

Ceara Rickard  


1 July 2021

Health and Environment Committee  
Parliament House  
George Street  
BRISBANE  
QLD 4000

By email: [hec@parliament.qld.gov.au](mailto:hec@parliament.qld.gov.au)

Dear Health & Environment Committee

**Re: Voluntary Assisted Dying**

I write this submission, drawing on my experience of living with a terminal illness, my experience and knowledge of navigating complex ethical issues as a registered psychologist, advocacy related to voluntary assisted dying across Australia, and listening to the stories and voices of hundreds of people who support this much needed legislation.

I am thirty-five years old and have metastatic breast cancer. There is no cure and I will be lucky to reach the age of forty. I feel strongly that I and others should have access to VAD, and that VAD legislation be safe and accessible to those Australians who need it. I advocate for VAD not only for me, but for all of us, including those of you who may read my submission, even if you do not believe you would ever wish to access VAD for yourself. For me personally, I don't know if I will access VAD yet – but I am determined to have the choice. I know that in other countries and in Victoria, even people who access VAD and have the medication available choose not to administer it.

Whilst I live interstate now, I was born in Bundaberg and spent my childhood there. I have many family and friends still in QLD – my parents own a house in Bundaberg still. I have a sister in Brisbane, a brother on the Gold Coast and numerous other relatives and loved ones in QLD. I also write to represent their wishes. My family want me to have choices at end of life – and whilst I am most likely to die in South Australia, I want my friends and loved ones to have the same choices I will have if I am alive at the end of the implementation period. It is critical that I support my family and loved ones in QLD to access to the best possible law.

In this submission, I will comment on key areas of legislation.

I support the principles underpinning the Act.

I would also like to be very clear that it is a form of coercion for family, friends and loved ones to attempt to convince someone to continue to try treatment after treatment after treatment when the patient does not wish to do so. This can occur when loved ones may be too scared or distressed to acknowledge or accept the inevitability of death of their loved one. This can lead to increasing suffering, and people dying in a hospital bed when their true wish was to remain at home. The pressure placed on people living with terminal illness can be quite horrific. My view is that terminally ill patients should have choices about their care of end of life, and that this issue ultimately comes

Ceara Rickard

down to the rights of the individual to be free of coercion, including coercion to continue on against their will.

### **Health care worker not to initiate discussion about voluntary assisted dying**

If health care workers are not permitted to initiate discussion about voluntary assisted dying, access to VAD will be limited to those patients who follow the news or are very aware of their rights of legislation. My view is that this will lead to discrimination against patients who may not be interested in following the news or politics, patients who may not have good literacy skills, and patients from culturally and linguistically diverse backgrounds. This is unacceptable.

People with a terminal illness have every right to know each of their options. It is impossible to engage in informed consent if patients are unaware of the choices they have available to them. Informed consent is integral to the right to information in the Australian Charter of Healthcare Rights, and recognised in Professional Codes of Conduct.

I find the restriction on health care professionals being able to discuss VAD in Victoria to be utterly abhorrent, because it forces health care professionals to engage in behaviour that is unethical if they wish to comply with the law and be able to continue to practice!

I much prefer the Tasmanian model, which permits health care professionals to discuss VAD in the context of providing information about other care and treatment options also. This is precisely what ethical health care professionals should be doing, to ensure that patients have the information required to engage in genuinely informed consent.

As treatments progress for terminal illness, they can become increasingly gruelling due to the side-effects. Through my engagement with fellow cancer patients in various support groups and my own reading, I know there often comes a time when treatment creates incredible suffering, and so patients will often need to cease treatment towards the end of life. A life of constant and unbearable suffering with no relief in sight is no way to live. Patients approaching that point who are telling their health professionals that they are suffering should know they have access to VAD if they qualify. Rather than being banned, discussion of VAD should be required when people are approaching end of life, as part of the broader discussion of palliative care options. Refusing to give patients information about all end-of-life care options available to them is paternalistic and demeaning. It is our lives, our treatments, and our choices.

### **Eligibility**

Prognostic timeframes are not appropriate. We know from research that prognostic estimates from doctors are typically a guess at best, and that doctors, like many other health professionals can tend to be optimistic. That is not a criticism, but it does mean that by enforcing a prognostic timeframe, patients are being told that they may be required to ensure immense suffering, only to die before they meet the prognosis requirements.

My view is that the role of medical professionals should be to establish if the suffering someone experiences is permanent, to determine if other treatment options are available that may relieve the suffering (and offer them), and if their condition is likely to result in their death. It should not be up to a medical profession to dictate how long one must suffer. It should be up to the patient to determine if the level of suffering they experience is intolerable. Timeframe is irrelevant.

Ceara Rickard  


Imposing a timeframe is not about supporting patients right to choices, and that should be the key principle informing the legislation.

I would like politicians considering this bill to consider the worse pain they have ever experienced. It may have been an injury, broken bone, or period of illness. Then I want them to consider what it would feel like if they were told the pain they experience would be permanent. In my case for example, I have already experienced pathological fractures to my bones from cancer. I currently write this submission from my hospital bed. I am currently experiencing such severe pain in my nerves and weakness in my left leg due to my cancer that I am on strong painkillers and cannot walk. I am not yet at the point where my suffering is intolerable, but if the worse pain and suffering I have experienced with my cancer was permanent with no hope of relief, I would want the choice to access VAD regardless of how long my doctors think they can keep my heart beating. I have been able to cope because we have been able to treat my pain with good palliative treatment. If those treatments were to fail, how long should I be required to suffer to satisfy a prognosis requirement? I wish I could put politicians in my body, just for a few hours or days and then swap back. They have not walked in my shoes (not that I can actually walk right now). I wish they could, perhaps then they would understand.

If Politicians debating this bill are more worried about the idea that someone might access VAD too early and insist on a prognostic timeframe, a minimum of 12 months would be an improvement on the other states.

#### **Use of telehealth**

I acknowledge the use of telehealth is a fraught issue considering the Commonwealth Criminal Code. Nevertheless, I strongly encourage QLD to not disallow it in practitioners, but to ensure that that training covers the issue thoroughly. I would further like activism from all states that legislate VAD to seek change. I see this as an issue of health care equity.

#### **Contact persons acting on behalf of an end-of-life patient**

Any patient seeking to access Voluntary Assisted Dying and self-administer medications must have the right to nominate a "contact person". The opposition argument that patients should not be able to nominate someone to collect medication or act on their behalf is utterly ludicrous. It is highly disrespectful to me as a person to say that I should not be able to ask someone to act on my behalf. For crying out loud, I already have nominated power of attorney and guardians for when I become incapacitated as I have every right to do. Nominating a contact person to act on my behalf regarding VAD seems little different to nominating someone to act on my behalf in other ways. Patients accessing VAD may not be able to mobilize and may be too ill to access medication. Preventing patients from being able to nominate a contact person is something I see as a cynical method by the opposition to try to prevent patients from being able to exercise choices at end of life.

#### **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.

Ceara Rickard  
**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. IN Tasmania, nurses are permitted to act as an administering practitioner.

Were I to remain where I currently reside in Tasmania, I am certain that if I chose an administering practitioner, it would be a nurse involved in my care who strongly supports my rights to end of life choices. I have little doubt she will complete the training in Tasmania and would see being an administering practitioner as an honour. She is a highly skilled and experienced nurse who has worked with me since my metastatic breast cancer diagnosis. She has visited me at home, knows my family and has been a constant support. She is amply qualified and skilled to be an administering practitioner, and would do so with grace. I also want to highlight that nurses are frequently present when patients die. They are a common source of support to both patients and the bereaved and are amply skilled to fulfil this function.

**Conscientious objection by entities**

I consider the thought of a faith-based organisation having the right to object to my choices to be so appalling and unacceptable that it is difficult to put into words. I am angry that faith-based organizations would seek to act as though they have a moral high ground on this issue. In my view, their desire to control the bodies of people as though they are their personal property is a fundamental issue and driver of the opposition to VAD.

Further, I believe that any facility that seeks to deny patients information about VAD or hinders or obstructions individuals seeking to access the service should lose any government funding, with leaders being sentenced to jail. This may appear a stiff sentence, but I think such action is commensurate with torture and should be treated accordingly.

**Independent Government Facility to provide Voluntary Assisted Dying Services**

End of life patients need the process to be accessible and streamlined. We do not need to be bogged down in paperwork at the end of our lives, with delay after delay, and subtle tactics designed to gaslight and harm us by removing our choices. I am quite certain that without significant protections, this will occur in certain faith-based facilities. Facilities should be patient centred as the priority, but unfortunately that is not always the case.

What worries me most is the number of hospitals in QLD that are managed by the Catholic Church who are strongly in opposition to me and other patients having rights over our own bodies at end of life. I would like consideration to a dedicated unit of health professionals providing VAD services in a mobile, state-wide service. This would accommodate the wide geographical spread of the QLD population and ensure patients living in regional services do not miss out on appropriate services.

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

I agree that entities that do not provide Voluntary Assisted Dying services must publish that fact openly and with transparency to all those individuals who attend/visit their facility, whether they have a diagnosed terminal illness or not. Again, in my view this is another aspect of supporting

Ceara Rickard  


patients to engage in informed choices. My choice would be, if possible, to never enter a facility that would seek to deny me VAD, something I consider a fundamental human right.

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

Data and information should be collated to determine that the legislation proves to be effective. The implementation of the scheme should include rigorous data collection systems with flexibility to adapt as the scheme rolls out.

**Further clarification required re any proposed amendments to this legislation**

I have heard concerns about whether any VAD legislation that is passed could be amended/expanded through a separate "sub-committee process" within the overall parliamentary process. This should not be used as an argument for opposing the legislation.

Yours sincerely,

Ceara Rickard