From: [redacted]
To: Care Inquiry
Subject: Aged Care
Date: Sunday, 14 April 2019 10:41:20 PM

I am not in favour of Euthanasia. There are places where care can be given to people who are terminally ill. They can be given the necessary pain control drugs to make them comfortable.

The future of Aged Care is dependent on the care given to the residents of the Aged Care facilities.
The new facilities I have visited are built to look like a hotel,with lobbies and lovely furnishings, these are very expensive and it costs a lot of money to be admitted to them.
If the person entering such a place is mobile and able to shower and toilet themselves they adapt very well to life in such a facility.
On the other hand a person who has been affected by a stroke and is unable to shower and toilet themselves it is not a good experience.

They are dependent on staff to answer their calls for attention. They are alone In their room for a lot of their time, unless they have family members living close by who are able to visit regularly.
There needs to be more staff available and more trained nurses employed in order to help improve the quality of life for these people.
Thanking you for the opportunity to express my thoughts on Aged Care.
I am,
Yours faithfully,
(Mrs.) Nina Moore. from my iPad

From: Therese Madam
To: Care Inquiry
Subject: Euthanasia submission
Date: Monday, 15 April 2019 3:20:14 PM

Dear Sir/Madame.

I wish to ask you to seriously consider helping the elderly and mentally challenged to find their place in their family and society, and to help them realize that life IS worth living, even when there are difficulties,disappointments and pain. If people know that there is help available, then they are less likely to consider euthanasia.

Yours sincerely,

Therese Madam

The Chairperson
Health Committee
Parliament House Queensland 4000

Re Inquiry into Aged Care, End of Life Care, Palliative Care (PC) and Voluntary Assisted Dying (VAD)

Dear Committee Members

I have read your terms of reference and examined your 38 issues for consideration.

I am a retired medical practitioner. In my earlier career, I saw the issues from a clinician's perspective in General Practice (and in hospital care). In the latter part of my career, I became a Public Health Physician and have considered these questions from the population health perspective.

I do **not** support the proposal to legislate for Voluntary Assisted Dying (VAD) in Queensland.
I **do support** any activities to expand Palliative Care Services to meet the needs of people seeking this assistance.

I worked in Queensland Health for many years as a Medical Epidemiologist. I appreciate the challenges of a decentralised state and have some appreciation of the way health care delivery has evolved over time in this state.

In my clinical and demographic roles, I considered the Cause of Death statistics from various points of view. I will focus on elderly people and those with illnesses likely to lead to imminent death in my initial remarks. Your own paper covers the problem of the burden of chronic diseases affecting all modern western populations. I am also aware of the special needs of indigenous groups in this particular area.

I would have thought we should also make special reference to the Culturally and Linguistically Diverse nature of our urban and rural communities given how multicultural our modern Australia has become. There will be many sensitivities to address given differing customs surrounding death and dying.

I come from a religious perspective viz a traditional Christian one. All life is sacred and humans be they health professionals or otherwise are charged to "First Do No Harm". I would rather see the law support that view rather than the law lead society in a different direction.

I accept that across the world, in similar populations to ours, forms of euthanasia, physician assisted dying and other practices have been written into legal codes with various inclusion and exclusion criteria. Your own paper acknowledges the instability of the categories for comparison purposes. I would argue that that is a reason for not rushing into this realm even if Victoria has a legislated model waiting to commence soon. Why can't Queensland wait till after the Federal Government's Royal Commission into Aged Care Services is completed and there is more time to assess how the Victorian experience is working ?

I will cite some experts I have been following and respected over the time I have been following these debates.

Prof Margaret Somerville is a lawyer and ethicist in the health training and delivery contexts who examined these issues over many years in Ontario, Canada. She is Australian and has returned to Australia in recent years. I believe her legal and ethical concerns are valid. We may be altering the very intention of our institutions and weakening the ethical standing of the practitioners asked to assist with these morally ambiguous choices.

Your paper speaks of the risks to the vulnerable and requests that safeguards be described. That is paramount if this legislation were to proceed. Prof Somerville speaks well to how our institutions are changed by implementing a third process of support for artificially shortening life alongside the traditional roles of healing and palliating those who are dying. This third way is a version of suicide despite the euphemistic terms employed to hide that fact.

When I worked in Qld Health, the problem of suicide prevention was a very substantive one in all age groups, including the aged subgroups. Governments rightly put much resource to addressing this tragic problem. The advocates for VAD do not adequately address the change to our culture that such laws introduce even if you are secular in outlook.

I have not yet read the Qld Health Review of Palliative Care (PC) Service delivery in Qld.
I imagine there is always a need to go on improving in that area.
I am a Fellow in the Faculty of Public Health Medicine of the Royal Australian College of Physicians (RACP), although presently retired. I am aware of all the work that was done by many palliative care physicians, nurses, allied health groups and patient advocacy groups in trying to address the standards for good palliative care in this country. The years of work at a national level by Prof Ian Maddox led to better training at all levels in the health care and aged care sectors. This is the better way to champion quality of care in this realm.

The domains between hospital care, residential aged care and community care are very complex when it comes to the needs of patients who become terminally ill.
So it is good your committee is examining how best to integrate these services since the funding and models are split across both government sectors (commonwealth and state) but also the “not for profit” and “for profit” private sectors.

I have great admiration for some examples of services I have had some connection with. For example, the Wesley Palliative Care Service and St Vincent’s services (Kangaroo Pt) as inpatient examples or the Karuna and Canossa services as community based services.

Anecdotally, I have listened to various health professionals navigate this network of services on behalf of their patients or clients. Sometimes it works well and other times less well. I hear those examples on the media and I have watched the Australian activists eg the media based ones and the doctors and their organisations promoting such euthanasia services. They also employ many anecdotal arguments to lobby state governments as to the need for this step at this time in our history.

I acknowledge it is difficult and expensive to bring every doctor and nurse and allied health practitioner contributing to these care decisions up to the optimum level of care. But I believe the Palliative Care model best addresses these ideals. We are a wealthy and compassionate country and we should aspire for such standards.

I would add that it is easy in these anecdotal domains to imply that cases of intractable pain and/or suffering are everywhere. The implication is that it is a widespread problem that we must have other avenues beyond "usual care" to provide autonomous individuals their right to choose.

Firstly, your terms of reference did not address the many ways people die in a modern society. A large proportion are still sudden deaths. Many other people with slower dying processes are not suffering universally badly as the media and Hollywood would like to portray. If the dying person has a loving support system(eg families who care for them) and good continuity of health care (eg good general practitioners and community based home supports); a faith of some type (religious or otherwise) and so on, then death and dying can be faced and accepted with dignity.

There are many doctors who have spoken to the way "usual care" can be extended to meet the needs of patients at the end of their lives. This is employing the strengths of the doctor-patient relationship to turn to more palliative methods while adjusting the "usual care" one had been offering up to that point, accordingly.

Some I have heard talking are Dr Ken Hillman (Sydney) and Dr Charlie Cork (Melbourne). Each has published popular works on "A good life to the end" and "Letting go: how to plan a good death" respectively. Both work in the Intensive Care realm and advocate the wisdom of Advanced Health Care directives and the futility of unnecessary prolonged treatment in the face of terminal illness.

That being said. There is existential suffering where because of the type of terminal illness pathway eg some forms of disseminated cancer or some forms of degenerative neurological disease (as well as many other illness settings), where the challenge is greater.

Dr Kym Boon, Consultant Psychiatrist (and Pain Specialist) at Royal Brisbane Hospital, Dr Dan Fleming, ethicist from St Vincent Health Services and Prof Ben White, Lawyer from Queensland University of Technology have recently addressed the challenges of implementing the Victorian model in Queensland on Radio National, Big Ideas program, in March 2019.

Dr Boon eloquently pointed to the problems of navigating legal capacity and consent in the myriad of real life situations people can face. The message I hear is one of warning about assuming all has gone well in other jurisdictions despite all the safeguards, especially those overseas.

If all staff treating dying patients were better trained in the transitions that need to be navigated when passing from treatment modalities to palliative approaches to care then may be many of the horror stories in the popular press and media would start to dissipate.
Even better, what supposing we used our media to encourage conversations re how dying and death can be a positive experience not only for the dying person but for those in attendance.

Doctors and other health practitioners are humans also and not without their own fears, anxieties and concerns about dying. The desire to cure, the imperatives of a cancer research trial (not handing the patient over from treatment to palliation until too late) and many other examples can all complicate a simple trajectory to an acceptance of death as the outcome.

A word on different demographic groups in the community

I believe these laws are bad for young people under 18 years of age who are till forming their identities and capacities, legal or otherwise, to judge between what is good for them and what is not. As I alluded in the suicide prevention paragraph, we are sending a wrong message to society as a whole, especially the young. Again, specialised palliative care may also be needed for younger people with complicated dimensions of suffering while dying. But I believe palliative care is a better option than promoting VAD.

People living with mental health disorders, those with chronic disabilities or even those who lack family and friends as Carers are all vulnerable in a society that now has introduced the option of a death culture. They can feel the mainstream culture de-valuing rather than respecting their worth. It is easier to write protocols about inclusion and exclusion criteria. Not so easy to sort out what is coercion and what is not. Not so easy to be sure if a frail aged person is responding to unstated pressures within their family and seeing themselves as a burden and choosing death over life.
Again I refer to the expert psychiatrist (Dr Boon) for finding the right balance here.

A word on life and death
Although the two intensivists talk well about the boundary between life and death being much better understood, I believe there are many unknowns in individual cases. I have seen people whom you thought would die in some stated period, on average. But no individual is an average and prognosticating is an imperfect art as anyone charged with that responsibility would know.
There would need to be safeguards on the practitioner side of the process as well as on the person seeking assisted dying side.

A word on spiritual, emotional needs and the business of de-developing as we die.
A natural death is more than just an individual choice.
It involves other people – the community of kin and friends who care about the dying person; the health practitioners who must assist with the spectrum from treating for life maintenance through to withholding interventions that will no longer extend life when the natural end is near. De-development is letting go of functions we once had mastered in earlier adult life and can no longer maintain in the face of bodily systems breaking down. Naturally, this will be accompanied by many mixed emotional responses. Palliative care is meant to address all these facets.

The unknowns can be recast as the “business of dying”. Maybe our indigenous brothers and sisters and people from other cultures have much to teach we Anglo-Saxon cultures.
Maybe we should stop overvaluing personal autonomy, important as it is, and begin educating ourselves and everyone in our society that death and dying still has some mysterious values that a reductionist science and secular mindset threatens to rob us of.

Some comments should this committee proceed to recommending Voluntary Assisted Dying (VAD) for Queensland.

Re your issues, numbered 37 and 38

- Yes. Doctor's should be given conscientious objection rights so as not to violate their religious values or to transgress other ethical worldviews they may hold
- In like manner, I don't believe compulsion would be beneficial to the doctor-patient relationship in dealing with the difficult last days of life. In the Victorian model, it is likely to take some considerable time, given the steps mandated, to approve and prescribe the drug to allow self-terminating one's life. Many people receive their scripts and decide not to go through with it. For that reason alone, the euthanasia service is hardly in the position to support the person while "usual care" is still being needed by the dying person in this limbo space.
- I do not believe most caring clinicians, who are looking after terminally ill patients with due diligence, would leave them in a vacuum to find their way forward unsupported

Summary and Conclusion

I think it is important to not rush a bill and/or legislation into existence just because Victoria and other jurisdictions have gone down that path. In my view, more activism and not enough attention to all the valid concerns of history have led to these changes here and overseas in the first place. Statistics can be misleading given any statistician knows they can be manipulated to show whatever the service advocate wishes to say. I would be more open to the so-called data from the Netherlands, Oregon or Canada were it to include vignettes stories of real cases of VAD suitably anonymised. I have recently read a set from Palliative services here in Queensland and they spoke to the ambiguities, the complexities and yet the skill and compassion of those caring for people at this most significant time. If I did not see some adverse outcome in these overseas euthanasia services, I would find it hard to believe what I was being told.

The euphemism of being a progressive and just society can sometimes lead to adverse and unintended outcomes despite our good intentions. We should resist being panicked into actions that would be changing the fundamental basis of our western societies and the laws and institutions that govern them.

These actions could damage the profession of medicine, nursing and allied health disciplines.

Our fundamental charge is to support life. As a Christian, I accept death is a natural part to the lifespan we are afforded. There are many crises to deal with as that span is shortened or lengthened by natural calamities and the like.

Because we humans think we can control life, we over-reach and believe we can control death as well. I have argued there is important "end of life" business to be done while we are dying.

I believe the so called evidence that palliative care can not address some of the symptoms that complicate slow deaths is overstated. And vulnerable groups will be adversely affected even if well provisioned champions push politicians and the public in the media landscape.

And in the centre is the dying person. I would speak to the stories of relatives and friends I know who are going through various aspects of what I point to right now. But this is a public document. I am happy to expand in another forum where privacy can be afforded.

Although I do not practice clinically now, I observe colleagues doing that. I observe that most health care professionals are highly committed to their patients wellbeing including assisting them having the best death possible. Let's stop pretending that even with all the committee oversight in the world that someone going out the door with a lethal script is not in an unenviable position.

Since I believe palliative care can address their physical suffering and help them to face their existential challenges, I would encourage the committee recommend to government that we strengthen not only dedicated palliative care units and palliative support in the homes but that we strive to lift the standards across all sectors of aged care and hospitals as well. This is to ensure that personal care workers, working in the aged care sector, as much as highly trained clinicians working alone or in teams in health care settings, would see it as a privilege to assist the dying patient in their final journey on this earth.

We all will face death eventually. Let us not complicate that process any more than it already is with control methods dressed up as right to choose, individual rights and other such language.

Personhood is much richer than that. And issues of justice will still be being addressed beyond the grave. Personal dignity is something we arrive at in relationship with loved ones and professional carers. A faith in someone outside yourself can do much to alleviate existential distress. Palliative care has evolved organically to meet just such circumstances.

Magnetic Island Community Development Assoc
Heritage Infrastructure and Planning Group
PO Box 133, Nelly Bay,
Magnetic Island, Queensland 4819

ABN 88 303 909 978 Incorporated Association: 11505

Contact: Les Sampson,
President

email:micda.president@gmail.com

Ph [redacted]

18/6/2019

Mr Aaron Harper, MP
Member for Thuringowa and Chair
Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee
Parliament House, George Street
Brisbane Qld 4000
Email: health@parliament.qld.gov.au

Dear Mr Harper

RE: Your committee's inquiry into aged care, end-of-life and palliative care and voluntary assisted dying.

I am writing to you to express the views of the Magnetic Island community about end-of-life and palliative care in our local community. These views were collated at a community meeting held on 15th June 2019, facilitated by staff from the Palliative Health unit at the Townsville Hospital and Health Service. I understand that the period for formal submissions to the above inquiry has closed. However, we also understand that the work of your committee is not yet complete, and we ask that our views be taken into account in your final deliberations.

About Magnetic Island

Magnetic Island is a high continental island within the Great Barrier Reef World Heritage Area, approximately 8km off the coast of Townsville. It is home to a residential population of around 2500 people. Being a popular tourist destination, this number more than doubles during school holidays and peak visitor season. However, our focus in this submission is on the permanent residential population and their end-of-life and palliative care experiences and needs.

In the 2016 census[1], the median age within this community was 54 years (compared to 37 years for Queensland), and 24.7% of the population was aged 65 years or over (compared to 15.2% for Queensland). Magnetic Island is a favoured location in which to retire. Not surprisingly, a smaller

[1] https://quickstats.censusdata.abs.gov.au/census_services/getproduct/census/2016/quickstat/318021483?opendocument

proportion of the community on the island (49.4%) works full time compared to the Queensland figure (57.7%), and the median weekly income of a household ($851) is significantly lower than that for Queensland ($1402). However, our community enjoys a higher proportion of residents engaged in unpaid voluntary work within a community organisation or group (25.7% compared to 18.8% for Queensland). In summary – our community is older than the state average and thus likely to have a greater proportion of residents in need of end-of-life and palliative care support; we are poorer and therefore vulnerable to excessive costs of accessing services; yet we are an engaged community with a significant voluntary track record, and capacity for greater voluntary involvement in end-of-life and palliative care needs of the community.

Magnetic Island is serviced by a passenger ferry service (15+ services per day)[2] and a car and passenger service (7+ services per day)[3] . The cost of ferry travel is significant as it is geared around the tourist holiday traveller – priced at $10.80 - $34[4] for a return trip per person (noting typically patient plus escort) not including on-ground transport in Townsville (~$30 taxi fare to the hospital if case does not qualify for PTS). The total travel time from Magnetic Island to the Townsville Hospital, by ferry and road transport, is typically well in excess of 1 hour. There are no scheduled services for transport from Magnetic Island to Townsville between 11pm and 6.10am, and during various natural disasters services are reduced further or possibly suspended completely for days at a time. During these times, the only transport options are by sea via the coastguard or water police (weather permitting), or Care Flight helicopter (subject to availability).

What is the current experience of end-of-life and palliative care?

Magnetic Island's health needs are currently serviced by a community clinic within the Townsville Hospital and Health Service, and a private mixed-billing GP practice. The clinic provides a 24/7 accident and emergency service, and is staffed by 2 FTE registered nurses split between 4 permanent and 4 casual nurses, supported by a medical superintendent with a right to private practice (who currently works within the GP practice). This is a very busy clinic – in 2013-14 FY the facility posted the highest number of accident and emergency presentations (3624) out of any of the 53 community clinics listed[5]. The private GP practice is staffed by registered nurses and various numbers of full or part time GPs (including currently the MSRRP for the clinic), and is available by appointment during typical opening hours. The clinic staff have tremendous capability and experience in community nursing and palliative care, but their scope of practice and resourcing is focused on their accident and emergency role. We believe that third parties (Anglicare and Bluecare) are contracted by Queensland Health to provide in-home nursing and other support to aged care and palliative clients. However we understand that they do not currently have the capacity to support the identified needs of these clients.

On the one hand, the community clinic is recognised as a 'rural and remote' facility[6], however on the other hand the facility does not appear to be resourced as such, perhaps because it is deemed to be too convenient to the Townsville Hospital and Health Services to qualify for subsidised patient transport services (eg PTS or PTSS) despite the clinic being the only 24/7 facility, the isolation from

[2] https://www.sealinkqld.com.au/ferry/timetables/magnetic-island
[3] https://magneticislandferries.com.au/ferry/magnetic-island-ferry-timetable/
[4] https://www.sealinkqld.com.au/ferry/prices/magnetic-island
[5] https://www.health.qld.gov.au/clinical-practice/engagement/networks/rural-remote/rural-facilities/community-clinics
[6] https://www.health.qld.gov.au/clinical-practice/engagement/networks/rural-remote/rural-facilities/map

transport options after hours, and significant inconvenience, time and cost of travel as outlined earlier. Magnetic Island is recognised in the level 7 remoteness category in the Modified Monash Model[7], but The Magnetic Island Health Service (the clinic) is not listed as an eligible facility to claim against the Medicare Benefits Schedule as a COAG s19(2) exemption initiative to improve access to primary care in rural and remote areas.

At the community meeting held on 15 June 2019, a number of community views and experiences about local end-of-life treatment and care were presented including:

- An elderly woman cared for her terminally ill husband at home, with the support of the GP, until she could no longer cope at which time the GP arranged transfer to the Townsville Hospital where he died 2.5 days later against his wishes (which were to die at home). At no time were palliative care services sought or accessed;
- An elderly Traditional Owner was unable to die on country which was his wish, and instead died in the Townsville Hospital due to lack of access to adequate in-home end-of-life care;
- A middle-aged woman lived with her terminally ill friend for nearly 3 months to support her full-time through her end-of-life. They were supported locally by QAS and the community clinic during crisis moments, and the patient was able to die on the island which was her wish. No support was sought nor accessed from the Palliative Care service.
- A professional carer described her experience providing end-of-life and palliative care to various clients on a private employment basis. This option worked well but involved significant cost to the client.
- Patients undergoing palliative chemotherapy and other treatments in Townsville need to travel to Townsville at significant cost and discomfort.
- It was noted that a major proportion of end-of-life residents are forced to move into residential care facilities in Townsville due to inadequate services on Magnetic Island. This dislocates and isolates our people from community and support networks.

What does the community want for end-of-life and palliative care?

Participants at this same community meeting expressed their priorities and desires for a greater and more holistic patient-centred approach to end-of-life and palliative care on Magnetic Island. Specifics include:

- Provision of a patient's freedom to be in control of decision making, including through expressing wishes in a 'statement of choice';
- A system that supports a decision to stay on Magnetic Island preferably at home, if that is the patient's wish, noting that remaining on the island is often culturally spiritually and emotionally important to both patient and carer(s), including by providing access to companionship;
- Minimise the need to travel to Townsville for medical review and treatment. It was noted that telehealth is available at the community clinic and that the relevant software is available for download by patients and their carers for bedside telehealth, although this facility is rarely utilised;
- We do note that the internet and mobile signals are not completely reliable on Magnetic Island, and that this needs to be addressed for streamlined access to telehealth;

[7] http://www.doctorconnect.gov.au/internet/otd/publishing.nsf/Content/locator

- When travel to Townsville is essential, there needs to be a bridging of the logistics and cost to the patient through review of criteria to access PTS or PTSS;
- Where it becomes essential or there is a choice for a patient to move to a supported living facility, this should be provided on Magnetic Island. It was noted that there are currently no residential facilities on the island, although the Magnetic Island Community Care group have developed a business case for such a facility and are currently seeking funding;
- Medical management for pain should be kept at tolerable levels balanced against maintenance of mental clarity, for as long as possible. This will require an expansion of on-ground generalist palliative care resources (nurse and doctor FTE) with on-line support from specialist resources based in Townsville. It was noted that although clinic staff have a significant capability in palliative and end-of-life care, current resourcing and capacity is limiting deployment of this capability and the focus is on accident and emergency;
- There is a need for greater security and certainty around treatment decision making. This could be achieved through both timely access to specialist palliative care resources, as well as training of carers, and professional development of clinicians (eg PEPA and End of Life Essentials modules through Caresearch).
- Allied health resources should be included in the holistic picture.

Rest assured that the community of Magnetic Island does not expect the Queensland government to fully fund all elements of the desired model. In true community spirit, discussions are already underway for establishing a network of trained professional and volunteer carers within the community, and a working group has been formed to develop a business case and source resources where needed. However, we do wish to identify that Queensland Health's current service focused model of end-of-life and palliative care has failed the community of Magnetic Island, by expecting island residents to access centralised services and facilities in Townsville, often forcing residents to relocate away from their homes and community support. Because Magnetic Island is an acknowledged remote location, provision on island of end of life and palliative care for its residents will require increased resourcing and a more holistic patient-centred approach.
Our future vision is to work collaboratively with all services including those delivered through Queensland Health, to develop a workable whole-of-community strategy for person-centred end-of-life and palliative care into the future.

Yours sincerely

Les Sampson

Les Sampson, President.
MICDA

CC:
Mr Scott Stewart MP, State member for Townsville Townsville@parliament.qld.gov.au
Mr Phillip Thompson MP, Commonwealth member for Herbert **herbert**@lnpq.org.au
Mr Tony Mooney AM, Chair, Townsville Hospital and Health Service Board.
Townsville_HHB@health.qld.gov.au

[redacted]

From: denisekd
To: Care Inquiry
Subject: VOLUNTARY EUTHANASIA
Date: Monday, 15 April 2019 1:10:16 PM

Dear Sir/Madam,

I wish to submit my opposition to the legalisation of Voluntary Euthanasia.

The main reasons I oppose legalisation are:-

i) Once legal, that opens up the opportunity for illegal euthanasia.

ii) People become used to the idea of "killing" someone to put them out of their misery but where does it lead to down the track? Will those born with, or who have acquired, a disability or the elderly who have dementia or similar, be terminated to put them out of their misery by a legal guardian?

iii) What if someone states or signs a form that they want to be euthanised but changes their mind at the last minute but the family or doctor thinks it's better for the person to go through with it (they have the signed form).

iv) I firmly believe that by legalising euthanasia, it is not ethical and will lead to terrible situations and decisions.

On a personal note, my son passed away with cancer so I know the suffering and sorrow but I also know that if he was euthanised, albeit "voluntary", I would still feel like he was murdered.

ONCE LEGALISED, YOU HAVE CROSSED THAT FINE LINE!

Denise Dixon
[redacted]
PARREARRA QLD 4575
[redacted]

From: Alan M. Barker
To: Care Inquiry
Subject: Assisted euthanasia
Date: Monday, 15 April 2019 12:27:30 PM

AGAINST. To be permitted would lead to inumerable instances of families looking after their own interests, be it financial or giving of their time. I have seen too many instances where families want their elders 'out of the way'.

Further, it would be totally against my Christian principles, where life is precious and to be preserved.

I am 84 and have no desire to that there be the possibility of someone administering a drug to 'end it all'

Alan Barker

[redacted]
Capalaba
Qld 4157

From: Anne Window
To: Care Inquiry
Subject: Submission to the inquiry into aged care, end-of-life and palliative care and voluntary assisted dying
Date: Monday, 15 April 2019 3:53:15 PM

Dear Health Committee

In addition to my earlier submission, in opposition to voluntary assisted dying, which is below, I forgot my telephone number, which is [redacted].

Also, I agree to the publication of my comments as a submission.

Kindest regards

Anne Window

Date: 15 April 2019 at 3:39:58 PM AEST

To: careinquiry@parliament.qld.gov.au
Dear Health Committee,

Submission to the inquiry into aged care, end-of-life and palliative care and voluntary assisted dying

I am strongly opposed to voluntary assisted dying, both on practical and moral grounds.

Some may be tempted to believe that this would increase the choice available to those dying, but in reality it would diminish choice because of the pressure imposed on patients to end their lives by budget-conscious hospitals or even family members. I therefore hope that the committee will see fit to rule out assisted dying as being beneficial to the community at an early stage of the inquiry.

I also wish to stress that assisted dying cannot really be considered as a medical option at all. From the earliest times, medical professionals have defined themselves as healers, a calling which could not be more dissimilar to those who deliberately kill or facilitate death. The Hippocratic Oath makes this distinction very clear by forbidding doctors to ‘give a deadly drug to anybody if asked for it, nor making a suggestion to this effect’. I therefore hope that the committee will not confuse assisted dying with the work of medicine.

For the reasons mentioned above, I urge the committee to reject assisted dying and instead concentrate on improving real end-of-life options, such as access to quality palliative care for all in Queensland.

Yours sincerely,

Mrs Anne Window

[redacted]

ORMISTON
QLD 4160

From: Bernadette Hickey
To: Care Inquiry
Subject: Legalising euthanasia would be a dangerous idea for Queensland
Date: Sunday, 31 March 2019 5:46:25 PM

Re: Legalising euthanasia would be a dangerous idea for Queensland

Dear Committee Inquiry,

Doctors are there to preserve life, not end it. No one has the right to end another's life, and when we start to try to legalise this, the ramifications are enormous. Eventually, it could be your life someone wants to end. Please, let's take care of each other from the moment life starts till its natural end.

Sincerely,
Bernadette Hickey
[redacted]

[redacted]
Penshurst, AU-NSW 2222

From: Brian Drage
To: Care Inquiry
Subject: Legalising euthanasia would be a dangerous idea for Queensland
Date: Friday, 5 April 2019 7:32:30 PM

Re: Legalising euthanasia would be a dangerous idea for Queensland

Dear Committee Inquiry,

Prohibition on doctors killing patients is a longstanding rule. The World Medical Association and Australian Medical Association oppose euthanasia on the basis that it undermines the doctor/patient relationship of trust. I think better strategy would be to inject more funds into the care and well-being of the people that fit into this category. So they don't feel so alone, so they know that there are other alternative paths. So there can be more access to counselling, Pastoral Care, and affordable medical care. Sincerely Brian Drage

Sincerely,
Brian Drage
[redacted]
[redacted]
Upper Coomera, AU-QLD 4209

From: Cara Whittred
To: Care Inquiry
Subject: Submission re euthanasia...
Date: Monday, 15 April 2019 1:02:57 PM

Dear Panel,

I am writing this submission from both a personal perspective and also from a professional perspective. My father passed away in the palliative care unit at the Prince Charles Hospital 8 years ago, and I have been a Registered Nurse and Midwife who has worked in and with terminally ill and palliative care patients over many years. I can very definitely understand the deep concern around issues of pain and suffering in terminal or life-limiting illness especially as my father battled prostate cancer for some years, and a close friend went through a long journey with breast cancer recurrences before passing away in a palliative unit on the Gold Coast.

What I can say is that I do not support euthanasia in any way shape or form. What I wholeheartedly support, however, are palliative care choices - whether they include home-based care or in palliative care units, hospice care etc. There is such a scarcity of appropriate palliative and hospice care facilities in hospitals as well as in the community and this is where huge funding should be directed in my view.

It seems to be a constant refrain around issues of intractable pain associated with life-limiting illnesses, but this has certainly not been my experience. And there are so many options and combinations available now. What needs to be addressed is specialist training and education for medical, nursing and allied staff working in these areas - and not only concerning physical pain but also issues around mental anguish and distress etc in patients/ clients and their loved ones...ie wholistic care. I remember reading a comment by an oncology consultant of many years experience, that even some palliative care medical staff can be remiss regarding effective, up-to-date pain relief combinations and options.

The other issue of greatest concern for me could best be described as 'the salami effect'. Belgium rejected the idea of euthanising children initially but over time it has become legal. The boundaries are constantly pushed back and even though 'strong safeguards' to prevent abuse is always cited across jurisdictions that have legalised medical or physician-assisted euthanasia, the reality is over time they have proved very ineffective. No wonder many of the vulnerable in our society, particularly our indigenous brothers and sisters, the aged and disabled shudder in fear when approached about euthanasia and related issues...

Thank-you for the opportunity to contribute a submission.

Yours sincerely,
Cara E Whittred (Ms)
[redacted]
Mitchelton, 4053, Qld.
[redacted]

'

From: Carol Sullivan
To: Care Inquiry
Subject: VAD should NOT be allowed
Date: Monday, 15 April 2019 10:20:11 PM

To whom it may concern,
I wish to express my concern with proposed legislation relating to euthanasia.

I believe this will open the door to higher suicide rates. We already know that many case of depression lead to suicide and we also know that most cases of depression can be overcome with diet, exercise and support programs. TOO MANY people are dying from suicide. Having Voluntary assisted dying will OPEN THE DOOR! This is not acceptable.

Please DO NOT pass this legislation.

Kind Regards, Carol

Do you want to make a difference?

Carol & Richard Sullivan
[redacted]
Pimpama Qld 4209
[redacted]

From: CHRISTINE LENZ
To: Care Inquiry
Subject: Re: VAD
Date: Monday, 15 April 2019 10:08:52 PM

Dear Sir/Madam,

I wish to submit my view to the committee regarding the enquire into VAD.

I am opposed to VAD and do not support legislation which would allow this to take place.

I currently work as a Registered Nurse and Bereavement Counsellor for Metro South Palliative Care at a large public hospital.

I believe as a service and as a Multi-Disciplinary Team we deliver holistic care to our patients enabling them to live life to the end with dignity.

Each patient and their family are supported from their first contact with MSPC throughout their journey by a compassionate team of Doctors, Nurses, Social Workers, Occupational Therapists and Counsellors.

We not only care for and treat physical symptoms, but support the complex emotional journey which is unique to each person and their family.

In my work I find that patients need time to process what is happening, to put into words their end of life wishes so that they can choose what they want their final weeks or days to look like. No one has the right to Take away their right to choose this path. In my work I rarely meet patients wanting to die more quickly. There is an apparent lack of knowledge around how death can look and more community education about what Palliative Care is should be promoted. Fear of dying could well be the driving force behind the desire to legislate VAD.

Patients time on the ward or in their homes is so precious, particularly as it often allows patients and their families to reunite and come to acceptance of their future loss. Complex or complicated grief is currently statistically 10-15% but if legislation was changed, I believe the statistics would increase rapidly, with attendant mental health issues.

If their were more funding for specialist PC units, then VAD would not be required.

There is a danger also of families wishing to decide for the patient when they should die, rather than the patient fulfilling their own wishes. Who will then stand up for the patient?

I do not think anyone has the right to take another's life and truly believe that if Palliative Care is properly, professionally delivered then there should be no need for VAD. Patients can die with dignity and families can be with them at all times if they wish. Our service supports physical, spiritual and emotional care of the terminally ill and their families in bereavement.

I earnestly request that you do not legislate for VAD.

Yours sincerely,

Christine Lenz.

[redacted]
INDOOROOPILLY 4068.

[redacted]

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: Dale Holley

Day time phone number: ( ) [redacted]

Email address: [redacted]

Address: [redacted] Kalinga QLD *Postcode:* 4030

What would you like to tell the committee?

The experiences of all who have had loved ones endure a terminal physical illness or the equally heart-wrenching protracted mental deterioration illnesses, are difficult to live through for all parties. Reading, or listening to, those stores are harrowing experiences. The trauma of watching one's own loved ones endure suffering, against their articulated wishes, is beyond my ability to express - I am in awe of those who have been able to tell us of their heartbreak.

I would like to know, should I ever be in a position where, not only was I diagnosed with a terminal illness, but also where I no longer have the mental capacity to make decisions, that I could end my life with dignity - lawfully - without having to travel to another country to do so.

While I understand there are those who do not support VAD, I fail to see why their beliefs should impact - overrule - my own.

Perhaps consideration could be given to a directive similar to the Advanced Health Directive where, when we are in sound mind, we articulate and formalise our wishes and these may not be over-ridden, no matter how well-meaning others' wishes maybe.

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:_____

Their daytime phone number: :_____

What is your relationship with that person or persons, or your role in the organisation?_____

I am authorised by ..... to provide these comments on their behalf.

Signature: DE Holley ..... **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

SUBMISSION

The Queensland Parliamentary 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

Debra Cheyne

[redacted]

Dunlop ACT 2615

[redacted]

INQUIRY INTO AGED CARE, END-OF-LIFE AND PALLIATIVE CARE, AND VOLUNTARY ASSISTED DYING

Thank you for the opportunity to make a public submission. I note the Committee's full terms of reference. The focus of this submission is point 1b.

Babies don't get to choose how they come into this world. For some it is a natural birth while for others birth is assisted with the use of medical intervention such as forceps or caesarean. As mothers there's not a lot of choice because we rely on the advice of the medical profession to bring our precious child into the world.

By the time we become adults, however, we have formulated strong views on many topics and we make **choices** on all aspects of our lives: housing, health and fitness regimes, our faith, education and politics to name a few. Why then, when diagnosed with a terminal illness, can't we choose the manner in which we wish to end our lives?

As an adult I want to choose how I leave this world, and have the right to decide when and where to end my life. I don't want to be in hospital or palliative care. I want to be able to make this decision with the assistance of my doctor before the illness and/or medication renders my mind useless.

My decision has been reinforced through personal experience watching my husband endure a painful end of life in a Queensland Hospital where no amount of medication eliminated the pain. The sense of helplessness watching a loved one die an agonising death is heartbreaking AND totally unnecessary. My loved one didn't have a choice, but I hope to.

My wish is to die with dignity. Across the world VAD options are already in place – Europe, Canada, the United States and Taiwan have already enacted assisted dying legislation. Australians deserve this right, too, and I applaud the Victorian Government's decision to introduce VAD from July 2019. There are plenty of guidelines from around the world to ensure genuine fears are allayed and I note there are 68 safe guards in the Victorian legislation.

It's my right to choose.

Debra Cheyne

[redacted]

Dunlop ACT 2615

From: john casey
To: Care Inquiry
Subject: Submission to Inquiry into Voluntary Assisted Dying
Date: Friday, 12 April 2019 11:03:43 AM

May I refer specifically to the following Issues for Consideration :

no 27 : I submit that assistance in dying is not part of health care ;
medical practitioners are bound traditionally by the Hippocratic
prohibition on killing patients .

no 37 : I submit that doctors bound by medical ethics and guided by
conscience should NOT be legally obliged to participate in VAD .

no 38 : Nor should they be legally obliged to pass on the abhorrent
practice to others .

submitted by Dr John H Casey PhD FRACP

[redacted] Carseldine 4034

From: Noel Preston
To: Care Inquiry
Subject: Submission to Aged care etc ctee inquiry
Date: Monday, 15 April 2019 12:49:19 PM
Attachments: euthanasia UE.doc

A SUBMISSION FROM REV.DR.NOEL PRESTON AM

I offer this brief submission plus attachments in recognition of the laudable inquiry being undertaken into aged care, end of life and palliative care and voluntary assisted dying.

My submission will canvass only some of the considerations before this committee.
I do not claim any current expertise in these matters. However, my experience includes academic qualifications in Applied Ethics, and Training in theology and social ethics, years in pastoral care visiting oncology patients and my own lived experience as a cancer patient . (In my retirement at aged 77 I have Advanced Prostate Cancer currently undertaking treatments for metasteses spread to bones and lymph nodes.)

As background, I attach to the following observations two documents extracted from published texts of mine.

OBSERVATIONS:

1. In appropriate circumstances (the chief of which is medical judgement that a patient is within months of dying and there is "unnecessary suffering"), there is no intrinsic moral objection to voluntary assisted dying. In saying this I affirm that considerations of "the sanctity of life" and "the quality of life" may converge.

2. That said the complexities of legislating these circumstances are several and difficult. Any legislation should provide clear exemptions for practitioners to conscientiously object to participating in assisted dying.

3. As the committee would be aware, there is now considerable experience in drafting such legislation overseas and within Australia. Though I have not studied these other situations, I am inclined to the view that the legislation in Oregon, USA has much to commend itself. Interestingly, I believe that the "take up" of assisted dying in that jurisdiction is about 40% of those prescribed the life ending drug.

4. The availability of , and resourcing of, world best practice palliative care must remain a paramount consideration. And in my view is adjunct to the propositions above.

Faithfully,
Noel Preston (15/4/19)

Dr Noel Preston AM
[redacted]
Wellington Point
Queensland 4160
[redacted]

To get your free copy of "Beyond the Boundary" and other articles visit http://www.noelpreston.info

1.Euthanasia (Extracted from N. Preston, *Understanding Ethics 4th edition,*2014, Federation Press, ch.7)

Euthanasia (literally, 'a good death') refers to cases where death is brought about or allowed because death is thought to be in that individual's interest, normally because the patient is suffering from an incurable and terminal illness. In these cases the ethical justification may be summarised colloquially as "he (or she) is better off dead". It is therefore inaccurate to associate the term 'euthanasia' with the extermination camps of Nazi Germany or with ideas of killing off the so-called useless or undesirable members of society. For instance, to kill someone merely because some other person decided they were too old could not count as euthanasia. Therefore, there is little virtue in the argument against euthanasia on alarmist 'slippery slope' grounds; nonetheless, as our previous discussion about values illustrated, and as our later analysis in this section will indicate, caution over the social consequences of instituting euthanasia as a medical practice may be justified.

"Euthanasia, in the strict sense, is understood to be an action or omission which of itself and by intention causes death, with the purpose of eliminating all suffering".[i] There are several distinctions which help categorise different instances of euthanasia.

The first distinction is between *voluntary* and *involuntary* euthanasia. Voluntary euthanasia involves the informed consent of the one who is to die, whereas involuntary euthanasia proceeds without that consent, when the individual is incapable of informed consent (for instance, a comatose adult).

These categories can be combined with another distinction, that between *active* and *passive* euthanasia. In the active cases there is direct intervention to cause death, whereas in the passive case there is no direct intervention though the patient is allowed to die, and procedures which might prevent death are withdrawn. Now, let us summarise, illustrate and combine these categories:

(i) *active voluntary*, covers cases of assisted suicide or so-called mercy death, for example, the deliberate administration of a lethal injection with the patient's previous consent (even perhaps via a previously declared 'living will').

(ii) *passive voluntary*, covers cases where someone is allowed to die and where they have expressed a wish so to do, for example, meeting the request of a patient not to treat a secondary illness, like pneumonia, when that patient is already dying of cancer.

(iii) *passive involuntary*, covers cases where someone is allowed to die even though they have not clearly expressed a wish, for example, turning off life-support machines for a comatose accident victim whose brain function will never return, according to best medical opinion.

(iv) *active involuntary*, covers cases of so-called mercy killing, where someone is caused to die even though they are incapable of expressing a wish on the matter, for example, promoting the death soon after birth of severely impaired anencephalic babies.

Though not all cases of euthanasia fit neatly into these categories, it is instances of active intervention that are most problematic ethically as well as legally. Despite ambiguities in the law, there is a wide community consensus supporting passive voluntary euthanasia, and possibly passive involuntary euthanasia.[ii] Even amongst Christian moral theologians opposed to euthanasia and to changes in the law especially, there is an openness to considering the morality of certain cases based on further distinctions. They may call on a distinction between the use of *extraordinary and ordinary means* of treatment. Some[iii] prefer to use terms such as 'proportionate' and 'disproportionate' or 'reasonable' and 'unreasonable' rather than 'ordinary' and 'extraordinary'. Extraordinary means could include the continued use of life support machinery when it is believed that the patient will never recover consciousness, whereas ordinary means are those that keep the patient comfortable and pain-free but may not prolong life. As it is usually employed, the distinction may be clinically useful because it allows for quality of life factors (such as cost and psychological stress) as judged by the patient. It is sometimes difficult to be precise about this distinction and, in an ethical sense, its significance is debatable.

Similarly, to cover the fact that moral choices often include subsequent consequences which may be unavoidable, some ethical commentators invoke the *doctrine of double effect*.[iv] Suppose a doctor gives a terminally ill cancer patient an overdose of morphine, sufficient to kill the patient. If the doctor intends only to reduce the patient's pain or suffering, and not to kill the patient, then according to the doctrine of double effect, the doctor's action is not wrong, even though he or she can foresee that the patient will die presumably from

the overdose. Critics complain that this distinction is unclear and therefore untenable. What is more, they say, it may open up a line of argument which can be used to defend any evil act provided it is merely foreseen but not intended.

A further distinction is that made between actions which *allow someone to die* and those which *cause someone to die*. Here attention and significance is given to the moral intent of an action, not simply its mode or outcome. Some say that if a physician allows someone to die by withdrawing a respirator but does not intend them to die, that should not count as a (morally reprehensible) case of euthanasia. But how, we might ask, is there any practical or moral difference between allowing someone to die when it is known that they will die, and actively promoting their death? This is the issue taken up in a debate between James Rachels and Thomas Sullivan.[v] Rachels defends a liberal approach to euthanasia invoking utilitarian/humanitarian arguments supplemented by a Kantian-like appeal to the Golden Rule. Sullivan defends a conservative approach by invoking a deontological style 'sanctity of life' principle augmented by a rule-utilitarian argument that the systematic acceptance of active euthanasia will lead to a damaging lessening of respect for life in society.

It is interesting to note how various normative theories can be used to support similar and opposing positions on euthanasia. One may be in favour of, or opposed to, euthanasia on either or both utilitarian and deontological grounds. Once again, the ethic of response provides a framework for assessing and deciding among the competing factors in a decision about euthanasia. Of course, it is a useful tool only to those who acknowledge that quality of life considerations are to be put alongside a profound respect for life including the dignity of the person, within a principled framework guided by our obligations to keep faith with each other.

Overall, it is not inconsistent with an ethic of response to argue that, in certain cases, euthanasia, even 'active involuntary situations', is justifiable as morally fitting. However, should, or how can, that conclusion be translated into law and social policy? There are certainly major objections to the legalisation or decriminalisation of euthanasia to be considered:

- is there not a danger that legalised euthanasia will put undue pressures on medical practitioners and nurses, subtly altering their duty to care?
- is it possible to devise a law which is not open to abuse?
- is it not conceivable that carefully framed laws might later be amended or extended by regulation, bypassing public debate?
- might not legalised euthanasia open the door for elderly people to be quietly disposed of against their will?
- if euthanasia is legal, might not an old person feel pressured to die because they are a burden to their relatives?

The ethic of response with its concern for social justice, universality, accountability and social solidarity also infers that a major consideration for particular, individual cases of euthanasia is the broader social impact of the ethical decision. For this reason the judgment of Baroness Warnock, in the 1994 *Report of the Select Committee on Medical Ethics of the House of Lords* opposing a law change on euthanasia, expresses a perspective which should weigh heavily in any responsible decision:

> Ultimately, however we do not believe that these arguments are sufficient reason to weaken society's prohibition of intentional killing. That prohibition is the cornerstone of law and of social relationships. It protects each one of us impartially, embodying the belief that all are equal. We do not wish that protection to be diminished and we therefore recommend that there should be no change in the law to permit euthanasia. We acknowledge that there are individual cases in which euthanasia may be seen by some to be appropriate. But individual cases cannot reasonably establish the foundation of a policy which would have such serious and widespread repercussions. Moreover dying is not only a personal or individual affair. The death of a person affects the lives of others, often in ways and to an extent which cannot be foreseen. We believe that the issue of euthanasia is one in which the interest of the individual cannot be separated from the interest of society as a whole.[vi]

Warnock's views speak to the debate about euthanasia. This debate has been vigorously promoted in recent decades. The Netherlands has had pro-euthanasia legislation for some time while the state of Oregon in the USA allows medical preactitioners, who judge a patient to be terminally ill and within six months of death, to prescribe, on voluntary request, a drug enabling persons to take their own lives. Interestingly, the data

shows that many who have requested a prescription subsequently decline to use it, but find solace in the fact that they could if they chose. However, for instance, in 2013 a court in British Colombia overruled a lower court judgement allowing doctor-assisted suicide. In Australia, the Northern Territory *Rights of the Terminally Ill Act* 1995 which legalised euthanasia[vii] was overturned by Australia's Federal Parliament which then instituted measures effectively making an offence of the promotion of euthanasia. Meanwhile, again in 2013, Tasmania's State Parliament debated legislation for a *Death with Dignity Bill.* It failed to pass by a narrow margin. In other Australian jurisdictions where euthanasia is still illegal, a minority of medical practitioners admit to practising active voluntary euthanasia and most of them feel they have "done the right thing".[viii] Though to date in Australia, euthanasia remains under a legislated veto, many would argue that the growth of a *de facto* understanding between doctors, patients and their families to promote 'a good death' is to be encouraged.

Euthanasia policy is also likely to be influenced by two contemporary developments. The first, developments in palliative care, represents part of the case that there are positive alternatives to euthanasia in a 'bad dying' process. The claim is that through more sophisticated pain relief measures and the caring of the hospice movement support for a 'good death', without active termination of life, is possible.[ix]

The other development is what is claimed to be the complex social cost of an ageing population. (By 2026 the average life expectancy of men will have reached 82 and women 86 years.) Can societies afford the escalating costs of keeping people alive to an advanced age especially when a large proportion of limited resources are devoted to the terminally ill? This utilitarian consideration is arguably unfair and disrespectful of persons, and needs further factual substantiation. However, it is on the community agenda and rightly or wrongly, may subtly influence social policy with respect to euthanasia.

In the community debate over euthanasia, religious believers represented by Christian churches are officially cautious, even hostile, though it must be added that many individual Christians have another view and are even active in groups such as the Voluntary Euthanasia Society.[x] The major churches in Australia have expressed concern about the moves to legalise euthanasia. Their official views toward a legislated acceptance of euthanasia have shifted very little in the past twenty years. So, a resolution passed unanimously by the national body of the Anglican Church in 1995 is seemingly still representative of official Christian councils. The General Synod resolved *inter alia*:

> affirms that life is a gift from God not to be taken, and is therefore not subject to matters such as freedom of individual choice.
>
> … questions whether a practice of voluntary euthanasia can easily be prevented from sliding into a practice of involuntary euthanasia.
>
> … affirms the right of patients to decline treatment but not to expect the active intervention by medical staff to end their lives …[xi]

Undoubtedly, one's beliefs influence how one approaches life and death dilemmas, especially euthanasia[xii]. Some simply claim that only God can take an individual's life. Other critical questions relate to one's beliefs about suffering: might not suffering be redemptive and purposeful? Does it make any difference that it is the suffering of dying? Might we not cheat ourselves of something life has to offer when we terminate life prematurely? On these questions, Elizabeth Hepburn offers a fitting observation with which to conclude this brief discussion:

> A philosophy which sees suffering as absurd will lead us to seek relief in the form of euthanasia. We must decide whether we will interpret the dispossession we experience in the face of suffering as absurdity or mystery. If we opt for mystery we will be committed to living

---

i John Paul II (1995) in *Evangelica Vitae*, Vatican City, n 65.

ii See Baume, P (1995) "Voluntary Euthanasia – Mercy or Sin", *New Doctor*, Winter, pp 13-14.

iii McCormick, R, above, n 10.

iv Hepburn, E, above, n 9, pp 19-20, provides a fuller account of the doctrine. In a note to me, Elizabeth Hepburn says that, in practice, according to many specialists this Doctrine of Double Effect does not apply because it is not the overdose of narcotic analgesics which kill the patient but the underlying illness.

v The Rachels and Sullivan papers are reproduced in Chapter Three of Mappes, T and Zembaty, J (eds) (1992), *Social Ethics*, New York: McGraw-Hill.

vi Reproduced in *National Outlook*, September 1995, p 21.

[vii] Hepburn, E, above, n 9, pp 48 ff for a summary of international legislative developments. This text also includes the Northern Territory *Rights of the Terminally Ill Act* 1995 in full as an appendix. The draconian measures outlawing the promotion of euthanasia came into law in Australia on 6 January 2006 via *The Suicide related Materials Offence Act* and are aimed at bodies like Exit International and the activities of Dr Phillip Nitschke.

[viii] See Kuhse, H and Singer P "Doctors' practices and attitudes regarding voluntary euthanasia", *Medical Journal Australia* 1988; 148, pp 623-627 and Baume, P and O'Malley, E "Euthanasia: attitudes and practices of medical practitioners", *Medical Journal Australia*, 1994; 161, pp 137-144.

[ix] It is claimed by palliative care authorities that fewer than five per cent of terminally ill cancer patients are not able to benefit from pain relief techniques.

[x] See Kenneth Ralph's contribution to Kuhse, H (ed) (1994) *Willing to Listen, Wanting to Die*, Penguin, pp 187-200.

[xi] Reproduced in "Euthanasia and Palliative Care", a paper of the Social Responsibilities Office, Anglican Diocese of Brisbane, Australia.

[xii] Personally I have explained my own wishes regarding euthanasia and dying in my memoir, *Beyond the Boundary*, especially pp 270-272.

[xiii] Hepburn, E (1995) "Moral dilemma of euthanasia", *Courier-Mail*, 23 June 1995, p 17.

2. A PERSONAL REFLECTION (from N.Preston, *Beyond the Boundary – a Memoir*, 2006, Zeus Publications, p. 270-272)

And so, as part of living out the second half of my life, I ask "Given the probability that I will be shadowed by cancer to the point of my death, how would I like to die? How, if at all, can this dying be an enriching experience?" I cannot avoid the question, just as I cannot really manage or forecast its answer. Obviously, I desire to die with a minimal sense of suffering and a maximum sense of loving. Like many I may be fearful as I "walk through the valley of the shadow of death" for even as I have confronted the "little deaths" throughout my life to date, or entered into those contemplative rehearsals which provide a glimpse of the unity between my life and life's myriad wholeness, I often struggle for the courage to engage life while death lurks around the corner. Still, I hope that when I am crossing the ultimate boundary I will find assurance by trusting that even death is part of the gift of life.

When Bazz was crossing that boundary, terminally ill with cancer, we had the vet "put him down". As an ethicist and a cancer survivor I have not hesitated to sign an *advanced health directive* which mandates my carers, under certain circumstances, to deny me extraordinary measures to prolong my life. But what of euthanasia? Just as we showed mercy to Bazz limiting the misery of his dying, is that what I desire for myself? While I may indeed desire such a death, I wonder whether there is often a complexity in the relationship of mind and body peculiar to the human dying situation which other animals do not have. This idea suggests that we should not simply equate euthanasia for non-human animals with euthanasia for our species. Nonetheless, I am thankful that I live in a time when the science and practice of palliative care is becoming more refined and widespread. I certainly pray that medical science will aid me in my dying. That said, there are surely times when the deliberate ending of life is the best that life offers. In other words, there are occasions when euthanasia of human beings is morally justified.

I find somewhat spurious the philosophical attempts to delineate a moral difference between the deliberate use of drugs to relieve pain, knowing that they will result in death, and the deliberate giving of a fatal dose. However, there are important and deeply spiritual considerations which require that the process of euthanasia is pursued in such a way that it respects the whole person, remembering that the answer to the questions about euthanasia will differ from individual to individual. That process must take account of each person's significant relationships and be guided, not simply by the dying person's wishes but also by sound medical judgment about the inevitability

and proximity of death. Furthermore, this matter invites us to clarify our philosophy of suffering. For me that involves addressing both the mystery and the futility of the suffering which precedes death, along with an almost impossible judgment about the distinction and relationship between the sanctity and quality of life. Right to lifers and pro-choice protagonists polarize that relationship and exaggerate that distinction, quite inaccurately I think. Where euthanasia is concerned, ideological or theological standpoints or the heavy hand of the law are not always helpful. It is my view that quality of life assessments should be seen as an extension of reverence for the sanctity of life; and, therefore, medical judgments made on quality of life criteria do not necessarily violate the sanctity of life.

I recognize also that the question of assisted dying and even of assisted suicide has social, cultural and legal ramifications in which my personal, moral wishes must be contextualised. It is one thing for individual doctors, families and patients to act by their consciences in such matters but a much more difficult one for legislators and the courts on behalf of whole societies to make euthanasia the law of the land. The public debate about euthanasia remains an area where social compassion and sensitive community discussion is needed more than sensational campaigns by either side.

From: rorydonn@aol.com
To: Care Inquiry
Subject: Euthanasia
Date: Monday, 15 April 2019 12:50:23 PM

Please do not allow the lives of Queenslanders to be terminated by legal euthanasia. As an anatomical pathologist I sometimes encounter cases where the clinical diagnosis is subsequently proven incorrect. I am concerned that, Queenslanders may be subjected to euthanasia when in fact they have easily treatable conditions which have been misdiagnosed or overlooked. How many medical mistakes have already been buried?

Yours faithfully
Dr. Rory Donnellan
[redacted], Logan Reserve, Qld 4133

From: Eddy Pomfrett
To: Care Inquiry
Subject: Euthanasia, assisted dying.
Date: Monday, 15 April 2019 3:54:22 PM

To Whom it may concern,

I am strongly against assisted dying. The potential for misuse is enormous no matter what safeguards are put in place.

Please register my objection to the bill.

Sincerely,
Edwin Pomfrett. [redacted]

From: Elizebeth Flower
To: Care Inquiry
Subject: Legalising euthanasia would be a dangerous idea for Queensland
Date: Sunday, 14 April 2019 7:42:36 PM

Re: Legalising euthanasia would be a dangerous idea for Queensland

Dear Committee Inquiry,

Prohibition on doctors killing patients is a longstanding rule. The World Medical Association and Australian Medical Association oppose euthanasia on the basis that it undermines the doctor/patient relationship of trust. In countries such as the Netherlands which legalised euthanasia many years ago, elderly folk who fear they are becoming a burden on others, often feel it a duty to end their lives, even though it would be their preference to live longer. Once it is legalised, it tends to lead to greater risks of the vulnerable being coerced, even against their will, into accepting an end to their lives.

Sincerely,
Elizebeth Flower
[redacted]
[redacted]
Chatsworth, AU-QLD 4570

INQUIRY INTO AGED CARE, END OF LIFE AND PALLIATIVE CARE AND VOLUNTARY ASSISTED DYING

It would be appreciated if the following comments could be considered by the Inquiry into Aged Care, End of Life and Palliative Care and Voluntary Assisted Dying.

My comments relate to Voluntary Assisted Dying and are based on my own views.

I am totally in favour of Voluntary Assisted Dying due to the following reasons:

1. Everybody who has a terminal illness should be permitted to determine his/her own time of death through assisted euthanasia, based on the amount of pain he or she is suffering – or at the level of deterioration in some conditions where a debilitating loss of brain function or mobility is imminent. This will provide:

- an easier acceptance by Queenslanders generally that when they die, the prospect of experiencing great pain or experiencing a loss of functions will be dramatically reduced;
- an easier acceptance by an individual at the time of a notification of a terminal illness, for the same reason above;
- a situation where the patients will be able to die with dignity. They can die calmly waiting for sleep without worrying that they may lose control of their bowel and urinary functions, develop a death rattle, hallucinate etc. (all common symptons in the dying) while their grieving family looks on helplessly and suffers through this experience as well.

2. While medication used to control pain for the dying ie palliative care - has advanced, it is not effective in every condition.

3. When a dying person reaches the stage of becoming unresponsive, his/her hearing is the last to go. However that person can't talk to let anyone know he/she is in pain. While there may be some signs that the person is in pain distress (eg moaning), this is not necessarily interpreted by carers or medical staff as a symptom of pain – when it very well could be. Locked in syndrome is no fun for any patient but it would be like a terrible torture if that person was in great pain and was not assisted due to ignorance of the fact.

4. We euthanase animals who are in pain – human beings in Queensland are not afforded the same opportunity. If we want euthanasia we must move to Victoria – or travel to an overseas country like Switzerland. It's not as if legal euthanasia is a new initiative. Active human euthanasia is legal in the Netherlands, Belgium, Colombia, Luxembourg, and Canada. Assisted suicide is legal in Switzerland, Germany, the Netherlands, and in the US states of Washington, Oregon, Colorado, Hawaii, Vermont, Montana, Washington, D.C., and California.

5. While I cannot speak officially for my friends and family, I have not yet found one amongst them who does not agree with euthanasia.

6. All my comments above are qualified with the fact that the access to euthanasia must be tightly controlled to prevent abuse.

7. If Queenslanders could have their say through some sort of ballot, the amount of support for the introduction of euthanasia would be realised – if not clearer.

Thanks for the opportunity to state my views to the Inquiry.

Eve Teague
[redacted]
Shorncliffe
[redacted]
[redacted]

From: Gabrielle Iriks
To: Care Inquiry
Subject: Pilgrimmum@gmail.com
Date: Friday, 5 April 2019 3:32:10 PM

Re: [redacted]

Dear Committee Inquiry,

Prohibition on doctors killing patients is a longstanding rule. The World Medical Association and Australian Medical Association oppose euthanasia on the basis that it undermines the doctor/patient relationship of trust. Prohibition on doctors killing patients is a longstanding rule. Legislative safeguards have proved insufficient to prevent wrongful deaths. Governments have a fundamental responsibility to legislate to protect vulnerable citizens. Coercion cannot be outlawed – whether overt or implied, when euthanasia is an option people are made to feel they are a burden (including people with disabilities who already feel a need to justify their existence.) It is dangerous to legalise euthanasia when palliative care is underfunded. Overseas jurisdictions that have legalised euthanasia and assisted suicide have seen the categories of people to whom euthanasia is applied expand. Suicide contagion is a real risk when governments convey the message that some suicides are considered ‘good’. Legalizing euthanasia undermines suicide prevention messages. Yours sincerely, Gabrielle Iriks

Sincerely,
Gabrielle Iriks
[redacted]

[redacted]
Parkwood, AU-WA 6147

From: Gaylene Wildey
To: Care Inquiry
Subject: Please don"t recommend euthanasia
Date: Friday, 5 April 2019 7:35:29 PM

Re: Please don't recommend euthanasia

Dear Rob Hansen,

I am requesting that you not allow euthanasia into our state. My mother and my sister were terminally ill, my brother and i nursed my mum, my niece and i nursed my sister until she died. They both died naturally. I considered it a privilege and honor to nurse my mum and my sis until their time was up. It is a difficult time for the family caring for a loved one, but the depth of love given was really what they needed. In our case we chose to lovingly care to the end. There is no way i could've asked for euthanasia for my precious mum, or my sis. My sister died with her family and loved ones around her, my mum with me beside her. Both were at peace, there was no fear in them because of all the love. Is it because people are selfish now, they don't want to take responsibility for their parents, who looked after them when were sick. Do they just want to take the easy way out for themselves. Are they really considering the other person who is facing eternity? Lets start caring and loving our sick and lonely loved ones, no matter how hard it is. Lets love them and change their lives for the better. Our lives will change too, for the better. Please consider very carefully before you decide on this. Yours sincerely Gaylene Wildey

Sincerely,
Gaylene Wildey
[redacted]
[redacted]
Robina, AU-QLD 4226

Health Committee
Parliament House Qld 4000
careinquiry@parliament.qld.gov.au
15 April 2019

Graham Hill
[redacted]
A: [redacted] Wishart Qld 4122

Regarding Voluntary Assisted Dying

To the committee

I would like to present my objection to the implementation of Voluntary Assisted Dying in Qld (VAD).

The introduction of VAD changes the nature of the way that life is viewed. Rather than valuing all human life and every effort being made to encourage healing and wholeness, VAD changes the community perception of sick and elderly, they become candidates for the supposedly 'quick and easy solution'.

Extensive and widely available Palliative Care services are in place in Qld and these cater marvelously for people who are currently at end of life stages. In my work as a consultant, I have engaged with team in Palliative Care in Qld Health who pride themselves in achieving stellar outcomes for end of life patients.

VAD introduces a confusion about the purpose of Health Services, Hospitals and Health Personnel as is currently occurring in Victoria. Institutions that have long been renowned as places of hope, healing and overcoming disease are now being tasked with ending life, and the attendant expectation that those who go there may not be expected to return.

I express my opposition to VAD being introduced into Qld

Thank you

Graham Hill

From: Gregory Carle
To: Care Inquiry
Subject: Should euthanasia be allowed in Queensland
Date: Monday, 15 April 2019 12:57:18 PM

Who gives the right to anybody to terminate the life of another? Nobody on earth has that right and so it should remain that way. Even if it were true that those proposing this change were truly genuine what is there to stop somebody down the track from reinterpreting the law to suit themselves so that people suffering some temporary mind numbing illness didn't become a victim of convenience. We condemn people groups that seek to destroy "damaged people or people with unwanted traits" just because. Legalising euthanasia could and would be the thin edge of the wedge and needs to be banned from the very beginning.

Greg Carle
[redacted],
Goondiwindi, Qld 4390

Sent from Yahoo7 Mail on Android

From: helencoz@hotmail.com
To: Care Inquiry
Subject: Legalised assisted dying will inflict terrible mental stress on the elderly
Date: Wednesday, 10 April 2019 6:57:33 AM

Please accept my submission to the inquiry into voluntary assisted dying.

I strongly oppose the legalisation of assisted dying and ask that you rule it out at an early stage from your consideration of legitimate end-of-life care options.

This is because even the availability of legal assisted dying would inflict terrible psychological pressure on elderly or severely ill people to prematurely end their lives when they would otherwise have no desire to do so. And this pressure will only increase if it were ever to become the dominant method for disposing of old people. In such a climate, effective palliative care would be scarce and much more expensive, increasing the pressure to submit to doctors' and relatives' wishes especially when there are fewer people of working age to bear the cost of medical care for the elderly as the population ages.

I therefore pray that the committee will use the opportunity presented by this inquiry to safeguard Queensland from these outcomes before the financial arguments begin to weigh more and more heavily upon the debate. In order to protect the availability of effective palliative care choices, I pray that you will recommend that assisted dying not be legalised.

Yours sincerely,

Helen Cozynsen

[redacted]
Bray Park
QLD 4500

From: Helen Dolden
To: Care Inquiry
Subject: Submission to Inquiry into aged care, end-of-life and palliative care, and voluntary assisted dying
Date: Friday, 12 April 2019 11:52:27 AM

Name: Ms Helen Dolden
Phone: [redacted]
Email: [redacted]
Address: [redacted] Sheldon 4157

I give permission for my submission to appear on your website.

I support legalising VAD because I believe that in a civilised and rational society people must have the right to choose death when their suffering has become intolerable. I am not satisfied that palliative care is always adequate.

My mother-in-law entered a then brand new aged care facility at age 103. We were told that all necessary palliative care was provided. Two weeks before she died she became unable to swallow and was put on morphine. She was given no fluids by nasal tube or by drip. She became increasingly agitated, and during the last week cried out almost non-stop, flailing her arms. Despite the family's pleas, she never seemed to receive enough morphine to ease her distress.

The last weekend was the worst, when her doctor was off and the locum said he could not increase the doctor's morphine prescription, despite her obvious acute distress. (My sister, who was a career nurse with many years in aged care, said this 'weekend' situation often arises).

On the Monday the home called in a 'government' palliative care nurse (for whom they have to pay - the nurse said they were calling her in less frequently), and she immediately increased the morphine. My mother-in-law died the next night.

The whole experience traumatised my partner, his sister and myself. The thought of going into aged care now terrifies us, and we are very clear in our understanding that palliative care can be woefully inadequate (and when the reasons are apparently 'administrative' that is utterly pitiful and insulting).

We think dignity and quality of life are more important than mere existence. We believe that sufficient medication (whether by doctor prescription for self-administration or by doctor administration) must be given to control pain, even if this hastens death. Let those who
insist on life at any cost have that choice.....but let the rest of us choose to die in peace and with dignity.

Thank you.

Helen Dolden

Sent from my iPad

Helen Paine,
[redacted],
Condon. QLD. 4815.
[redacted]

I wish to express my wholehearted agreeance to be able to make the choice for myself to die if I get to the stage that doctors cannot help me to have quality / pain free life and if I get to the stage in my life that I cannot do anything for myself and I am only existing, unable to walk, move, eat and in constant pain, I want to make the decision to say, "**YES, I WANT TO DIE WITH DIGNITY'.**

I watched each of my five sisters die with cancer, they slowly deteriorated, lost all their ability to live life and I had to slowly watch the life drain from them. It still plays on my mind. They wanted someone to just end their suffering and if they had the opportunity to die, my sisters would have opted for it.

I don't want my life to end in this way and if I get to a stage that I cannot do anything for myself and the pain is unbearable or have dementia, I want to be able to say enough is enough and "**DIE WITH DIGNITY.''**

"I agree to have this submission published on the Queensland Parliamentary website."

Regards,
Helen Paine

Submission to HCDSDFVPC (Queensland Parliamentary Committee) Inquiry into Aged-Care, End-of-Life and Palliative Care and Voluntary Assisted Dying

My submission relates to the delivery of palliative care services in Queensland, specifically my family's experience with St Vincent's Palliative Care Hospital in Brisbane.

Palliative care is supposedly "person and family-centred care" with the goal of "optimis(ing) quality of life" for those dying from terminal illness, and supporting them and their families/carers. In fact, St Vincent's Palliative Care's website describes their service this way https://www.svphb.org.au/our-services/clinical-services/palliative-care:

> *…we focus on optimising quality of life for people with life-limiting illness - with **compassion, integrity and dignity**.*
> *we believe that working with **patients and their families** is the key to providing exceptional healthcare. .. It means that we involve you in planning and delivering your care, so we can **meet your individual needs and preferences**.*
> *In providing person-centred care we:*
> - *recognise that each patient and family is different*
> - *help **you and your family** develop healthcare skills and knowledge*
> - *support **you and your family** to make decisions about your care*
> - ***respect your choices, values, beliefs and culture**.*
>
> *We have an experienced and **highly qualified** team of palliative medicine physicians, clinical nurse consultants, specialist nurses, allied health professionals, counsellors and pastoral carers. They are **leaders in their fields** who will support you **and those closest to you**.*

This sets an expectation for the highest quality palliative care service, supporting both the terminally ill person and their family. Unfortunately, this was not my family's experience.

Question 19 – Do the standards of palliative care and end-of-life care provided in Queensland meet clients' and the community's expectations?

My experience with St Vincent's Palliative Care, for the palliation and end-of-life care of my mother, did not meet my and my family's ("our") expectations. The degree to which some of the nurses failed us and failed to meet the hospital's aims (described above) was unimaginable.

My mum died from terminal lung cancer. She was 75. For approximately two weeks, from 25 November 2017, she was a patient in bed 9, level 3, St Vincent's Brisbane, having admitted herself (at our encouragement) in response to coughing up massive blood clots. She died there two weeks later, at 4.50am, on Saturday, 9 December 2017. We (her family) knew she was dying and we expected it any day. (By this stage she had outlived her 2 month prognosis by a couple of weeks.) However, we were not adequately prepared for her end-of-life symptoms, and were not adequately supported through the process.

Before entering hospital, we had been caring for her at home. She had increasing dyspnoea and had been gradually losing her mobility, someone always had to escort her to the bathroom and shower her. She wanted to die at home, but this new symptom of coughing up blood clots was frightening, so she agreed to go to hospital. If we had had access to a community nurse then, perhaps we could have kept her at home. Unfortunately, she was a very proud woman and had previously rejected home nursing help. We knew that arranging a nurse could take weeks, because we had tried it earlier, but mum had been too proud to follow through with the home help when she was still capable of doing things herself, and she had changed her mind.

I have mixed feelings now about having encouraged her to go to hospital and wish we had cared for her at home. Mixed, because for most of the two weeks she was there, mum was treated compassionately and professionally by the doctors and nurses who looked after her, and my family was well-informed and supported – on one occasion, a nurse had stayed with me and mum while she coughed blood and we found it reassuring to have that support; on their rounds, the doctors assessed mum's condition and informed us about likely future developments; they also held two family meetings with us in the first week, to provide information. However, a terrible incident I experienced at the end of a mum's life was simply not acceptable. I strongly believe the nursing staff who were on duty in hospital on the night mum died mismanaged mum's care and neglected to share information with and support me and my family in the last hours of her life and immediately following her death. There were also some earlier, minor incidents of poor communication and lack of compassion from nurses, and loss of dignity for mum. If St Vincent's is the best palliative care the community can hope for in Brisbane, I would rather struggle at home than go to hospital.

Her last day of life was the worst. That day, mum was not cared for properly, with the dignity she deserved, and I believe she died in fear, and possibly pain, gasping for breath (agonal breathing) for at least an hour. We, her family, were not adequately helped to understand what was happening to her, nor helped to manage our own distress. Instead, the nursing staff on duty and their actions/inactions that night increased our distress (beyond the difficulty of dealing with mum's imminent death).

Then, after mum died, the nurses we had come to know during the two weeks were nowhere to be seen, while those who dealt with us were officious and gave false platitudes, which we found scripted, ingenuous and lacking compassion.

St Vincent's Hospital's system, protocols and culture did not support us and instead contributed to our suffering. Specifically:

1. **Some nursing staff lacked compassion and their communication style was inappropriate for a palliative care hospital**

I experienced a communication breakdown with the staff at the hospital, which meant I was not prepared for nor supported through the distressing symptoms mum experienced as she was dying. I experienced a lack of genuine compassion from staff during mum's final hours. I also felt helpless to advocate for mum with the staff who didn't listen or respond appropriately. I think mum may have suffered. I suffered compounded emotional distress.

We were not offered a family meeting during the last days of mum's life, so I didn't really know what to expect at the end. She was actively dying. But we didn't know that (no one would tell us), so I was alone with mum that last night. Around midnight, I had rung for the nurses as mum was having trouble coughing up mucous or blood and was becoming distressed. Nobody came. Suddenly, mum looked at me, wide-eyed and terrified, she was gurgling and red in the face and her eyes were bulging out, then she choked on her own mucous (or blood) and fell into a coma, or had a stroke and went limp. I hit the emergency buzzer as multiple doctors had previously told me I could do if mum choked and was distressed.

The nurse in charge, who attended, then spent many precious minutes telling me off for pressing the emergency buzzer instead of getting some medication to calm mum and make her comfortable, and reassuring me.

> Extract from my notes of that night:
> Nurse: "*What are you doing, you can't press that buzzer, it's for people who need to be resuscitated*."
> Me: "*Mum's choking. Dr X said I could. Please get her a sedative, she's frightened and choking to death*."
> Nurse: "*No. You listen to me, I don't care what Dr X said, you cannot be ringing that buzzer, it's against hospital regulations*."
> Me: "*My mum's choking to death, please can you get her a sedative.*"
> Nurse: "*Listen to me. Your mum is FINE! I was in the other room drawing up medications for another patient who is dying. What are you thinking? I have many patients to attend to, I can't just come running whenever you call me. This is just not appropriate."*
> Me: "*Alright, I'm sorry, can we argue about this later? Would you just go get the medicine? My mum is dying, she's choking, she's scared and needs to be sedated."*
> Nurse: "*No! No, your mum is not choking, she is not afraid, she is fine, look at her. You cannot behave like this. And you can not push that button. It's highly inappropriate. Which one did you push?*" (searching for a way to turn it off)
> Me: "*that one*." (pointing to button, which nurse turns off). "*Please, can you just help my mum and get her the medicine.*"
> Nurse: "*No. Your mum is fine. You must listen to me. I'm trying to tell you, you can't press that buzzer*."
> Me: "*Ok. You weren't here, you don't know my mum, you didn't see her face, she's afraid. Dr X said I could.*"
> Nurse: "*Well, Dr X is not in charge of this hospital.*"
> Me: "*Then get out! If you won't help her, get out!*"
> Nurse: "*Ohhhhhh, no. You can't talk to me like this. Your behaviour is highly inappropriate, you're being very rude. And Dr X isn't in charge around here.*"
> Me (looking into mum's vacant eyes): "*Mum, just go! They're not going to help you.*"
> Nurse: "*Your behaviour is highly inappropriate…….*" (this went on for ages, then finally): "*I can go get something to clear up those secretions. I'm going to have to have words with Dr X about this.*" (referring to the doctor who told me I could press the buzzer, then walks out).

I was not prepared for the nurse yelling at me. Witnessing your loved one choking in fear is incredibly distressing. Being yelled at by a nurse on top of that is just unimaginable. I had assumed all the staff at the hospital would be compassionate and supportive, but this particular nurse was not.

I found this nurse insensitive, non-cooperative and authoritative. She showed disrespect for the doctors and took it upon herself to decide what was, in her view, in the best interests of my mum and our family. I felt pushed around by her, even after she returned with the medication, when she grabbed me for a long hug I didn't want, then sat me down with a cup of tea and started making arrangements to rearrange the room with extra chairs. The memory of arguing with her as my mum died does little to support my trust in hospitals.

The above exchange triggered an irreparable hostility from the nurses on duty that night toward me and my family, which lasted for the final five hours of mum's life, and thereafter. I called my sister and partner to come in as I thought mum had had a stroke and I needed their support (I was unsure what had happened to mum). The nursing manager spoke to us and tried to repair the situation, but trust was broken with that nurse, so we asked for a new nurse. We were not offered access to a doctor and assumed there were no doctors on duty in the middle of the night. The new nurse subsequently treated us poorly as well; we believe she was probably coached by her colleague to see the exchange from the nurse's perspective.

I was not prepared for mum's subsequent breathing changes. Mum then moved through various stages of death rattle and agonal breathing (full body gasps) for the next five hours. Having no support or compassion from the hospital staff through that experience was terrible. My sister and I were left floundering in bewilderment for those final five hours as mum died, experiencing a complete loss of communication and cooperation from the nurses. Mum's level of comfort during her subsequent death rattle and final hour of agonal breathing was not explained and no reassurances were given.

The new nurse didn't check on mum at all without us calling using the buzzer. If we asked a question, the nurse gave a hostile one-word answer. We didn't know what medications she was giving her, whether mum's pain was being adequately managed (they were terminally slow in getting her medicines), or whether she was suffering. In mum's last hour, while she was full body gasping, my sister asked the nurse how we could tell that mum was in pain and needed pain relief. The nurse said, "that's for us to use our judgement". My sister then asked what she thought and only then did the nurse say she thought mum needed some pain relief. The communication breakdown did not help mum receive pain relief quickly, so she may have suffered as a result.

I certainly suffered a great deal watching mum go through her final hour of agonal (gasping) breathing. And I am so hurt and disappointed that the palliative care hospital did nothing to help alleviate that. I knew mum was going to die; it was my job to make sure she had a comfortable, pain-free death. I am not sure that was the case and I continue to question whether I could have done better at home.

2. We were not given sufficient notice of mum's impending death

I wasn't given enough notice of when to call family who wanted to keep a bedside vigil, despite mum's end-of-life symptoms being self-evident for at least 12 hours and repeatedly asking for the advice. The nurses kept telling me they didn't know. They wanted me to order her food for the next day. Perhaps mum was not assessed carefully enough; nobody listened to my feedback about her status. As a result, mum held on too long, suffering to allow time for family members to get there.

In the first week and a half of her hospitalisation, the doctors couldn't tell us how long it would be before mum died and we accepted this, understanding everyone's experience differs. However, in the last 24-36 hours, mum's symptoms indicated she could die soon (I googled it – loss of consciousness, Cheyenne-Stokes breathing, apnoea, incontinence, from the previous night and all through that last day). I kept asking for information as some family members wanted to be there to keep vigil.

Around midnight, I was alone with mum when she had the choking episode and began the death rattle breathing. I could have avoided being alone (and coped better with family support) if I had known she might die that night. If mum had been properly monitored and assessed, the staff, with all their expertise, should have been able to advise me earlier that mum was LIKELY to die within hours, so I could have had someone with me.

When my sister got to the hospital (about 4 hours before mum died), we continued to ask what mum's status was and how long it might be. As the experts, the staff should have known that mum's death may have occurred in a matter of hours and been able to tell us so clearly. They would not give us ANY indication of a timeframe until mum started the agonal (gasping) breathing, an hour before she died. An hour before she died, the nurse said mum was hanging on, "waiting for something". I believe mum waited an hour for my brother to arrive and suffered unnecessarily as a consequence. If the nurses had suggested I call my brother earlier, perhaps mum would not have had to "wait" for him.

3. Inconsistency in the way nurses preserved mum's dignity and respected her wishes.

I had assumed that the staff in one of the top palliative care hospitals in the country, delivering "person-centred care", as described on the hospital's website, would have been specially trained to help dying people and their families in a personalised, compassionate way. But this was not always the case. An example of disrespect occurred in the first week when I took a short break to have dinner with my partner. A nurse had tried to make mum walk to the bathroom unassisted, initially refusing to help her, saying she should be using a walker. This had shamed mum for being unable to walk. The nurse had also belittled her for not washing her hands quickly enough, saying, "come on, aren't you done yet?" Naturally, mum was upset by this treatment. The indignity of being a 75-year-old woman, capable just a few weeks ago, dying, and having to ask someone to help her to the bathroom was made worse by an uncaring nurse. It also made me feel less comfortable about leaving her alone for any length of time.

As mum got closer to death, and was less able to move or communicate, some of the nursing staff began to treat her impersonally and speak about her as though she was part of a collective of dying people. Or they spoke about mum in front of her as though she wasn't there. Mum looked anxious when her head was dropped lower than her feet by the nurses who turned and changed her, but the nurses didn't speak to her or reassure her. I worried they were frightening her or upsetting her even though she couldn't tell us. They often tried to get us to leave the room when they changed her.

Her wishes were not consistently respected. On the night mum died, I was not able to successfully advocate for her. The nurse in charge brought a male nurse to help change mum. Mum had been clear all along she did not want to be changed by a male, a preference that was respected when she was more conscious. That night, the nurse in charge did not show any empathy – she merely said there was no choice and the male nurse had changed mum the day before anyway (which I doubted). I felt frustrated and helpless at not being listened to. I just hoped mum was not aware of what was happening. That loss of dignity was hurtful.

4. **The hospital seemed short staffed and managed by untrained/unspecialised, or de-sensitised nurses who had a lot of authority.**

In the last hours of mum's life, the inexperience of nurses left us feeling confused. When mum's breathing changed – she was rattling, then moaning, then gasping – we found it very distressing. We were given vague explanations: "your mum cannot clear her secretions; the moaning is just part of it" – "it" being "the death process". These words were not particularly helpful, did nothing to address mum's comfort level, or reassure us in any way. The inexperienced nurses just stood there observing, having no clue as to what to say or do to help. I felt it was better if they just they left us be.

Other nurses seemed de-sensitised, e.g. the nurse who yelled at me as mum was dying, when she should have been getting medications to make mum comfortable, who also listed the symptoms of active dying in front of mum. While she had seen it all before, this was my first time seeing someone (someone I loved) die. She spoke to me as though I should have known better.

Nurses were non-responsive to buzzers and some refused to stay and support us during mum's distressing symptoms (e.g. coughing up blood clots), using the excuse they were too busy. I hate to imagine the suffering endured by people without family there to support them. The slowness with which nurses responded to calls and drew up pain medications was unacceptable, especially in the last days when the pain got worse. They had no sense of urgency, which prolonged mum's suffering. By appearances, at the end, I doubt she was given adequate and timely pain medications as promised by the doctors on earlier visits and as requested by me (I can't be sure whether her pain was adequately managed, and I don't know how aware she was).

As there wasn't a doctor on duty, the nurses had autonomy to decide mum's medication dosages, within a dosage range written up by the doctors, without referring to us or a doctor. On one occasion, the nurses told us they'd given mum extra Oxynorm (up from 5mg to 7.5mg). Later, the doctor said only 5mg was written up in her chart. Another time, medication

she'd been given was not written up in her chart until much later on. I think there's a potential risk this could cause staff confusion and accidental dosage errors. It was difficult for me to make the adjustment from having a full-time, hands-on carer role, supervising medications and care, to being excluded from those decisions.

5. After mum died, the nursing staff treated us so poorly and without compassion.

After mum died, we were given time to be alone with her body. Not one of the nurses who had cared for mum over the previous two weeks came to say anything to us. My sister brother and me had had lived there with her and done half their job for them by staying at that hospital 24/7. We had walked mum to and from the toilet and helped her into bed, shifted her bed up and down, fed her, called for medications, been with her when she vomited and coughed blood, basically cared for her so they didn't need to check on her all of the time. And we had gotten to know the nurses too, during that time. After mum died, they didn't approach us at all. A nurse who had cared for my mum very well came to the door, but she didn't enter and never said anything to us.

At some point in the morning, a random nurse who we'd never met entered the room. She acted as though she knew my mum well, but none of my family knew her. It was strange and felt false. We had to go to the nurse's station to ask for someone to explain what we should do next. A nurse we didn't know explained the process in a cold and officious way.

As we were leaving the hospital, the nurse who had attended mum during the night called out to stop my dad. She made a point of saying directly to him and only him, "*I'm very sorry for your loss*." He was the LEAST involved in mum's care and wasn't willing to come in that night and he was the only one who was shown any compassion. Not one bit of kindness or compassion was shown to me, my sister or brother.

Some weeks later, we received a letter in the mail offering us bereavement counselling through the hospital. We refused, having lost all trust in the hospital during that last night when mum died.

6. The hospital did not satisfactorily respond to our complaint

On 2 February 2018, my sister and I met with the doctors, nursing manager and psychologist to give a verbal complaint about our experience and seek an apology. We explained we didn't want anyone else to experience what we had gone through and wanted to know what the hospital would do about it. The doctors appeared shocked at what had happened, explained mum must have had a respiratory event that caused hypoxia, and that the nurse should have focused her attention on reassuring me and treating my mum (i.e. should have focussed on WHY I had pressed the emergency buzzer rather than THAT I had pressed it). They apologised. I asked for a follow up on what they were going to do to make sure this didn't happen to anyone else. They said they would review the evidence, including the buzzer logs to assess the timeframes between when I had pressed it and response times, and speak to the nurse on duty, then get back to me.

On 4 April 2018, I called the hospital to follow up as I had not heard anything. The nursing manager apologised for not getting back to me, but: "*there were a lot of things going on;* [the nurse in question] *had just returned from 6 weeks leave overseas*." Her response was quite broad and didn't specifically address the things we raised.

She said she had spoken with the nurse about her communication style and made her aware of the hospital's protocol for escalation using the emergency buzzer (as I had correctly done). She said the nurse was surprised that we had taken her so negatively as she was only trying to help and didn't mean to sound abrupt. She suggested the nurse undertake further training in communication and dealing with difficult situations and explained staff can have more than one difficult situation occurring at once.

She hadn't checked the buzzer logs because the system had been down for a couple weeks, there had been other things going on, but she "*didn't think it would show much anyway*". She also told me mum didn't technically choke.

Regarding why we weren't notified to call family in, she said it's difficult to know when death will occur and impossible to give timeframes as they see all kinds of scenarios. She said the doctors had warned us that mum was going to die.

I told her I wasn't exactly satisfied with her response, mainly because she put it all down to just a misunderstanding. I asked her to provide her response in writing. She then told me she was retiring and would hand the matter over to her successor to manage.

On 5 July 2018, I received the written response from the hospital (which I have attached). The response goes some way toward addressing our concerns – the hospital had tried to find a way to prevent this from happening to anyone else. However, it took too long for them to respond – 5 months from when the complaint was made. And this extends the bereavement process.

I also disagree that "*Night staff had a conversation with the family at 2300 on 8/12/17 and explained the end of life process and care pathways*" – what actually happened was: I asked the nurse "*should I go to sleep, stay awake to keep vigil or call my sister*" the nurse said, "*we don't know, your mum could die tonight, but I think it's too soon to call your sister*" and then she rattled off some symptoms to watch out for, many of which mum had already exhibited for hours. In any case, I don't know what they mean when they refer to "*end of life pathways*". This is hospital jargon which does not help me.

Although my acute distress has healed, I wanted to make this submission to raise awareness that the end of life process is not always straight forward for everyone. Often times it is fraught with confusion and difficulty even when connected with the hospital system which is supposed to be staffed by highly trained professionals.

Question 21 – How can the delivery of palliative care and end-of-life services in Queensland be improved?

We do need to improve the palliative care system in hospitals. Some suggestions I have include:

- palliative care nurses need to be highly specialised and qualified to work in palliative care – don't send in a nurse who just stands around not helping during the dying process – every moment of a terminally ill person's last days is precious
- palliative care nurses need more specialised training in communication and compassionate responses (e.g. learning about maintaining dignity through language and behaviour; avoiding inappropriate boundary crossing through hugging; empathy)
- a rotational job program may help to give palliative care nursing staff a break from witnessing dying every day and stop them from becoming de-sensitised to people's experiences, making them better able to offer genuine support
- more staffing resources (doctors and nurses) are needed – there should be a doctor available at night and all patients and their families need to be informed there is one
- we need death doulas, who exist outside the hospital system/medical model, but who have experience in supporting and advocating for the terminally ill and their families in and out of hospital
- there should be frank resource materials for families about what they might experience at the end of life and how they can cope with the experience, e.g. when to contact family members, when they should use the emergency buzzer, etc – let's not be afraid to be direct because death is profound and graphic
- families could use some training in how to support the terminally ill person through the palliative care and the death process, e.g. something like pre-natal classes, but for the families of the dying
- hospitals need to improve their response speed, e.g. a 24-hour pharmacist stationed within the palliative care hospital ward could draw up medications, so all the nurses have to do is administer them
- the health system needs to be more flexible to accommodate the rapid decline experienced by terminally ill people – e.g. we need to reduce the red-tape and wait times involved in getting home nursing care (people want to die at home).

Q.25 Should voluntary assisted dying (VAD) be allowed in Queensland? Why/why not?

I wish to quickly share my views on the desirability of supporting voluntary assisted dying (VAD), in particular how it relates to palliative care. I understand it has been suggested there is no cross-over between VAD and and palliation, but I disagree. While I respect the need for protective systems and protocols around VAD to ensure it occurs in a controlled environment when someone has chosen to end their life on some future date, I also point out the fear (of prosecution) within the medical profession – doctors, nurses – around stepping over some arbitrary line between medicating for palliation and overmedicating so that it then ends someone's life. I believe the line is arbitrary because doctors and hospitals treat this differently and inconsistently based on their own personal belief systems and the pressures and indoctrination of the medical profession, which is aimed at prolonging life. Anecdotally, I know this varies depending on who the treating professionals are.

I believe terminally ill people are being left to suffer unnecessarily because the level of medication they require to feel comfortable might (just might) be enough to end their lives. Take for example my friend's mother who was unable to receive necessary painkillers as her liver could not tolerate them since it was already destroyed by cancer. She was forced to suffer and my friend with her. And with my own mother, the nurses refused to give her a sedative when I asked for one, even though I was her enduring power of attorney for health matters and the doctors had assured me if my mother choked or experienced fear at the end of her life they would quickly sedate her. I was told the level of my mum's pain medication was decreased as she got closer to death. She could not tolerate morphine and was on a continual low dosage of fentanyl with irregular top ups for breakthrough pain (when we guessed she was feeling pain and when the nurses weren't too busy elsewhere to be able to attend to her and administer it). When she could speak, she told us it hurt all over. I was not at that point concerned that mum would be given a lethal dosage of painkillers. I was chiefly concerned with her not suffering and would have supported her getting higher dosages of medication, even if that shortened her life (and suffering) by those last few, agonising hours.

If doctors and nurses were not so frightened of litigation, perhaps they could assist people to feel more comfortable (at their and their family's request). So I believe we do need to relax the laws on VAD so that people are given more choices. As many before me have said, we treat our pets better than we treat each other.

Conclusion

How can a hospital claim to adequately support people's comfort levels at end of life if nurses are too busy, impatient and too slow in responding to a person's pain?

A terminally ill person is often supported on a rotational basis by different family members who leave to attend to their own lives for a while and take it in shifts to be with the person. The hospital needs to improve the way they communicate with the whole family, not just sharing a piece of information with one family member and hoping it will be passed on to the next person. My family should have been offered more frequent family meetings, especially as mum deteriorated toward death. Potential symptoms of end-of-life and active dying should have been explained to the whole family group and we should have received reassurance about how her comfort would be managed and what we could do to help.

My mother had lung cancer. Obviously, this meant she had breathing issues the whole time she was in hospital (and before). She also coughed blood. She had pleurisy and a collapsed lung. Surely someone in the hospital could have predicted she might go into respiratory distress and explained the symptoms to us as a family, prepared us for what we might encounter.

In the absence of that family meeting, it would have been beneficial if the nurses on duty the night she died had offered some kind of reassurance, especially that mum was not suffering.

Hospitalisation was a last resort for mum, only taken as we could no longer care for her at home, something we had been doing for a couple of months beforehand. Naturally, we were still very engaged in her care to the end. We continued to take an interest in the dosing and

dispensing of her medication, were still very engaged in medical decisions and we supported her physically and emotionally as she declined. The hospital staff should have worked with us better and had the goal of helping us through the process.

Hospitals must treat people with respect and dignity on each and every day, and in each moment of their last days of life, and acknowledge and support their high level needs during end stage cancer. Dying without compassion and dignity in a top palliative care hospital in this country, where every human life is valuable, is simply unjustifiable. If nursing staff cannot be compassionate toward people who are about to die and their families, they need a new profession.

Jaana Hokkanen

Subject: FW: St Vincent's hospital
Attachments: Mrs Hokkanen.docx

Begin forwarded message:

From: [redacted]
Date: 5 July 2018 at 11:14:35 am AEST
To: [redacted]
Subject: St Vincent's hospital

Dear Jaana
How are you?
Its [redacted] here, I am the acting NUM on palliative care at St Vincent's hospital. I spoke to you over the phone regarding the reply to your queries in relation to Mrs Hokkanen's passing here at St Vincent's. Please find attached a brief reply to your concerns.
Please contact me, should you have any further concerns in this regard.
Many thanks.
Kind Regards
[redacted]

Dear Jaana

I am writing in reply to the points you had asked some clarification /response for. I am very sorry that you felt that Mrs Hokkanen's end of life symptoms were not managed well and the staff failed to provide compassionate care to you and Susan.

As per Mrs Hokkanen's notes and upon talking to the Dr involved, I just want to mention these following things:

- She was reviewed by medical team on 8/12/18 morning and they had concluded that her condition was deteriorating and probably heading towards the end as she was barely responding that morning.
- They had increased her syringe driver significantly to make her journey as comfortable as possible till the end.
- The syringe driver orders get reviewed every 24 hours.
- All the terminal drug orders were charted
- Night staff had a conversation with the family at 2300 on 8/12/17 and explained the end of life process and care pathways.
- End of life pathways were commenced at 0100 on the 9/12/17
- Mrs Hokkanen was given fentanyl (for pain) 75mcg at 2015, 0020 and 0400, Glycopyrrolate 400mcg (for excessive secretions) at 0035 and 0345 and Midazolam (for restlessness and anxiety) at 2015, 0020 and 0400, as per ordered, on 8/12/17
- Nurse Manager after hours was notified and also came to the ward to assess the situation for support.
- Secretions/ rattly breathing is a part of dying process and in 7% of cases medications are not 100% effective to dry up the secretions.
- Night staff tried their best to communicate to family and provide compassionate and dignified care to patient and family.
- Mrs Hokkanen passed away at 0455.

On behalf of our team, I would like to extend our deepest apology about your experience. All staff involved has been spoken to and we have taken the necessary measures to ensure no one feels the way you felt. A riskman report has been entered in St Vincent's Hospital Brisbane's quality improvement system, which is permanent record of this incident about your experience. The doctors, Social worker and the counsellor have developed a new booklet for families to help them understand and deal with the process post the death of their family member. We again offer you and other family members to see our counsellor for the ongoing support, as we understand it has been a very difficult time.

In the end I would like to say that, we take great pride in our service and results and this impacts us deeply as well.

We value your feedback and constantly strive to improve from the past experiences.

Thanking You

Kind regards

[redacted]

From: Jean Weber
To: Care Inquiry
Subject: Submission to the inquiry into aged care, end-of-life and palliative care
Date: Sunday, 7 April 2019 3:20:39 PM

I support voluntary assisted dying because I think that should be my right as a human being. I am 76 and in good health, but I want to know that I can die with dignity when the time comes.

I agree to have my submission published.

Jean Weber
[redacted]
Condon 4815
[redacted]

From: Jennie Bonell
To: Care Inquiry
Subject: Submission re voluntary assisted dying
Date: Monday, 15 April 2019 12:52:43 PM

To Whom it may concern,
I, Jennifer Bonell of [redacted] Toowoomba, wish it to be known that I strongly oppose the introduction of V A D. I believe as a Christian that life is given by God and from conception until death, only He has the right to end a life.
Even apart from my Christian belief, I consider it would be too dangerous because it would be next to impossible to have sufficient controls in place to ensure such dying would in fact be voluntary.
I appreciate the opportunity to express my opinion.
Jennie Bonell
Sent from my iPad

We are a couple in our late sixties. As we approach an advanced age, we have no desire to be a resident in a nursing home with no quality of life either through physical infirmity or advanced dementia. We would rather have the choice to voluntarily terminate our lives before degenerating to that state. At that point we may not yet be in significant physical pain. The issue is not just about unbearable pain, it is about **quality of life**. Palliative care to prolong a physical existence with no quality of life is not the answer.

We wish to be able to make a decision on our end of life while we still have the capacity to do so and have our wishes complied with. We have witnessed parents and other close relatives slide into a mental state which provided no quality of life even though they were suffering no unbearable pain or physical distress. Under no circumstances do we wish to endure that ending for ourselves and would entertain going to Switzerland to end our life with dignity if that is what we need to do. That said, we may need to make that decision earlier than otherwise required.

Surely with the high and increasing cost of aged care and end of life care it makes more economic sense to allow people to make the decision to terminate their life at the time of their own choosing rather than keeping them alive just for the sake of continued existence.

Without a change in the euthanasia laws in this state and nation, we (and others) may possibly be driven to attempt various forms of non-assisted suicide, however these are uncertain and mostly do not allow death with dignity.

We do not believe our choice in this matter should be decided by pressure groups from churches of which we are not members, and the doctrines of which we do not necessarily endorse.

Any VAD legislation should not only provide the opportunity for persons with physical infirmities (which may or may not involve unbearable pain) to end their lives with dignity, it should also provide for persons while still of sound mind to indicate a desire for their life to be terminated when they reach a predetermined state of mental incapacity and for that wish to be enacted.

VAD legislation should allow for assisted suicide not only by a medical practitioner but also by a trusted family member or friend provided there is clear evidence of the desire for this to happen, e.g. by a sworn and witnessed statement or a video recording. There would need to be clear evidence of undue coercion or that the person was unaware of what they were doing for this to be overruled.

Counselling services should be made available but should not be compulsory, nor should the opinion of a counsellor be allowed to override the decision of an individual that his or her life should be terminated.

Doctors should not be compelled to assist with the termination of life, though there could be a voluntary register of doctors willing to do so in certain circumstances.

We urge the Queensland Parliament to implement Voluntary Assisted Dying legislation as early as practicable. The overriding consideration should be the welfare of individuals and their right of self-determination, not the doctrines of religious or other pressure groups.

Jill Douglas and Greg Jones
[redacted]
Centenary Heights 4350

[redacted]

From: Joan Reading
To: Care Inquiry
Subject: Dying with dignity
Date: Friday, 12 April 2019 1:09:03 PM

I truly believe in voluntary assisted dying should be legalised in Queensland

Sincerely Joan Reading

[redacted]

Sent from my iPad

From: John Brancatisano
To: Care Inquiry
Subject: Legalising euthanasia would be a dangerous idea for Queensland.
Date: Sunday, 14 April 2019 7:51:48 PM

Re: Legalising euthanasia would be a dangerous idea for Queensland.

Dear Committee Inquiry,

Dear Sir/Madam Euthanasia is misplaced compassion. It instigates the direct action of a doctor assisting a person with a terminal illness to end his / her life by means of use of lethal medicine .This such law cannot be made safe. We have no right to kill people or assist them to their own suicide. These actions are morally and ethically wrong. To legalise euthanasia would threaten the lives of vulnerable people. The care and civil protection that are given to the sick and suffering would greatly diminish thereby exploiting and exposing them to greater risk. Euthanasia would at first be allowed only for people with a terminal illness. Overtime this law could be loosened to the extent that would allow for people who suffer from depression and disabled people to prematurely end their lives. This has been shown in countries such as Belgium who have allowed euthanasia for children and to the mentally ill. In Holland they have allowed euthanasia as law to end elderly peoples' lives due to them being a burden to society. Legalising euthanasia would put the medical staff at risk. It would place unreasonable pressure on them .In May 2002 on the Gold Coast, Nancy Crick was euthanised. It was speculated she had terminal cancer.. An autopsy revealed that she was not terminally ill or had any trace of cancer. As Dr Phillip Nitschke quoted " It did not matter whether she was dying , had cancer or what her body weight was. All that mattered was that she wanted to kill herself and wanted help to do it." His belief was "People may want to end their lives at any stage and for any reason." Euthanasia goes far from prolonging life. It is direct and intentional killing. The medical staff work very hard to reduce pain and promote healing . Their responsibility is to make life comfortable for the terminally ill. This is done through palliative care. As human beings we are responsible to love and care for the sick and suffering. As medical advances lead to longer and healthier lives, we must appreciate people who are elderly or have other disabilities as a gift to society. By doing this, we are teaching the next generation a set of morals. Our ability to care for the vulnerable reflects on who we are as a nation It would be very much appreciated if you gave this issue a great deal of thought Yours sincerely John Brancatisano

Sincerely,
John Brancatisano
[redacted]
[redacted]
Clifton Springs, AU-VIC 3222

From: thedean@lycos.com
To: Care Inquiry
Subject: Submission to the Inquiry into Voluntary Assisted Dying
Date: Sunday, 14 April 2019 8:42:49 PM

After seeing my grandmother, and my father, and some very close friends, some of middle age, all die a very slow and lingering and traumatically agonising death, I now believe it is well and truly time for a civilised society to introduce Voluntary Assisted Laws to give people a choice if they have had enough, to die with dignity. And at a time of their choosing.

So I vote YES YES YES to VAD.

Signed
John Maloney

My name is
JOHN MALONEY
AGE 65

My Address is
[redacted]
Surfers Paradise. QUEENSLAND 4214

My Email is
[redacted]

Telephone:
[redacted]

Ms Jan Hall
[redacted]
BANKSIA BEACH QLD 4507

2 April 2019

Committee Secretary
Health Committee
PARLIAMENT HOUSE QLD 4000

Dear Sir/Madam

SUBMISSION – VOLUNTARY ASSISTED DYING (VAD) IN QUEENSLAND

I wish to make a formal submission in support of changes to legislation relating to voluntary assisted dying (VAD).

I am 72 years of age and facing the inevitable ailing health and prolonged periods of sickness which complement the final years of living. I am now the age my Mum was when she died of bowel cancer and cannot help but to reflect on her death and the death I will face when the time comes.

My Mum fought a good battle but sadly succumbed to the cancer in 1997. During her final months, I left my family to go and care for my Mum fulltime in her own home. Because of the commitment of her family, she was afforded the opportunity to die at home with loved ones at her side in familiar surroundings. After speaking with others who have lost family members, I understand this is an opportunity few are given.

Although Mum was surrounded by family, she suffered terribly and indignantly. The cancer tore through her internal organs, shutting them down one by one. She began vomiting faeces and soiling herself. My Mum had been such an active, vibrant soul, yet here she was wearing nappies and relying on others to clean her up, invading her intimate privacy in an attempt to maintain some degree of comfort and hygiene.

My Mum deserved so much more. She openly voiced her desire to die when her health deteriorated to a point of hopelessness. Mum deserved to die with dignity at a time of her choosing, at a time that only she could identify as the time her suffering should stop.

My Mum supported voluntary assisted dying.

Furthermore, my 93 year old mother-in-law is currently in aged-care dying slowly of old age. She can no longer move independently and relies on facility staff to move her around. She is totally reliant on carers for showering, feeding and dressing. She regularly suffers from respiratory infections and urinary tract infections.

Like my own Mum, my mother-in-law has also had to resort to wearing nappies, spending indefinite periods of time in her own urine and excrement. Facility carers appear overworked and get around to changing her when they can. My mother-in-law wants to die, she has said so. Queensland's

current legislation, however, prevents this from happening and so she will continue to suffer until her body surrenders.

There is no better time than now to address Queensland's need for the implementation of voluntary assisted dying legislation. I don't want to die in the same indignant way my Mum did. Nor do I want that for my own children and grandchildren in the future.

Please take the time to listen to the people of Queensland and act now. After all, we are the Smart State. Lead the way.

For your consideration.

Yours sincerely,

Jan Hall

From: Kay christensen
To: Care Inquiry
Subject: Palliative care must be the priority
Date: Sunday, 14 April 2019 6:38:28 PM

Re: Palliative care must be the priority

Dear Rob Hansen,

Euthanasia, or assisted dying as it is termed, is incompatible with a society which values human life & seeks to protect the vulnerable. Legalized assisted dying will change the community's view of the elderly, disabled & ill, representing an expedient way out which will save time, effort & government funding. It will undoubtedly be sought both by people who aren't necessarily dying but who fear the changed circumstances deterioration may bring, as well as by their carers. No safeguards will prevent people from feeling their medical condition is becoming a burden on those around them & this will eventually pressure them into choosing assisted dying. There are no safeguards in the legislation that will prevent it from abuse; even if such safeguards were to be included in the original legislation, experience from overseas illustrates beyond any doubt that the boundaries will be changed, often much faster than we might expect. It is commonly argued that people should be able to escape unbearable pain, but with modern medicine very few people suffer excruciating pain at the end of life. Pain can be controlled; this is the essence of palliative care. Euthanasia should never be looked upon as a replacement for palliative care in order to minimize the health dollar being spent upon end of life situations.

Sincerely,
Kay christensen
[redacted]

[redacted]
Robina, AU-QLD 4226

From: Kel Ackland
To: Care Inquiry
Subject: Submission.
Date: Sunday, 7 April 2019 2:08:01 PM

My name is Kel Ackland. I live at [redacted], Bushland Beach.4818. My phone No is [redacted]. E-mail address is [redacted] .

My mother died in a nursing home in Townsville in1999, when she was 94. For the last 2 years of her life my family and I watched her die very, very slowly. She was in pain for a lot of the time with regular Morphine injections. If she were a family pet the RSPCA would have a good case for prosecution.

Several years down life's journey my wife developed Alzheimer's. I was her primary carer until I could find a placement in a Townsville nursing home. It was a painful downward spiral for her, and a traumatic time for my family and I.

As human beings we all deserve some dignity when our time comes. Voluntary Assisted Dying with all the proper rules and regulations, is what we need.

I would certainly agree to have my submission published on your website if needed.

Kel Ackland.

From: Kerri-Ann Caswell
To: Care Inquiry
Subject: Please don"t recommend euthanasia - its too dangerous
Date: Monday, 15 April 2019 12:23:48 PM

Re: Please don't recommend euthanasia - its too dangerous

Dear Rob Hansen,

Thank you for your service to our community. I am writing as a concerned Queenslander about the proposal of "Assisted Dying " or euthanasia for our State. Recent discussions in the community and in the media around abuse of our elderly and also disabled citizens shows that not all people can be trusted with care and good judgement with our elderly and vulnerable. Making euthanasia legal would just exacerbate this and put those who need our care, more at risk. In countries such as the Netherlands, which has had assisted suicide for many years, there are many problems and alarming stories emerging, including euthanasia happening without an explicit request from the person being killed.(defendhumanlife.blogspot.com.) Legalising euthanasia does not fit with a society that says human life is valuable. Please do not recommend Assisted Suicide be made legal in Queensland. Yours Sincerely, Kerri-Ann Caswell

Sincerely,
Kerri-Ann Caswell
[redacted]

[redacted]
Kuraby, AU-QLD 4112

From: outlook_D91CC358E553C1DE@outlook.com
To: Care Inquiry
Cc: [redacted]
Subject: Enquiry into euthanasia
Date: Monday, 15 April 2019 1:03:17 PM

To the members of the committee enquiring into the question of euthanasia.

Support for euthanasia is usually based on the concept of individual human autonomy. The argument is often based on arguments like the following:

> "If I am a mentally competent adult suffering a severe illness or condition and in unbearable pain and distress because of my condition, why should I not be able to choose to die in an acceptable way and, as a corollary, why should I not be entitled to receive medical assistance to ensure that my death is as peaceful and comfortable as possible. After all, it is my life and no-one will be harmed if I choose to end my life."

Put in such terms, euthanasia can appear to be compassionate, respectful and, indeed, beneficial for the suffering person and without risk for the community.
However, despite the emotion surrounding this issue, it may not be so simple. It is most important that the committee consider this question thoroughly and in a rational and dispassionate way.

I think that it is self evident that the committee should put to one side arguments based on religious belief.

One important consideration is the question of personal autonomy in our modern society. It needs only a short reflection to appreciate that personal autonomy is always subject to the common good of society. Examples could be multiplied. It is absolutely clear that personal is not a trump card defeating all other considerations.

In all past societies, life has been treated as an absolute good not as a good subject to circumstances or conditions. Even societies which practiced intentional killing in the form of human sacrifice or the killing of the disabled, the aged and the infirm were motivated, as I understand it, not by compassion for the victims but for the welfare of the group. The sacrificed virgin was the greatest of sacrifices not because the life of the victim was worthless but because it most valuable. The killing of the aged and infirm was necessary for the survival of the group which was a greater good.

Request for euthanasia always reflects a person's, possibly reluctant, decision that his or her life has no further meaning or value. Traditionally, the person was given whatever support, encouragement and care was available to assist the person to appreciate the continuing worth of their life. By approving euthanasia, the society is signifying agreement with the suffering person that their continued life is pointless and has no value. It is a very grave decision to take that position.

Any mentally competent person from pre-teens to advanced age might well become irrevocably convinced that their life has lost all meaning and is no longer worth living. This may be because of adverse living conditions, severe poverty, loss or despair or simply weariness with life. It is logically inconsistent to deny such persons the personal autonomy given to others. It is

impossible to effectively oppose suicide when every person who commits suicide is convinced that their life in worthless and that they would be better off dead.

The issue of mental incapacity whether because of infancy, accident, age or infirmity is extremely problematic. Surely the rational decision is that the availability of euthanasia for such persons must be made by others, whether they be parents, guardians, attorneys or the State as the protector of all children or persons lacking mental capacity.

Consistent with reason, why should a severely deformed, retarded or ill infant, with no prospect of a decent, happy or fulfilling life but with every prospect of continual pain, dependency, multiple surgery and the certainty of an early death not be compassionately euthanised after thorough medical assessment?

The same situation arises when adult persons lack mental capacity because of accident, illness, age or mental infirmity. Surely these persons cannot be excluded from access to euthanasia. Clearly, someone must decide for them whether their lives have any continuing point or value and if not to process them for compassionate euthanasia.

In my opinion, it is clear that euthanasia should not be made legal in Queensland because of the certainty of a number of destructive effects on our community. Respect for individual autonomy is not sufficient to overcome these effects. It is a delusion to believe that the detrimental effects on our society can be avoided by appropriate regulation.

If euthanasia is based on personal autonomy, it is inconsistent to deny the procedure to any rationally competent person whose decision is firm and repeated regardless of that person's state of health. This is an inevitable progression.

It is also inevitable that once approved, euthanasia will be made available for the mentally incompetent of whatever age.

Compassion for those who believe their lives have no continuing value should be directed to providing the best treatment, care and support available. I understand that high quality palliative care is frequently effective in such cases.

Respectfully,

KERRY FRANCIS BOULTON

Particulars of the person making this submission.
Name: Kerry Francis Boulton;
Address: [redacted] Paddington Queensland 4064
Phone: [redacted]
Email: [redacted]

SUBMISSION TO THE QUEENSLAND INQUIRY INTO AGED CARE, END OF LIFE AND PALLIATIVE CARE

AND VOLUNTARY ASSISTED DYING.

I AM FORWARDING THIS SUBMISSION BECAUSE I HAVE RECENTLY WATCHED BOTH MY NINETY SIX YEAR OLD PARENTS PASS AWAY, AND NOT IN THE MANNER THAT THEY WANTED, AFTER LIVING A FULL AND HAPPY AND INDEPENDENT LIFE.

MY FATHER WAS A WORLD WAR TWO AIRFORCE FLYING INSTRUCTOR AND FARMER AND MY MOTHER WAS A WELL EDUCATED UNIVERSITY GRADUATE.

THEIR END OF LIFE WAS PAINFUL, VERY PROLONGED AND UNDIGNIFIED AFTER BEING EXTREMELY ACTIVE AND INDEPENDENT AND CARING FOR OTHERS FOR MANY YEARS.

MY PARENTS WHO HAD BEEN MARRIED FOR SEVENTY TWO YEARS, WISHED TO DIE TOGETHER WHILE THEY STILL HAD THEIR MENTAL FACULTIES TO MAKE THESE DECISIONS. THEY CONTINUALLY BEGGED US TO HELP THEM FIND A WAY TO DIE. THIS ADDED UNDUE PRESSURES TO FAMILY WHO FELT TERRIBLE AT NOT BEING ABLE TO ASSIST THEM. THIS WAS WHAT THEY WANTED AND THIS WAS FULLY UNDERSTOOD BY THE FAMILY. THE SITUATION PUT ADDED PRESSURE AND GRIEF ON THE FAMILY WATCHING THEM SLOWLY DIE OVER AN EIGHTEEN MONTH PERIOD. IT WAS VERY SAD FOR MY MOTHER WHO PASSED AWAY NINE MONTHS AFTER MY FATHER. SHE BECAME VERY DEPRESSED AND UNRESPONSIVE. SHE JUST WANTED TO DIE.

WHILST PALLIATIVE CARE WAS ADMINISTERED TO BOTH MY PARENTS, IT WAS GROSSLY INADEQUATE WHEN THEY WANTED TO DIE. ALTHOUGH THE CARE IN A NURSING HOME WAS GIVEN TO THEM IN A VERY PROFESSIOAL AND SENSITIVE MANNER, IT CAUSED MY PARENTS GREAT DISTRESS AND HEART ACHE, NOT TO MENTION THEIR WORRY OF THE FINANCIAL BURDEN.

THIS IS NOT AN ISSUE THAT SHOULD BE DICTATED TO B POLITICS OR RELIGIOUS BELIEFS BUT BE AN INDIVIDUAL CONSCIENCE DECISION.

I WOULD LIKE THE GOVERNMENT TO DRAFT AND PUT FORWARD AN END OF LIFE BILL.

K Homewood

KIM HOMEWOOD

[redacted]

[redacted]

WARRA Q 4411

[redacted]

From: [redacted]
To: Care Inquiry
Subject: Submission
Date: Sunday, 31 March 2019 4:32:41 PM

Submission to the Inquiry into aged care, end-of-life and palliative care and voluntary assisted dying

I am a strong supporter of voluntary assisted dying and am writing in the hope that my views, as a person living with a life-limiting illness, will be noted by the Inquiry.

I have some insight into end of life care, having nursed both my mother (who died of breast cancer) and my father (who died of heart failure) at home in [redacted], QLD through their final illnesses until their deaths.

I have a genetic heart condition, the same condition which my father died from. As such, I feel I have 'looked into a crystal ball' at the most likely scenario of my own death. I have no children to care for me, and having experienced first hand the significant limitations of palliative care, I feel frightened and powerless when I think about being completely at the mercy of the medical fraternity at my most vulnerable, as I die. I try not to dwell on the potential circumstances of my death. I am a happy, busy, productive, and loved, wife, sister and friend. I've had a serious senior corporate career in multi-national businesses. I'm a qualified foster carer (although not fostering at present). It is clearly not true that voluntary assisted dying is reached for by people when at their most vulnerable, and therefore those seeking this service should be protected from themselves. Being cognisant of the alternatives, I am rationally choosing it as my preferred method of death (hopefully) decades before I need it. I have faced up to my mortality - I have been facing up to it for years.

I had my first surgery aged 17. It was major open heart surgery and it was shocking. Since then I've had 6 further surgeries related to my heart condition. I have had an implanted defibrillator for 20 years (currently I have a fifth device). This bulky machine paces my heart constantly and will provide a shock if I have a cardiac arrest (which I am at high risk of). I take handfuls of medications daily, and have done since I became symptomatic at 12 years old. At 44, despite my ill health, I love my life. I certainly do not have a death wish - I'm doing everything I can to stay here for as long as possible. But when the day comes that treatment is exhausted, when my heart has failed, if my pain is making me desperate, and if my breathlessness is making me frightened, and if my body is swollen with fluid such that I can't get out of bed, and if my family have witnessed enough suffering, I will ask my cardiologist to turn off my defibrillator. I would then like the choice to take a tablet and go to sleep with my family around me, rather than experience weeks in hospital away from my family. Lonely, desperate weeks of pain, paralysis, fluid distention, incontinence, a drug-induced haze, and an inability to breathe normally.

I am a calm, rational, mature, and educated person. I do not tell my personal story easily. In doing so, I am hoping you will see the powerful benefit that assisted dying laws will bring to people like me. People living with life-threatening illnesses who have an intimate insight into the limitations of end of life care. I may never choose to use assisted dying laws, but it would be life-affirming to know my wishes will be respected at the end of my life, and it would be an enormous comfort to know I have the option of a peaceful death.

I know well the limits of palliative care. I wish end of life care services could offer everyone a decent pain free death, but they simply cannot For those who cannot be helped and are suffering, the only option our society currently offers is a cruel death, or a lonely, frightening suicide. I believe assisted dying should be an option within our palliative care system.

In terms of the model, the Oregon (US) model seems to me to offer excellent safeguards and reporting.

Thank you for your time.

[redacted]

Please note due to the personal nature of my submission, I would appreciate it if it could be published anonymously. Thank you.

From: Jo Enderby
To: Care Inquiry
Subject: VAD
Date: Monday, 15 April 2019 12:50:47 PM

No! We do not want "Voluntary Assisted Dying" in Qld. Life is precious from conception to natural death. Lindsay & Joanne Enderby, [redacted]. Sarina, Qld 4737.

From: [redacted]
To: Care Inquiry
Subject: Submission VAD Qld
Date: Monday, 15 April 2019 3:59:33 PM

To
Health Committee Secretary

My life is precious. All of our lives are precious!

However, should I be faced with a terminal illness full of pain and discomfort, I would appreciate the right to make my own decision and be afforded the opportunity to die with dignity.

My father, during the last stages of a long battle with cancer, was not afforded this opportunity and so after much suffering, took matters into his own hands. This was a devastating experience for my Mother and us, his daughters. Given the chance, we could have been there with him offering all the love and support he so deserved. He was instead alone and died in a most violent manner.

My right to make a decision for myself to die peacefully and with dignity does not force anyone else to do likewise.

I am therefore frustrated that other people's beliefs should hinder my decisions and actions.

I would like to die with dignity and on my own terms.

[redacted]
Sent from my iPad

From: Maria Ronca
To: Care Inquiry
Subject: Legalising euthanasia would be a dangerous idea for Queensland
Date: Sunday, 14 April 2019 6:22:27 PM

Re: Legalising euthanasia would be a dangerous idea for Queensland

Dear Committee Inquiry,

Prohibition on doctors killing patients is a longstanding rule. The World Medical Association and Australian Medical Association oppose euthanasia on the basis that it undermines the doctor/patient relationship of trust. I am totally against the legalization of euthanasia and assisted suicide, being voted in by the Queensland Government. You have as the governing authority, given to you by Almighty God, to legislate and protect the people you serve. You are using your office to undermine and betray the people you serve. You are wolves in sheep's clothing SHAME ON YOU. Your move to legalize euthanasia I evil. Sincerely Maria Ronca

Sincerely,
Maria Ronca
[redacted]

[redacted]
Kings Park NSW, AU-NSW 2148

From: Mel Jes
To: Care Inquiry
Subject: Submission regarding euthanasia
Date: Monday, 15 April 2019 12:20:35 PM

To Whom It May Concern,

Question *#25: Should voluntary assisted dying (VAD) be allowed in Queensland? Why/why not?*

I am strongly opposed to any form of VAD or euthanasia being allowed in Queensland)or Australia). As a registered nurse, who has worked in palliative care, I believe good palliative care is where the focus should be and often the general public does not understand it does not have to be a case of either dying in agony, slowly and without dignity or euthanasia as the only alternative. There is always the option for good palliative care, so even a slow, progressive, serious illness that leads to death can be managed well and treatments given for comfort and pain relief, such as morphine, that may hasten death but death is never the first intention. When we as a society allow the intentional killing of a human, whether it be by the doctor or though assisting the person to commit suicide, we completely devalue life and this is a dangerous path to travel. Please instead invest more time and energy into making the public aware that good palliative care is a better option for a peaceful death and do not allow this legal reinforcement of intentional killing to become law.

Kind regards,
Melinda Jesudason RN, JP (Qual)
[redacted] Pullenvale Q 4069

Inquiry into aged care, end-of-life and palliative care, and voluntary assisted dy

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: MICHAEL GANNAWAY

Day time phone number: [redacted]

Email address: [redacted]

Address: [redacted] Upper Mount Gravatt, QLD Postcode: 4122

What would you like to tell the committee?

See Annexure A

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:_____

Their daytime phone number: :_____

What is your relationship with that person or persons, or your role in the organisation?_____

I am authorised by ..... to provide these comments on their behalf.

Signature:..... Date: .....

Need Help?

If you have any questions about the inquiry or making a submission, please call the committee secret

07 3553 6626 or 1800 504 022 Free call

The right to choose for yourself when your life is at an end should be one of the most fundamental of all human rights.

It astounds me that we live in a society today where the law still denies us this right.

As a non-religious person I deeply resent being legally bound by such laws which impose someone else's religious beliefs on to me.

I have personally seen both of my parents suffer from medical conditions before they died, and I suffer medical conditions myself even now. Sure there need to be safeguards in place to prevent misuse of euthanasia rights, but I would certainly appreciate having the option when it comes time for me to die to have it done in a controlled legal way. I believe the current status quo of having to suffer in silence or break someone else's religious based law in order to die in peace and potentially traumatise others in the process is a very poor alternative.

And yes, the current focus on the dollar, and lack of accountability, transparency and actual *care* in our aged care system is disgusting. I know this from personal experience also with my father, and he was supposedly in one of the better aged care facilities. My mother's recent death from cancer was perhaps a kinder outcome for her than the prospect of going into so-called aged "care".

I also think that an externally assessed online public ratings system, similar to that used in child care should be set up, and direct input from a good spread of actual residents and their families should be regularly but randomly sought for this as an integral part of this process. Comparisons of staffing, response rates, and the incidence of things such as falls and bed sores should be included. This way people have a clear way of comparing facilities and rewarding those who offer better care.

From: Naomi Kochi
To: Care Inquiry
Subject: Question #25: Should voluntary assisted dying (VAD) be allowed in Queensland? Why/why not?
Date: Monday, 15 April 2019 12:58:46 PM

To whom it may concern

I do not believe that voluntary assisted dying should be allowed in Queensland. I understand that it is painful to watch a loved one suffer before death, and that many are afraid of facing pain and/or loss of capacity themselves before death, but I believe that much suffering can be eased through appropriate palliative care, thus making VAD (voluntary assisted dying) unnecessary. I have three other objections to VAD:

1. It diminishes the value of human life, by allowing it to be terminated prematurely. Perhaps unconsciously, allowing VAD sends the message that the life of someone who is disabled or in pain may not be worth living. Furthermore, it is not hard to imagine a situation where a terminally ill person feels that they are morally obligated to end their own life to reduce the 'burden' of others having to care for them.

2. I believe that at least some people will be pressured to embrace VAD due to the financial motives of those who stand to benefit from their death.

3. Physician involvement in VAD (which is likely to occur in some form) places doctors in a situation they should not have to be in - the situation of intentionally causing the death of their patient.

Thank you for your consideration,
Naomi Kochi
[redacted], Mt Sheridan 4868

From: Pat Doyle
To: Care Inquiry
Subject: Legalising euthanasia would be a dangerous idea for Queensland
Date: Sunday, 7 April 2019 11:06:10 AM

Re: Legalising euthanasia would be a dangerous idea for Queensland

Dear Committee Inquiry,

To the Qld Parliament Euthanasia Committee Prohibition on doctors killing patients is a longstanding rule. The World Medical Association and Australian Medical Association oppose euthanasia on the basis that it undermines the doctor/patient relationship of trust. Four years ago I saw my husband die after a long battle (7 years) with renal cancer and spinal /bone secondaries. Together we had our tough times; our very sad times but I know should he ever had asked me to take his life in my hands I would never have agreed . Similarly he had no time even mildly suggested that they would be an option our life ,together and indeed his life was to precious . Together we tried to make the very best of the time that we had . Despite how hard we try to do the right thing in life there are always regrets - I have many but I would not want to add assisting him in dying to my regrets. What consideration has been given on the impact of those decisions years down the track. Please instead of opting out can we not opt in to be up there with world best practice for palliative care and pain management to allow as long as possible the quality of life. Along with the struggle comes many many graces and leanings I am grateful for the lessons that he taught me and that I now feel able to share with others yours Pat Doyle (Mrs)

Sincerely,
Pat Doyle
[redacted]

[redacted]
MAWSON, AU-ACT 2607

From: Paul Bonner
To: Care Inquiry
Subject: Volutary assisted dying
Date: Friday, 12 April 2019 2:09:08 PM

Good afternoon
I wish to add my voice to the many people who have raised the proposal that adults are allowed to choose to end their life if they are terminally ill.
My mother died slowly and painfully of leukemia.
Many times I wished there was a way we could help her but there was nothing that we could do legally.
People should be able to make a choice with the support of their family to end their life rather than continue to a slow and painful death.
My mother was a beautiful loving mother who was a trained nurse.
It was so sad to watch her slowly dying and it was even worse to see my father, who loved her and cared for her, having to see the love of his life fade away.
Please help others to be able to have a choice.
It is our right to have a choice.
Regards
Paul Bonner
[redacted]
Buderim 4553
[redacted]

From: Peter Lucas
To: Care Inquiry
Subject: I am a Queenslander - assisted dying is not caring
Date: Sunday, 7 April 2019 6:34:20 PM

Re: I am a Queenslander - assisted dying is not caring

Dear Rob Hansen,

I am writing to express my concerns regarding voluntary assisted dying. I believe this will adversely affect community values and attitudes towards elderly people - it will open a Pandora's box of unforeseen consequences, like attitudinal changes in Nazi-Germany where unprofitable and vulnerable individual were conveniently eliminated to unburden society. This will also serve to ultimately 'cheapen' life and also make individual feel that they are a burden on society. The medical practices we have are currently best in the world and medical researchers are continuously working towards cures for diseases and better ways of ameliorating the suffering of patients. I believe that doctors should not be compelled to break their Hyppocratic oath by killing people.

Sincerely,
Peter Lucas
[redacted]
[redacted]
Burleigh Heads, AU-QLD 4220

From: Peter Willison
To: Care Inquiry
Subject: We are a caring state
Date: Monday, 8 April 2019 7:10:52 AM

Re: We are a caring state

Dear Rob Hansen,

Legalised euthanasia is incompatible with a society that values human life and seeks to protect the vulnerable. Legalising assisted dying will change the community's views towards our elderly people, those with a disability, and the sick. It presents a "quick and easy" solution in the form of death. Assisted suicide will undoubtedly be sought for people who are not necessarily dying, but who simply fear the changed circumstances that a deterioration in their condition might bring. There are no safeguards that prevent people from feeling that their medical condition is becoming a burden on those around them. This will eventually pressure them to choose assisted dying. Sincerely Peter Willison

Sincerely,
Peter Willison
[redacted]
[redacted]
Gordonvale, AU-QLD 4865

From: Rex Frazer
To: Care Inquiry
Subject: Some ideas are just full-on dangerous. Euthanasis is one such "dumb" idea.
Date: Friday, 12 April 2019 2:20:20 PM

Re: Some ideas are just full-on dangerous. Euthanasis is one such "dumb" idea.

Dear Rob Hansen,

Worse than dumb and dangerous, euthanasia is an euphemism for premeditated murder, - totally wrong-headed thinking. Research of recent history in Holland and Belgium on this issue CLEARLY shows the lack of morals and total disrespect for the sanctity of life in officials, legislators and some medical establishment personnel in these countries. Why would a parliament want to consider imposing similar disasters on Queenslanders? Why add to the crazy message that says it's alright to kill babies but we'll fight hard to prevent suicide, with,... and we'll kill you when you are sick? (or your relatives are sick of you?) Coercion of vulnerable, emotionally dependent ill patients will expand with legalizing euthanasia. Take it off the table. As has been said before; "any legislation that harms the vulnerable is "dumb" legislation." As a Committee please focus on doing good for the society of Queensland and be particularly protective of the vulnerable in our midst. There are no safeguards that prevent people from feeling they are a burden on those around them. This pressure to be killed is an horrendous end-of-life scenario which legalising euthanasia makes possible and then normal. Palliative care is the proper option to end of life “choices.” Improved care, not killing, should be promoted not euthanasia. May your deliberations be life-affirming.

Sincerely,
Rex Frazer
[redacted]
[redacted]
Mirani, AU-QLD 4754

From: Richard Masefield
To: Care Inquiry
Subject: Euthanasia Bill -for
Date: Sunday, 7 April 2019 1:18:45 PM

I am for The Euthanasia Bill.

Richard C. Masefield
[redacted]
Tinana, Qld 4650
[redacted]

Richard Masefield
Sent from my iPad

From: Rob Hickson
To: Care Inquiry
Subject: Palliative care must be the priority
Date: Monday, 8 April 2019 11:39:35 AM

Re: Palliative care must be the priority

Dear Rob Hansen,

Taking your own life is Suicide and it doesn.t matter what other names it is given. God is the giver of life and the taking of life. From the day of birth your life span is known by God and if you take your own life prior to the nominated time then you are saying you are God and you are not and that will be taken into account on Judgement Day when we will all be judged on what we have done with / in our lives Rob

Sincerely,
Rob Hickson
[redacted]
[redacted]
Charleville, AU-QLD 4470

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.

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Health Committee
PARLIAMENT HOUSE QLD 4000
Fax: 07 3553 6699
Or scan and email it to:
carenquiry@parliament.qld.gov.au

Your details:

Mr/Ms/Mrs/Dr: [redacted]

Day time phone number: ( ) [redacted]

Email address: [redacted]

Address: [redacted] Noosa Heads *Postcode:* 4567

What would you like to tell the committee?

As a disability pensioner of many years and illnesses & mile long, I find that ageing is increasing my pain + sicknesses causing more depression & anxiety.

My breath becomes shorter each time I walk to the shops & have no intention to live a full life in pain, depression

I have no family to care for me, my friends are my age or older,

My bones break all the time as I fall lots, & even doing the simplest task

causes great pain.

To be quite frank if Voluntary assisted dying is not brought in then perhaps I might as my next door neighbour did she did it herself & was there for 3 days before she was discovered.

This is a huge problem in Japan, please do not let it become a huge problem in Aust.

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:

I do not want my name published

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:_____

Their daytime phone number: :_____

What is your relationship with that person or persons, or your role in the organisation?_____

I am authorised by [redacted] **to provide these comments on their behalf.**

Signature: [redacted] **Date:** 15/4/2019

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

From: Roger Bonell
To: Care Inquiry
Subject: Euthanasia
Date: Monday, 15 April 2019 1:04:35 PM

To Whom it may concern.
I wish to express my objection to Euthanasia in Queensland because l do not believe in people assisting others to die.
Yours sincerely
Roger Bonell
[redacted] Toowoomba 4350

From: Ruth Ferguson
To: Care Inquiry
Subject: Palliative care must be the priority
Date: Monday, 8 April 2019 11:28:34 AM

Re: Palliative care must be the priority

Dear Rob Hansen,

I am 72 years old. If euthanasia (lawful killing) is made law, how long will it be before others decide I am a burden on society? Will it matter if I am coerced into death because I am made to think I am of no use or profit any more? Who will decide which of those who are disabled in any way are not worthwhile keeping alive any more? Life is precious. Please remember we have expert palliative care. Our lives don't need to be 'shortened'. Please value your parents' and grandparents' lives. Sincerely, Ruth<write your submission here>

Sincerely,
Ruth Ferguson
[redacted]
[redacted]
Smithfield, AU-QLD 4878

Spiritual Palliative Care

[redacted],
Noosaville BC, 4566
[redacted]

14th April, 2019

The Honourable Aaron Harper
Chair
Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee
PARLIAMENT HOUSE QLD 4000
Via Email

Dear Mr Harper

Queensland Parliamentary inquiry into aged care, end-of-life care, palliative care and voluntary assisted dying

I thank the committee for the opportunity to make a submission in relation to the above inquiry.

I currently am an individual, fee for service provider in the end of life space, undertaking roles as a Spiritual Counsellor and End of Life Doula, which is a role providing practical, compassionate, non medical support to people dying and those close to them. I also deliver specialist training to care and health professionals in the end of life space on the topics of serving our dying better and strengthening their resilience to continue working in this sometimes challenging space.

I am also a past President and Vice President of Dying With Dignity Queensland (DWDQ), an organisation which seeks to have voluntary assisted dying legislation enacted in Queensland.

Lastly, I am also an Ambassador for Death Over Dinner, a project which seeks to encourage people to have end of life plan conversations prior to crises occurring.

Introduction
Dame Cicely Saunders, the founder of the modern hospice movement gave us this quote: *"How people die remains in the memory of those who live on."*

In the course of my work, I come across both individuals along with care and health professionals have both extremes in terms of memories of how people die. It is very clear, that the heartbreaking experiences leave lingering spiritual and emotional trauma to varying degrees, while the "good death" memories work towards facilitating healthier and easier grieving experiences.

A “good death” according to the Grattan Institute Report, Dying Well, released in September 2014 is defined as:
“A good death gives people dignity, choice and support to address their physical, personal, social and spiritual needs.”

In a TED talk by BJ Miller who is a former Executive Director of Zen Hospice Project in San Francisco, he states:
“...healthcare was designed with diseases, not people, at its centre. Which is to say, of course, it was badly designed. And nowhere are the effects of bad design more heartbreaking or the opportunity for good design more compelling than at the end of life, where things are so distilled and concentrated. There are no do-overs.”

The focus of all of my work is that we (as both a community and individuals) can live these experiences that are dying and death better for everyone involved - our dying, their loved ones and the health and care professionals who support them.

I address below some of the clauses for consideration by the committee. I speak to these clauses from my personal experiences as well as being a care professional in the end of life space and experiences while as a committee member and President and Vice President of DWDQ.

Clauses
#6 Are adequate numbers of home care packages available in areas at the levels required?

No. I am aware of people who have received their assessments as being approved for home care packages, but died prior to funding being available to meet their needs.

#9 Do aged care staff receive training that is appropriate and adequate to prepare them for the work?

Not always. More training is needed around strengthening resilience to reduce both burnout and desensitisation.

Last year, I commenced delivering training around strengthening resilience for care and health professionals serving people at the end of their life. It became very apparent quite quickly that not all professionals are supported in this area. One nurse shared with me her experiences of caring for a patient over a six year period. When this gentleman died, she naturally shed some tears. Her manager told her to “build a bridge and get over it.” This is horrifying. We need compassionate care professionals, but they also need to be supported appropriately.

Other aged care staff frequently shared stories of not being able to tell other residents that someone had died and the distress that caused them. This also says to the other residents that they will not be remembered, acknowledged or considered having been important when their time comes.

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

We can improve the delivery of care by having compassion as an active value, not just a feel good soundbite, underpinning every aspect of what we do.

One aged care provider I have worked with has a team called the Final Friends Team. We have a group of volunteers who are on a roster to sit with elders who either have no loved ones or whose loved ones cannot be with them in their final days and hours. We do this to ensure that as much as possible, people do not die alone. This is compassion in action.

We can improve the delivery of care by ensuring that we are honouring the wishes of residents as they relate to end of life care.

I had one lady in her early 60's who was living with advanced Motor Neurone Disease. Because of her care needs, she was living in an aged care facility. When I started working with her she had a small amount of head movement and was able to slightly move one finger. She was also shortly to lose the ability to speak. She continually clearly stated that she had had enough of living and had it been available to her she would have chosen voluntary assisted dying. She had documented that she just wanted comfort care.

Each time she got a chest infection, she was whisked off to hospital for treatment, despite this being against her wishes. I raised this with the care facility and the next time, she was not moved and died within 48hrs. I believe for her, this was a blessed release.

#20 How will demand for palliative and end-of-life services change in Queensland as the population increases and ages, and what changes to the delivery of these services will be needed to meet future demands?

The Dying Well report states,
"The baby boomers are growing old, and in the next 25 years the number of Australians who die each year will double. People want to die comfortably at home, supported by family and friends and effective services."

This report also states,
"Surveys consistently show that between 60 and 70 per cent of Australians would prefer to die at home. Hospitals and residential care – nursing homes – are their least preferred places to die. Yet over the past 100 years home deaths have declined and hospital and residential care deaths have increased.1 Today only about 14 per cent of people die at home. Fifty-four per cent die in hospitals and 32 per cent in residential care."

This quote from the Bringing Our Dying Home report by Horsfall et al, released in 2012 sums up the situation quite well.
"That most people do not experience dying and/or death in places of their choosing is an astonishing fact; a fact that, collectively, we are either ignorant of or just silent about. It is a fact that speaks to our failings as a society at a time of life that occurs for each and every one of us."

The greatest challenge in meeting this need, no doubt, relates directly to the cost of providing support services, not just for the person dying, but also their carers. According to ABS (2015) Survey of Disability, Ageing and Carers, there were 2.7 million unpaid carers. This means more than 10% of our population are unpaid carers.

According to Deloitte Access Economics (2015) The Economic Value of Informal Care in Australia 2015.The estimated replacement value of unpaid care provided in 2015 is $60.3 billion - over $1 billion per week. That is a phenomenal amount for any government/ community to try and cover.

These figures are based of the current numbers of people dying. Clearly, as a community we cannot expect any government to fully meet these needs. However, what is clear is that increased funding will be required for aged care, palliative care and community based care services. Of course, these funding increases are not solely the responsibility of the state, but for the Commonwealth as well.

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

We can improve the quality and delivery of these care services by both shifting our focus from institutionalised care to more community based care and increasing funding to facilitate this.

Atul Gawande in his book Being Mortal states:
"*You don't have to spend much time with the elderly or those with terminal illness to see how often medicine fails the people it is supposed to help. The waning days of our lives are given over to treatments that addle our brains and sap our bodies for a sliver's chance of benefit. They are spent in institutions— nursing homes and intensive care units— where regimented, anonymous routines cut us off from all the things that matter to us in life. Our reluctance to honestly examine the experience of aging and dying has increased the harm we inflict on people and denied them the basic comforts they most need. Lacking a coherent view of how people might live successfully all the way to their very end, we have allowed our fates to be controlled by the imperatives of medicine, technology, and strangers."*

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

Queensland is a huge state geographically, which brings with it inherent challenges in the provision of care. I had one lady that I served who lived outside the catchment of any community based care providers which resulted in her having to attend hospital for symptom management of her particular chronic illnesses. The situation was compounded for this lady in that she often stated that she found the hospital staff trying to "force" her into active treatments for her illnesses, as opposed to symptom management.

Partly due to these factors, she moved nearly 1,500kms from Bauple to Cairns. She had daughters in both geographic regions, but was able to receive more appropriate care in Cairns. However, moving such a great distance with her illness complexities was challenging experience and not her preferred option.

Voluntary Assisted Dying

I passionately believe that we should have voluntary assisted dying legalised in Queensland.

This is fundamentally a matter of choice and individual rights to our life. It is also a compassionate approach. How can it be deemed compassionate for someone to need to choose to refuse food and/or fluids and/or other treatment to hasten their expected death, as opposed to receiving/ingesting medication that would address this?

In my role as as President of DWDQ, I spoke with over one third of the members of parliament at the time (the previous parliament). Opponents to the creation of the legislation often stated that *"things were working as they were"* and acknowledged that people are currently secretly assisted to die.

There are three issues with this:

1. We do not know who is pushing this agenda. Is this something that the patient wants? Is this something that their family/loved ones want? Is this something that the care/health professional want?
2. There are no safeguards for care/health professionals who act in this way. They may be acting in accordance with the patient's wishes, but there is still the potentiality for a criminal investigation and possibly charges/conviction to result.
3. As this is unregulated, we have no way of capturing how frequently this is occurring and in what circumstances.

Members of Parliament also spoke to people having the option to suicide. There are a number issues with this:

1. People need to have the physical capability to be able to take such actions. Numerous diseases and illnesses may leave people incapable of taking the necessary actions.
2. There are no guarantees that these people will succeed in their course of action and may in fact, end up being in a worse situation.
3. People are choosing violent means of ending their lives and this can result in trauma for those who discover them.
4. They may need to take this action earlier than they would otherwise be ready to die. I know of one lady with Motor Neurone Disease who chose to end her life when she started losing the ability to use her remaining functioning hand. She would have been quite prepared to continue to live longer, had she had the option of voluntary assisted dying.
5. People need to take these actions covertly so as to not involve people they love. This also means dying alone.

Another objection that is levelled by opponents is that this is against God's Law. While yes, we are generally considered a Christian society, organised religion is fundamentally based on man's interpretation of God's word. This, of course, is fraught with danger.

Personally, in light of the revelations around sexual abuse within the Catholic Church and their responses to those revelations, I also have great concerns about them being considered a moral authority on any topic.

I believe the model that is shortly to come into force and effect in Victoria is a good balance of support and safety. I particularly like that it is not limited to people with terminal illnesses.

I would like to think that we could allow legislation that includes well informed under 18's reviewed on a case by case basis, but appreciate that this may be a step to far for our community at this time.

The Oregon Death With Dignity 2018 Data Summary states,
"Since the law was passed in 1997, prescriptions have been written for a total of 2,217 people under the DWDA; 1,459 people (65.8%) have died from ingesting the medications."
This clearly indicates that there is a palliative benefit to having a "just in case" option. Indeed, I have had numerous people express to me that while they know they might not be eligible for assistance under voluntary assisted dying legislation, they still feel that there is benefit in knowing that it might be available to them, should they need it.

Conclusion

Mahatma Ghandi gave us this truth
"The true measure of any society can be found in how it treats its most vulnerable members."

While I believe we have purity of intent to be a great society in this respect, I'm afraid that on too many occasions we come up short. However, the situation is not lost. We can achieve this by:
- Having a compassionate, caring focus
- Increase funding in aged, community and palliative care
- Adequately training and equipping health and care professionals to reduce burnout and desensitisation
- Ensuring that we honour individuals by adhering to their wishes
- Creating voluntary assisted dying legislation

Thank you for your consideration of this submission.

Yours sincerely

Sharon G Tregoning (Mrs)
M. Divinity, Dip Counselling, JP (Qual)

From: Steve Melidonis
To: Care Inquiry
Subject: Legalising euthanasia would be a dangerous idea for Queensland
Date: Monday, 8 April 2019 8:22:54 AM

Re: Legalising euthanasia would be a dangerous idea for Queensland

Dear Committee Inquiry,

I am apposed to voluntary euthanasia on the grounds that why should we allow someone to make a decision on their own life when clearly a lot of the time they could recover from their ailment! Prohibition on doctors killing patients is a longstanding rule. The World Medical Association and Australian Medical Association oppose euthanasia on the basis that it undermines the doctor/patient relationship of trust.

Sincerely,
Steve Melidonis
[redacted]
[redacted]
South Side, AU-QLD 4570

From: T Craven
To: Care Inquiry
Subject: Legalising euthanasia would be a dangerous idea for Queensland
Date: Monday, 8 April 2019 10:40:32 AM

Re: Legalising euthanasia would be a dangerous idea for Queensland

Dear Committee Inquiry,

Prohibition on doctors killing patients is a longstanding rule. The World Medical Association and Australian Medical Association oppose euthanasia on the basis that it undermines the doctor/patient relationship of trust. Legislative safeguards have proved insufficient to prevent wrongful deaths. Governments have a fundamental responsibility to legislate to protect vulnerable citizens. Coercion cannot be outlawed – whether overt or implied, when euthanasia is an option people are made to feel they are a burden (including people with disabilities who already feel a need to justify their existence.) It is dangerous to legalise euthanasia when palliative care is underfunded. Overseas jurisdictions that have legalised euthanasia and assisted suicide have seen the categories of people to whom euthanasia is applied expand. Suicide contagion is a real risk when governments convey the message that some suicides are considered ‘good’. Legalizing euthanasia undermines suicide prevention messages. Euthanasia creates a culture of death and encourages ritualised suicide in the form of "euthanasia celebrations". Prognosis (predicting how long a person will live for) is notoriously inaccurate beyond a few days. Euthanasia is dangerous as a form of medical practice with errors in diagnosis up to 20% and prognosis up to 50% and cannot achieve workable safeguards. For example in Belgium, 32% of euthanasia deaths are performed without specific request or consent of either the patient or family despite "safeguards" (CMAJ June 15, 2010). Euthanasia will create a hazard to people who want medical care and do not want to be offered suicide as a routine option. This is currently happening in jurisdictions with euthanasia such as Canada. Euthanasia will lead to a decline in palliative care services as doctors who don't want to be involved in euthanasia move out of the profession.

Sincerely,
T Craven
[redacted]

[redacted]
Randwick, AU-NSW 2031

From: cheauyan Tang
To: Care Inquiry
Subject: Fw: state parliament inquiry into aged, palliative and end of life care and possible VAD legislation
Date: Monday, 15 April 2019 1:15:50 PM

Sent from Outlook

From: [redacted]
Sent: Monday, April 15, 2019 2:25:18 AM
To: careinquiry@paliament.qid.gov.au
Cc: careinquiry@paliament.qld.gov.au
Subject: state parliament inquiry into aged, palliative and end of life care and possible VAD legislation

Tammie Tang
[redacted]
Atherton. Qld. 4883
15/04/2019
To The Paliament House,

Being a Christian, I am writing in concern to bringing in euthanasia.

The Labor, 1 Green, and an Inderpendant party had voted for abortion to be legalised, that is euthanasia at the early stage of life. This is against my beliefs. I strongly have views that this grave notion will harm humanity and especially the women of this country.

I do suggest you read Bishop Tim Harris on Protecting Life article in the Catholic leader.

Tammie Tang
Sent from Outlook

A443389

From:	Tim Rushbrook
To:	Care Inquiry
Subject:	[SPAM ?] Euthanasia Bill Submission
Date:	Monday, 15 April 2019 12:53:03 PM
Importance:	Low

'llTo whom it may concern,

As a long-time resident of Queensland I am deeply concerned about the possibility of weakening laws that prohibit the deliberate killing of human beings. My submission seeks to highlight specifically how the weakening of euthanasia laws would inexorably increase the long-term risk of my son being undesirably killed against his will.

My 7 year old son has Down Syndrome and is unequivocally accordingly at risk in our society. It is clear that Queensland is following the whole world as it increasingly de-values and de-means those who do not fit the mould of those who objectify the physical appearance of able-bodied, healthy, young, "attractive" people, an objectification that utterly dominates every kind of media to which we are all exposed, from shopping billboards to movies. This obsession with attractiveness means many people like my son with Down Syndrome are killed before they are born. Few people truly value life to the extent that they will embrace having a child with a disability or possibly even a minor physical deformity. Thus we discriminate against disability in utero without even seeking to hear from or understand those like me who would share the tremendous benefits of having a child like my son. With weakened euthanasia laws it is not at all unlikely that this discrimination against my son could easily be radically extended to a time in his life - perhaps several decades from now - when he may require close medical care. We already see situations in some European countries like Holland where euthanasia was long ago legalised. There people are now able to be involuntarily killed in the name of the "relief of suffering". It is clear that in **some** cases this "suffering relief" is an untrue excuse put forward when the reality is that the carers prefer not to be burdened with inconveniently having to look after someone in need. This kind of euthanasia then starts to horribly look like abortion: killing for the sake of convenience.

Many people assume that people with disabilities neither enjoy life nor positively contribute to societal life. In my own experience nothing could be further from the truth. My son with Down Syndrome loves life as much or possibly even more than my other sons. Our extended family has benefited in a multitude of unforeseen ways by the unexpected arrival in 2011 of a baby with Down Syndrome. Almost everyone who knows him loves and enjoys my son.

What a tragedy if by unnecessary legislation we unwittingly increase the probability that people like him could be subjected to the very worst excesses of discrimination: killing for the sake of convenience. Weakening euthanasia laws present a slippery slope leading inexorably in that direction.

Sincerely,

Timothy Rushbrook
[redacted]
Eatons Hill QLD 4037

From: Valda de Vries
To: Care Inquiry
Subject: We are a caring state
Date: Sunday, 7 April 2019 11:32:44 PM

Re: We are a caring state

Dear Rob Hansen,

<write your submission here>I believe that the taking of life is immoral. Doctors should be preserving life not ending it. This is what a doctor gives an oath to. Preserving LIFE. My Father -in-Law is now 103. A person like this may be pressured into this type of death if this was introduced. I have lived in the Netherlands and know that many who did not want to die actually did. If you the parliament of Queensland introduce and pass this. Then you personally will be responsible for the future well being of numerous people. If they die when they in actually want to live , You will be held responsible in God's sight. We believe , " Do not kill, murder." This is the law here where we live. Do you say sometimes it is OK to kill, murder? How will you make the difference? This already happens and the people are charged. Are these people now to be set free because the law is now changed? It is OK to kill some people? Do you propose to change the law for murder . Yes! It's OK to knock off, kill,those who don't contribute, sick, cost to much money. Not worth saving? The list is endless. Those with mental illness. These are most at risk. I wish to alert this government that this is a slippery slope which leads to unnecessary deaths as already experienced in Holland and Belgium. I humbly ask you not to imbark on the death of those vulnerable to this insidious suggestion of DEATH . Valda de Vries

Sincerely,
Valda de Vries
[redacted]

[redacted] Forest Lake
Brisbane, AU-QLD 4078

From: cvagius
To: Care Inquiry
Subject: Submission against Voluntary Assisted Dying
Date: Monday, 15 April 2019 1:06:26 PM

Dear Sir/Madam,

There are several key points points pertaining to the naming of the Bill. Already the more precise terms of Euthanasia and Voluntary Assisted Suicide have been dropped from the discussion to turn something truly horrific into something more palatable to the general community.

The problem with Voluntary Assisted Dying is that it is so open to abuse. Also, people making such decisions are sick and of course their judgement is often impaired in a system biased towards killing. Also, even if there are safeguards which will limit the abuse these will be very difficult to enforce. As a result, there will be a bias towards less enforcement of safeguards pertaining to VAD that these safeguards become ineffective. In some European countries like the Nethrtlands and Switzerland there are only scant safegaurds to protect the patient and 18 year olds and in some cases 15 year year olds are allowed to euthanize. My fear here is once we mount ourselves upon the slippery slopes of VAD there will be no stopping the holocaust that follows.

Unfortunately for our society we have been hooked by fear. There is a sustainability equation that runs through the mind of many that runs like this:

Sustainability equals resources divided by population. Now that our resources are fixed we need to decrease our population to become more sustainable. So killing has become fair game through such instrumentalities as VAD.

This hypothesis although badly flawed is the hook being used by the New World Order to dupe us into thinking that the world is at the end of its sustainability limit. It is a classic case of the haves obtaining more and the have nots of getting less and the ndvof democracy with the minority well to do dictating to the majority!

On another note, doctors will not want to do it nor will our nurses and all you will be doing is forcing through an ugly piece of legislation to make these people do what they are or meant to do. As a result, our health care professional system will end up devoid of anybody who really cares!

The real solution is proper funding of the palliative care system. According to Dr Phillip Goode, Head of Pallative Care at St Vincent's Hospital, there is a dire shortage of pallative care teams. For example he mentions that the approved ratio of pallative care doctors to patients should be 2 doctors per 100,000 of population which works out to 65 such doctors in Queensland. Currently, there are 35 paid positions in Qld. This would indicate to me a real bias against pallative care funding by the present government. Even though pallative care is costly and VAD relatively inexpensive by comparison the former is the right option for this government to take for two reasons.
1lt will restore the dignity to the dying that they are rightly entitled too.

2 We will have a healthcare system based on preserving life and our hospitals not becoming pits for the holocaust victims of VAD.

Members of Parliament, let us not become penny wise and pound stupid and make us

proud Queenslanders and howl down any form of VAD and increase the funding for pallative care.

We all have to die someday. Just maybe if we had more pallative care places and the system is funded well enough for people to be able to talk it up, many of us would be less interested in dying sooner!

God bless you all!

Regards,
Vince Agius

PS l am available to discuss any of the above points with your committee.
I can be contacted on the above email address.
Sent from my Samsung Galaxy smartphone.

From: Vivienne Cole
To: Care Inquiry
Subject: Question 25: Should voluntary assisted dying (VAD) be allowed in Queensland? Why/why not?
Date: Monday, 15 April 2019 12:23:36 PM

I am deply concerned about this bill and the potential consequences of it being passed. As one who has been very ill some 30 years ago and having had a mind befuddled by life saving treatment, I know how easy it is to feel like you want to die. I was going downhill with a potentially terminal medical condition for 9 months before I began to recover. The treatment affected me emotionally, mentally and physically . I often expressed a wish to die when the suffering was intense,

However, with a change if treatment I began the recovery process. I still have this disease which has been stable for a long time and I have lived a full and rich life though in some ways limited. I would hate euthanasia to be legal the. My family found it very difficult to see me suffer. I think it is often loved ones who can't bear to see people suffer and want to see their pain ended.

To me this is a dangerous bill.

Thank you

Vivienne a Cole
[redacted] Raceview 4305

From:	Warwick
To:	Care Inquiry
Subject:	FW: VAD submission
Date:	Sunday, 14 April 2019 8:42:25 PM

From: Warwick
Sent: 14/04/2019 08:40 PM
To: careinquiry@parliament.qld.gov.ay
Subject: VAD submission

To Qld Parliament.
Re question 25.
No, VAD should not be allowed in Queensland. Circumstances can change, suffering can be alleviated, the meaning of life can alter. On the other side, death is irrevocable, and people may be subtly or unsubtly brought to consider it.
Warwick Adeney
[redacted] Milton 4064
[redacted]

From: gumsony@iinet.net.au
Sent: Monday, April 15, 2019 6:34 PM
To: careinquiry@parliament.qld.gov.au
Subject: SUBMISSION re: Should voluntary assisted dying be legalised in Queensland?

The Secretary
Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee
Queensland Parliament
Brisbane

15.04.19

Submission, re:

Should voluntary assisted dying be legalised in Queensland?

My views on aged care, end-of-life and palliative care and voluntary assisted dying.
Question #25: Should voluntary assisted dying (VAD) be allowed in Queensland?
No.

Why not?

Terms used

All terms used **must** be defined: viz each one:-
"Voluntary", and "assisted", and "dying".

As well, often terms like “euthanasia” are used and they mean different things to different people. For example, for some people, "euthanasia" may mean assisted killing; for others, assisted dying. Hence, as mentioned, all terms must be defined.

Motives

Motives provide the base-line of the action. For example, a person on life support for whom the procedure is futile, turning off the life support is not intentional killing or voluntary assisted dying – it is removing artificial intervention from the inevitable outcome. I have had direct involvement with this with my only sister. Likewise, increased medication to relieve the patient of unbearable pain is not assisted dying even if it does hasten the inevitable death; it is to help keep the patient comfortable until death.

Best practice

In our sophisticated society where all manner of support is available and all manner of understanding of the needs of the human person is understood, the best practice for people approaching death, or in a terminal illness situation is Palliative Care. Human life must be respected.

Hard cases make bad law

The idea behind "hard cases make bad law" is obvious. Laws should be made for the benefit of the general population. They should reflect and regulate normal circumstances.

Good law is not based on exceptions – and especially not exceptions wrapped in emotion. The law should embody sound reasoning rooted in a desire for justice, not warm feelings.

Unfortunately, to the detriment of society, we have already seen the Queensland government succumb to the emotional stories in the current laws regarding abortion. No dignity or forethought is accorded the targeted unborn individual. Allowing VAD or VAK [killing] is the chink in the law regarding other individuals at the other end of life - at first. Meaning, we have seen the chink open to a chasm in the Netherlands and Belgium, and go beyond the dying and even the elderly. Australians / Queenslanders have better medical skills available and do not need that.

However, with an ageing population, more practitioners should be encouraged into specialising in end of life needs - psychological; spiritual; counselling [for the patient, and with the next-of-kin]; whichever specialist medical field eg oncology, and pain management physicians; legal; appropriate accommodation; and so on.

Conclusion

In short, all terms used within the topic must be defined; the motive must be to bestow the dignity of care on the dying; and laws must serve the community not be a servant of emotions.

Recommendation

Over and over it has been shown that a holistic care of a person at the end of life gives them the feeling of being valued, and thereby a serenity and acceptance that belies their condition. There needs to be more Palliative Care units/accommodation, and specialist training in all areas of human function at end-of-life.

Yours faithfully
- Merle Ross
ID:
Merle Ross
[redacted]
The Range Q 4700
[redacted]

From: Carmel Doolan
To: Care Inquiry
Subject: Legalising euthanasia would be a dangerous idea for Queensland.
Date: Friday, 5 April 2019 9:00:05 AM

Re: Legalising euthanasia would be a dangerous idea for Queensland.

Dear Committee Inquiry,

Prohibition on doctors killing patients is a longstanding rule. The World Medical Association and Australian Medical Association oppose euthanasia on the basis that it undermines the doctor/patient relationship of trust. In other countries,Legislative safeguards have proved insufficient to prevent wrongful deaths.

Sincerely,
Carmel Doolan
[redacted]

[redacted]
Cairns, AU-QLD 4870

From: Ellen Miller
To: Care Inquiry
Subject: Legalising euthanasia would be a dangerous idea for Queensland
Date: Friday, 5 April 2019 11:12:38 AM

Re: Legalising euthanasia would be a dangerous idea for Queensland

Dear Committee Inquiry,

Dear Sur/Madam, Prohibition on doctors killing patients is a longstanding rule. The World Medical Association and Australian Medical Association oppose euthanasia on the basis that it undermines the doctor/patient relationship of trust. Also, It is dangerous to legalise euthanasia when palliative care is underfunded. Sincerely Ellen Miller

Sincerely,
Ellen Miller
[redacted]
[redacted]
Waterford, AU-WA 6152

From: Emily Grubb
To: Care Inquiry
Subject: Legalising euthanasia would be a dangerous idea for Queensland
Date: Wednesday, 3 April 2019 2:00:45 PM

Re: Legalising euthanasia would be a dangerous idea for Queensland

Dear Committee Inquiry,

Prohibition on doctors killing patients is a longstanding rule. The World Medical Association and Australian Medical Association oppose euthanasia on the basis that it undermines the doctor/patient relationship of trust. Also, safeguards in other countries where euthanasia has been legalised have not prevented abuses. Euthanasia is not a good thing for Australia.

Sincerely,
Emily Grubb
[redacted]
[redacted]
Watsonia North, AU-VIC 3087

From: Florence Lehmann
To: Care Inquiry
Subject: Legalising euthanasia would be a dangerous idea for Queensland
Date: Thursday, 28 March 2019 2:33:29 PM

Re: Legalising euthanasia would be a dangerous idea for Queensland

Dear Committee Inquiry,

Prohibition on doctors killing patients is a longstanding rule. The World Medical Association and Australian Medical Association oppose euthanasia on the basis that it undermines the doctor/patient relationship of trust. It is too open misuse.

Sincerely,
Florence Lehmann
[redacted]
[redacted]
Riverview, AU-QLD 4303

From: Fred Sharpe
To: Care Inquiry
Subject: Legalising euthanasia would be a dangerous idea for Queensland
Date: Friday, 5 April 2019 3:55:41 PM

Re: Legalising euthanasia would be a dangerous idea for Queensland

Dear Committee Inquiry,

Prohibition on doctors killing patients is a longstanding rule. The World Medical Association and Australian Medical Association oppose euthanasia on the basis that it undermines the doctor/patient relationship of trust. I personally do not believe in legalizing euthanasia and assisting suicide. Sincerely Fred Sharpe

Sincerely,
Fred Sharpe
[redacted]
[redacted]
Worongary, AU-QLD 4213

From: Gregory McKenzie
To: Care Inquiry
Subject: Legalising euthanasia would be a dangerous idea for Queensland. The power over life and death should not be given to people not thinking clearly.
Date: Monday, 15 April 2019 6:46:11 AM

Re: Legalising euthanasia would be a dangerous idea for Queensland. The power over life and death should not be given to people not thinking clearly.

Dear Committee Inquiry,

Prohibition on doctors killing patients is a longstanding rule. The World Medical Association and Australian Medical Association oppose euthanasia on the basis that it undermines the doctor/patient relationship of trust.

Sincerely,
Gregory McKenzie
[redacted]
[redacted]
Chatswood, AU-NSW 2067

From: Lidia Galea
To: Care Inquiry
Subject: Legalising euthanasia would be a dangerous idea for Queensland
Date: Friday, 5 April 2019 7:17:45 AM

Re: Legalising euthanasia would be a dangerous idea for Queensland

Dear Committee Inquiry,

Prohibition on doctors killing patients is a longstanding rule. The World Medical Association and Australian Medical Association oppose euthanasia on the basis that it undermines the doctor/patient relationship of trust. I urge you to keep at the forefront this crucial foundation of our entire medical system when considering this bill.

Sincerely,
Lidia Galea
[redacted]

[redacted]
Bonython, AU-ACT 2905

From: Lisa de Weger
To: Care Inquiry
Subject: Legalising euthanasia would be a dangerous idea for Queensland
Date: Monday, 1 April 2019 8:18:06 PM

Re: Legalising euthanasia would be a dangerous idea for Queensland

Dear Committee Inquiry,

Prohibition on doctors killing patients is a longstanding rule. The World Medical Association and Australian Medical Association oppose euthanasia on the basis that it undermines the doctor/patient relationship of trust. Legislative safeguards have proved insufficient to prevent wrongful deaths. Suicide contagion is a real risk when governments convey the message that some suicides are 'okay' or 'good'. Legalizing euthanasia undermines suicide prevention messages. I'd like to stand and be counted in history for the protection of human life, from birth to natural death and would hope my government would be doing the same! The results of this inquiry will be affecting my vote.

Sincerely,

[redacted]
[redacted]
Tivoli, AU-QLD 4305

From: Margaret Mantei
To: Care Inquiry
Subject: Legalising euthanasia would be a dangerous idea for Queensland
Date: Friday, 5 April 2019 6:30:18 PM

Re: Legalising euthanasia would be a dangerous idea for Queensland

Dear Committee Inquiry,

Dear Mr Mark McArdle, I oppose the legalisation of euthanasia, as palliative care is underfunded, it also undermines suicide prevention, I also oppose it on my religious convictions. Prohibition on doctors killing patients is a longstanding rule. Your Sincerely Margaret Mantei

Sincerely,
Margaret Mantei
[redacted]
[redacted]
PELICAN WATERS, AU-QLD 4551

From: Patricia Burke
To: Care Inquiry
Subject: Legalising euthanasia would be a dangerous idea for Queensland
Date: Thursday, 2 May 2019 5:19:35 PM

Re: Legalising euthanasia would be a dangerous idea for Queensland

Dear Committee Inquiry,

Prohibition on doctors killing patients is a longstanding rule. The World Medical Association and Australian Medical Association oppose euthanasia on the basis that it undermines the doctor/patient relationship of trust. It is against the law of God

Sincerely,
Patricia Burke
[redacted]

[redacted]
Bathurst2795, AU-NSW 2795

From: Beryl & Lloyd Orchard
To: Care Inquiry
Subject: Legalising euthanasia would be a dangerous idea for Queensland are here
Date: Saturday, 13 April 2019 1:52:00 PM

Re: Legalising euthanasia would be a dangerous idea for Queensland are here

Dear Committee Inquiry,

Prohibition on doctors killing patients is a longstanding rule. The World Medical Association and Drs.Medical Association oppose euthanasia on the basis that it undermines the doctor/patient relationship of trust. Drs.are meant to save lives

Sincerely,

[redacted] Surfers Paradise Q'ld 4217
Surfers Paradise, AU-QLD 4217

The Honourable Mr Aaron Harper
Chair
Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee
Queensland Parliament
Qld 4000

Dear Mr Harper

Queensland Parliamentary inquiry into aged care, end-of-life care, palliative care and voluntary assisted dying

We wish to extend our thanks to the committee for the opportunity to provide input into the inquiry. We the *Queensland Specialist Palliative Care Services Directors' Group* present the following submission concerning specialist palliative care in Queensland. The views expressed within this submission are our own and based on our experience of palliative care service provision.

Your sincerely

Dr Greg Parker FRACGP, FAChPM
Chair
Qld Specialist Palliative Care Services Medical Directors' Group

On behalf of:
Dr Louise Welsh, Dr Andrew Broadbent, Dr Patti Lee-Apostol, Dr Phillip Good, Dr Carol Douglas, Dr Bill Lukin, Dr Richard Corkhill, Dr Robyn Brogan, Dr James Stevenson, Dr Bruce Stafford, Dr Janet Hardy, Dr Ross Cruikshank, Dr Ralph McConaghy, Dr Anthony Herbert, Dr Elizabeth Reymond, Dr Edward Mantle, Dr Soe Yu Aung, Dr Peter Whan

Thank you for giving us the opportunity to contribute to this inquiry.

Introduction

We provide this submission as a concerned group of experienced, palliative medicine physicians. We work in the public and private sectors and provide care at a grassroots level for adult, adolescent-young-adult and paediatric members of our communities. We believe that dying people and their families should receive the right care at the right time and in the right place. That is our focus. We also believe our speciality is optimally placed to lead the development of palliative care services across Queensland to deliver such patient centred, equitable care.

This submission takes into consideration the terms of reference and specifically items 17 to 24 of the issues paper. We describe the current palliative care landscape including issues and gaps, articulating priorities with pragmatic recommendations.

It has been six years since the most recent inquiry into palliative care in Queensland. Little has changed. Overall the issues and recommendations from the previous inquiry continue to remain relevant and urgent[1].

Queenslanders continue to struggle to access equitable and needs based palliative care due to:

- poor service resourcing and infrastructure dictated by obsolete and disparate funding models.
- lack of direct engagement from the government and policy makers with expert and experienced specialist palliative care clinicians
- lack of integration between hospital and community-based specialist palliative care services
- lack of a state-wide approach to palliative care
- inadequate current specialist workforce

Any growth in specialist palliative care service development has been piecemeal and has resulted from opportunistic funding rather than arising out of baseline health service design and planning with dedicated funding.

Immediate priorities of this submission for consideration:

1. The State Government to provide **specialist palliative care services or the most senior palliative care service provider in those areas that lack a specialist service with adequate funding to deliver palliative and terminal care packages** to achieve better outcomes for end-of-life care in the community
2. The State Government to fund additional **palliative medicine physicians to provide on call clinical backup services for generalist community prescribers/clinicians across Queensland** as part of a rostered 24-hour consultancy role

3 The State Government to **fund palliative care services in all Hospital and Health Service districts (HHS's) to a level in accordance and on par with the highest level of Clinical Services Capability framework (CSCF) across all services** in that HHS as mandated by Queensland Health. This needs to be coupled to accountable implementation.

4 The State Government to establish **a mechanism for regular direct engagement between relevant policy makers and specialist palliative care services** to enhance understanding and address requirements of palliative care service delivery across the state. This can be accomplished by engagement with the *Qld State-wide Specialist Palliative Care Services Directors' Group.*

5 The State government commit to **fund a specialist palliative care workforce in line with current Palliative Care Australia guidelines** and develop a **strategy to increase the future specialist workforce** through accredited training pathways

What currently happens in Palliative Care Provision in Queensland?

There are regional, rural and remote communities with no direct access to specialist palliative care. Clinicians in these places and their surrounds spend time ringing around the state to ask for specialist palliative care advice. Clearly, this make-do model is not sustainable and unfortunately adds further burden to already stretched palliative care services and leads to less than optimal patient outcomes and service delivery.

There is a lack of access to home equipment. An essential part of home-based palliative care. Medical Aids Subsidy Scheme guidelines, for example, historically exclude palliative patients from access to equipment. The expectation is that these are funded by specialist palliative care services that may not be budgeted for this. It then becomes Hospital and Health Service (HHS) dependent and a postcode lottery, -that is some patients in a HHS will be funded for equipment, where as those in other HHS's will not.

Arranging a palliative care package for a patient is often a confusing and complex process for patients and their carers. They struggle to negotiate the complexities of the National Disability Insurance Scheme (NDIS), My Aged Care and Queensland Community Care funding scheme often leading to unacceptable delays in provision of care or in some instances no care at all. Some of these schemes do not fund nursing support. Many patients die before their package is approved.

If a patient requires an urgent palliative care home visit outside of business hours or on a weekend, their needs will often not be met. Unfortunately, out of hours home based care is not universally available, as services are not routinely funded to provide it. Emergencies don't always conveniently occur during "normal working hours". Patients in most instances in this situation must present to an emergency department. Palliative care has not been given the recognition as an area of service in which it is essential to provide 24/7 care.

The demand for specialist palliative care and the increasing complexity of end of life disease treatment and community expectations is resulting in critical need to address the specialist palliative care workforce issues that continue to challenge the sector. There is a clear capacity-demand gap that can no longer be ignored. An adequate specialist palliative care workforce across medical, nursing and allied health disciplines remains critical to achieving comprehensive best practice palliative care to meet current as well as future community and system demand.

Workforce planning and development remains challenging due to a serious underinvestment in the sector. This underinvestment needs to be urgently addressed. For example, the total funded full time equivalent (FTE) palliative medicine specialist positions in Queensland are 38.4FTE positions while the required FTE positions equate to 92.94FTE positions[2].Clear demonstrable evidence of the gap and challenges faced in Queensland specialist palliative medicine medical workforce planning is highlighted in the report prepared by the Queensland Palliative Medicine Training Oversight Committee[2]. This theme is reproducible in other areas of the specialist palliative care workforce, namely nursing and allied health.

There have been several palliative care reviews and scoping studies (funded by the state government) over the last 10 years seeking to understand palliative care service provision in Queensland and to look at planning for the future. These are potentially important pieces of work, yet they have not been made publicly available. Such information is important for us all to understand past, current and future palliative care needs, and we think they should all be made publicly available.

Why is Palliative Care important?

Death is a universal health outcome. Equitable access to comprehensive palliative care, therefore, must be recognised as a fundamental human right and an essential component of value-based safe and high-quality health care for all. It cannot and should not be considered an optional extra of any health service.

Our society is aging well; however, this is accompanied by complexities for care and specific needs as death approaches. Much good work is being done in the context of preventative, curative and restorative medicine; however, people are living and dying with more complex chronic severe diseases and multimorbidities, requiring increasing supports from the health care system. This fact is often ignored. Due to limited workforce resourcing, specialist palliative care consultation teams in the acute care setting are struggling to meet demand for palliative care input and ongoing clinical support with consequential poor patient and family outcomes.

Specialist Palliative Care

Specialist palliative care is a highly organised and structured framework of care supported by appropriate infrastructure allowing impeccable assessment coupled with comprehensive whole person care and support to the patient/family unit both during severe illness and in bereavement. It is delivered by a highly skilled interdisciplinary team guided by the clinical leadership of a palliative medicine physician. Patients at any stage of their terminal disease trajectory, at any time of the day or night regardless of geographic location need to be able to access this care with the least amount of additional burden, especially the burden of navigating our complex health system. The aim of the framework of palliative care is to provide choice at end of life, regarding where the individual is cared for and dies concordant with the individual's expressed wishes and overseen by specialists in the field. It requires team planning and capacity, supported by adequate resourcing and infrastructure.

A Framework of Care

Many things need to change in palliative care services across Queensland to meet future demand. New models of care are required that pragmatically address the real situations, faced by the community and healthcare providers, rather than those aspirationally suggested in policy and strategy documents determined by funding silos. Increasingly members of the community are seeking legislative change to access voluntary assisted dying because they have witnessed the poor quality of dying that is still too frequent in Queensland.

Assuming that there is recognition of the terminal nature of a person's disease trajectory, a vital starting element is, *advance care planning* particularly if this subject has not been previously addressed. This is followed by *care delivery* with constant review of needs including physical, spiritual, psychosocial and ultimately end-stage and bereavement care. Optimal care aligns to the National Palliative Care Standards and Palliative Care Australia Service Development Guidelines and is achievable in real time with adequate resourcing[3]. It includes two major elements:

Element 1: Advance Care Planning *("Let us understand your wishes")*

Advance care planning (ACP) is an essential component of best palliative care and needs to be incorporated into all models of care to ensure patient-centred care and high-value outcomes for Queenslanders.

End of life can be a difficult, confusing, painful and emotional journey for the person and their significant others as well as for the treating practitioners. The absence of a clear end-of-life decision and treatment pathway for the patient can lead to futile care and inappropriate use of health care resources[4]. Best practice recommends the preparation of advance care plans which document end-of-life preferred processes[5,6]. Such plans also allow patients' choices to be known by substitute decision makers, families, and carers who can help to ensure the end-of-life plan is carried out when the patient can no longer directly communicate their wishes, to inform treatment decisions. Early advance care planning discussions provide sensitive,

honest information to patients and their families and carers to minimise unexpected and/or adverse outcomes and increased bereavement burdens.

The value of dedicated ACP facilitators has been recently demonstrated across Queensland. People, who, with the assistance of an ACP facilitator, who completed an advance care plan, expressing and clarifying their wishes, were significantly more likely to die out of hospital, spent significantly fewer days in hospital in their last 6 months of life and were less likely to be admitted to ICU, in their terminal admission, compared with those who did not complete an advance care plan. In clinical reality, completion of an advance care plan translates to more people being cared for in their environment of choice, avoiding potentially non-beneficial care and fewer unwanted transfers from community settings to hospital settings[7].

ACP documents need to be accessible by clinicians. There is clear need for a systematised approach to information sharing. This has been achieved by the establishment of the Queensland Office of Advance Care Planning supported by technological infrastructure allowing easy visibility through a portal called The Viewer. Funding for this project unfortunately remains time limited and recurrent funding is currently uncertain.

- **Recommendation**: commitment from the State Government to recurrently fund the Office of Advance Care Planning and dedicated ACP facilitators within specialist palliative care and/or similarly appropriate services in each HHS. This will ensure necessary culture change as well as public and staff ACP education. The return on investment is indisputable[7].

Element 2: Palliative and End-Of-Life Care delivery *("Once we know your end-of-life wishes we can build a tailored palliative care plan for you")*

To meet patients' preferences to be cared for at home for as long as possible, models of palliative care need to have a focus on community care, although the backup and availability of in-patient care with 24-hour access remains essential. General practitioners (GPs) are a key part of a patient's health care management and are even more important when the patient needs palliative care. However, there are challenges in more recent times as less GPs are motivated to provide the time-intensive input required for quality palliative care, including home-visits and attendances at residential aged care facilities (RACF's), advance care planning sessions, opioid prescribing, counselling, the organisation of equipment and domiciliary nursing and allied health services and after-hours visits. GPs are not adequately remunerated for these activities. Further, after-hours deputising medical services are loath to attend palliative patients at home or in RACFs, and, by default, many refer patients to hospital resulting in poor patient outcomes and high-cost care. Growing opioid phobia is resulting in fewer GPs being prepared to script patients for fear of investigation by the Australian Department of Health.

New models of care are needed to improve quality palliative care for all. To achieve best practice palliative care outcomes, models of care should be organised around specialist palliative care services in partnership with GPs and brokered to other primary healthcare providers as available within local areas and tailored to local caseloads. These models should not only focus on terminal phase of end-of-life-care, as has occurred previously due

to lack of funding but should expand to include earlier palliative care. Specialist palliative care core presence in other specialist multidisciplinary team (MDT)meetings across acute hospital settings is crucial.

Today, only a small proportion of people die suddenly, most die from conditions with a predictable trajectory, experiencing a prolonged period of disability, frailty, and illness and then dying at an older age. While it is relatively easy to predict an eventual fatal outcome in many chronic diseases, the actual timing of death is much more unpredicatble[8]. In 2015, the five leading causes of death in adults for example included coronary heart disease, cerebrovascular disease, dementia, chronic obstructive pulmonary disease, and cancer[9,10]. If death is expected, care can be planned for whenever it eventually happens.

To meet increasing demand new models must incorporate technologies such as telehealth and electronic patient information systems. Telehealth partnerships are required to link Level 6 specialist palliative care services and regional and rural generalist services according to patient flow patterns, extending across hospital and health service boundaries where necessary.

To address equity issues, models need to target at-risk, vulnerable and isolated populations with a focus on true person-centred care, not postcode centred care, reducing variation of access and services available to patients.

- **Recommendations:** Commitment from the State Government to:
  - fund palliative care services in all Hospital and Health Service districts (HHS's) to a level in accordance and on par with the highest level of Clinical Services Capability framework (CSCF) across all services in that HHS as mandated by Queensland Health. This needs to be coupled to accountable implementation.
  - adequately invest in Specialist Palliative Care services across all settings of care to provide coordinated, evidence-based, systematised, equitable and accountable care. Such care should be based on a comprehensive framework of palliative and end-of-life care. It needs to be supported by an adequate workforce inclusive of specialist medical, nursing, allied health and administrative staff, together with appropriate and readily available infrastructure inclusive of but not limited to, palliative and terminal care packages that meets the needs of the community 24 hours a day, 7 days a week. There needs to be a state-wide approach especially addressing inequities across rural regional and remote areas
  - ensure investment takes place at a hospital level so that a Palliative Medicine Specialist can be a core member of cancer and chronic complex disease MDT's

Additional points that need consideration:

Need for a Clinical Model of Palliative Care Excellence in Residential Aged Care Facilities

Residential Aged Care Facilities (RACFs) are the hospices of today and into the future. The number of deaths occurring in these facilities continues to grow. Yet there is high-level consensus agreement that quality end-of-life care is very challenging in this environment.

> **Recommendation:** Queensland would benefit from the establishment of a clinical palliative care centre of excellence within an RACF. This could be achieved in partnership between a Level 6 Palliative Care Service and one of the larger palliative RACF providers. The facility would allow best end-of-life care to be modelled and taught to incumbent and visiting staff. It would also allow the RACF workforce to learn about quality improvement processes and to be mentored by specialist palliative care staff to drive a clinician-owned "bottom-up" approach to best practice.

Need for a comprehensive specialist digital palliative care solution to benefit palliative care patients across Queensland

Specialist Palliative Care services currently struggle with real-time information sharing and data capture. In Queensland integrated electronic medical records (ieMR) currently stops at the hospital door and is in its generic phase rather than fit for purpose. Community specialist services have to depend on multiple piecemeal solutions to capture patient information, consistent outcome data and jurisdictional activity data. The ability to mine aggregated relevant inputted palliative care data from a fit for purpose digital solution would allow services, the system and the community to be informed of current and evolving patient needs into the future and the requirements for service to be optimised.

> **Recommendation:** That the State Government commits funding to develop a dedicated specialist palliative care digital solution

Need for Clinical Educators within Specialist Palliative Care Services

Specialist palliative care services need to provide ongoing education to generalists, other specialists and the public within the catchment area, including rural and regional areas, of the specialist service. These clinical positions need to be dedicated for education; staff cannot simply be expected to add education to their already crowded clinical duties. A specialist palliative care education officer increases the capacity and sustainability of primary community care providers, including GPs, to deliver quality care at the end of life.

> **Recommendation:** That the State Government support funding to ensure that high level specialist palliative care services have a dedicated full time equivalent palliative care educator on staff

Palliative Care Queensland (PCQ)

Palliative Care Queensland is a driving force in creating and supporting ongoing community awareness of dying and death as a natural part of living and advocating for high quality palliative care across the state. This peak body is dependent on shoe string core funding of $115,000, remaining under constant threat of having to scale back its efforts in supporting the community and sector.

> **Recommendation:** That the State Government adequately enhances funding to PCQ

Clinical research

High quality clinical care is informed and improved by clinical research. Palliative care clinicians are currently overwhelmed by the demands of patient care that they do not have anytime dedicated to this important aspect of improving practice. It is a core part of clinical practice that there is dedicated time for clinicians to participate in clinical research.

> **Recommendation:** That all HHS's and Palliative Care services have in place KPIs related to clinical research and clinicians are given dedicated time to perform clinical research.

Voluntary Assisted Dying (VAD)

Specialist palliative care services are concerned with ensuring equitable access to comprehensive palliative care for all of those in need. VAD is not part of palliative care practice, though there continues to be misconceptions around the relationship between palliative care and voluntary assisted dying.

VAD becoming part of health care in Queensland will be decided by society and legislators. Independent of whether or not legislation is passed in favour of VAD, it needs to be made clear that proper investment in frontline palliative care for the most vulnerable members of our society cannot be neglected.

Summary of recommendations

- Commitment from the State Government to:
  1. provide specialist palliative care services or the most senior palliative care service provider in those areas that lack a specialist service with adequate funding to deliver palliative and terminal care packages to achieve better outcomes for end-of-life care in the community
  2. invest in additional medical palliative care consultants to provide an on call clinical backup service for generalist community prescribers across Queensland
  3. fund palliative care services in all Hospital and Health Service districts (HHS's) to a level in accordance and on par with the highest level of

Clinical Services Capability framework (CSCF) across all services in that HHS as mandated by Queensland Health. This needs to be coupled to accountable implementation.

4. adequately invest in Specialist Palliative Care services across all settings of care to provide coordinated, evidence-based, systematised, equitable and accountable care. Such care should be based on a comprehensive framework of palliative and end-of-life care and in line with national palliative care standards. It needs to be supported by an adequate workforce inclusive of specialist medical, nursing, allied health and administrative staff, together with appropriate and readily available infrastructure inclusive of but not limited to, palliative and terminal care packages that meets the needs of the community 24 hours a day, 7 days a week. There needs to be a state-wide approach especially addressing inequities across rural regional and remote areas
5. ensure investment takes place at a hospital level so that a Palliative Medicine Specialist can be a core member of cancer and chronic complex disease MDT's
6. commit to funding a specialist palliative care workforce in line with current Palliative Care Australia guidelines and develop a strategy to increase the future specialist workforce through accredited training pathways
7. commit recurrent funding to support administration of the Queensland Palliative Medicine training pathway
8. establish a mechanism for regular direct engagement between relevant policy makers and specialist palliative care services to enhance understanding and address requirements of palliative care service delivery across the state. This can be accomplished by engagement with the *Qld State-wide Specialist Palliative Care Services Directors' Group.*
9. recurrently fund the Office of Advance Care Planning and dedicated ACP facilitators within specialist palliative care services and/or similar services in each HHS. This will ensure necessary culture change as well as public and staff ACP education. The return on investment is unequivocal.
10. The State Government to additionally fund level 5 and 6 (CSCF) services in neighbouring HHS's to provide a hub of clinical and educational support to smaller HHS's that have a lower level CSCF
11. establish a clinical palliative care centre of excellence within an RACF. This could be achieved in partnership between a Level 6 Palliative Care Service and one of the larger palliative RACF providers. The facility would allow best end-of-life care to be modelled and taught to incumbent and visiting staff. It would also allow the RACF workforce to learn about quality improvement processes and to be mentored by specialist palliative care staff to drive a clinician-owned "bottom-up" approach to best practice. This needs to be scalable across the state

12. commit funding to the development of a dedicated specialist palliative care digital solution
13. ensure that high level specialist palliative care services have a dedicated full time equivalent palliative care educator on staff
14. ensure that all HHS and Palliative Care services have in place KPIs related to clinical research and clinicians are given dedicated time to perform clinical research.
15. ensure that each HHS funds adequate palliative care service provision and is accountable via defined Key Performance indicators such as direct access to inpatient beds 24/7, access to specialist palliative care 24/7, investment in specialist community palliative care, adherence to the CSCF.
16. ensure adequately enhanced funding for Palliative care Queensland

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5.State of Queensland (Queensland Health). *Statewide strategy for end-of-life care 2015*.

6.Royal College of Physicians. A*dvance care planning: Concise Guidance to Good Practice Series, No. 12*. RCP. 2009.

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19.Australian Bureau of Statistics. *Causes of Death, Australia, 2015*. Cat. No. 3303.0. Canberra: 2016.

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From: [redacted]
To: Care Inquiry
Subject: No assisted dying legislation can ever be adequately safeguarded
Date: Friday, 12 April 2019 10:09:00 AM

My submission to the Assisted Dying Inquiry:

I urge you not to recommend legalising assisted dying in Queensland.

No matter what safeguards are put in place, no euthanasia or assisted dying law is ever safe from abuse. In time, as international experience has shown, the financial and social pressures to shorten life prove far too great; and the safeguards built into the legislation prove far too little to stop wide-scale coerced, and in some cases, involuntary killing. Consider the testimony of Dutch Professor Theo Boer, once an advocate for the Dutch euthanasia laws and a member of the evaluation committees, who recently told the British Press, “I was wrong! Don’t go there!”

And Ethicist Wesley Smith explains that this outcome is inevitable: “The carefully shaded moral distinctions in which the health-care intelligentsia and policymakers take so much pride are of little actual consequence in the real world of cost-controlled medical practice, in busy hospital settings, and among families suffering the emotional trauma and bearing the financial costs of caring for a severely brain-damaged relative. Once killing is seen as an appropriate answer in a few cases, the ground quickly gives way, and it becomes the answer in many cases.”

When ‘assisted dying’ is legalised, those dying have little real power to resist it and their real end of life options are greatly diminished. Please consider these dangers and recommend Queensland does not go down this path.

Yours sincerely,

Margaret Ochsner

[redacted]
REEDY CREEK
QLD 4227

DECIDED TO WRITE AGAIN (LATE, SORRY) RATHER THAN MISS THE OPPORTUNITY TO SUGGEST YOU ACTUALLY VISIT AN AGED CARE FACILITY WITH DEMENTIA SPECIFIC AREA

MY EX HUSBAND HAS RECENTLY BEEN CONFINED TO SUCH A PLACE.

THE STAFF IN THE MAIN ARE WONDERFUL BUT DUE TO BORNOUT AND STRESS THERE IS A REGULAR TURNOVER, CAUSING INADEQUATE NUMBERS & ONGOING TRAINING WITH CONSEQUENT PROBLEMS.

YOU WILL WITNESS THE FORCED SUFFERING OF THE LIVING DEAD WHERE MOTIONLESS BODIES LIE IN BEDS TOTALLY DEPENDANT ON OTHERS TO KEEP THEM CLEAN & COMFORTABLE, FED & HYDRATED. UNABLE TO COMMUNICATE PAIN OR DISCOMFORT OR RECOGNISE FAMILY & FRIENDS.

ITS OFTEN QUITE A WHILE BETWEEN NEEDING & RECEIVING ATTENTION SO THE DISTINCTIVE AROMA OF A VERY NEGLECTED PUB/PUBLIC TOILET, PERVEDES THE FACILITY

FAMILIES DON'T SEEM TO VISIT ONCE RECOGNITION HAS CEASED AND THEY NEVER KNOW IN WHAT CONDITION THEY WILL FIND THEIR LOVED ONE.

WE NEVER KNOW WHAT IS AHEAD OF US - IT COULD HAPPEN TO YOU OR YOURS. - PLEASE MAKE IT EASIER ON ALL OF US AND VOTE FOR VOLUNTARY ASSISTED DYING & BY ALL MEANS INVESTICATE THE DELIVERY OF AGED CARE IN ITS PRESENT FORM. OVERSEAS OPERATORS ARE HERE PURELY TO MAKE A PROFIT - ITS NOT THEIR OWN CITIZENS THEY ARE HOLDING TO RANSOM.

Sincerely - Eleanor Southwick