Submission into the Voluntary Assisted Dying Bill 2021

Submission No.: 1189

Submitted by: Go Gentle Australia

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Position: I/We support the Voluntary Assisted Dying Bill but

recommend some changes to it.

Comments in relation to: Conscientious objection by either individuals or

entities, Oversight and review, Other

Attachments: See attachment

Submitter Comments:

Submission No 1189



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Submission to

Queensland Health Committee

In response to

Voluntary Assisted Dying Bill 2021

1 July 2021



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Go Gentle Australia: prefatory notes

Go Gentle Australia (GGA) was established by Andrew Denton in 2016 to improve the national conversation around dying and to work for the introduction of safe voluntary assisted dying laws, appropriate to the circumstances of Australia's medical, political, and social culture.

GGA grew out of a ground-breaking series of podcasts created by Andrew Denton and his production/research team. The *Better Off Dead* (2016) series presented first-hand accounts of Voluntary Euthanasia/VAD law in action around the world and brought together, for the first time, voices and arguments from all sides of the assisted dying debate.

In the years since, GGA's extensive engagement in VAD debates in South Australia (2016), Victoria (2017), Western Australia (2019), Tasmania (2021) and South Australia again (2021), means we have built a strong understanding of the political realities – and challenges – of developing a law which balances the competing needs of access for those who may require assisted dying, and safeguards to ensure that those for whom the law is not intended cannot access it.

In 2021, Andrew Denton and Go Gentle released a second series of <u>Better off Dead</u>. Focussing on the first year of Victoria's VAD law, it explored how that law has operated in practice; what have been the experiences of those who have accessed it, or of family members whose loved ones have; and what have been the experiences of doctors who have undertaken VAD training and participated in assessing people for eligibility.

Recorded over 11 months it is a unique record: the first oral history of Victoria's law, bringing together the voices of the terminally ill, their families, GPs, specialists, palliative care physicians, pharmacists, VAD care navigators, and members of the Voluntary Assisted Dying Review Board.

This second series also measures the accusations of those who opposed (or continue to oppose) Victoria's law against the reality of how it has worked in practice, told in the words of those at the frontline.



Chapter 1: General remarks

Overall, we support the proposed Queensland Voluntary Assisted Dying Bill 2021.

In our view, the QLRC has done a thorough job of taking into account lessons and experiences from other jurisdictions in order to craft an optimal VAD law for Queensland.

In this submission, therefore, we intend only to address the following issues which, in our opinion, require stronger focus:

- Institutional Conscientious Objection
- The Need for an Ombudsman role / complaints mechanism
- Review Board reporting requirements
- Commonwealth law restrictions which have created greater suffering for some seeking VAD



Chapter 2: Institutional Conscientious Objection

We strongly support the bill's provisions on Institutional Conscientious Objection (Subdivision 3 'Access to Voluntary Assisted Dying').

While we believe that the right of individuals to conscientiously object is fundamental to a law whose first word is 'voluntary', we see it as imperative that the rights of the **people for whom this law has been written** – Queensland's terminally ill - are in no way compromised by a blanket allowance for institutions to do the same.

We believe that the provisions laid out in Subdivision 3 honour both these rights.

We attach (<u>Appendix A</u>) a letter from Catholic Health Australia, dated June 3, sent to the Hon Stephen Wade (MLC), Minister for Health and Wellbeing in in South Australia during the recent parliamentary debate which saw VAD legalised in the State.

It lays out CHA's objections, essentially to what is proposed in Queensland's law.

These were amplified by a recent article published in The Australian ('Fears of faith-based health withdrawal due to assisted dying bill', June 27, 2021), where the following was stated:

"Churches and other critics of the Queensland legislation say it will compel faithbased hospitals to admit outside doctors to help dying patients request VAD and potentially administer the lethal dose on the premises.

Chief executive of St Vincent's Health Australia, Lincoln Hopper, said institutional conscientious objection was in "name only" in the Queensland legislation because Catholic hospitals would have to allow entry to outside doctors or others seeking to assist a patient with VAD. "It's one thing for the bill to grant us capacity to withdraw our hospitals and staff from participating in VAD, but to then allow our facilities to be used by others in the same practice ... goes against the very foundations of our work," he said.

Mater group of hospitals CEO Peter Steer cautioned: "We need our staff and patients to have a strong sense of certainty and safety about the care we provide."

This last claim - that the law as it is proposed threatens the sense of 'certainty and safety' felt by patients and staff - is a clear distortion of the reality that VAD law is about individual choice; that it has strict eligibility requirements; and that to access it requires the navigation of multiple safeguards and considerable determination.

Any suggestion that this can, somehow, impact others' safety or sense of certainty, is without foundation.



Taking CHA's June 3 letter to the Hon Stephen Wade as our guide, we offer the following thoughts.

i. A Global View: 'institution before individual'.

- The question is, if there is conflict between the 'conscience' of an institution and the legal right of a terminally ill person to pursue VAD, whose interests should prevail? Some argue that it should be the interests of religious institutions which prevail. Those who adopt this position should be open that they are choosing to prioritise the interests of institution over those of the individual.
- However, it is a reality that some (dying) people won't have realistic access to a nonreligious institution at the end of life; while others may be too ill to consider transfer to
 another facility in the face of blanket institutional refusal. These people will, in effect, be
 denied access to a legal service to which they are entitled (VAD) by an enshrined right to
 institutional conscientious objection.
- This likelihood is reinforced by the Vatican's most recent encyclical on VAD / euthanasia, Samaritanus Bonus (September, 2020),:
 - Institutional collaboration with other hospital systems is not morally permissible when it involves referrals for persons who request euthanasia .. even if they are legally admissible.
- Enshrining institutional conscientious objection into VAD law will have the effect of creating two classes of Queensland citizens those who have options to be transferred (and, therefore, options to access VAD), and those who do not.

ii. Some responses to global statements made in the letter from Catholic Health Australia:

"Our Code of Ethical Standards for Catholic Health and Aged Care Services in Australia sets out our commitments for the compassionate care of those who both have a life-limiting illness and are nearing the end of their lives: to heal and never to harm; to relieve pain and other physical and psycho-social symptoms of illness and frailty; and to never abandon patients."

• To leave someone who is dying - and who has sought legal relief to their suffering through VAD - in a situation of uncertainty and anxiety about being able to access that relief, is to do harm, in particular, psychological harm.

"Though our services always strive to ensure that those in our care die in comfort and with dignity, a consistent feature of our ethic of care is that we do not assist them to end their own lives or provide euthanasia. Our position is consistent with the



Hippocratic ethic, and is shared by the Australian Medical Association and the World Medical Association. "

- Modern medical schools don't take or administer the Hippocratic Oath.
- The Hippocratic ethic 'do no harm' is not a prohibition against VAD. Indeed, many doctors cite it as a reason to provide VAD.
- CHA's position is not consistent with the Royal Australian College of GPs, Palliative Care Australia, or the Australian Nursing and Midwifery Federation, each of whom is either supportive of, or neutral on, VAD.
- The AMA does not represent a majority of doctors (less than 30%). Its opposed stance is inconsistent with the views of its members, 60% of whom said in its own survey that VAD should be provided by doctors if legalised.
- The Canadian Medical Association resigned its membership of the World Medical Association, partly on the basis of the WMO's opposition to VAD.

iii. Some thoughts on the notion of 'conscience:

- Conscience is a person's moral sense of right and wrong. Only natural persons have conscience.
- While institutions are "persons" in law, they are merely corporate persons, not natural persons. They do not therefore have a natural mind that processes thoughts and feelings to inform the decisions and actions of a single real person.
- Rather, institutions have a set of ideological rules (which are not "conscience"). For
 example, Catholic Health Australia has a Code of Ethical Standards, as do all healthcare
 institutions, religious or not. However, Catholic Health Australia's code of ethical
 standards, unlike secular ones, is shaped and limited by doctrinal religious ideologies of
 the Holy See.
- An institution's ideological rules, where they require a certain action or demand abstinence from certain actions by everyone, extinguish the actual, real consciences of natural persons who work in, or are clients of the institution.
- Thus, in the Catholic Healthcare example, ideological rules laid down by clergy in Rome would fully and permanently extinguish the consciences of all who hold other, varying views on VAD.
- The Queensland parliament represents the people of Queensland, not the Vatican or any other presumptive authority.



iv. Response to misleading claims made by CHA

The CHA makes the point that "In respecting the likely right of people to access VAD, so should the right to not be involved in VAD be respected. It must be recognised that sharing accommodation with someone or caring for someone who accesses VAD can have profound psychological impact."

- The claim that "sharing accommodation with someone or caring for someone who accesses VAD can have profound psychological impact" requires evidence.
- Even if it were true, it must also be recognised that sharing accommodation with someone who dies painfully, or in ways which cause them mental and physical distress, can have a profound psychological impact.
- In either (and in every) case, it is the actual suffering of a person at the end of their life not the potential and secondary suffering of bystanders that should be the primary focus of appropriate medical care.

CHA argues that people "can seek sanctuary from the VAD scheme and choose to live or serve in communities where VAD is not offered. Further, it offers those vulnerable to coercion a level of protection and security to be in a facility where VAD is not part of any care plan."

- The core of VAD is that it is voluntary. It is not part of any care plan unless it is explicitly requested by the patient. Two years of operation in Victoria has shown no evidence of coercion of people towards VAD. In fact, the evidence (both witnessed and anecdotal) indicates that the opposite is happening that families, doctors, and institutions continue to, in different ways, make efforts to persuade or discourage people from their VAD choice.
- It <u>is</u> coercion, however, to impede someone from their legal right to access VAD in a situation where, either through lack of alternative venues, or inability to be transferred, they are not able to pursue that right.
- CHA talks of 'coercion' yet its own procedures force (coerce) workers in Catholic facilities
 to sign a coercive document re adherence to its values. There are many views within the
 Catholic Church about VAD. For example, in this episode of Better Off Dead you can hear
 senior oncologist, and devout Catholic, Dr Philip Parente, explain how he moved from a
 position of conscientious objection to VAD, to being a doctor who sees it as fundamental
 to his duty of care.



CHA goes on to state:

"If a person is so unwell or frail that a transfer becomes difficult, it is most likely that there will not be time, capacity or eligibility to pursue a VAD process, and effective palliative and end of life care becomes the highly desirable option, regardless of the ethics of the service provider."

CHA's argument that if someone is too ill to be transferred, that they will not be able to
access VAD anyway is contradicted by multiple examples from the first two years of
Victoria's law. Testimonies from families, doctors, and the Statewide Pharmacy Service
demonstrate that the majority of people who access VAD do so when their illness has all
but runs its course and when they are too depleted, or suffering too much, to continue.
One example – the story of 71 year old Phil Ferrarotto, dying of multiple, metastatic
cancers - can be heard here.

v. Evidence from Victoria of how 'institution before individual' has led to suffering for the individual

- Perhaps the most concerning problem with CHA's position is that it requires acceptance
 that a competent adult eligible for VAD who is unable to be safely transferred from a
 Catholic facility will be denied the opportunity to access VAD. This 'institution before
 individual' choice is very clear in the final paras of this section and means that a person
 may effectively be trapped in their facility until they have the death chosen for them by
 the facility.
- Why should a person who has a legal right to VAD be told they cannot pursue that right simply because they are too sick? In what way does this fulfil CHA's mission statement of 'compassionate care for people at the end of their lives', and of 'never doing harm'?
- What is being supported here by CHA is the very essence of coercion and, worse, of the most vulnerable person imaginable someone who is close to death who is suffering.
- There are occasions where extreme pain prevents the ethical transfer of patients with capacity and a reasonable prognosis to consider VAD access. Any assessment that a person is 'too unwell or frail to transfer' should be made by a doctor and not by a health policy director.
- Some (dying) people won't have realistic access to a non-Catholic institution, and therefore will be practically denied access to VAD by an enshrined right to institutional conscientious objection.
- For an example of how putting 'institution before individual' can negatively impact an individual, consider the case of Colin M, a 79-year-old Melbourne man who was dying of metastatic bowel cancer. Despite having been assessed by two doctors and been found



eligible for VAD in 2020, the Catholic aged care institution in which he lived, refused to let the pharmacists into the facility to deliver the medication. To make matters worse, they left Colin – whose every day was filled with fear and anxiety that he would die painfully before the medication arrived – waiting for <u>nine</u> days before informing him of their refusal. You can hear Colin's story, and of the distress this refusal caused him and his family, <u>here</u>.

vi. Enshrining institutional conscientious objection in law is not a 'compromise'

- CHA asserts that allowing institutional conscientious objection (ICO) "strikes a considered compromise between the rights of the individual and the rights of staff, other residents and patients, and entire institutions to avoid involvement in VAD.
- This is not an act of compromise it is an act of assertion, as it assumes that all staff share the same view about VAD. As for "other residents and patients", what rights do they have over any other patients' decisions about their medical care? Surely such decisions are confidential and should be treated as such? Why should 'other residents and patients' be made privy to them unless that is what the person making the decision wants?
- CHA further asserts: "Catholic providers of health and aged care services have a sound track record of open and honest communication with patients and residents of the services which will and won't be provided in our care. This, in and of itself, will almost entirely prevent a situation occurring of a patient or resident in our care requesting access to VAD and means any opposition to this amendment is the contemplation of the exception, rather than the rule."
- The experience of Victoria (and also Canada see below) shows this not to be true. While some Catholic health providers in Victoria have demonstrated a compassionate and flexible approach to VAD requests, others have chosen to put their interests and ethics ahead of those of terminally ill people seeking VAD.

vii. Should CHA 'good faith' claims be taken at face value?

 Claims that CHA's 'sound track-record' of acting well in this area are seemingly contradicted by Vatican instructions to Catholic health care workers published in Samaritanus Bonus in September 2020:



Institutional collaboration with other hospital systems is not morally permissible when it involves referrals for persons who request euthanasia .. even if they are legally admissible.

• In any clash between the wishes of a terminally ill person and instructions from the Vatican, it is not hard to imagine which side CHA will take.

By claiming, in effect, that they should be 'trusted to do the right thing', CHA is challenged by evidence, not just from the first two years of Victoria's VAD law, but also from Canada (where Medical Assistance in Dying has been legal since 2016). Examples include:

Doreen Nowicki, a woman in her late 60s with advanced motor neurone disease¹. She was living in a continuing care facility run by a Catholic provider. She was taken from her bed with a mechanical lift, put in a wheelchair, and brought out of the facility to benches situated across the street (off the property) for her VAD eligibility assessment. This was intensely distressing for her.

Bob Hergott, a 72-year-old man also with motor neurone disease, had to leave the hospital where he had been an in-patient for five years, cross the street in the rain to a bus shelter, and meet the two witnesses required as he signed his form requesting VAD².

An institutional objection can also result in extreme pain to the patient. Ian Shearer was an 87-year-old man with spinal stenosis. His pain medications were reduced to ensure he would have decision-making capacity following the transfer. The ambulance was more than three hours late. The time waiting for the ambulance was increasingly painful and the trip across the streets of Vancouver was agonising. ³

Institutional objections have also resulted in limitations or removal of access. Gerald Wallace was an 80-year-old man with pancreatic cancer in a rural hospital run by a Catholic organisation. He was prevented from accessing VAD and died 4

Finally, CHA claims that:

"Critically, Catholic providers of health and aged care services have a sound track-record of open and honest communication with patients and residents of the services which will and won't be provided in our care. This, in and of itself, will almost entirely prevent a situation occurring of a patient or resident in our care requesting access to VAD and

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¹ CBC Coverage of Doreen Nowicki (n 25).

 $^{^{\}rm 2}$ CBC Coverage of Bob Hergott (n 25

³ Tom Blackwell, 'BC Man Faced Excruciating Transfer after Catholic Hospital Refused Assisted-Death Request', *National Post* (online, 27 September 2016) https://perma.cc/DE36-V9TA.

⁴ Jennie Russell, 'Camrose Man Died in Pain after Covenant Health Hindered Access to Assisted-Dying Services, Son Says', *CBC News* (online, 1 December 2018)



means any opposition to this amendment is the contemplation of the exception, rather than the rule."

This claim - that CHA's position on VAD will almost entirely avoid the issue arising - is not plausible for numerous reasons. Some may have been permanent residents in these facilities for many years, pre-dating the legalisation of VAD; some may seek VAD but have no reasonable alternative place to live; some of Catholic faith may want access to VAD too (consistent polling show upwards of 70% support for VAD amongst Catholics); and some may change their minds about VAD as their circumstances change.

In summary:

The whole point of VAD law is to hand some measure of power back to terminally ill people. People who, up until now, have been largely disempowered within the medical system when it comes to end-of-life choices. To enshrine institutional conscientious objection into VAD law is to effectively remove that power from some dying individuals and hand it back to institutions.

Therefore, we believe that the right of an institution to refuse VAD services (as recognised in Queensland's law), must be balanced with protection of the rights of the patient to seek access to a legal treatment option.

An institution must never be allowed to keep their residents/patients in the dark about their legal right, nor must they be allowed to obstruct their access to that legal right.

Institutions should be mandated to:

- Disclose to existing residents/patients, immediately upon inquiry, if this option will not be available
- Disclose upfront, and prominently in all published material (online and physical) to any new entrants to their institution for residency or treatment what their position is and that VAD will not be made available through their involvement.
- Refer patients who request VAD to appropriate sources of information about the availability of VAD (eg the government website or care navigator service).
- If a person seeking VAD is to be denied the opportunity to take-life ending medication on the premises, the institution must arrange at their cost, within 48 hours of declining a request, for a transfer to a facility that will accept a patient seeking VAD
- They must not obstruct transfers of patients who seek access to VAD



- If a person is deemed too ill to be transferred then medical professionals must be allowed into the facility (be it a hospital, residential, or any other facility) for assessments and, if required, administration. Access must also be given for delivery of the medication.
- In case of residential care facilities (where residents essentially rent their
 accommodation and it is legally regarded as their home), conscientious objection to
 participate must only include the act of assisting with the VAD administration, but not
 administration by an external medical practitioner, the assessment process (where no
 staff involvement is required), or the delivery or storage of legally distributed life-ending
 medication.

There should be financial penalties built into the Act for institutions, or individuals, who block, harass, or attempt to coerce people from their legal choice to VAD (see following section).



Chapter 3: Complaints mechanism

While there are provisions in the bill (Part 7, Review by QCAT) that allow for appeals in relation to residency, decision-making capacity, and voluntariness, there is no pathway or mechanism for people to flag issues with blocked access.

The first two years of Victoria's law have shown that there have been instances where people seeking to access VAD have faced what could best be described as 'coercion in reverse': Efforts to discourage them from pursuing their legal rights.

Chair of Victoria's Voluntary Assisted Dying Review Board, Justice Betty King calls these the 'known unknowns'.

'There's a few that actively try to dissuade. And that's a complete reversal of conscientious right to object to it. You don't have the conscientious right to change someone's mind. Anecdotally we've had feedback about the person being told that it would take too long, you'd be dead before this. That palliative care is infinitely better. That this is a painful process. The number who go to their doctors and make a request and get 'oh, no, no, you don't qualify or no, that's not for you', or that went to the local GP and they said 'yes, I'll do the training' and five weeks later, nothing had happened. Then they've come back and been told 'Oh, no, I've changed my mind', or 'I don't think you're right for it anyway'

Unfortunately, Victoria's Review Board has no remit to explore efforts to discourage or impede people from accessing VAD, or to report on them.

Even once the medication has been legally accessed, it became clear from our extensive interviews with families and medical professionals in Victoria, that instances of harassment or discrimination related to VAD still exist. You have already heard the story of Colin M, the 79-year-old Melbourne man dying of metastatic bowel cancer, who was, for nine days, blocked, by the Catholic aged care facility at which he lived from receiving life-ending medication to which he was legally entitled.

Another family told us of their wife and mother, in her 70s and dying of cancer, who was days away from using the medication. Uninvited, a senior Catholic palliative care physician came to their house at the same time as a nurse from her hospital was visiting, accused the son of coercing his mother into choosing VAD, then attempted to talk the dying woman out of her choice. Her husband told us:

'I almost threw the doctor out of the house. It's very distressing to see your wife of 44 years essentially harassed by someone'.



And Professor Michael Dooley, Director of Victoria's Statewide VAD Pharmacy Service, recounted to us situations he had encountered in some faith-based palliative care wards:

I have been in situations where there may be a decision that they don't do voluntary assisted dying on that ward. So, when the patient decides to access voluntary assisted dying, they are then moved.

If you've been somewhere with the nursing staff you know, and you've been there for a long period of time, being moved in a lift to another ward you've never been to, to nursing staff you've never been to because you're going to take that medication that evening that is no way patient centred, in any shape or form. And those circumstances are rare. And the majority of cases they do manage it beautifully and are completely supportive.

One of the main focusses of VAD laws is to protect the vulnerable. It is hard to imagine anyone more vulnerable than a person who is dying. For that person then to face harassment of discrimination because of their choices is inexcusable.

We strongly urge that Queensland become the first Australian state to create a pathway for complaint, that is both clear and direct, should an applicant, or the family of an applicant, feel they have been impeded or discouraged from pursuing the VAD pathway.

Ideally, this would sit within the Voluntary Assisted Dying Review Board, who will have the capacity to hear complaints; warn doctors about inappropriate behaviour when it occurs (for example, failing to respond to a first request within the mandated 2-day period); if necessary, refer them to the appropriate professional body for sanction; and include as part of their annual reporting requirements.

Financial penalties built into the Act - for institutions, or individuals, who block, harass, or attempt to coerce people from their legal choice to VAD- should perhaps be considered.

This 'complaints pathway' should be clearly advertised on the VADRB website and explained to applicants by Care Navigators as part of any educational material supplied.



Chapter 4: Review Board reporting requirements

There is no more contested public health policy than that of Voluntary Assisted Dying.

Neither is there one whose proper functioning is more critical. In the words of Justice Betty King, Chair of Victoria's Voluntary Assisted Dying Review Board:

'This is the ending of a life and it ought to be treated in a serious manner. Because it's a serious thing to do.'

The role of a Review Board in ensuring compliance with VAD law cannot be overstated. In Victoria, there has been a marked scrupulousness to their approach under Justice King.

As GP, Dr Nick Carr, who is qualified to assess for VAD, put it when asked if he knew of any other area of medicine with an equivalent level of scrutiny:

'Not that I know of. No, this is top level'

However, the Review Board has another important function, which is to supply data on which future governments can base assessments about how the law is functioning; whether or not it is doing so effectively; and if it needs to be amended in order to better achieve its objectives.

Key to this is a good understanding pf who uses the law, why, and in what circumstances.

In Victoria, this has been interpreted as raw data around demographics, gender, and illnesses of those accessing VAD.

While useful, we believe this information provides only limited insight into VAD and its place within the medical system.

We urge that Queensland's Review Board include, as part of its remit, information about the circumstances driving people's VAD choice.

A strong template for this exists in Oregon, where patients who access VAD are asked to complete a questionnaire asking them to rate their end of life concerns, ie;

- Losing autonomy
- Less able to engage in activities making life enjoyable
- Loss of dignity
- Losing control of bodily functions
- Burden on family, friends, caregivers
- Inadequate pain control, or concern about it
- Financial implications of treatment



Further data is supplied on whether or not patients are receiving palliative care (either at home, or in hospital); their level of education; their insurance status; whether or not they had received a psychiatric evaluation; whether or not they had informed their family; any complications that had arisen with the medication; and the number of days between first request and death.

In the interests of transparency surrounding VAD, and a greater understanding of it, we urge that all these be made a part of the QLD VADRB's remit.

For reference, here is the 2018 Data Summary of Oregon's Death with Dignity Act⁵.

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Chapter 5: Commonwealth law restrictions which have created greater suffering for some seeking VAD

The Commonwealth Criminal Code currently makes it illegal to use a carriage service to discuss matters related to suicide. This has had the effect, in Victoria, of precluding Telehealth from being used as part of the VAD assessment process.

In fact, it has had an even greater chilling effect than that. As GP, Dr Nick Carr told us:

'I had a guy ring me up from Echuca and he said, you mean I've got to get someone to stick my wheelchair in the car and drive me down to Melbourne every time I talk to you? And I said yes, I'm breaking the law, talking to you now.'

We spoke with families whose seriously-ill loved ones had been seriously affected by this de facto ban on Telehealth for VAD.

Lisa Hogg's mother, Margaret, was dying of a progressive neurological disease. The two-hours-each-way car trip she was forced to endure to be assessed by a neurologist was extremely difficult for an 81-year-old woman who was already suffering:

'We left the left the home at 10 in the morning for a 1.30 appointment. We knew the journey would be quite arduous for mum anyway, and we thought we'd get there and we'll have time to have a bite to eat. Just relax a little bit settle in, because mum was very anxious also that she wouldn't pass the test. And we got 15 minutes down the road and mum was incredibly uncomfortable in my sister's car. And we had to stop and get more pillows.

We had to stop twice more on the way to help reposition her in the car and then we got, stuck in roadworks for about half an hour. So in the end, we got to her appointment with about five minutes to spare. And we had to literally get her into the wheelchair, get her into the appointment. ... she'd had no lunch ..., She was already exhausted because it was three and a half hours since she left the home. And the appointment was for an hour and a half so by the time she finished it was three o'clock and my sister and I were so stressed because we could see mom just physically just falling down, she was exhausted.'



Dr Kristin Cornell's father, Allan, was dying of Motor Neurone Disease. She recorded her thoughts as she had to take her dad for a second neurologists' appointment.

'We're going to get our taxi pull in. They didn't turn up last time, so we had to bundle him into the car. But I honestly don't think I'd be able to do that this time, he's so weak. So it has been ...really difficult. A lot of hurdles and in MND time is everything. So, um, yeah ... really stressful to be in this position again'

While Telehealth will not always be necessary – or appropriate – for assessing VAD, it is clear from these examples (supported by testimonies from Victorian doctors) that its absence as an option is causing unnecessary suffering to people who have already suffered too much.

In a state as geographically vast as Queensland, the problem presented by the Commonwealth Criminal Code (which was written before VAD was legal) will be even more acute.

We support the view put forward by the QLRC that VAD is not suicide. And we support the use of Telehealth in assessing for VAD where appropriate.

However, regardless of how these questions are addressed by Queensland's parliament it is clear that only a change to the Code will provide guaranteed protection to medical practitioners who use a carriage service to discuss VAD.

Should Queensland make VAD legal, that will mean five of Australia's six states have done so, and we would expect them to petition the Federal Government as a group to do this.

In the meantime, we support the interim position of petitioning the <u>Commonwealth</u> <u>Director of Public Prosecutions</u> to issue a guideline that, where a person is acting in accordance with state voluntary assisted dying legislation, offences in the Commonwealth Criminal Code will not be prosecuted.

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Appendix A – Letter from Catholic Health Australia



The Hon Stephen Wade MLC Minister for Health and Wellbeing By email: ministerforhealth@sa.gov.au

3 June 2021

Dear Minister

I write in response to your letter of 31 May 2021 regarding the Voluntary Assisted Dying Bill 2020 and the issue of Institutional Conscientious Objection.

Our Code of Ethical Standards for Catholic Health and Aged Care Services in Australia sets out our commitments for the compassionate care of those who both have a life-limiting illness and are nearing the end of their lives: to heal and never to harm; to relieve pain and other physical and psycho-social symptoms of illness and frailty; to withdraw life-prolonging treatments when they are medically futile or overly burdensome or when a person wants them withdrawn; and to never abandon patients. We continue our long commitment to improving this compassionate care through research and advancement, and we endeavour to do whatever we can to ensure that it is available to all people who need and want it.

Though our services always strive to ensure that those in our care die in comfort and with dignity, a consistent feature of our ethic of care is that we do not assist them to end their own lives or provide euthanasia. Our position is consistent with the Hippocratic ethic, and is shared by the Australian Medical Association and the World Medical Association.

With these principles in mind, I am grateful for the opportunity to address the possibility of an institutional conscientious objection (ICO) clause in the Bill and what form it might take. As I understand, the options currently being considered are:

- That the Bill remains silent on ICO, much like the Victorian VAD Bill which has addressed ICO in policy.
- Adoption of the amendment tabled by Mr Steve Murray MP, which proposes, inter alia,
 offering a service provider the right to refuse to authorise or permit the carrying out of any
 part of the voluntary assisted dying process in relation to any resident or patient on the
 premises and requiring the service provider to undertake reasonable steps to transfer the
 patient or resident to another facility that offers VAD should they request it.
- Adoption of an amendment, based on the draft Queensland Bill and included as an
 attachment to your letter, which requires that any institution which conscientiously objects
 to VAD to not hinder a person's access, and to allow reasonable access for that person, to
 VAD services.



I will address the merits of each option from most desirable to least desirable, on an assumption that the Bill is supported by Parliament.

Amendment tabled by Mr Steve Murray MP

If a Voluntary Assisted Dying scheme is introduced, it must be voluntary in the truest sense (for those who seek it and those who provide it). The scheme should not compel persons or organisations to act against their conscience and therefore must respect the choices of those who want nothing to do with VAD (including patients, residents, staff and institutions).

This amendment requires a number of commitments from service providers and offers a number of benefits:

- Patients and residents across South Australia will continue to have the opportunity to seek out compassionate care where VAD is not offered as part of service delivery. In respecting the likely right of people to access VAD, so should the right to not be involved in VAD be respected. It must be recognised that sharing accommodation with someone or caring for someone who accesses VAD can have profound psychological impact. Adoption of this amendment will mean that South Australians can seek sanctuary from the VAD scheme and choose to live or serve in communities where VAD is not offered. Further, it offers those vulnerable to coercion a level of protection and security to be in a facility where VAD is not part of any care plan.
- In accessing this right to ICO, a service provider must inform any prospective resident or
 patient that access to VAD is not permitted on the premises. This means that residents or
 patients who may wish to one day access VAD should choose a service where the option exists.
- We also recognise that there may be instances where a patient or resident has chosen care in a Catholic facility knowing that VAD is not offered, but then changes their mind. In accommodating this person's request for VAD while recognising the rights of staff, and other patients and residents, to a facility where VAD is not offered, the amendment requires that the service provider ensures arrangements are in place to transfer that person to another facility where they may access VAD. If a person is so unwell or frail that a transfer becomes difficult, it is most likely that there will not be time, capacity or eligibility to pursue a VAD process, and effective palliative and end of life care becomes the highly desirable option, regardless of the ethics of the service provider.

This amendment strikes a considered compromise between the rights of the individual and the rights of staff, other residents and patients, and entire institutions to avoid involvement in VAD. Critically, Catholic providers of health and aged care services have a sound track record of open and honest communication with patients and residents of the services which will and won't be provided in our care. This, in and of itself, will almost entirely prevent a situation occurring of a patient or resident in our care requesting access to VAD and means any opposition to this amendment is the contemplation of the exception, rather than the rule.

No Amendment

The current Bill does not recognise ICO in any form, consistent with Victorian VAD legislation. In Victoria, ICO is recognised by way of Department of Health policy. In practice, this means that service providers can choose to be non-participants and this requires that they have clear processes in place for responding to requests for VAD, including ensuring that a requesting person has information about the service's position on VAD, and knows where they are able to access information about VAD if they so wish. Of their own volition, many services in Victoria — including our Catholic health and aged care services - have also committed to supporting transfer of a patient or resident who wishes to seek VAD elsewhere.



No amendment to the Bill may result in similar circumstances in South Australia to Victoria and this will mean that Catholic services can continue to operate in South Australia (as they do in Victoria). However, Government policies are subject to change without the oversight of Parliament, and therefore the provisions are tenuous at best. It means operators cannot necessarily make long term plans for service provision and one possible consequence of this is how it affects future investment decisions of providers where there is uncertainty in their enduring ability to operate.

Therefore, the amendment tabled by Mr Steve Murray is preferred to no amendment at all.

Amendment based on Queensland Bill

This amendment has profound and far-reaching implications for all health and aged care services in South Australia. In addressing these implications below, I wish to reiterate the Catholic ethic that we will never provide or facilitate VAD services. That said, the implications would also exist for other providers, whether secular or faith-based.

Firstly, the amendment will require those hospitals that do not provide VAD services to allow medical practitioners onto the premises to make decisions which override any decisions by the admitting doctor (i.e. the hospital doctor in charge of that person's care during the hospital admission). This privilege is to be extended to the administration of the VAD substance itself. To make clear the gravity of this clause: it is creating a circumstance in which an external medical practitioner who has no knowledge of a service, no decision-making authority within that service, and no responsibility to that service, its staff, or the people under its care will be authorised to enter and provide a VAD related service, and to override decisions of (or make decisions in lieu of) the medical practitioner who is directly responsible for a patient's care and wellbeing. As you would be aware, this is a breach of duty of care protocols that are essential to the high quality and safe care we provide in Australia. It would be unprecedented and should not be contemplated in any circumstances.

Notwithstanding this breach of ordinary medical practice, the amendment would require hospitals to accredit said medical practitioners for the specific and explicit purpose of providing VAD services on their premises. In the case of Catholic services, our accreditation process requires medical practitioners to agree to abide by our Code of Ethical Standards whilst providing compassionate care on behalf of, or within, our services. Setting up such a clause would require us to create an accreditation process which contradicts this fundamental commitment. Authorising medical practitioners in this way constitutes an unacceptable level of involvement in VAD in our services. Furthermore, the provision of such a service in a hospital setting necessarily involves all staff involved in the provision of that person's care in the hospital and directly compromises their right to individual conscientious objection.

Where this amendment applies to VAD services to be provided in an aged care facility rather than a hospital, it raises similar prospects of requiring the complicity of the entity. Examples include:

- circumstances where the coordinating and consulting medical practitioners need to make
 enquiry as to the person's decision-making capacity and whether they are acting freely and
 without coercion such enquiry, should it be carried out purposefully, would require the
 involvement of the facility's care team, which would draw them into the VAD process in a
 problematic way; and
- circumstances where drug storage protocols require the central storage of medicines and other substances (including VAD substances) for reasons of safety would require the involvement of facility staff in a problematic way.



The need to carry such specific requirements for service providers through these clauses, under the guise of ICO, is not necessary, and is counter to the very nature of what ICO should be about. Indeed, the creation of such prospects – which pits the Catholic ethic against legal requirements – draws into question the very viability of enduring Catholic services in South Australia.

It goes without saying that, no matter what the final Bill looks like, complex cases will arise in all services, including our Catholic services. As the legal maxim says, hard cases make bad law. Those who work in health and aged care are experts at resolving complexity. In the context of VAD, our services in Victoria have a two year track record of managing this complexity well and in a way that does not compromise our commitments to care, nor a person's right to seek VAD from another provider. Coercing such services into the provision of VAD on the grounds that there will be difficult cases is both unnecessary and unethical

Conclusion

Should it be introduced, a Voluntary Assisted Dying scheme must be voluntary in the truest sense (for those who seek it and those who provide it). The scheme should not compel persons or organisations to act against their conscience. It must offer choice.

Catholic services have long contributed to the fabric of health and aged care services for South Australians, and it is our wish to continue to do so.

We recognise that Voluntary Assisted Dying may well pass into law next week. Should that occur, Catholic services should be given the opportunity to offer an uncompromising alternative to VAD and sanctuary from VAD, where those in our care die in comfort and with dignity, and those who wish to access VAD can seek it outside of our services.

The amendments tabled by Mr Steve Murray MP will allow us to continue with certainty and purpose, as will, to a lesser extent, the option of no amendment at all. We encourage you to carefully consider your support for the amendments which support Catholic services in South Australia.

If you would like to discuss these matters further, please contact me at

or on

Yours sincerely

James Kemp

Health Policy Director Catholic Health Australia