

Submission to the University of Tasmania re End-of-Life Choices (Voluntary Assisted Dying) Review

Thank you for the opportunity to make a Submission on this legislation. While my response is on behalf of the group *Christians Supporting Choice for Voluntary Assisted Dying*, in my role as Spokesperson, National Co-ordinator and a Co-founder of the group, I do state that they are my responses, although I believe they represent, as much as possible, the views of our members as they have been expressed to me since our group began in 2009.

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Safeguards and protections for vulnerable people.

The overriding principle of VAD legislation should be that a patient should be in control of their suffering as much as possible and have autonomy to the maximum extent possible. It has been clearly demonstrated that simply having the option of VAD has important palliative value it is own right.

The aim of VAD legislation should be to enable a person approaching death to access VAD with appropriate checks and balances, not to impose a system of hurdles and roadblocks that result in making access as difficult as possible.

The vulnerable

I submit that the current End of Life Choices (VAD) Bill 2020 has ample safeguards and protections for the vulnerable. There is no evidence of coercion of the 'vulnerable' from eg Oregon, with 20+ years of legislation. Dr Nick Carr, who has been involved with a number of VAD procedures in Victoria states *"There is no coercion. You can't coerce older people into going through this process. And that's what the laws protect against, anyway."* (Ref: <https://www.theadvocate.com.au/story/6869597/assisted-dying-law-a-positive-experience-gp/>)

On the other hand, the truly vulnerable, those dying and trying to access VAD may feel pressured to accept PC and be grateful. (See addendum 1) Please note this comment is not to diminish the value of PC. However, the evidence from PC itself, collated by Wollongong University PCOC, is that PC cannot mask all end of life suffering adequately, and the additional choice of VAD is rational and humane. Palliative Care should have increased funding at the same time this VAD law is passed in Tasmania.

I am pleased an amendment to the Tasmanian VAD Bill which would have permitted conscientious objection by some facilities (entities) to allow VAD, failed. I submit a facility/entity should not be permitted to refuse any legal medical treatment to be carried out on their premises, and that would include VAD. This should certainly apply if the facility/entity receives public/government funding. The suggestion has been made that some religious facilities should be allowed to refuse access to VAD on their premises, based on '**religious freedom**'. It is one thing for a person to have the right to refuse to be involved, but different altogether for an entity to be able to say – "we know this is your home, and you have lived here for 'x' years, but because you want a legal medical procedure that we do not agree with – you are out." This would be blatant discrimination!

- "Religious freedom" must not be used to deny a dying person in their own home in certain facilities their right to have a doctor visit them for a medical examination, and if appropriate, to explain all legal end of life choices, including palliative care, stopping all treatments, stopping eating and drinking. (Including VAD).

- "Religious freedom" must not be used to deny a dying person in their own home in certain facilities their right to have any legally prescribed medical substance delivered to that home.

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- "Religious freedom" must not be used to deny a dying person in their own home in certain facilities their right to swallow any legally prescribed medical substance at a time of their choosing, should they decide to take it!

I submit that for others to seek to deny a person the above access to VAD on the grounds of religious freedom is inhumane and discriminatory. It is also important to note that three out of four Christians (Vote Compass 2019) support VAD as an end of life choice, and they should not have their religious views on VAD overruled by a small but vocal minority who oppose this choice.

We do not want the situation to arise where a person was accessed for MAiD in Canada in a bus shelter because the facility they lived in did not permit even this aspect of VAD. Others have died while being transported elsewhere in an ambulance!

Safeguards

I am not convinced that having a Commission rather than a Commissioner, as in the original draft legislation, is needed as a safeguard. I understand that the Asbestosis Compensation Commissioner in Tas deals with approximately the same number of cases that could be expected for VAD, and is medical/legal assessment related. I understand it comprises 1 person, 1 deputy and staff. That said, it is more important to have the VAD legislation passed, regardless of whether oversight is by a Commission or a Commissioner.

Prognosis

Sadly, I think it would be very unlikely that Tasmania (or any jurisdiction in Aus) would have an Act without the 6 months and 12 months for neurodegenerative illnesses. Thankfully there is the amendment to allow people to apply to the Commission in exceptional circumstances outside the prognosis period. (Part 6, (c)(3)) It would be a backwards step if the Bill were amended to remove this option.

There must be this provision for reducing waiting periods. We would not want the situation that has arisen in some jurisdictions where the patient is afraid to accept sufficient pain relief on their last days in case it makes it impossible for them to make their final request. This is inhumane.

My comment on this aspect to the Consultation Paper by the QLRC on the Queensland VAD law relating to prognosis was as follows -

"It is very difficult to accurately predict a time frame to death, unless the person is reaching the terminal phase of their illness.

The degree of suffering being experienced by the person who meets the other eligibility requirements should be overriding criteria for access. If the aim of the VAD Act is to give the option to avoid futile enduring untreatable suffering, then it is not rational to have a time limit, as with some degenerative illness the severe suffering can be longer than any arbitrary time eg of 12 months. There seems little point in two doctors saying, *'Well we appreciate your suffering is unbearable, and that you will die. However we need you to endure that for another 'x' months until we can say with some confidence you are expected to die within 12 months!'* "

Waiting periods between assessments.

- If a person requires major surgery needed to save their life, I understand they must give consent. If they wish not to consent to that surgery they are not compelled to wait eg 9 days before they can say 'no' to ensure their decision is 'well considered.' There is no legal requirement that a person who wishes to eg. refuse further dialysis treatment, essential for them to stay alive, needs have that refusal considered and repeated over a period of time, as far as I am aware.

- In most cases for patients requesting VAD, they have already undergone months or years of treatment. For example, chemotherapy, which though aimed at prolonging life, may actually shorten it, and also reduce that remaining quality of life. This has given them ample time to consider end of life

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options including VAD. Regrettably this vitally important point is rarely mentioned in VAD debate by MPs.

- No waiting period is mandated for the decision to use terminal sedation as a last resort in palliative care. Indeed, no consent is required from the patient either – it is a decision made by the treating doctor.

As stated previously, it is important that the VAD Bill does not legislate more hurdles for people to access. The current Bill does not require PMPs and/or CMPs to be specialists and I submit this should remain. The diagnosis of the condition will have been made by a specialist before the person even attempts to access VAD – the GPs involved are only assessing eligibility NOT necessarily diagnosing the condition. I understand there are limited numbers of specialists in Tasmania.

This proviso is adequate and preferable to the need for a specialist, as, particularly for some of the rarer illnesses that are incurable, the number of such specialists who have undergone the VAD training and who are willing to participate can be limited – making it unnecessarily difficult for the patient to access this second opinion, as has happened in Victoria. In that state, there are reports that a very sick person in a remote area may be forced to travel to Melbourne for their second assessment.

The VAD law needs to be structured in such a way that **a patient can decide to have VAD as a medical treatment, in the same way as they can already decide to accept or refuse other medical treatments that may kill them, such as chemotherapy.** Since people who choose not to have chemotherapy are making a choice to die at a time and manner of their choosing, then VAD is the medical treatment to enable them to do this, just as chemotherapy is the medical treatment that people can choose to try and extend their life even if it may kill them earlier instead.

Raising the subject of VAD

I trust that Part 4 17, that enables the medical practitioner, provided all other treatment and PC options are discussed at the same time – to also raise the subject of VAD, can remain. This is permitted in WA but not in VIC. Discussing all such treatment options should be a duty of care by the doctor. Not to allow this would discriminate against the less educated, those without internet, and those for whom English is not their first language.

Telehealth

I note Clause 137. I do hope some provision for telehealth consultation can remain, as this VAD legislation is not suicide (Clause 138). I note the VIC VAD Report of Operations to Dec 2019 states: *The Board recognises the importance of conversations around voluntary assisted dying being conducted in person. However, it must be noted that there is potential for a significant impact to be experienced by rural and remote Victorians unable to use telehealth technology to complete appointments.*

Finally, when structuring this law, I trust the University of Tasmania Review Panel reviewing the proposed VAD law will consider the positive aspects that the VAD choice has given in jurisdictions with this law. This includes

- opening up the whole conversation about dying.
- an assisted death for people with cancer described as 'beautiful'.
- the grieving process is improved. While those left still regret the death, the knowledge that it was what their loved one wanted, and that they had the opportunity to say appropriate farewells, is a very positive aspect.
- the nature of dying is changing in a positive way. Rather than dying hooked up to machines in a hospital room, the person can make their choice. Some choose to have a 'wake' just before they die, where family and friends can say those nice things about a person to their face, rather than at a funeral service. Others choose to die watching a beautiful sunset. I have noted, some die singing!
- the VAD law puts the patient in control, rather than the doctors or the politicians.

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- Dr Cam McLaren, oncologist, describing the death of the first patient he assisted as “..... *it was emotionally exhausting, but most of all, it was beautiful.*”

Ref, for the circumstances leading to this previous statement, showing the value of VAD

Dr McLaren Reference: <https://berwick.starcommunity.com.au/news/2020-03-12/the-decision-to-die/>

Addendum 1. Tim Edwards and his experience with palliative care. This article demonstrates why VAD legislation is needed, and the limitations of palliative care. Legislation in Tasmania needs to address and avoid such a situation arising in Tasmania. I would have thought PC would have done everything possible to prove to the family that PC is always effective, and so VAD would not be needed. Clearly PC was sadly lacking!

Tim Edwards and I visited our local MP, shortly before his death, to lobby for the choice of VAD.

Dying from a terminal illness - a family perspective

by Jessica Edwards

Tim Edwards, or 'Big Man' as I called him, was my father and a daily reminder of the person I am and the person I should strive to be. Many people who met Tim briefly thought him to be a cynic. In truth he was an idealist. After many years as an accomplished professional, Tim spent the last decade of his life working tirelessly at educating people on climate change and chipping away at the political framework that has for years prevented the adoption and implementation of an effective climate change policy in Australia and globally.

Tim was a passionate but likeable man - though spending time with him often felt like getting caught in the intellectual equivalent of a spin cycle. He was a great Dad and mentor to all four of his children (myself, Matt, Andy and Chris) and along with his 'partner in crime', my mother Jan, led a life to be admired.

Tim Edwards passed away on 16 February 2018, after fighting mesothelioma to the bitter end for the better part of two years. He acquired 'meso' (as he called it) from being exposed to asbestos during a summer job when he was 18. Almost five decades later the disease had taken over his body and he could not breathe. I watched him take his last peaceful breath at home with his family and ever faithful dogs.



Tim Edwards: "Surely I have the right to make my end as good as it can be?"
- 21 January, 2018

Throughout his disease Tim suffered from depression, extreme breathlessness and a never-ending list of painful symptoms from the disease and from multiple rounds of chemotherapy. In the final months Tim was in a great deal of pain, could barely eat or drink and could not breathe or function without the oxygen machine. His heart and lungs were surrounded by cancer. He had multiple pulmonary embolisms and a plethora of secondary medical issues.

Tim approached death as he approached everything in life, practically and with extreme clarity of mind. He was an outspoken advocate for assisted dying and believed strongly in having the right to choose when and how he ended his life. The passions of Tim's life were his family, his dogs, the outdoors and changing the world for the better. His disease progressed to a level that these passions were taken away from him. It was at this point that Tim should have been entitled to call it quits.

His disease was terminal. He had only two choices remaining to him - dying well or dying horribly.

In the end, Tim's position on assisted dying worked strongly against him, with his palliative care doctors and nurses, in my view, undertreating him and one of them repetitively lecturing a grieving family about the illegality of assisted dying (even the day before he passed away). In the final days of his life, we took turns sitting with him and watching him sleep. At one point he woke up, looked at me and asked "when are they going to let me go". All I could do was look at him in tears and say "I don't know - this is not the way it should be".

When Tim passed away the first feeling I had was not sadness, but immense relief. Relief that his suffering was over. Relief that he would no longer be poked and prodded by the palliative care staff. Relief from a feeling that we had somehow failed him by letting him suffer the way he did in his final days.

I believe that if Tim had been given the opportunity to choose his time and his way, those final days would have been drastically different. My hope for the future is that for all those families who face a similar fate, the NSW Government gives them the opportunity to do it with dignity and with the least amount of pain and suffering possible.