process.*

[redacted] *has also been a great help in listening and helping me come to grips with things.*

We were so very lucky to have such a long and very happy marriage for almost 53 years. We have a very loving family and we will be there for each other and I am sure this will help us through.

Thankyou once again for the help you were able to give. I feel it was a privilege for me to be able to take care of [redacted] *at home and a privilege that not everyone gets.* [redacted] *was so much a part of his home & I feel it was only fitting for him to pass from this world in the place he loved most. It was with your help that made this possible.*

Yours sincerely,

[redacted]

Karuna Hospice Facebook Testimonials

DATE	TESTIMONIAL
13/10/18	Karuna staff are walking beside me as I care for my husband. They give me the strength to go on. Not only do the nurses bring expert palliative care into our home, they bring love and compassion to the whole family. We have experienced spiritual support visits from the Venerable Chodron. I cannot express how much I admire and am grateful to Karuna! Not forgetting the Volunteer visits and staff behind the scenes who make things tick.
07/03/18	I was absolutely blown away to meet these caring people who after many years became my late sister, [redacted], family and friends, during her last months and days. They looked after her at home, then when it was time, and she was admitted to hospital they made their regular visits to [redacted] every day. Their compassion and care was amazing and heart-warming to see and be part of. They made the whole family feel informed as each stage became near. They never failed to make her comfy. They were awesome and I am forever grateful to have had them look after and care and give our sister so much Love and reassurance through each day. A big Thank you for your awesome dedication and work you all do on a daily basis. With much love [redacted] ([redacted] in RSA)
09/10/18	Sincere and dedicated organisation
23/08/14	Wonderful people to help you on a journey with you relative, friend or someone really special to you. It is 8 yrs since i was introduced to Karuna with my beloved husband, i am in constant love they have given to me and my family at the time. I now help out with them now when i can. Such a beautiful people and nurses to help you on your life journey. God Bless these people.
12/06/18	The most caring and compassionate nurses and organisation who assisted me with caring for both my parents to the end of their lives.

09/03/16	This is a wonderful organisation that assisted us to keep my Dad home for his final days. Their help let him pass peacefully and with dignity. I will be forever grateful for their calming and respectful ethic, you made my Dads passing bearable.
04/10/17	Karuna does wonderful work, helping people to stay in their own homes and be around loved ones, whilst facing their final journey. The beautiful people at Karuna give amazing support, medical, psychosocial and spiritual. They also support the families after the passing of their loved one with bereavement counselling. What a wonderful service.
19/03/18	The kindest care. I have seen Karuna's nurses and volunteers light up the darkest rooms with compassion, excellent pain management and expert guidance.
13/05/14	Amazing people. Thank you so much for caring for my partner, my daughter, myself and my family when we so needed the love, care and support
15/05/14	It was terrific to be part of the celebration with other volunteers. So many caring people trying to make a difference.
30/04/14	Amazing people who took wonderful care of our dad in his last months.xx Thanks to all.
14/08/14	I am so inspired by the support of Karuna
24/02/19	Karuna were beyond amazing with caring for my dad. The biography was such a great idea! All nurses were wonderful - they listened to dad as well as family members and were so supportive, helpful and caring. It has been over 3 years since we used Karuna but we all still talk about the amazing care dad received
18/03/19	Lovely compassionate people

Civil Liberties Australia
Box 7438 FISHER ACT 2611
[redacted]

Submission to Queensland Health etc Committee:

Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying

Civil Liberties Australia's position is that end-of-life choice is an individual human right.

The state has no authority over the right of people to make their own individual choice regarding ending their life. Any such attempt at legislation is moot, because it is unenforceable after the event anyway.

Where people freely choose to end their own life, but are physically incapable of doing so, it is their right to receive assistance to implement their free choice. The state has a role in crafting simple laws to ensure such a person is making a completely free choice.

People who, through their religious or like belief, are opposed to individual choice over end-of-life are free to exercise their own convictions for themselves. They are not free to impose their beliefs on people with different (or no) religious or like beliefs. The state has no role in a secular democracy in legislating to preference particular religious beliefs, which are individual (or group) choice matters.

Supporting the common sense of the above statements, public opinion polls over decades have shown overwhelming support – regardless of religious belief – for the right of terminally ill people to have medical assistance to die, provided there are legislated safeguards ensuring the choice of death is freely made. Parliamentary representatives should endorse the expressed wishes of the vast majority of the electorate, usually reported in reputable polls as greater than 70%. For elderly people (over 70), for whom the issue is perhaps of greater importance and relatively more timely, support for such legislated free choice is even higher (more than 80%) in most polls.

Knowing that one has control over the end-of-life life decision gives peace of mind in what are usually distressing physical circumstances. That mental empowerment is a crucial factor for many older people in ill health. If a state negates that practical choice, it is effectively inflicting additional mental pain on someone in terminal ill health in what could amount to "unusual punishment".

Civil Liberties Australia urges the Queensland Parliament to again stand up for human rights by legislating for assisted individual choice over end-of-life, with responsible safeguard mechanisms. Victoria has done so: the ACT and the NT have demonstrated they would also do so were their citizens permitted equal rights to those of the States.

Yours truly

Dr Kristine Klugman OAM
President

12 April 2019

ADDENDUM:

In response to customary questions, Civil Liberties Australia believes:

1. Current medical practices are putting caring doctors at risk of their careers. There is no clear-cut option for medical professionals (doctors, nurses, etc) to act as their personal conscience and compassion dictates to end suffering at the request of a patient, when ending suffering is the very reason for the professionals' dedicated choice of occupation.

2. The wishes of the overwhelming majority of Australians is that is that there be clear and practical, legislated, end-of-life choices for seeking medical help to die.

3. Stringent conditions included in all assisted dying legislation world-wide to protect individuals' rights can be drawn on for sensible law.

4. Australian efforts so far are prone to an over-timid approach, for example in Victoria. We urge the Queensland Parliament to model legislation on similar provisions overseas. Internationally, nations and provinces/states have laws with proven safeguards and long track records of not encouraging untoward practices.

5. States are free, constitutionally, to make their own laws in this critical aspect of human life/death (we note that such freedom has been usurped from Territories by the federal government in a way that deprives Territory citizens of equal rights). Should the Australian government attempt to over-rule state rights, Civil Liberties Australia believes the states should take concerted action to protect their own constitutional position. (The anomaly in relation to citizens of the Territories **must eventually** be removed under international equal rights provisions).

6. Personal medical direction instruments – providing mandatory instructions to doctors, hospitals, etc in advance of an incident – should carry very clear options for a patient to pre-determine his or her choice to have his life actively terminated in specific circumstances. Once formally lodged with the state health system at any one health facility, the instructions should be electronically available immediately at all other state (and national) health facilities. Health system data holdings should be so organised that such stored instructions are brought into operation immediately on formal admission of a person – who has previously lodged an instruction document – to any hospital/medical facility in Queensland, or at first interaction with Queensland Ambulance care, police attention or the like.

Civil Liberties Australia does not believe any medical professional should be obliged to act contrary to his or her personal beliefs. Medical people who do not wish to take part in helping someone to fulfil his or her freely stated wish to die should be free to step aside without personal consequence or employment recrimination.

Author: President Dr Kristine Klugman; co-author CEO Bill Rowlings

ENDS CLA submission

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GYMPIE & SOUTH BURNETT DIVISION

Your details: Mrs Anna Katrina van den Brenk
Day time phone number: [redacted]
Email address: [redacted]
Address: [redacted] Tin Can Bay Postcode: 4580

What would you like to tell the committee?

At the Gympie & South Burnett Division of the Queensland Country Women's Association (QCWA) meeting held in Murgon on 11th April 2019, the following Motion was carried:

Voluntary Assisted Dying "**that the Queensland Country Women's Association requests that the State Government introduce a bill to legalise assisted dying in Queensland, to be carried out with strong safeguards and protections to patients, healthcare professionals and families**."

This will now proceed to be voted upon by members representing Branches from all over Queensland as a Resolution at the 97th QCWA State Conference to be held in Maryborough in October this year.

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: n/a

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: Gympie & South Burnett Division, Queensland Country Women's Association

Their daytime phone number: ([redacted] (Division President, Mrs. Julia Ashcroft) What is your relationship with that person or persons, or your role in the organisation? I am the Division Marketing & Publicity Officer

I am authorised by Gympie & South Burnett Division of the QCWA, in accordance with the Minutes of Meeting 11th April 2019 to provide these comments on their behalf.

Signature: ***Date: 15.04.2019***

ESSA
EXERCISE & SPORTS SCIENCE AUSTRALIA

SUBMISSION TO THE **QUEENSLAND HEALTH, COMMUNITIES, FAMILY VIOLENCE PREVENTION COMMITTEE**

INQUIRY INTO **AGED CARE, END-OF-LIFE AND PALLIATIVE CARE AND VOLUNTARY ASSISTED DYING**

APRIL 2019

ESSA
EXERCISE & SPORTS SCIENCE AUSTRALIA

Founded in 1991, Exercise & Sports Science Australia (ESSA) is the peak professional body and accrediting authority for over 7,000 university qualified and Accredited Exercise Physiologists, Exercise Scientists, Sports Scientists, and High Performance Managers.

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INTRODUCTION

Exercise & Sports Science Australia (ESSA) welcomes the opportunity to respond to the 'Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying'.

ESSA has addressed questions on aged care service provision as the peak professional body and accrediting authority for 8,000 university-trained exercise professionals whose members are Accredited Exercise Physiologists (who design and deliver effective programs for people with chronic conditions, injuries or disabilities) and Accredited Exercise Scientists (who work to improve the health, fitness and well-being of the general population).

ESSA is a member of the National Aged Care Alliance (NACA), a representative body of peak national organisations in aged care, including consumer groups, providers, unions, and health professionals, working together to determine a more positive future for aged care in Australia. ESSA has drawn some of the content in this submission from various position papers developed by NACA.

ESSA is only responding to Section 1 a of the Terms of Reference, "the delivery of aged care, end-of-life and palliative care in Queensland across the health and ageing service systems" and is not responding to end-of-life or palliative care services in this submission.

ESSA gives permission for this submission to be published in full or in part.

Leanne Evans
Policy and Relations Advisor
Exercise & Sports Science Australia
[redacted]

Anita Hobson-Powell
Chief Executive Officer
Exercise & Sports Science Australia
[redacted]

DELIVERY OF AGED CARE IN QUEENSLAND ACROSS THE HEALTH AND AGEING SERVICE SYSTEMS

Exercise & Sports Science Australia Recommendations for the health and aged care delivery system:

Recommendation 1:

- **Influence the COAG Health Council (CHC) to firmly integrate and embed a wellness and reablement approach into the national aged care system.**

Recommendation 2:

- **Ensure that any future national and state aged care funding models reward and recognise independence, functional outcomes and quality of life.**

Recommendation 3:

- **Upskill the aged care workforce (including general practitioners and nurses) with affordable and accessible training on wellness and reablement and the value of exercise.**

Recommendation 4:

- **(i) Ask the Queensland Minister for Health to support via the COAG Health Council (CHC) two recommendations from the Report from the Allied Health Reference Group[1] for the Medicare Benefits Schedule (MBS) Review Taskforce**
  - **Introduce initial assessment appointments (of more than 40 minutes) for allied health professionals.**
  - **Increase the number of allied health appointments under team care arrangements (TCAs; item 721 and 723) by stratifying patients to identify those with more complex care requirements.**
- **(ii) Expand access to exercise interventions (including resistance and/or weight bearing plus balance exercises) delivered by Accredited Exercise Physiologists and Accredited Exercise Scientists within Queensland public health system.**
- **(iii) Enlist the support of the Queensland Treasurer to endorse exercise physiology as an eligible GST-free health service by the Council on Federal Financial Relations (CFFR).**

Recommendation 5

- **Increase the health literacy of older people about the benefits of exercise using existing evidence-based resources which could be distributed in paper based formats.**

Recommendation 6

- **Embed consumer choice and control by actively engaging aged care consumers in the assessment and planning of care needs and goals so they receive respectful and responsive care that meets their preferences, needs and values.**

[redacted]

[redacted]

[1] Medicare Benefits Schedule (MBS) Review Taskforce, Report from the Allied Health Reference Group 2018, Canberra, MBS Review Taskforce.

EXERCISE & SPORTS SCIENCE AUSTRALIA

Adopt a wellness and reablement approach and outcomes funding model

The current aged care system does not focus on wellness and reablement (W & R) to support older Queenslanders to achieve greater independence and quality of life and live their lives to the fullest. The system does not support referrals to exercise physiologists and exercise scientists nor provide adequate access to resistance and/or weight bearing plus balance exercises to allow for rehabilitation to better physical health and independence of age, level of disease or disability.

Successful rehabilitation is possible with exercise interventions. Research[2] confirms employing resistance training in the Residential Aged Care (RAC) setting shows:

> "Significant improvements in muscle strength and functional performance occur in response to training, despite advanced age, presence of chronic diseases, extremely sedentary habits, and functional disabilities in older institutionalized individuals."
>
> Furthermore, "the incorporation of a training exercise program is an effective means to preserve independence levels by maintaining or improving the ability to perform activities of daily living and the implementation of this type of exercise program should be promoted and incorporated into the recreational schedules of long term care institutions".

For community dwelling adults, this form of exercise can have even more powerful outcomes in relation to prolonged independent living and a reduction in care needs. There is a plethora of data available for both home-based[3] and clinic-based[4] delivery.

In 2018, the Commonwealth Department of Health released the Nous Group's national review of wellness and reablement approaches[5] within the aged home care sector. It noted "embedding W & R in the home care sector marks a radical shift from traditional service delivery" (page 2).

The key finding of the review was:

> "There is strong support for W&R approaches, and some great examples of the approaches are emerging across the country. However, W&R approaches are not yet deeply embedded or consistently applied across the home care sector" (page 2).

Several key messages also emerged about the implementation of W&R approaches on a sector-wide level:

- "There is strong support across the home care sector for the W&R philosophy…..
- Sector leadership is fully committed and providing strong endorsement…..
- The review found ample evidence of the benefits of W&R" (page 3)

[redacted]

[2] Valenzuela, T. (2012). Efficacy of progressive resistance training interventions in older adults in nursing homes: a systematic review. Journal of the American Medical Directors Association, 13(5), 418-428.
[3] Lewin, G. F., Alfonso, H. S., & Alan, J. J. (2013). Evidence for the long term cost effectiveness of home care reablement programs. Clinical interventions in aging, 8, 1273.
[4] Liu, C. J., & Latham, N. (2011). Can progressive resistance strength training reduce physical disability in older adults? A meta-analysis study. Disability and rehabilitation, 33(2), 87-97.
[5] Nous Group, Wellness and reablement: A summary of consultations across the home care sector, 15 May 2018, commissioned by the Australian Government Department of Health.

Lack of financial incentives is the biggest barrier to embedding a wellness and reablement approach, especially for service providers with "a business model built on outputs and older dependency-focused services". There is a

> "lack of recognition for the additional time needed to implement and deliver W&R approaches: 'We still get paid the same, whatever the outcome' "(page 4).

Recommendation 1:

- **Influence the COAG Health Council (CHC) to firmly integrate and embed a wellness and reablement approach into the national aged care system.**

Recommendation 2:

- **Ensure that any future national and state aged care funding models reward and recognise independence, functional outcomes and quality of life.**

Upskill the Aged Care Workforce

To fully embrace a wellness and reablement approach, aged care staff need training on:

- wellness and reablement (specifically on maintaining and increasing independence, functionality and quality of life) and in some cases reversing frailty.
- incorporating principles from the World Health Organisation which recently highlighted the need to focus on the functional independence of older adults rather than using a single traditional medical approach[6].
- the holistic health needs of consumers, specifically their physical, mental/emotional, social connectedness, and nutrition needs
- the value of exercise e.g. via the ESSA supported program Exercise is Medicine® Australia which offers a solution to managing chronic diseases, Australia's leading cause of ill health and death.

Training should not be at the expense of quality roles and employment conditions. ESSA refers the Committee to NACA's 2017 Aged Care Workforce Position Paper[7] which addresses the challenges of attracting and retaining a competent and appropriately qualified future aged care workforce. The paper notes "better employment conditions and quality jobs lead to improved care[8]".

Recommendation 3:

- **Upskill the aged care workforce (including general practitioners and nurses) with affordable and accessible training on wellness and reablement and the value of exercise.**

[redacted] [redacted]

[6] Maurice, J. (2016). WHO puts healthy ageing on the front burner? The Lancet, 387(10014), 109-110.
[7] National Aged Care Alliance, POSITION PAPER, Aged Care Workforce, June 2017 https://naca.asn.au/wp-content/uploads/2018/11/Aged-Care-Workforce-Position-Paper-2017.pdf (Accessed 14 April, 2019)
[8] Carr, S. (2014). Pay, conditions and care quality in residential nursing and domiciliary services. York: Joseph Rowntree Foundation, as cited in National Aged Care Alliance, POSITION PAPER, Aged Care Workforce, June 2017 https://naca.asn.au/wp-content/uploads/2018/11/Aged-Care-Workforce-Position-Paper-2017.pdf (Accessed 14 April, 2019)

Embed access to and funding of exercise interventions within aged care funding models

The 2018 Australian Institute of Health and Welfare report 'Physical Activity across the life stages[9]' notes that

- only 25% of people aged 65 and over met the physical activity guideline of doing 30 minutes of physical activity on five or more days
- with increasing age from 75 onwards, the proportion of women meeting the physical activity guideline decreased (19% for those aged 75-84, 9.5% for those aged 85 and over) whereas the proportion of men remained the same
- the majority (84%) of people aged 65 and over "completed no strength-based activities at all and only 13% met the strength-based activities on all 7 days"
- fewer men and women met the strength-based activity guideline (than the physical activity guideline) and only 8.1 % of women aged 85 and over met the strength-based guideline.

These figures reinforce the need to focus on supporting for people aged 65 and over, especially women to access age appropriate and evidenced-based exercise options.

Whilst a number of government reviews since 2011 have highlighted the positive benefits of exercise interventions, little progress has been made in respect to embedding exercise into aged care.

A Commonwealth *Review of the Aged Care Funding Instrument*[10] in 2011 identified

> "where enhancements could be considered as part of ongoing work with the industry and health professionals. For example, issues were raised about the pain management items in ACFI Question 12 – Complex Health Care, including that:
>
> • the interventions specified by ACFI, such as therapeutic massage and the application of heat packs, are too narrow and not consistent with contemporary best practice;
>
> • there are other care modalities with better evidence based support that could be included such as exercise, distraction and psychological interventions; and
>
> • the list of allied health professionals able to provide directives and particular interventions is too restrictive and should be broadened to include other allied health professionals".

A recent *Review of the Aged Care Funding Instrument Report* in 2017 by Dr Richard Rosewarne and others[11] highlights

> "a growing body of evidence of the range of positive outcomes from physical therapy interventions with older frail persons. It not only improves or maintains functional ability, but can also impact on the management of chronic diseases and their associated risks, reducing falls, and improving social and quality of life outcomes" (page 37)

[redacted]

> "Exercise Physiologists are not recognised in the list of Health Professionals in the ACFI User Guide (page 38). However, their practices fit strongly into the planned Therapy Program and their inclusion is recommended in the new R-ACFI Therapy Program model" (Page 38).

[9] Australian Institute of Health and Welfare 2018. Physical activity across the life stages. Cat. no. PHE 225. Canberra: AIHW

[10] Australian Government Department of Health and Ageing, 2011, The Review of the Aged Care Funding Instrument, Canberra: Australian Government Department of Health and Ageing, page 13.

[11] Dr Richard Rosewarne, Janet Opie, Dr Richard Cumpston, Victoria Boyd and Akira Kikkawa 'Review of the Aged Care Funding Instrument Report, Part 1: Summary Report', Applied Aged Care Solutions Pty Ltd, 2017.

A 2015 Deloitte Access Economics report "Value of Accredited Exercise Physiologists in Australia (Summary)[12]" commissioned by ESSA outlines a summary of the benefits and costs for a number of chronic conditions, due to interventions by AEPs in Table 1 below and in an infographic (Appendix A).

Table 1: Benefit Cost Ratio and Annual Savings per Person in Health System Expenditure from Accredited Exercise Physiologists' interventions

Condition	Benefit Cost Ratio (benefit is shown to the health system and savings in productivity versus the cost of AEP interventions)	Annual savings per person in health system expenditure
Pre-diabetes	6.0	$1,977
Type 2 diabetes	8.8	$5,107
Mental illness (depression)	2.7	$10.062 (per case averted through exercise) $2,239 (for people still in recovery at one year follow up)
Cardiovascular disease	6.2	$11,847
Chronic back pain	14.6	Research not available
Osteoarthritis	4.0	Research not available
Rheumatic diseases	4.2	Research not available

Access to Accredited Exercise Physiologists within the health care system can be expanded through changes to the Medicare Benefits Schedule (MBS). ESSA highlights two important allied health recommendations from the Medicare Benefits Schedule (MBS) Review process in Recommendation 4 below which can improve access to exercise physiology services for older Queenslanders with chronic conditions.

A significant barrier to older Queenslanders to access exercise physiology (EP) services is the charging of a Goods and Services Tax (GST) on EP Services:

- within private health insurance schemes
- for residents in residential care facilities and treatment and consultations for general clients
- charged to the Department of Veterans' Affairs (DVA) except where it is part of GST-free hospital treatment.

The only exemption on GST for older Queenslanders is for EP Services charged to an Australian government agency (e.g. DVA or a government-operated hospital), an insurer or a compulsory third party scheme operator, where it is part of GST-free hospital treatment.

Appendix B is an information flyer which shows the level of complexity of when GST is payable by AEPs. This flyer was recently reviewed and approved for distribution to ESSA members by the Australian Taxation Office.

[redacted]

[12] Deloitte Access Economics, 2015, Summary Report Value of Accredited Exercise Physiologists in Australia: Exercise & Sports Science Australia, https://www.essa.org.au/wp-content/uploads/2015/10/Deloitte-Report-2015_Value-of-AEPs-in-Australia_Summary.pdf (Accessed 14 April 2019)

Recommendation 4:

- **(i) Ask the Queensland Minister for Health to support via the COAG Health Council (CHC) two recommendations from the Report from the Allied Health Reference Group[13] for the Medicare Benefits Schedule (MBS) Review Taskforce**
  - **Introduce initial assessment appointments (of more than 40 minutes) for allied health professionals.**
  - **Increase the number of allied health appointments under team care arrangements (TCAs; item 721 and 723) by stratifying patients to identify those with more complex care requirements.**
- **(ii) Expand access to exercise interventions (including resistance and/or weight bearing plus balance exercises) delivered by Accredited Exercise Physiologists and Accredited Exercise Scientists within Queensland public health system.**
- **(iii) Enlist the support of the Queensland Treasurer to endorse exercise physiology as an eligible GST-free health service by the Council on Federal Financial Relations (CFFR).**

Increase the health literacy of older people about the benefits of exercise

The disease burden due to physical inactivity increases with age, particularly due to the increased occurrence of chronic conditions in later life. Dementia, stroke, coronary heart disease and diabetes are the four most common chronic conditions linked to the physical inactivity burden for older adults[14].

Whilst internet access among older Australians is rising, there are still large gaps in access. A report[15] for the Office of the Australian Government's eSafety Commissioner found close to two-thirds of those aged 80 years and over, 45% of those aged 70-79 years and 25% of those aged 60-69 did not have a digital device at home for personal use. This means that word of mouth and paper-based materials are required for large numbers of the aged population.

Many older adults with chronic conditions are not confident about exercising and many feel "too old" or "too injured" to exercise.

ESSA's Exercise Right is an evidenced based information website inspiring people to live happier and healthier lives through motivational stories, engaging content and evidence-based tips. Free Fact Sheets on over ten chronic conditions are proved: (e.g. arthritis and diabetes) along with other information on key topics like falls prevention, heart health and mental health. Information from Exercise Right is being used by various state government health departments for consumers. http://exerciseright.com.au

The ESSA supported Exercise is Medicine® Australia also has over 30 Fact Sheets for consumers on various health conditions. http://exerciseismedicine.com.au/public/factsheets/

[redacted] [redacted]
Within Exercise Right, there are a series of eight exercise videos funded by the Queensland Government for its Healthier.Happier initiative. http://exerciseright.com.au/active-videos/

[13] Medicare Benefits Schedule (MBS) Review Taskforce, Report from the Allied Health Reference Group 2018, Canberra, MBS Review Taskforce.

[14] Australian Institute of Health and Welfare 2017. Impact of physical inactivity as a risk factor for chronic conditions: Australian Burden of Disease Study. Australian Burden of Disease Study series no. 15 Cat. no. BOD 16. Canberra: AIHW.

[15] Office of the eSafety Commissioner, Understanding digital behaviour amongst adults aged 50 years and over, Final Report, September 2017

ESSA supports the continued use of its evidence-based resources by the Queensland Department of Health provided attribution is given.

Recommendation 5

- **Increase the health literacy of older people about the benefits of exercise using existing evidence-based resources which could be distributed in paper based formats.**

Consumer Choice and Control

Providing opportunities for older people to exercise choice and control over the care they receive promotes their autonomy and can positively contribute to their health, wellbeing and quality of life. Overall, older people have indicated a strong preference for self-directed models of support[16].

In the case of physical activity, there is a growing body of evidence[17] that older adults are more likely to initiate and maintain physical activity if they feel confident about their ability to succeed and if they are afforded a variety of opportunities to actively participate in physical activity. If older adults can choose exercise-program characteristics (such as group-based versus individual activity programs and choice of exercise location), they are more likely to adhere to a program.

Recommendation 6

- **Embed consumer choice and control by actively engaging aged care consumers in the assessment and planning of care needs and goals so they receive respectful and responsive care that meets their preferences, needs and values.**

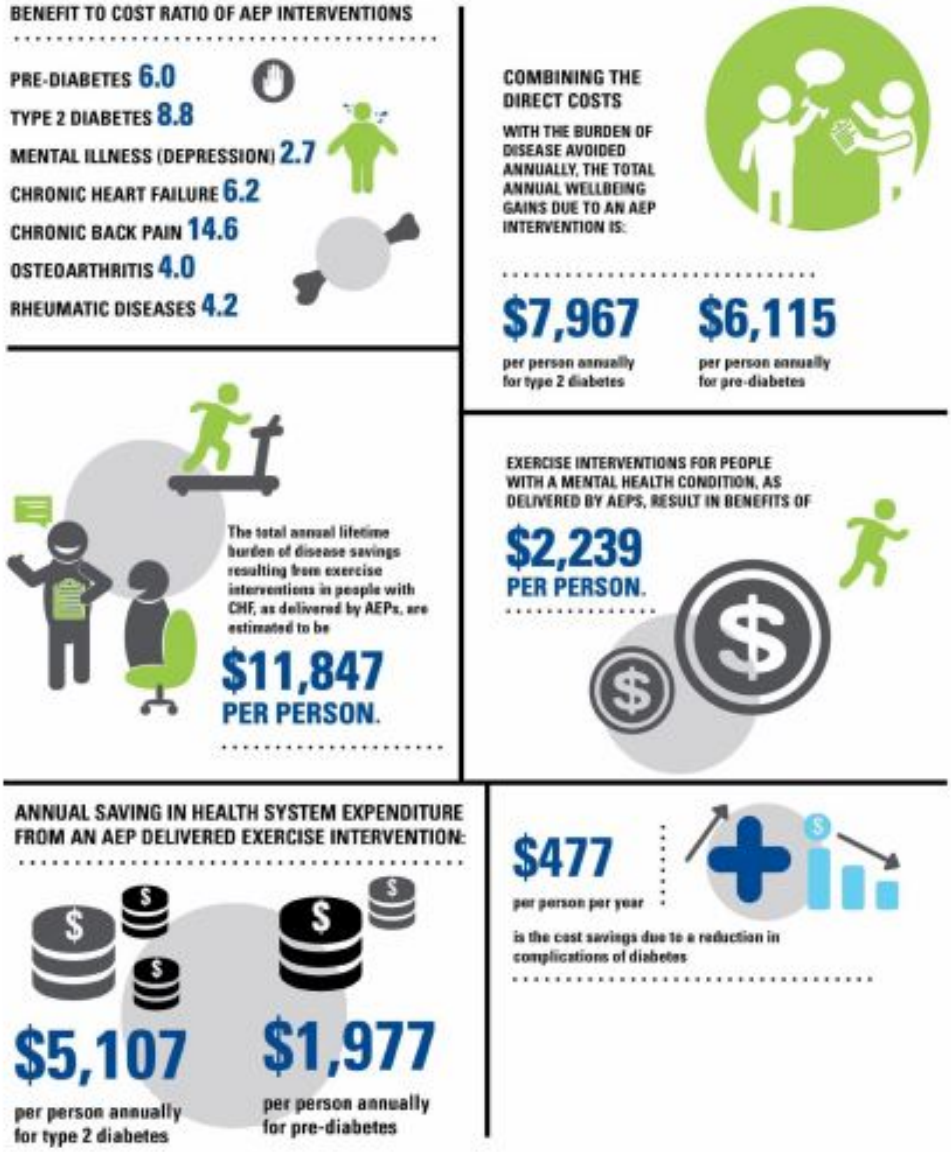
[redacted] [redacted]

[16] Crozier, M., Muenchberger, H., Ehrlich, C. & Coley, J H. (2012). Self-directed Support: A state, national, international understanding. Griffith University, page 21.

[17] Cress, M. E., Buchner, D. M., Prohaska, T., Rimmer, J., Brown, M., Macera, C., Dipietro, L., & Chodzko-Zajko, W. (2005). Best practices for physical activity programs and behavior counseling in older adult populations. Journal of aging and physical activity, 13(1), 61-74.

EXERCISE & SPORTS SCIENCE AUSTRALIA

Appendix A: Benefit Cost Ratio and Annual Savings per Person in Health System Expenditure from Accredited Exercise Physiologists' interventions



[redacted] [redacted]

Appendix B: Information Flyer on GST

Exercise Physiology Services & GST:

Registering for GST:

As an Accredited Exercise Physiologist (AEP), if your business has an annual GST turnover of **$75,000** or more, you will be required to *register for GST* and lodge *Business Activity Statements (BASs)* with the ATO. However, you can voluntarily choose to register for GST even if your annual GST turnover is less than $75,000. Your annual GST turnover is worked out as either your turnover for the current month and the previous 11 months or your turnover for the current month and the projected GST turnover for the next 11 months.

A BAS is a tax return which reports the GST you have collected and the GST you have paid and determines the net amount that is payable to the ATO each period. You can choose to lodge your BAS monthly or quarterly. If you are registered for GST and your annual GST turnover is less than $75,000, you can elect to lodge annually unless you have chosen to pay GST by instalments. The BAS returns are in addition to your annual income tax return.

When does GST apply?:

Most services provided by AEPs are classified as ***taxable services*** and ***will*** attract GST. When providing a taxable service, you will be required to remit the GST to the ATO. GST is equal to 10% of the service value and ***must*** be included in the advertised price. You may need to charge a higher price for your services to take GST and GST credits into account. When invoicing, ensure to itemise the GST separately to the service provided. Please refer to the ATO for further information on invoicing.

Some services provided as an AEP directly to a patient will be ***GST-free services***, and you will not need to charge any GST on these services or remit any amounts to the ATO.

Summary of GST on typical Exercise Physiology (EP) services:

Taxable Services	GST-free Services
o EP Services charged to another business entity# (e.g. contract services)	o EP Services charged to patients where a Medicare benefit is payable to the patient for the EP Services (whether bulk-billed or charged directly to a client who claim Medicare rebates)
o EP Services charged within the workers compensation system (e.g. SIRA, iCARE)	o EP Services charged to an NDIS participant who is a resident in a residential care facility
o EP Services charged to the Department of Veterans' Affairs (DVA) except where it is part of GST-free hospital treatment* *Note: This is invoiced through Recipient Created Tax Invoice (RCTI) – required for each provider number*	o EP Services charged to patients as part of GST-free hospital treatment*
o EP Services charged within private health insurance schemes	o EP Services charged to an Australian government agency (e.g. DVA or a government-operated hospital), an insurer or a compulsory third party scheme operator, where it is part of GST-free hospital treatment*
o EP Services charged to an NDIS participant other than where the EP service is listed as a GST-free service in the next column	o EP Services charged to a residential care facility that is operated by an Australian government agency, an insurer or a compulsory third party scheme operator, where it is part of GST-free residential care that they supply to their residents*
o EP Services charged to a resident in their residential care facility (other than an NDIS participant)	
o EP treatment and consultations for general clients	

#In some limited cases, the other business entity can on-supply your services GST-free to patients, but this does not make your EP Services GST-free when charged to that other business entity.

**Please speak with the hospital/residential aged care facility for confirmation on whether the services you are providing fall under these requirements.*

While you need to pay GST on most of the services you provide, you are also entitled to ***claim*** a credit for any ***GST*** you have paid on expenditures for your exercise physiology business. These GST credits will then offset the amounts collected and reduce the total amount owed to the ATO.

How do I pay GST?:

At the end of each month or quarter (or at the end of the year if you lodge annually), you will prepare and lodge a BAS with the ATO and pay your GST liability. Once you have registered for GST, the ATO will automatically start sending you a BAS to complete, based on the information provided on your application.

By keeping a record of all invoices issued and expenses paid during the period, you can then calculate the net amount of GST you have collected, and what will need to be paid to the ATO. To help manage cash flow, it is also suggested that you put the GST you collect into a separate account, so it is available at the end of the quarter when your obligations arise.

What if I'm not registered for GST?:

If you are ***not required*** to register for GST, and are not voluntarily registered for GST, there is no obligation for you to pay GST or charge a higher price for your services to take GST into account. There will be no GST amounts payable to the ATO, but you can't claim any GST credits for your expenses. Your invoices issued won't include a tax component.

Why do AEPs need to charge GST?:

Typically, medical services are GST-free to ensure equitable access to health care for all Australians. A health care service is GST-free if it is classified as an ***'Eligible Health Service'*** as defined by the GST law. While AEPs are recognised as allied health professionals by Medicare, at present, Exercise Physiology is NOT an ***'Eligible Health Service' for the purposes of GST***, and therefore, not automatically exempt from GST.

ESSA has made multiple representations to the Federal Government to have Exercise Physiology classified as an ***'Eligible Health Service'***, and therefore GST-free. However, any variation of the GST requires a consensus of ***all*** states and territories and the Federal Government. ESSA continues to raise this issue in discussions with both State and Federal Government representatives. You can help to support this campaign to remove GST from AEP health services by downloading the ESSA letter template and sending this to your local Federal Member and/or Senator for your state.

Please note, this is general information only and ESSA always advises that you consult your accountant for further guidance regarding your individual business circumstances.

[redacted] [redacted]

ESSA
EXERCISE & SPORTS SCIENCE AUSTRALIA

www.essa.org.au

15 April 2019
Committee Secretary
Health Committee
Parliament House QLD 4000
careinquiry@parliament.qld.gov.au

Dear Committee Secretary

RE: Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying

The Leukaemia Foundation welcomes the opportunity to provide a submission to the *Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee* on its inquiry into aged care, end-of-life and palliative care and voluntary assisted dying.

Our submission focusses on voluntary assisted dying (VAD) as part of the broader inquiry.

The Leukaemia Foundation is the only national charity dedicated to helping those with leukaemia, lymphoma, myeloma and related blood disorders. We provide practical and emotional support to Australians diagnosed with a blood cancer at no cost, thanks to the generosity of the community through our fundraising efforts.

Blood cancer is a complex set of diseases that can affect anyone at any stage of life. Advances in treatments and care are transforming the way Australians live with a blood cancer; however, incidence rates are increasing and blood cancer is one of the biggest causes of cancer death in Australia.

The Leukaemia Foundation supports peoples' right to choose the treatment and care options that are right for them and their families. For some, this will include the option of accessing VAD.

We therefore welcome efforts from all State, Territory and Federal governments to ensure that people living with a blood cancer have access to the full range of services to meet their changing needs – from the moment they step into the doctor's office, through to the type of test, treatment, supportive and palliative care options they are offered.

As you are aware, the Victorian Government will be introducing its VAD framework in June 2019. The Leukaemia Foundation is preparing for the introduction of this framework and we expect there will be a call on our services in Victoria for advice and assistance in navigating the scheme.

Questions that have already arisen in the context of Victoria include the role of service providers, like the Leukaemia Foundation, in witnessing official requests to access VAD – particularly people who may have a limited support network of friends and family. We are also considering our role in requests for referrals to VAD navigators at hospitals/treatment centres.

The intersection of VAD in the public health setting with service providers and organisations like ours, that work directly with patients, is certainly an area where we welcome further engagement with Governments so that our joint services best meet the individual needs of patients and their families.

We also encourage Federal, State and Territory Governments to work together to ensure that people throughout Australia, wherever they live, have equal access to health services, access to treatment, access to support services and access to opportunities that will help them live their life to its full potential.

With the introduction of the VAD framework in Victoria, questions will inevitably arise from people in other jurisdictions about accessing the scheme.

Alongside our position supporting peoples' right to choose the treatment and care options that are right for them and their families, we also strongly believe that people must have equal access to treatment and care options – no matter where they live.

We therefore strongly urge that the Queensland Government works alongside its State and Territory counterparts and the Federal Government to ensure that these principles of equality and fairness are embedded throughout the health system in Australia.

The Leukaemia Foundation's priority is to ensure that all Australians living with blood cancer have access to the best therapies and treatments available, which improve time spent in remission, survival and quality of life.

If we can provide any further assistance on this matter, please contact Emily Forrest, Head of Policy and Advocacy on [redacted] or mobile [redacted]

Yours sincerely

Bill Petch

Chief Executive Officer

About us

Since the Leukaemia Foundation was established in 1975 in Queensland, we have partnered with Government and the community to support people living with blood cancer and their families.

We are a major provider of accommodation, transport, psychosocial and other support services to people living with blood cancer, in addition to being a philanthropic funder of blood cancer research.

That support continues today.

The Leukaemia Foundation currently provides funding for around 170 apartments throughout Australia, which meant almost 12,000 patients were able to stay with their families during treatment in 2016-17, at no cost to the patient.

We deliver more than 175,000 passenger trips each, covering more than 4.8 million kilometres in patient transport services.

Through patient support services the Leukaemia Foundation delivers psychosocial services to more than 1,600 people each year, helping to reduce patient and family anxiety, improving survival outcomes and wellness.

As a major investor in blood cancer research, we have funded more than $47 million in fundamental and translational research since 2002 alone – delivering improvements in survival and quality of life.

ANTI DISCRIMINATION COMMISSION QUEENSLAND

Our ref: BNE3414954

15 April 2019

Committee Secretary
Health Committee
PARLIAMENT HOUSE QLD 4000

By email: careinquiry@parliament.qld.gov.au

Dear Secretary

Inquiry into aged care, end-of-life and palliative care, and voluntary assisted dying

Thank you the opportunity to provide a submission to this inquiry. The terms of reference include inquiring into the views of the Queensland community and relevant health practitioners on the desirability of supporting voluntary assisted dying, including provisions for it being legislated in Queensland and any necessary safeguards to protect vulnerable persons.

This submission is confined to providing information on human rights relevant to voluntary assisted dying.

I note that in undertaking the inquiry the Committee is to consider the current legal framework, and relevant reports and materials in other jurisdictions, including the Victorian Government's inquiry into end-of-life choices, the *Voluntary Assisted Dying Act 2017* (Vic), and implementation of the associated reforms.

The Issues paper for the inquiry identifies that there is no universally accepted definition of assisted dying or of euthanasia. For the purpose of this submission, the terms 'voluntary assisted dying' and 'voluntary euthanasia' are used interchangeably.

A 2016 Issues paper of the Australian Human Rights Commission, *Euthanasia, human rights and the law*, concludes with a human rights-based analysis of voluntary euthanasia and commentary of the practice informed by human rights principles. The analysis states:

> **6 Analysis**
>
> An analysis of international human rights law relevant to the practice of voluntary euthanasia does not lead to 'the' answer. Rather it reveals a balancing of rights, the appropriate balance of which may be subject to competing views.

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> The right to life does not (as a corollary) include a right to choose to die. But nor does it require a State to ensure that a person's life is protected when this is against the express wishes of that person. In the case of a request for voluntary euthanasia, the State's obligation to protect life must be balanced against the right to personal autonomy which is contained within the right to privacy.
>
> Laws prohibiting access to voluntary euthanasia may interfere with the right to respect for private life as guaranteed under article 17 of the ICCPR, and as such need to be able to be justified as a legitimate limitation of that right.
>
> In relation to access to passive euthanasia, it is important to note that to subject a person to medical treatment against their will or without their consent may violate their physical integrity and breach their rights under article 17 (and possibly article 7) of the ICCPR.
>
> Further, the Disability Convention makes clear that people with disability are entitled to the same respect for their rights to life, health, physical integrity and personal autonomy as people without disability.
>
> If a State does choose to legalise voluntary euthanasia, article 6 of the ICCPR requires that the legislation includes strict and effective safeguards against abuse. In order to be compatible with the right to freedom of thought, conscience and belief, such laws may need to include an appropriately worded 'conscientious objection' provision.
>
> The analysis suggests that there is no one identifiable right that necessarily requires the legalisation of voluntary euthanasia, nor is there one identifiable right that prevents its legalisation, provided stringent safeguards are instituted. It would seem from a human rights perspective, the option exists to support legalisation of voluntary euthanasia practices provided that sufficient safeguards are put in place to prevent 'arbitrary' (including discriminatory) deprivations of life.

The AHRC Issues paper identified that the following rights under the *International Covenant on Civil and Political Rights* (ICCPR) may be engaged by the practice of voluntary euthanasia:

- right to life (article 6)
- freedom from cruel, inhuman or degrading treatment (article 7)
- right to respect for private life (article 17)
- freedom of thought, conscience and religion (article 18).

The *Convention on the Rights of Persons with Disabilities* contains specific obligations in relation to people with disability that are also relevant.

The *Human Rights Act 2019*, which is expected to commence on 1 January 2020, primarily protects human rights drawn from the ICCPR, as well as two rights drawn from the *International Covenant on Economic, Social and Cultural Rights* (ICESCR).

The following rights under the *Human Rights Act 2019* may be engaged in relation to voluntary assisted dying:

- recognition and equality before the law (section 15) – drawn from articles 16 and 26 of the ICCPR
- right to life (section 16) – drawn from article 6(1) of the ICCPR
- protection from torture and cruel, inhuman or degrading treatment (section 17) – drawn from article 7 of the ICCPR
- freedom of thought, conscience, religion and belief (section 20) – drawn from article18 of the ICCPR
- freedom of expression (section 21) – drawn from article 19 of the ICCPR
- privacy and reputation (section 24) – drawn from article 17 of the ICCPR
- protection of families and children (section 26) – drawn from articles 23(1), 24(1) and 24(2) of the ICCPR
- right to health services (section 37) – drawn from article 12 of the ICESCR.

The Victorian Scrutiny of Acts and Regulations Committee conducted a 'Charter Analysis'[1] of the Voluntary Assisted Dying Bill 2017, which has since become an Act in Victoria. The analysis involved consideration of similar rights in the Charter to those identified above. That Committee made the following observations and comments on the Bill:

- A deprivation of life by assisted dying may be 'arbitrary' if the person's consent to voluntary assisted dying is the result of outside pressure, irrationality or depression.
- The Charter rights of people under 18 or who have an incurable, advanced, progressive illness, disease or medical condition that is non-fatal or only fatal in the long-term to enjoy their human rights without discrimination may be engaged.
- The Charter right of people who are refused a voluntary assisted dying permit, despite otherwise being eligible for access to voluntary assisted dying and complying with Part 3 of the Bill, to equality before the law may be engaged.
- The Statement of Compatibility accompanying the Bill did not address how health practitioners (other than the co-ordinating and consulting medical practitioners) are to be given an opportunity to not participate in voluntary assisted dying.
- Various clauses limited how anyone, including family members, could discuss assisted dying with a person who may have a fatal illness.

The observations and comments of the Victorian Scrutiny of Acts and Regulations may assist this Committee in identifying human rights considerations relevant to

[1] Under the *Charter of Human Rights and Responsibilities Act 2006* (Vic) (the Charter), the Scrutiny of Acts and Regulations Committee is required to report on the compatibility of proposed legislation with the human rights under the Charter. The Queensland *Human Rights Act 2019* provides for a similar obligation on portfolio committees of the Queensland Parliament.

voluntary assisted dying, and to address issues such as safeguards to protect vulnerable people and conscientious objection of medical practitioners to voluntary assisted dying.

The approach of identifying the human rights that may be engaged and considering whether any limitation of the rights is reasonable and justified in accordance with section 13 of the *Human Rights Act 2019* would assist the Committee in this inquiry. It will necessitate finding an appropriate balance of human rights.

Yours sincerely

NEROLI HOLMES
Acting Commissioner
Anti-Discrimination Commission Queensland

Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying

Queensland Parliament
Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee

April 2019

Contact: Lisa Hillan
Director Programs, Policy and Knowledge Creation
Aboriginal and Torres Strait Islander Healing Foundation
PO Box 4363, Kingston ACT 2600
p 02 6272 7500

The Healing Foundation
April 2019

1. Introduction from the CEO

The Healing Foundation is a national Aboriginal and Torres Strait Islander organisation that partners with communities to address trauma and to promote positive healing outcomes for individuals, families and communities. Under the leadership of our Aboriginal and Torres Strait Islander Board and Stolen Generations Reference Group, we have become the lead national agency supporting evidence based healing programs and creating an understanding of the historical legacy of trauma and its manifestation in contemporary Aboriginal and Torres Strait Islander communities.

The Healing Foundation is pleased to contribute to the Queensland Parliamentary inquiry into aged care, end-of-life and palliative care and voluntary assisted dying. We wish to emphasise the importance of taking a trauma-informed, culturally-relevant approach to aged care for Aboriginal and Torres Strait Islander people.

It is well recognised that Aboriginal and Torres Strait Islander communities experience poor outcomes across a broad spectrum of social and economic indicators. New evidence now demonstrates that outcomes are even worse for Stolen Generations and their descendants, establishing an irrefutable link between the experience of trauma leading to poor social and economic outcomes for individuals, families and communities.

What is also evident is that government policies and programs seemingly disregard the level of trauma in our communities, and in many instances, exacerbate that trauma by imposing service models that continue to marginalize and disempower Aboriginal and Torres Strait Islander people.

The inquiry is an opportunity to emphasise the need to ensure Queensland policy and service systems provide culturally-responsive and trauma-informed care that meet the special needs of elderly Aboriginal and Torres Strait Islander people. The special nature and complexity of these needs is highlighted in the recently released AIHW report on vulnerabilities of Aboriginal and Torres Strait Islander people aged 50 and over[1], and in our commissioned work related to the specific experiences of Stolen Generations[2].

Consistent with the vision of the Aged Care Diversity framework[3], and given the high level of trauma and disadvantage experienced by Stolen Generations, it is essential that strategies and systems aimed at ensuring quality of care systems for ageing Australians specifically highlight the special needs of elderly Stolen Generations survivors and their descendants.

This submission provides practical approaches that can be applied to increase the effectiveness of policy and programs aimed at improving the wellbeing of elderly Aboriginal and Torres Strait

[1] Australian Institute of Health and Welfare 2019 Insights into vulnerabilities of Aboriginal and Torres Strait Islander people aged 50 and over—in brief https://www.aihw.gov.au/reports/indigenous-australians/vulnerabilities-aboriginal-torres-strait-50-over/contents/table-of-contents

[2] The Healing Foundation in press Our Healing: Meeting the urgent needs of Stolen Generations and addressing intergenerational trauma

[3] *"All older people experience a high quality aged care system that ensures equitable access and outcomes and embraces their diverse characteristics and life experiences."* *https://agedcare.health.gov.au/support-services/people-from-diverse-backgrounds/aged-care-diversity-framework*

Islander people, and for taking into account the complex needs of Stolen Generations. It identifies the sources and impact of trauma and the elements of healing approaches, and draws out the implications for providing culturally appropriate aged care.

We recommend that Queensland aged care policy, programs and services embed:

- design, delivery and ongoing evaluation of cultural competency and trauma awareness training programs that address racism, ensure accountability and measure meaningful compliance within aged care services. This is not only critical to improve the quality of service provision, it is essential to avoid inflicting further trauma on an already vulnerable and marginalised client group.
- healing and trauma-informed approaches that are applied holistically to aged care services and support for Aboriginal and Torres Strait Islander people. Assistance to navigate the aged care system and to connect across service domains should be staffed by Aboriginal and Torres Strait Islander people who are trained in trauma-informed practice. Where they are supporting Stolen Generations, they should have specialist knowledge and preferably lived experience of the Stolen Generations.
- leadership, collaboration and coordination across all levels of government, the non-government sector, industry and, most importantly, Aboriginal and Torres Strait Islander people to promote and support trauma and healing-informed policies, programs and services for elderly Aboriginal and Torres Strait Islander people.
- urgent action to ensure that Stolen Generations can access aged care services and support that meet their complex needs and which do not re-traumatise survivors. Organisations supporting and providing services to Stolen Generations must adopt trauma-informed, culturally relevant approaches at all levels including in their underpinning policies and systems, as well as for individual workers.
- commitments to co-design of policy and programs, and to investments in community-led services and programs that are supported over the long-term, so that self-determination becomes a reality for Aboriginal and Torres Strait Islander communities. This means, for example, that initiatives taken to address the needs of the Stolen Generations must be led by Stolen Generations members and centred on the needs that they themselves have identified.
- recognition of the value of cultural knowledge and how it can inform policy formation and service delivery.
- a strong evidence base with a commitment to co-evaluation that informs and empowers local decision-making at all levels, including local models of aged care.

Richard Weston
April 2019

2. About the Healing Foundation

The Healing Foundation is a national Aboriginal and Torres Strait Islander organisation that partners with communities to address trauma and to promote positive healing outcomes for individuals, families and communities. Under the leadership of our Aboriginal and Torres Strait Islander Board and Stolen Generations Reference Group, we have become the lead national agency supporting evidence based healing programs and creating an understanding of the historical legacy of trauma and its manifestation in contemporary Aboriginal and Torres Strait Islander communities.

3. Towards a trauma-aware/healing-informed, culturally relevant aged care system and workforce that can achieve good outcomes for elderly Aboriginal and Torres Strait Islander people

This submission to the Queensland Parliamentary Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying focuses on informing the Committee's responses to the questions:

- is the aged care system meeting the current needs of older Queenslanders, including those people with special needs?
- 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?
- is the mix of staff appropriate for different settings within the aged care sector?

Section 11-4 of the Commonwealth *Aged Care Act 1997* requires that the provision of care for people with special needs is considered in planning for, and the allocation of, new aged care places under the Act. Section 11-3 of the *Aged Care Act 1997* identifies Aboriginal and Torres Strait Islander peoples, care leavers, parents separated from their children by forced adoption or removal as people with special needs.

Government policy and program settings must go beyond good intentions and result in real improvements in outcomes for Aboriginal and Torres Strait Islander peoples, and in particular take into account the special needs of the Stolen Generations and their descendants.

The Healing Foundation's submission in relation to the current Productivity Commission Inquiry into the Social and Economic Benefits of Improving Mental Health sets out the case for taking trauma-informed, culturally-relevant approaches to delivering services and support to Aboriginal and Torres Strait Islander people (Attachment 1)[4].

Evidence demonstrates that outcomes for Aboriginal and Torres Strait Islander people will be enhanced by:

- recognising the extent of intergenerational and collective trauma and the associated trauma burden

[4] The Healing Foundation submission to Productivity Commission Inquiry into the Social and Economic Benefits of Improving Mental Health 2019 (attached). https://www.pc.gov.au/__data/assets/pdf_file/0016/240415/sub193-mental-health.pdf

- adopting effective healing frameworks that recognise that collective trauma requires collective healing
- an overarching policy framework that is integrated across all sectors and embedded in systems, frameworks, policies and services
- acknowledging the primacy of Aboriginal and Torres Strait Islander values and cultural governance
- commitment to programmatic co-design principles that privilege Indigenous knowledge
- building capacity for healing/informed approaches and trauma-informed services
- developing and promulgating a strong evidence base and applying evidence-based practices, with a commitment to co-evaluation that informs and empowers local decision-making.

It is also important to recognise that there are diverse needs within Aboriginal and Torres Strait Islander communities, and in particular to have increased understanding and support for Stolen Generations and their families. These needs are set out in the Healing Foundation's submission to the Aged Care Diversity Framework - Action Plan for Aboriginal and Torres Strait Islanders[5] (Attachment 2).

Trauma is pervasive, collective and intergenerational

International and national evidence demonstrates that colonisation and past and present government policies have led to trauma for Aboriginal and Torres Strait Islander people across generations. This trauma limits (or removes) the ability to act in empowered ways and leads to a number of negative outcomes, which in turn mean Aboriginal and Torres Islander people are limited in their capacity to initiate / take up development opportunities – regardless of external resources. Healing is an essential (although not sufficient) condition of any support for Aboriginal and Torres Strait Islander development in Australia. This characterisation of the context for enabling better outcomes for Aboriginal and Torres Strait Islander people can be applied in all domains, including aged care.

Governments, service providers, and indeed many Aboriginal and Torres Strait Islander communities themselves, are currently ill-equipped to deal with the complex trauma facing many of our people. If external service providers and government fail to address collective trauma, policies will continue to undermine individual and community development. People will likely respond to the ongoing impact of trauma with negative behaviours for themselves and their families. Further, even when offered opportunities to change the situation the lack of control will mean that people are less likely to take up those opportunities. Finally, ongoing attempts by others to 'help' in such situations, without attention to underlying trauma and related issues, runs the risk of extending and perpetuating a sense of lack of control (and trauma) rather than promoting healing[6].

We cannot allow a failure to understand and respond to this trauma burden to prevent significant improvements in outcomes for elderly Aboriginal and Torres Strait Islander people. Trauma and

[5] The Healing Foundation submission to Aged Care Diversity Framework, Action Plan for Aboriginal and Torres Strait Islanders, 2018, unpublished (attached).
[6] Social Compass 2016 A Theory of Change for Healing, prepared in partnership with the Institute for Human Security and Social Change p14

healing remains a key missing ingredient in Australia's Indigenous reform efforts. Unless we factor recognition of intergenerational and collective trauma into the co-design of Aboriginal and Torres Strait Islander programs and program evaluations for aged care, we will be faced with another set of services that fail to meet the needs of Aboriginal and Torres Strait Islander people.

4. Addressing the needs of Stolen Generations

Section 11-3 of the *Aged Care Act 1997* identifies Aboriginal and Torres Strait Islander peoples, care leavers, parents separated from their children by forced adoption or removal as people with special needs. These categories encompass the Stolen Generations. Stolen Generations have been identified as a 'special needs' group, by DOHA and others in submissions to the National Aboriginal and Torres Strait Islander Health Plan and to the review of aged care but this has not necessarily led to a systemic response that ensures policies and programs specifically cater for the experiences of the Stolen Generations and their families[7].

Two-thirds of Stolen Generations were already aged 50 or more in 2015, and the remaining third will be aged 50 or more by 2023[8]. Qualitative and quantitative analysis recently undertaken for the Healing Foundation indicates that Stolen Generation survivors have complex needs and are significantly more disadvantaged than Aboriginal and Torres Strait Islander people of a similar age who were not removed.

The work published by the Australian Institute of Health and Welfare[9] demonstrates that for Stolen Generations aged 50 and over in 2014-15, 89% did not have good health (using a composite health measure); 76% did not own their own home; 79% relied on government payments as their main source of income; and 64% had household incomes in the lowest thirty percent. Almost 40% have poor mental health, nearly 70% have a disability, and 18% have a profound disability[10].

Approximately one third reported they had problems accessing services in the previous 12 months[11].

Almost 25% of Stolen Generations aged 50 and over live in Queensland (approximately 3450 people in 2014-15), **making up 13.5% of all Aboriginal and Torres Strait Islander people aged 50+ in the state[12].**

[7] McCausland R, Nettheim, A, & Kang C Qualitative *analysis of documentation of the contemporary experience and needs of the Stolen Generations*, Research Paper for the Healing Foundation, December 2017 unpublished

[8] Australian Institute of Health and Welfare 2018 Aboriginal and Torres Strait Islander Stolen Generations and descendants Numbers, demographic characteristics and selected outcomes https://www.aihw.gov.au/reports/indigenous-australians/stolen-generations-descendants

[9] Australian Institute of Health and Welfare 2018 Aboriginal and Torres Strait Islander Stolen Generations aged 50 and over. Infocus, published November 2018 https://www.aihw.gov.au/reports/indigenous-australians/stolen-generation-aged-50-and-over

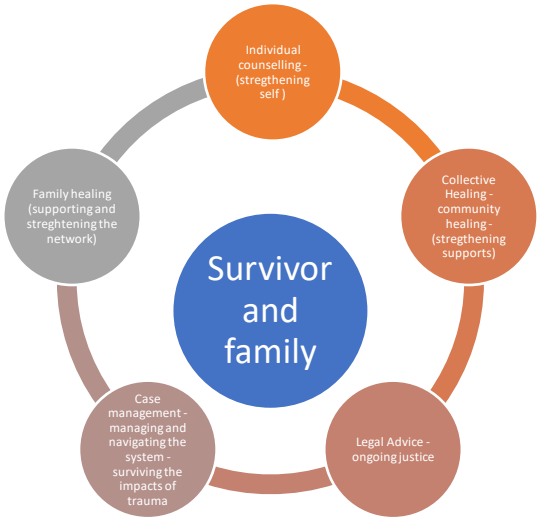
[10] Australian Institute of Health and Welfare 2018 Aboriginal and Torres Strait Islander Stolen Generations and descendants Numbers, demographic characteristics and selected outcomes https://www.aihw.gov.au/reports/indigenous-australians/stolen-generations-descendants

[11] Australian Institute of Health and Welfare 2018 Aboriginal and Torres Strait Islander Stolen Generations aged 50 and over. Infocus, published November 2018 https://www.aihw.gov.au/reports/indigenous-australians/stolen-generation-aged-50-and-over

[12] Australian Institute of Health and Welfare 2018 Aboriginal and Torres Strait Islander Stolen Generations aged 50 and over. Infocus, published November 2018 https://www.aihw.gov.au/reports/indigenous-australians/stolen-generation-aged-50-and-over

Fourteen per cent (14%) of all respondents to the Royal Commission into Institutional Responses to Child Sexual Abuse were Aboriginal and Torres Strait Islanders[13]. Nearly 1000 Aboriginal and Torres Strait Islander individuals came forward to tell of the distressing impact of childhood sexual abuse in institutions that they suffered and the trauma inflicted on their lives. Many of these survivors were elderly and are also members of the Stolen Generations. This indicates that the trauma burden for our Stolen Generations and their descendants is significant, pervasive and due to a lack of comprehensive government responses, remains largely unresolved.

Many survivors experience complex trauma needs and many require additional case management supports to assist them to deal with the impact of that trauma. Many are now interacting with multiple systems and require support to deal with health, homelessness and intergenerational trauma family issues, as well as aged are. We have illustrated an emerging model of healing aimed at to supporting survivors needs.



The Healing Foundation submission to the Aged Care Diversity Framework, Action Plan for Aboriginal and Torres Strait Islander people[14] recommended that:

- healing frameworks should be applied holistically to aged care services and support for Aboriginal and Torres Strait Islander people. This is an opportunity to establish an aged care system/framework that acknowledges the history and impact of colonisation, and subsequent policies such as removing children from their families

[13]Royal Commission into Child Sexual Abuse 2017 A brief guide to the final report: Aboriginal and Torres Strait Islander Communities.

[14] The Healing Foundation submission to Aged Care Diversity Framework, Action Plan for Aboriginal and Torres Strait Islanders (attached).

- in order to exercise greater self-determination in relation to policies and decisions that impact on them, Stolen Generations must be invited into negotiations that determine services and policies as an equal negotiating partner
- initiatives taken to address the needs of the Stolen Generations must be led by Stolen Generations members and centred on the needs that they themselves have identified
- urgent action is needed to ensure that Stolen Generations are able to access aged care services and support that meet their complex needs, and which do not re-traumatise survivors
- funding and programs need to be in place that enable Stolen Generations and their descendants to address intergenerational trauma and achieve healing including through individual counselling; intergenerational healing strategies; collective healing approaches such as healing camps and on-country programs; and in healing centres accessible to Stolen Generations across all jurisdictions in cities and regional and remote areas
- aged care support and services need to be sufficiently flexible and resourced to enable enhanced cultural connection for elderly Stolen Generations and their families, including support to return to country and being buried on country
- non-institutional models of aged care and support need to be urgently investigated and adopted to avoid re-traumatisation. This includes services and support from Aboriginal and Torres Strait Islander organisations with specific focus on Stolen Generations, and avoiding government and non-government service providers who were historically associated with removal of children
- organisations supporting and providing services to Stolen Generations must adopt trauma-informed, culturally relevant approaches at all levels including in their underpinning policies and systems, as well as for individual workers
- direct points of contact and clear pathways are required to assist Stolen Generations survivors to navigate the service system by providing information and making referrals to appropriate services would be useful additions to service systems. Such points of contact should be staffed by people who are trained in trauma-informed practice and have specialist knowledge about the Stolen Generations, and preferably who are Aboriginal or Torres Strait Islander people and with lived experience of Stolen Generations.

The implication for the aged care system is that there is an urgent need to ensure that there is a workforce equipped to support and care for a cohort of elderly survivors who have experienced severe trauma as a result of being forcibly removed from their families, and then who may have been abused in institutional care. Survivors are more likely to suffer from poor mental health, and are very likely to have physical disabilities and chronic illnesses. Many fear being re-institutionalised, and want services provided by organisations that were not associated with earlier removal policies.

The acknowledgement of this trauma, its impact, and the need for culturally-relevant, trauma-informed services must be embedded in organisational policies, systems and practices. Staff and management at all levels must be equipped and supported to provide trauma-informed and culturally relevant care.

This includes offering a choice of service models, co-designed and negotiated with the full cooperation of Stolen Generations and their carers. It also involves ensuring that clients are integral in setting and measuring performance standards.

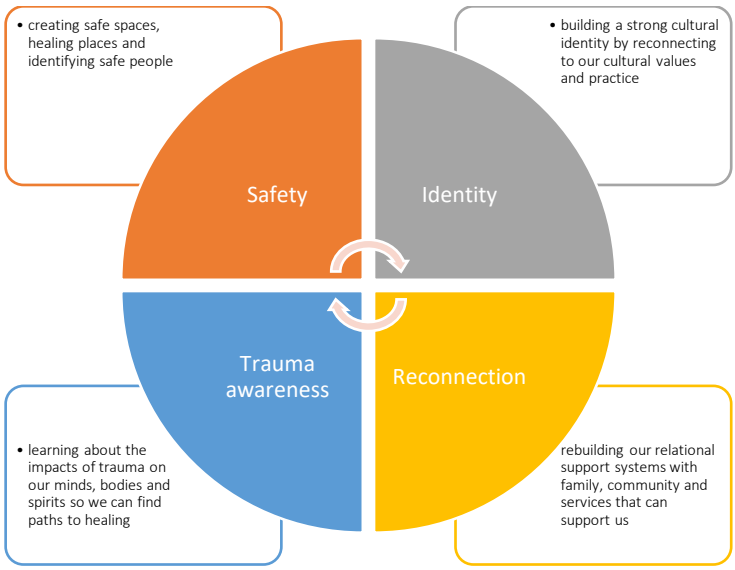
In principle, these settings are similar to those recommended for the broader population of elderly Aboriginal and Torres Strait Islander people[15]. In practice, supporting and caring for Stolen Generations requires a greater level of diligence to avoid re-traumatisation and to address the complex needs experienced by survivors.

As part of the Action Plan for Healing for Stolen Generations, the Healing Foundation has funding from the Department of the Prime Minister and Cabinet to work with Stolen Generations, their carers and other stakeholders to develop resources for the aged care sector that focus on the special needs of the Stolen Generations. However, much more needs to be done in this area to prevent further traumatisation and ensure a workforce that is culturally capable and trauma responsive.

4.1 Healing

Through its work, the Healing Foundation has developed four pillars of trauma recovery[16]:

- Safety: creating safe spaces, healing places and identifying safe people to support healing;
- Identity: building a strong cultural identity by reconnecting to our cultural values and practice;
- Reconnection: rebuilding our relational support systems with family, community and services that can support us; and
- Trauma awareness: learning about the impacts of trauma on our minds, bodies and spirits so we can find paths to healing.



[15] Department of Health 2019 Actions to support older Aboriginal and Torres Strait Islander people https://agedcare.health.gov.au/actions-to-support-older-aboriginal-and-torres-strait-islander-people

[16] Healing Foundation with Adams, M, Bani, G, Blagg, H, Bullman, J, Higgins, D, Hodges B, Hovane, V, Martin-Pederson, M, Porter, A, Sarra, G, Thorpe A and Wenitong M 2017. *Towards an Aboriginal and Torres Strait Islander violence prevention framework for men and boys.* The Healing Foundation and White Ribbon Australia

Healing-informed approaches based on these pillars can improve outcomes across a range of health and well-being domains, including mental health and social and emotional well-being.

International and local research indicates that healing programs should be specific to local regions and groups, and are best delivered on country by people from the same cultural group as participants[17]. Localisation of healing can ensure a trauma-informed approach delivered by skilled workers who understand the history and collective experiences of local Aboriginal people, 'both traumatic and positive'.[18] Quality healing balances Indigenous and western concepts, may provide for individual support within a broader collective approach, and supports cultural and spiritual renewal concurrently with psychological and therapeutic support.

Holistic healing for individuals, families and communities needs a strong focus on spirituality and culture. It is critical that aged care programs focussed on Aboriginal and Torres Strait Islander people are underpinned by Aboriginal and Torres Strait Islander principles and values including:

- respect: this includes respect for Aboriginal and Torres Strait Islander culture, kinship structures and governance and for principles of respect that guide conversations and ensure safety for everyone at a local level
- accountability and confidence: people must be accountable for their behaviour; government and other service providers must be accountable to community and community leaders; and members must demonstrate accountability to each other. We must work with communities to restore their confidence in governance
- safety: everyone – including women, children, Elders and men – has the right to feel safe and live in peaceful household and community environments. Everyone must be afforded protection through traditional cultural lore/law and under mainstream Australian law

Community healing requires the creation of 'safe spaces'. A common element in many programs that create safety is leadership by Aboriginal and Torres Strait Islander people who have made considerable progress on their own healing journey. Healing works best when it is in combination with other strengths and activities. For example, when there is a good organisation or a strong community with other activities established and where healing can come in as part of a wider package of change. This suggests healing is not a 'cure' on its own but works best when it is part of a comprehensive enabling approach[19]

Aboriginal and Torres Strait Islander cultural governance[20] allows communities to engage in governing with a focus on empowering Indigenous decision-making. Cultural governance facilitates strong leadership and representation with integrity that gives voice and effect to community members through appropriate engagement channels – and processes that are inclusive, accessible,

[17] The Healing Foundation (2014). Our Healing Our Solutions: Sharing Our Evidence
[18] Caruana, C 2010, *'Healing services for Indigenous people*', Family Relationships Quarterly, vol. 17, pp. 3–9. in The Healing Foundation 2014 Our Healing Our Solutions: Sharing Our Evidence':18
[19] Social Compass 2016 A Theory of Change for Healing, prepared in partnership with the Institute for Human Security and Social Change for the Healing Foundation, unpublished.
[20] Healing Foundation with Adams, M, Bani, G, Blagg, H, Bullman, J, Higgins, D, Hodges B, Hovane, V, Martin-Pederson, M, Porter, A, Sarra, G, Thorpe A and Wenitong M (2017). *Towards an Aboriginal and Torres Strait Islander violence prevention framework for men and boys.* The Healing Foundation and White Ribbon Australia

open and transparent – so that decisions are made in accordance with, for, and by the will of the people. It involves honouring and respecting traditional cultural process, lore and practice, and charging the local leadership with responsibility to govern. When strong cultural governance is respected, honoured, consulted and followed, it enables successful community led and owned solutions, offering greater potential for local buy in or support, which increases the likelihood of positive outcomes and contributes to broader community transformation.

4.2 Co-design and co-evaluation of policy, programs and services

Aboriginal and Torres Strait islander people continue to face barriers to effective engagement with the services that are funded to support them[21]. Communities tell us that government and the non-government organisations funded by them continue to impose programs and services, rather than engage in genuine co-design processes that allow communities to identify their own needs, priorities and indicators of success and who is best placed to deliver those services. Additionally, governments continue to fund non-government agencies that have a recent history of removal of Aboriginal and Torres Strait Islander children and then question why community members are not engaging with the service.

Government commitment to programmatic co-design principles that privilege Indigenous knowledge is a critical element of achieving effective policy and program outcomes. For example, the approach to developing the Commonwealth Government's Aged Care Workforce Strategy[22] was based on 'consultation' with people and organisations. In contrast with 'consultation', co-design of programs involves services and communities working together from the outset to develop services and programs that are genuinely informed by the clients. By working directly with Aboriginal and Torres Strait Islander people on every aspect of strategy design and evaluation, communities can ensure that actions are designed to be safe, accessible and culturally and locally relevant.

An effective co-design process empowers communities, promotes leadership, supports self-determination to become a reality, and ensures that programs and strategies are based in local cultural knowledge and practice. In turn, this community-led approach enables Aboriginal and Torres Strait Islander communities to tailor actions to the circumstances of individual communities and/or regions.

Co-design processes also provide opportunities to acknowledge the 'tensions in relationships [between communities and governments and other service providers] and lack of trust that is the result of this history'[23], which is essential if effective partnerships are to be established. It also allows service delivery to be tailored to cultural boundaries, which are often quite different to administrative or jurisdictional boundaries. Co-design requires a genuine willingness for government and non-Indigenous organisations to change and, to some extent, surrender control. It 'demands that public service staff shift from fixers who focus on problems to enablers who focus on abilities,

[21] The Healing Foundation submission to the Social and Cultural Determinants of Health. Department of Health, 2017. See My Life, My Lead Consultation Report
[22] Department of Health Aged Care Workforce Strategy Resources https://agedcare.health.gov.au/aged-care-workforce-strategy-resources
[23] Social Compass 2016 A Theory of Change for Healing, prepared in partnership with the Institute for Human Security and Social Change for the Healing Foundation, unpublished.

enabling community ownership and a continued commitment to local needs, culture and knowledge systems'[24].

Co-design allows communities the opportunity to identify their own goals, Co-design also allows communities the opportunity to identify their own goals, aspirations and indicators of success, which can inform a meaningful evaluation framework.

The Healing Foundation recognises the importance of applying evidence-based practices in achieving improved outcomes for First Australians. Aboriginal and Torres Strait Islander programs and services tend to be subjected to evaluations focused on the measurement of centrally determined outcomes that give no consideration to Aboriginal and Torres Strait Islander views on what constitutes success.

Western theoretical frameworks underpin evaluation approaches that seek to measure individual outcomes, with no regard for the collective nature of Aboriginal and Torres Strait Islander communities.

Evaluation frameworks must have a true commitment to co-creation of knowledge, create safe spaces for our communities to share wisdom and acknowledgement for their understanding and consider indicators of community-level change. To this end the Healing Foundation supports reflective practice with communities, empowering them to build their own evidence, rather than relying on external evaluators to undertake outcome analysis in isolation of community.

We support the establishment of a fully resourced, specialist platform for sharing knowledge, best practice models and guidance to overcome common challenges in Aboriginal and Torres Strait Islander aged care. Such forums provide space for community developed knowledge and practices, guidance for educators and other support professionals, as well as community driven leadership in the space of culturally responsive trauma informed practice. Readily available and easily applicable information about evidence-based practice is an invaluable resource to build capacity among service managers and staff.

4.3 Workforce

This section describes the implications for workforce development, inherent in the previous sections about trauma, healing and program co-design and co-evaluation.

Clearly, organisations working alongside Aboriginal and Torres Strait Islander communities must have the workforce capability to work effectively with people and communities impacted by trauma, and to adopt healing approaches to service delivery that empower Aboriginal and Torres Strait Islander people. From a workforce perspective, this means that staff (including managers) at all levels must be equipped and supported to put healing and co-design approaches into practice.

[24] Healing Foundation (2015). Our Men, Our Healing: Creating Hope, Respect and Reconnection. Evaluation Report Executive Summary.

Common elements of a trauma-informed service model[25] include understanding trauma and its impacts, creating safe places[26], employing culturally competent staff, actively involving trauma survivors in their healing, sharing power and governance through community co-design, providing integrated holistic care, and supporting safe relationship building to promote healing.

The work of the Healing Foundation supports organisations and workers to become trauma-informed and to apply collective healing approaches in delivering programs and services. An analysis of Training and Education[27] projects funded by the Healing Foundation to provide work place training opportunities for developing skills for understanding and managing the outcomes of trauma, indicated that the great majority of participants did not understand that trauma played a role in their own lives and behaviours, and that developing this understanding was transformative in many cases. The independent evaluation found that the workforce training provided workers with the opportunity to better understand the impact of trauma and grief on the communities where they work. The data showed a significant improvement in workers' confidence to recognise and address trauma as a result of the training which in turn better positions services to assist in Aboriginal and Torres Strait Islander healing.

Despite increasing references to trauma awareness across the health sector, feedback from community practitioners and members suggests there is still a significant gap in the accessibility of genuinely trauma-informed psychological and therapeutic support. Atkinson suggests common elements of a trauma-informed service model include understanding trauma and its impacts, creating safe places, employing culturally competent staff, actively involving trauma survivors in their healing, sharing power and governance through community co-design, providing integrated holistic care and supporting safe relationship building to promote healing (Atkinson 2013)[28]. Trauma-informed practitioners are mindful that the symptoms of trauma can be misdiagnosed and that the presence of trauma can undermine the potential impacts of therapeutic interventions (Miller and Najavits 2012)[29].

Where trauma impact in community is significant, it can result in a large load for staff of service providers and community members including high staff turnover. Much more needs to be done to provide qualified healing training and supervision for Aboriginal and Torres Strait Islander organisations to be able to deal with highly traumatised people, including supporting staff. This would not only enable them to support their staff well, but would increase the quality of the supports available for survivors and the opportunity to heal.

[25] Atkinson J 2013. 'Trauma-informed services and trauma-specific care for Indigenous Australian children'. Closing the Gap Resource Sheet No 21.
[26] Given the levels of trauma among Aboriginal and Torres Strait Islander people it is also important that safety planning is conducted for any gathering where discussion could trigger trauma among participants. Safety plans should include establishing rules of respect, having a time out space, identifying people with counselling skills to support participants, and follow-up to ensure the safety and wellbeing of participants after any yarn that explores trauma-awareness.
[27] The Healing Foundation (undated) Training and Education Vol 2, Journey to Healing December 2012-November 2013
[28] Atkinson J 2013. 'Trauma-informed services and trauma-specific care for Indigenous Australian children'. Closing the Gap Resource Sheet No 21.
[29] Miller NA, Najavits LM. Creating trauma-informed correctional care: a balance of goals and environment. *European Journal of Psychotraumatology*

5. Conclusion

This submission provides practical approaches that can be applied to increase the effectiveness of policy and programs aimed at improving the wellbeing of elderly Aboriginal and Torres Strait Islander people, and for taking into account the complex needs of Stolen Generations.

We recommend that Queensland aged care policy, programs and services embed:

- design, delivery and ongoing evaluation of cultural competency and trauma awareness training programs that address racism, ensure accountability and measure meaningful compliance within aged care services. This is not only critical to improve the quality of service provision, it is essential to avoid inflicting further trauma on an already vulnerable and marginalised client group.
- healing and trauma-informed approaches that are applied holistically to aged care services and support for Aboriginal and Torres Strait Islander people. Assistance to navigate the aged care system and to connect across service domains should be staffed by Aboriginal and Torres Strait Islander people who are trained in trauma-informed practice. Where they are servicing Stolen Generations, they should have specialist knowledge and preferably lived experience of the Stolen Generations
- leadership, collaboration and coordination across all levels of government, the non-government sector, industry and, most importantly, Aboriginal and Torres Strait Islander people to promote and support trauma and healing-informed policies, programs and services for elderly Aboriginal and Torres Strait Islander people
- urgent action to ensure that Stolen Generations can access aged care services and support that meet their complex needs and which do not re-traumatise survivors. Organisations supporting and providing services to Stolen Generations must adopt trauma-informed, culturally relevant approaches at all levels including in their underpinning policies and systems, as well as for individual workers
- commitments to co-design of policy and programs, and to investments in community-led services and programs that are supported over the long-term, so that self-determination becomes a reality for Aboriginal and Torres Strait Islander communities. This means, for example, that initiatives taken to address the needs of the Stolen Generations must be led by Stolen Generations members and centred on the needs that they themselves have identified
- recognition of the value of cultural knowledge and how it can inform policy formation and service delivery
- a strong evidence base with a commitment to co-evaluation that informs and empowers local decision-making at all levels, including local models of aged care.

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Attachment 1

2019

Productivity Commission

The Social and Economic Benefits of Improving Mental Health

SUBMISSION BY THE ABORIGINAL AND TORRES STRAIT ISLANDER HEALING FOUNDATION

Executive Summary

The Healing Foundation is a national Aboriginal and Torres Strait Islander organisation that partners with communities to address trauma and to promote positive healing outcomes for individuals, families and communities. Under the leadership of our Aboriginal and Torres Strait Islander Board and Stolen Generations Reference Group, we have become the lead national agency supporting evidence based healing programs and creating an understanding of the historical legacy of trauma and its manifestation in contemporary Aboriginal and Torres Strait Islander communities.

This submission highlights irrefutable evidence, demonstrating the link between trauma and poor social and economic outcomes for Aboriginal and Torres Strait Islander people. It highlights the importance of an Indigenous focused and led response and presents a framework for achieving sustainable social and economic benefits for Aboriginal and Torres Strait Islander communities.

Aboriginal and Torres Strait Islander conceptualisation of health is holistic. It encompasses mental, physical, cultural and spiritual health. Improving mental health outcomes for Aboriginal and Torres Strait Islander people requires a collaborative approach, including services outside the health sector such as; employment, education, housing, family services, crime prevention and justice. Focusing exclusively on the delivery of mental health services is limiting and is unlikely to lead to measurable results.

In addressing mental ill-health, it is important to recognise that Aboriginal and Torres Strait Islander communities are very diverse. The challenges and experiences of communities in remote settings are vastly different to the experiences of communities that reside in rural or urban settings. Furthermore, traditional cultural and language practices vary greatly.

The Australian Institute of Health and Welfare Report for Indigenous Health Welfare (2015) stated that Indigenous adults living in non-remote areas were significantly more likely to have high or very high levels of psychological distress than those in remote areas (32% and 24%, respectively).

It is well recognised that Aboriginal and Torres Strait Islander communities experience poor outcomes across a broad spectrum of social and economic indicators. New evidence now demonstrates that outcomes are even worse for Stolen Generations and their descendants, establishing a clear link between the experience of trauma leading to poorer social and economic outcomes for individuals, families and communities. The Australian Institute of Health and Welfare report on Stolen Generations and their descendants, published in November 2018, confirmed that there is an estimated 17,150 Stolen Generations across Australia. The report paints a disturbing picture of health, social and economic factors for Stolen Generations:

- 70% rely on government payments as their main source of income
- 62% live in households within the lowest three income percentile bands
- 62% of working age are not employed
- 39% (over the age of 50) report poor mental health

Intergenerational trauma is a thread that links chronic diseases, poor emotional health, mental illness, substance/alcohol abuse, and disengagement from education and work, among other issues. There is also clear evidence that if not healed, trauma negatively affects neurological development which can be passed on to future generations[1].

[1] Van Der Kolk, B. (2014), The Body Keeps the Score

Past government approaches have exclusively focused on the symptoms of mental ill-health, including domestic and family violence, alcohol and substance misuse, child welfare and justice issues. There needs to be a new approach where these symptoms are addressed in unison with tackling root causes. In recognition of this, the most effective policy and service delivery models are nimble and tailored, rather than one dimensional in their approach.

The Healing Foundation has identified eight key focus areas for change:

1. Focus on early intervention
2. Make the system easier to navigate
3. Improve accessibility of services
4. Design better service models via meaningful co-design
5. Establish better ways of measuring success
6. Improve workforce skill and capacity
7. Eliminate suicide and its impact
8. Support effective Indigenous healing frameworks

Recommendations

The Healing Foundation puts forward the following recommendations to support and enable social and economic benefits of improving mental health for Aboriginal and Torres Strait Islander communities:

- Invest in specialised and targeted mental health support options for Stolen Generation survivors and their families, in recognition of the unique and complex challenges that they face, as substantiated by the disturbing AIHW data referenced in this submission.

- Invest in localised, culturally competent mental health support service infrastructure, particularly in regional and remote areas where the cost of accessing mental health support services is beyond the reach of many vulnerable high need's groups.

- Commit to co-design of mental health policy, service delivery models and programs, so that locally developed healing responses are resourced, monitored and evaluated to strengthen the evidence base and enable greater culturally based solutions to emerge.

- Increase the number of trauma informed, trained and qualified Aboriginal and Torres Strait Islander staff across all spectrums of the mental health service sector, in response to the high proportion of Aboriginal and Torres Strait Islander clients that require servicing.

- Invest in the design, delivery and ongoing evaluation of cultural competency and trauma awareness training programs that address racism, ensure accountability and measure meaningful compliance. This is not only critical to improve the quality of service provision, it is essential to avoid inflicting further trauma on an already vulnerable and marginalised client group.

- Strategies are required to assist Aboriginal and Torres Strait Islander people to effectively navigate the mental health system (refer to community education and advocacy recommendations), to connect to appropriate support, particularly in regional and remote areas where service infrastructure is sparse.

- Organisations supporting and providing mental health services must adopt trauma-informed, culturally relevant approaches at all levels of service provision, including in their underpinning policies and service systems.

- Structural and systemic racism/discrimination needs to be eradicated from the mental health sector urgently. Improvements should be monitored closely via the implementation of client satisfaction surveys for marginalised client groups, to measure improvements against benchmark indicators.

- A comprehensive and targeted Workforce Development Plan is required as a matter of urgency. This should aim to address skill shortages, improve workforce retention rates in regional and remote areas and importantly, to set measurable and transparent targets for the recruitment of an Aboriginal and Torres Strait Islander Workforce as its main objective.

- A comprehensive Safety and Emotional Wellbeing Plan is required to prevent burnout of the workforce, ensuring that workers themselves have strong social and emotional wellbeing to provide quality services to clients. This is especially important for Aboriginal and Torres Strait Islander Workers that have the added burden of carrying community pressures and obligations that exceed the responsibilities of their professional roles.

Introduction

This submission highlights irrefutable evidence, demonstrating the link between trauma and poor social and economic outcomes for Aboriginal and Torres Strait Islander people. It highlights the importance of an Indigenous focused and led response and presents a framework for achieving sustainable social and economic benefits for Aboriginal and Torres Strait Islander communities.

Nationally, Aboriginal and Torres Strait Islander communities have suffered significant trauma because of colonisation. Generations have experienced wave after wave of debilitating shocks and harmful events including massacres, forced removal of children, forced removal from country, the destruction of Indigenous forms of governance, and the breakdown of family and community functioning. This experience has left individuals, families and communities in immense pain and has resulted in wide spread trauma that is cumulative and collective in nature.

The Australian Institute of Health and Welfare report on Stolen Generations and their descendants, published in November 2018, confirmed that there is an estimated 17,150 Stolen Generations across Australia, of these 56% were women and 46% men. The majority of Stolen Generation Survivors reside in either New South Wales, Queensland or Western Australia (73% in total). The report paints a disturbing picture of health, social and economic factors for Stolen Generations:

- 67% live with a disability or restrictive long-term condition
- 70% rely on government payments as their main source of income
- 62% live in households within the lowest three income percentile bands
- 62% of working age are not employed
- 39% (over the age of 50) report poor mental health

Compared to other Aboriginal and Torres Strait islanders in the same age group that **were not** removed from their families, Stolen Generations are:

- 3.3 times more likely to have been incarcerated within the past 5 years
- 1.8 times more likely to rely on government payments as their main source of income
- 1.6 times more likely to be unemployed
- 1.6 times more likely to suffer poor health
- 1.6 times more likely to have experienced homelessness in the past 10 years
- 1.5 times more likely to have mental health problems

It is important to recognise that the abovementioned figures are compared to a reference group of other Aboriginal and Torres Strait Islander aged 50 and over. The figures would be much worse if they were compared to the mainstream population.

The Healing Foundation has a Stolen Generations Reference Group that provides critical guidance for work relating to Stolen Generations. One of the strongest messages from this group, has been to focus on the needs of future generations and to address intergenerational trauma as a priority.

Intergenerational trauma is a thread that links chronic diseases, poor emotional health, mental illness, substance/alcohol abuse, and disengagement from education and work, among other issues. There is

also clear evidence that if not healed, trauma negatively affects neurological development which can be passed on to future generations[2].

In 2014/15 there were an estimated 114,800 descendants of Stolen Generations. This equates to 33% of the adult national Aboriginal and Torres Strait Islander population (or 1 in 3). Compared to other Aboriginal and Torres Strait Islanders, Stolen Generation Descendants are:

- 2.0 times more likely to have experienced discrimination in the past 12 months
- 1.9 times more likely to have experienced violence in the last 12 months
- 1.6 times more likely to be in poor health
- 1.5 times more likely to have been arrested by Police in the past 5 years
- 1.4 times more likely to have low levels of trust in the general community
- 1.4 times more likely to report poor mental health

This data demonstrates the devastating impact of trauma and how it directly leads to poorer social and economic outcomes.

Trauma and Mental Health

Emerging evidence continues to strengthen the link between the experience of trauma and poor mental health outcomes. The National Aboriginal and Torres Strait Islander Suicide Prevention Strategy 2013 emphasised the importance of acknowledging that trauma is a key element of mental health issues for Aboriginal and Torres Strait Islander people.

Medical research has also proven that trauma interferes with neurobiological development and undermines capacity to integrate sensory, emotional and cognitive information into a cohesive whole. This results in 'unfocused' responses to stress, resulting in significantly increased engagement in medical, correctional, social and mental health services.

Living with trauma diverts a person's energy to manage the physical and emotional impacts of trauma. This, along with poor educational outcomes, undermines the ability of Aboriginal and Torres Strait Islander people to engage in employment, which is correlated with poverty, overcrowded housing and poor standards of living.

It is important to understand the impacts of collective trauma as opposed to individual trauma, with research demonstrating that significant events that impact whole communities, have devastating social consequences, causing community breakdown and loss of connection to community. This emphasises the need to prioritise collective healing responses rather than focusing on individual treatment interventions. Given that communities live collectively and experience distress collectively, this is critical to creating real change.

Despite increasing references to trauma awareness across the mental health sector, feedback from Aboriginal and Torres Strait Islander practitioners and community members, suggest there is still a significant gap in the accessibility of genuinely trauma-informed psychological and therapeutic support.

[2] Van Der Kolk, B. (2014), The Body Keeps the Score

National Healing Forums

Since 2016, the Healing Foundation has facilitated 19 national healing forums across the country, engaging government and non-government agencies and Aboriginal and Torres Strait Islander community members in the identification of key issues that are impacting on the social and emotional wellbeing of Aboriginal and Torres Strait Islander communities.

The healing forums provide a unique opportunity for communities to have strong voice in identifying issues that are impacting on them, and to devise locally developed solutions and options to address those issues. The Healing Foundation utilises these national healing forums to validate emerging evidence and to ensure that priorities are determined in genuine partnership and collaboration with local Aboriginal and Torres Strait Islander communities, instead of - on behalf of them.

Social and Economic Benefit Realisation

The Healing Foundation has identified eight key focus areas that will lead to social and economic benefits relating to mental health for Aboriginal and Torres Strait Islander people. Each of the eight elements are depicted in the following chapters of this submission.

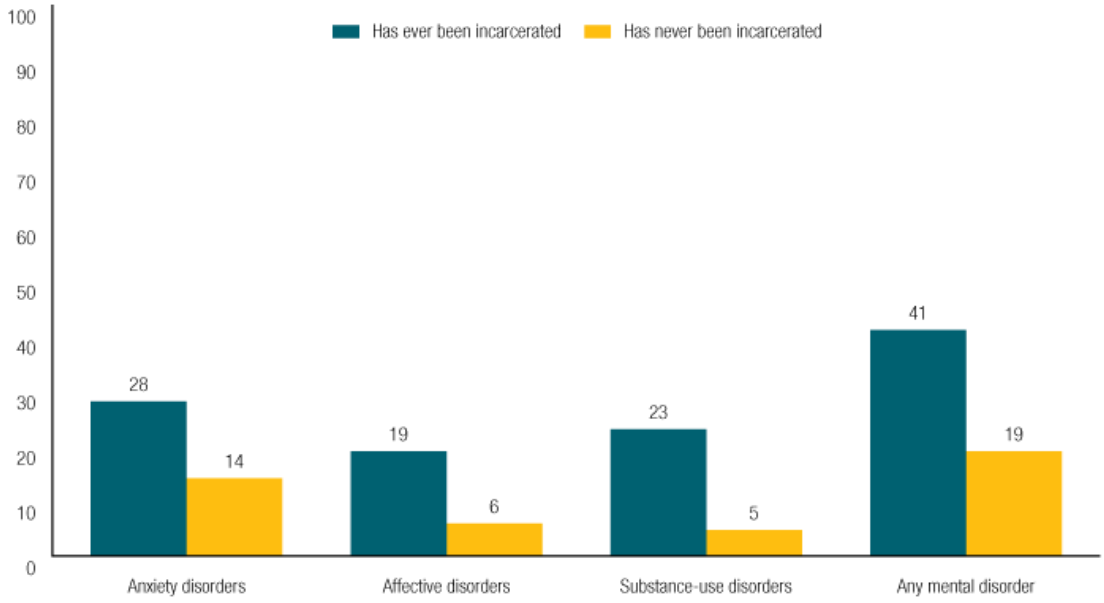
1. Focus on early intervention

Throughout various national healing forums, many Aboriginal and Torres Strait Islander community members expressed frustration regarding a perceived lack of early intervention focus in regard to the delivery of mental health services. It was perceived that primary investments were being made at the back end of the service system, when people were in crisis rather than any kind of early intervention approach.

This was seen to impede early diagnosis and effectively results in people living with complex mental illness without treatment or support. The intergenerational trauma needs of young Aboriginal and Torres Strait Islander people were seen to be neglected, with no clear focus on identifying mental health issues as they relate to Aboriginal and Torres Strait Islander young people.

Data suggested that Aboriginal and Torres Strait Islanders are commonly 'falling through the cracks' and not being diagnosed with a mental illness until they are at crisis point, or eventually incarcerated. An Australian Bureau of Statistics survey found that, among 385,100 people who reported ever having been incarcerated, the rate of those who reported having a mental health disorder in the prior twelve months was 41%, which is more than double the rate among the population who have never been incarcerated (ABS 2008 in AIC 2009). The study found higher reporting of a range of mental health disorders, including anxiety, affective disorders, substance use disorders and other mental disorders (AIC 2009).

Table 2. 'Mental disorders and incarceration history', AIC Crime Facts Info No 184



The New South Wales Prison Inmate study found the rates of mental illness and cognitive disabilities among Aboriginal and Torres Strait Islander prisoners is higher than the rate among the non-

Indigenous population[3]. This is consistent with higher rates of mental health-related hospitalisations for Aboriginal and Torres Strait Islander people, with data from 2012-13 demonstrating a rate that is more than twice the rate of the non-Indigenous population (National Mental Health Commission 2014).

Corrective Services New South Wales reports that the overall recurrent cost per inmate, per day is $172.80, which is significantly lower than the national average of $214.94[4]. This equates to an annual cost of $63,072.00 per inmate in New South Wales and a national average of $78,453.10 per annum. There is potential for significant savings to be realised, by transferring efforts into early intervention (by diagnosing people early) and providing them with quality services and support in the community - before they offend.

Aboriginal and Torres Strait Islander community members support a greater proportion of funding being targeted at the front end of the service system, with programs that focus on identifying mental ill-health as early as possible. This may occur through initiatives delivered within preschools, primary schools and via targeted programs delivered by frontline service providers such as Aboriginal Medical Services.

Aboriginal and Torres Strait Islander community members call for further investments in community education initiatives, targeted at raising community awareness of the signs of trauma and mental health. This will lead to more people being identified early, as being at risk or suffering from mental illness, and improved capacity for families and communities to provide support to them and pathways towards treatment.

Once people are effectively diagnosed (via a commitment to early intervention), services should aim to address the holistic needs of families, as the impact is often greater than on the individual alone. Currently Aboriginal and Torres Strait Islander families are carrying a huge burden caring for people with mental illness that have either been not diagnosed, misdiagnosed or have simply not engaged in care or treatment due to services being inaccessible or unresponsive to their complex needs.

Often the burden is resting on the shoulders of young people that need to care for their siblings, parents or extended family due to a lack of available localised support services. This severely stifles their own capacity to realise their potential in terms of current and prospective education and employment. This is particularly pronounced in regional and remote Australia where access to professional supports are limited and sometimes non-existent.

2. Make the system easier to navigate

Via national healing forums, Aboriginal and Torres Strait Islander people have reported a lack of awareness concerning mental health at a community level. Consequently, many individuals are resorting to self-medication to cope with their unresolved trauma. This diminishes their capacity to participate in gainful employment, further compounding high levels of socio-economic disadvantage. It also leads to other complex social problems including violence, child neglect, incarceration and

[3] Baldry E, McCausland R and Dowse L (2015). 'A predictable and preventable path: Aboriginal people with mental and cognitive disabilities in the criminal justice system'. UNSW.
[4] Corrective Services New South Wales, Fact Sheet 1, NSW Prison System

family breakdown – all of which, can drive mental ill-health at a community level and increase the cost burden to governments.

Despite increasing references to trauma awareness across the health sector, feedback from Aboriginal and Torres Strait Islander practitioners and community members suggests there is still a significant gap in the accessibility of genuinely trauma-informed psychological and therapeutic support. Communities report that some therapeutic services are implementing harmful practice, opening up community members to talk about distressing life events, and then not returning for over a month.

To address poor levels of existing community awareness, there is a need for increased investment in targeted community education campaigns that aim to increase community awareness of trauma and mental health generally, services that are available and avenues to initiate help. Furthermore, service models should be person centred and place based in their approach, putting the needs of clients first and designing services based upon the needs of local communities rather than a one-dimensional approach. This can be achieved by adopting a genuine process of co-design – elaborated on later in this submission.

In addition to better education and person-centred approaches, Aboriginal and Torres Strait Islander communities have highlighted the need for investment in trained and qualified mental health advocates within local communities. These advocates would be utilised to represent Aboriginal and Torres Strait Islander clients and their families when they require mental health support. They could potentially be responsible for driving local education campaigns, creating awareness of support services and building effective referral pathways for clients and families to engage with services.

The establishment of mental health advocates would allow clients to tell their story of trauma once, rather than multiple times, reducing the risk of compounding their experience of trauma. Furthermore, this investment would lead to economic efficiencies in the delivery of services, with clients being pointed in the right direction from the beginning of their journey, rather than shopping around for service options.

Wherever possible, mental health advocates would reside within the local community, so they can provide responsive services and to ensure that they are best placed to build a trusting relationship with clients and families. The Healing Foundation would support measurable targets relating to the recruitment of Aboriginal and Torres Strait Islander identified workers, matched against local demographic profiles.

3. Improve service accessibility

The National Review of Mental Health Programs and Services concluded that access to mental health services depends on ‘where you live, who you know, how much money you have and the extent to which you can self- advocate’. Unfortunately for many Aboriginal and Torres Strait Islander people, this translates to very poor access.

The national review recognised that people with mental illness are ‘moved between disconnected silos of intervention, including hospital wards, patchy support systems in housing, education and employment, and overstretched community and non-government services. It also highlighted specific weakness in supports for Aboriginal and Torres Strait Islanders due to cultural incompetence within services. Services ‘lacked a social and emotional wellbeing framework and failed to provide referral pathways from primary health to specialist services.

These findings are consistent with anecdotal feedback that The Healing Foundation has gathered through engagement with front line practitioners, service providers and clients.

The inherent low socio-economic status of remote communities necessitates superior investment; however, this is not the case in reality. Urban areas continue to attract most of the investment from government and remote areas continue to suffer poorer outcomes due to their neglect.

National healing forum participants from remote areas, consistently report a lack of basic support service infrastructure at a community level. People are being forced to travel outside of their community (often vast distances), to access much needed mental health assessment, let alone support. The lack of basic local service infrastructure not only impacts on individuals, families and communities in crisis situations, it stifles potential for the realisation of any sustainable outcomes that would effectively close the gap in Aboriginal and Torres Strait Islander disadvantage.

In circumstances when individuals and families from remote communities can afford to travel to access support, the financial, personal and emotional cost of maintaining that support usually results in an eventual discontinuation of service provision. Worse still, it can exacerbate the issues that initiated their motivation to seek support in the first place.

Feedback gathered by the Healing Foundation at recent New South Wales Healing Forums confirmed that regional communities are becoming increasing disillusioned with 'fly in and fly out' service delivery models. Trauma is further amplified by the need for individuals to constantly form a new rapport with a high turnover of different staff and service providers. Clients are often required to repeat their story of trauma repeatedly to seek support and this is a traumatising experience.

Some jurisdictions do not have appropriate base line services. For example, the Northern Territory does not have a territory wide child and youth mental health system despite the clear levels of distress evident in their population including high youth suicide. In remote parts of Western Australia there is very limited access to any child psychiatric services. In lieu of professional therapeutic support services, communities are attempting to address and resolve the burden of trauma themselves or as a collective social network with limited resources and overstretched individuals.

The only meaningful and logical solution to these issues is a commitment to establishing better service infrastructure in rural and remote areas. The need for increased service infrastructure will be further amplified as populations continue to grow and disperse from urban areas and capital cities, driven by pressures associated with congestion and high living costs. The design of these services should ideally occur via a genuine process of co-design with local communities to ensure that initial investments reflect the actual needs and priorities of local communities.

4. Better service models via meaningful co-design

Often the traditional government approach to community engagement involves a consultation process specific to rolling out a new initiative that has had limited community input. This approach has proven to fail and has essentially led to a situation where Aboriginal communities are reporting that they often feel over consulted and tired of talking about problems with no solutions.

In contrast with the term consultation - co-design involves service providers and communities working together from the outset to develop new approaches that are genuinely informed by clients. By working directly with Aboriginal and Torres Strait Islander men, women and children on every aspect of program design and evaluation, communities will ensure that programs are designed to be safe, accessible, culturally and locally relevant.

Genuine co-design empowers communities, promotes leadership, supports self-determination to become a reality, and ensures that programs and strategies are based upon local cultural knowledge and practice. In turn, this community-led approach enables Aboriginal and Torres Strait Islander communities to take control of their lives and participate more fully in the economy by solving the social issues that otherwise impede this.

The Healing Foundation's work experience has built evidence that - healing programs are most effective when delivered on country by people from the same cultural group, as participants are supported by local skilled workers who understand the history and collective experiences of local Aboriginal people, both traumatic and positive.

Government funded services need to reframe their thinking of Aboriginal and Torres Strait Islander clients as hard to reach and instead recognise their failure to build trust and safety with clients as a symptom of problematic service delivery[5].

There are opportunities for the mental health sector to contribute to improved outcomes by empowering Aboriginal and Torres Strait Islander communities to design and deliver their own healing solutions supported by partnerships with trauma-informed health services. The co-design process should include genuine partnership discussion concerning governance, oversight and accountability for new services, to ensure maximum value for money and efficiencies in the way that services are managed.

The Healing Foundation's extensive community reaffirms that Aboriginal communities are keen to get involved in these discussions to inform the development of innovative local solutions.

5. Establish better ways of measuring success

Typically, governments develop benchmarks and key performance indicators on behalf of Aboriginal and Torres Strait Islander communities, rather than negotiating what success means to the lives of Aboriginal and Torres Strait Islander people in a real sense. This failed approach is demonstrated by the relatively poor performance against closing the gap targets. In response to this poor performance, community leaders have voiced valid concerns that the targets themselves were poor and misaligned to what communities perceive as success.

There needs to be a new approach where Aboriginal and Torres Strait Islander communities are directly involved in determining what success means to them. This needs to be embedded as an integral part of policy and program development in all sectors, including mental health.

[5] Mitchell and Chapman 2010 as cited in Healing Foundation et al (2017). Towards an Aboriginal and Torres Strait Islander Healing Framework for men and boys

6. Improve workforce skill and capacity

Feedback obtained from a series of New South Wales Healing Forums throughout 2018, reported that the mental health workforce encounters significant challenges in meeting demand for services, particularly in regional and remote areas. Issues such as inadequate access to training, skills shortages, an insufficient representation of Aboriginal and Torres Strait Islander workers across all levels of the service sector and poor staff retention are all impacting on service standards and quality. In many regional and remote communities there is ongoing difficulty attracting trained and qualified workers.

Dealing with trauma and its consequences including depression, anxiety and associated mental health disorders requires significant skill to ensure that harmful practice and further trauma does not occur. Many mainstream services lack cultural competency, skill and knowledge and their methods are continuing to further traumatise Aboriginal and Torres Strait Islander people rather than effectively addressing their service needs.

Many mental health staff lack education about the nature and impact of trauma on Aboriginal and Torres Strait Islander people. Staff need skill development and targeted training, so they are better equipped to respond effectively.

A prominent issue that was raised throughout a series of 6 New South Wales Healing Forums in 2018 was the extent of structural and systemic racism/discrimination that exists within the broad health services sector (including mental health). A number of community members shared harrowing personal experiences of being treated unfairly when seeking frontline health services within public hospitals and also amongst community run health services.

It was reported that racism and discrimination occurs both overtly and covertly. This seriously undermines the trust of clients and acts as a primary deterrent for vulnerable clients seeking to engage services. Furthermore, it adds to their trauma burden and exacerbates mental ill-health. Racism and discrimination need to be clearly identified and accountability mechanisms introduced, so there are consequences for individuals and organisations that are found to condone, practice or perpetuate harmful practice.

In many regional and remote communities there has been difficulty attracting trained and qualified Aboriginal and Torres Strait Islander staff. Building pathways that support the ongoing development of the mental health sector workforce will increase the available number of culturally informed mental health and Indigenous practitioners and therefore increase capacity of the sector to respond to demand. There needs to be further investment in quality and accessible training and skill development to attract more workers to the sector.

Training and development should not only be directed at prospective employees, it is equally important to ensure that enough resources are being targeted at the existing workforce, not only to improve the quality of service delivery but also as a mechanism to retain staff. Better staff retention will result in economic benefits.

Regional and remote communities experience a high rate of staff turnover. Often workers do a stint in a remote area due to the attached incentives and as a way of gaining valuable experience that is attractive in terms of building career experience. While this is beneficial for the workers themselves, it burdens clients with disrupted relationships and increased need to tell their story of trauma repeatedly. This also results in excess expenditure in relation to recruitment of new workers, their induction training and for regional and remote areas, their relocation.

The sector needs to develop a targeted staff retention strategy to address this issue. An important component of any strategy is succession planning and wherever possible the employment of people that reside in the remote community or at the very least reside in a neighbouring community. This will result in much better sustainability of service models.

The Healing Foundation has also observed that committed workers in regional or remote areas often suffer 'burn out' as they struggle to cope with the high demand and pressures of servicing a relatively high volume (due to poor staff to client ratios) of complex clients. Aboriginal and Torres Strait Islander workers have conveyed the challenge of being on call 24/7, with community members approaching them for support at any time. The sector needs a strategy to ensure the safety and wellbeing of the existing workforce as a priority, so that workers are well enough themselves to offer quality support to clients.

The Healing Foundation has recently partnered with Gallang Education and Training Centre to develop a Healing Accredited Short Course. The short course will equip existing and potential Aboriginal and/or Torres Strait Islander workers with the skills and knowledge to better understand and empathise with people experiencing complex trauma resulting from the impact of colonisation. The short course will enable learners to access further study pathways through options such as Credit Transfer and RPL (Recognition of Prior Learning) for units of competency across other qualifications, essentially providing critical pathways for Aboriginal and Torres Strait Islander people to enter the mental health workforce.

Aboriginal and Torres Strait Islanders communities also call for more support for mental health carers, to enable them to participate in employment. It has been highlighted that many people find it difficult to participate in education and employment when they are required to care for family members experiencing mental ill-health. More flexible education, employment and training initiatives are required – targeted at carers, with the aim of providing them with increased options to balance their caring obligations with employment opportunities.

7. Eliminate suicide and its impact

Indigenous suicide is a significant health challenge for Australia. Suicide has emerged in the past half century as a major contributor to the overall Indigenous health and life expectancy gap. In 2014 it was the fifth leading cause of death among Indigenous people, and the age-standardised suicide rate was around twice as high as the non-Indigenous rate.

Indigenous children and young people are particularly vulnerable, comprising 30 per cent of the suicide deaths among those under 18 years of age. In addition, Indigenous 15–24-year olds are over five times as likely to suicide as their non-Indigenous peers. As males represent the significant majority of completed Indigenous suicides, gender can also be understood as a risk factor.

The National Review of Mental Health Programs and Services Report (2014) highlights that wellbeing outcomes for Aboriginal and Torres Strait Islander people in Australia have worsened dramatically over recent years.

Suicide rates were highest for Aboriginal and Torres Strait Islander people aged 25–34 years (39.9 deaths per 100,000 population), around three times the rate for non- Indigenous Australians of the same age. From 2004–05 to 2012–13, the hospitalisation rate for intentional self-harm increased for

Aboriginal and Torres Strait Islander Australians increased by 48.1 per cent, while the rate for other Australians remained relatively stable.

Regional and remote communities are reporting the devastating impact of grief and loss that they are experiencing and flow on effect that is occurring from generation to generation. Increasingly younger people are carrying the burden of caring for their parents or extended family members that have been traumatised.

In 2017, the Healing Foundation facilitated the country's first ever National Youth Healing Forum in Queensland. Young people from all over the country came together to articulate (the priority issues that were impacting on them, their peers and their communities. Suicide featured as a prominent issue. A headline quote from the National Youth Healing Forum Report reads: *"We need increased focus on positive programs that keep people happy and healthy rather than only targeting them at crisis point."*

The youth healing forum participants talked about the toll that suicide is having on their families and communities. They identified the following main factors that contribute to the high rate of Aboriginal and Torres Strait Islander suicide:

- There is a general lack of support options and services available to assist people
- Some people feel too ashamed to disclose their issues
- We need to find new ways of reaching out to people and encouraging them to seek support
- People are using drugs and alcohol at a very young age. This creates longer term mental health and developmental problems and can exacerbate feelings of depression, bi-polar or schizophrenia
- There is a lack of available support services for people who have experienced family violence, abuse or neglect
- There is a high emphasis on young people needing to be carers at an early age. The pressures that families are putting on young people results in those children becoming parents themselves at a very young age—generational perpetuation of the problem[6].

Feedback gathered from recent New South Wales Healing Forums confirmed that education about suicide and self-harm is needed in schools and across whole communities. They also highlighted a need for targeted suicide and self-harm awareness education to police, teachers, lawyers, magistrates, health workers, corrections staff, disability services and other community service providers of the triggers and risk factors that present when a person is at risk.

Communities have reported that the vast majority of critical events occur during weekends or outside of normal business hours for the few services that do exists, leaving untrained and unprepared community members grappling with how to deal with complex issues. Community members, parents and kin are therefore the front line of the mental health response.

Service models need to be designed with more flexibility and with the needs of clients at the forefront. The Healing Foundation strongly endorses a co-design approach, ensuring that communities have direct input into the design and operation of mental health services.

In the past two decades the communities of Yarrabah (in Queensland) and the Tiwi Islands (Northern Territory) have both seen suicide rates fall dramatically from very high rates that were experienced in the 1990s.

[6] National Youth Healing Forum Report, Healing Foundation 2017

In 2017, The Healing Foundation, in partnership with the Aboriginal and Torres Strait Islander Suicide Prevention Evaluation Project (ATSISPEP), commissioned Dr John Prince to undertake research to identify factors that may have been effective in reducing the rate of suicide in both communities. The research culminated in a report titled 'Stories from community – How suicide rates fell in two Indigenous communities.

Over the course of the research more than 40 community members were interviewed in Yarrabah and over 60 community members in the Tiwi Islands. The report found that the most significant factor to address suicide effectively included the community first reaching a shared consensus that suicide prevention is required, coupled with the community being empowered to create local solutions collectively with strong cultural leadership. The report also identified critical factors that assist in terms of suicide prevention these include:

Prevention factors

- Programs that create community awareness about suicide risk factors
- Training of frontline staff to identify suicide risk factors in clients as early as possible
- Access to counsellors and mental health support within the local community
- Identification of critical risk periods and services targeted at those times
- Local crisis response teams to respond quickly and decisively after a suicide incident
- Continuation of care and support post incident to facilitate healing
- Cultural competence of mental health staff

Community elements

- The community is empowered to be directly involved in devising solutions
- Elders are involved and provide strong cultural leadership to decision making
- Solutions are devised within a cultural framework

The report emphasises that solutions cannot be formulated by government on behalf of Aboriginal communities or imposed upon communities. There needs to be more meaningful dialogue at a local level, more appreciation for locally developed solutions, and a commitment to resourcing those solutions.

8. Support effective Indigenous healing frameworks

Healing refers to the process by which people come to a stronger sense of self-identity and connection and through this can address the distress that they experience changing how they are able to interact. Healing involves a holistic and ongoing approach that is deeply rooted in culture and addresses physical, social, emotional, mental, environmental and spiritual wellbeing.[7]

It is vital that healing is recognised as an ongoing and long-term process that requires slow, deliberate and meaningful work. Multiple generations of collective and cumulative trauma cannot be solved through short-term, one-off programs or events. Time is needed to build connections and relationships, to reconnect with culture and to work towards self-determination emerging as a reality for Aboriginal and Torres Strait Islander communities.

[7] Aboriginal and Torres Strait Islander Healing Foundation Development Team 2009 'Voices from the Campfires: Establishing the Aboriginal and Torres Strait Islander Healing Foundation'. Commonwealth of Australia.

A critical element of healing programs is an emphasis on restoring, reaffirming and renewing a sense of pride in cultural identity, connection to country, and participation in and contribution to community.

Collective healing reinstates and reconnects Aboriginal and Torres Strait Islander communities to their core cultural value systems, where obligations and reciprocity were central to community survival. Without enabling the reclaiming and reconnection to these value systems, Aboriginal and Torres Strait Islander people will remain over-represented in the justice, child protection and indeed the mental health system.

Collective healing moves away from the 'treatment' of individuals to a model where 'individuals develop their own skills and capacities to empower healing in themselves and their families and communities'[8].

Healing is an essential condition of any support for Aboriginal and Torres Strait Islander development in Australia[9]. Incorporating healing into a collective process of self-determination enables Aboriginal and Torres Strait Islander people to identify and deal with the underlying causes of trauma.

For example, an independent evaluation[10] of the Northern Territory Men's Healing projects, demonstrates the benefit of developing healing strategies through a genuine co-design process. It also demonstrates the importance of striking the right balance between therapeutic support and cultural practice to achieve positive outcomes across several health and wellbeing domains.

The initiative empowered Aboriginal men through cultural, education and therapeutic healing activities, facilitated access to support services, increased their confidence and capacity to gain meaningful employment and overcome issues such as family and domestic violence, alcohol and other drug use, self-harm, incarceration and poor health and social and emotional wellbeing. The evaluation found:

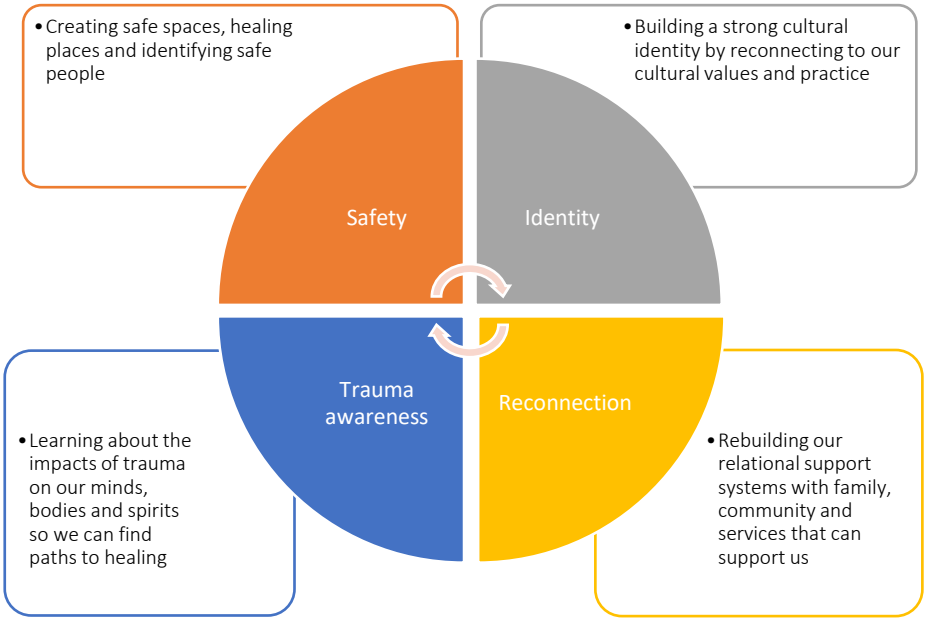
- a reported decrease in incidence of family and domestic violence and less violence generally in communities;
- reduced observable rates of self-harm and suicide during the life of the program in two of the communities;
- women feeling safer and more supported by the men in their families and communities;
- increased health and emotional wellbeing among men in the communities;
- increased leadership as men take responsibility for their past, present and future; and
- increased re-emergence of cultural celebrations and ceremonies, some of which had not occurred in the communities for decades, and;
- a reduction in recidivism and reoffending over the life of the program including a reported 50 per cent reduction in the number of men registered with the NT Department of Correctional Services within the Wurrumiyanga area (where the program has been running the longest)

The challenge for the Healing Foundation has been having state and territory governments invest in these approaches. Despite these significant results the Northern Territory government did not invest and support this work and would not take this initiative to scale, despite originally funding the work.

[8] Collective Healing for members of the Stolen Generations Aboriginal and Torres Strait Islander Healing Foundation 2014b:14
[9] Social Compass 2016 A Theory of Change for Healing, prepared in partnership with the Institute for Human Security and Social Change p16
[10] Healing Foundation 2015. 'Our Men, Our Healing: Creating Hope, Respect and Reconnection'. Evaluation Report Executive Summary. https://healingfoundation.org.au//app/uploads/2017/03/OMOH-60-pg-report-small-SCREEN-singles.pdf

Too many times evidence-based programs showing great results, such as these across Aboriginal and Torres Strait Islander communities are defunded, not supported and allowed to close due to government policy or inaction. This in its self is a false economy, meaning that communities must always start again, can never build traction and are continuously having to rebuild or pivot to address issues that are interconnected. This traumatises the Aboriginal workforce and makes them less likely to engage in future work. This trauma cycle is something that will need to be stopped to make real gains.

Through its work, the Healing Foundation has developed four pillars of Indigenous trauma recovery[11]:



Four Pillars of Indigenous Trauma Recovery

1. **Safety:** creating safe spaces, healing places and identifying safe people to support healing;
2. **Identity:** building a strong cultural identity by reconnecting to our cultural values and practice;
3. **Reconnection:** rebuilding our relational support systems with family, community and services that can support us; and
4. **Trauma awareness:** learning about the impacts of trauma on our minds, bodies and spirits so we can find paths to healing.

Healing-informed approaches based on these pillars can improve outcomes across a range of health and well-being domains, especially in terms of mental health.

Quality healing balances Indigenous and western concepts may provide for individual support within a broader collective approach and supports cultural and spiritual renewal concurrently with psychological and therapeutic support.

[11] Healing Foundation with Adams, M, Bani, G, Blagg, H, Bullman, J, Higgins, D, Hodges B, Hovane, V, Martin-Pederson, M, Porter, A, Sarra, G, Thorpe A and Wenitong M 2017. *Towards an Aboriginal and Torres Strait Islander violence prevention framework for men and boys.* The Healing Foundation and White Ribbon Australia

International and local research indicates that healing programs should be specific to local regions and groups and are best delivered on country by people from the same cultural group as participants[12]. Localisation of healing can ensure a trauma-informed approach delivered by skilled workers who understand the history and collective experiences of local Aboriginal people, 'both traumatic and positive'[13].

Healing is an ongoing process that needs to be integrated across the broad ambit of laws, policies and services that relate to Aboriginal and Torres Strait Islander people. Trauma-informed approaches must therefore be embedded in all aspects of systems that engage with and impact on Aboriginal and Torres Strait Islander peoples and in cross-sector initiatives that span the community, health, education, employment, justice sectors and beyond.

Recommendations

The Healing Foundation puts forward the following recommendations to support and enable social and economic benefits of improving mental health for Aboriginal and Torres Strait Islander communities:

- Invest in specialised and targeted mental health support options for Stolen Generation survivors and their families, in recognition of the unique and complex challenges that they face, as substantiated by the disturbing AIHW data referenced in this submission.

- Invest in localised, culturally competent mental health support service infrastructure, particularly in regional and remote areas where the cost of accessing mental health support services is beyond the reach of many vulnerable high need's groups.

- Commit to co-design of mental health policy, service delivery models and programs, so that locally developed healing responses are resourced, monitored and evaluated to strengthen the evidence base and enable greater culturally based solutions to emerge.

- Increase the number of trauma informed, trained and qualified Aboriginal and Torres Strait Islander staff across all spectrums of the mental health service sector, in response to the high proportion of Aboriginal and Torres Strait Islander clients that require servicing.

- Invest in the design, delivery and ongoing evaluation of cultural competency and trauma awareness training programs that address racism, ensure accountability and measure meaningful compliance. This is not only critical to improve the quality of service provision, it is essential to avoid inflicting further trauma on an already vulnerable and marginalised client group.

- Strategies are required to assist Aboriginal and Torres Strait Islander people to effectively navigate the mental health system (refer to community education and advocacy recommendations), to connect to appropriate support, particularly in regional and remote areas where service infrastructure is sparse.

[12] Aboriginal and Torres Strait Islander Healing Foundation (2014). 'Our Healing Our Solutions: Sharing Our Evidence';
[13] Caruana, C 2010, *'Healing services for Indigenous people'*, Family Relationships Quarterly, vol. 17, pp. 3–9. in Aboriginal and Torres Strait Islander Healing Foundation 2014 Our Healing Our Solutions: Sharing Our Evidence':18

- Organisations supporting and providing mental health services must adopt trauma-informed, culturally relevant approaches at all levels of service provision, including in their underpinning policies and service systems.

- Structural and systemic racism/discrimination needs to be eradicated from the mental health sector urgently. Improvements should be monitored closely via the implementation of client satisfaction surveys for marginalised client groups, to measure improvements against benchmark indicators.

- A comprehensive and targeted Workforce Development Plan is required as a matter of urgency. This should aim to address skill shortages, improve workforce retention rates in regional and remote areas and importantly, to set measurable and transparent targets for the recruitment of an Aboriginal and Torres Strait Islander Workforce as its main objective.

- A comprehensive Safety and Emotional Wellbeing Plan is required to prevent burnout of the workforce, ensuring that workers themselves have strong social and emotional wellbeing to provide quality services to clients. This is especially important for Aboriginal and Torres Strait Islander Workers that have the added burden of carrying community pressures and obligations that exceed the responsibilities of their professional roles.

Attachment 2

Submission to developing an Action Plan for Aboriginal and Torres Strait Islanders under the Aged Care Diversity Framework

March 2018

1. Introduction from the CEO

The Healing Foundation is pleased to contribute to the Aged Care Diversity Framework - Action Plan for Aboriginal and Torres Strait Islanders. We wish to emphasise the importance of taking a trauma-informed approach to aged care for Aboriginal and Torres Strait Islander people. We also want to share new knowledge from our current Action Plan for Healing project detailing the specific experience and needs of Stolen Generations survivors.

There is a significant body of research, including the Healing Foundation's own experience, which identifies systemic barriers to health and wellbeing for Aboriginal and Torres Strait Islander people. What is evident from the research is that the risk factors that undermine Indigenous wellbeing are symptomatic of, and exacerbated by the collective and intergenerational trauma stemming from colonisation, forced removals and other government policies. What is also evident is that government policies and programs seemingly disregard the level of trauma in our communities, and in many instances, exacerbate that trauma by imposing service models that continue to marginalize and disempower Aboriginal and Torres Strait Islander people.

Section 11-3 of the *Aged Care Act 1997* identifies Aboriginal and Torres Strait Islander peoples, care leavers, parents separated from their children by forced adoption or removal as people with special needs. These categories encompass the Stolen Generations. Stolen Generations have been identified as a 'special needs' group, by DOHA and others in submissions to the National Aboriginal and Torres Strait Islander Health Plan and to the review of aged care (Scorecard Report 2016, Appendix B, p. 17), but this has not necessarily led to a systemic response that ensures policies and programs specifically cater for the experiences of the Stolen Generations and their families.

Consistent with the vision of the Aged Care Diversity framework[1], and given the high level of trauma and disadvantage experienced by Stolen Generations, it is essential that the Action Plan for Aboriginal and Torres Strait Islanders specifically highlights the special needs of elderly Stolen Generations survivors.

This submission draws from evidence to:

- describe the demographics and experience of Stolen Generation survivors and their families and how this differs from the Aboriginal and Torres Strait Islander population who did not experience removal;
- emphasise the need for trauma-informed support and services for elderly Stolen Generations; and
- provide examples of aged care support and services proposed by Stolen Generations as being appropriate for their special needs.

Two-thirds of Stolen Generations were already aged 50 or more in 2015, and the remaining third will be aged 50 or more by 2023. The Aged Care Action Plan for Aboriginal and Torres Strait Islanders is an important opportunity to provide a framework for the special attention that elderly survivors deserve. Our recommendations (see section 5) are:

- Healing frameworks should be applied holistically to aged care services and support for Aboriginal and Torres Strait Islander people. This is an opportunity to establish an aged care system/framework that acknowledges the history and impact of colonisation, and subsequent policies such as removing children from their families.

[1] *"All older people experience a high quality aged care system that ensures equitable access and outcomes and embraces their diverse characteristics and life experiences."*

- In order to exercise greater self-determination in relation to policies and decisions that impact on them, Stolen Generations must be invited into negotiations that determine services and policies as an equal negotiating partner.
- Initiatives taken to address the needs of the Stolen Generations must be led by Stolen Generations members and centred on the needs that they themselves have identified.
- Urgent action is needed to ensure that Stolen Generations are able to access aged care services and support that meet their complex needs, and which do not re-traumatise survivors.
- Funding and programs need to be in place that enable Stolen Generations and their descendants to address intergenerational trauma and achieve healing including through individual counselling; intergenerational healing strategies; collective healing approaches such as healing camps and on-country programs; and in healing centres accessible to Stolen Generations across all jurisdictions in cities and regional and remote areas.
- Aged care support and services need to be sufficiently flexible and resourced to enable enhanced cultural connection for elderly Stolen Generations and their families, including support to return to country and being buried on country.
- Non-institutional models of aged care and support need to be urgently investigated and adopted to avoid re-traumatisation. This includes services and support from Aboriginal and Torres Strait Islander organisations with specific focus on Stolen Generations, and avoiding government and non-government service providers who were historically associated with removal of children.
- Organisations supporting and providing services to Stolen Generations must adopt trauma-informed, culturally relevant approaches at all levels including in their underpinning policies and systems, as well as for individual workers.
- Direct points of contact and clear pathways are required to assist Stolen Generations survivors to navigate the service system by providing information and making referrals to appropriate services would be useful additions to service systems. Such points of contact should be staffed by people who are trained in trauma-informed practice and have specialist knowledge about the Stolen Generations, and preferably who are Aboriginal or Torres Strait Islander people and with lived experience of Stolen Generations.

We welcome further conversations about how to put these recommendations into practice with input from Stolen Generations, their organisations and carers.

Richard Weston
March 2018

2. About the Healing Foundation

The Healing Foundation is a national Aboriginal and Torres Strait Islander organisation that partners with communities to address the ongoing trauma caused by colonisation and subsequent actions such as the forced removal of children from their families. Our work helps people create a different future.

In 2016, the Healing Foundation embarked on developing a Theory of Change (TOC) for healing, designed to enable better definition of the building blocks necessary to bring about long term, sustained change in healing from trauma for Aboriginal and Torres Strait Islander people. It is the first time that trauma knowledge has been combined with an Aboriginal and Torres Strait Islander worldview.

The context that guides our TOC for healing is[2]:

- Colonisation and past and present government policies had led to trauma for Aboriginal and Torres Strait Islander people (across generations)
- Such trauma limits (or removes) the ability to act in empowered ways and leads to a number of negative outcomes for Aboriginal and Torres Strait Islander people
- Such outcomes mean Aboriginal and Torres Islander people are limited in their capacity to initiate / take up development opportunities – regardless of external resources
- Healing is an essential (although not sufficient) condition of any support for Aboriginal and Torres Strait Islander development in Australia.

Our Theory of Change builds a clear narrative about how healing creates positive social change for Aboriginal and Torres Strait Islander communities, families and individuals. The work demonstrates that sustained and positive change is more likely to occur at the individual, family and community level when there is positive alignment across three key domains. Investment in these domains of change, enables empowerment, resources and opportunities to emerge.

The three key domains to support quality healing are:

- a policy context that enables healing;
- the identification of healing network and champions that lead healing; and
- the development of responses to deliver healing.

Our theory of Change provides the context for all of our program and advocacy efforts.

3. About the Action Plan for Healing

In 1997, the Human Rights and Equal Opportunity Commission published the *Bringing Them Home* (BTH) Report. A significant milestone in the nation's history, the Report provided a basis for addressing the rights and needs of the Stolen Generations and for progressing reconciliation based on an acknowledgement of Australia's past.

To coincide with the twentieth anniversary of the BTH Report in 2017, the Healing Foundation commissioned a review to revisit the principles and recommendations of the BTH Report, and to examine their advancement in the contemporary policy landscape.

[2] Social Compass 2016 A Theory of Change for Healing, prepared in partnership with the Institute for Human Security and Social Change p4

The review was conducted by Patricia Anderson AO and Edward Tilton Consulting during the second-half of 2016. Informed by consultations with Stolen Generations organisations across the country, and led by the Healing Foundation 's Stolen Generations Reference Group, the report *Bringing Them Home 20 years on: an action plan for healing* outlined a plan of action to meet the continuing and emerging needs and rights of the Stolen Generations. Its recommendations were based on the priorities identified by the Stolen Generations consulted; on the evidence of the effects of the failure to implement the BTH recommendations; and on the original BTH Report's recommendations and underlying principles. The Healing Foundation's Stolen Generations Reference Group endorsed the findings and recommendations of the Review.

The Department of Prime Minister and Cabinet subsequently funded the Healing Foundation to build on *Bringing Them Home 20 years on*, through an *Action Plan for Healing* consisting of three activities:

- a holistic needs and demography analysis of the Stolen Generations and their families;
- improving access and preservation of family history records, working with the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) and the Link-Up sector; and
- preparing trauma-informed resources to support members of the Stolen Generations entering the Aged Care sector, including disability support.

As a first step towards the needs analysis, in mid-2017 the Healing Foundation commissioned qualitative and quantitative background papers to understand what is already known about the experience and needs of Stolen Generation survivors and their families. The qualitative paper analysed Stolen Generation testimony to national and state inquiries and consultations[3]. The Australian Institute of Health and Welfare (AIHW) used the series of National Aboriginal and Torres Strait Islander Social Surveys (NATSISS) and the National Aboriginal and Torres Strait Islander Health Surveys (NATSIHS) conducted by the Australian Bureau of Statistics, to derive demographic data and comparisons of the characteristics of Stolen Generations and their families with Aboriginal and Torres Strait Islander people who did not experience removal. [4] These ABS surveys do not directly identify the Stolen Generations and their descendants. The AIHW developed proxy measures for these two groups and the data cited from the AIHW report in this submission relate to these proxy measures.[5]

This submission draws on those papers, and from direct engagement with Stolen Generations including recent yarning circles held as part of the events commemorating the tenth anniversary of the Prime Minister's apology to Stolen Generations.

4. Ageing and the Stolen Generations

Survivors of the Stolen Generations are ageing. Based on the 2014-15 NATSISS, approximately 65% of Stolen Generations are aged 50 and over. Stolen Generations currently make up approximately 14% of the Aboriginal and Torres Strait Islander population aged 50 and over[6]. Nationally, this means that in 2014-15, close to 13,800 Stolen Generation survivors were eligible for aged care. Another 7000 Stolen Generation

[3] McCausland R, Nettheim, A, & Kang C (unpublished) *Qualitative analysis of documentation of the contemporary experience and needs of the Stolen Generations*, Research Paper for the Healing Foundation, December 2017

[4] AIHW (unpublished) *Action Plan for Healing: quantitative analyses Contemporary demography of the removed population and comparative analyses of their characteristics* draft report, Feb 2018.

[5] The proxy measure used in the AIHW report to identify the surviving members of the Stolen Generations is the cohort of survey respondents who were born before 1972 and who reported having been removed from their family. The proxy measure for the descendants of the Stolen Generations is the group of survey respondents aged 18 years and over who reported that a relative from an older generation (parents, great/grandparents, aunties and uncles) had been removed from their families.

In the AIHW report, for the purposes of comparative analyses with other Indigenous adults who had not experienced any type of removals, the descendants of Stolen Generations further exclude those individuals who also reported that they themselves had been removed from their own families (in addition to having elder relatives who were removed). The comparative reference groups who did not experience removal were defined as follows: (a) for the Stolen Generations: the group of Aboriginal Torres Strait Islander survey respondents who were born before 1972 but who self-reported not having been removed from their family; and (b) for the descendants of the Stolen Generations: the group of Aboriginal and Torres Strait Islander survey respondents aged 18 years and over who reported neither having been removed from their own families nor having any relatives removed.

[6] AIHW(unpublished)

survivors were already aged 46-49 years in 2014-15, and will be eligible for aged care within 5 years. Nationally one third of adult Aboriginal and Torres Strait Islander people (close to 115,000 people in 2014-15) have parents, grandparents, great-grandparents, aunties and/or uncles who were removed.

The AIHW analysis demonstrates that Stolen Generations and their descendants are significantly more disadvantaged in a number of areas, compared to Aboriginal and Torres Strait Islander people who were not themselves removed or who are not descended from people who were removed. This means that Stolen Generations and their descendants are generally much more disadvantaged than non-Indigenous Australians of a similar age.

The information in black is included in the Aged Care Diversity Framework[7]. The additional information (in *italics*) is derived from the AIHW draft report[8].

There are over 100,000 older people from Aboriginal and Torres Strait Islander communities' in Australia. There are half a million care leavers in Australia who are now between 40 and 90 years of age, with the numbers of parents separated from their children by forced adoption or removal still unknown
Nationally, approximately 14% of Aboriginal and Torres Strait people aged over 50 were removed from their families.

Almost 15,000 older Australians experience homelessness or are at risk of homelessness
40% of Stolen Generations have experienced homelessness compared to 12% of non-Indigenous people of similar age. A quarter own their own home, compared to 80% of non-Indigenous Australians of similar age. Stolen Generations reported significantly higher rates of currently sleeping rough and of staying at refuges compared to Aboriginal and Torres Strait Islander people of similar age who were not removed.

One in ten Australians over sixty-five lives with cognitive impairment and dementia. Over half of older Australians experience some sort of disability
Almost 40% of Stolen Generations aged 50 and over have poor mental health. Nearly 70% have a disability, 18% have a profound disability.

More than one in ten older Australians live in regional, rural and remote communities
21% of Stolen Generations live in remote areas; and 79% live in non-remote (regional and urban areas).

One in twelve older Australians experience significant financial or social disadvantage
65% of Stolen Generations aged 50 and over live in households with incomes in the lowest 3 deciles. Almost 80% rely on Government payments as their main source of income.

One in twelve older Australians have four or more chronic diseases.
Additionally, due to their poorer health status and higher levels of socioeconomic disadvantage, Aboriginal and Torres Strait Islander elders have health care and support needs that differ from those of other older Australians. Aboriginal and Torres Strait Islander elders have a life expectancy that is approximately 10 years less than the general population and experience dementia at rates between 3 to 5 times higher than the general population.
Stolen Generations survivors are 1.6 times more likely to not to have good health (based on the AIHW composite score) than Aboriginal and Torres Strait Islander people of the same age who were not removed. Compared to non-Indigenous Australians of a similar age, Stolen Generations survivors are:

- *4.5 times as likely to have had a heart disease*
- *3.9 times as likely to have had a stroke*
- *3.0 times as likely to have kidney disease*
- *2.6 times as likely to have poor self-assessed health.*

It is essential that the aged care system understands and accommodates the history and particular needs of the Stolen Generations and their descendants, in order to ensure the best possible care for survivors.

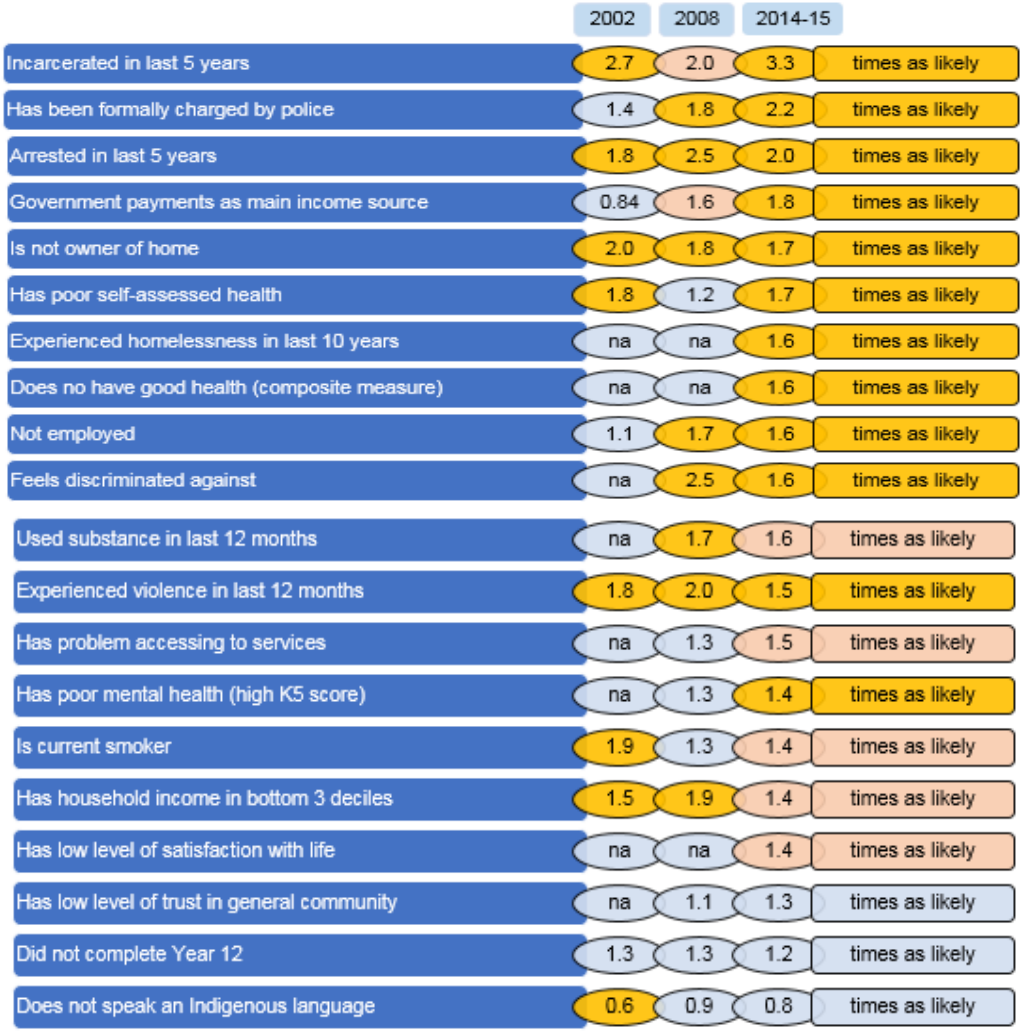
The analysis of testimony from Stolen Generations to national and state-based inquiries indicates that they and their descendants have complex needs. Health and wellbeing and social and economic factors are seen as intersecting and compounding.

[7] Aged Care Diversity Framework https://agedcare.health.gov.au/support-services/people-from-diverse-backgrounds/aged-care-diversity-framework
[8] AIHW (unpublished)

One issue that has been highlighted again and again is that the needs of Stolen Generations survivors, their families and communities are complex, and that policy makers, program developers and service providers need to understand, and respond to, that complexity (Scorecard Report 2016, p. 23)[9].

4.1 What is different about the experience of Stolen Generations?

The AIHW analysis indicates that Stolen Generations are significantly more disadvantaged in a number of areas when compared to Aboriginal and Torres Strait Islander people of similar age who were not removed. The following infographic illustrates the effects of removal on selected outcomes for Stolen Generations[10].



Stolen Generation survivors are more likely than Aboriginal and Torres Strait Islander people of similar age who were not removed to report having had chronic health conditions such as cancer, diabetes, heart disease, stroke, back-pain and eyesight problems. They are also more likely to report having moderate or high levels of psychological distress, and to have a severe or profound physical disability. More than two thirds live with a disability or a restrictive long-term health condition[11].

[9] Rule, J. and Rice, E. (2015). *Bringing them home: scorecard report 2015*. Canberra: National Sorry Day Committee http://apo.org.au/node/54628 in McCausland et al (unpublished)

[10] AIHW (unpublished) Logistic regression estimates of odds ratios on the effects of being removed on selected outcomes, results from 2002, 2008, and 2014–15 NATSISS, cohort born before 1972. na denotes data not available in that specific survey on the variable of interest. The colour scheme indicates whether the estimated odds ratio (OR) is close to 1 or statistically different from 1 at the 5% and 10% test level. Orange denotes the OR is significantly different from 1 at the conventional 5% test level. Pink denotes the OR is significantly different from 1 at the 10% level. Light blue means the estimated OR is not significantly different from 1 even at the 10% test level (meaning the outcome measured does not vary significantly between the removed and not-removed population in this cohort).

[11] AIHW (unpublished)

This in turn means that Stolen Generations need greater support and funding for health care and rehabilitation (NSW Reparations Inquiry 2016, p. 51)[12].

Stolen Generation survivors are more likely to have personal and household incomes in the bottom thirty percent, and are significantly less likely to own their own home, than Aboriginal and Torres Strait Islander people of similar age who were not removed.[13] Just under 30% report that they live alone[14.]

Elderly survivors may not have any family to support them, and may be reluctant to go into a nursing home. Chief Executive Officer of the Kinchela Boys' Home Aboriginal Corporation, pointed out "*that for those who were institutionalised 'going into residential care is quite scary'*" (NSW Reparations Report, 2016, p. 143)[15].

4.2 Descendants of Stolen Generations

Descendants of Stolen Generations are also disadvantaged in comparison to their peers who are not descended from people who were removed. This intergenerational trauma means that it may difficult for families to care and support elderly Stolen Generation survivors.

Family breakdowns have been linked to the trauma of forced removal, and this in turn has perpetuated intergenerational nature of that trauma:

> *A lot of partners have not been able to stick around with their men because of all the traumatic issues and stuff that they have not dealt with. Then there are other strong women who have put themselves through the wringer, like my mum, to stay.* (NSW Reparations Report, 2016, p. 35)[16].

Descendants of those who experienced forced removal report feeling disconnected from family and community. Intergenerational trauma may be linked to family violence, domestic violence and substance abuse:

> *[The families'] trauma has been the result of trying to support the KBH Men and yet being the victims of the behaviours instilled during their time at KBH, including alcohol and substance abuse, domestic violence and social and emotional disconnection* (Kinchela Boys' Home 2016, p. 34)[17].

The Marumali Program Review (2014)[18] stressed the need to consider second and third generations, as descendants of the Stolen Generations are also victims who have suffered deprivation of *"community ties, cultural and language and entitlements to traditional land"* (p. 503). It notes that these people may live with traumatised parents who require support, and that descendants themselves may suffer added disadvantage, live isolated from other Aboriginal people, come from families reluctant to engage with government agencies or Aboriginal services, and have trouble obtaining the requirements for Proof of Aboriginality.

4.3 What do we know about the needs of Stolen Generations?

There are three overarching requirements that are critical in responding to the needs of Stolen Generations:

1. Self-determination

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[12] New South Wales Parliament Legislative Council, General Purpose Standing Committee No. 3. (2016). *Reparations for the Stolen Generations in New South Wales – 'Unfinished Business'*. Sydney, NSW in McCausland et al (unpublished)
[13] AIHW (unpublished)
[14] AIHW unpublished)
[15] NSW Reparations Report in McCausland et al (unpublished)
[16] NSW Reparations Report in McCausland et al (unpublished)
[17] Kinchela Boys Home Aboriginal Corporation submission to NSW Reparations Report In McCausland et al (unpublished)
[18] Peeters, L., Hamann, S. and Kelly, K. (2010). The Marumali Program: Healing for Stolen Generations. In: N. Purdie, P. Dudgeon and R. Walker, eds., *Working Together. Aboriginal and Torres Strait Islander mental health and wellbeing principles and practice*. Canberra: Department of Health and Ageing, pp. 285-292. https://www.telethonkids.org.au/globalassets/media/documents/aboriginal-health/working-together-second-edition/wt-part-6-chapt-29-final.pdf in McCausland et al (unpublished)

Aboriginal and Torres Strait Islander peoples must be able to exercise greater self-determination in relation to policies and decisions that impact on them. This means being seen as an equal negotiating partner in determining services and policies, rather than the more usual 'consultation'.

2. Stolen Generations-led and -centred responses

Initiatives taken to address the needs of the Stolen Generations need to be led by Stolen Generations members and centred on the needs that they themselves have identified.

For example, the Victorian Taskforce Report (2009)[19] states:

Despite State and Commonwealth funding, the Victorian Government received consistent feedback from members of the Stolen Generations that their needs were not being met, that they lacked input into services designed to help them and that key service gaps were adversely affecting their healing process. Feedback received through the Victorian Koorie Records Taskforce consultation forums (held in 2001) indicated a strong consensus on the need for services to be designed and provided by members of the Stolen Generations themselves (p. 7).

[Stolen Generations] have the right to be given time to take control of their healing. Most importantly, they have the right to have a say in how services should be designed to assist them, which is partially the reason why to date there have been flaws in service delivery – lack of consultation (p. 26).

3. Urgency

Given the age and frailty of many Stolen Generation survivors, there is an urgent need for reparations, for the provision of meaningful support, and to address the intergenerational impacts of removal.

These overarching requirements are consistent with the strategic imperatives listed in the Aged Care Diversity Framework[20] that recognise that older people must be viewed as partners in the aged care system ie equity of access and outcomes; empowerment; inclusion; quality; capacity building; responsive and accountable. The evidence and research available to the Healing Foundation clearly demonstrates that healing is supported by programs and policies that are co-designed with people with lived experience and implemented by trauma-informed workforces.

Services that address the impacts of removal need to be *'designed, provided and controlled by Aboriginal people themselves"*, and by the Stolen Generations specifically, as only they can fully comprehend the effects of the removal policies. Trauma-informed services are essential to avoid re-traumatisation of individuals.[21] (Marumali Program Review, 2010, p. 497-9).

4.4 Healing

The Healing Foundation submission to the Closing the Gap refresh (attached) sets out the need for adopting a healing framework that underpins policies and programs, and practical suggestions for improving outcomes for Aboriginal and Torres Strait Islander peoples. We recommend that a similar framework is applied to the development of the Aged Care Diversity Framework - Action Plan for Aboriginal and Torres Strait Islanders.

[19] Aboriginal Affairs Victoria. Stolen Generations Taskforce (Vic.), (2009) *Stolen Generations Taskforce: report to Victorian Government*. Melbourne VIC.: Dept. of Victorian Communities in McCausland et al (unpublished)

[20] Aged Care Diversity Framework Framework https://agedcare.health.gov.au/support-services/people-from-diverse-backgrounds/aged-care-diversity-framework

[21] Peeters, L., Hamann, S. and Kelly, K. (2010). The Marumali Program: Healing for Stolen Generations. In: N. Purdie, P. Dudgeon and R. Walker, eds., *Working Together. Aboriginal and Torres Strait Islander mental health and wellbeing principles and practice*. Canberra: Department of Health and Ageing, pp. 285-292. https://www.telethonkids.org.au/globalassets/media/documents/aboriginal-health/working-together-second-edition/wt-part-6-chapt-29-final.pdf in McCausland et al (unpublished)

For Stolen Generation survivors and their descendants, addressing intergenerational trauma and healing is as an ongoing process that needs to be approached in a variety of ways, including through individual counselling, intergenerational healing strategies, collective healing approaches such as healing camps and on-Country programs, and in healing centres accessible to Stolen Generations in every jurisdiction[22].

"We suffered collectively and we need to heal collectively" (NSW Reparations Report 2016, p. 55).

Several reports identified the need for specific services and support for the families and descendants of the Stolen Generations to heal the ongoing impact of the trauma experienced as a result of past policies and practices of removal (NSW Reparations Report, Healing Foundation Reports, Marumali Program Review, WA BTHCWA Annual Reports). For example, a submission from the Kinchela Boys Home, in relation to their request for a Healing Centre, stated:

We need to be supported so we can lead the healing of our families and help put an end to the intergenerational trauma that continues to harm them (NSW Reparations Report, 2016, p. 59)[23].

Kinchela survivor Michael Welsh echoed this sentiment, saying[24]:

We do not want this hate to go to our children or to our grandchildren and great grandchildren. Our children need to be connected to this healing process too. Our journey's almost over, our children's journeys are only just beginning (Healing Foundation Report 2017, p. 41).

Effective service responses for Stolen Generations must acknowledge the diversity of Aboriginal and Torres Strait Islander cultures and languages. Culture, language and identity are significant because of their connection to social and emotional wellbeing.

Cultural reconnection remains important for Stolen Generations, particularly programs that involve getting back to Country. These programs need to be available and supported in urban and regional areas[25].

For elderly survivors and their families getting back to Country and being buried on-country is very important. Aged care programs will need to be sufficiently flexible to accommodate and support re-location.

4.5 Aged-care services and support

Stolen Generation survivors have identified culturally appropriate aged-care facilities, services and support as urgent emerging needs[26].

A Stolen Generations-specific approach is critical, given that institutional care will be particularly problematic for Stolen Generations survivors[27]. A lot of people would find it re-traumatising to go into an aged-care facility, and the possibility of Stolen Generations-specific institutions such as those planned for the former residents of the Cootamundra and Kinchela homes may be an alternative that might ameliorate the risk of trauma.

[22] NSW Reparations Report in McCausland et al (unpublished)
[23] NSW Reparations Report in McCausland et al (unpublished)
[24] Healing Foundation, (2017). Bringing Them Home 20 years on: An action plan for healing. https://healingfoundation.org.au//app/uploads/2017/05/Bringing-Them-Home-20-years-on-FINAL-PRINT.pdf in McCausland et al (unpublished)
[25] McCausland et al (unpublished)
[26] McCausland et al (unpublished)
[27] Draft report, Action Plan for Healing knowledge circle 13 February 2018 (unpublished)

Kinchela and Cootamundra committee members have proposed the idea of a joint aged-care facility for former residents who consider each other family (Healing Foundation Report, 2016, p. 29)[28]. The Kinchela Boys' Home Aboriginal Corporation have already been delivering aged care and disability services to former residents of the home and to other Aboriginal community members in partnership with Annecto Western Sydney, allowing them to stay comfortably at home with the support required[29].

Funding to assist family members to care for Stolen Generations survivors at home might be a better approach[30].

"Aged care is a big thing. Mum and Dad were institutionalised in the dormitory system, then us being removed … We became Mum's carers. My biggest regret is that we had to put her in fulltime care because we didn't have the resources to keep her out of an institution."

The NSW Reparations Report identified a need for appropriate aged care services and housing options for members of the Stolen Generations and reported on some moves towards meeting it in a couple of regional areas. In NSW, there are Aboriginal Aged Care facilities in the rural towns of Kempsey and Nowra, but none in Sydney.[31] The NSW Reparations Report also identified a need to allocate places in existing aged-care facilities to members of the Stolen Generations, particularly in places where it would help them stay connected to family, community and culture (p. 143-145)[32].

4.6 Stolen Generations-specific, trauma-informed and holistic services are urgently needed.

Public sector and service organisations across the board including in and around the aged care system need to achieve trauma-informed, cultural competency. Embedding such trauma-informed, cultural competency needs a more comprehensive approach than just the requirement for an individual to attend a training course:

Inquiry participants raised the need for greater emphasis on education and awareness about the history and impacts of past forced removal policies and practices, and the need for genuine cultural awareness and competency – particularly in regard to the impacts experienced by members of the Stolen Generations and their descendants – for public sector staff providing services to Aboriginal people (NSW Reparations Report 2016, p. 171)[33].

Service-delivery agencies need to recognise that their client base is still suffering the effects of trauma.

Government workers in Housing, Centrelink and so on, need to be aware that they are dealing with survivors of trauma, with many people suffering from post-traumatic stress disorder (South Australia Consultations 2017, p. 9)[34].

Service delivery agencies need specialist training to better equip them in their interactions with members of the Stolen Generations, in order to *"focus on the specific trauma, loss and grief experienced by members of the Stolen Generations, and the ways in which this can impact their access to services"*, including barriers such as lack of knowledge about the types of services available, distance and transport issues, as well as

[28] Healing Foundation, (2016). Healing For Our Stolen Generations: Sharing Our Stories. https://healingfoundation.org.au//app/uploads/2017/02/Healing-for-Our-Stolen-Generations-Sharing-Our-Stories-2.pdf in McCausland et al (unpublished)
[29] McCausland et al (unpublished)
[30] Draft report, Action Plan for Healing knowledge circle 13 February 2018 (unpublished)
[31] NSW Reparations Report in McCausland et al (unpublished)
[32] NSW Reparations Report in McCausland et al (unpublished)
[33] NSW Reparations Report in McCausland et al.
[34] South Australian Department of State Development, (2017). *South Australia Stolen Generations Community Reparations Fund: Summary of Consultations.* Adelaide: South Australian Department of State Development. https://statedevelopment.sa.gov.au/upload/aboriginal-affairs/stolen-generations-policy/Summary%20of%20Consultations.pdf?t=1511752279992 in McCausland et al (unpublished)

people's reluctance to engage with government departments as a direct result of their previous experiences (Scorecard Report 2015, p. 149)[35].

Direct points of contact and clear pathways to assist Stolen Generations survivors to navigate the service system by providing information and making referrals to appropriate services would be useful additions to service systems. Such points of contact should be staffed by people who are trained in trauma-informed practice and have specialist knowledge about the Stolen Generations, and preferably who are Aboriginal or Torres Strait Islander people (NSW Reparations Report, Victorian Taskforce Report)[36], and with lived experience of Stolen Generations (Knowledge Circle, Feb 2018)[37].

A significant percentage of Stolen Generations members reported difficulty in accessing and using services, particularly in some regional areas. The taskforce found that those who work in the field are highly committed to the process of healing, however they lack support and resources with which to deliver effective services (Victorian Taskforce Report 2009, p. 24)[38].

Regional areas in particular have service delivery gaps that need addressing. The NSW Reparations Report[39] found these areas require specifically trained workers using culturally appropriate methods (2016, p. 53).

Participants in the recent yarning circles indicated that it is essential that support staff interacting with Stolen Generations survivors, including counsellors, nurses and aged-care workers, be provided with trauma-informed and culturally appropriate education and training.

"There should be a compulsory, face-to-face assessment for all people working with our mob".

Yarning circle participants also recommended redirecting funding from non-Aboriginal organisations such as NGOs and other government agencies and instead reinvesting in community programs that implement trauma-informed solutions.

4.7 Social and emotional wellbeing services

There remains a need for "developing 'strong' mental health and social and emotional wellbeing programs for Stolen Generation survivors and their families" (NSW Reparations Report 2016, p. 141)[40].

Stolen Generations have expressed a number of concerns about the counselling services provided under the previous Bringing Them Home program and current Social and Emotional Wellbeing program[41]. Evaluation of the programs noted successes and some limitations, including inconsistency (NSW Reparations Report 2016, p. 48, p. 54)[42]. Issues include the change of title from Bringing Them Home counsellors to Social and Emotional Wellbeing counsellors, which some people felt took the focus off the Stolen Generations and lowered awareness of this specific role (2016, p. 50). Another problem is that funding for programs is not ongoing.

Regional and remote communities continue to experience difficulty in responding to the complex needs of Stolen Generation survivors, given that these areas often lack specialist Aboriginal services such as rehabilitation, mental health and counselling, even though they "are integral to the future health and wellbeing of the Aboriginal and Torres Strait Islander community" (NSW Reparations Report 2016, p. 142)[43].

[35] Scorecard Report 2015 in McCausland et al (unpublished)
[36] NSW Reparations Report, Victorian Taskforce Report in McCausland et al (unpublished)
[37] Draft report, Action Plan for Healing knowledge circle 13 February 2018
[38] Victorian Taskforce Report in McCausland et al (unpublished)
[39] NSW Reparations Report in McCausland et al (unpublished)
[40] NSW Reparations Report in McCausland et al (unpublished)
[41] McCausland et al (unpublished)
[42] NSW Reparations Report in McCausland et al (unpublished)
[43] NSW Reparations Report in McCausland et al (unpublished)

5. Summary of key actions for inclusion in the Aged Care Diversity Framework, Action Plan for Aboriginal and Torres Strait Islanders

This section summarises key actions that should be included in the Aged Care Diversity Framework, Action Plan for Aboriginal and Torres Strait Islanders in order to ensure that services and policies support rather than harm Aboriginal and Torres Strait Islander people.

- Healing frameworks should be applied holistically to aged care services and support for Aboriginal and Torres Strait Islander people. This is an opportunity to establish an aged care system/framework that acknowledges the history and impact of colonisation, and subsequent policies such as removing children from their families.

- As part of the Action Plan for Aboriginal and Torres Strait Islanders, special attention must be paid to the needs of Stolen Generation members as they have complex needs arising from their experience of forcible removal. Within 5 years (by 2023), Stolen Generation survivors will be aged 50 and over. It is essential that their special needs are addressed urgently.

- In order to exercise greater self-determination in relation to policies and decisions that impact on them, Stolen Generations must be invited into negotiations that determine services and policies as an equal negotiating partner.

- Initiatives taken to address the needs of the Stolen Generations must be led by Stolen Generations members and centred on the needs that they themselves have identified.

- Urgent action is needed to ensure that Stolen Generations are able to access aged care services and support that meet their complex needs, and which do not re-traumatise survivors.

- Funding and programs need to be in place that enable Stolen Generations and their descendants to address intergenerational trauma and achieve healing including through individual counselling; intergenerational healing strategies; collective healing approaches such as healing camps and on-country programs; and in healing centres accessible to Stolen Generations across all jurisdictions in cities and regional and remote areas

- Aged care support and services need to be sufficiently flexible and resourced to enable enhanced cultural connection for elderly Stolen Generations and their families, including support to return to country and being buried on country.

- Non-institutional models of aged care and support need to be urgently investigated and adopted to avoid re-traumatisation. This includes services and support from Aboriginal and Torres Strait Islander organisations with specific focus on Stolen Generations, and avoiding government and non-government service providers who were historically associated with removal of children.

- Organisations supporting and providing services to Stolen Generations must adopt trauma-informed, culturally competent approaches at all levels including in their underpinning policies and systems, as well as for individual workers.

- Direct points of contact and clear pathways are required to assist Stolen Generations survivors to navigate the service system by providing information and making referrals to appropriate services would be useful additions to service systems. Such points of contact should be staffed by people who are trained in trauma-informed practice and have specialist knowledge about the Stolen Generations, and preferably who are Aboriginal or Torres Strait Islander people and with lived experience of Stolen Generations.

6. Action Plan for Healing – Activity 3, Resources for Stolen Generations in Aged Care

The evidence presented in this submission indicates that there is a pressing need to develop aged care services that cater for the specific circumstances of the Stolen Generations.

The aged care activity of the Action Plan for Healing aims to work with Stolen Generations to identify the training and information that they would want health and aged care providers to have in order to increase support and access for elderly Stolen Generations.

Current training resources that are provided for aged care providers are not focused on Stolen Generations alone. They do not adequately reflect the contemporary experience of Stolen Generations, nor the emerging trauma research in aged care.

The Healing Foundation intends to work with Stolen Generations, and aged care providers and educators to develop training resources that to support the development of a trauma-informed aged care sector that is better able to meet the needs of Stolen Generations confidently and safely. It will include consultation with the Stolen Generations to ensure that resources are in line with their expectations and experiences.

This work will be informed by other projects including the development of the Aged Care Diversity Framework Action Plan for Aboriginal and Torres Strait Islanders.

7. Conclusion

The Healing Foundation welcomes the opportunity to contribute to the development of the Aged Care Diversity Framework Action Plan for Aboriginal and Torres Strait Islanders.

We recommend that the Plan embeds a holistic healing approach to supporting and providing services to elder Aboriginal and Torres Strait Islander people. In particular, we have presented evidence that demonstrates the 'gap within the gap' facing Stolen Generation survivors and their families, with recommendations for addressing their complex needs. We welcome further conversations about how to put these recommendations into practice with input from Stolen Generations, their organisations and carers.

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Our Ref: SLASS:2019

14 April 2019

Queensland Parliament
Health Committee
Parliament House, Qld, 4000

BY EMAIL ONLY: careinquiry@parliament.qld.gov.au

Topic: **Inquiry into aged care, end-of-life palliative care and voluntary assisted dying**
Matter: **Submissions in relation to the inquiry into aged care**

Introduction

We refer to the inquiry into aged care, end-of-life palliative care and voluntary assisted dying (paper no. 3) and thank you for providing us with the opportunity to make submissions in relation to same.

Background and experience

The Cairns Community Legal Centre Inc ("**the Centre**") is a not for profit community organisation that has been operating since 1991. The Centre provides legal services for the benefit of community members experiencing disadvantage.

The Centre provides a number of services including its specialist Seniors Legal and Support Service ("**SLASS**"). The SLASS has been operating since 2007 and includes the provision of both legal and social work services within the areas of elder abuse and financial exploitation of seniors. The work undertaken through SLASS involves legal advice, social work assistance, information and referrals, casework and community education.

Submissions

We wish to submit on the following issues for consideration regarding the inquiry into aged care.

1. **Is the aged care system meeting the current needs of older Queenslanders, including those people with special needs? Why or why not?**

   The volume of the ageing population requiring additional assistance at home exceeds the number of home packages and support programs available. The current data provided by the Australian Government Department of Health states there can be a maximum wait time of 12+ months to the first package and a further 12+ months to receiving the approved package.[1] This indicates that there is a growing ageing population who are currently without aged care services, meaning that the current system is not meeting the needs for older Queenslanders in that older persons are not receiving the services they need within the timeframes required.

   In addition, we have seen that there is pressure being placed on the Commonwealth Home Support Program (CHSP) to *top-up* the hours approved in the initial Home Care Package. This pressure shows that the number of initial Home Care Packages is insufficient in meeting the needs of older Queenslanders. And while there has been an increase in the number of service providers since the introduction of the

[1] Home Care Reforms, ACAT Assessors – Wait Times "Home Care Package Wait Times" by Australian Government, Department of Health dated 13 September 2017.

National Queue in February 2017, many of these providers only have approval to provide older persons with services allocated in the initial home care package, meaning that in some cases older persons are approved for higher levels of care but allocated lower levels and are unable to *top-up* their hours through CHSP.

Ultimately, this lack of hours and/or services is generating an added burden on our current carers; in addition to creating further pressures for clients to request support from family members. This physiological stress due to the change in relationship dynamics can often cause the family member to become burnt-out. In addition, these family members are assisting and supporting the older person on top of their usual daily obligations, such as full-time work and raising families. This carer burn-out can result in a lack of patience and tolerance towards the older person, which may lead to neglect, physical or physiological abuse and financial exploitation of an older person.

In relation to those older persons who have special needs, there are a raft of issues that individually affect the different groups or categories of older persons with special needs. These issues range from accessibility of services due to locality or homelessness to carers resources and availability to provide culturally and linguistically appropriate services. While this submission does not address each of these matters it is noted that we see many older persons who do face these barriers when attempting to navigate the already complicated and complex nature of the aged care system.

2. Are the current waiting times for both residential and home care places adequately meeting the needs of older Queenslanders?

As stated above, the current data provided by the Australian Government Department of Health states there can be a maximum wait time of 12+ months to the first package and a further 12+ months to receiving the approved package.[2] It is noted that 92,000 people were accessing home care packages at June 2018, up from 64,000 two years earlier, but there are currently 128,500 people either on the waiting list or not receiving their approved level of care.[3] Moreover, it is noted that as at 30 June 2018, the wait time for a level four package was almost two years. Almost one in four died while waiting on an interim package and almost half (43 per cent) entered residential care while in the queue.[4]

With additional pressures on family members to care for our ageing population, it is clearly not appropriate that older persons are facing a wait time of 12+ months for a basic home care package and in some cases a 2 year wait time for certain packages. In many cases older persons are being forced into residential care based on these wait times and lack of support and/or assistance at home. This ultimately results in residential facilities filling beyond capacity, staff and resources.

Without the necessary staff and resources available in the facilities, again we see the pressure of limited staff managing multiple patients, creating further opportunities for burn-out and consequently abuse of the older person.

Conclusion

We again thank you for providing us with the opportunity to make submissions in relation to inquiry into aged care, end-of-life palliative care and voluntary assisted dying (paper no. 3).

If you require anything further from us in relation to our submissions, please feel free to contact us on the number provided above or by return email.

Yours faithfully
CAIRNS COMMUNITY LEGAL CENTRE INC

per:
Seniors and Legal and Support Service

[2] Ibid.
[3] "Waits for aged home care 'cruel, unusual'" article published by the National in AAP and on myGC.com.au dated 22 March 2019.
[4] "Questions raised about official home care wait figures" article by Judy Skatsson in Community Care Review dated 27 March 2019.

LUTHERAN CHURCH OF AUSTRALIA
QUEENSLAND DISTRICT
ABN 30 051 602 996

Introduction

The Lutheran Church of Australia Queensland District (LCAQD) provides retirement living, aged care and home care services through its department Lutheran Services. The LCAQD also provides education, youth, early learning and other ministries to Australians locally and abroad.

Lutheran Services is a not-for-profit organisation that has been serving the people and communities of Queensland since 1935. We strive to provide quality, contemporary care and support for people of all backgrounds. Young people and their families. People living with disability or mental illness. People experiencing domestic violence or hardship. And – most significantly in their growing numbers and evolving needs – older Australians.

As part of the Lutheran Church, we aim to walk together with congregations, communities and individuals to tend to human need in the spirit of Christian love and service. In our faith and focus, we support those we serve to pursue the life they hope for, and the communities we are part of to thrive.

Our services to older Australians include residential aged care, residential respite, independent retirement living, home care and allied health services. We operate nine residential aged care, nine independent retirement living and 12 home care services across South-East and Western Queensland. We also operate an allied health clinic in Logan. We aim to provide holistic, industry-leading care and support – from creative engagement and spiritual expression to dementia support and palliative care.

Aged care

As at June 30 2018, we had 1192 staff looking after the following clients:

Residential aged care	881
Residential respite	23
Home care	124
Commonwealth home support	429

We operate 2.5 percent of the residential aged care beds in Queensland. As a longstanding and leading provider of services to older Australians – and as an employer of aged care support workers – Lutheran Services is committed to developing a highly responsive, respected and sustainable aged care system.

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An aged care system that:

- Supports the complex needs and heartfelt hopes of older Australians and their loved ones.
- Strives to satisfy the evolving requirements of this valued and vulnerable sector of our society.
- Unites policy makers, funding bodies, regulatory agencies and care providers like Lutheran Services in the pursuit of a shared vision.
- Integrates seamlessly with all levels of healthcare.
- Meets community expectations, public demand and professional standards.
- Recognises and supports the passionate staff who work for us and realise our vision – often in very challenging circumstances; often for comparatively modest remuneration.
- Provides accessible and affordable support to older Australians – when and where they need it, and in a manner that suits their personal preferences.

Aged care issues for consideration

Demand for aged care services

Queensland will need to support more seniors in years to come. The total numbers of seniors needing retirement living, home support and aged care accommodation will increase, as will their proportion of the population. This will be felt across the state, but particularly in population centres of the south east.

The number of people aged 75 and over in South East Queensland will rise from 211,361 in 2016 to 510,087 by 2036 (Source: ABS time series). This is an increase of 298,725 people aged 75+ in South East Queensland.

The demand for aged care services that include pastoral care and end of life care in the Christian tradition will also be high. People identifying as Christian aged between 50 and 64 in 2016 was 59.5 percent of the Australian population.

Not only is this ageing phenomenon significant for retirement living and aged care providers, it is also needs to be reflected in planning schemes of local authorities throughout the region. It should feature prominently as a major force of change on land use and transport in the region. For example meeting the needs of aged care residents, including those with Alzheimer's, Parkinson's or other physical or mental disabilities, does not involve a one size fits all "nursing home" solution.

The industry is also fast responding to advances in aged care with a variety of residential care solutions that explore new models of service delivery. Many of these different models such as group housing, 'care farming', or senior's hubs may not fit within land uses identified by local governments.

Regional, rural and remote

Lutheran Services has its roots in regional communities. As a provider of care in some smaller rural communities, we experience challenges in providing services.

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We would recommend an aged care funding system that recognises the additional costs of providing aged care services in rural, regional and remote locations, where demand is smaller, and is often provided by not-for-profit organisations.

As a provider in rural and regional communities, it is also sometimes difficult to find and retain staff. A funding system that recognises this, including potentially higher remuneration required to meet staffing needs, is also recommended.

Other issues of being a regional provider include the downturn of rural economies and recent extended periods of drought. We find ourselves responding to higher levels of psychological distress, not only in residents, but at times with staff as well.

For our rural sites of Kingaroy, Biloela, Laidley and Somerset, one of the most significant barriers to safe and timely care is the length of time required to allocate a Home Care Package to an eligible recipient. It is of particular concern in the South Burnett (Kingaroy) region.

There are additional challenges in delivering this care efficiently, as travel time to home care clients in rural locations (such as Kingaroy and Biloela) can exceed an hour one way. We see the benefit of additional incentives or offsets to providers providing home care in these locations.

Access to specialist medical services and allied health clinicians is also challenging in rural and remote areas, and the additional costs of providing these services is not adequately supported by current funding. Further research is the area of tele-health consultancies (and appropriate Medicare claiming by supporting clinicians) is also recommended.

Socioeconomic and social disadvantage

Lutheran Services has a long history of providing care to older Australians and other vulnerable or special needs populations. As a result, we have high levels of concessional residents – those who are unable to pay for their accommodation deposits or contributions in our aged care services. At some of our sites, up to 70 per cent are concessional residents.

We are now witnessing a new category of social disadvantage in our respective care communities – single older women with limited or no real assets, savings or superannuation funds. The system needs to recognise the difficulties of ageing for this particular demographic.

Also, as a result of this, Lutheran Services has much smaller pools of working capital via Refundable Accommodation Deposits (RADs) to invest in infrastructure and technological upgrades. This often results in slower upgrades and improvements.

We would see merit in the offering of grants or low interest loans to not-for-profit organisations to deliver the most contemporary infrastructure options to those who cannot afford to pay upfront accommodation deposits. Many rural people (even if they are housing owners) have lower or insufficient equity to pay upfront accommodation deposits due to low median house values in these communities. This necessitates our organisation to borrow funds commercially to build new infrastructure.

People with disabilities or mental illness

Lutheran Services is a long-term provider of care for people with persistent mental illness and those with a wide range of disabilities. We offer these services in our specialised permanent, semi-

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permanent, transitional and respite facilities. In some circumstances, we have had no alternative but to offer places in our aged care facilities for younger people with severe disabilities. With the implementation of the NDIS, we are exploring alternative solutions to create the best caring environments for our communities of all ages with special needs.

We are seeing increasing demand from people who are ageing who also have longstanding and persistent mental illnesses. With treatment options involving newer antipsychotic and psychotropic medications for this community, we are supporting people to age well into their sixties and beyond. The growth of this special needs group requires a new and sensitive approach to their care. We are in the early phases of planning for dedicated services in Nambour on the Sunshine Coast to meet the emerging care needs of this community.

Access to home care

In some of our service locations, numerous eligible recipients of home care packages are waiting excessive periods of time to receive services that will support them to continue living safely at home (longer than 12 months in Kingaroy in the South Burnett for instance). This can result in the older person experiencing a more rapid onset of frailty, requiring them to enter residential aged care via unplanned hospital admissions.

Additional Home Care Packages are urgently required for providers in regional, rural and remote settings, with potential loadings to address the significantly increased travel times to deliver care.

Another issue is that there is currently a great divide between the Level 4 Home Care Package and full-time residential aged care. This divide inherently creates risk for older persons living at home who require more than 12 to 15 hours of support per week. As a result, these individuals can become increasingly frail, putting them at greater risk of falls and hospitalisation due to preventable injuries and wider issues of frailty.

The recently announced initiative to create a higher level Home Care Package is a welcome first step. As an aged care and home care provider, we strongly encourage a rapid rollout of more comprehensive support options for older Australians continuing to live in their own homes.

There may be merit in exploring ways to expedite the process, from the determination of eligibility via ACAT, to the access and delivery of care at the client's choice and direction.

Staffing

For providers like Lutheran Services to create the best quality and safest care environments, access to a skilled, compassionate and motivated workforce is essential. We are aware of the workforce taskforce report A Matter of Care and support the findings and recommendations. We have commenced our own review of how we structure our workforce, aiming to provide comprehensive care and lifestyle coordinators to work alongside clinical care personnel.

As a provider in small rural communities, we often experience significant challenges in the recruitment and retention of registered nurses and allied health practitioners. In these locations we are unable to compete for the small numbers of available personnel, given the wages and conditions state-funded health services are able to offer. As a result we pay additional retention incentives or more expensive locum or agency rates. This further erodes our viability and

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sustainability in these smaller and isolated communities.

A potential solution is an integrated approach to care using a hub model, whereby staff can work across jurisdictions in rural and remote communities, in a shared arrangement between employers – creating opportunities for all to benefit from these limited pools of resources.

Public health care system

Australian hospitals over the past few decades have reduced their length of stay for planned and unplanned activity. As a result, some residents in our care require additional "post-acute" care in addition to their routine care. This may take the form of post-operative wound management, restorative care or dedicated rehabilitation.

In our review of clinical incidents, we have observed that some residents who were in-patients have been discharged back into our care with very complex post-acute care wound management and other post-acute intervention requirements. In some cases, this brings into question the initial discharge decision by hospital. We see benefit of a community-based visiting specialist to oversee wound management for residents post-hospitalisation and for those with complex care needs post-discharge (such as stomas or amputations).

Suitable health care services

As a generalisation, consistent general practice care is better in smaller communities where the GP has often been the long-term primary care provider for our resident over many years. Our services in Biloela, Kingaroy, Toowoomba and Laidley have good relationships with local GPs enabling good access and continuity of care.

However, in some large metropolitan locations, general practice is more variable, with our services having to communicate and coordinate with multiple GPs, including locum or deputising services. This has been a particular challenge at Woodridge (Trinder Park), Caboolture (St Paul's) and Tallebudgera (St Andrews), where multiple GPs require additional orientation to the service, staff, IT systems and care plans.

The current funding incentives for GP consultation and multidisciplinary team leadership at key points of clinical care – such as discharge planning, rapid clinical deterioration, palliative care planning and planning care for residents with cognitive decline – impact negatively and increase pressure on clinical teams to provide care for residents at these times. The current incentives do not allow for consultation of a protracted and complex nature.

It is also worth noting the difference between funding for palliative care in a Residential Aged Care facility and in hospital.

Case conferencing including allied health, psychology services and specialist nursing services would be supported with access to specifically itemised funding for the participation of these clinicians.

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Alternative models for the delivery of aged care services

Lutheran Services has numerous service locations, representing a variety of physical infrastructure configurations. Some of these built-form configurations were developed in times past to suit now superseded modes of care – such as "low care" in the 1970s to 1990s. These are not the best configurations for the quality care of residents with the highest care needs today. It is a challenge for a provider like Lutheran Services to maintain or modify such infrastructure in line with the changing profile and demands of contemporary aged care.

Contemporary thinking suggests providers of future residential services should offer smaller pods or clusters of bedrooms with common areas, thus creating a stronger, home-like experience. We have demonstrated the benefits of such a model with one of our newer developments. Northridge Salem at Toowoomba has created a smaller, more intimate care environment, resulting in fewer complaints or concerns of care.

Several of our sites have ample space to plan and develop such smaller configurations – particularly Trinder Park in Woodridge and Immanuel Gardens in Buderim.

Technology

New technology and mobility aids have potential benefit for residential aged care, home care and retirement living. Technological devices for monitoring movement, such as accelerometers for responding to falls, could advance the care responses in both residential and home settings. These devices are freely available, however there are some policy and operational frameworks required to ensure their optimal use without compromising personal autonomy, choice and dignity.

Technology could greatly reduce social isolation and improve connectivity for older Australians living alone or in rural or remote settings. Lutheran Services is in the process of developing a strategy to make communication aids more widely available to promote connectivity for those in our care – to each other, to their loved ones and to the world more generally.

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End of life and palliative care

In the last century, medicine and improved public health measures in Australia have been very successful in increasing life expectancy. However, this has changed the pattern of ageing and the pattern of dying. Increased longevity has created a new population of people burdened with complex and chronic disease and "advanced frailty". For this population the traditional models of care, focussing on curative and life-prolonging treatments, without automatically having concurrent goals of enhancing quality of life for patients and their families, can contribute to unnecessary and prolonged suffering at the end of life.1

Many people find it hard to face the dependency, helplessness, and discomfort that so often accompanies ageing, chronic disease and impending death. Such patients need increased levels of support from family, carers, health practitioners and chaplains and they need to be respected, cared for and loved as people created and loved by God. They need to be able to have trusting relationships with those charged with their care and feel confident that they are in safe hands and no longer need to worry about what is happening.2

The Lutheran Church of Australia, through Aged Care and other diaconal ministries, has opportunities to serve people at the end of life in physical and psychological caring; and providing spiritual care to assist with a 'good death' for those in our care.3

At each of our Lutheran Services aged care sites, we are committed to provide chaplaincy to the dying, alongside professional palliative and end-of-life care.

Advance care planning

With increased longevity and reduction in unexpected death from infectious diseases, it is more possible to predict, within a small number of years, when death may occur.

Even though the trajectory towards death can be variably predictable, it is important to engage with the process of predicting progress towards death, and advanced care planning can be undertaken for optimum management of this process. Clinical tools have been developed to assist in this process. 4 Advance care planning is a journey with people and their families, which encompasses starting the conversation; establishing the person's priorities for their life and any goals that are outstanding; discussing values and beliefs; and what will help quality of life; discussing specific details about treatments and symptom management; and documenting the conversation.

There are also legal documentation processes that assist with decision-making particularly as the person may lose capacity. These include having a Will; appointing Enduring Power of Attorney (EPOA) for health and finance; and completing an Advance Health Directive.

1 ANZSPM position statement – ANZSPM Position Statement (2014) on Quality End-of-Life Care - Part 1
2 Catholic Health – Code of Ethical Standards for Catholic Health and Aged Care Services in Australia, 2001; Part II Specific Issues; Chapter 4 Older persons and others with special needs. p35-41 http://www.cha.org.au/code-of-ethical-standards
3 LCAQD – Lutheran Services – Diaconal Witness Statement on Lutheran Services

Palliative Care

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Definition

Palliative Care applies to non-specialist care and is defined by the World Health Organisation as:

"...an approach to care that improves the quality of life of patients (adults and children) and their families who are facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual. Palliative care also respects the choice of patients and helps their families to deal with practical issues, including coping with loss and grief throughout the illness and in case of bereavement."[4]

Compassionate and expert palliative care is not confined to end-of-life care and can be provided in parallel with curative treatment, having different goals and focus. Palliative care is usually multidisciplinary and it is part of whole-person care that is not disease specific and therefore can be complementary to curative treatment.

"Palliative care is most effective when considered early in the course of the illness. Early palliative care not only improves quality of life for patients but also reduces unnecessary hospitalisations and use of health services. "[4]

Palliative care is never about withdrawing treatment or 'doing nothing'. It requires as much work and expertise as curative treatment but the goals are different. Access to palliative care is considered a human right by the World Health Organisation.

Specialist palliative care is only one component of palliative care service delivery. A sustainable, quality and accessible palliative care system needs to be integrated into primary health care, community and home-based care, as well as supporting care providers such as family and community volunteers.[4]

End-of-Life care

Recognising when a person is approaching the end of their life is essential to delivering appropriate, compassionate and timely end-of-life care. There needs to be rigour in assessment of symptoms including physical, cognitive, psychological, social and spiritual domains. A formal diagnosis of the 'terminal phase' needs to be made so this phase can be managed effectively. Care of the dying should be considered 'urgent care' that is managed by those skilled in this area. It is as important as care for reversible conditions.[5]

4 World Health Organisation – Palliative Care - fact sheet number 402, http://www.who.int/mediacentre/factsheets/fs402/en/

5 Australian Commission on Safety and Quality in Health Care – National consensus statement: essential elements for safe and high-quality end-of-life care, https://www.safetyandquality.gov.au/publications/national-consensus-statement-essential-elements-for-safe-and-high-quality-paediatric-end-of-life-care/

When it is recognised that a person has entered the terminal phase, this needs to be communicated to the person, substitute decision makers and families. Uncertainties and ambiguities need to be discussed openly and honestly and communication needs to be on going. This will empower people and their families to direct their own care, where possible, and express needs and wishes for this

phase. Documentation of communications is important for future reference and decision-making.

There are ethical issues that need to be considered in end-of-life care:

- It is important not to harm people approaching the end-of-life by providing burdensome investigations and treatments that can be of no benefit.
- Doctors are not obliged to initiate or continue treatments that will not offer a reasonable hope of benefit or improve the person's quality of life (unless required by law).
- People also have the right to refuse treatments. This may be in advance, formally in an advance health directive or informally in documentation of conversation or consultation with the person.
- Giving palliative care is legal so long as the health professional's intention is to reduce or relieve a patient's pain and suffering, not hasten death. This is the case even if the health professional knows death may be hastened by providing palliative care. This is known as the 'doctrine of double effect'. However the majority of interventions given in end-of-life care by skilled health care teams neither hasten nor obstruct the person's natural dying.[6,7]

Care of the person and their family extends beyond death. Respectful treatment of remains and observance of cultural or religious practices need to be considered. Families also need to be cared for with appropriate time and space to grieve and follow up with bereavement counselling if this is wanted. [7]

If end-of-life care is well managed, symptoms should be minimised and the transition from life on earth, through death, to life in eternity is made as smooth as possible. In most cases, suffering at the end of life can be prevented, or significantly reduced. It is often suffering and loss of control that people are frightened of more than death itself.

To this end, Lutheran Services is participating in the End of Life Directions for Aged Care (ELDAC) program which is funded by the Australian Government Department of Health and is being delivered by a consortium of three universities including the Queensland University of Technology, and five national bodies from the aged, palliative and primary care sectors. It aims to improve the quality of end of life care for all older Australians, and to ensure our services are the highest quality to ensure optimal outcomes for older people at end of life. We are currently working on this at two of our sites and are aiming to roll the program out across our other sites.

6 Australian Commission on Safety and Quality in Health Care – National consensus statement: essential elements for safe and high-quality end-of-life care, https://www.safetyandquality.gov.au/publications/national-consensus-statement-essential-elements-for-safe-and-high-quality-paediatric-end-of-life-care/

7 End of Life Law in Australia - https://end-of-life.qut.edu.au

Voluntary assisted dying

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Euthanasia

Definition

Euthanasia is a deliberate, intentional act of one person to end the life of another person in order to relieve that person's suffering. The term euthanasia is often used in different ways. The most common are:

- Voluntary euthanasia**:** Euthanasia is performed at the request of the person whose life is ended, and that person is competent.
- Non-voluntary euthanasia: Euthanasia is performed and the person is not competent. They are deemed to be 'suffering' by others and are not able to consent.
- Involuntary euthanasia: Euthanasia is performed and the person is competent but has not expressed the wish to die or has expressed a wish that he or she does not die. They are deemed to be 'suffering' by others.
- Physician-assisted suicide occurs where a person requests a doctor to assist them in committing suicide, for example, a doctor provides a person with a prescription to obtain a lethal dose of drugs

Both euthanasia and assisted suicide are currently illegal in all Australian States and Territories and may result in a person being charged with murder, manslaughter or assisting suicide. An exception to this will occur in June 2019 after the Victorian state parliament passed the Victorian assisted dying bill which will become law on 19 June.

Former inquiries in Western Australia and New Zealand show that this is an issue which is a concern in our society and is continuing to be progressed in different jurisdictions. It raises complex issues for both secular and church organisations, particularly those organisations caring for the sick, the ageing and the dying.

The Lutheran Church of Australia (LCA) Commission on Social and Bioethical Questions (CSBQ) issued a Euthanasia or Mercy Killing (1981) statement that was endorsed by Synod (see http://www.lca.org.au/departments/commissions/social-bioethical-questions/), which is still relevant, and is still upheld by the LCA.

To summarise this statement, the LCA rejects the practice of euthanasia in all its forms, because such killing is contrary to the word and law of God. The church's past, present, and future proposals for euthanasia legislation is based, above all, on ethical considerations concerning the life and the death of human beings. The 'right to life' of every person must be protected by law. The 'right to die' concept is completely foreign to sound biblical ethical principles.

Each person is understood by the Lutheran faith as a cherished creature of a loving creator and as such we believe in promoting the life given to that person.

It is worth noting that the majority of health organisations also remain opposed to euthanasia.[8]

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It is also worth noting the Victorian legislation allows medical practitioners who have an objection to voluntary assisted dying the right to refuse to provide information about assisted dying, to participate in the process the Act establishes, and to supply drugs or be present at the time an assisted dying substance is administered.

8 Australian Medical Association – Position Statement on Euthanasia and Physician Assisted Suicide 2016, https://ama.com.au/position-statement/euthanasia-and-physician-assisted-suicide-2016; and ANZSPM position statement – ANZSPM Position Statement (2013) on The Practice of Euthanasia & Assisted Suicide

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Our recommendations

1. The Lutheran Church of Australia Queensland District calls for greater efforts to improve and extend palliative care and other measures to reduce suffering in our society. Such measures have demonstrated productive outcomes in the management of pain and the care of those at the end of their earthly life;
2. We call on the Queensland Parliament to support adequate training programs for medical and para-medical personnel so that specialised palliative and end-of-life care for such patients is readily available; and
3. We call on the Queensland Parliament to make a firm commitment to refuse the passing of any bill which comes before it regarding legalising any form of euthanasia.

15 April 2019

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Mr Aaron Harper MP
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Dear Mr Harper and Committee members

Heart Foundation submission to Inquiry into aged care, end-of-life and palliative care, and voluntary assisted dying

The Heart Foundation appreciates the opportunity to provide a submission to the Queensland Parliamentary Health Committee's review into aged care, end-of-life and palliative care, and voluntary assisted dying.

In keeping with the Terms of Reference established for the Inquiry, the Heart Foundation submission primarily addresses:

(1) (a) the delivery of aged care, end-of-life and palliative care in Queensland across the health and ageing service systems.

About the Heart Foundation, heart disease and an ageing population

The Heart Foundation is a charity dedicated to preventing heart disease and improving the heart health and quality of life of all Australians through our work in prevention, support and research.

Cardiovascular disease or CVD (including heart, stroke and vascular disease) is a leading cause (14%) of the disease and injury burden for Queenslanders. Despite significant reductions in CVD death rates, almost 1 in 3 deaths and 1 in 20 hospitalisations are due to CVD.[1] It also accounts for around one tenth of hospital spending. Overall, Queensland has the second highest CVD disease burden rate, after the Norther Territory. Importantly, there is also substantial variation across population groups with the greatest burden reported for Indigenous Queenslanders, those of low socioeconomic status, and those living in remote areas.

Having CVD has a major impact on quality of life and self-reported health. Those with CVD are four times more likely to report poor health than those without, which is higher than any other long-term condition.

CVD rates increase markedly with age for both males and females, as age is the largest risk factor for CVD. Further, as people age, their health needs become more chronic and complex. In particular, the rates of heart failure[1] and atrial fibrillation[1] increase significantly with older

[1] Queensland Health. The health of Queenslanders 2018. Report of the Chief Health Officer Queensland. Queensland Government. Brisbane 2018. Available at: https://www.health.qld.gov.au/__data/assets/pdf_file/0032/732794/cho-report-2018-full.pdf

age. Therefore, it is very important that appropriate prevention and management strategies are in place for the older population.

Encouragingly, much of CVD is preventable through improvements in CVD risk factors including blood pressure and cholesterol, smoking, body weight, alcohol and food and nutrition, and physical activity.[2]

Once a person has a chronic cardiac condition, however, ongoing management is required. Heart failure is a chronic, progressive and incurable condition. Nearly 40% of patients diagnosed with heart failure will die within 12 months of their first hospitalisation for heart failure and will experience a range of debilitating symptoms which are highly distressing to them and their carers.

The Heart Foundation is concerned that people with advanced heart failure are not receiving timely access to appropriate palliative care.

Heart Foundation recommendations

The Heart Foundation has seven recommendations which we believe will improve health outcomes for older people:

Recommendations for aged care to increase physical activity and healthy eating	
1	Develop a state-wide older person's health services plan to support aged care services to build capacity, and to promote the health and wellbeing of older people including interventions to stay healthy, connected and active through increasing physical activity and supporting healthy eating.
2	Support the addition of exercise to the Federal Age Care Funding Instrument (ACFI) to enable exercise to be adequately provided in aged care settings.
3	Promote supported, group-based exercise programs for older people and encourage participation in established community-based programs such as *Heart Foundation Walking* groups to increase physical activity.
4	Increase access to supportive environments that make it easier for people to be active; including building the infrastructure needed, like pathways for walking and cycling, shaded areas, greater access to affordable user-friendly public transport to keep people active and connected.
5	Invest in educating the aged care workforce and increase the health literacy of older people about exercise, and healthy eating in line with the Australian Dietary Guidelines to maintain a healthy weight.
6	Ensure that a consumer-directed approach to the provision of healthcare is implemented to improve wellness, reablement and restorative care.
Recommendation for palliative care for people with advanced heart failure	
7	Ensure timely referral to palliative care is considered in patients with advanced heart failure to alleviate end-stage symptoms, improve quality of life, and decrease rehospitalisation.

[2] Queensland Health. The health of Queenslanders 2016 – Key facts: Cardiovascular disease. Report of the Chief Health Officer Queensland. Queensland Government. Brisbane 2016. Available at: https://www.health.qld.gov.au/__data/assets/pdf_file/0031/644854/cardiovascular-disease-factsheet.pdf

Recommendations for aged care to increase physical activity and healthy eating:

Increase physical activity

1. **Develop a state-wide older person's health services plan to support aged care services to build capacity, and to promote the health and wellbeing of older people including interventions to stay healthy, connected and active through increasing physical activity and supporting healthy eating.**

We support the Queensland Government's commitment in June 2016 to develop a state-wide health policy and subsequent older persons state-wide health services plan in the Queensland age-friendly community action plan[3].

Consistent with the World Health Organization report on ageing and health, a state-wide plan for older persons should have a focus on health and wellbeing and should support older people to have local access to services that optimise physical and mental health.

Staying physically active, eating well and maintaining social relations are crucial for aging well and preventing and reducing the impacts of CVD and other chronic diseases. Maintaining a healthy lifestyle enables people to stay in the home environment for longer and reduces hospital admissions.

A consumer-directed approach to the provision of healthcare that focuses on wellness, reablement and restorative care should be considered as per the Commonwealth Home Support Programme Good Practice Guide for living well at home.[4]

2. **Support the addition of exercise to the Federal Aged Care Funding Instrument (ACFI) to enable exercise to be adequately provided in aged care settings.**

A policy lever that the State Government could advocate for at a Federal level is the addition of exercise to the Federal Aged Care Funding Instrument (ACFI). A recent Australian trial of an exercise program in long-term aged care settings, demonstrated a 55%[5] reduction in falls by people who participated in the exercise program. The program is cost-effective[6] given falls cost the Australian health economy more than any other form of trauma.

Absence of ACFI funding for exercise is a barrier to ensuring effective exercise programs are widely delivered throughout aged care settings.

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[3] Queensland Government. Queensland: an age-friendly community action plan. 2016. Available from: https://www.communities.qld.gov.au/resources/dcdss/seniors/age-friendly-community/qafc-action-plan.pdf?_sm_au_=iVVk5F46sff41Q3F

[4] Australian Government Department of Social Services. Commonwealth Home Supported Programme (CHSP) Living well at home: CHSP Good Practice Guide.2015. Available from: https://agedcare.health.gov.au/sites/default/files/documents/06_2015/good_practice_guide_version_web_accessible_pdf.pdf

[5] Hewitt J, Goodall S, Clemson L, Henwood T, Refshauge K. Progressive resistance and balance training for falls prevention in long-term residential aged care: A cluster randomized trial of the Sunbeam program. Journal of the American Medical Directors Association. 2018 Apr 1;19(4):361-9.

[6] Hewitt J, Saing S, Goodall S, Henwood T, Clemson L, Refshauge K. An economic evaluation of the SUNBEAM programme: a falls-prevention randomized controlled trial in residential aged care. Clinical rehabilitation. 2018 Oct 30:0269215518808051.

3. Promote supported, group-based exercise programs for older people should be facilitated and participation in established community-based programs such as the Heart Foundation's Walking groups promoted.

Physical activity can prevent and improve many chronic health problems (including heart disease and stroke), prolong physical function and independence, improve mood, memory function, and enhance social connections.[7,8,9] Currently, 75% of adults aged over 65 are not meeting the recommended amount of physical activity.[3]

Some physical activity programs are having great success engaging older people in physical activity. For example, the Queensland Heart Foundation Walking groups have over 6660 active walkers across 290 groups spread across the state. The walkers (average age 64 years) have been involved in a total of 209, 981 individual walks recorded in the period from March 2018 – March 2019 and over 85% of participants are retained in the program at 6 months.

4. Increase access to supportive environments that make it easier for older people to be physically active and connected.

Exercise programs will be most effective if they are implemented within an environment that also supports people to be healthy and active, rather than in isolation. That means we need to build communities that are healthy and active by design. The Heart Foundation has developed a resource to support planners, local, state and federal governments to design healthier places - http://www.healthyactivebydesign.com.au/.

Supportive environments have the infrastructure needed to make it easier for people to be physically active, such as connected walking and cycling pathways and shaded areas. They also have supportive legislation such as reduced speed limits in busy areas with high pedestrian use to make places safer for older pedestrians and bike riders. This environment makes it easier for people to make healthier choices.

5. Invest in educating the aged care workforce and increase the health literacy of older people about exercise and healthy eating in line with the Australian Dietary Guidelines to maintain a healthy weight.

Support healthy eating

Aged care services have an exceptional opportunity to enhance the health of older adults by providing food that aligns with the Australian Dietary Guidelines and where appropriate, the Heart Foundation's Heart Healthy Eating Principles[10]. The Australian Dietary Guidelines provide considerations for older people in each guideline where relevant.

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[7] Department of Health 2017. Australia's Physical Activity and Sedentary Behaviour Guidelines. Canberra, Australia: Department of Health. Viewed 4 March 2019. Available from: http://www.health.gov.au/internet/main/publishing.nsf/content/health-pubhlth-strateg-phys-act-guidelines?_sm_au_=iVV1pvrqqtvv08Tt

[8] Taylor D 2013. Physical activity is medicine for older adults. Postgraduate Medical Journal 90(1059):26–32

[9] AIHW 2017. Impact of physical inactivity as a risk factor for chronic conditions: Australian Burden of Disease Study. Australian Burden of Disease Study series no.15. Cat. no. BOD 16. Canberra: AIHW.

[10] National Heart Foundation of Australia. Heart Healthy Eating Principles. Available from: https://www.heartfoundation.org.au/for-professionals/food-and-nutrition/heart-healthy-eating-principles

In Australia 5–11% of people eligible for Home and Community Care services are malnourished.[11] In acute care in Queensland, 20–30% of admitted people have malnutrition, with the prevalence increasing with age and the number of health problems.[12]

The Heart Foundation supports the 2013 Australian Dietary Guidelines, which recommend that older adults eat nutritious food and keep physically active to help maintain muscle strength and a healthy weight.[13]

Improve social and emotional wellbeing.

Social and emotional wellbeing is important for maintaining good heart health, engaging in healthy activities (e.g. physical activity and healthy eating) and adhering to medical care and therapies (e.g. taking medications).

Rates of depression and anxiety in older people who are frail and need support are much higher than their healthy counterparts. An Australian study found that nearly 35 per cent of people living in residential care facilities were depressed[14].

Poor mental health is an independent risk factor for CVD. Depression can also affect the recovery of people with heart disease and increase their risk of further heart problems.

A range of interventions, such as those highlighted in the beyondblue's What works to promote emotional wellbeing in older people, can enhance wellbeing.

Physical activity is also an important preventative and therapeutic intervention to enhance wellbeing. Programs such as the Heart Foundation Walking program and the Walk Wise program (which aims to boost physical activity rates among Australians aged over 65 years) are important programs for enhancing health and wellbeing among the elderly while also providing social benefits.[15]

6. Ensure that a consumer-directed approach to the provision of healthcare is implemented to improve wellness, reablement and restorative care.

The Committee may wish to seek further information on models of care in other states that have taken a broad healthy ageing approach such as the active and healthy ageing advisors established in Victoria that aim to promote, build and support the health and wellbeing of older people.

[11] Leggo M, Banks M, Isenring E, Stewart L, Tweeddale M. A quality improvement nutrition screening and intervention program available to Home and Community Care eligible clients. Nutr Diet 2008;65(2):162–67. 308.

[12] Banks M, Ash S, Bauer J, Gaskill D. Prevalence of malnutrition in adults in Queensland public hospitals and residential aged care facilities. Nutr Diet 2007;64(3):172–78.

[13] National Health and Medical Research Council (NHMRC). Australian Dietary Guidelines. 2013. Canberra: National Health and Medical Research Council.

[14] Wells, Y., et al. (2014) "What works to promote emotional wellbeing in older people: A guide for aged care staff working in community or residential care settings. Melbourne: beyondblue.

[15] National Heart Foundation of Australia. Heart Foundation Walking. https://walking.heartfoundation.org.au/

The rationale for establishing active and healthy ageing advisors is based on the National Ageing Research Institute's *Healthy Ageing review*[16] which highlighted that a combination of strategies to enhance healthy ageing are more effective than stand-alone interventions. These advisors could play a pivotal role in promoting, building and supporting the health and wellbeing of older people, particularly those experiencing disadvantage and social isolation.

In Victoria, these advisors' roles include:

- Working closely with local government on positive aging planning and creating age-friendly communities;
- Identifying and supporting local leaders and champions of healthy aging;
- Embedding healthy aging policy and strategy within existing successful initiatives; and
- Building the capacity of relevant organisations and workforce to grow and support healthy aging across various settings.

Recommendation for palliative care for people with advanced heart failure

7. **Ensure timely referral to palliative care is considered in patients with advanced heart failure to alleviate end-stage symptoms, improve quality of life, and decrease rehospitalisation.**

The Heart Foundation is concerned that people with advanced heart failure do not receive timely access to appropriate palliative care. We strongly believe that people living with advanced heart failure must be considered and that increased and earlier referral to palliative care services needs to be facilitated.

Despite heart disease being a leading cause of death in Australia, most people with non-malignant chronic conditions never access specialist palliative care services.[17] Currently in Queensland, access to palliative care is variable and inequitable and does not align with the Australian National Palliative Care Strategy 2018 which recommends that appropriate and effective palliative care is available to all Australians who need it along with their families and carers.

Inequitable access to palliative care is further pronounced in rural and remote communities, Aboriginal and Torres Strait Islander populations, as well as non-cancer patients and older people living in residential age care facilities.[18]

Heart failure in high-income countries like Australia is increasing due to an aging population and improved survival rates due to efficacious therapy. The prevalence of heart failure among adults in Australia is approximately 2%[19], however, among persons 70 years or older the

[16] Department of Health and Human Services. Healthy ageing literature review. 2019; State of Victoria, Melbourne, Victoria.

[17] Palliative Care Outcomes Collaborative. National Report on Patient Outcomes in Palliative Care in Australia: January - June 2013. Univ Wollongong: Wollongong, 2013.

[18] Queensland Health. Statewide strategy for end-of-life care 2015. Available at: https://www.health.qld.gov.au/__data/assets/pdf_file/0022/441616/end-of-life-strategy-full.pdf

[19] Chan YK, Tuttle C, Ball J, Teng TK, Ahamed Y, Carrington MJ et al. Current and projected burden of heart failure in the Australian adult population: a substantive but still ill-defined major health issue. BMC Health Serv Res 2016; 16(1):501.

prevalence rate is estimated to be greater than 10%.[20] A recent study[21] in the United Kingdom demonstrated that the absolute number of heart failure cases increased by 23% between 2002 to 2014.

Due to the high and increasing prevalence rates, heart failure results in an enormous economic burden on the health care system; developed countries spend approximately 1-2% of their health budget on heart failure.[22]

Heart failure especially affects the elderly, with 80% of heart failure related hospitalizations and 90% of heart failure related deaths occurring among patients aged 65 years or older.[23] Nearly 40% of patients diagnosed with heart failure will die within 12 months of their first hospitalisation, and will experience a range of debilitating symptoms which are highly distressing to them and their carers.

The Heart Foundation strongly recommends that the Queensland Department of Health takes up the recommendations in the recently released Heart Failure guidelines[24]. These guidelines were developed by experts in the field and outline the benefits of incorporating palliative care services into a multi-disciplinary approach and make recommendations based on current evidence for managing end-stage heart failure.

The key recommendation from the guidelines is:

- **Referral to palliative care should be considered in patients with advanced heart failure to alleviate end-stage symptoms, improve quality of life, and decrease rehospitalisation. Involvement in palliative care should be considered early in the trajectory towards end-stage heart failure.**

These guidelines clearly outline the benefits of incorporating palliative care services into a multi-disciplinary approach and make recommendations based on current evidence for managing end-stage heart failure.

The guidelines cite a very strong evidence base demonstrating that the introduction of palliative care is associated with significant improvements in quality of life and a reduction in symptom burden and rehospitalisation.

Key practical advice for service delivery that is directly relevant to the Queensland review is included in the Heart Failure Guidelines:

- The palliative care service should work collaboratively with the patient's heart failure team and GP. This could also be extended to joint home visits by a heart failure nurse and palliative care nurse until the patient develops a strong collaborative relationship

[20] Steenman M, and Gilles L. "Cardiac aging and heart disease in humans." *Biophysical reviews* 2017; 9(2): 131-137.
[21] Conrad N, Judge A, Tran J, Mohseni H, Hedgecott D, Crespillo AP et al. Temporal trends and patterns in heart failure incidence: a population-based study of 4 million individuals. The Lancet. 2018 Feb 10;391(10120):572-80.
[22] Liao L, Allen LA, Whellan DJ. Economic burden of heart failure in the elderly. PharmacoEconomics. 2008;26(6):447–62.
[23] Lesyuk W, Kriza C, Kolominsky-Rabas P. Cost-of-illness studies in heart failure: a systematic review 2004 -2016. BMC Cardiovascular Disorders. 2018. 18:74.
[24] Atherton JJ, et al. National Heart Foundation of Australia and Cardiac Society of Australia and New Zealand: guidelines for the prevention, detection, and management of heart failure in Australia 2018. Heart, Lung and Circulation. 2018 Oct 1;27(10):1123-208.

with the palliative care team, after which time the heart failure nurse may reduce their visits.

- It is important that the collaborative care plan is patient and family-centred.
- In patients with an ICD (Implantable cardioverter defibrillator) discussions concerning deactivation should occur between the patient, their family, and their cardiologist.
- Patients with heart failure should be encouraged to have an advanced care plan (ACP) soon after diagnosis, regardless of their clinical status.

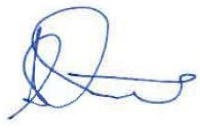
To ensure timely access to palliative care for patients with heart failure:

- Palliative care services in all Hospital and Health Services districts are required to be funded to a level in accordance with the Clinical Service Capability framework in order to provide coordinated, evidence-based and equitable care.
- Infrastructure such as palliative and terminal care packages that meet the needs of the community 24 hours a day, 7 days a week require consideration.
- To encourage ACPs, the provision of dedicated ACP facilitators across all Hospital and Health Services should be considered. The value of ACP facilitators has recently been demonstrated in Queensland and showed that those who completed an advanced care plan translated to more people being cared for in the environment of their choice, avoiding potentially non-beneficial care and fewer unwanted transfers to hospital.[25]
- Further, it is important that the broader health team is educated about the potential benefits of palliative care for people with chronic heart failure and how and when palliative care should be accessed to ensure timely care provision.
- Skills and training would be beneficial for all heart failure team members, including the cardiologist, to feel confident in being able to have conversations with people with heart failure and their families regarding end-of-life planning, palliative care and advanced care planning.

We urge the inquiry to give full consideration to the implementation of these key recommendations in the Queensland context.

The Heart Foundation is available for consultation and to appear as a witness. I look forward to hearing the outcomes of the Committee's inquiry.

Yours sincerely



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Contact: Alison Durham, Advocacy Manager, Heart Foundation [redacted]

[25] Office of Advanced Care Planning. Evaluation of the Office of Advanced Care Planning: Towards a standardised Queensland Wide System of Advanced Care Planning. Evaluation report presented to Health Purchasing Strategy Unit. March 2018.

Submission by the Roman Catholic Bishops of Queensland to the 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 [Paper No 3, 56th Parliament, 2019]

15 April 2019

Introduction and Summary of Key Points

1. The Roman Catholic Bishops of Queensland welcome the opportunity to address the issues raised concerning aged care, end-of-life and palliative care, and voluntary assisted dying by the Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee in its issues paper (Paper No 3, 56th Parliament, 2019).

2. Catholic agencies have a long history of providing health and aged care to Queenslanders and are substantial providers of palliative care services. The spirit of care for others that motivated the early Catholic pioneers of this care in Queensland continues to motivate those institutions today and motivates us too in making this submission.

3. The inquiry is an important opportunity for all Queenslanders. Through considering questions about what happens to us towards the end of our lives and the choices we have, we are indirectly

considering far deeper questions about the kind of society we are living in, and the kind of society we want to live in.

4. Such questions are central to the notion of the common good, one of the founding values of the Commonwealth of Australia. Government and the laws it makes exist to protect the common good, the common wellbeing of all people.[1]

5. We are all members of this society: young and old, rich and poor, believers in God and non-believers alike. And together, through our elected politicians and the structures of government, we have a say in the kind of society we live in, in how best to protect the common good. This is especially important when the matters being considered will affect all of us—most of us will age, and all of us will die. All of us will have family and friends in that position.

For many of us, this process of aging and dying may be a time of increasing vulnerability—physical, psychological, or spiritual. The deeper question that this inquiry is addressing, then, is how should we as individuals and as a society respond to the vulnerabilities inherent in aging and dying, inherent, in other words, in being human?

6. In what follows, we submit:

- that our society is rightly founded on the protection of human dignity, human freedom and the common good, which is the good of all human beings, both as individuals and collectively. The common good includes human flourishing and the sum of material goods necessary for that flourishing. Consequently, the exercise of freedom is always qualified and understood in relation to the common good.
- that in light of this commitment to freedom and the common good:
    - the current shortfalls in aged care should be addressed as a matter of urgency in ways that respect the human dignity of older Australians, and especially their flourishing through the use of their freedom in meaningful ways. Access to timely and adequate health services is very important for those in residential aged care.
    - Palliative care services should be improved both in quality and in accessibility.
    - Education about what high quality palliative care is, namely a commitment to improved quality of life for those with life-limiting conditions, should be supported to challenge the myths surrounding palliative care that create false and unwarranted fears and uncertainties about the dying process.
    - Research into how palliative care can be improved, as well as into how palliative care can improve outcomes related to individual and community meaning-making in life and death, should be supported and encouraged.
    - 'Voluntary assisted dying,' should *not* be legalised in the state of Queensland:
        - because it undermines human freedom by presenting a false choice between horrible dying and intentional killing;

[1] *Official Report of the National Australasian Convention Debates: Sydney 1891* (Sydney: University of Sydney Library, 1999); available at http://adc.library.usyd.edu.au/view?docId=ozlit/xml-main-texts/fed0054.xml;collection=;database=;query=;brand=acdp

- because it undermines the meaningfulness of all life and with it the very idea of a society founded on respect for human dignity and protection of the common good;
- because the law, which should affirm the equality and worth of all, would ultimately be sending the message that some lives are less worthy. Such a message puts vulnerable people at risk; and
- because such legislation would send the wrong message at a time when Queensland has the second highest rate of suicide in Australia.

The Commitment to Freedom and the Common Good: freedom needs the right conditions

7. It is true, and indeed right, that we live in a society that recognises the need to protect human dignity and freedom. Our freedom should be protected from unjustifiable interference.

8. At the same time, our society is rightly concerned with ensuring that the necessary conditions are in place to allow people to use their freedom in appropriate ways: in ways that contribute to their own flourishing, the flourishing of others, and the flourishing of society as a whole. When these necessary conditions are not in place, our opportunities to make choices about the things that matter most are more limited.

9. It is also true, however, that the protection of human freedom it not without restriction. The law places numerous restrictions on human freedom. For example, the law does not allow us to do things that disproportionately endanger our lives, the lives of others, or the overall good of society. A very simple example are the rules of the road. Knowing which choices warrant such limitations is part of the challenge for law makers.

10. When it comes to matters of aging and dying, having our valid choices expressed, heard, and acted upon is very important for individuals and for society. This requires both that our freedom is protected from unjustifiable interference and limitation, and that society provides the necessary conditions for us to exercise our freedom in an appropriate manner.

11. We maintain that both the protection of freedom and the necessary conditions for the appropriate expression of freedom are not yet adequately met in our society in relation to questions of aging and end of life care.

    As a consequence, it might appear to people that their options when it comes to aging and end of life care are more limited than those options really ought to be. Indeed, it may lead them to believe incorrectly that what in other circumstances would clearly be the wrong thing to do, may be the right thing to do.

The onus is on us as a society to make sure that the necessary conditions are in place to make the best choice. Otherwise, we are in danger of thinking that we are protecting people's freedom when we simply do as they ask, when in fact the choices they are making are not real choices because they are choices made in circumstances in which we as a society have failed to provide the necessary conditions for them to make better choices.

12. In listening to what people are saying about aging and dying, we need to make sure that we are hearing the question correctly. If not, we are in danger of giving the wrong answer—an answer that is ultimately unhelpful for the individual and ultimately frustrates the good of society as a whole.

    The fact that some people express a wish to actively end their lives does not mean that the answer must be to allow them to do so. The fact that many people experience suffering and loneliness in sickness and old age does not mean that the solution is to end the suffering by ending the life of the person suffering. The fact that many people fear becoming a burden does not mean that we should confirm to them that they are a burden and that it would be better for them and us if they were no longer here. The fact that many people fear what they think will be a loss of dignity or autonomy does not mean that the answer is to allow them to think that ending their own lives is the ultimate expression of their dignity or autonomy.

    Rather, the question is how to deal with the experience of suffering, of feeling that one is a burden, of the fear of loss of dignity or autonomy, and of death in ways that ultimately affirm the meaningfulness of all human lives and our life together as a community? In other words, how do we best protect and foster human dignity, human freedom and the common good?

What kind of society are we living in?

13. The very fact that this inquiry is being held is evidence enough to know that that aged care is not always perfect, and palliative care is advancing but still not adequately resourced, accessible, understood, or integrated into clinical practice.

14. It is also clear that given these circumstances of the society we are living in, there are fears and uncertainties that lead many to ask whether death would not be better. These include fears of loss of dignity, independence, autonomy, control, pain and suffering, and being a burden. Indeed, in some cases, people resort to desperate measures and take their own lives.[2]

What kind of society do we want to live in?

15. The kind of society we want to live in is premised on two key and interrelated ideas: human dignity and the common good.

16. As affirmed in the Queensland Human Rights Act 2019, all human beings have inherent dignity and worth, equality and freedom.

[2] R. Fedele, "Spotlight on the harsh reality of suicide in Australian nursing homes", online news article, *Australian Journal of Nursing and Midwifery,* 20 May 2018: available at https://anmj.org.au/spotlight-on-the-harsh-reality-of-suicide-in-australian-nursing-homes/

17. The common good is the good of all these human beings, both as individuals and collectively. It includes human flourishing and the sum of material goods necessary for that flourishing.

18. Sometimes there can be conflicts in the interests or rights of individuals or groups, or between and individual and the society.

19. Nonetheless, such conflicts, which may result in the limitation of certain rights by authorities, should always be resolved in ways that do not separate the good of the individual from the good of society, nor the good of society from the good of an individual. Only in so doing can a society strike the fine balance in which all human beings can find fulfilment.

20. At the same time, the awareness of the common good implies that no individual within that society should insist on exercising, or should be allowed to exercise their rights in a way that damages the common good, either through damaging themselves, others, or indeed the fundamental fabric that holds a peaceful, considerate, and flourishing community together.

21. Given this understanding of the society we want to live in, i.e., a community of interconnected individuals whose individual wellbeing is always tied to the wellbeing of others, we frame our responses to the way things are, as highlighted by the issues paper and the questions it raises.

Aged Care

22. Populations in developed countries like ours are aging. But it is also true that people are living better more active lives for longer, and the time at which they need substantial care has been both delayed to much later in life and condensed in duration. Given this reality, dignity and the common good are best served when people are aided in living independently for as long as they are able and desire to. At the same time, encouraging independence should never end up as forced isolation or loneliness.

23. When older Queenslanders are infantilised or treated as less than a human of equal dignity, we have failed as a society. When living under such conditions leads to existential crises of such magnitude that some people will ask to die, we have failed as a society. Every effort should be made to improve aged care in ways that respect the dignity, equality and freedom of individuals.

24. Quality aged care must go beyond simply avoidance of harm and provision of basic survival needs like food and shelter. It must include attention to ways in which aging Queenslanders can continue to exercise as much control as possible over their lives, and continue to feel that they are related to others in meaningful ways, for their own good and the good of those who care for them. People realise their inherent dignity as a sense of pride and self-worth in and through meaningful interactions with others.

25. Provision of adequate health care to people in aged care facilities is of vital importance. Nobody should have their access to high quality health care (to which they are entitled as a member of the community) limited because of where they live. There is evidence that this is sometimes not the case in the care of aged care residents. Many of these issues are being addressed as part of the

Royal Commission into Aged Care Quality and Safety. We would like to reiterate the concerns raised in the Catholic Health Australia (CHA) submission to the Royal Commission by CHA's Director of Aged Care, Nicolas Mersiades, in particular:

- Access to high-quality GPs should be improved, especially for people who cannot travel easily to surgeries.
- Aged care residents are more likely to die in distress in a hospital due to a lack of skills and resources regarding palliative care, especially in-reach services, in aged care. Such services should be improved.
- Access to timely and effective dental care should be improved.
- Access and provision of mental health services in aged care facilities should be improved, especially in light of the high rates of self-harm in aged care.
- The interface between hospitals and aged care should be improved.[3]

Palliative Care and End of Life Care

26. In Queensland, high quality palliative care is offered in Brisbane by Catholic hospitals, the Mater (20 public/private inpatient beds shared with oncology), St Vincent's Private Hospital Brisbane (40 inpatient beds), and Canossa Private Hospital (6 public and 6 private inpatient beds). These services also are involved in outpatient and community palliative care. Other initiatives include the St Vincent's Health Australia, Northern Peninsula Area (NPA) Family and Community Services and Apunipima Health Council 3-year Palliative Care project in Cape York. Catholic services in Queensland have demonstrated ongoing improvement in these services, in line with other developments elsewhere in the Catholic sector in Australia and demonstrated in Catholic Health Australia's recent report on *Palliative Care in the Catholic Sector.*[4]

27. Nonetheless, palliative care funding in Queensland appears to be inadequate, which compromises the capacity of health care providers to adequately care for those dying. For example, Palliative Care Queensland, in its 2018/2019 Pre-Budget Submission, has stated there needs to be an additional $100 million in funding over three years to increase the specialist palliative care workforce to nationally recommended levels.[5]

[3] Nicolas Mersaides, "Statement of Nicolas George Mersiades," Royal Commission into Aged Care Quality and Safety, 31 January 2019, pp. 3-5; available at https://www.cha.org.au/images/agedcare/2019/Statement-NGM-050219.pdf

[4] Ibid., p.13.

[5] Palliative Care Queensland, *Time for Excellent Palliative Care in Queensland: 2018/2019 Palliative Care Queensland Pre-budget Submission,* available at https://palliativecareqld.org.au/publications-positions-submissions/

28. When people suffer needlessly or undergo burdensome and futile treatment under the belief that they must stay alive at all costs, or because some in the medical fraternity are afraid to concede defeat, we have failed as a society. Whilst suffering is part of the human condition, needless suffering is deplorable. Consequently, we strongly support improvement in palliative care, access to it, resources for it, and integration of palliative care with other treatments, including those where there is still a prospect of beneficial treatment.

29. Palliative care should not be understood only as end of life care, or as something that happens when all hope is lost. It should especially not be understood as 'passive euthanasia' and should not be spoken about in a way that equates or includes as part of its understanding any kind of intentional direct ending of a patient's life, whether voluntarily by the patient, non-voluntarily, or involuntarily. There is high quality evidence to the contrary and every effort should be made to educate the health community and the wider community about what high quality palliative care is. Above all it is about improving the quality of life of patients with life-limiting conditions, their families, and their caregivers.[6]

30. We also support efforts to encourage people to have meaningful discussions with their loved ones about death and when it might be appropriate to withhold and withdraw treatment and to engage in advanced care planning.

31. There is a long tradition of moral reflection on the legitimacy of withholding and withdrawing treatment. We support respect for patient autonomy in questions of starting or ending treatment, which means respecting their wishes where these are known, and their best interests where these are not. Where treatment becomes disproportionate, that is, either overly burdensome, or very low likelihood of benefit, that treatment can be legitimately stopped or not started.[7] The intention is not to end the life of the patient, but rather to avoid overly burdensome or clinically futile treatment. Such an action does not constitute an intentional direct ending of the life of a person and so is not to be understood as 'voluntary assisted dying', euthanasia or physician-assisted suicide.

32. We the Roman Catholic Bishops of Queensland commit to doing our part to facilitate meaning-making in ways that affirm life and its meaningfulness.

Voluntary Assisted Dying

33. Should Voluntary Assisted Dying be legalised in Queensland?

No

34. If we as a society begin to embrace a rhetoric that some 'life is not worth living', then we have failed as a society. If we as a society begin to embrace a rhetoric that a person can do whatever they like, whenever they like and however they like simply because they are essentially free, then we have

[6] Catholic Health Australia, *Palliative Care in the Catholic Sector* (Catholic Health Australia, 2019), p. 5.
[7] Catholic Health Australia, *Code of Ethical Standards* (Catholic Health Australia, 2001), Chapter 5.

failed as a society. If we as a society allow people to believe that their only choice is between a slow and painful death, and so-called 'voluntary' assisted dying, then we have failed as a society. High-quality palliative care clearly shows that none of these outcomes are necessary.

35. What is presented in the issues paper as "Voluntary Assisted Dying" undermines human dignity, human freedom, and the common good.

36. What is 'Voluntary Assisted Dying'?

As the issues paper notes, there is not a common understanding of what 'Voluntary assisted dying' is. However, it is possible to clearly label the actions involved. A person who is judged competent (itself a disputed concept)[8] to make such a decision is legally aided, either through provision of the means or by active injection of the means by another, to intentionally kill themselves. Some might say that we should avoid the use of *kill* in this context because it is morally charged. We disagree: 'murder' is morally charged; 'kill' is not. Killing is a clear descriptive verb. The reason that killing is appropriate here is because, though a person who would access such a service may indeed be dying of some terminal disease, it is not the disease that ultimately kills the person in this case. It would be the intentional actions of the person and their assistants, actions which are intended to end the life of the patient before the disease or anything else does.

As explained in point 31 above, legitimate withholding or withdrawing of disproportionate treatments does not constitute 'voluntary assisted dying'. Proper understanding of these processes, of their place in dealing with the realities of human mortality, and how through early and supportive discussions about death and dying, including the use of advanced care planning, they can contribute to a 'good' death, is to be supported and encouraged.

37. Human freedom is undermined by false choices

Legalising intentional direct killing of oneself or another in a peaceful society ('voluntary assisted dying') especially undermines human freedom when a person is presented with a false choice between dying horribly and killing themselves. It undermines freedom because the choice offered is a false one. There is ample evidence that high quality palliative care means that death need not be a horrible experience.[9] If we are not providing high quality aged care and palliative care, then we should make every effort do so. No one should have to die horribly, and no one should have to feel that their only way to avoid it is to kill themselves. The offer of such a choice is a violation of human freedom and frustrates flourishing.

38. The common good is undermined because the meaningfulness of life is challenged

[8] Annabel Price, Ruaidhri McCormack, Theresa Wiseman and Matthew Hotopf, "Concepts of mental capacity for patients requesting assisted suicide: a qualitative analysis of expert evidence presented to the Commission on Assisted Dying," *BMC Medical Ethics*, 15: 22 (2014): http://www.biomedcentral.com/1472-6939/15/32
[9] Michael Ashby, "How We Die: A View From Palliative Care," *QUT Law Review*, 16, 1 (2018): 5-21.

Legalising active and intentional killing of a human being ('voluntary assisted dying'), be it by one's own hand, or at the hand or with the assistance of another, undermines the common good. It does so because it undermines the very ideas that ground the notion of the common good, namely, that life is meaningful and worth living, that community and relationship are important, that we have duties and rights as members of that community, and that we truly flourish not as islands of autonomy but as interconnected meaning-making beings. One's life is meaningful not merely because one has the capacity to choose, but also because one is part of a community in which all need to learn to deal meaningfully with suffering and death together in ways that foster the ultimate meaningfulness of life, and of each person's life. We exercise our autonomy precisely as meaning-makers within this community. Whilst death and dying are a normal part of life, active self-destruction, in which the ultimate intention is to end one's life, is not.

39. The common good is undermined because the role of the law as being good for all is challenged

Normalising intentional self-killing or aid in killing by legalising it through the law normalises the idea not only that some lives are meaningless, but that *life* can be meaningless. The law would no longer protect the common good or the dignity of individuals by affirming that life in common is always meaningful. Without this fundamental commitment, the law is in danger of undermining the very reason for its existence, namely, to protect human dignity and the common good. If human life is not affirmed by the law as meaningful in a fundamental way, then the grounds to assert the recognition and protection of human dignity or indeed even respect for autonomy are undermined. Why should autonomy of the individual be respected if the law holds that the exercise of that autonomy is ultimately meaningless? Indeed, the purpose of the law and government itself is called into question. This is something we should resist. The law and the government are meaningful precisely because we affirm the meaningfulness not only of individual lives but also of our life in common.

40. Freedom and the common good are undermined by the message that some life is not worth living

A law that would allow direct intentional killing ('voluntary assisted dying'), even if only under strict circumstances, opens the way to a culture in which life is disposable. In such a society, even the provision of medical care can become subjected to a rationalisation of the worthiness of a particular person to receive it. Even with all the legal protections in place that say that aid in dying should only be voluntary, a subtle shift takes place in society such that when a person who some think 'ought' to elect to be killed asks instead to live out their days, they are met with derision and scorn. If it is true that some people feel that they want to die because they do not want to be a burden, how much more at risk would such people be in such a culture. In Oregon, the percentage of people who have listed feeling like they are a burden as among the reasons for accessing physician assisted suicide has steadily increased since the law's introduction in 1998 from 36.7 to 61.1 per cent. In 2018, feeling like a burden was the fourth most given reason for physician-assisted suicide in Oregon.[10]

[10] Public Health Division, Center for Health Statistics, *Oregon Death with Dignity Act: Data Summary 2018* (15 February 2019); available at

41. Freedom and the Common Good are undermined if it increases the risk of suicide

A law that allows direct intentional killing ('voluntary assisted dying') may increase suicide at a time when Queensland has the second highest rate of suicide in Australia. The Werther Effect, whereby highly publicised suicides can lead to a series of copycat suicides, is well established. There is also evidence that this effect occurs in relation to assisted suicide.[11] Of particular concern here is that the law may be failing in its pedagogical duty to society by subtly sending the wrong message to people already vulnerable to suicide, namely that it is okay for them to kill themselves.

Surely, in the kind of society that we want to have, a society that affirms individual dignity, the common good, and the meaningfulness of life, it would be more reasonable to expect a request to be allowed to kill oneself to be met with help and support that affirms one's deep worth and meaningfulness rather than to be affirmed in one's feeling that one is worthless, that one's life is meaningless, and that one would indeed be better off dead? We maintain that affirming worth and meaningfulness is by far the more appropriate response. Legalising voluntary assisted dying risks sending the wrong message at a time when there is great concern about the levels of suicide in Queensland.

Conclusion

42. We, the Roman Catholic Bishops of Queensland, support the protection of human dignity, human freedom and the common good. It is clear that in the areas of aged care, palliative care and end of life care, there are many ways in which our society is not yet adequately achieving the protection of these values, and sometimes indeed violating these values. We applaud all efforts to improve aged care and palliative care that help us as individuals and communities deal in more meaningful and life-affirming ways with the vulnerabilities of our own mortality, especially in the current social conditions of Queensland. In light of this commitment, we also reiterate our conviction that no form of 'voluntary assisted dying' should ever be viewed as an entirely adequate solution to the problem of dying. There are better ways to die, and every effort should be made to support these, especially at a time where our society is not yet doing these in the best possible way.

https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year21.pdf

[11] Tanja Neuner, Bettina Hübner-Liebermann, Göran Hajak, Helmut Hausner, "Assisted suicide on TV—the public 'License to Kill'?", *European Journal of Public Health*, 19, 4 (2009): p 359–360, https://doi.org/10.1093/eurpub/ckp053.

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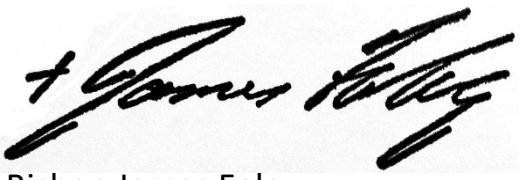

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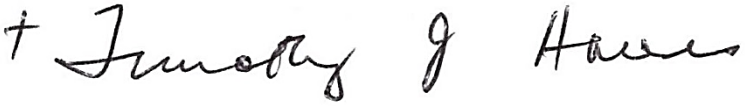

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Bishop of Townsville

Bishop Ken Howell
Auxiliary Bishop of Brisbane

ST VINCENT'S HEALTH AUSTRALIA
UNDER THE STEWARDSHIP OF MARY AIKENHEAD MINISTRIES

SVHA Submission: *Queensland Parliamentary Inquiry into Aged Care, Palliative Care and Voluntary Assisted Dying*

Project Sponsor
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Date
15th April 2019

Final Submission

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1. Introduction

1.1 Background

St Vincent's Health Australia

St Vincent's Health Australia (SVHA) is the nation's largest not-for-profit health and aged care provider. We operate two public hospitals, 10 private hospitals and 17 aged care facilities in Queensland, New South Wales and Victoria. Along with three co-located research institutes – the Victor Chang Cardiac Research Institute, the Garvan Institute of Medical Research and St Vincent's Institute of Medical Research – we work in close partnership with other research bodies, universities, and health care providers.

SVHA has been providing health care in Australia for 160 years, since our first hospital was established in Sydney in 1857 by the Sisters of Charity. When the first five Sisters arrived in Australia in 1838 they carried with them the vision of their Founder, Mary Aikenhead, to reach out to all in need of care and particularly to the poor and vulnerable. It is the legacy entrusted to us by the Sisters of Charity that continues to inspire St Vincent's Health Australia to strengthen and grow our mission.

SVHA employs over 19,000 staff and operates more than 2,600 hospital beds and 1,100 residential aged care places. In our hospitals, we provide more than 1 million episodes of care for patients each year.

We are a clinical and education leader with a national and international reputation in medical research. Our areas of expertise include mental health; drug and alcohol services; homeless health; prisoner health; heart lung transplantation; bone marrow transplantation; cardiology; neurosurgery; cancer; clinical genomics; HIV medicine; palliative care; respiratory medicine; and aged psychiatry.

In Queensland, St Vincent's Private Hospital Brisbane (SVPHB) operates the largest Palliative Care (PC) inpatient facility in the State, a 40 bed specialist palliative care (SPC) inpatient unit with shared public and private beds. Since its inception in 1958, this hospital site - previously known as Mount Olivet - has been providing Palliative Care Services and Aged Care Services to the people of South East Queensland.

SVPHB provides a multidisciplinary community specialist palliative care service for patients within the Brisbane City Local Government area, including home visits 24 hours a day, seven days a week when needed. Between our community specialist palliative care service and our inpatient palliative care unit we provide a seamless model of transition, where patients can be directly admitted into a bed 24 hours a day, 7 days per week.

St Vincent's Health Australia currently proudly owns and operates over 17 aged care communities under the St Vincent's Care Services (SVCS) banner in communities across Queensland, New South Wales and Victoria. SVCS also manages (on behalf of a Religious Congregation) a residential aged care community located in Cronulla, Sydney.

Across all its aged care communities, SVCS currently provides 1,622 residential aged care beds (there are more than 200,000 residential aged care places in Australia), 330 retirement living units, 230 home care places, 175 CHSP and 61 private clients which represents support to over 2,000 elderly Australians.

Close to 40% of SVCS's residential aged care residents are from low means or disadvantaged backgrounds. These residents are provided with supported accommodation through a Government-funded Commonwealth payment that covers all or part of their accommodation charges.

The organisation's first South East Queensland aged care community opened back in 1977 at Kangaroo Point, Brisbane. Since 1977, SVCS have increased their commitment to the elderly in Queensland by operating nine communities aged care and/or independent living. These communities provide 889 residential aged care beds and 228 retirement living units. In addition, SVCS provide services to the elderly through home care, CHSP and private clients.

SVCS is currently in the process of finalising the transition of a further two South East Queensland aged care communities that will add an additional 189 residential aged care beds and 256 retirement village units to its current portfolio.

1.2 Executive Summary

SVHA is well placed with our extensive experience in delivering quality hospital, health and aged care to provide feedback to the questions posed in the Issues Paper issued by the Parliamentary Inquiry into Aged Care, Palliative Care and Voluntary Assisted Dying in 2019.

SVHA understands the interface between end of life planning and access to quality and culturally appropriate palliative care services in a large decentralised state such as Queensland. SVHA supports appropriate end of life care as outlined by the World Medical Association.

SVHA does not support the introduction of Voluntary Assisted Dying (VAD) in Queensland. Instead, we are strong advocates for better planning, investment and access to palliative care and end of life services across the State.

SVHA welcomes the chance to engage with the Parliamentary Inquiry as it provides us with an opportunity to emphasise Queensland's unique position to introduce a world class service end of life care system which:

- Responds to the needs of Queenslanders and provides access to quality health care and palliative care support regardless of where they live
- Encourages better coordination across health and aged care systems and supports holistic care of patients and eradicates red tape and administrative duplication between agencies and levels of Government
- Supports the development of, training and retention of a skilled end of life management workforce
- Draws on, and makes use of technology and other innovations to deliver advice, support and services to regional and remote Queenslanders who are entering their end of life stage to better support them
- Considers alternative models of end of life care models which incorporate the diverse cultural and geographical challenges of the State and
- Incorporates research into new and innovative care for people at the end of life.

More importantly, SVHA believes this Inquiry provides an opportunity for Queensland to develop a whole-of-state end of life strategy. Despite "which level of Government" funds services, SVHA's position is the individual's needs must be at the centre of service planning, delivery and care.

A key plank of this strategy should be investment in public education about what constitutes best practice end of life and palliative care as well as a state-wide workforce development and training plan which encourages end of life and aged care as a viable career option.

The following submission has been informed by representatives, including our leading palliative and end-of-life care specialists, other clinical and non-clinical leaders, from our public and private hospitals and aged care facilities. This submission sets out SVHA's advice regarding aged care, palliative care and voluntary assisted dying.

More importantly, our submission puts the individual at the centre of our advice to the Inquiry. The emphasis of care should be on the individual and not "who and which level of Government provides the care".

We must never forget that future models of end of life and aged care services must always take into account the needs of the individual, families and their communities, and we must always provide as well, for those amongst our communities that cannot afford private health care, as they approach their end of life stage.

1.3 Table summary of key points in Submission

Topic	Submission
End of Life Stage	The volume and complexity of Queensland's health and aged care needs is changing significantly. SVHA's position is the individual's needs must be always be at the centre of service planning, delivery and care. SVHA calls for better coordination across health and aged care systems and supports holistic care of individuals. SVHA calls for eradication of red tape and administrative duplication between primary, acute and aged care agencies and levels of Government. (State and Commonwealth) SVHA supports the opportunity this Inquiry offers to develop a new "master plan" for coordinating care and support to Queenslanders during their end of life stage as a model and example for the rest of Australia. SVHA calls for investment in alternative models of care and service, informed by local community and cultural considerations. SVHA supports the incorporation of research findings/evidence into new and innovative care for people at the end of life stage.
Skilled and qualified health workforce	SVHA supports the development of training, development and retention of a skilled end of life management workforce across medical, aged care and community sectors.
Public Education	SVHA calls on the State Government to invest in better public education across the spectrum of aged care, palliative care and bereavement management. SVHA encourages the State Government to support the establishment of wellness hubs – such hubs could act as a source of information and advice to families and friends of those experiencing ageing or advancing special needs of a loved one.

Aged Care	SVHA supports improving the transitioning of individuals between different systems and agencies to minimise impact on their health and quality of life. SVHA believes the State has a role to play in improving the infrastructure, service and workforce conditions to attract health professionals and aged care workers to the sector. SVHAs view is the coordination of care of people across "systems" – from GPs, to hospitals to aged care – needs to be improved and strengthened and this involves strengthening the coordination between both levels of Government (State and Federal).
Palliative Care	Euthanasia/VAD is not part of palliative care practice. Palliative care in Queensland needs be better resourced. This Inquiry has an opportunity to firstly evolve the current design, planning, funding and service delivery models for palliative care in Queensland so that the needs of its citizens can be better met. Demand for palliative and end-of-life services will only increase as Queensland's population increases and ages. SVHA advocates that access to direct admission to inpatient palliative care facilities 24/7 and advice needs to be invested in to better support the needs of individuals and their families, health practitioners and residential aged care facilities. Future planning for services must involve metropolitan and rurally based Aboriginal and Torres Strait Islander representatives in the design and delivery end of life services, enabling people to die on country or in a place that is culturally safe. SVHA supports increased investment in public education about palliative care, as a means of empowering the community to understand what options they have available to them at this stage of life. A new workforce strategy should be developed and implemented to grow the palliative care workforce across Queensland. Bereavement care is integral to palliative care and all palliative care services should be funded and staff to provide a comprehensive bereavement service to all patients and their families/community.

[redacted]

Voluntary Assisted Dying (VAD)	SVHA does not support the introduction of VAD in Queensland. SVHA advocates for better planning, investment and access to palliative care and end of life services across the State of Queensland. SVHA believes the state of Queensland has an opportunity to firstly invest and put in place a world class palliative care and end of life care system.

[redacted]

Queensland's Aged Care Services System

Please find following SVHA's responses to the Issues Paper Questions.

In Australia, aged care services are predominantly funded by the Australian Government with a smaller number of aged care places funded by states and territories, including the Queensland Government. We also note this Inquiry is aware of the current Australian Government's *Royal Commission into Aged Care Quality and Safety*.

1) Is the aged care system meeting the current needs of older Queenslanders, including those people with special needs? Why or why not?

Understanding what the aged care system can offer can be daunting to elderly people and their families. In our experience, some residents can find themselves 'stuck' in parts of the system which can greatly affect their health and well-being at a time in their lives when they are vulnerable. For elderly people and their families, the challenges accessing appropriate aged care servicing are compounded when clients are based in regional and rural Queensland where there can be reduced availability of aged care facilities and support.

Australia's current aged care system offers a mix of different levels of Federal and State Government funding, eligibility rules and requirements. What this means in practice, is an individual is required to engage and coordinate at their time of need, appointments and documentation across a wide range of health and community-based providers over the primary health, acute care, human services, and aged care portfolios, all of which have differing administrative processes and requirements, as well as differing timeframes for approval of items, such as home care packages. The amount of "administrative work and coordination" that must occur across many agencies can be unnecessarily daunting and overwhelming. Following are some the ways the system struggles to meet the needs of older Queenslanders, including those people with special needs:

- ***Lack of continuity and coordination of holistic management of care of an individual, particularly when they are transitioning between different systems and agencies*** - Referral and discharge between hospitals and aged care facilities requires the coordination of referral processes, sign off, form-completion, and approval from a multitude of health professionals across acute, sub-acute and primary health systems, and State and Federal agencies. Unsurprisingly, a person's experience of referral and discharge to and from a hospital or aged care facility is often less than satisfactory. Residents often become stuck, or are left stranded, in parts of the system which do not best suit their needs, waiting on one set of documentation to be completed or information to be approved for sharing between providers.

For example, the receiving aged care facility is often not provided with the appropriate notice of discharge, nor the relevant information by the hospital about an incoming resident. What this means is that important health information about the resident is not available to staff at the facility and this can result in readmission of the client back to hospital.

- ***Distribution and lack of specialised and skilled aged care workforce*** - A key challenge in Queensland's aged care system is the uneven distribution of specialised, well-trained and job-ready professionals who are experienced in geriatric care, ranging from healthcare workers to personal care/community care workers. It is critical that residents have access to the necessary skillset in the workforce, particularly for those clients who may be experiencing disorders such as dementia and/or requiring palliative care when they need it.

- ***Access to GPs and specialists*** – poor access to GPs, lack of GPs specialising in aged care and waiting lists for specialists, especially in regional/remote areas where there are fewer GPs and specialists impacts on residents and those living in their homes.

- ***Increasing number of clients with cognitive impairment/dementia ageing and in need of specialist infrastructure catering for special needs clients*** – with challenging complex behaviours, changing conditions particularly amongst our elderly population, there will be a need to strengthen the skills, training and experience of the aged care workforce, as well as update and/or build better purpose built facilities so they are able to deliver the appropriate care to both elderly residents, and for those with special needs that need to be accommodated within a residential service**.**

2) Are the current waiting times for both residential and home care places adequately meeting the needs of older Queenslanders?

SVHA notes that recent industry data indicates industry occupancy rates for aged care are declining, suggesting there is bed capacity in the current system. As well, the Federal Government in 2018/2019 announced an additional 10,000 Home Care packages to address increasing demand for home care support. While such figures indicate that there is some additional home care package and bed capacity in the state system, it is SVHA's experience that the ability of residents to access the right care, with the right carers, in their location is still a challenge due to key factors such as:

- **Length of time for aged care approvals** - due to delays in approval of home care packages across all levels – basic to high – it is difficult for individuals to access the right care in their location in a timely manner and it results in individuals waiting many weeks for a response.

- **Impact of rural and regional living** - with such a decentralised population, the distribution of facilities and an appropriately skilled workforce is a strategic challenge

for Queensland. So, while on paper and/or in data there are indications the "numbers are right" to address demand, the distribution of service providers and beds, and the presence of a local well-trained and experienced aged care workforce, needs to be factored into the planning of the state's aged care system.

From our experience the impact of these factors can directly impact on the physical and emotional health of individuals and families.

In the future, applications for home care and residential support packages need to be streamlined and better coordinated through investment in back-end systems so individuals and their families are not left "hanging" or "hoping" for confirmation of support over many weeks at a time when people need support the most.

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?

SVHA notes the Australian Government's *Royal Commission into Aged Care Quality and Safety* is currently canvassing the views of the community about whether Australia's residential, home care and other aged care services are meeting their expectations. SVHA has made a Submission to the Commission.

SVHA's Queensland aged care facilities operate under the 44 expected outcomes of the current Australian Aged Care Quality Standards. Our facilities have in place the required clinical, management, workforce and facility procedures, consumer practices, and safety and quality frameworks to ensure our care meets the required standards.

It is our view, however, that often the standards we and other aged care providers are required to meet do not always equate with resident expectations regarding the type of holistic care they or their families desire. Standards are an important benchmark for the delivery of safe and quality care, however facilities in the future need to be supported to be able to offer the holistic care that residents and their families expect.

We note that aged care facilities are somebody's home.

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?

By 2056, those aged over 65 will increase from 15 per cent to 22 per cent and the proportion of people aged over 85 will double[1]. The projections indicate that growth in this age bracket will likely translate into growth in other chronic diseases such as obesity, diabetes and dementia.

[1] Catholic Heath Australia (CHA): Palliative Care in the Catholic Sector Report March 2019; page 7 Source: ABS 3222.0 – Population Projections, Australia, 2012 (base) to 2101*

SVHA believes there is an opportunity for the Queensland Government to lead the development of a comprehensive 'master plan' for aged care and end of life care in the state, in partnership with the Federal Government, local community organisations, and service providers to:

- Identify, plan for, and position complementary services where the need will be in the future
- pilot new models of care and services, informed by community input and need
- improve coordination of care between primary health, hospitals and aged care providers
- afford aged care providers with an opportunity to upgrade their facilities, workforce, and service models to better meet the needs and expectations of residents
- attract, train and retain an effective aged care workforce, including building provision into the system to up skill existing health professionals in hospitals and GPs
- plan for the better use of technology among individuals to help address geographical distance, and at times, the lack of available location-based age and personal care workforce.

While aged care services are predominantly funded by the Australian Government, this Inquiry provides an opportunity for the two levels of Government to work together in a complementary manner to coordinate planning and investment in Queensland's aged care sector – in order to better meet the needs of Queenslanders as a model and example for the rest of Australia.

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?

As outlined in Question 2, SVHA believes that the distribution of facilities and available primary health, community based support services should be factored into the discussion about the number and location of, aged care beds for different levels of care. Future funding and systems should have better flexibility to support the ranges of care needed when the demand arises so resident's and people ageing in their homes have their needs met.

6) Are adequate numbers of home care packages available in areas at the levels required?

SVHA notes the Australian Government released extra home care packages in 2018/2019 nationally however, from our experience:

- the packages are not being released fast enough
- in some areas, it is difficult to support the implementation of the packages due to a lack of available and localised personal care/specialist aged care workforce
- funding does not extend to resolving underservicing in some areas. For example, it does not take into account the travel time of an organisation's staff to an individual's home.

Because of these impediments, SVHA believes there needs to be some adjustments to the contracting and funding conditions for service providers, to afford them an opportunity to better service, recruit and train an experienced aged care support workforce which can

better support elderly people and those with special needs in aged care based in regional and rural Queensland.

7) Are there sufficient staff in the aged care sector to meet current and future workloads?

The current and future supply of a well-trained, skilled and job ready workforce for the aged care sector is currently subject to extensive examination by the *Royal Commission into Aged Care Quality and Safety.* In our response to the Commission's provider survey, SVHA advocated that the critical issues underpinning future workloads in the aged care sector are:

- **Strengthening training and job readiness pathways** – universities and vocational education institutions must graduate students with knowledge and skills that meet the future skill requirements of the aged care sector. This should include incorporating new modules of learning with an emphasis on dementia and palliative care.

- **Improving the workforce conditions to attract health professionals and aged care workers to the sector** – this would help attract and retain a qualified and committed workforce and help address high staff turnover and heavy workloads.

- **Improving infrastructure and services**– in hospitals and aged care facilities so that resident's needs between the systems can be better supported by well-trained and qualified staff.

- **Better promotion of the aged care sector** – the Australian aged care sector is not always viewed as an attractive industry for a career. Critical to the future workforce pipeline to meet need in the aged care services, is the promotion of the sector as a beneficial place to work, with well-supported training, standards, positive work culture and service delivery.

8) Is the mix of staff appropriate for different settings within the aged care sector?

Overall our experience is that the mix of highly skilled and job ready staff are difficult to retain in the aged care sector.

Under the current funding framework, it can be difficult for an aged care facility to put in place a staffing mix model which meets the mix of resident needs.

Equally it can be difficult to access external complementary health and other services to support staff skill mix. This can be particularly challenging in regional, rural and remote settings. The following factors can impact on the mix of staff in the aged care sector:

- Resident choice when it comes to health care can be impacted when there is poor access to local GPs (especially in regional/remote areas).

- Waiting lists for geriatric specialists are extensive. Specialists do not always conduct service visits which is a challenge for residents and facilities, as well as for their families who often must take them to appointments.

- The current funding model does not afford aged care facilities with the opportunity to staff services with more registered nurses, nurse practitioners, allied health, counselling and social work professionals.

- A lack of local GPs specialising in aged care. There is often a lack of interest amongst the GP/Primary Health sector in developing specialised medical skills relating to the elderly demographic. Given Queensland has put in place a rural GP training program, SVHA would be supportive of additional learning and training in caring for the elderly being incorporated in this program.

9) Do aged care staff receive training that is appropriate and adequate to prepare them for the work?

As is the case in many industries, staff may have completed their formal qualifications for training but they also need to be "job-ready" upon graduation.

SVHA's view is that there is an opportunity to evolve the current vocational education and health professional pathways so that individuals can obtain valuable work experience and exposure to this sector early and more frequently throughout their training, including when GPs complete specialist training.

This may help improve number of health professionals and community care workers considering a career in aged care as well with the supply and retention of a skilled, job-ready, and committed workforce.

One idea to improve the job readiness of aged care staff includes evolving current medical, health and community care training frameworks so that students have earlier placements and additional modules in aged care services in their course.

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 substantial cost to Queensland's public health system if elderly persons are left waiting in hospital wards while a suitable aged care place is found for them.

While we understand this question gives rise to a wider discussion about 'State vs Commonwealth' funding responsibilities, it is important to see the transition of an elderly person from hospital into aged care as involving the same spectrum of care.

An individual in this position is less likely to be worried about which level of Government "pays for what" and just wants a continuity of good quality care and access to support so their quality of life is maintained with dignity and respect.

It is our view that the coordination of care of people across "systems" – from GPs, to hospitals to aged care – needs to be improved and strengthened. Both levels of Government need to ensure the necessary funding and frameworks are in place, and administrative burden and roadblocks removed, so that individuals making the transition are well

supported, and service providers are afforded an opportunity to deliver quality and person-centred care.

To do this, one suggestion SVHA proposes relates to shared access to electronic medical management systems (EMSs). EMS in the future could better support discharge and health care planning between hospitals, GPs and aged care facilities to help improve coordination of information and care across different agencies.

However, this idea is not new, and nor is the point that levels of Government need to work differently together and evolve their systems to be better at responding to the needs of individuals, particularly at a vulnerable time in their lives.

11) Are suitable health care services being provided within residential aged care settings and/or aged care providers?

Lack of funding is a significant barrier. The Aged Care Funding Instrument (ACFI) provides a basic standard of care and services but in our experience it is insufficient to meet rising community expectations. Exacerbated by indexation arrangements, it is also failing to keep pace with sector-wide wage movements. For example, it is difficult under the current funding model to build additional GP, specialist, allied health, and mental health/social work support into care models.

In relation to Home Care, SVHA advocates that additional case management funding should be provided to help support and cover GP and service providers time to prepare and coordinate care to individuals.

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?

The volume and complexity of Queensland's health and aged care needs will change significantly over the next thirty years.

SVHA understands that in Australia, by 2056, those aged over 65 will increase from 15 per cent to 22 per cent and the proportion of people aged over 85 will double. Further, Australia has growing rates of chronic disease such as diabetes, obesity and dementia[2].

According to Queensland's population projections 2018 edition, produced by the Office of Government Statistician Queensland Treasury, the age structure of the Queensland population is projected to change significantly in the 50–year period to 2066.

While there will be increasing numbers of persons in all age groups including school–aged children, a significant increase in both the number and proportion of people in older age groups is projected. Queenslanders aged 65 years and older accounted for 14.7% of the

[2] Catholic Heath Australia (CHA): Palliative Care in the Catholic Sector Report March 2019; page 7 Source: ABS 3222.0 – Population Projections, Australia, 2012 (base) to 2101*

population in 2016—this is projected to increase to 23.8% under the high series, and 25.8% under the low series by 2066[3].

Based on these projections, in the future, we expect to see an increasing number of residents with cognitive impairment/dementia which means an increase in complex behaviours (e.g.: aggression, intrusive behaviour).

This will mean, for example, that GPs, nurses and other support workers who work with elderly people may not have the specialist knowledge specific to dementia and require input from a geriatrician or access to further training in this field.

SVHA advocates there is a real opportunity for Queensland to create a "master plan" for its future aged and home care system but it will require:

- A different approach to funding and coordinating aged care and complementary health services between federal and state levels of Government
- Encouraging GPs and registered nurses to take an interest in aged care services and uptake training and employment in this field
- Changing the funding model so that GPs are supported to provide more primary care services for residential aged care
- A concerted state-wide strategy to holistically manage the health and care needs of over 65s across the state
- An increase in dementia education and training and care support for health professionals and community care workers
- Improvement in the interplay between specialities and other part of the health system, such as allied health
- Funding and support for transport options to help residents maintain connection with their community and attend hospital/specialist appointments
- Trialling new models such as "hospital in the aged care facility "or increasing the number of nurse practitioners working in the aged care sector and affording them the opportunity to access MBS items
- Increasing the use of technology in the delivery of aged care services.

13) How can the delivery of aged care services in Queensland be improved?

SVHA believes it's time to develop an aged care master plan for Queensland which addresses:

- Difficulties in establishing and maintaining partnerships with hospitals by putting in place services that pursue a collaborative approach to resident care.
- Poor communication between hospital and aged care facilities, which is often reflected in the way hospitals discharge aged care residents, a process that often involves little or no consultation with the aged care providers. If the hospital discharge process is improved, better follow up care will be the flow on effect.

[3] Queensland Government population projections, 2018 edition: Queensland; Queensland Treasury

[redacted]

- Trialling new models such as “hospital in the aged care facility” or increasing the number of nurse practitioners working in the aged care sector and affording them the opportunity to access MBS items.
- Improving the use of technology, particularly for discharge from hospital. For example, we believe better technology could help with tracking a resident’s appropriate medication upon discharge. Currently, a hospital’s poorly managed discharge of an elderly person to an aged care facility – without the appropriate details around their ongoing medication – can result in up to two days wait as the regular GP has to review the prescription first and provide clearance.
- The difficulties in organising follow up care post hospital and other health professional sessions
- Improving regional and remote acute care access
- The difficulties in accessing psychogeriatric care for residents because of the limited availability of services
- Improving specialist mental health care for older Australians and
- Improving dental and other health services and addressing the difficulty encountered with urgent referrals.

14) Are there alternative models for the delivery of aged care services that should be considered for Queensland?

The rise of patient-centred care in health and aged care services design, means future residents of aged care services will hold a range of ideas for what alternative models should be considered.

SVHA strongly supports that future models should always take into consideration the voice of the resident and their families as part of the service design. Following are a few ideas for future models informed by our experiences of delivering aged care services in Queensland:

- **Use of different mix of health staff** – important that health professionals other than medical specialists are provided with up skilling and training in areas such as aged care, gerontology, dementia management, pain management, wound care, continence management and other chronic diseases.
  In the future, nurse-led teams consisting of other allied health support are an option to consider. These teams could coordinate with local GPs and aged care services to help support individuals in their home care environment.

- **Opportunity to establish wellness hubs** – such hubs could act as a source of information and advice to families and friends of those experiencing the ageing or advancing special needs of a loved one. These hubs could help promote the use of technology, raise community awareness about care and support needs, and de-stigmatise the ageing process, especially for those individuals keen to remain in their home with support.

- **Serving Aboriginal and Torres Strait Islander residents better** - Funders and facilities should be sensitive to the needs of Aboriginal and Torres Strait Islander peoples and support alternatives to residential care, understanding the impact of trauma arising from re-institutionalisation. Recent AIHW data forecasts that by 2023, all remaining Stolen Generation survivors will be eligible for aged care. There is a

need to support alternative and culturally appropriate care to those who experienced significant trauma in their childhood due to forcible removal, at their last stage of life.[4]

15) How will the model of aged care develop with evolving technology and medical practices?

Technology, robotics, artificial intelligence and the expansion of telehealth will assist future aged and home care services to better plan the care for elderly people and to intervene earlier when it comes to their health needs.

An increased use of technology will also help providers proactively manage individual's needs as well as empower them to engage in their own monitoring, condition management, and connect and engage with other individual's online, enlisting them to be part of their own care.

16) What are the key priorities for the future?

As outlined in Question 12, the age structure of the Queensland population is projected to change significantly in the 50–year period to 2066.[5]

SVHA's view is the gap between aged care funding and resident's expectations, needs to be addressed. Queensland has a real opportunity to trial a new way forward in areas such as:

- **Information sharing** – across systems – needs infrastructure investment, better integration, real-time discharging information, and access to hospital records. (e.g.: the rolling out of Queensland's new EMR system presents an opportunity for this to occur). This will address many current challenges, including unavoidable admissions.
- **Improve the mix of the aged care workforce** - including trialling and funding mobile allied health and dental services to aged care facilities.
- **Improve access to medical support** - such as after hours and palliative care, in regional and remote settings.
- **Improve access to pharmaceutical services.**
- **Support and fund regular education in dementia and palliative care for all staff** - This could include funding pilots which train nurse practitioners with advanced skills in geriatrics and with prescribing rights to all aged care facilities, which would improve timely access to medical care, reduce unnecessary emergency department presentations, and improve follow up care.
- **Increased use of nurse practitioners-** the provision of palliative and wound care, particularly in regional areas, would also help.
  Embedding advance care planning into aged care facilities – both through public education of planning for your own future, and through education to providers of aged care facilities so people are given the opportunity to remain in place if they wish to have end of life care in their aged care facility.

[4] Healing Foundation 19 February 2019 Media Release "Stolen Generations want a commitment on aged care"
[5] Queensland Government population projections, 2018 edition: Queensland; Queensland Treasury

Queensland's Palliative Care Services

17. What are the palliative care services offered in Queensland?

St Vincent's Private Hospital Brisbane (SVPHB) provides inpatient in-hospital palliative care services to private and public patients. SVPHB has a 40-bed inpatient unit dedicated to the care of public palliative care inpatients within the Metro South Queensland Health zone of Brisbane, and privately insured patients.

We provide a multidisciplinary community specialist palliative care service for patients within the Brisbane City Local Government area, including nurse visitations 24 hours a day, seven days a week when needed. SVPHB Medical Specialists provide consultation liaison services to St Vincent's Private Hospital Northside. The inpatient/community service is fully integrated and patients are able to be admitted directly into an inpatient bed 24 hours a day, seven days per week.

SVPHB initiates and publishes high quality research with the aim of improving patient outcomes. Recent research has included increasing the understanding of patient and carer journeys to and through palliative care (including participants from culturally and linguistically diverse communities), innovative models of community palliative care (via a partnership with Bupa), documenting changes in patient's preferred place of death, quality use of medications and reasons for admission to hospital from community palliative care.

SVPHB is a member of the Palliative Care Clinical Studies Collaborative, Cancer Symptom Trials and Queensland Palliative Care Research Group.

18. Are palliative care and end-of-life care services meeting the current needs of Queenslanders? Why or why not?

High quality palliative care needs to be properly resourced in Queensland.

Although the State has some high quality services, many Queenslanders miss out because of inadequate resourcing and lack of specialist access to services. This Inquiry has an opportunity to evolve the current design, planning, funding and service delivery models for palliative care in Queensland so that the needs of its citizens can be better met.

For example, while 70% of people say they want to die at home, about half of all deaths in Queensland occur in hospital, costing the state approximately $776 million per year.[6]

Queensland is a state with a dispersed decentralised population. As a result, there are gaps in the provision of palliative care across Queensland, including lack of available experienced palliative care professionals and care support workers in many areas of regional, rural and remote areas.

However, even in a capital city like Brisbane, there is inequity in current service provision.

[6] "Time to build a Palliative Care Culture in Queensland Manifesto 2017/2018"; Palliative Care Queensland; 2017, page 3

For example, public patients in the Metro South HHS area have access to inpatient palliative care through SVPHB's agreement with the Metro South. However Metro North HHS will not pay for any public patients in the Metro North area who wish to be admitted as an inpatient to SVPHB. This means patients and families have to sometimes travel a longer distance to another palliative care facility. Of particular concern are the number of tenuously-housed and vulnerable patients in Brisbane's inner city who are unable to access inpatient palliative care close to their home.

A second example is that for patients on the SVPHB community specialist palliative care service there is inequity in the payment and access to equipment at the end of life. Metro South HHS will subsidise and provide access to equipment but Metro North HHS will not do that for patients on the same service living in the Metro North area.

While from the state health agency's administrative perspective the zone boundaries are important, in practice they create a significant deficit in the care of people requiring palliative care, just because they happen to be based in a particular geographical location.

Patients, their families and carers want to access the best palliative care when and where they need it. They don't always consider the zone boundaries that dictate their service access. This is not an example of fair and equitable access to palliative care.

19. Do the standards of palliative care and end-of-life care provided in Queensland meet clients' and the community's expectations?

Palliative care is a core component of healthcare. In Australia, one in six public acute hospitals have a palliative care unit.[7]

Queensland palliative care services have a reputation of providing high quality care. At SVPHB, our palliative care services adhere to clinical guidelines in palliative care and ACHS standards. We participate in the Palliative Care Outcomes Collaborative (PCOC). At SVPHB we are also accredited to train palliative medicine specialists through the Royal Australasian College of Physicians (both with advanced trainees and diploma candidates).

There are many misconceptions around palliative care that members of the community may have, including that it is simply about dying.

Palliative care improves the quality of life of patients and their families facing life-threatening illness. It prevents and relieves suffering through the early identification, assessment and treatment of pain and other symptoms, including physical, emotional, psychosocial and spiritual.[8]

Palliative care is not about shortening or prolonging life, it is about helping patients have the best life possible.

[7] Australian Institute of Health and Welfare, *Palliative Care Services in Australia*, May 2017
[8] World Health Organisation's definition of palliative care

[redacted]

Palliative care:

- Promotes **patient independence** by helping people decide which treatments they would like to continue, and which have become too burdensome and should be stopped.
- Promotes a **multidisciplinary approach** – specialists, nurses and allied health workers work together to ease pain and other symptoms, providing psychological and emotional support, and bereavement support.
- Happens in a **range of locations** – the home, hospital, hospice, and/or aged care facility.
- Is for anyone diagnosed with an advanced, life-threatening illness – such as cancer, but also other non-malignant conditions, such as neuromuscular disorders – and should be routinely introduced **alongside active treatment**.

There is strong evidence on the benefits of palliative care in relieving symptoms and pain, but also improving quality of life, mood, satisfaction with care (for patients[9] and their family carers[10]) and, in some cases, even survival.[11]

Among the thousands of deaths our palliative care teams witness, patients' symptoms are well-managed, people are able to communicate their preferences, and say their farewells. It's common for families to comment on how peaceful a death was.

Misconceptions about palliative care

There are many misconceptions about palliative care.

One of the biggest misconceptions is that euthanasia is part of palliative care and is performed in palliative care facilities. Euthanasia/VAD is not part of palliative care practice.

Addressing another misconception, there is sometimes a viewpoint that many patients are given 'terminal sedation' at the end of life to hasten a patient's death. And that somehow 'terminal sedation' is euthanasia by stealth.

The use of opioids and sedative medication at the end of life to relieve distress, suffering and symptoms is an important component of palliative care. An aim of palliative care is for patients and families to live as well as possible and then die as well as possible. Such use of medications at the end of life has been extensively researched – including by SVPHB

[9] Parikh RB, Kirch RA, Smith TJ, Temel JS. *Early specialty palliative care — translating data in oncology into practice*. New England Journal of Medicine, 2013; 369: 2347-51.
[10] Christakis NA, Iwashyna TJ. *The health impact of health care on families: a matched cohort study of hospice use by decedents and mortality outcomes in surviving, widowed spouses*. Social Science and Medicine, 2003; 57: 465-475.
[11] Temel J, et al, *Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer*, New England Journal of Medicine, 2010; 363:733-742.

clinicians[12]. All the research in this area has consistently shown that the use of opioid and sedative medication, used within clinical guidelines, does not shorten a patient's life.

Many misconceptions around palliative care are held by health professionals. Too often referrals to palliative care are made by clinicians when a person is very close to the end of life or when death is imminent. This means patients miss out on the benefits that palliative care can deliver throughout their treatment. There can be concerns by health professionals that a referral to palliative care means 'giving up' or 'losing hope'. In fact the opposite is true and there is now extensive research showing that early referral to palliative care for malignant and non-malignant conditions can improve quality of life.[13],[14]

Specialist palliative care services are not involved in every expected death, and there can be wide variation in the quality of care provided where there has not been training or experience in palliative and end of life care.

SVHA supports increased investment in public education about end of life care, including palliative care, as a means of empowering the community to understand what options they have available to them at this stage of life

Further consideration needs to be given to growing the palliative care workforce in Queensland.

Palliative care is an important area of health, and there is an opportunity to develop a workforce strategy that promotes providing further training, up skilling and access to specialist support for health and community-based services in those locations where there is no specific palliative care service

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?

Demand for palliative and end-of-life services will only increase as Queensland's population increases and ages. In the future, some of the key factors that should be considered when planning to meet the demand for palliative care and end-of-life services in Queensland include:

- The ability to provide integrated palliative care for patients with malignant and non-malignant conditions across the spectrum of care – hospital, community, aged care facilities
- Provision of ongoing training and up skilling to local health and community care workers in areas where there is no stand-alone palliative care service unit

[12]Good PD, Ravenscroft PJ, Cavenagh J. Effects of opioids and sedatives on survival in an Australian inpatient palliative care population. Internal medicine journal. 2005 Sep;35(9):512-7.

[13] Temel J, et al, Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer, New England Journal of Medicine, 2010; 363:733-742.

[14] Higginson IJ, Bausewein C, Reilly CC, Gao W, Gysels M, Dzingina M, McCrone P, Booth S, Jolley CJ, Moxham J. An integrated palliative and respiratory care service for patients with advanced disease and refractory breathlessness: a randomised controlled trial. The Lancet Respiratory Medicine. 2014 Dec 1;2(12):979-87

- More involvement and engagement of general practitioners, including access to after hours and home visits for palliative care patients
- The need to increase the capacity of specialist palliative care services to support residential aged care facilities
- The role of technology such as a means of supporting services, health professionals, individuals and their families particularly in their homes.

From our experience, the majority of patients admitted to current services have a cancer-related diagnosis but this will change as people with life limiting conditions are increasingly referred to palliative care.

Equitable access to community palliative care requires investment in a multidisciplinary team providing holistic care. One of the key tenants of quality palliative care is holistic care of a person, and that includes seeing the person within their social context.

This is actually what personalised care is: recognising the individual needs of patients.

The only way to truly provide this care is via a multidisciplinary team because no one practitioner can provide this care. We see it as important to have a team involved including (but is not limited to) doctors, nurses, social workers, physiotherapists, occupational therapists, psychologists, counsellors and pastoral care workers.

It is also important to have a general practitioner as a constant in a patient's care, including having the ability to provide home visits. Where people live in communities that have limited access to medical care, it is important to up skill other health workers in providing palliative care.

Bereavement care is also integral to palliative care and all palliative care services should be funded and have staff to provide a comprehensive bereavement service to all patients.

In the future, it will be important to support a well-trained health workforce to support palliative care in Queensland. For example, SVPHB is a training facility for new Palliative Medicine Specialists.

The current Palliative Care Australia recommendations for delivery of Palliative Care include having a ratio of 2 FTE Palliative Medicine Specialists for every 100,000 population. That would mean approximately 100 FTE Palliative Medicine Specialists in Queensland. Current estimates suggest that there are approximately 35 FTE in Queensland, meaning there is a significant shortfall in staffing.[15]

SVHA's position is that there is an urgent need to increase training positions and Palliative Medicine Positions across the state to meet future demand, as the shortfall is particularly acute in regional, rural and remote areas.

[15] Queensland Palliative Medicine Training Oversight Committee, Integrated training pathway and palliative medicine workforce report. August 2018

[redacted]

21. How can the delivery of palliative care and end-of-life care services in Queensland be improved?

SVHA's view is that all patients should be able to access palliative care based on their needs, not determined by diagnosis, prognosis, and geography. There needs to be different service and care options available for patients across the state, and support should be able to be accessed for in home care.

This means designing and funding different models of palliative care to suit the needs of local communities as opposed to utilising a "one size fits all" approach. Our experience shows that there is a need for greater flexibility for patients to access community palliative care programs. SVHA offers the following examples to illustrate our point:

- There needs to be equitable access to both inpatient and community palliative care irrespective of where a person lives. Some simple examples of inequity within the Brisbane Metro area includes that public patients residing in Metro North cannot be admitted to SVPHB inpatient facilities – even though for many dying patients that is the closest palliative care facility to them
- Funding and provision of equipment such as hospital beds – there is variation to access depending whether a patient lives north or south of the Brisbane River
- All publicly and privately funded palliative care services should have clear KPIs to which they are accountable
- We advocate that people requiring palliative care services should have:
  - Access to direct admission to inpatient palliative care facilities 24/7;
  - Access to specialist palliative care service advice (either in person or via videoconference facilities) 24/7; and
  - Access to specialist community and home-based care.

In addition, every cancer multidisciplinary team meeting should have a Palliative Medicine Specialist and/or a Palliative Care Nurse as a core member of the team to ensure appropriate and timely referral and improved outcomes for patients and their families.

In our view, if all patients with a life-limiting illness had access to the above services, and KPIs were achieved across Queensland, there would be a substantial improvement in palliative care delivery and outcomes.

To provide an example of SVHA supporting a trial of new model of palliative care, over the last two years, SVPHB in partnership with Bupa has conducted a very successful pilot program to provide palliative care services for Bupa members in their homes in the community. This program aimed to increase access to palliative care services for Bupa patients and their carers and provide them with greater support in the community. The results demonstrated:

- Increased home death rates
- Decreased acute hospital death rates
- Very high preferred place of death achieved
- Very high patient/carer satisfaction
- Substantial cost saving per patient[16]

[16] SVHA could formally present the outcomes of this two-year pilot program if required.

[redacted]

One of the more important findings from this study was that a preference for a home death depended on service availability and expectations of patient and family. It showed that if there is more support in the community available to patients and carers then more people want to die at home, and more people actually do die at home.

It is critically important to increase support for carers caring for someone with a life-limiting illness at home (especially in the last three months of life). The current system of MyAgedCare fails to provide timely access to community support packages (eg: it sometimes takes four-six weeks for ACAT to conduct an assessment to approve someone for a Level 4 package and following that it may be 10-12 months before it can be allocated).

Inadequate carer support often results in premature hospitalisation. It would be beneficial if specialist palliative care services could directly tap into a Level 4 package (or other similar packages) for palliative patients registered with the service, without waiting for MyAgedCare approval.

Finally it is important to recognise the need for adequately funded bereavement services.

22. What are the particular challenges of delivering palliative and end of life care in regional, rural and remote Queensland?

All the challenges in metropolitan areas are amplified in rural, remote and regional Queensland – there are issues around staffing, adequate skill mix, access to after-hours care, access to inpatient palliative care beds and access to GP services who are trained and supported in palliative care service provision.

23. What are the particular challenges of delivering palliative and end of life care for Aboriginal and Torres Strait Islander communities?

The key principle of delivering palliative and end of life care is it should be person-centred and take into consideration the cultural needs of patients. One of the major challenges in Queensland is remoteness and access. For example, for communities in Cape York, the closest palliative care services are in Cairns, some 1000kms away. For people living in the Northern Peninsula Area's five communities who have a life-limiting illness, accessing end of life care often means leaving the community, family and country to travel to Cairns.

With some of the highest levels of chronic disease in the country and an average life expectancy of 58 years, there's considerable need for high-quality and culturally appropriate end of life care across the Cape York and Torres Strait regions. From our experience, following are some of the key factors to take into consideration at service level:

- Involving metropolitan and rurally based Aboriginal and Torres Strait Islander representatives in the design and delivery end of life services is critical. The development of a palliative care model, signed off by the communities and which meets their unique needs is important at community level
- Speaking in plain language (avoiding using only clinical terminology) to the patient/resident and their family members when explaining care options and

procedures. For example, the word “palliation” may not be familiar to community members and their families

- The appointment of an Aboriginal Health Worker to coordinate training and service integration on the ground.
- Aboriginal and Torres Strait Islander communities should feel welcomed and trust community programs and inpatient facilities.
- There needs to be recognition of the significance of dying and how that is approached differently in different cultures *(See case study below)*
- End of life and palliation episodes for Aboriginal and Torres Strait Islander communities may be times of sombre silence, or – more likely in the Torres Strait Islander context – times of talking, singing and laughing with, or around, the patient/resident and an inter-generational audience. The great wailing is likely to occur after passing, therefore; ideally care spaces should accommodate this likelihood and allow also for the sleeping in of family members.
- Design and layout of the facility is central to patient care so family and community members have a space where they are able to express their emotions without the concern they are upsetting other nearby patients. Other practicalities like access to a fridge and the ability to serve the patient/resident traditional foods if possible, also needs to be considered. Further, having access to nature in some capacity is also ideal.
- Understanding that “dying” is not necessarily seen culturally as an event in one moment. There is a lead up period and post-passing “sorry time”, so support for the patient, family and community members during the period, not just on the day of passing, is a critical cultural consideration, as there is an impact on family and community that just doesn’t occur in the passing stage. Therefore service provision needs to factor in this approach.
- Support for family and community members to travel to visit and support the patient in palliative care is critical, particularly when patients are not able to pass away on country.
- Access to Aboriginal and Torres Strait health professionals and support staff so patients and their families can feel culturally safe, welcomed and empowered both in home care and/or in a facility
- Training of GPs, locums, and Queensland Health employees in how the service works, to improve integration and cultural awareness.

Case study – SVHA supports Northern Peninsula Area palliative care services

In 2017 St Vincent's Health Australia committed $450,000 to bring culturally appropriate palliative care services to five Aboriginal and Torres Strait Islander communities in the Northern Peninsula Area (NPA) of Cape York as part of a Memorandum of Understanding (MOU) with Northern Peninsula Area Family and Community Services (NPAFACS) and Apunipima Cape York Health Council (Apunipima).

People living in remote Cape York communities – in particular the five Aboriginal and Torres Strait Islander communities of Bamaga, Seisia, Injinoo, Umagico and New Mapoon – experience some of the highest levels of chronic disease and poorest health outcomes in Australia and yet didn't have access to local palliative care. The nearest palliative care was more than 1000 kms away in Cairns.

St Vincent's Health Australia responded to a need, raised by NPAFACS through Apunipima, for expert guidance to develop a high-quality, culturally appropriate palliative care service tailored and accessible to the communities of the Cape. SVHA signed an MOU which outlines SVHA's commitment over five years to achieve in partnership with NPAFACS, Apunipima and the communities of the NPA, including:

- *Participation in the Commonwealth Government's palliative care education program (Program of Experience in the Palliative Approach or PEPA) which includes capacity for palliative care specialists to visit Aboriginal health services to facilitate palliative care learning.*
- *provision of advanced palliative care training for local staff;*
- *community capacity building through ongoing clinical support;*
- *development of a culturally appropriate model of care and a business plan to establish a permanent palliative care service, and;*
- *provision of specialist care and support of palliative care clients via telehealth.*

Central to this work was SVHA clinicians and key staff first listening to the communities about their palliative care needs and what they wanted so the care service model was developed informed by the views of the communities so they can die respectfully, at home, on country and with family.

The project has developed a fully documented Model of Care which has been informed by community consultation and refined through activity-based research.

Twenty seven (27) patients have been supported over the past fourteen months. Sixteen (16) of those patients have been supported away. There at least another thirty (30) patients that the program is expecting to support over the next twelve months.

24. What are the key priorities for the future?

This Inquiry provides the State with an opportunity to evolve and put in place palliative care and end -of-life care support, which will meet the needs of Queenslanders. There need to be KPIs (such as those suggested above) to ensure each HHS provides an equitable and high quality palliative care service for all Queenslanders.

The following are the key priorities for future reform of the current system:

- **Access to direct admission to inpatient palliative care facilities 24/7** - Consideration should be given to increasing number of palliative care facilities particularly in areas with population growth. To complement expansion in services, funding should also be provided to up skill the local workforce and/or to attract

[redacted]

specialist staff, and community based services. Service planning should enable patients to have direct access from the community into a palliative care bed. (without needing to go through emergency 24 hours a day, 7 days per week)

- **Access to specialist palliative care service advice 24/7** - All patients in need of palliative care should have access to it no matter what time of the day or week. It is important patients have access to skilled assistants in nursing (AINs) or enrolled nurses (ENs) in the last few days of life. Providing this extra in house support of between 6-24 hours per day for the last few days of life would make an enormous difference to the support and ability of those patients who choose to die at home to actually stay at home in the last few days of life.

- **A need to increase capacity of specialist palliative care service support to residential aged care facilities** - Specialist palliative care 'rounds' to patients in residential aged care facilities can help reduce hospital admissions at the end of life. There is a current gap for specialist palliative care services to provide medical and nursing support and education. There is large variation across Queensland as to what is provided from community specialist palliative care services to Residential Aged Care Facilities (RACFs). It can be challenging for RACF staff to deal with patients who are dying and support is needed. A program to up skill RACF staff and GPs as well as providing consult/share care with GPs is needed. SVHA believes that each RACF should have direct linkages to community specialist care services and that the palliative care providers do regular rounds at the facility.

- **Investment in public education about palliative care** - As detailed there is variable knowledge and understanding about what palliative care is and does. It is important that a comprehensive and detailed public education campaign is undertaken to improve public knowledge. It is especially important that the public understands what palliative care is and what it aims to provide, and how it is distinctly different to euthanasia and VAD.

[redacted]

Voluntary Assisted Dying

25) Should voluntary assisted dying be allowed in Queensland? Why or why not?

SVHA does not support voluntary assisted dying (VAD).

Instead, SVHA recommends the Queensland Government address the currently underfunded palliative care system and increase the availability of services across the state. It would be unacceptable if patients choose to have VAD because they didn't have access to high quality, comprehensive palliative care.

SVHA's position is Queensland must invest more in palliative care and end of life care instead, for the following key reasons.

- **Invest more in palliative care and end of life services**

As outlined in this Submission, Queensland has poor coverage for universally agreed upon end of life care interventions, which are recognised as human rights by the United Nations.[17]

Such care incorporates access to a full range of palliative care services, including adequate pain relief, psychosocial and spiritual care, advanced care directives, and support of the right to withdraw or withhold burdensome treatments. There is inadequate access to palliative care for vulnerable groups, such as Aboriginal and Torres Strait Islander people culturally and linguistically diverse communities, and others living in poverty, but inequity of access and care is also obvious geographically in a decentralised state such as Queensland.

The State should invest further in strengthening the reach and improving the access of all Queenslanders to palliative care and end of life planning first. Our experience of working with patients across our hospitals, and in particular palliative care units is, that when there is absence of adequate end of life care, VAD may be seen as the only viable option. Patients facing end of life choices should never be put in a position where they think the only option available to them is VAD.

Our experience from participating in discussions about the VAD legislative framework in Victoria, is any form of 'safeguard' which purports to protect patients from potentially only considering VAD by informing patients about palliative care, is meaningless if there are no adequate palliative care options.

If this legislation is introduced into Queensland with the current under-resourcing and under-provision of palliative care there is a real risk that patients will be asking for VAD because of inadequate symptom control, or wishing not to be a burden on others or fearing loss of autonomy."[18]

[17] THE RIGHT TO END-OF-LIFE PALLIATIVE CARE AND A DIGNIFIED DEATH, CONTRIBUTION FROM UN-ECLAC FOR THE EXPERT GROUP MEETING ON "CARE AND OLDER PERSONS: LINKS TO DECENT WORK, MIGRATION AND GENDER", 2017. https://www.un.org/development/desa/ageing/wp-content/uploads/sites/24/2017/11/ECLAC-contribution.pdf

[18] This is evidenced through 21 years of data captured in Oregon: https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Pages/index.aspx

This is important to recognise because the research shows that requests for VAD are not for pain and symptom control, but rather because of a person's ideal or values, and their experience of loss of (or fear of loss) of dignity.

Through this Inquiry, the State of Queensland has an opportunity to invest and put in place a world class palliative care and end of life care system, one that models how patients can secure access to end of life care by supporting innovative service models which are designed to meet the needs of culturally diverse communities and patients living in regional, rural and remote areas.

- **Combat suicide rate**

SVHA argues the contradiction of society's efforts to address the problem of suicide on one hand while potentially introducing legislation that affords individuals an opportunity to voluntarily choose dying.

Some parts of Queensland have the highest suicide rates in the world, and our society rightly laments when we see people, old and young, who see no hope in their current life situation and for whom suicide appears as the only option. In such cases, our society rightly avoids blame towards the victim, and seeks instead to address the various tragic circumstances, which led to this to prevent others from doing the same. Often this involves addressing lack of adequate support networks, socio-cultural factors, and any health conditions, which include a high risk of suicide.

In such a context, establishing a group of select people for whom suicide is not only tolerated but valued, and indeed praised (as recent media coverage surrounding those who have travelled to Switzerland to end their lives reveals) sends a deeply confusing and contradictory message to those who we are trying to help, and undermines our society's attempts to say that suicide is never an answer.

SVHA argues that addressing the problems which give rise to a desire for VAD can be achieved through the means our society already commits to responding to the tragedy of suicide by addressing lack of adequate support networks, socio-cultural factors and health needs and concerns of individuals.

- **Impact on health professional's traditions and morale**

In a similar way, legislating for VAD, when it involves health practitioners, undermines fundamental commitments of healthcare professionals, which are upheld in the Hippocratic tradition of medicine.

These include commitments to cure where possible, to care always and never intentionally to inflict death. In addition, this tradition of care trains clinicians to provide effective pain management and to respect patients' decisions (or, if they are not competent, their substitute decision-maker's decisions) to forgo treatments that are too burdensome or medically futile: in doing so, it ensures that clinicians act in accordance with the needs and preferences of the patients. This said, this tradition of care – which is the foundation of

modern medicine – never accepts that intentionally inflicting death on patients nor assisting them to take their own lives are part of healthcare. Making them as such undermines healthcare.

These statements are consistent with the World Health Organisation and the Australian Medical Association's positions on assistance in suicide and euthanasia.[19]

Legislation such as VAD gives rise to unprecedented ethical issues and potential distress for caregiving staff and families. Cases in other jurisdictions bring this to the fore.

There are examples from facilities in Canada which has in place 'Medical Assistance in Dying' (MAiD) legislation, which illustrate some of the ethical issues and distress such legislation can give rise to:

(1)

- A resident from an aged care facility accesses MAiD, but instructs caregiving staff not to inform his family nor other residents;
- The staff farewell the resident from their facility, knowing that he is leaving to be euthanized, but cannot disclose this to family or other residents;
- When the man is deceased, the staff need to explain this both to family and to other residents, creating a situation *not unlike* other suicides or unexpected deaths, but with the added emotional complexity of 'knowing all along';

(2)

- A long term in-patient at a sub-acute palliative care service has been through the process and has been approved for MAiD;
- The patient has selected a day on which the MAiD procedure will be completed;
- Their condition is such that they require aggressive medical treatment to live until their preferred MAiD day. If the patient chose not to undertake such treatment, they would die naturally and with adequate pain management before this time;
- The patient requests such treatment from medical staff, who provide it whilst knowing that its purpose is to prolong life until euthanasia can be enacted;

Even setting aside these somewhat extreme cases, issues surrounding how staff deal with cases in which someone dies in a way that would once have been tragic (i.e. suicide) and is now normalised (through a 'voluntary assisted dying' regime) gives rise to distress and grief which are not solved through legislative instruments.

[19] https://www.wma.net/policies-post/wma-resolution-on-euthanasia/
https://ama.com.au/position-statement/euthanasia-and-physician-assisted-suicide-2016

❖ **Cost of VAD**

SVHA also argues that legislating for, and rolling-out, a regime such as VAD is a costly exercise, both in terms of the funding expended on the regime and also the burden that health services take on in responding to the legislation. It is unconscionable to spend valuable health dollars on introducing VAD when many Queenslander's do not have adequate access to palliative care.

26. How should VAD be defined in Queensland? What should the definition include or exclude?

'VAD' should be defined in very clear terms so as to distinguish it from interventions which are uncontroversial and upheld as universal human rights, but which are often confused with VAD regimes, including fully adequate pain relief and the withdrawal or refusal of overly burdensome treatments. It is irresponsible to push through policy which clouds its outcomes by using euphemisms such as 'voluntary assisted dying', which distract from what is actually being legislated.

The definition of 'VAD' should be limited to the direct and intentional administration of a substance that has the goal of causing a patient's death, or the prescription of a substance for self-administration with the same goal. The definition should use the language of the World Health Organisation and the Australian Medical Association which refer to these interventions as 'euthanasia' and 'physician assisted suicide'.

27. If you are a health practitioner, what are your views on having a scheme in Queensland to allow VAD?

SVHA does not support VAD being introduced. (See responses to Questions 25 and 28) In the event VAD is introduced in the State we advocate consideration be given to:

- Clarity about the referral process
- The right of health care providers and individual health practitioners to exclude themselves from participating in VAD process and
- The need for guidelines around what to do in case of an adverse outcome of VAD – for example – the patient does not die, or patient suffers a brain injury

28. If there is to be a VAD scheme, what features should it have?

We note that our response to this question is not to be understood as tacit support for the introduction of a VAD regime. That said, should the state of Queensland choose to introduce such a scheme, we argue that the following need to be considered to mitigate some of its harmful effect:

- The state should guarantee that any person who is seeking VAD is also afforded the opportunity for meaningful exploration of palliative care options, which would include the capacity to *access* and *receive* such options in their preferred location.

[redacted]

- Research demonstrates that the desire for a hastened death often dissipates once palliative interventions take effect, hence this is an important safeguard against the coercion noted above
- The process should include rigorous assessments for various forms of coercion: 1) clear and obvious coercion (such as a person of influence prompting and encouraging the decision, which is against the person requesting's will) and 2) tacit coercion (such as a person feeling like a burden because of socio-cultural norms about aging and disability which give them this impression). We note that both forms of coercion cannot be adequately identified outside of meaningful therapeutic relationships
- That the lethal substance used to cause death be strictly regulated to ensure that it does not present a danger to other people
- That it should be made clear that VAD is not part of palliative care practice and that VAD will not be performed in palliative care facilities and
- That individual health practitioners and facilities/services must consent to participating in the practice of VAD, and there is no obligation to do so.

Questions 29 to 38

SVHA does not support the introduction of VAD therefore we will refrain from responding to questions 29 to 38.

Churches of Christ in Queensland response to the inquiry into aged care, end of life and palliative care and voluntary assisted dying.

April 2019

About Churches of Christ

Churches of Christ in Queensland has a significant presence in Queensland, Victoria and Vanuatu with over 300 services in more than 100 communities, touching tens of thousands of lives each year.

We operate a range of missional and community care services to assist families, the elderly and people in need through church communities and our care services groups operated through Churches of Christ Care.

We provide a range of services for seniors including retirement living, home and community care, home maintenance and modifications programs, and residential care.

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Background

Churches of Christ Care holds people at the centre of our services. In our Seniors and Supported Living services, we focus on giving people choice. To improve how we give people choice, we have implemented our award-winning Positive Wellbeing Model of Care. This model draws out people's strengths, needs and preferences for care, while involving the people who are important to them. Doing this allows us to deliver holistic care that improves quality of life and allows people to be active and engaged. This approach encourages people to have early conversations about what they would like to happen at the end of life, giving them greater opportunity for choice.

Dying is an inevitable part of life, and our goal is to enable people to die with dignity, in a setting of their choice. We believe that by offering people dignity in death, we honour the importance and sacredness of their life.

The question of what makes a good death can be overlooked in health policy and practice, and can be hindered by a fragmented health system. As people enter into end of life, we can offer them choice around how they will be cared for, what kind of treatments they have and where they will be when they die. Supporting people at end of life is a significant clinical practice and policy challenge that we must face as the population ages. Below we have provide response to certain questions that were raised to the inquiry into Aged Care, end of life and palliative care and voluntary assisted dying.

Question One: *Is the aged care system meeting the current needs of older Queenslanders, including those with special needs? Why or why not?*

In general, there are beds available in most communities throughout the state (including regional, rural and remote areas) to support citizens seeking residential aged care with occupancy rates averaging less than 93% in general.

In most communities, planned respite (usually for minimum 1 or 2 weeks) is also available. However, there may be less availability of emergency short term respite, to some extent impact by the high administrative and regulatory requirements for residential aged care admissions.

We experience challenges for younger severely disabled people requiring residential care and unable to find age appropriate group settings to meet their needs. We seek to accommodate such people where we believe we can meet their needs. However we are very conscious that they are joining a community of very frail, elderly people who are generally in the last months or years of their life and that this is not necessarily the setting of choice for younger people with a disability.

Older people with dementia or other conditions particularly mental health issues, which cause severe behavioural symptoms provide significant challenges for residential aged

care settings, with significant risk to other frail elderly residents and staff. The Commonwealth Government has committed to establish at least one small unit (c. 10 beds) in each Primary Health Network, based on current and projected demographics 10 beds will be insufficient to assess and accommodate people experiencing such severe symptoms. The roll out of that program is anticipated over the coming 3-4 years.

Question Two: *Are the current waiting times for both residential and home care places adequately meeting the needs of older Queenslanders?*

In Residential Aged Care – in general yes. With 28 services throughout metropolitan, regional, rural and remote locations, we are generally able to accommodate resident's required residential aged care. Exceptions to this are in some cases were people are seeking a secure dementia unit for their family member – these are generally in high demand. As well, where there is availability, it may not be the service of choice, or it may be in a shared rooms or a room with shared bathroom, etc. There have been until recently a shortage of RAC beds in Toowoomba. However the opening of 2 new services in the first half of 2019 is expected to address this unmet demand. In some instances, people are assessed as being eligible for RAC but whose needs are what would be termed 'low care'. Where services are staffed to meet high care needs (i.e. generally where a person requires access to 24/7 registered nursing care), it is generally not viable to offer beds to people with low needs as government subsidies associated with low care needs are not sufficient to cover staffing costs at most RAC services. The availability of Home Care packages throughout Queensland is insufficient to meet current and future needs, forcing many into RACFs services earlier than they would have preferred in order to access care and services

Question Four: *How will demand for aged care services change in Qld as the population increases and ages, and what changes to the aged are system will be needed to meet future demands for aged care?*

Consumer expectations of care and staffing standards are increasing. Families of seniors are significantly more likely to articulate their expectations and concerns and expect prompt response to any care or services they consider sub-standard. These heightened community expectations are creating tensions and financial pressures in the highly regulated RAC environment with over 40 % of providers currently operating at a financial loss. The Commonwealth Govt continues to issue further Residential Aged Care bed licenses based on identified need in the community. For these licenses to then become operating residential aged care services, the financial viability of RAC will need to improve. Access to GPs for RAC residents continues to represent a challenges and is anticipated to increase with GPs opting not to provide services to people in this setting. Nurse practitioners provide a potential alternative to some of this GP care, if they can be educated and attracted to the sector. Registered training organisations who train most aged care staff, will need to continue to engage closely with the sector to ensure their graduates are 'fit for purpose' when they complete their certificate level training. There are currently shortages of allied health professionals looking to work in aged care (RAC) – in particular physiotherapists. This is largely driven by the current funding model which does not reward re-ablement and evidence based practices. The ability to attract and retain clinicians, particularly nurses into key senior roles will continue to be a challenge as we see a burgeoning in retirement from the sector of the baby boomer workforce. The salary discrepancy between the acute care and the aged care sector and the portrayal of aged care being seen as a poor second cousin to the acute sector continues to have a negative effect on recruitment to the sector. The lack of funded Graduate programs for nursing and allied health disciplines in the aged care sector does not providers recruiting those just starting out in their field and considering aged care as a career path.

Question Ten: *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?*

Delays in ACAT (Aged Care Assessment Team) assessments which are required for people looking to enter residential aged care, can cause people to remain in hospital for extended periods of time. The availability of suitably educated staff in the acute sector on how to care for those, in particular with cognitive impairment frequently results in poor care outcomes. Increased incidence of Delirium. The reduced availability of acute care beds.

Question Eleven: *Are suitable health care services being provided within residential aged care settings and/or aged care providers?*

Gaps in healthcare access for residents in residential aged care are significantly greater than people in the broader community and include:

- Dental – there are few mobile dental services. Whereas previous generations of seniors often had dentures so required nominal dental care, we are seeing more and more seniors in our care with their own teeth who require dental care and are challenged to access that either in our service or be able to travel to dental surgeries to receive such care
- Mobile X-ray – this type of service was once prevalent particularly in metro areas but is generally not available now. The result is the residents who have had a fall where there is a suspected break, will be transferred by ambulance to hospital to X-ray. This service provided in the RAC offered the option for the GP and resident/family to determine if hospitalisation was the appropriate next step or not.
- Hospital outreach for complex care eg in-dwelling catheter, complex wounds and IV antibiotics. These services are available to a limited extent in some hospital and health services and provide opportunity both for residents to remain cared for in the 'home' (RAC), as well as providing the opportunity for RAC RNs to be upskilled. These services are very much valued by our RAC services.
- Post hospital sub-acute support. Our RAC services are experiencing a pattern of increasingly earlier discharge from hospital which results in residents returning to the RAC with significant medical care requirements. Post hospital sub-acute support is rare in such circumstances, resulting too often in early return of such residents to hospital for further care
- Psychogeriatric care.

Question Fifteen: *How will the model of aged care develop with evolving technology and medical practices?*

Technology is offering some real potential to improve the life and care for seniors in residential aged care. These include:

- Paincheck – an application to measure pain levels of people who are unable to speak/verbalise their pain levels
- Teleconsultation – to provide access to RAC residents in regional/rural/remote locations as well as in metro areas to medical specialists
- Remote tracking sensors – to support resident dignity and choice to mobilise while ensuring residents can be safe if venturing beyond the RAC
- Robotics – for example to delivery food and laundry within a RAC, to refocus staff time towards residents
- 'Skype' type capability to lessen the isolation for residents from family and friends within RAC
- Family access to real time resident information eg activities of the day, wellbeing of residents, etc

Dignity, choice and a palliative approach

As death approaches, people's needs and choices vary. By identifying people's choices early, we can adapt and individualise the care we provide to allow people to have a good death. Research tells us that:

> A good death gives people dignity, choice and support to address their physical, personal, social and spiritual needs[1].

A palliative approach does not start in the last days or weeks of somebody's life. It begins early, when people first come into our care. A palliative approach brings people, their families and care staff, such as General Practitioners and nurses, together to have open and regular conversations about people's choices around death. This approach normalises talking about death and dying, and increases people's confidence when asking health professionals questions about their care. Taking a palliative approach means that we know and respect people's care choices at end of life[2].

1 Swerissen. H. and Duckett. S. (2014). p.2.
2 University of Queensland/ Blue Care Research and Practice Development Centre. (2012). *The Palliative Approach Toolkit*. Available at: http://www.caresearch.com.au/caresearch/Portals/0/Documents/WhatisPalliativeCare/PA-Toolkit/01809-CEBPARAC_module%201%20web.pdf

Providing spiritual care

Taking a palliative approach means not shying away from people as they contemplate the big questions at the end of life. What has my life meant? Have I made a difference? And what happens next?

At Churches of Christ Care, we view spiritual care as being as important as physical care, and even more so at the end of life. Working as a team our nurses and chaplains along with family members are able to be attentive and listen to people as they near the end of life, offering them comfort and compassion. By doing this, we foster a sense of openness and spiritual wellbeing for those in our care, which is part of offering people dignity at the end of life.

The role of Advance Care Plans

A palliative approach also encourages the development of Advance Care Plans. These are designed to give people choice around their future care and give them time to consider the tough questions while they are still able to do so. The Advance Care Plan process allows people to consider what's important to them, their beliefs, goals, values, preferences, quality of life as defined by them, and how they want to be cared for. The plan is about thinking ahead in case they are unable to communicate decisions about their own future care[3].

Having a written advance care plan can improve end of life care and reduce unwanted treatments and hospitalisation.

The benefits of a palliative approach

Individuals

A palliative approach facilitates early conversations to draw out what may have been unspoken and encourages people, their families and staff to explore issues beyond day-to-day care. These conversations provide people with information and choice, which can decrease or even stop unwanted transfers to hospital. People often chose to stay in familiar surroundings with familiar faces and the familiar touch from those providing regular care for them[4]. Knowing that they will be cared for and their choices will be respected increases people's sense of positive wellbeing, and also has a positive impact on their family and friends.

The community

Our views on death are influenced by our culture, religious beliefs and by how our loved ones experienced death. By improving the way we approach the end of life, focusing on giving people choice and dignity, we have the opportunity to transform people's perceptions of death and dying.

A palliative approach places death and dying in the context of quality of life and positive wellbeing and is inclusive of a person's family and friends. When done well, this approach provides an experience of death that moves beyond the person dying and influences how their children and family begin approaching their own lifespan and journey to dying well. It

[3] Australian Government. (2015). *Palliative Care – Advance Care Planning.* Available at: http://www.health.gov.au/internet/main/publishing.nsf/Content/acp

[4] University of Queensland/ Blue Care Research and Practice Development Centre. (2012).

can create a ripple effect, getting conversations about death and dying happening even earlier and starting to change minds across generations about what death can look like and mean. As these positive experiences are shared with others, slowly the experience of death can transform from something unthinkable to something that can be experienced with dignity.

Summary

Key points

- Dying is an inevitable part of life.
- We believe that by offering people dignity in death, we honour the importance and sacredness of their life.
- Supporting people to have a good death is a significant clinical practice and policy challenge that we must face as the population ages.
- Churches of Christ Care supports the Grattan Institute's view that "a good death gives people dignity, choice and support to address their physical, personal, social and spiritual needs."[5]
- Churches of Christ Care has adopted the palliative approach as a framework for increasing the dignity and choice for people at the end of life.
- A palliative approach promotes open communication between a person, their family and the care teams.
- A palliative approach acknowledges a person's choice through documented advance care plans for improved end of life care and can reduce unwanted hospital transfers.
- A palliative approach begins soon after a person comes into our care, not just in the last days or weeks of somebody's life. The approach begins early, when people are able to communicate their needs and wishes openly.
- Knowing that their choices will be upheld at the end of their lives, increases a person's sense of positive wellbeing.
- For those tasked with caring for a loved one who is dying, being aware of the person's wishes and having access to services to support them as carers can relieve significant stress.
- A palliative approach places death and dying in the context of positive wellbeing and involves a person's family and friends. This approach provides an experience of death that moves beyond the person dying and influences how their children, family and community view dying well.

5 Swerissen. H. and Duckett. S. (2014). Dying Well. Grattan Institute. Retrieved from: http://grattan.edu.au/wp-content/uploads/2014/09/815-dying-well.pdf p.2.

The Presbyterian Church of Queensland
ABN 43 015 755 489

Our ref:
Date: 15 April 2019

To the Committee Members

We present here a submission by the Presbyterian Church of Queensland in relation to the inquiry into aged care, end-of-life and palliative care and Voluntary Assisted Dying.

We trust that this submission will be helpful to your work.

Yours faithfully

Rev Michael O'Connor
Moderator of Assembly

Rev Peter Barson
Clerk of Assembly

Dr Robyn Bain
Convener – Gospel in Society Today Team

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What we do
We are committed to making known the good news of Jesus Christ and His claim on our lives.

The Presbyterian Church of Queensland

This submission has been prepared by the Gospel in Society Today team (GiST) on behalf of the Presbyterian Church of Queensland (PCQ). Approximately 7500 people attend PCQ churches across Queensland each week. PCQ has sought to faithfully serve the Queensland community in many ways for almost two centuries, and is directly involved in providing health care, aged care, community and chaplaincy care as well as school and tertiary education.

For further information regarding the position of the GiST team and PCQ, please contact the convenor of the committee:

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[redacted]

[redacted]

We welcome and are thankful to the Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee for this opportunity to make a submission regarding voluntary assisted dying (VAD). We are also very thankful for this inquiry and we pray that God will give you wisdom and courage in this important work.

Summary of Our Position

In this submission, we detail our responses to the following issues for consideration:

Question 21 - **How can the delivery of palliative care and end-of-life care services in Queensland be improved?** We support Aged and Community Services Australia (ACSA) recommendations in their submission to the committee that increased provision of palliative care services be funded, particularly for those dying in residential care services and in their own homes.

Question 25 - Should voluntary assisted dying (VAD) be allowed in Queensland? We urge the Committee to recommend that Voluntary Assisted Dying *not* be allowed in Queensland. We urge this in order to safeguard compassionate care for the suffering and vulnerable in our community. Instead, we ask the committee to recommend increased provision and access to high quality palliative care services.

Question 37 - Should medical practitioners be allowed to hold a conscientious objection against VAD? We argue that medical practitioners should be not only allowed to hold a conscientious objection against VAD but should be supported and protected in their stance.

Question 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? We argue that if practitioners hold a conscientious objection to VAD, they should not 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.

Reasons for Our Position

As Christians, we believe that God speaks to us in our suffering and dying with a message of solid hope and deep compassion. We experience His care for us through relationship with His Son, Jesus Christ. Knowing personally the profound hope and comfort Jesus brings to us in

even the most severe suffering, we long to share this with the people of Queensland as they face suffering and dying too.

We believe that the practice of VAD is not a compassionate response to suffering. God's message of compassion In Jesus Christ provides a very different perspective to suffering and dying compared to the beliefs and assumptions that drive VAD. The Bible shapes our perspective as follows:

- Humans are not autonomous beings but wholly dependent on the life-giving generosity of God. We have been made to enjoy Him and thrive in obedience to His words to us. Every person, every life and every decision we make about our life is significant because we are God-made and God-purposed. We are also made to thrive within interdependent human relationships that seek to honour and care for the other.

- This life now is not all there is. Our life now and after death is in the hands of God. Trying to wrest control from God, including control over our own life and death, is an expression of defiance towards Him. The universal human desire for self-rule leads to self-centred relationships and profound suffering. It deserves His judgement. Death and the subsequent eternal punishment of separation from God is His punishment for self-rule. Thus, death does not lead to nothingness and death itself does not release us from suffering.

- Only God can provide our release from judgement. In love He chose to do so through Jesus Christ. Only through turning from self-rule to trust in Jesus' death and resurrection on our behalf can our suffering be fully relieved after death. Trusting Jesus, therefore, provides hope and perspective through suffering. A 'good death' is only found in Jesus.

- To act with compassion means pointing those who are suffering and dying to true release in Jesus. This involves affirming the value of every person by showing them unconditional, generous, thoughtful and skilful care to the end of their lives. Medical care is God's gift for helping and restoring people according to His design. It is not compassionate to enable others to take life and death into their own hands, and to allow individual choice that may harm the vulnerable. These measures provide no way out of suffering, both now and in the future.

End-of-Life and Palliative Care: Issues for Consideration

21. How can the delivery of palliative care and end-of-life care services in Queensland be improved?

We urge the committee to consider and accept Aged and Community Services Australia (ACSA) recommendations in their submission to the committee. These are:

- increased provision of palliative care services be funded for those dying in residential care services and in their own homes. This includes upskilling of the aged care workforce as well as increased access to palliative care resources and equipment.
- Training of health professionals in palliative care skills including specialists, GPs, nurses, allied health practitioners and carers
- Identification of core palliative care medications and supporting medical practitioners to implement anticipatory prescribing of these medications.
- Resourcing of palliative care facilities
- Research into end-of-life care.

We also urge the committee to pay particular attention to the following factors in palliative care provision: lower socioeconomic status, non-English speaking and indigenous backgrounds, regional areas, nursing homes, very young age and non-cancer diagnoses.

Voluntary Assisted Dying: Issues for Consideration

25. Should voluntary assisted dying (VAD) be allowed in Queensland? Why/why not?

We urge the committee to recommend that Voluntary Assisted Dying *not* be allowed in Queensland.

We urge this in order to safeguard compassionate care for the suffering and vulnerable in our community. Advocates of VAD argue that individual people should be able to choose the way in which they die. While we agree that the state should uphold considerable freedom of individual choice, this should not be upheld to the detriment of supportive and protective social relationships within Queensland communities.

The current prohibition on taking the life of a person or enabling their suicide is a vital boundary for protecting people and relationships within our communities. As a Christian denomination that cares for the elderly, sick and vulnerable in multiple ways, we hold reasonable and grave concerns that the legalisation of VAD, while opening up choice for a few, will have profoundly negative consequences for many in Queensland

Our main reasons for arguing this position are as follows:

a. **While VAD legislation in Victoria and overseas seeks to ensure patients act without coercion, this does not take into account the subtle coercion that the choice of VAD itself creates.** Individual choices are profoundly shaped by social beliefs and structures. The process of VAD assessment supports those patients who adhere to VAD criteria in thinking that euthanasia or suicide is a valid and logical choice. This validation then creates tension within a health care culture that also seeks to honour and support life. Terminally ill patients will find themselves in a situation where hastening death is an option always at hand. They may well feel they need to defend to themselves and perhaps to others why they choose to stay alive, especially when they sense the burden of their care on others. Indeed, the same may eventually be felt by those with long term disabilities and chronic illnesses. It is telling that while an increasingly large percentage of the population are in favour of VAD, a very much smaller percentage of terminally ill patients desire it. In the face of death, patients generally desire more time, not less.[1] No VAD legislation can ensure that the quiet

[1] M. Best, 'Euthanasia' (October 2016) https://freedomforfaith.org.au/library/euthanasia

concerns and doubts of older, vulnerable and disabled people are adequately heard, and their desires and choices protected.[2]

b. **No legal safeguards can fully guard against the abuse and misuse of Assisted Dying practices, including the occurrence of Involuntary Euthanasia.** Transgressions and loosening of legal requirements have been demonstrated in jurisdictions in which VAD is allowed.[3] Moreover, we must acknowledge that, in the real world, those health professionals, family and friends close to a terminally ill person may encourage and enable VAD for reasons of personal gain. No formal safeguards can prevent subtle or masked expressions of selfishness in the use of VAD.

c. A community that supports VAD makes harmful assumptions about the nature of compassion and intolerable suffering.

- Fear, a sense of isolation and existential suffering in the terminally ill are major drivers of requests for VAD.[4] The compassionate response to those experiencing such suffering is not to allow a hastened death but to gather around them, tending to those needs and demonstrating the value of their lives. Indeed, our community would greatly benefit from recovering practices of generously and patiently attending to the dying, learning how to face our own deaths in the process. People are more than independent choice makers — they need loving relationships that provide physical, emotional, psychological and spiritual care in the face of death.

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[2] J. Bishop, 'The Hard Work of Dying: Refusing the False Logic of Physician Assisted Suicide' (July 2014) https://www.abc.net.au/religion/the-hard-work-of-dying-refusing-the-false-logic-of-physician-ass/10099182

[3] J. Pereira, 'Legalizing euthanasia or assisted suicide: the illusion of safeguards and controls' in *Current Oncology* 18(2) April 2011, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3070710/
I. Tuffrey-Wijne, L. Curffs, I. Finlay and S. Hollins, 'Euthanasia and assisted suicide for people with an intellectual disability and/or autism spectrum disorder: an examination of nine relevant euthanasia cases in the Netherlands (2012–2016)' in *BMC Medical Ethics* 19(17), 2018. https://bmcmedethics.biomedcentral.com/articles/10.1186/s12910-018-0257-6

[4] Dees MK, Vernooij-Dassen MJ, Dekkers WJ, Vissers KC, van Weel C, 'Unbearable suffering': a qualitative study on the perspectives of patients who request assistance in dying', Journal of Medical Ethics, 37 (12), 2011, pp. 727-34.
N. Richards, 'Assisted Suicide as a Remedy for Suffering? The End-of-Life Preferences of British "Suicide Tourists', *Medical Anthropology: Cross-Cultural Studies in Health and Illness,* 36 (4), 2017.

- A culture that allows VAD makes certain assumptions about what constitutes intolerable suffering and a life no longer worth living. In a society that values autonomy, independence, control and self-sufficiency,[5] those who are disabled, mentally ill, non-productive and dependent are easily judged to have intolerable lives. We argue, however, that vulnerability, interdependency and relationships of exchanging care are a natural part of flourishing human life. In both suffering and taking on the 'burden' of care for others, are opportunities for love, growth and finding meaning.

d. **Increased access to high quality palliative care rather than VAD is the compassionate response to suffering in our community.** Where good palliative care is available, the vast majority of patients receive the holistic care, including relational support and symptom control, needed to maximise quality of life as they die. Our responsibility as a community is not to attempt to minimise suffering by causing death, a practice that could all too easily substitute for the compassion, skill and relationships human beings need during the hardest moments of their lives. Our responsibility is to minimise suffering through maximising care. Indeed, we strongly commend the committee for undertaking an inquiry into aged care, end-of-life and palliative services.

37. Should medical practitioners be allowed to hold a conscientious objection against VAD? If so, why? If not, why not?

We argue that medical practitioners should be not only allowed to hold a conscientious objection against VAD but should be supported and protected in their stance.

Our previous argument that allowing VAD in Queensland would have profoundly negative consequences for many patients in our health care system as well as for the community more

[5] D. Fleming, 'The compassionate state? Voluntary Assisted Dying, neoliberalism and the problem of virtue without an anchor' (March 2019) https://www.abc.net.au/religion/compassionate-state-voluntary-assisted-dying-neoliberalism-and/10937504

generally logically implies that no doctor, nurse or other health practitioner should be obliged to participate in or support the practice of VAD.

We urge the committee to consider the central role that medical practitioners would play in providing VAD. The shift away from the fundamental values of healing and protecting human life from harm, the weight of assessing patients for VAD, and the administration of lethal medication have been found to have very significant emotional and psychological effects on medical practitioners.[6]

We also urge the committee to consider the pressure that VAD legislation would place upon medical practitioners to provide VAD. Sources of pressure and even intimidation could be individual patients, relatives, health care facility managers, fellow health care practitioners and the community at large.[7]

We encourage the committee to recommend that those medical practitioners with conscientious objections to VAD be supported and protected in their choice.

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 argue that if practitioners hold a conscientious objection to VAD, they should not 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.

[6] K. Stevens, 'Emotional and psychological effects of physician-assisted suicide and euthanasia on participating physicians' in *Issues in Law and Medicine* 21(3) Spring 2006, https://www.ncbi.nlm.nih.gov/pubmed/16676767
R. Pies, 'How does assisting with suicide affect physicians?' (January 2018), https://theconversation.com/how-does-assisting-with-suicide-affect-physicians-87570

[7] K. Stevens, 'Emotional and psychological effects of physician-assisted suicide and euthanasia on participating physicians' in *Issues in Law and Medicine* 21(3) Spring 2006, https://www.ncbi.nlm.nih.gov/pubmed/16676767

Such a requirement violates the rights of practitioners who both feel such a referral makes them complicit in act of the VAD and is contrary to their duty of care for patients.

Moreover, a genuinely secular society should not privilege the beliefs of one over another by allowing a patient's freedom of conscience and choice to override that of a practitioner. Indeed, it is beneficial for the integrity of health care provision that health care practitioners are able to act as self-consciously moral agents. To override the freedom of conscience of practitioners would likely force some into another profession and deter new entrants. Moreover, it is unreasonable to legally require such practitioners to make a referral for VAD if measures are taken to make VAD widely available in Queensland.

Conclusion

We call upon the committee to recognise:

- The need of every person for physical, emotional, relational and spiritual care as they face death
- That our responsibility as a community is not to attempt to minimise suffering by causing death, a practice that could all too easily substitute for the compassion, skill and relationships human beings need during the most difficult moments of their lives. Our responsibility is to minimise suffering through maximising care.
- That VAD would introduce harmful assumptions about the nature of compassion and intolerable suffering, creating coercive pressure on vulnerable sufferers and medical practitioners to use VAD, and undermining the choice to die a natural death.

Hence, we urge the committee to recommend that:

- Palliative Care service provision be improved, particularly for those dying in residential care services and in their own homes.
- Voluntary Assisted Dying *not* be allowed in Queensland.
- medical practitioners should be not only allowed to hold a conscientious objection against VAD but should be supported and protected in their stance.

- if practitioners hold a conscientious objection to VAD, they should not 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.

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: Ms Kerri Lanchester

Day time phone number: ([redacted]

Email address: [redacted]

Address: [redacted], Jindalee *Postcode:* 4074

What would you like to tell the committee?

Please 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: Leading Age Services Australia

Their daytime phone number: : Kerri Lanchester, QID State Manager [redacted]

What is your relationship with that person or persons, or your role in the organisation? Member Services Advisor

I am authorised by Kerri Lanchester **to provide these comments on their behalf.**

Signature: Chris Edith **Date:** 12 April 2019

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

LASA Submission Queensland Government Inquiry into aged care, end of life and palliative care and voluntary assisted dying

Leading Age Services Australia (LASA)

Leading Age Services Australia (LASA) is the national peak body representing and supporting providers of age services across residential care, home care and retirement living. Our purpose is to enable a high performing, respected and sustainable age services industry delivering affordable, accessible, quality care and services for older Australians. We represent our Members by advocating their views on issues of importance and we support our Members by providing information, services, training and events that enhance performance and sustainability.

LASA's membership base is made up of organisations providing care, support and services to older Australians. Our Members include private, not-for-profit, faith-based and government operated organisations providing age services across residential aged care, home care and retirement living. 55% of our Members are not-for-profit, 37% are for-profit providers and 8% of our Members are government providers. Our diverse membership base provides LASA with the ability to speak with credibility and authority on issues of importance to older Australians and the age services industry.

LASA is pleased to provide comment on the *Queensland Government Inquiry into aged care, end of life and palliative care and voluntary assisted dying*. This submission responds to the *Issues Paper* on the inquiry into aged care, end-of-life and palliative care and voluntary assisted dying by the Queensland Parliament's Health, Communities, Disability Services and Domestic and Family Violence Committee (the Health Committee), closing 15 April 2019.

In preparing this submission, LASA consulted with its 149 Queensland member organisations in relation to the issues and questions presented in the I*ssues Paper* that LASA identified as relevant to aged care. Should you have any questions regarding this submission, please do not hesitate to contact Kerri Lanchester, Queensland State Manager on [redacted] or email: [redacted]

Introductory comment

LASA would like to make the Health Committee aware that the aged care sector is a key provider of End-of-Life care. Nationally, about 60,000 people die in a residential care facility (RACF) each year. Providers of Residential Aged Care Facilities (RACFs) are involved in facilitating advanced care planning and the delivery of palliative care for many of their residents. People with medical conditions that may make them eligible for Voluntary Assisted Dying (VAD) often live in residential aged care during the last phase of their lives.

LASA encourages the Health Committee to employ lessons from overseas in countries where palliative care and VAD dying practices are considered to be world class, with the highest levels of compassion and consumer choice applied.

Response to the Issue Paper Questions:

General 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?

A: LASA considers that funding and structural issues are impeding the aged care system's ability to comprehensively meet the needs of older Queenslanders who require aged care support. LASAs current election campaign – 'I Care For Aged Care" highlights as two main issues the:

- the funding emergency in residential aged care, which sees an estimated 43 per cent of facilities currently operating at a loss, with even greater pressure being experienced by facilities operating in rural and remote locations
- the unacceptable impact on older Australians that sees more than 120,000 older Australians waiting, sometimes for more than year, to receive essential care and services in their home.

2. Are the current waiting times for both residential and home care places adequately meeting the needs of older Queenslanders?

A: Please see LASA answer to Question 1 above

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?

A: LASA considers that the majority of providers meet the recognised standards in aged care, with many providers going beyond these minimum standards, in providing high quality, consumer focused care. However, LASA also acknowledges that aged care providers must take responsibility for failures in care that have been identified in the media and now by the Royal Commission. However, resource constraints and difficulties in recruiting a suitable workforce affect providers' capacity to deliver care to a standard the community considers desirable.

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?

A: LASA anticipates that demand for home-based aged care services will increase and that these may be offered in conjunction with housing and lifestyle services, such as retirement living. For example, LASA members are already providing delivery of alternative and multi-faceted care, including Ageing in Place models. LASA supports an integrated aged care system delivering services across the senior's housing and retirement living, home care and residential care sectors. LASA supports aged care at home reform in line with the Australian Government's reform agenda, read more

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?

A: In general sufficient residential care places are available but supply and demand varies according to geographical regions. The more rural and remote residential care providers may not have enough beds, while there may be an over-supply in metropolitan regions. Unacceptable wait times for home

care packages can have the impact of more clients going into residential care, which means that some providers now have a wait-list for residential care beds.

6. Are adequate numbers of home care packages available in areas at the levels required?

A: No. LASA's 3rd Home Care Provider Survey Report (March 2019) shows that wait-times are often much longer than those published on My Aged Care. Key issues identified by Home Care Providers include:

- 65 per cent of Home Care Package (HCP) providers indicated that the actual wait times of consumers on the national queue to be assigned a HCP were often between six and twelve months longer than those published on My Aged Care;
- 50 per cent of HCP providers also reported actual wait times as often being greater than twelve months longer than those published on My Aged Care;
- Many people on the queue never received the level of care that they were assessed as needing and instead passed away, or were exited from a HCP to hospital or residential care;
- Despite high levels of unmet need, the level of unspent HCP funds may have reached around $450 million;
- Unspent HCP funds at 1 October 2018 reflect an average of near $5,000 per HCP consumer, suggesting total unspent HCP funds could be near half a billion dollars, nationally;
- There is widespread concern among providers about inappropriate HCP expenditure requests from consumers.

7. Are there sufficient staff in the aged care sector to meet current and future workloads?

A: Aged care services operate with differing levels of staffing, depending on their mix of residents and for this reason they use different models to determine the sufficiency of staff. Service providers in rural and remote areas however, face particular challenges in workforce recruitment and retention. LASA supports the investment in a skilled workforce in line with recommendations from the *Aged Care Workforce Taskforce Strategy Report (Aged Care Workforce), A Matter of Care*, read more.

8. Is the mix of staff appropriate for different settings within the aged care sector?

A: Aged care services operate under various models to determine appropriate staff mixes. Surveys of consumer and resident care needs are undertaken regularly by home care and residential care providers to determine the appropriate mix of staff. The appropriateness of aged care providers' staffing levels and mix are monitored by the regulatory authorities.

9. Do aged care staff receive training that is appropriate and adequate to prepare them for the work?

A: The aged care workforce includes a mix of skills and skill levels such as personal care workers, enrolled nurses, registered nurses, nurse practitioners, allied health professionals , and support staff. Thus there are varying levels of training depending on the role the staff member is undertaking. However, concern exists that education for entry into the nursing profession does not include a sufficient component about health care in ageing. Vocational training for Personal care workers has been found to vary in quality and to lack some necessary content. However, a number of steps have been undertaken to review and improve workforce training and workforce supply issues in aged care.

Australia's first Aged Care Workforce Industry Council was set up earlier this year to drive the work needed to rapidly grow the workforce for the benefit of all Australians. The industry peak bodies Leading Age Services Australia, the Aged Care Guild and Aged and Community Services Australia have thrown their support behind the Aged Care Workforce Industry Council. The Council met for the first time in February 2019.

Further an Aged Services Industry Reference Committee has been established to respond to relevant recommendations in the Aged Care Workforce Strategy and to ensure that the national education and training system is able to deliver an agile workforce that can provide safe and quality care to older Australians in a variety of settings. This includes addressing the current and future competencies and skill requirements for new workers entering the sector and existing staff needing to upskill in both the vocational education and training (VET) and higher education sectors.

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?

A: LASA recognises that this is a complex area, with particular importance being in the interface with the primary and acute health systems. As noted in the Aged Care Workforce Taskforce Strategy Report:

Older Australians have increasingly complex care needs that frequently require multidisciplinary services drawn from across aged, health and disability care. However, poor coordination of funding across these systems, along with professional practice and education silos, contribute to reduced access to care, diminished care experience and increased costs for consumers and governments.

11. Are suitable health care services being provided within residential aged care settings and/or aged care providers?

The current Accreditation Standards for residential aged care includes Standard two which regulates the quality of health and personal care to be delivered in the aged care setting.

From July 1 2019, the Aged Care Quality and Safety Commission expects all organisations providing aged care services in Australia to be compliant with the new Aged Care Quality Standards. In the new Standards, Standard 3 Personal care and clinical care regulates the quality of health care provided in all aged care settings.

Many of the local Primary Health Networks and Hospital and Health Services in Queensland are undertaking innovation projects to support greater collaboration between the health and aged care sectors.

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?

A: The current focus of the aged care system is around wellness and reablement, restorative care and consumer outcomes, which is being embraced by LASA members but warrants additional resourcing and a multi-pronged approach.

13. How can the delivery of aged care services in Queensland be improved?

A: Again, this requires a multi-pronged approach. Part of this would be good integration of aged care services (residential services in particular) with primary care and tertiary care as well as community services. Notably, Australian research studies have shown that outreach services from the tertiary sector to support the delivery of health care in residential aged care has prevented some admissions of residents to hospitals[1]. Paying attention to workforce issues is also required as noted in the Aged Care Workforce report:

The taskforce has maintained its focus on a wider definition of 'the workforce' to ensure it included all of the touchpoints' for consumers in their ageing journey—from 65 years of age until end of life and from 50 years of age for Aboriginal and Torres Strait Islander people, and for the homeless and other prematurely ageing populations. For many older Australians this will include financial planning, primary health services, carers, in-home care, functional health care providers, specialist care providers, residential care, acute and subacute care, as well as system facilitators and navigators.

In relation to Home Care, LASA's 3rd Home Care Provider Survey Report (March 2019) recommends:

- Reducing Home Car Packages (HCP) wait times to no more than three months from the time of assessment to the time an older Australian receives support in their home;
- Limiting the level of unmet HCP demand, this phasing in of maximum wait times should be supplemented by prioritising the queue based on an individual's means and giving people the option of using their home equity to fund their care needs;
- All unspent HCP funds returned to Government should be recycled into additional HCPs.
- The Department of Heath should publish clearer guidance for both providers and consumers on appropriate uses of HCP funds.

Further, the Aged Care Quality Standards to be introduced this year do focus on quality outcomes for consumers rather than provider processes. This will make it easier for consumers, their families, carers and representatives to understand what they can expect from a service. It will also encourage innovation, excellence and continuous improvement in the delivery of care.

14. Are there alternative models for the delivery of aged care services that should be considered for Queensland?

A: New models of aged care are emerging. For example dementia villages are being built and are now starting operation and it is anticipated that such a setting will be conducive to improving residents' quality of life2. Also, some residential aged care providers shift away from the larger institutional setting to accommodate their residents in smaller villas in groups of 6 to 8 residents3. LASA supports members in examining alternative models for the delivery of aged care services, including the continuation of age care reforms and a focus on ageing in place.

15. How will the model of aged care develop with evolving technology and medical practices?

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[1] Chapman, M, Johnston, N, Lovell, C et al. 2016 'Avoiding costly hospitalisation at end of life: findings from a specialist palliative care pilot in residential care for older adults'. BMJ Supportive and Palliative Care Published Online First 8 August 2016 doi: 10.1136/bmjspcare-2015-001071.
Johnston, N, Lovell, C, Wai-Man, L et al. 2016 'Normalising and planning for death in residential aged care: findings from a qualitative focus group study of a specialist palliative care intervention'. BMJ Supportive and Palliative Care Published Online First14 July 2016 doi 10.1136/bmjspcare-2016-001127.
[2] https://www.abc.net.au/news/2017-07-19/australian-first-dementia-village-set-to-open-in-tasmania/8724772
[3] https://www.agedcareguide.com.au/talking-aged-care/village-like-dementia-care-city-style
https://www.theweeklysource.com.au/lyndoch-livings-doreen-power-named-aged-care-ceo-of-the-year/

A: LASA supports members in exploring options for advances in technology and innovation through support of the Aged Care Industry Information Technology Council (ACIITC) and our own innovAGEING program. innovAGEING coordinates a community of practice for age services innovators, showcases examples of innovation in our industry, and celebrates age services innovation through a national awards program. Open to all individuals and organisations, the aim of the network is to foster and promote innovative, consumer-centric solutions to meet the increasingly complex needs of older Australians.

16. What are the key priorities for the future?

A: Key priorities for aged care in the future are funding, quality of care and access to care. The capacity of providers to deliver care is constrained by the resources that are available to them. LASA suggests following solutions to the funding constraints:

a. Implement the Tune Review recommendations to increase consumer contributions for those who can afford to pay
b. Set a fair interest rate on unclaimed lump sum accommodation payments
c. Fast track home care for those with low-means
d. Support those on the home care queue to use their home equity
e. Commence integration of Commonwealth Home Support and Home Care Programs
f. invest in research to build the foundation of long-term reform

Other measures to improve funding for aged care that involve significant additional public support:

I. Indexation correction for residential care
II. Targeted relief for regional and remote facilities
III. Boost to funding for behavioural and psychological symptoms of dementia
Introduce maximum wait times for home care
IV. Maintain the real value of home care packages
V. Begin investing in a skilled workforce

<u>Quality of care</u>

Older Australians need confidence that when they need care and support they can readily access good quality care that is safe and affordable. This care needs to be flexible to meet their personal needs and be provided to them with compassion and professionalism. As users of a service, older Australians need to have control over the choices they make and need to be able to compare the services that are offered to them to make an informed choice. Older Australians need to be assured that any concerns they have will be addressed fairly and expeditiously via a resolution focused complaints mechanism. Older Australians need to be fully informed and aware of their rights and their responsibilities when engaging with the aged care system.

A number of key reports have found that the majority of older Australians accessing the aged care system receive good quality care. These include various international comparisons along with data from the 2015 Australian Bureau of Statistics Survey of Disability Ageing and Carers reported by the Productivity Commission which indicates that:

- of those people aged 65 years or over who reported a need for, or received formal services in the previous six months, 76.1 per cent were satisfied with the range of services available; and

- of those people aged 65 years or over who received formal services in the previous six months, 89.2 per cent were satisfied with the quality of assistance they received.

This is also similar to the findings from the Consumer Experience Reports undertaken by the then Australian Aged Care Quality Agency in 2017-18, which found that approximately 91.7 per cent of residential care residents (or their representatives) regarded the facility as well run.

Notwithstanding this, LASA acknowledges that there have been instances of unacceptable failures in care. There has been recent year on year increases in complaints to the Aged Care Quality Commissioner. Similarly, there has been an increase in instances of provider non-compliance with the aged care quality standards, as assessed by the Australian Aged Care Quality Agency. Whilst there may be a number of contributing factors to this situation, these reports rightly raise concerns with regards to standards of quality and safety in the aged care system[4].

The recent Final Report of the Community Affairs Reference Committee on Effectiveness of the Aged Care Quality Assessment and accreditation framework concludes that it is a 'universally accepted truth that a poor standard of care is being experienced by too many RACF residents'.

The responsibility for many reported instances of substandard care, mistreatment or abuse lies directly with individual employees and/or their organisations. There are also though, system issues which inhibit the ability of providers and individual care givers to offer older Australians the care they deserve. Despite the funding pressure that they are under, providers have continued to increase the number of hours of care per resident, but this cannot continue indefinitely, and some providers have reported that they are already being forced to cut back on staffing[5].

Access

My Aged Care (MAC) was implemented to provide a streamlined entry point into the aged care system in Australia. It is intended to make it easier for older people, their families, and carers to access information on ageing and aged care, have their needs assessed and be supported to find and access services.

While MAC is slowly improving as a portal for aged care consumers, implementation (along with the underlying complexity of aged care system's structure, programs, rules, etc.) has caused significant confusion for aged care consumers and their families and referrers. There are limitations with the mode of delivery (web-based portal and telephone help line) and there have been implementation issues within these modes.

The home care system is being challenged by the implementation of significant changes, whilst also straining to keep up with growing demand, but overall reports show it is meeting the needs of those who are receiving care at home.

Notwithstanding this, it is also clear there is a significant number of older Australians who have yet to access care or who are receiving care at a lower level than that at which they have been assessed to need. Across the journey of access to home care there are systemic barriers causing these delays to receiving appropriate care. There are wait times for consumers from contact with MAC to being assessed and then wait times on the national queue to receiving actual services. Often the home care services delivered are below the assessed level because of the unavailability of a package at the appropriate level.

[4] https://www.agedcarequality.gov.au/reports
[5] http://www.stewartbrown.com.au/news-articles/26-aged-care/166-june-2018-aged-care-sector-reports-released

End-of-life and palliative care

18. Are palliative care and end-of-life care services meeting the current needs of Queenslanders? Why or why not?

A: While LASA supports the work of the current palliative care and end-of-life care services, it recognises that an integrated, coordinated and adequately funded approach is required. End-of-Life care (EOLC) should include advanced care planning, palliative care and may include voluntary assisted dying (VAD).

19. Do the standards of palliative care and end-of-life care provided in Queensland meet clients' and the community's expectations?

A: LASA believes that this would not currently be the case.

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?

A: LASA emphasises the need for State and Commonwealth Governments to ensure the adequacy of funding and service models for palliative care across specialist palliative care services, outreach palliative care services to residential care and in the home and palliative care in residential care.

21. How can the delivery of palliative care and end-of-life care services in Queensland be improved?

A: LASA emphasises the need for adequate and coordinated funding, including the availability of training and support services (such as telephone counselling) to staff in all spectrums of aged care, from support workers to management.

22. What are the particular challenges of delivering palliative and end of life care in regional, rural and remote Queensland?

A: The lack of access to resources and support including funding to adequately train and support staff and/or funding to buy in assistance from external sources, particularly in regional and remote areas.

23. What are the particular challenges of delivering palliative and end of life care for Aboriginal and Torres Strait Islander communities?

A: Specific consultation with Aboriginal and Torres Strait Islander communities was not undertaken by LASA at this time but could be undertaken at a later date.

24. What are the key priorities for the future?

A: As outlined above, this requires a coordinated approach across the health and aged care sector. LASA supports ongoing education and training, including to families and carers.

Voluntary Assisted Dying (VAD)

A: In relation to the questions about VAD LASA has not been able to gather specific feedback from members at this stage. LASA members include faith-based organisations who may hold very particular views on this matter. Other providers may be supportive of VAD but may not be able to speak on behalf of their respective organisations.

However, LASA references its submission paper to the Victorian Department of Health and Human Services, and the link to the Victorian VAD Implementation Taskforce, read more.

Life: the basic human right
Right To Life Australia

The Right to Life Australia Inc.

15 April 2019

The Hon. Mr Aaron Harper
Chair Health, Communities, Disability Services, Domestic and Family Violence Prevention Committee
Queensland Parliament Qld 4000
careinquiry@parliament.qld.gov.au

Inquiry into Aged Care, End-of-Life and Palliative care and Voluntary Assisted Dying

Dear Committee

Right to Life Australia Inc. is a non-denominational, non-party political group working to uphold the right to life of every person from conception to natural death.

To the Queensland government that is contemplating legalising physician assisted suicide I must say – **do not take this very dangerous step**.

Take note of the action of the British Parliament who in 2015 voted overwhelmingly (330:118) against legalising assisted suicide. Why did the British Parliament take this step when several European countries have already been practising legalised euthanasia for some years now?

The answer is simple. British MPs listened to the advice of Professor Theo Boer of Holland who had been a prime instigator of their euthanasia legislation at its inception seventeen years ago.

His advice to British MPs – don't do it!

The reason for his action was quite simple. The categories of killable patients over the years had increased tremendously so that the so-called "right to die" had become a "duty to die". 25% of all deaths in Holland are now by physician assisted suicide!

In Switzerland where the late Professor Gould – 104 years old – had sought physician assisted suicide (simply because he was tired of living) we learnt from the ABC's coverage of it in Foreign Correspondent that since its inception in that country, physician assisted suicide had increased four-fold. https://ab.co/2UzthH0

The situation in Belgium is particularly bad with the categories of killable people having increased alarmingly.

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We must ask ourselves why this has occurred and appears to be extending in countries that have a high standard of medical and palliative care – countries in which highly skilled doctors and medical scientists have made numerous strides in improving the treatment and outcomes of so many very serious diseases and disabilities from accidents.

There is only one major reason for this development and that is the embracing of the principle of the life not worthy to be lived.
The Andrews Government's Voluntary Assisted Dying Bill 2017 narrowly passed the Victorian Parliament on 29 November 2017 and is due to commence on 19 June 2019. www.legislation.vic.gov.au http://bit.ly/2BGRz7b

This radical bill will allow doctors to kill terminally ill Victorians either by lethal injection or by giving the drugs to the person to self-administer.

We are not talking here about the situation where life-support machines (which are maintaining a patient's life artificially) are switched off to allow nature to take its course.

We are talking about a much bigger step authorising Victorian doctors to assist with the suicide of a person.

Yet suicide rates have increased by 9% in Australia in just a year, with calls for more to be spent on suicide prevention. The Age 27/9/2018 http://bit.ly/2XbaGxG

Doctors Oppose Euthanasia.

Overwhelmingly the majority of doctors worldwide oppose legalised euthanasia.

The World Medical Association opposed Victorian euthanasia urging MPs to block the bill arguing that assisted dying goes against "medical ethics." The Australian 27/10/17 World Medical Association calls on Victorian MPs to reject euthanasia bill http://bit.ly/2ONH61L

The organisation based in Geneva, represents more than 10 million physicians.

Victorian Doctors Oppose Euthanasia

Assoc. Prof Mark Yates, former President Australian Medical Association (Vic)

"....we know now, quite clearly, that inheritance impatience is having an impact on older people. And as a geriatrician, I get to see the best. But sadly, I also see the worst of human nature and irrespective of our legal construct, now we cannot protect the elderly.....Despite 68 different regulations.....100 cancer specialists (who have written to the Parliament), and 100 palliative care physicians who have written to Parliament

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The Right to Life Australia Inc.

can't be convinced that this is safe legislation." 3LO radio interview with Jon Faine 20/9/17 http://bit.ly/2V3tAJo

Dr Karen Hitchcock, Physician, Alfred Hospital (Vic)

"Over the 12 years that I have worked as a doctor in large public hospitals, I have cared for hundreds of dying patients. No one has ever died screaming or begging for me to kill them. Patients have told me they want to die. My response to this is "Tell me why." It is rarely because of pain, but it is often because of despair, loneliness, grief, the feeling of worthlessness, meaninglessness or being a burden. I have never seen a dying patient whose physical suffering was untreatable." The Monthly Dec 2015-Jan 2016 Dr Karen Hitchcock - The right to die or the right to kill? http://bit.ly/2j2qHTe

Undoubtedly – the so-called "right to die" – if embraced in legislation – will eventually become a "duty to die" especially for the aged and infirm.

Yours sincerely

Margaret Tighe
PRESIDENT

THE FOLLOWING MATERIAL ALSO SUPPORTS THE SUBMISSION:

Dr Daniel Mulino MLC Parliament of Victoria End of Life Choices Minority report p 343

Former Prime Minister Paul Keating: Voluntary euthanasia is a threshold moment for Australia, and one we should not cross Sydney Morning Herald 19/10/17

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ACSA
Aged & Community Services Australia

QUEENSLAND GOVERNMENT – HEALTH COMMITTEE

PALLIATIVE CARE

SUBMISSION TO THE INQUIRY INTO AGED CARE, END-OF-LIFE AND PALLIATIVE CARE AND VOLUNTARY ASSISTED DYING

APRIL 2019

ABOUT ACSA

Aged & Community Services Australia (ACSA) is the leading aged care peak body supporting over 700 church, charitable and community-based, not-for-profit organisations throughout Queensland and around Australia. Not-for-profit organisations provide care and accommodation services to about one million older Australians.[1]

ACSA represents, leads and supports its members to achieve excellence in providing quality affordable housing and community and residential care services for older Australians.

Aged care providers make a significant $17.6 billion economic contribution to Australia, representing 1.1% of GDP by producing outputs, employing people and through buying goods and services. The direct economic component is akin to the contribution made by the residential building construction and sheep, grains, beef and dairy cattle industries.[2] In many regional and rural areas aged care is the largest employer, which is where the majority, if not all, providers are not-for-profit.

ACSA members are important to the community and the people they serve, and aged care services, support and housing is a key future growth sector for Queensland and often the one of the largest employers and economic contributors to our many small communities.

[1] Australian Government, Department of Health, 2016-17 Report on the Operation of the *Aged Care Act 1997*, November 2017.

[2] Deloitte Access Economics, Australia's aged care sector: economic contribution and future directions, Aged Care Guild, June 2016, page 24.

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PALLIATIVE CARE SERVICES

INTRODUCTION

The Queensland Government through the Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee has invited submissions to the Inquiry into aged care, end of life and palliative care and voluntary assisted dying.

ACSA is currently engaged with the Royal Commission into Aged Care Quality and Safety and have submitted a witness statement and written submissions. ACSA's Chief Executive Officer, Pat Sparrow has appeared at the Royal Commission as a witness.

It is our purpose for the Queensland inquiry to make a submission on palliative care. ACSA previously made a submission to Queensland Health's "Palliative Care Services Review" in August 2018.

The Queensland Department of Health (DOH) provides funding to Queensland Hospital and Health Services and non-government organisations to provide palliative care services in a range of settings including community aged care and residential aged care settings.

Recently there have been some major initiatives relating to palliative care including the development of *The Care at the end of life: Implementation Plan 2015 – 2025* (Queensland Health) and in February 2018, the updated *Palliative Care Service Development Guidelines and National Palliative Care Standards* (Palliative Care Australia) were released.

In March 2018 a report by the Australian Productivity Commission entitled *Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services* was released. This report included key recommendations for consideration in the provision of end-of-life services including:

- State and Territory Governments should increase the availability of community based palliative care services to ensure people with a preference to die at home can access support to do so.
- End-of-life care should be core business for aged care facilities and the quality of end-of-life care in residential aged care should align with the quality of the end-of-life care available to other Australians.

The report also stated that the most cost-effective way for the government to provide palliative care services is to increase funding for community based palliative care services as community based palliative care can cost less than hospital-based care.

To ensure current palliative care services meet current and future palliative care service demands, DOH is undertaking a review of palliative care services to develop an informed and strategic approach to the provision of further palliative care service arrangements. DOH identifies the review will include consideration of existing services and the demand, and the projected demand, for palliative care services as well as explore development options and models for optimum services.

ACSA MEMBERS PROVISION OF PALLIATIVE CARE

ACSA's members provide palliative care services in residential aged care and community care settings.

Palliative care services provided by members can include, but are not limited to, one or more of the following supports in both community and residential aged care settings:

- Activities of daily living support including showering, meals, cleaning and activities.
- Transport services including attending medical officer/hospital appointments.
- Emotional and pastoral/spiritual support.
- Carer/family support including respite services.
- Clinical care including medication management, pain management/support, skin/wound care, dietary/nutrition management and other specialised nursing care needs. Clinical services are provided by specialist palliative care nurse practitioners, registered nursing staff and / or general practitioners (GPs).

Each older person requiring palliative care services has a different need and/or preference regarding their end-of-life experience.

The Queensland's Chief Health Officer Report titled 'The health of Queenslanders in 2016' identified:

- The population has doubled over the 33 years since 1983.
- The population is projected to reach 5.7 million by 2026, an 18% increase in 10 years.
- The Indigenous Queenslander population is projected to increase from about 203,000 in 2014 to 271,000 in 2026—a 34% increase over this period.
- The majority of deaths (60%) occur in people aged 75 years and older with 40% being premature.

Providers are not adequately funded to respond to be all things to all older people requiring palliative care and due to the increasing demand for these services, struggle to meet the ever-increasing demand in a timely manner.

The recent independent StewartBrown[3] financial survey (data used by Government) shows that 43% of residential aged care providers were making a loss at March 20188 compared with 31% in 2015-169. This loss increases to 58% in outer regional and remote facilities. And the situation is predicted to get even worse. The Stewart Brown report also calculated a $7.30 per day, per resident shortfall for residential aged care services.

Providers can assist in providing basic palliative care but would be working closely with GP's, geriatricians, specialized palliative care and pharmacists in a multi-disciplinary team approach. The ability to access these key partners is influenced by factors including location, access and cost. We believe access to basic palliative care plus these key partners should be available older people irrespective of their chosen environment.

CHANGES REQUIRED TO IMPROVE PALLIATIVE CARE DELIVERY IN QUEENSLAND

Palliative care is an important part of residential and community aged care services. Once an older person enters residential aged care, it is generally acknowledged that they are unlikely to leave the service permanently prior to death and therefore access to specialised palliative care services and resources is critical. Those who remain in their own homes have limited access to specialised palliative care services and resources to assist their families and themselves to have an end-of-life experience of their choice. It is critical older people have equity of access to palliative services relative to the general population irrespective of their chosen environment.

[3] StewartBrown, Aged care financial performance survey, Residential Care Report, March 2018.

To improve the experience of older people and their carers/families requiring palliative care services:

- Increased availability to palliative care service and resource information.
- A multi-disciplinary and coordinated approach to the provision of palliative care services to ensure a holistic approach to palliative care services.
- Increased understanding of the differing cultural palliative care needs of older people and how these needs impact on their death experience.
- Increased access to palliative care specialists, resources and alternative therapies to effectively manage palliative care symptoms such as pain management, skin care management and management of other symptoms.
- Access to qualified, skilled palliative care staff.
- Greater support for carers and families of older people requiring palliative care services including respite support, counselling and bereavement services.
- Increased flexibility for specialised palliative care staff, residential aged care, community care providers and GPs to facilitate the provision of palliative care services that are adaptable to meet individual older people's palliative care needs and preferences.

It is critical that Queensland's health system provides quality palliative care services for older people, their families and our communities by striving for palliative care service options that are directed by consumer choice.

FUTURE REQUIRMENTS FOR PALLIATIVE CARE DELIVERY IN QUEENSLAND

Palliative care knowledge and expertise are not consistently embedded into the delivery of care across different health care sectors and professions by health care professionals who do not specialise in palliative care.

In 2016/17 the average age of entry to residential aged care was 82 years for men and 84.6 years for women with the average length of stay being about 34.6 months, however this is decreasing with many more people now staying for only 6 to 12 months[4].

This coupled with an aged care funding model that does not adequately address the provision of palliative care support for clients and residents, has resulted in a need for:

Access to palliative care specialists
Aged care providers report that access to palliative care advice and support services are limited. Support is required through:

- Access to advice and support for GPs and the aged care workforce to specialist palliative care services 24 hours a day.
- Enhanced specialist palliative care outreach services to provide palliative care support that can be provided within residential and community aged care services, avoiding unnecessary hospitalisations.

[4] Australian Government, Department of Health, Report on the Operation of the Aged Care Act 1997, 2016/17.

- Greater access and networks between residential aged care services, community care services and specialist palliative care services.

There are severe shortages of specialist GPs, nurses and allied health staff with specialised palliative care skills, experience and knowledge.

Increased funding to increase the capacity of the aged care workforce to support adequate aged care staffing and specialist palliative care services to manage the holistic requirements and fluctuating palliative clinical and emotional needs of an older person approaching end of life is required.

Access to GPs to carry out visits at short notice can often be problematic. The Australian Medical Association *Aged Care Survey 2017* identified more than 35 per cent of the doctors surveyed reported that they plan to not take on new patients in residential aged care, reduce the number of visits, or stop completely, over the next two years, and the proportion of doctors visiting residential aged care services has dropped by 13.5% since 2015.
This coupled with the requirement for GPs to visit more frequently due to rapid health changes as a palliating older person deteriorates can put additional pressure on residential and community aged care staff and impact on the quality of palliative care services for the older person.

Access to palliative care equipment and resources
Currently, residential and community aged care providers are inadequately resourced to provide palliative care services and appropriate equipment may not always be readily available.
The demand for, and cost of, palliative care resources and equipment is hard to predict and can result in limited palliative care equipment being available for use by older people in both the residential and community aged care setting.

Access to palliative care medications
Systems need to be developed to ensure for rapid access to the required palliative care medications aimed at reducing distressing end of life symptoms.

GPs need to be upskilled in best practice for managing end of life symptoms and the use of anticipatory prescribing so that nursing staff can administer in a timely manner.

Access to specialised palliative care medications can be delayed due to lack of access to GPs or other palliative care specialists. A timely access to these medications ensures an older person experiences a comfortable, pain-free death.

Increased and more timely palliative care funding for residential and community aged care providers
The delivery of high-quality palliative care needs to be carefully considered in conjunction with current reviews of funding models.

However, the lack of adequate palliative care funding to residential and community aged care providers has resulted in the lack of:

- Sufficiently skilled palliative staff.
- The availability of palliative care equipment and resources.
- Access to palliative care specialists.

RECOMMENDATIONS

To ensure older Queenslander's palliative care needs and preferences are met, ACSA recommends:

- Increased and more timely funding for the provision of palliative care services to enable older people to have the death experience of their choice, whether they choose to have that experience in their own home or in a residential aged care service.
  Increased funding can assist:
  - The upskilling of the aged care workforce.
  - Increased access to palliative care resources.
  - Increased access to palliative care equipment.

- Assistance for GPs, allied heath staff and other specialists to attain specialised skills and knowledge in palliative care.
- Increase palliative care education in registered nursing formal education programs.
- Identify core palliative care medications and support GPs and other relevant specialists to implement anticipatory prescribing of palliative care medications.

ACSA also recommends further research and aged care sector consultation is undertaken into palliative care.

Dying with Dignity
New South Wales

Submission for the 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

Written by Dr Elizabeth Jacka

on behalf of Dying with Dignity NSW

Website – dwdnsw.org.au

ABOUT US

Dying with Dignity NSW (DWD NSW) is a law reform organisation pursuing a change in the law that will enhance self-determination and dignity at the end of life. Our aim is legislation that entitles a mentally competent adult experiencing unrelievable suffering from a terminal or incurable illness to receive medical assistance to end their life peacefully, if that is what he or she wants. As well as our role in advocacy and lobbying to bring about a change in the law, we promote the use of Advance Care Directives to assist with patient control at the end of life (EOL) and we provide our members with information about changes in the legal climate for EOL, both in Australia and overseas. We are a not-for-profit organisation limited by guarantee and we rely on membership, donations and bequests in order to continue our work.

We also take phone calls from a substantial number of people each year who ring us to seek information about their end of life options. Of course, we have to explain to them that voluntary assisted dying (VAD) is illegal in all parts of Australia except Victoria (from June 2019). In the course of these conversations we learn a lot about the background to our callers' desire to obtain relief from their suffering and believe that we have gained considerable knowledge over the years about the reasons people seek VAD.

In addition, in the context of the debate on the Voluntary Assisted Dying Bill debated in the NSW Legislative Council in 2017, and the recent NSW election, we ran two *Do Gooder* campaigns where we asked the public to contact their politicians and tell them why the member of the public wanted VAD to be legalised. Over 4000 people emailed their MP's and we therefore had access to the stories they told. Time after time they told stories of bad deaths, of watching loved ones end their lives in excruciating pain and anguish, and how much the writer suffered knowing they could do nothing to alleviate their loved one's ordeal. Our submission is informed by the large amount of anecdotal evidence we have gathered about how often bad deaths occur.

We welcome the Queensland Parliament's Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying (VAD). We intend to address our remarks to the question of VAD and will respond to the specific questions outlined in the Issues Paper. We will make

reference to the findings of the two recent Australian inquiries – in Victoria and Western Australia, as well as to the large amount of evidence about how VAD regimes in other countries are operating.

If the Committee would like a representative of Dying with Dignity NSW to appear at the public hearings, our President, Penny Hackett would be happy to do so.

THE QUESTIONS

Should voluntary assisted dying (VAD) be allowed in Queensland? Why/why not?

Palliative Care can't do everything

We believe that VAD should be available to everyone in Australia as a natural part of a set of options available to patients at the end of life. Such options include palliative care but there is ample evidence available to demonstrate that it is not effective in a small but significant number of cases.

In a 2006 policy statement Palliative Care Australia Council wrote,

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

Australian research demonstrates that palliative care is not always effective. Based on data collected by approximately 100 palliative care facilities across Australia every year, we know that a small yet significant percentage of dying patients cannot have their symptoms controlled, even with the best efforts of palliative care. A recent report from the "Palliative Outcomes Collaboration Report 2016" shows that the percentage of patients experiencing severe pain can be as high as 10.3% in the unstable phase of their illness and for patients in the terminal phase of their illness 3.6% had severe pain, 3% had severe psychological distress and 6.5% had other severe physical symptoms such as breathing problems, choking and nausea (Palliative Care Outcomes Collaboration, Patient Outcomes in Palliative Care, National Results for January - June 2016.)

Evidence of bad deaths (WA)

The West Australian Report of the Joint Select Committee on End of Life Choices presented powerful evidence of the kinds of cases where palliative care does not work well and people suffered extremely at the end of life with resultant trauma for their families. It reports that the typical symptoms experienced at end of life (dyspnoea, nausea and vomiting, pain, respiratory infections and agitation/delirium) are very difficult to control, even with the best palliative care, and existential suffering is not really dealt with at all. This is particularly true of a group of neurodegenerative diseases such as MND, Huntington's disease, Parkinson's disease and dementia. There were submissions and evidence to that Inquiry from both medical practitioners and citizens. A typical example is the following (speaking of MND):

"There are some symptoms and distress that are impossible to adequately treat such as tenacious thick mucus in the back of the throat where the people with MND (PwMND) cannot cough and these cannot be controlled by a cough-assist machine; breathlessness where non-invasive ventilation is not tolerated and morphine is insufficient; and existential mental distress caused by being totally dependent. The fear of these impossible to control symptoms lead some PwMND to request an assisted earlier death from health professionals or can lead them to commit suicide while they are still capable of doing so". (MY LIFE, MY CHOICE - The Report of the Joint Select Committee on End of Life Choices, p.95).

There are many similar stories in the WA Report, all pointing to situations where VAD would have been a compassionate option when all other options had run out. The anecdotal evidence DWD NSW has collected bears out this pattern.

It is happening now but 'under the table'

A famous book by Roger Magnusson, published in 2001, *Angels of Death: Exploring the Euthanasia Underground*, reported on the extent of unofficial assisted deaths that were occurring at that time and there is no reason to think that hasn't continued. If it does occur it does so in a completely unregulated way, which is highly undesirable but also is extremely inequitable, as it is a matter of pure luck if one patient is assisted to die when others in the

same circumstances are not. There is further evidence of the practice which was summarised in the *Australia 21 Report*, written by the Centre for Health at QUT as follows:

> "A study by Kuhse et. al. concluded that in 1995-6, 1.8% of all deaths in Australia occurred due to VE and 0.1% were due to voluntary assisted dying (VAD). …[T]hese statistics are broadly comparable with the position in permissive jurisdictions." (Ben White and Lindy Willmott, *How Should Australia regulate voluntary euthanasia and assisted suicide?*, Australia 21 Report, Queensland University of Technology, 2012, p. 20.)

There is also a body of anecdotal evidence. In 1995 seven Melbourne doctors (one of whom was Dr. Rodney Syme) published an open letter to the Victorian premier admitting to having performed euthanasia.

Health professionals have no legal protection

Another problem, as outlined in the *Victorian Inquiry into End of Life Choices Final Report*, is that at the present time health professionals have no protection if they do want to relieve the suffering of their patients which leads to many cases where patients are not given enough medication to relieve their pain because the medical staff are afraid of prosecution. The famous "doctrine of double effect" is not so easy to judge in practice. Professor Paul Komesaroff gave the following evidence:

" A genuine and abiding problem with the current legal situation remains unresolved; doctors who follow current best practice by providing whatever care is needed to alleviate pain and suffering cannot be confident that they would be protected form criminal prosecution for murder, manslaughter or aiding and abetting suicide should they be actively involved in the death of their patient." (Parliament of Victoria (2016), *Inquiry into End of Life Choices, Final Report*, p. 203).

Suicide amongst the elderly

The absence of a regime for assisted dying has meant that desperate individuals have been taking extreme steps to end their lives when their suffering has become intolerable. This

includes suicide by various gruesome means such as hanging, poisoning, suffocation etc. Australian Bureau of Statistics figures show that "the oldest group (85 years and over) [had] the highest suicide rate (28.2 per 100,000) in 2009." (Australian Bureau of Statistics, 4125.0 – Gender Indicators, Australia, Jan 2012)

During the Victorian Parliament's *Inquiry into End of Life Choices*, the Victorian coroner presented stark evidence about the number of elderly people committing suicide because of severe end of life pain and suffering for which the medical establishment could provide no relief. He reported that such deaths were occurring at the rate of about one a week. The methods used included hanging, severing wrists, poison and firearms. All these people died alone and in great agony because of the absence of a compassionate alternative. (Parliament of Victoria (2016), *Inquiry into End of Life Choices, Final Report*, p. 193 ff.)

This evidence was borne out in the Western Australian Inquiry. The State Coroner provided the Inquiry with a report into suicides in Western Australia. Using data supplied by the National Coronial Information System, the Coroner reported on 199 cases where the deceased had been diagnosed with a terminal or debilitating condition. Many of these suicides had been achieved in similarly violent ways to the Victorian case. The Report went on to cite overseas research which shows the same pattern. It also made the point that in the absence of legal assisted dying people were killing themselves earlier than they needed to out of fear that if they waited longer they might not be able to do so. (*MY LIFE, MY CHOICE - The Report of the Joint Select Committee on End of Life Choices*, pp, 141-5).

The Australian community supports it

Opinion polls in Australia consistently show strong support for a regime of voluntary assisted dying. Polls taken by a variety of polling organisations over the last ten years have demonstrated levels of support for voluntary assisted dying of between 70% and 85%.

No ethical distinction between terminal sedation and VAD

A common way for people at the end of life to hasten their own deaths is by ceasing to eat and drink. The suffering incurred by this process is not justified. Some patients at the very end of life are given palliative or terminal sedation which sees them die slowly over days or

weeks, a process that is witnessed by distressed family and friends. DWD NSW sees no ethical distinction between terminal sedation and VAD. Dr Rodney Syme quotes a US expert as follows:

> "In terminal sedation, not only is the patient's death clearly foreseen, it is in fact the end point of what is being done. … These goals do not differ from those of physician-assisted death or, for that matter, voluntary euthanasia."
>
> Rodney Syme, Time to Die (2016), Melbourne University Press, p. 94.)

In fact, it could be argued that VAD is the more ethical practice since it makes the final dying process shorter, meaning family members are not spending days watching the slow death of their loved one with whom they can no longer communicate. It also gives the patient and the family and friends time to say a proper goodbye. It also is voluntary in a way terminal sedation is not. Having myself watched three people die under terminal sedation, I cannot recall the patients being asked whether they wanted to be placed in a coma until they died.

Overseas evidence shows there is no abuse and no 'slippery slope'

There is ample evidence from overseas jurisdictions that demonstrates that, provided safeguards are in place, no abuses have occurred. The most relevant case for our purposes is Oregon, where an assisted regime has been in place for over 20 years. It is most relevant for us because all the schemes that have been canvassed by various states in Australia have broadly followed the Oregon model, although the Victorian scheme is actually much more restrictive than Oregon. The *Oregon Department of Health* keeps a very close watch on how the scheme has operated and reports, first of all that assisted deaths form a very small proportion of deaths overall, and that in the over 20 years of operation there has been no reported misuse of the law. It has also not been changed over that period, confounding the claims of VAD opponents that there is inevitably a 'slippery slope'.

How should VAD be defined in Queensland? What should the definition include or exclude?

VAD should be defined in the way it has been in the Reports of the Victorian and West Australian Inquiries.

Voluntary assisted dying means that a person who meets a set of eligibility requirements should be able to obtain a prescription via their doctor for a substance that will end their lives and that, except in cases where the patient is physically incapable, this substance should be self-administered.

If you are a health practitioner, what are your views on having a scheme in Queensland to allow VAD?

DWD NSW cannot comment under this heading but notes that a substantial number of doctors are in favour of VAD (e.g. Doctors for Assisted Dying Choice) and that recent surveys of doctors show that approximately half support VAD.

If there is to be a VAD scheme, what features should it have?

It should have unambiguous and rigorous eligibility conditions (see below).

- Patients requesting VAD should be assessed by two independent (of each other) doctors. Their duty is to test the patient against the eligibility requirements and to explain to the patient all her/his options, including further treatment for their condition, palliative care and counselling if requested. They should also ascertain whether the patient has decision-making capacity and make sure that she/he is not being coerced into requesting VAD.

- There should be no mandatory psychiatric examination; such an examination should be done only if the two assessing doctors are unable to determine whether the requester has decision-making capacity and/or is being coerced. In the vast majority of cases at least one of the two assessing doctors will be the patient's GP and will have the background knowledge of the patient that will lead to a correct assessment of her/his eligibility.

- All relevant options for treatment and amelioration of her/his suffering have been explained to the patient.

- It should be able to operate in all relevant settings, home, hospital, nursing home and palliative care institution. Where necessary staff to be involved in VAD should receive special training.

- A register of health practitioners who are willing to be involved in VAD should be developed over time so that patients are assisted to connect with such doctors in a timely manner. This didn't happen in Canada and California where there was no interval between the passing of a VAD law and its operation, leading to an undesirable level of disorganization and confusion in the early stages. This suggests that a period of implementation planning should occur, as in Victoria, between the passing of the law and the commencement of its operation. However, the period allowed in Victoria (18 months) seems excessive and would have disappointed many desperate people. As experience grows in Australia, following the commencement of the Victorian scheme, implementation phases in other jurisdictions, such as Queensland, can be shorter.

- There should be a robust oversight and review function (either the Health Department as in Oregon or a separate body as in Victoria). This oversight body should not be involved during the process of the patient requesting and being allowed to access VAD but all cases should be reported to the body which would have the power to investigate possible breaches. (See below for more detail).

- Once a VAD law is passed in Queensland, relevant health professionals (Doctors, nurses, palliative care specialists, pharmacists) should be involved in its planning and implementation.

- It should be possible for health practitioners who have a conscientious objection to VAD to opt out of the scheme. However, they should be obliged to refer the patient to a doctor who is willing to participate in the VAD scheme. The register of health practitioners mentioned above should assist with this.

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 four features of the Victorian scheme which are excessive and will make it difficult for patients to access VAD in a timely manner. The first is the need to have to obtain Health Department approval for each and every prescription of the lethal substance. This means patients have to navigate, not only an assessment by two doctors plus a specialist or psychiatrist if required, but also wait on a bureaucratic decision. Once a safe procedure for managing the drug has been set up during the implementation phase there should be no need to duplicate this by having the Health Department involved in every case.

The second is the ban on doctors being able to initiate a discussion with the patient about the possibility of VAD. We believe that, because good medical practice at the end of life involves informing the patient about all options, once VAD is legal it is surely part of the suite of options available to the patient and it would be negligence to omit the VAD option once it is legal.

The third is the very long gap between the passing of the law and its coming into operation. As outlined above, states which introduce VAD after Victoria should be able to learn from Victoria's experience and not have to reinvent the wheel and thus have a shorter time between the passing of the legislation and its commencing operation.

The fourth is the setting of a time frame for a legitimate request to be approved. The Victorian law specifies that the patient should have disease which is expected to cause death with 6 months or 12 months for a degenerative illness. The West Australian Inquiry disagreed with this, saying:

> "In the course of the inquiry the Committee found that a predicted timeframe until death as an eligibility criterion can result in some individuals being unfairly excluded. And may not be clinically justified. People with progressive chronic or neurodegenerative disease may experience intractable suffering for months or years before they die. …. The Committee has recommended that those who are eligible for VAD must be experiencing grievous and irremediable suffering related to an

advanced and progressive terminal, chronic or neurodegenerative condition that cannot be alleviated in a manner acceptable to that person, where death is a reasonably foreseeable outcome of the condition." (My Life, My Choice, Joint Select Committee on End of Life Choices Report No.1, Chair's Foreword)

We agree with this position.

Who should be eligible to access VAD and who should be excluded?

The eligibility requirements should be:

- Adult (at least 18 years old)
- Be an Australian citizen or permanent resident who is normally resident in Queensland.
- Have a terminal illness or a debilitating and irreversible chronic disease such as MND, Parkinson's, MS, COPD, heart failure.
- Be experiencing unbearable physical and/or mental suffering which cannot be alleviated in a manner acceptable to the person.
- All options acceptable to the patient for treating the disease and easing the suffering have been exhausted.
- The fact that a person has a mental illness or a disability should not automatically bar her/him from accessing VAD, provided all the eligibility requirements have been met. People with a mental illness can have decision-making capacity in spite of their condition. But mental illness and/or disability would not qualify a person to access VAD unless they also had a terminal or chronic illness as outlined above.

Should the scheme be limited to those aged 18 and over? If so, why? If not, why not?

DWD NSW believes that the scheme should be limited to those who are 18 years or older. 18 is the legal age at which people are acknowledged to be capable of making their own

decisions. It is the age at which parents cease to have the legal responsibility to provide for their children, it is the age at which people are allowed to vote and to go to war. Having said that, this cut-off is of course arbitrary; there may be many 16 year-olds who have more decision-making capacity than some 21 year-olds but the bar needs to be set somewhere.

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?

As outlined above, DWD NSW takes the view that eligibility for VAD should not be limited only to those with a terminal illness but should also be available to those with a progressive degenerative condition for which there is no cure and which will gradually rob the person of all independence and normal function. Arguably the suffering of this category of patient is even worse than those with terminal disease, for whom the terminal phase of their life might last only a few weeks, whereas sufferers from degenerative diseases can be in a state of total disability and disfunction and consequent suffering for a much longer time.

What features should be included in a process to allow a person to legally access VAD?

- Request made either orally or in writing.
- Patient assessed by first doctor as to eligibility and all relevant options for treatment clearly explained and offered.
- Person makes second request in writing. Second doctor assesses and confers with first doctor.
- If necessary the patient is referred to a psychiatrist.
- Person makes final request orally.
- First doctor prescribes lethal substance and brings it to the patient.

- Doctor ascertains that patient still wants to end her/his life. (Request can be withdrawn at any stage.)
- The patient administers the substance to themselves if capable or the doctor administers it if the patient is unable to, for example if they are unable to swallow or suffer from a physical disability.
- There should be at least three weeks 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 possible submission to the oversight body.
- There should be adequate measures to safeguard the lethal substance and ensure it does not fall into the wrong hands. Any unused substance must be returned to the pharmacy.
- After the patient's death, the death certificate should report the death as caused by the patient's underlying disease but also note that it was an assisted death.
- The death should also be reported to the VAD overseeing body (either the *Department of Health* or other designated body. As described below, this oversight body should investigate if they have reason to believe the eligibility conditions were not met. Their function would also be to provide regular reports to parliament about how the scheme is operating and make suggestions for its improvement, if needed.

What safeguards would be required to protect vulnerable people from being coerced into accessing such a scheme, and why?

The safeguards have been covered above. They include:

- the rigorous testing of eligibility criteria;
- the mandatory time that needs to elapse between the first and final request;
- the monitoring by the oversight body; and

- the strict rules governing the management of the lethal substance.

Should people be provided access to counselling services if they are considering VAD? If so, should such counselling be compulsory? Why?

People considering requesting access to VAD should be offered counselling if they ask for it but it should not be compulsory. Countless conversations with callers to DWD NSW demonstrate that the vast majority of people who would like to have this kind of access are making entirely rational choices in view of their advanced age and their multiple medical problems. They are very far from being mentally ill, even though opponents of VAD often make the assumption that to entertain the idea of VAD for oneself is a sure sign of mental instability.

How could a VAD scheme be designed to minimise the suffering and distress of a person and their loved ones?

We have addressed much of this above, but just to highlight a few points. The most important thing that a VAD scheme should be is timely and not overly bureaucratic. Patients in the last phase of life and their relatives should not be faced with distressing amounts of red tape. Rather the emphasis should be on excellent patient care and good communication with all parties. There should be a high quality of information available about how the scheme works and, as suggested above, a register of health professionals who are trained and willing to participate in the process. This would suggest that if an assisted dying regime was introduced in Queensland sufficient resources should be made available for these purposes.

Should medical practitioners be allowed to hold a conscientious objection against VAD? If so, why? If not, why not?

Yes. Compelling medical practitioners to participate in a process to which they hold a conscientious objection would result in bad outcomes for the patient and for the practitioner.

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?

Yes, they should be compelled to refer the patient on. If VAD is legal, and therefore not prohibited, there is no societal reason why a patient should not be referred to a practitioner who is registered as being willing and able to participate in a VAD scheme.

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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~~: Leanne Boase

Day time phone number: 1300 433 660

Email address: [redacted]

Address: 204-218 Dryburgh St North Melbourne *Postcode: 3051*

What would you like to tell the committee?

The Australian College of Nurse Practitioners (ACNP) appreciates our inclusion in the information gathering process, and we would like to sincerely thank the Queensland Parliament Health Committee.

The ACNP, as the professional organisation representing Nurse Practitioners (NP) and Advanced Practice Nurses across Australia, requests that any future work or related committees also includes Nurse Practitioners and Advanced Practice Nurses.

For many years, nurses have been leaders in the supportive health care of multiple groups of patients for whom palliative care and voluntary assisted dying are in consideration or required, and this is a key specialty area of work for Nurse Practitioners.

Many of our members representative of both private and public health services, have in excess of 15 years experience in Palliative Care and care of people with terminal illness. They have a wealth of knowledge and experience to inform this inquiry, and we have consulted with them on the relevant issues to inform this response.

Policy and process

1.	A clear definition and delineation between of assisting dying and palliative care is required to prevent misinterpretation.
2.	Several good advanced care planning processes are in place in some health services i.e. Metro South HHS, these should be more universal/standardised were possible to prevent confusion and improve communication between health sectors.
3.	Medical dominated models of care should be phased out and replaced with a patient-centred multidisciplinary models. These models should include Nurses and Nurse Practitioners within their funding to support these changes.
4.	Improved care support processes to reduce unplanned hospital admission of patients wishing to die at home, or in Residential Aged Care Facilities (RACFs), improving communication and access to services.
5.	Improve the communication in relation to Advance Care Plans between community health services and hospital-based health services
6.	RACF nursing ratios to support the higher care needs for these populations and remove the need to transfer residents out of their facilities to hospitals for end of life care
7.	Better home-based packages to support patients choosing to end life at home. There are significant barriers and delays within existing services, which lead to hospitalisations and admissions to RACFs
8.	All Voluntary Assisted Dying processes should be explored to ensure all patients are at the centre of their care. These processes should include Mental health assessments and the challenges of the non-malignant disease barriers.

Education

1.	Patient and family education about timing and options in advanced health planning should be early, and include all options. Nurses have supported this process well and should be funded to increase and improve this service.
2.	Better education is required to manage gaps in expectations for patients, families and health providers. This would include the withdrawal of treatment, services access and pathways for supportive care.
3.	Improve health care providers knowledge about home-based end of life support and service options to reduce unplanned hospital admissions.
4.	Better RACF staff, hospital staff and Medical Practitioner education on management of patient choices in palliative care and end of life matters

The NP role provides

1.	Support and advice to patient and families
2.	Support and advice to RNs and care staff as a clinical nurse leaders
3.	Timely and appropriate evidence-based care
4.	Promotion of open communication between all parties

5. A conduit between families and General Practitioners (GPs)
6. Support for GPs in the medical care of these residents or patients
7. An essential part of the clinical team with links to reduce or prevent hospital admissions

To achieve all these things the system needs to support viable funding models to continue and grow this service, and the numbers of Nurse Practitioners. The ACNP is strongly committed to advocacy for the Australian community, supporting the right to choose your health provider, as well as options in end of life care. We therefore intend to engage as a Stakeholder.

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: Australian College of Nurse Practitioners

Their daytime phone number: 1300 433 660

What is your relationship with that person or persons, or your role in the organisation? President

I am authorised by Australian College of Nurse Practitioners to provide these comments on their behalf.

Signature: **Date: 15/04/19**

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

Queensland Branch

AASW

AASW (Qld) Submission on the Inquiry into Aged Care, End-of-life and Palliative Care, and Voluntary Assisted Dying

Submission- April 2019

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Acknowledgement

This paper was prepared jointly by the AASW (Qld) Social Policy Sub-Committee.

Introduction

Who we are

The Australian Association of Social Workers (AASW) is the professional body representing more than 11,000 social workers throughout Australia. We set the benchmark for professional education and practice in social work, and advocate on matters of human rights, social inclusion, and discrimination.

The social work profession

Social work is a tertiary-qualified profession recognised nationally and internationally that supports individuals, families, groups and communities to improve their wellbeing. Principles of social justice, human rights, collective responsibility and respect for diversity are central to the profession and are underpinned by theories of social work, social sciences, humanities and Indigenous knowledges. Social workers consider the relationship between biological, psychological, social and cultural factors and how they impact on a person's health and development. Accordingly, social workers maintain a dual focus in both assisting with and improving human wellbeing and identifying and addressing any external issues (known as systemic or structural issues) that may have a negative impact, such as inequality, injustice and discrimination.

Our work with older Australians

Social workers have a long and proud tradition of working together with older Australians towards active ageing. This includes a strong commitment to promoting self-determination, dignity and respect.

Social workers are involved in the delivery of aged care and carer support services in a range of fields of practice including direct service delivery, service planning, service management, research and policy. Using effective interpersonal skills and maintaining a person-centred approach, social workers provide a range of services such as: complex psychosocial assessments, advocacy, mediation or negotiation, counselling, referrals, liaison and education. They support older Australians in many areas including health, housing, income support, Indigenous services, disability, workforce participation and community development.

Social workers work collaboratively with older people to identify goals and work towards positive outcomes. Furthermore, they are committed to recognising strengths in order to build capacity, create opportunities and take action. Therefore, social workers are uniquely placed to hold both a broad and an in-depth view of the multiple issues facing older Australians within a rights-based context and with a focus on wellness and social connectedness.

Submission

We thank the Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee (the Committee) for the opportunity to contribute to their inquiry on aged care, end-of-life and palliative care, and voluntary assisted dying.

At the broadest level the AASW holds the view that older adulthood, as a life stage, should provide people with opportunities to live healthy, positive and productive lives, connected to and participating in the life of the community. Older people have the life experience to make a valuable contribution to all aspects of society. They are entitled to the same rights as all other Australians and their goals and aspirations should be supported.

Reflecting the United Nations Principles for Older Persons[1], it is the AASW's position that older people have the right to:

- independence;
- exercise choice and control over their lives and deaths;
- pursue lifestyles of their choice and be free to express diversity with respect to their culture, language and sexuality, amongst other things;
- employment;
- opportunities and support to pursue healthy ageing lifestyle choices;
- participate in all aspects of society and be provided with opportunities to share their knowledge and skills with younger generations;
- self fulfilment which involves access to educational, cultural and recreational resources in their communities;
- be treated with dignity and respect;
- be free from discrimination and abuse;
- equitable and readily available access to a competent, comprehensive and affordable health and social support services that meet their individual needs.

The following submission addresses several questions posed in the Committee's issues paper, with our responses reflecting the above principles for ageing and the rights of older people. The AASW does not currently hold a formal position on voluntary assisted dying, so our comments are largely focused on opportunities to improve the aged care and palliative care systems. However, given the significant role social workers play supporting people and families in hospitals and palliative care, we would welcome the opportunity be involved in further discussions to inform safeguards, policy and practice should voluntary assisted dying become legal in Queensland.

Aged Care

Question 1.
Is the aged care system meeting the current needs of older Queenslanders, including those people with special needs? Why or why not?

The AASW believes that the current aged care system is not meeting the holistic needs of all older Queenslanders. We believe older people have a right to equitable and readily available access to capable, comprehensive and affordable health and social support services that meet their individual needs. The AASW acknowledges the Commonwealth Government's work to reform the aged care system to better meet people's needs, however, our members identify a number of ongoing concerns and challenges impacting Queenslander's access to the care they need.

[1] United Nations. 1991. *United Nations Principles for Older Persons*. Available at: https://www.ohchr.org/en/professionalinterest/pages/olderpersons.aspx

Access to aged care services is variable due to multiple structural issues which impactthe scope and depth of resources available. In this context, our concern is that those most vulnerable due to ethnicity, culture, socioeconomic status, ability and sexuality do not receive appropriate services and support.

The World Health Organisation has clearly identified the importance of those social determinants of health which consider the holistic needs of the person, including their emotional, social and psychological wellbeing along with physical health needs. As it stands, the current model of aged care is missing an equal focus on the psychosocial needs of the person. Furthermore, missing are holistic and targeted psychosocial approaches to palliative and end-of-life care for vulnerable populations, including people experiencing homelessness, culturally and linguistically diverse communities, and people identifying as lesbian, gay, bisexual, transgender, intersex and queer.

Social workers provide essential services to meet people's psychosocial needs and enable older people and their families to access the aged care system, particularly at the interface between health and aged care. Yet despite being a key allied health service, social work is often missing in services for older people outside of hospitals and particularly in residential aged care.

Accessing care - intake and assessment for support in home and community

Feedback from our members describes the current intake and assessment system as frustrating for both its clients and staff. My Aged Care was designed to be a simple and efficient one-stop-shop platform for information and assistance. In practice, there are three levels of assessment which are confusing, frustrating and repetitive, and do not necessarily lead to the provision of required services.

Our members have observed a lack of consistency in the training, skills and professional backgrounds of people involved in the aged care intake process. In the first point of contact, the person seeking assistance is connected to an Intake Officer. Intake officers are not qualified social workers or health practitioners and often have administrative backgrounds. They can lack skills to engage with older people who have complex needs and can have limited understanding of the specific social and health needs of particular client groups. This can lead to older people's presenting issues not being well explored and people feeling confused and overwhelmed by the process. Consequently, they are likely to avoid the system entirely and have their needs go unmet.

Following their contact with the intake officers, in most instances a person is referred to the regional assessors. The assessor roles are also non-practitioner roles, with the required qualification being a Certificate III or IV in a community services-related field. Depending on the individual assessor's experience and skills, there can be similar issues and challenges as those experienced at the intake stage.

If people require three or more services, they are then referred to an Aged Care Assessment Team (ACAT). This is a third point of contact and is the first time people meet with an appropriately trained practitioner. By this stage, people are telling their story for the third time. Overall, this process often results in under-assessment and the person seeking help being under-serviced.

Our members report that staff working in ACAT are aware of changes to the intake process coming in 2020, but they are not aware of the details yet. It is anticipated these changes will make the process more efficient and user friendly however, until these changes are implemented people will continue to be frustrated by the system's complexity at the point of entry.

Supporting people with complex needs

Accessing the aged care system and getting the right support can be particularly challenging for people with complex care needs. The AASW has identified a range of vulnerable groups who are particularly at risk of falling through gaps in our current system. This includes older people who:

- exhibit challenging behaviours related, for example, to drug and alcohol abuse;
- experience difficulties in engaging with the system, including those who will not seek or who would refuse assistance, even thought they would benefit from support to remain living in the community;
- are unable to identify or advocate for their support needs;
- are deterred by the 'user pays' system and/or are experiencing financial hardship;
- require assistance with service integration from multiple agencies;
- with dementia, memory loss or cognitive impairment requiring specialised support;
- with challenging domestic situations, such as where squalor and/or hoarding and self-neglect are issues;
- at risk of or experiencing elder abuse;
- require support with making informed choices and decision-making;
- have mental health issues, especially those with persistent non-acute mental health issues; and
- are from Aboriginal and Torres Strait Islander and culturally and linguistically diverse backgrounds.

We note that while the aged care system is moving to be more focused on consumer choice, this is often limited for people with complex needs as there is little incentive for providers to take on complex clients.

Addressing the mental health needs of older people

Older people often experience grief and loss, depression and anxiety when entering residential aged care facilities. This arises through the loss of their home, separation from loved ones (quite often their spouse) and loss of access to their community. Research has shown:

- Over half of all permanent aged care residents had symptoms of depression;
- Just under half of people entering residential aged care for the first time had symptoms of depression; and
- Residents with symptoms of depression had higher care needs.[2]

[2] Australian Institute of Health and Welfare 2013. Depression in residential aged care 2008–2012. Aged care statistics series No. 39. Cat. no. AGE 73. Canberra: AIHW.

In addition, people living with dementia and cognitive decline often experience significant confusion when moving into residential aged care as they are removed from their familiar environment. Carers and family members are also faced with feelings of guilt and loss through this change process. Within community settings, older people face isolation as their functional abilities decrease and they become less active in their communities.

There are occasions where a person's mental health needs can exacerbate a range of behaviours, which aged care providers can find difficult to manage. Our members working in hospital settings report that not all aged care providers have the skills or knowledge to understand mental illness and adopt strategies to provide appropriate support. Care workers can also struggle to communicate effectively with these clients.

Staff in community and residential aged care need to be able to access training and support for working with people with significant mental health issues that impact on their daily living and the care they are receiving. Severe Behaviour Response Teams (SBRT) provide information and support to residential aged care staff to better support residents experiencing very severe behaviours and psychological symptoms of dementia. The SBRT considers clinical factors which may underlie behaviours, as well as staff skills, staff confidence and environmental design factors known to impact on behaviour. This type of support is required so staff can implement appropriate care strategies in their work with residents experiencing mental health and cognitive issues. Without this support, older people can be sent to hospital and often cannot return to their home in aged care as facilities are unable to manage their behaviours.

We note new measures in the 2019-2020 Federal Budget, which include additional funding to provide mental health services to people in residential aged care to be delivered through Primary Health Networks. Should this program go ahead following 2019 Federal Election, this will provide additional support in addressing the mental health needs of older people.

Meeting people's social needs

Programs and activities focused on meeting the individual needs of the client to increase social connectedness need to be expanded. The Community Visitor's Scheme provides volunteers to conduct one-on-one social support to residents and clients in the community, however, some older people can find it difficult to engage with this service due to limited resources or reluctance to access the scheme. People are often concerned about the unknown factors of connecting with a stranger who is not associated with their home, facility or care provider. Having access to one-on-one skilled support through a social worker within their home facility or under the care provider would allow older people to develop a trusting relationship and receive targeted support which is more likely to improve their psychosocial wellbeing.

Unfortunately, group activities such as day respite, joint activities and outings in residential aged care do not always meet individual needs either. This is particularly true for people from special needs groups, and those with mobility restrictions or other functional limitations who cannot easily access such activities. Affordable transport in the community and residential aged care to access external activities is limited, sometimes with only one option available which is not always suitable.

Supporting people from culturally and linguistically diverse backgrounds

The 2016 Australian census found that over a third (37%) of people aged 65 years and over were born overseas, and nearly 20% of older Australians spoke a language other than English at home.[3] Older Australians from Culturally and Linguistically Diverse (CALD) backgrounds are a highly diverse group:

> with variations in country of origin, English language proficiency, length of time in Australia, reasons for migration, postmigration experiences, age, sex, religion, socio-economic status and geographical location. All of these factors highlight the concept of 'diversity within diversity' and are relevant to the provision of appropriate aged care.[4]

CALD groups tend to face significant barriers to accessing and receiving quality aged care services. This can be due to lack of knowledge regarding service procedures, unmet cultural needs, and communication and language barriers for people from non-English speaking backgrounds. A survey reviewing the effectiveness of the National Ageing and Aged Care Strategy for people from CALD backgrounds demonstrated that while many aged care organisations consider themselves well-equipped for meeting the needs of CALD clients (60%), less than 10% of individuals receiving care or their carers felt their organisation was well prepared.[5]

Methods of communicating appropriately with older people from non-English speaking backgrounds who experience English language difficulties can be a barrier within the aged care system. This can be due to:

- Lack of bilingual staff making it difficult for older people with English language difficulties to communicate their needs. This issue is compounded by the fact that many older migrants may revert back to their first language in later age, particularly when affected by dementia.[6]
- Interpreters can be expensive. Whilst the government provides interpreting services for operational aspects of a home care package, such as setting up a package, understanding statements and reviewing care plans, these services cannot be used to assist with delivering care services. Instead this cost must come out of a person's care package, which can make day-to-day communication challenging.
- Lack of available languages through translating and interpreting services is becoming a concern. Social workers in health settings in Brisbane have reported the majority of requests for face-to-face interpreters over the last six months have been refused as the language or dialect required is not available. This has been in both community

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[3] Australian Healthcare Associates. 2018. *Evaluation of the Partners in Culturally Appropriate Care Program: Final evaluation report*. Available at: agedcare.health.gov.au/sites/default/files/documents/01_2019/word_version-aha_final_picac_evaluation_report.pdf .

[4] Australian Healthcare Associates. 2018. p. 10.

[5] Department of Health. (2017). *Review of the Culturally and Linguistically Diverse (CALD) Ageing and Aged Care Strategy: Final Report.* Available at: agedcare.health.gov.au/sites/default/files/documents/11_2017/cald_review.pdf

[6] Tipping, S., & Whiteside, M. (2015). Language reversion among people with dementia from culturally and linguistically diverse backgrounds: The family experience. *Australian Social Work, 68(*2), 184-197. DOI: 10.1080/0312407X.2014.953187

and aged care settings and has included languages such as, Polish, German, Samoan and Bosnian.

- Phone interpreters are not always effective, particularly if people have hearing issues or phone coverage in an area is not adequate.

The aged care system is a complex system and lack of access to interpreters in specific languages and dialects can have a substantial impact on how people experience, understand and access care. Other barriers that can impact people's access to aged care include:

- A reluctance to request support due to difficulties accessing the system.
- Cultural norms such as filial responsibility for the elderly and community pressure, which can result in families caring for older relatives rather than accessing support.[7] This leads to a higher level of carer stress for this client group.
- Assumptions by care providers that the family is, or should be, providing support based on the older person's cultural background. This assumption leads to people's needs being under-assessed, which limits the level of appropriate care provided to a person and places increased emotional pressure on the family.

Language and other cultural barriers can limit people's early access to the aged care system, resulting in people accessing the aged care system in crisis, often through emergency services. These cultural nuances and assumptions are also not always picked up through the My Aged Care assessment process, which leads to older people from CALD backgrounds not receiving care that meets their needs.

Case vignette:

"We have supported clients [where English is not their first language] who have been waiting on a call back from My Aged Care, however, once they have tried calling twice, cannot make contact or have left a message, they close the file and do not let the referring agency know. Our clients have not understood a message or are unable to access their message system and so have not attempted to call back.

In addition, in our experience My Aged Care are not readily using interpreting services to communicate with clients, causing access barriers."

A common complaint in residential aged care facilities for multicultural clients is around food and completing rituals. This includes making coffee independently the way they are used to or having food that includes the spices and flavours of their culture. Food served in residential aged care facilities is not always culturally diverse and is not viewed favourably by this client group.

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[7] Yeboah, C. A . (2015). Choosing to live in a nursing home: A culturally and linguistically diverse perspective. *Australian Journal of Primary Health, 21*(2), 239–244. DOI: 10.1071/PY13164;
Tsianikas, M., Hurley, C. J., Skaltsas, M., Newman, L. A., & Walker, R. B. (2011). The social support and service needs of Australia's ageing Greek migrants: A literature review. *Modern Greek Studies Association of Australia and New Zealand, 15,* 274-286
Runci, S. J., O'Connor, D. W., & Redman, J. R. (2005). Language needs and service provision for older persons from culturally and linguistically diverse backgrounds in south-east Melbourne residential care facilities. *Australasian Journal on Ageing, 24*(3), 157–161. DOI: 10.111/j.1741-6612.2005.00106.x

CALD older people may present with different psychosocial needs than others in aged care. Due to language barriers and cultural differences, this group are at increased risk of social isolation. In addition, many people from culturally and linguistically diverse backgrounds may not have familial support networks in Australia. Older migrants may experience serious mental health outcomes due to past migration experiences and trauma, such as fleeing persecution or war. They may also be hesitant to access mental health services due to cultural stigma associated with mental illness.[8]

Holistically meeting the diverse needs of this population of older people in our community requires an equally diverse workforce and flexibility in service delivery to cater to their needs. While there are some residential aged care services that specifically cater to people from different cultural groups, these are limited. Yet, when we consider how many residential aged care facilities are 'communities within a community' and the diverse needs and backgrounds of the people living in these, the lack of culturally appropriate services offered is problematic. Providing environments that celebrate and cater to diversity ensure:

- people are understood and can understand no matter their language or background;
- people's cultural norms around gender and sexuality are understood so people do not feel uncomfortable or unsafe when someone from a particular gender provides personal care; and
- people's preferences for types of food, music, film and other entertainment are known and incorporated into the care environment.

Models of care must go beyond simply providing physical care and consider people's spiritual and cultural needs. Meeting these needs are essential to improved health and wellbeing outcomes and quality of life. While several studies have researched aged care for CALD people in Australia,[9] the field is under-researched and requires further study to better understand and respond to the needs of this group of people in aged care.

Responding to younger people in residential aged care

In recent years there has been a focus on re-housing younger people living in community residential aged care However, with delays in accessing appropriate housing options and support for specialist disability accommodation through the NDIS, many younger people are still placed in residential aged care.

There is also a service gap for adults under 65 who are experiencing a life-limiting illness and require additional specialist care needs which loved ones are unable to manage. Younger people often struggle to receive the right level of support in the community, are not unwell enough to stay in hospital, and are too well for end-of-life palliative care services. To receive the care they need, they often have to be admitted to residential aged care. This process can be complicated and prolonged for younger people who are admitted to hospital,

[8] Rao, V., Warburton, J., Bartlett, H. (2006). Health and social needs of older Australians from culturally and linguistically diverse backgrounds: Issues and implications. *Australasian Journal on Ageing, 25(4), 174 –179.* DOI: 10.1111/j.1741-6612.2006.00181.x.

[9] Maidment, J., Egan, R., & Wexler, J. (2011). Social work with older people from culturally and linguistically diverse backgrounds: Using research to inform practice. *Aotearoa New Zealand Social Work, 23*(3), 3-15. DOI: 10.11157/anzswj-vol23iss3id156;
Rao, Warburton & Bartlett, 2006; Runci et al. 2005; Tsianikas et al. 2011

and can mean that they spend the last months of their life waiting for transfer to residential aged care or interim care.

Younger adults who require significant personal care or palliation have their own unique set of care needs. The aged care system is not best suited to meet these needs and more must to be done by governments to ensure people have access to age-appropriate care in the community.

Caring for Care Leavers- the unique needs of Forgotten Australians

A further group requiring attention are Care Leavers, which is a special needs category used by the Commonwealth Government to cover Forgotten Australians and Former Child Migrants. This group can also include the Stolen Generations. All three groups were impacted negatively by government policies as children and are reported to consist of over 500,000 people across Australia. The trauma these individuals have experienced bring lifelong implications and often create fear and distrust of aged care.

Helping Hand, a residential aged care service in South Australia, has worked alongside Care Leavers and identified essential principles to support older people who have had significant negative experiences of being in care. The key to providing services to this group is building trust, listening and respecting the wishes of the individual. An example of providing appropriate care as informed by a person's past experiences, is arranging for female workers to attend to a woman who has experienced male-perpetrated sexual abuse. The work of Helping Hand has identified that it is essential to offer choice, transparency, understanding and support to realise the individual's human rights.[10] Unfortunately, the current funding models of residential aged care and community-based support can limit services' ability to provide appropriate responses, particularly around choices in staffing. This can act as a barrier to providing care that does not re-traumatise Care Leavers.

Meeting the needs of LGBTI older people

We recognise that the Commonwealth Government has released the National Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Ageing and Aged Care Strategy, and Aged Care Diversity Framework and resources.[11] The policy framework recognises that:

- there have been decades of inequitable treatment for LGBTI people;
- many LGBTI people have suffered stigma, family rejection and social isolation; and
- many LGBTI people have had a life experience of fear of rejection and persecution, coupled with the impact of potential or actual discrimination.

The AASW supports inclusive practices that incorporate the unique needs of people who identify as LGTBIQ, however, continues to identify the lack of resources and infrastructure to operationalise the delivery of person-centred care in aged care settings.

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[10] Helping Hand. 2019. *Real Care the Second Time Around.* Available at: helpinghand.org.au/wp-content/uploads/2019/01/Position-Statement-Forgotten-Australians.pdf .

[11] Australian Government. 2019. *LGBTI Ageing and Aged Care Resources*. Available at: agedcare.health.gov.au/support-services/my-aged-care/lgbti-ageing-and-aged-care-resources

Delivering inclusive and holistic care

The AASW recognises the complexity involved in delivering inclusive and holistic care to the diverse needs of older people in Queensland, and Australia more broadly. We argue that models of care must more fully consider and address the psychosocial care needs of older people if we are to meet both the *Human Rights Act 2019* that Queensland has enshrined in legislation, and our obligations under the various United Nations Conventions we are signatories to.

Social workers play a significant role in providing this dimension of support and care, yet social work is not a core aspect of aged care service delivery. A focus on consumer-driven care provides many benefits, but also many barriers for individuals who are vulnerable or marginalised. Social workers can support and advocate for this group. Without this continued focus, the likelihood of poorer quality of care and quality of life increases.

Question 2.
Are the current waiting times for both residential and home care places adequately meeting the needs of older Queenslanders?

Demand outweighs supply for community aged care. Older people assessed as having medium-care needs often have to wait for a long time, over a year, on the waiting list for Home Care Packages. As an interim measure they often receive home care support, which may not sufficiently meet people's needs.

Currently, the baseline level of assessed client's needs is considered fixed. There is an assumption that clients' levels of needs can only increase but not decrease, suggesting an assumption that older people's health does not improve. In practice, this means people may not access their full care packages if their health improves, but they can't be reassessed for lower package. For example, an older person may receive a Level 4 package (highest level of need) after a hospital discharge. If the person recovers, the level of need would not be reassessed and would remain the same. This contributes to unspent package funds within the system, which cannot easily be repurposed to address the needs of others on the waiting list.

There is also a need for transparency and accountability of fees being charged by aged care service providers and we welcome the recent announcement by the Commonwealth that publication of service fees on My Aged Care will now be compulsory. This will contribute to ensuring appropriate use of government funding in direct service provision and administration costs are proportionate to the direct services provided.

Question 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?

Social workers frequently work with individuals and families as they navigate the aged care system. While we cannot comment on behalf of the whole community, our members report that the aged care system is extremely confusing to navigate and our clients often experience distress because of system failures and issues around care.

Use of restraint

For people living with dementia, issues around restraint are ongoing, whether it be medical or physical restraints to manage behaviours viewed as undesirable. The use of restraint can be impacted by staffing levels, lack of appropriate training, use of agency staff unfamiliar with the client's needs and inappropriate living environments. Our members have reported cases where older people do not have any meaningful engagement from the staff supporting them, and at times even their basic daily care needs are not being met. Dementia-specific units can at times also be clinical environments devoid of home-like comforts.

Dignity of risk and decision-making capacity

Residents entering residential care are strongly encouraged to have enduring documents completed, particularly an Enduring Powers of Attorney for financial matters. Those nominated are often the representative which residential aged care facilities choose to speak with prior to accepting clients into their facility. While Advanced Care Planning discussions are encouraged and all members of society should know about know their rights, the practice of requiring people with decision-making capacity to nominate a person to look after their finances and health personal matters if they wish to enter care is ethically concerning.

Dignity of risk is another issue in relation to working with clients and residents with capacity concerns. Staff are not always trained and can lack awareness in understanding how to work appropriately with someone with questionable capacity. When this happens, they will often communicate with a person's nominated Attorney and bypass the older person who is still able to understand and communicate their decisions. Further work is required to develop standards for working with the older person at all times, as well as guidelines on how to do this effectively when a person has questionable capacity.

Question 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?

As is well known, Australia's population is growing older and as baby boomers move into old age, this trend is set to gather greater momentum over and beyond the next three decades.[12] The age composition of Australia's population is projected to change considerably as a result of population ageing. By 2051, there will be a much greater proportion of people aged 65 years and over than in 2004, and a lower proportion of people aged under 15 years. In 2004, people aged 65 years and over made up 13% of Australia's population. This proportion is projected to increase to between 26% and 28% in 2051 (respectively) and to between 27% and 31% in 2101.[13] This demographic trend is not new. It has been building for over a century and is likely to result in changes that will flow on to all aspects of social and economic life as both the number and proportion of older people in the community increase.

[12] Australian Institute of Health and Welfare, Older Australia at a glance, 4th edn, cat. no. AGE 52, AIHW, Canberra, 2007.
[13] Australian Bureau of Statistics, Population projects, Australia, 2004 to 2101, cat. no. 3222.0, ABS, Canberra, 2006.

While government agencies have tended to view this demographic shift with concern as a growing financial burden on the public purse, in reality, most older people live healthy and active lives, with aged care becoming a factor for only a proportion of the aged population, usually in the last two years of life. The potential increase in the contribution that older people can make in the future may be missed if they are viewed primarily as drivers of increased demand and cost to government. Already, many older people invest substantial time and effort in community volunteer activities. Similarly, a proportion of older people, who are also grandparents, often provide practical and financial support to their children and grandchildren.[14]

Meeting growing and changing demand in aged care would be facilitated by a paradigm shift in aged care policy and programs. Rather than viewing ageing through the prism of potential cost, older people should be seen as citizens with equal human and citizenship rights and the capacity to contribute to community and country. Such a shift would result in the Government asking:

> *How can we ensure the full range of rights of older people are protected and how can we increase their participation in all areas of community life?*

Both the Commonwealth and State governments have a range of initiatives to support older people and are increasing their planning and spending in this area as our population ages. Having recently passed the *Human Rights Act 2019*, there is an opportunity for the Queensland Government to re-examine its role in ensuring the rights of older people are protected. This includes improving how State Government services, such as health, interact with the aged care system.

Question 8.
Is the mix of staff appropriate for different settings within the aged care sector?

The report from the Aged Care Workforce Strategy Taskforce, *A Matter of Care: Australia's aged care workforce strategy*, makes a number of recommendations relating to staffing mix and workforce. We note that the Commonwealth Government has committed to implementing the recommendations of this report. The findings of the Royal Commission into Aged Care Quality and Safety are also likely to influence future action on staffing mix and capability in the aged care workforce. We believe the State Government should be guided by the findings of Aged Care Workforce Strategy Taskforce and the Royal Commission when considering any state-based responses to support the aged care workforce.

The AASW notes a significant gap in addressing the psychosocial needs of older people's transitioning to aged care. We believe social workers have a unique contribution to make to the mix of staff required to meet the needs of older people in Queensland. Social workers have the following skills, which are highly valuable in the aged care context:

- **Assessments.** There is sufficient research and literature highlighting the importance of addressing the psychosocial needs of aged care residents as they have a direct

[14] Royal Children's Hospital: Centre for Community Child Health Parkville, Victoria 2010, 'The changing role of grandparents'

impact on all other aspects of their physical and emotional wellbeing,[15] including daily care needs. Social workers' experience in undertaking comprehensive assessments improves quality of life for people in aged care. This has positive flow-on effects for families and reduces work pressures on aged care staff.

- **Counselling and therapy.** Transitioning to aged care is time of loss and grief for older people and their families. They often experience a range of emotions and complex situations arising from family dynamics. Social workers are appropriately skilled and experienced in working with individuals and families who are grieving and adjusting to illnesses, disability and the associated loss of independence, family and identity. Through individual, family and group work, social workers can play a crucial role in supporting people's adjustment, coping and psychosocial wellbeing.
- **Mediation and conflict resolution.** Family work is an important part of aged care as complex dynamics and history can compound already difficult situations. Social workers focus on exploring and assessing the full complexities of an older person's circumstances, which allows them to intervene and facilitate conflict resolution, particularly around decision-making.
- **Case management and service coordination.** Social workers have demonstrated experience assisting with advanced care planning, Enduring Power of Attorney and decision-making matters, managing guardianship orders, and working with people who no longer have capacity to manage their own affairs independently. They also have expertise in navigating complex health and social service systems to achieve the best outcomes for older people. Their focus on human rights, combined with their unique psychosocial perspective, offers a valuable contribution to the aged care industry as it transitions to a greater consumer focus.
- **Specialist expertise.** Social workers can provide expert support in the area of elder abuse, from assessment through to intervention. Developing effective responses to individuals experiencing abuse is difficult, especially where cognitive impairment is a compounding factor, or where older people may be reluctant to identify the harm they are experiencing as 'abuse'. Currently, there is a lack of services appropriately funded and equipped to intervene in complex situations where abuse is occurring, and social workers are well positioned to provide this service.
- **Hospital discharge planning.** Social workers engage with individuals and families to navigate the aged care system and prevent hospital readmissions through rigorous discharge planning and addressing of critical psychosocial determinants.
- **Practical assistance.** Transitioning to aged care is a stressful time, and social workers provide valuable practical support to people and families, including assistance with housing and accessing Centrelink.
- **Advocacy work.** The aged care system is complicated and older people frequently experience inequality within the broader health system and community[16]. Social workers are advocates who strive to empower and assist older people to self-advocate. Where people cannot advocate for themselves, social workers can act on their behalf and represent their needs and best interests. They also advocate for change within organisations and across systems to ensure people are treated fairly.

[15] AIHW 2013. Depression in residential aged care 2008-2012. Aged care statistics series no. 39. Cat. no. AGE 73. Canberra: AIHW

[16] Australian Association of Social Workers. 2013. *Ageing in Australia*.

In a complex system like aged care, this approach is an important safeguard for the rights of older people.

- **Education and resources.** The aged care workforce needs access to targeted training in order to identify and address the range of psychosocial experiences of older people and their families, such as grief and loss. Social workers focus on providing specialist education and resources to their peers, as well as the older people and families they work with, is an important value-add to the aged care system.
- **Policy and research.** By engaging regularly in policy development and research, social workers ensure their practice is evidence-based and is shared with their peers to continuously improve outcomes for older people.

By embedding social work systematically into the aged care sector, there is great potential to improve it's capacity to achieve equitable access and outcomes for older Australians, and fill market gaps in key areas. This will result in:

- Improved access to the aged care system;
- Support for Primary Health Networks to educate individuals about Advance Care Planning and facilitate early discussion and decision-making;
- Reduced length-of-stay in hospitals through better discharge planning;
- Reduction in inappropriate admissions to hospitals through early intervention; and
- Reduction in premature admissions into aged care facilities.

Question 9.
Do aged care staff receive training that is appropriate and adequate to prepare them for the work?

Complex Care Needs

Due to medical advancements and complexity of psychosocial care needs, many people in residential aged care require specialist assistance. For example, there is an increasing need for expertise and skills in tracheostomies, ventilator dependence, and behaviour management. There are very limited facilities that have the trained staff required to care for these cohorts.

Case vignette:

"We supported a client who waited in hospital for nearly two years for an appropriate aged care facility that was able to meet his complex care needs. The client was under 65, had impaired capacity, early onset dementia with aggressive behaviours that resulted from trauma to the head.

Very few residential aged care services had the staff training or facilities to manage this client's care needs. Cases similar in complexity are increasing as people live longer with advancements in medical care, but still require specialist care as a result of the medical interventions taken to prolong life (e.g tracheostomy care)."

Palliative care

Residential aged care is increasingly providing palliative and end-of-life care for older people. As a result, there is a growing need for staff education and skills to appropriately manage people's psychosocial care in this context. However, we acknowledge that capacity

to provide this care and these skills are impacted by the current aged care funding model, which only provides funding for palliative care in the final week or days of a person's life.[17]

Question 11.
Are suitable health care services being provided within residential aged care settings and/or aged care providers?

Residential aged care facilities will relocate patients to hospital when they cannot manage complex care needs, including difficult behaviours or end-of-life care. This can be very disruptive for people and, depending on the circumstances, can impact negatively on the relationships between individuals, families, hospitals and aged care providers. Ideally, a person should be supported to receive care and die in a location of their choice, with familiar people and surroundings. Structural issues impacting the interface between aged care and hospitals for those people at end-of-life require further examination.

Question 13.
How can the delivery of aged care services in Queensland be improved?

There are a number of opportunities to improve older Queenslanders' experiences at the health and aged care interface to ensure they are treated with dignity and respect, and free from discrimination and abuse. Social workers have a significant role to play in this space due to their expertise in psychosocial care, family work, and navigating complex systems while maintaining strong focus on older peoples holistic needs and human rights. When supporting older people to access the aged care system, social workers have identified the following opportunities to improve people's experiences in aged care:

- Developing universal standards or practice guidelines to facilitate communication between residents, aged care providers and their decision makers or families;
- Transferring psychosocial care as a part of discharge planning from hospitals to residential aged care facilities;
- Identifying and working with people around their experiences of grief and loss as they transition into residential aged care;
- Improving consistency of advanced care planning in residential aged care; and
- Providing support for families to understand and work through the financial implications and impact of a loved one transitioning to residential aged care.

Question 16.
What are the key priorities for the future?

The AASW makes the following recommendations to improve older Queenslander's access to equitable and readily available competent, comprehensive and affordable health and social support services that meet their individual needs. We see these as key priorities for meeting older people's needs into the future.

We recommend the Queensland Government investigates:

- Committing to a paradigm shift in health and aged care policy and programs, underpinned by the *Human Rights Act 2019*. Such a shift requires changing the view

[17] Productivity Commission 2017, Introducing Competition and Informed User Choice into Human Services: Reforms to Human Services, Report No. 85, Canberra.

that older Australians are a cost burden and seeing them as citizens who have the same human and citizenship rights as others in the community;
- Improving how State Government services, such as health, interact with the aged care system;
- Expanding current social work services at the interface between health and aged care to provide psychosocial support and advocacy for older people to access the care they need; and
- Expanding access to free translator services to people in the community who access aged care services.

Palliative and end-of-life care

Question 18.
Are palliative care and end-of-life care services meeting the current needs of Queenslanders? why not?

Palliative and end-of-life care services are not meeting the current needs of all Queenslanders. Palliative care teams provide expert, holistic care but this service should be available to all people living with an active, progressive and advanced disease, regardless of diagnosis or geographical location. Palliative care affirms life while recognising that dying is an inevitable part of life.[18] Death and grief associated with death is a normal process and one we must address in an open and transparent way to minimise impact and help families and friend adjust in a healthy and functional way.

People's experiences in hospital

50% of adults in Australia die in hospital.[19] Social workers in hospital settings regularly observe the following when working with people and families during this time:

- Specialist palliative care services are excellent. There are simply not enough, particularly in regional and remote areas. It is therefore not always possible to transfer to people to specialist Palliative Care Units and they remain in other hospital wards;
- When unable to access specialist palliative care, people are not always able to experience dying with dignity. While health professionals do their best in hospitals, shared wards, changing staff, sterile environments and limitations to family access can impact their experience;
- Though every consideration is made to accommodate a dying person's cultural, spiritual and religious needs, they may not be met due to structural and administrative restrictions within a hospital setting;
- There is limited access to community palliative care services. This creates greater demand for hospital services even though they cannot always provide best practice for those who are dying; and

[18] National Palliative Care Standards – 5th Edition
[19] Palliative Care Australia 2018, Background Report to the Palliative Care Service Development Guidelines, prepared by Aspex Consulting, Melbourne.

- The community has differing expectations around what happens at death. Historically, our culture has moved away from integrating the dying process into our community and has pushed it behind closed doors and into our hospital settings. While this is changing with increasing community preferences to die at home[20], people can change their minds and there can be disagreements within families around care location at end-of-life.

People's experiences in residential aged care

The number of people dying in residential care is expected to increase into the future, partly in response to a societal shift back to community-based end-of-life care. This trend will require advanced care planning to happen early, with aged care staff being skilled in having these conversations and providing palliative care and support.

There is a need to provide more holistic, person-centred palliative care focused on individuals' needs and wishes in residential aged care facilities. Taking this approach incorporates attending to the person's emotional, spiritual and psychosocial needs as an integral part of palliative care services. This can be difficult to achieve in residential aged care facilities where a medical model that does not take a holistic focus remains dominant.

While health services have expertise in managing palliation, the interface between residential aged care and health is poor and lack of resources for community-based specialist palliative care is an ongoing issue. This impacts people's access to care. For example, one Hospital and Health Service region in south-east Queensland has palliative care nurses to support residential aged care facilities, but no dedicated medical or allied health members. Regional and remote services are more reliant on GPs and visiting medical specialists for palliative support. This limits the ability of residential aged care facilities to access specialist palliative support from the health sector. Pain relief can also be an issue after hours and on weekends. If unable to access an after-hours doctor, people often have to be sent to hospital to access morphine to manage pain.

People's experiences in the community

If people are living in their home it can be difficult to access appropriate equipment, such as a hospital-style beds or hoists. On Level 1 and 2 Home Care Packages, people can access the Medical Aids Subsidy Scheme, however, this may not fully cater to an individual's needs.

When people are receiving higher level care packages they must use their package funds to access equipment. This can be costly, and renting or buying second hand may not be an option for some individuals or their families. Therefore, the person must decide whether to purchase equipment they need to remain in their home and relinquish certain care requirements, or face entry into residential aged care.

There is also a need for more short-term in-home overnight carer respite. Currently, people can only access longer-term residential respite, limited cottage respite or emergency respite care which do not necessarily meet the needs of all people and their carers.

Question 21.
How can the delivery of palliative care and end-of-life care services in

[20] Swerissen, H. and S. Duckett 2014. Dying well, Grattan Institute.

Queensland be improved?

The AASW is currently developing practice standards for palliative and end-of-life care practice and would welcome the opportunity to work with Government to improve care for Queenslanders. The AASW has identified a number of changes needed to improve delivery of palliative and end-of-life care, including:

- Greater community awareness and education about death and dying and advance care planning at every age on a macro level. A good international example of this can be found in the marketing strategy and "Speak Up" campaign in Canada;[21]
- Queensland standards for palliative care services both in health and community settings, in conjunction with new national guidelines;
- Targeted approaches to palliative and end-of-life care for vulnerable populations. Including people experiencing homelessness, culturally and linguistically diverse communities and people identifying as lesbian, gay, bisexual, transgender, intersex and queer;
- Improved access to specialist palliative care social workers or social workers with palliative care knowledge to address people's psychosocial needs;
- More residential aged care facilities with dedicated palliative care services or access to community-based specialist palliative care; and
- Greater focus on dignity and life story work for people at end-of-life.

Question 22.
What are the particular challenges of delivering palliative and end of life care in regional, rural and remote Queensland?

Access to health care and specialist services is an ongoing challenge in regional, rural and remote Queensland. There is currently limited access to specialist palliative care services and unique services are required to address the needs of those that live in regional, rural and remote Queensland compared with their major city counterparts.

[21] Health Canada. Implementation Guide to Advance Care Planning in Canada: A Case Study of two Health Authorities. March, 2008. Available at: hc-sc.gc.ca/hcssss/alt_formats/pdf/pubs/palliat/2008-acp-guide-pps/acp-guide-pps-eng.pdf

Question 23.
What are the particular challenges of delivering palliative and end of life care for Aboriginal and Torres Strait Islander communities?

The main challenge is access to end-of-life-care and palliative care in remote communities can often mean leaving your community. For example, Elders and people with chronic conditions in 15 communities in Torres requiring emergency care involves 1.45 hour flight, plus the trip to Thursday Island/Horn Island which can take up to 2 or more hours via boat.

Remote community Multi-Purpose Health Services, Hospitals and aged care hostels are not established or funded to provide hospice care to palliative patients. Senior medical staff decide on most appropriate health clinical care which often result in relocation to base hospitals to provide end of life and palliative care. For the individual this can translate as being taken away from country and surrounded by strangers in a cold lonely hospital ward who are providing treatment which will not cure you, you may not see anyone indigenous during the final weeks and days leading up to your death.

Dementia is also a terminal diagnosis and there is a lot of misunderstanding of dementia in the Aboriginal and Torres Strait Island communities. The challenge of the age care sector is to co-design a culturally responsive and meaningful model of care, particularly in remote communities.

There are also a diverse range of customary practices around death and dying for Aboriginal and Torres Strait Islander peoples and understanding and respecting these practices must be at the heart of any palliative and end-of-life care services for communities. Targeted approaches to providing culturally capable end-of-life care services for Aboriginal and Torres Strait Islander peoples must be a priority and should be under-pinned by the *Queensland Health Aboriginal and Torres Strait Islander Cultural Capability Framework 2010–2033*.

Voluntary assisted dying

Question 25.
Should voluntary assisted dying (VAD) be allowed in Queensland? Why/why not?

The AASW does not have a position on the legalisation of voluntary assisted dying at this time. This is a significant ethical issue for practitioners and is a subject for considered debate within the profession. However, we do recognise that voluntary assisted dying is supported by between 66 and 85 percent of the Australian community[22].

Given the significant role social workers play supporting people and families in hospitals and in palliative care, we would welcome the opportunity be involved in discussions to inform safeguards, policy and practice should voluntary assisted dying become legal in Queensland.

[22] Cartwright, C., & Douglas, C. (2017). Factcheck q&a: Do 80% of australians and up to 70% of catholics and anglicans support euthanasia laws? Retrieved from https://theconversation.com/factcheck-qanda-do-80-of-australians-and-up-to-70-of-catholics-and-anglicans-support-euthanasia-laws-76079

Question 28.
If there is to be a VAD scheme, what features should it have?

Any voluntary assisted dying scheme in Queensland should be well considered and draw from the experiences of Victoria as it implements its' scheme from June 2019. In doing this, particular attention should be paid to:

- Decision making and capacity assessment processes;
- The impacts of eligibility criteria on people's access to voluntary assisted dying;
- Demographics of people accessing voluntary assisted dying, with a focus on vulnerable groups;
- Impacts of having access to voluntary assisted dying on an individual's wellbeing and quality of life;
- Impacts of a person choosing voluntary assisted dying on family members;
- Impacts of participating in voluntary assisted dying on medical practitioners and supporting nursing and allied health staff;
- Effectiveness of conscientious objection provisions;
- How reviews are conducted by the second medical practitioner; and
- Operation of the Review Board.

Question 33.
What features should be included in a process to allow a person to legally access VAD?

An important feature to consider for any voluntary assisted dying scheme is an independent, multidisciplinary assessment team. This should include medical practitioners, nurses, psychologists and social workers. Members of the review team should bring skills and experience to create collective expertise in:

- Assessing terminal illnesses;
- Palliative and end-of-life care options;
- Decision-making and capacity assessment;
- Mental health assessment;
- Advanced care planning and Advanced Health Directives;
- Complex family work, including situations of family violence and elder abuse; and
- Counselling, including grief, loss and family therapy

This team would need strong guidelines for group-decision making, including what happens in cases where there is disagreement around a person's eligibility for voluntary assisted dying. There should also be a mechanism for oversight and accountability of this team. Assessment and reviews by this team would act as an important safeguard in identifying and protecting vulnerable people from coercion.

General Recommendations

Recommendation

The Queensland Government investigates:

- Committing to a paradigm shift in health and aged care policy and programs, underpinned by the *Human Rights Act 2019*. Such a shift requires changing the view that older Australians are a cost burden and seeing them as citizens who have the same human and citizenship rights as everyone else in the community;
- Improving how State Government services, such as health, interact with the aged care system;
- Expanding current social work services at the interface between health and aged care to provide psychosocial support and advocacy for older people to access the care they need; and
- Expanding access to free translator services to people in the community who access aged care services.

Conclusion

The AASW welcomes the opportunity to provide a response to the Parliament's inquiry into Aged Care, End-of-life and Palliative Care, and Voluntary Assisted Dying. Social workers have a long and proud tradition of working together with older Australians towards active ageing. This includes a strong commitment to promoting self-determination, dignity and respect. We would welcome future opportunities to provide further evidence to the Committee and work with Government as it implements any changes resulting from this Inquiry.

[redacted]

From: Esa Hukkinen [redacted]
Sent: Monday, 15 April 2019 3:00 PM
To: Care Inquiry
Subject: Question #25: Should voluntary assisted dying (VAD) be allowed in Queensland? Why/why not?

Christlife

PO Box 18311
Clifford Gardens, Toowoomba 4350
[redacted]

We defintiely shoiuld not be introducing voluntary assisted suicide. There are a plethora of reasons why this introducing this law is the wrong way to go.
Given the economic cliimate at present and the need to ut spending and assistance to the needy and the disabled, we need to seriously consider if this is the right time to introduce such a law.
Added to this, it is easy to envisage the possibility that in the future, all those with serious disabitlies or illnesss will be pressured into taking the assisted suicide option, even if they do not wish to end their life.
Also, we have to consider if we want to pressure doctors, who swear to uphold and preserve life, to performing operations and procedures that are against their ethical code and their sworn creed.
There is also the spiritual aspect. Volunatry assisted suicide can potentially rob a person of the opportunity to find spiritual wholeness and to be put in a position, an eternal position, that is eternally dangerous.
Finally, if voluntary euthanasia is legalised, we will see the value of life decreasing even further. Such a decrease in the value and sanctifty of life can only be detrimental to society in the longer term.

Many blessings for considering this emaiil.

Pastor Esa Hukkinen
Senior Minister

SUBMISSION
INQUIRY INTO AGED CARE, END-OF-LIFE AND PALLIATIVE CARE AND VOLUNTARY ASSISTED DYING

"Strong, inclusive and resilient mental health communities."

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Queensland Alliance for Mental Health Ltd

Queensland Alliance FOR MENTAL HEALTH

To the Committee,

Submission: Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying

Queensland Alliance for Mental Health (QAMH) is pleased to provide this submission to the Queensland Parliamentary Health, Communities, Disability Services and Domestics and Family Violence Committee to highlight our views on aged care, end-of-life and palliative care and voluntary assisted dying.

We would also like to draw the Committee's attention to Victoria's end of life and palliative care framework. QAMH hopes that Queensland will follow in its footsteps and establish a framework that is person-centred which provides high quality care, and dignified end-of-life choices. We recognise the significant amount of work involved in realising this, including the establishment of safeguards, criterion and procedures.

The Australian population is ageing, with older Australians a growing proportion of the total population. In 2017, 15% of Australians (3.8 million) were aged 65 and over; this proportion is projected to grow steadily over the coming decades.[1]

As such, it is the inevitable that we would have to address end-of-life care for the people of Australia. QAMH would like to address the following areas in relation to the mental health of our ageing population - *social inclusion*, and *intentional self-harm*.

Social Inclusion: integral to sustaining quality of life

This is one of the things QAMH advocates for in community mental health, to ensure that those who have a psychosocial disability can live a life that is fulfilling and not limited by their ability. Our members who provide support services are dedicated to help this cohort of people rebuild their lives, live independently in the community, and stay present and connected through social inclusion activities. We feel that this too, applies to the older adult population.

The more a person "feels" satisfied with life and enjoys a sense of well-being, the more likely he/ she will be able participate in social activities, develop friendships, explore interests, and enhance his/ her quality of life and life expectancy.[2]

Social isolation and loneliness amongst older Australians is a prevalent issue. When one is not well enough mentally and physically and is unable to participate in activities that allow them to bond and interact with society in a meaningful way, it diminishes one's sense of purpose and mental wellness. Human connections, mental health, physiological health, and emotional well-bring are all inextricably linked.[3] As members of society, we thrive on social inclusion.

Research studies have found a direct link between loneliness and health conditions such as Alzheimer's disease, obesity, increased vascular resistance, elevated blood pressure, increased hypothalamic pituitary adrenocortical activity, sleep disorders, diminished immunity, reduction in independent living, alcoholism, depression, suicidal ideation and behaviour, and mortality in older adults.[4]

QAMH would like to take the opportunity to highlight one of our member organisations, Footprints, who provide aged care services to their clients alongside other means such as transport and social support, and centre-based activities to help them remain connected and socially included. Transport is cited as one of the essential things for connectedness of seniors to their broader community and services.[5]

We would like to stress on the importance of social inclusion, and its intrinsic link to mental wellness. Given the points above, it would be difficult for an older adult to experience social inclusion, and to be able to sustain a quality of life that he or she had been accustomed to. As one's health declines, it will take a toll on social inclusion, which is apparent in a palliative care or end-of-life setting. Therefore, it is important to provide the autonomy, choice and control over the remainder of one's life.

Intentional Self-Harm: suicide rates amongst older adults

In 2017, in Australia, 3,128 people died from intentional self-harm rising 9.1% from 2,866 in 2016. Intentional self-harm was ranked the 13th leading cause of death in 2017, moving up from 15th position in 2016.[6]

The highest age-specific suicide rate was highest among males aged 85 years and older, recording 32.8 deaths per 100,000 persons.[7]

People aged over 65 years are more likely to have a chronic health condition present at death than younger cohorts. Notably, cancer was present in approximately 25.0% of suicides of persons aged over 85 years.[8] We can only make the assumption that this grim outcome is a result of limited choices for end-of-life and palliative care, and VAD.

Mental health and quality of life in older people can be impacted by physical illness, and unfortunately, mental health condition is prevalent in those with a chronic health condition. This is demonstrated in the Australian Institute of Health and Welfares 2016 health report, where the mental health conditions is reported as the main comorbidity among older people (over the age of 65) with a chronic obstructive pulmonary disease (COPD).[9]

Victoria's Council on the Ageing (COTA) submission for the development of the state's new end-of-life care framework expressed that the context of how people are dying has changed. More than ever, there is a need to consider the extended time period that older people, and those diagnosed with a life limiting illness have to contemplate dying and death.[10]

From our perspective as a mental health peak body, everyone is entitled to a life that is fulfilling and dignified. There should be equity of access to both residential and community aged care services, as well as community, hospice and acute end of life and palliation pathways. Perhaps this will then reduce the rate of self-harm amongst older adults.

Given the points above, circumstances such as a life limiting illness should enable a person to be eligible to access VAD. However, this will involve complex decision-making process, which needs to be jointly navigated by primary healthcare providers, alongside palliative care services. Care providers will require appropriate training on patient rights and autonomy, the ethics of life prolonging treatments and pain management, and empathetic communication.

Queensland Alliance FOR MENTAL HEALTH

Concluding remarks

It is vital to ensure that community-based end-of-life care and services continue to be available to older Australians. As an advocate for the community mental health sector, QAMH believes in equity, choice and a person-centred approach.

Our work supports Queensland Mental Health Commission's ***Shifting Minds: Queensland Mental Health, Alcohol and Other Drugs Strategic Plan (2018 – 2023)***, and its focus on not just connecting people to services but also ensuring the best possible quality of life for all Queenslanders through good mental health and wellbeing, and social and economic inclusion and participation. We strongly believe that an increased focus on the support for older adults with mental health conditions will yield positive results.

QAMH is the peak body for the community mental health sector in Queensland. We represent more than 130 organisations and stakeholders involved in the delivery of community mental health services across the state. At a federal level, we collaborate with Community Mental Health Australia, and we work alongside our members to build capacity, and to advocate on their behalf on issues which impact their operations and people experiencing mental health issues in our community.

On behalf of the Queensland community mental health sector, and particularly older adults with lived experience, we thank you for the opportunity to respond to this inquiry. QAMH welcomes the opportunity to discuss this submission with the Committee at any time.

Thank you.

Yours sincerely,
Jacklyn Whybrow
Acting Chief Executive Officer
Phone: 07 3252 9411 | Email: [redacted]

[1] Australian Institute of Health and Welfare. (2018). Older Australians at a glance. Accessed April 11 2019 from https://www.aihw.gov.au/reports/older-people/older-australia-at-a-glance/contents/demographics-of-older-australians/australia-s-changing-age-and-gender-profile

[2] Knight, T. and Mellor, D. (2007). Social inclusion of older adults in care: Is it just a question of providing activities?, International Journal of Qualitative Studies on Health and Well-Being, 2:2, 76-85. DOI 10.1080/17482620701320802. Retrieved from https://doi.org/10.1080/17482620701320802

[3] Cacioppo, J.T. (2008). Loneliness, Human Nature and the Need for Social Connectedness, pg. 131

[4] Franklin, A. and Tanter, B. (2011). AHURI Essay – Housing, loneliness and health. Australian Institute of Housing and Urban Research Institute Final Report No. 164. Pg. 6

[5] Queensland: an age-friendly community. Strategic direction statement (2016). Accessed April 11 2019 from https://www.communities.qld.gov.au/resources/dcdss/seniors/age-friendly-community/qld-an-age-friendly-community.pdf

[6] Australian Bureau of Statistics (2017). Causes of Death, 2017. Accessed April 11 2019 from https://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/3303.0~2017~Main%20Features~Intentional%20self-harm,%20key%20characteristics~3

[7] Ibid
[8] Ibid
[9] Australian Institute of Health and Welfare. (2016). Australia's Health 2016. Accessed April 11 2019 from https://www.aihw.gov.au/getmedia/666de2ad-1c92-4db3-9c01-1368ba3c8c98/ah16-3-3-chronic-disease-comorbidities.pdf.aspx
[10] COTA Victoria. (2015). Submission - Greater say for Victorians: Framework for end of life care in Victoria. Accessed April 11 2019 from http://cotavic.org.au/wp-content/uploads/2011/01/VictorianEndofLifeCareFrameworkfnl_COTAVic_December2015.pdf