Vale
Voluntary Assisted Life Ending

VALE – VOLUNTARY ASSISTED LIFE ENDING GROUP

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5 July 2021

Health and Environment Committee
Parliament House
George Street
BRISBANE
QLD 4000

By email: hec@parliament.qld.gov.au

Dear Health & Environment Committee

Re: Amended Submission - Voluntary Assisted Dying

I respectfully seek permission from the Health and Environment Committee to submit an amended late submission today, following my original submission sent on Thursday, 1 July 2021 to the Committee, to include an important Petition that reflects the support of Voluntary Assisted Dying Legislation in Queensland by 84,146 Queenslanders/Australians.

On behalf of many Queenslanders and other Australians, VALE has sought to represent the voices of those who are no longer with us, families left traumatised forever by their loved ones suffering and death and those of us who are living with a terminal/incurable disease. At the end of 2019 I launched a Change Org Petition calling on the Queensland Government to offer end of life options, i.e. Voluntary Assisted Dying, to Queenslanders. As an independent advocate, without any funding, being totally committed to my advocacy and whilst carrying out this work subject to my health and treatment regimes, I have devoted a great deal of time to sharing this Petition within many Community pages across our state. I have been amazed, but not surprised, at those who have chosen to share this Petition on with family and friends. The Petition has been shared on many community pages across Queensland in remote and regional areas whose community members were not always up to date with what was happening with the progress of this much needed debate. The support of Queensland – and other states across our nation – is clearly demonstrated by the number of signatures on this Petition (which grows daily). **The Petition stands at 84,146 signatures contained in over 3,840 pages, as at today's date.**

It is incredibly important that the Health and Environment Committee, and all Qld Politicians, acknowledge that there is such incredible support for end of life options.

It would prove incredibly challenging to have 3,840 pages printed, bound and sent to the Committee. The Petition, in PDF format, can be downloaded through the shared Dropbox link that I have created and included below. I sincerely hope that the Health & Environment Committee will acknowledge this work and the views of many Queenslanders when it comes to the Parliamentary debate in September.

https://www.dropbox.com/sh/jcr42cy1jdqxg6h/AAAcN_Tg3_VobrqBvFbO-t3Oa?dl=0

On behalf of the VALE – Voluntary Assisted Life Ending group, Queensland, my submission to you is on behalf of many advocates, individuals living with a terminal illness, front-line workers and nurses/palliative care nurses who have followed and supported my advocacy for Voluntary Assisted Dying Legislation in Queensland for the last four years.

I present my submission to you based on my experience of living with a terminal illness, nursing both parents through horrendous deaths, supporting/advocating for the introduction of voluntary assisted dying legislation across other states in Australia and overseas and based on listening to hundreds of stories shared with me by those who support this much needed and compassionate legislation.

I have previously submitted lengthy and comprehensive submissions to the Qld End of Life Choices Inquiry and also addressed the initial Terms of Reference at length, when requested by the Qld Law Reform Commission in the lead up to them considering the draft legislation. I have also sent in a submission as part of the "Gang of Four" (two other friends living with a terminal illness, myself and our friend who is a retired Palliative Care Level 3 Supervisor with post graduate qualifications in palliative Care). This is my third submission.

In relation to the draft legislation released by the Queensland Law Reform Commission I propose to address the key areas of the legislation only.

Principles

I concur with the principles that underpin the Act and also highlight that "coercion" can also incorporate families/friends of loved ones who would like them to accept anything and everything in order to sustain breath and a pulse because they cannot bear to lose them. This, too is a form of "coercion". Individuals living with a terminal/incurable disease often do not want to move outside of their home but have to spend their last years/months/weeks in a place they don't want to be because the care they require cannot be received within the home or family/friends are not able to provide that care, thus rendering the end of life patient "coerced" into being where they do not want to be.

Health care worker not to initiate discussion about voluntary assisted dying

As someone living with a terminal illness, as a member of a 6,500 member-base support group of international women living with terminal metastatic breast cancer, the legislation is about having peace of mind to be able to determine when **we** have had enough. Evidence-based research demonstrates that in the countries where VAD legislation exists, many do not take up the option.

It is crucial that people faced with a terminal illness **do** have all options discussed with them. How those options are actually delivered should be addressed and one should be entitled to expect that medical professionals who do support end of life options would deliver that information based on a "worse-case" scenario, providing peace of mind to the individual who (from my own experience) has already experienced a great deal of suffering and exhausted many treatment regimes.

Some individuals choose not to pursue any treatment regime because the side-effects of that treatment regime will cause intolerable suffering in itself. That should be their choice. Two friends are currently experiencing side-effects from their treatment regime for Stage IV vaginal cancer and terminal metastatic breast cancer that are so horrific that they are bed-ridden most of the week before they start their next round of treatments. Both have said they don't think they can sustain the treatment regime for much longer.

All options need to be discussed with the end of life patient and not totally restricted as is the case with Victorian legislation – this is incredibly wrong. It would naïve to believe that patients have not said to their healthcare team, along the path to death, "I've had enough. I can't do this anymore. I don't want to continue on with this treatment that is making me so ill I have no quality of life. I do not want to spend my days non compas mentis because of medications and pain medications which have their own side-effects.

So, one might assume the conversation is going to be with the end of life patient's GP or Specialist who will, you would hope, have taken the time to consider how a patient is coping. Sadly, the reality is that GPs and Specialists do NOT always enquire as to how the patient is coping with the treatment and its side-effects. That's not a criticism, it is a reality.

Eligibility

As outlined in my previous submission to the Qld Law Reform Commission, myself and many others question why there should be any "prognostic timeframe" after a diagnosis of an incurable/terminal illness. I ask again, "Who are these timeframes actually for?" They are not for the patient. Both my parents endured many years of suffering due to their incurable diseases which would not necessarily constitute "terminal" until the very horrific last 6 months. That being said, if there does need to be in place a "prognostic timeframe" to appease opposers of the legislation, then 12 months should be the very least.

The issue around Politicians wanting to determine "prognostic timeframes" is that many do not understand the "nitty gritty" and all that is involved in living with an incurable/terminal illness. Because of that, if they have not been exposed to a loved one having to live in such an horrific way, they cannot possibly understand why there should be no prognostic timeframes after a diagnosis.

Contact persons acting on behalf of an end of life patient

It is crucial that any end of life patient seeking to access Voluntary Assisted Dying, and "self-administer" should have the right to nominate a "contact person". Already, debate has included opposers saying that it is wrong to have a "contact person" to take charge of something so important. It must be remembered that some individuals will be bed-ridden and so ill that they are not able to act on their own behalf, go and collect prescriptions, etc. Once, again, the focus in this debate should be on the end of life patient.

Disposal of unused VAD medication

I believe any unused VAD medication should be returned to the supplier, in addition to completion of key documentation demonstrating a documented trail prior to return.

Cause of Death

I concur with the draft legislation that the cause of death, as recorded officially, should show the disease and not voluntary assisted dying.

Eligibility to act as administering practitioner

It is crucial that not only a medical practitioner but also a nurse practitioner and registered nurse (with a minimum of 5 years' experience) be allowed to act as an administering practitioner. Much debate took place about this during the Tasmanian debate about the qualification and expertise of registered nurses who already perform assessments and senior clinical and medical procedures on a day to day basis with those who are dying. Many who are dying within their home environment have come to know those nurses and there is a great deal of trust involved between patient and nurse.

Conscientious objection by entities

As outlined in my submission to the Qld Law Reform Commission, and as someone living with a terminal illness, having nursed both parents through terminal illnesses and having friends going through hell right at this time, to even contemplate they would need to move to another facility or have the focus removed from their plight based on an "entity's faith-based objection" whilst receiving funding (government and private sector) is hard to digest. Many, many supporters of VAD feel that this is totally unacceptable.

It is with scepticism that we acknowledge that faith-based groups will seek to have their way. In that event, just as appropriate safeguards are demanded by decision-makers, appropriate safeguards should also be put in place to ensure that any facility that does not offer Voluntary Assisted Dying services/information does nothing to hinder or obstruct an individual seeking to access information or access to the VAD service by those who are in charge of operating the facility.

Independent Government Facility to provide Voluntary Assisted Dying Services

Given that the majority of hospital facilities in Queensland are operated by the Catholic Church, and given this ongoing conundrum in every state that has debated Voluntary Assisted Dying – with considerable opposition by those of faith – would it not be worthy of consideration for the Qld State

Government to have a "stand alone facility" with "Fly-in/Fly out" health professionals appointed to assist in the provision of VAD services? Would this not be a common-sense approach to the whole issue of end of life patients having to be referred on? Again, it is with scepticism that I raise concern at religious-run facilities facilitating external VAD service providers to those in their care.

My concern also is the use of "reasonable steps" to facilitate the VAD process for those who are either a temporary or permanent resident of a facility that does not wish to provide VAD services. "Reasonable steps" could be open to a lack of real effort to actually facilitate the process. Perhaps some further safeguards which benefit those seeking to use the VAD service are required.

End of life patients need the process to flow smoothly. We already acknowledge that there are obstacles within the Victorian legislation that result in individuals dying before they can actually complete the process …

Relevant entities to inform public of non-availability of voluntary assisted dying

I concur 100% that entities that do not provide Voluntary Assisted Dying services need to ensure that they publish that fact openly and with transparency to all those individuals who attend/visit their facility who are living with/diagnosed with an incurable/terminal illness. This would then enable the patient to consider their options. The one fact I am so passionate about is the fact that often patients have to follow their preferred specialist to wherever their specialist works from – again, by allowing entities to object to providing a government funded suite of services, disadvantages the patient.

Telehealth

It is crucial that those who would seek to access Voluntary Assisted Dying, should the legislation pass in Queensland, have use of telehealth services when commencing the VAD process. I acknowledge the need for safeguards and for initial meetings to be face to face, but to expect someone dying from a disease – someone who is often so ill that they do not leave their home – to travel to a central location – at such time as they are dying – defies logic.

I have listened to many debates across different states regarding "telehealth". The Tasmanian debate on this was best outlined by Cassy O'Connor (Greens) and Michelle O'Bryne (Labor) who acknowledged how the Federal Government's legislation on telehealth came to fruition. This was as a result of the removal of The Rights of the Terminally Ill Act (NT) and followed the activities of Exit International/Philip Nitschke's private chat rooms to make illegal discussions about suicide.

It is very clear that the issue of not allowing "telehealth" options as part of the VAD process is going to have a hugely negative impact on the individual for whom the legislation is meant. No doubt this affects all states who have passed legislation and it would be hoped that the relevant Federal Government's Agency (the Attorney General) will seem to remedy this.

Collecting of appropriate data for the purposes of the Review Board's Reports

It has been acknowledged through the Victorian VAD Legislation process that some data is not collected and reported on, e.g. delays/obstacles/evidence to assist in the improvement of the Act at such time as that takes place. It is crucial that data and information is collated to determine that the legislation proves to be effective.

Further clarification required re any proposed amendments to this legislation

The rumour mill has given rise to some concerns being expressed by "some" politicians as to whether or not any VAD legislation that is passed could be amended/expanded through a separate "sub-committee process" within the overall parliamentary process. One might assume that this needs to be confirmed prior to the parliamentary debate taking place in September so that it may not be used as an argument for opposing the legislation.

Yours sincerely

Tanya Battel

VALE – Voluntary Assisted Life Ending