

SUBMISSION

PARLIMENTARY INQUIRY INTO VOLUNTARY ASSISTED DYING
LEGISLATIVE ASSEMBLY OF THE NORTHERN TERRITORY
LEGAL AND CONSTITUTIONAL AFFAIRS COMMITTEE

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Introduction

I offer this submission to the Legal and Constitutional Affairs Committee Inquiry to assist in the voluntary assisted dying journey in the Northern Territory

I will address the key questions (in dot point format) but will also provide additional information which may be of assistance to the Committee when deliberating on this issue.

Background

I am the Independent Member of the Legislative Council who successfully introduced and carried the Tasmanian End-of-Life Choices (Voluntary Assisted Dying) Act 2021. The Act received Royal Assent on 22 April 2021 and came into being on 23 October 2022 (18-month implementation period).

The Tasmanian Process and Journey:

- 2009 - Dying with Dignity Bill introduced by Greens Leader Nick McKim in the HA, the Bill (19 pages) was sent to a select inquiry, Bill was found wanting and not supported in the Lower House.
- 2013 - Voluntary Assisted Dying Bill introduced by Premier Lara Giddings and Nick McKim in the HA; was defeated 13-12 in the Lower House and did not proceed to the Committee Stage.
- 2016 - Voluntary Assisted Dying Bill introduced by Lara Giddings (Labor) and Cassy O'Connor (Greens Leader) in the HA and was defeated 16-8 and did not proceed to the Committee Stage.
- In 2017 I was approached by Tasmania's Dying with Dignity {DwDTas) President and was asked "if the Bill was re-introduced into the Lower House and if it was passed would I carry the Bill in the Upper House." I said I would, however, in carrying such an important Bill (if it were to pass) I needed to be more familiar with the issues, challenges and material.
- I then embarked on a largely self-funded international tour for 17 days, 5 countries (Netherlands, Belgium Switzerland, Canada and the USA), and had 22 meetings with very learned individuals across a range of professions.
- It was an invaluable experience and actually afforded me an international body of experts I could call on for opinion and advice. I also made podcasts available to all Members of Parliament of those meetings.
- On my return to Tasmania one of the "8" members in support of the 2016 Bill resigned and his place was taken by an MP who had made it known that she was not supportive of VAD.
- I approached DwDTas and suggested they consider that I introduce a Private Members Bill in the Upper House as it seemed certain that introducing the Bill downstairs would definitely fail {again).
- DwDTas was very pleased that I was offering that option however in my mind there was a distinct difference between introducing a Bill (My Bill) to carrying another Bill which may have passed (or not) in the lower house.
- I wrote to the Premier and requested that I have access to OPC (Office of Parliamentary Counsel) for such a significant piece of legislation. The Premier agreed however I received the distinct impression (reinforced by Anti-VAD Ministers) that the attempt would fail again (same Bill /same defeat scenario).

- I then (strategically) decided a different course of action to the previous Tasmanian attempts where legislation seemed to arrive on the Parliamentary table with very little input or involvement from the community.
- In late January 2020 I released a 122-page draft Bill for Community discussion, involvement and debate.
- In February 2020 I presented 35 (90 minute) forums to interested individuals in all of the 29 local Councils including both Flinders and King Islands. This action immediately created a widespread community conversation.
- I organised 240,000 pamphlets to be letter dropped by volunteers, tabled a petition of 13,000+ Tasmanian names, over 500 large corflute posters across the state, received, tabled and presented to each of the 40 politicians, 108 stories of lived experiences sent to me by Tasmanians, drip fed information to all politicians as the journey unfolded.
- I was not precious about the Bill and introduced improvements to the Bill as I received feedback from the community forums.
- The Bill tabled in August later that year was markedly different to the 2012 & 2016 Bill (to the chagrin of DwDTas) it was responsive to the needs and desires of the Tasmanian People. The eventual Act was close to 190 pages.
- The Bill contained very different clauses to previous legislative attempts from Tasmania, and even those successful acts in Victoria and Western Australia.
- National Bodies (Go Gentle Australia, Christians for Voluntary Assisted Dying, Palliative Care Tasmania) and notable Australians (Andrew Denton, Marshall Perron, Dr Rod Syme) were very supportive although I can remember Andrew contacting me in March 2020 and saying "Michael good on you for trying but with a Liberal Government with similar representation to other years we don't give you much of a chance to succeed but we will help." Go Gentle was an enormous help!
- It should be noted that (as in NT) there were opposing voices (and should be) for sensitive social issues. A number of religious organisations, the AMA (Australian Medical Association) including the Tasmanian Branch, Catholic Women's League for example were very much against the Legislation.

*Pleasing that the AMA have now amended their thoughts re VAD.

However, I always welcomed opposing views and oppositional involvement although at times needed to correct publicly, some of the assumptions and assertions they made about the Bill.

- I made myself accessible to media at all times and was constantly being asked to provide updates and information. I often was contacted by every day Tasmanians did find myself listening to some incredibly sad personal situations and circumstances and often those conversations were quite lengthy.
- I have presented 141 forums to the Tasmanian Community, and as mentioned previously all Local Councils (before the Bill was passed and I went back to many of those same communities once the Bill had passed). I presented 25 forums to the year 11 & 12 Colleges across the state, Conferences including Nurses, Doctors, Lawyers, Local Government even an environmental land-care conference.

- The 2020 End-of-Life Choices (Voluntary Assisted Dying) Bill was introduced in the Upper House by Mike Gaffney (MLC) was passed 15-0 and progressed to the Committee Stage, was then sent to the Lower House and was passed 19-6.
- It is my understanding that Tasmania is the only Parliament in the world to have one of its Chambers of Parliament unanimously pass a VAD/Euthanasia Bill.

Key Questions

1. ***Do you support making VAD legal in the NT?***

Yes, I unequivocally support making VAD legal in the NT.

For me, suicide is the choice between life and death whilst Voluntary Assisted Dying (VAD) is the choice between two deaths.

I believe the whole process is about an individual's right of 'choice'.

- (1) the eligible person's right to choose the time and place and manner in which they relive their suffering.

and

- (2) the health practitioner's right to choose if they wish to be involved (or not) with (a) the VAD process (need to undertake the training) and (b) each individual case that presents.

2. ***What eligibility criteria should a person need to meet before they can access VAD?***

The Tasmanian legislation allows persons who satisfy the following criteria the right to choose VAD:

- 18 years old
- A Tasmanian resident
- Capable of making decisions
- Acting voluntarily
- Suffering intolerably from a Relevant Medical Condition and has a 6-month prognosis (12 months for Neurodegenerative disorders)

I believe however, with the national change in access to VAD that the residency requirements will also change. The Tasmanian requirements are more flexible (& inclusive) than both the Victorian and WA.

It should be noted that in my original bill tabled, I did not have any time period (6 month and 12 month). That was introduced during the debate in Parliament.

3. ***How could the NT make sure that an eligible person can access VAD in a safe and effective way, including people living in remote areas and Aboriginal and Torres Strait Islander people?***

It is always the individual who was the primary focus of the Tasmanian legislation and the Act is so written to assist with the persons rights to progress if so desired.

Medical and Health Practitioners whilst making a determination regarding the persons eligibility do not make the decision. The decision to proceed (or not) with the VAD pathway is made by the person.

Doctors trained in Tasmania are supportive of the Geneva Declaration, which includes the following:

- The health and well-being of my patient will be my first consideration
- I will respect the autonomy and dignity of my patient
- I will share my medical knowledge for the benefit of the patient and the advancement of healthcare.

The Tasmanian EOLC (VAD) Act articulates if a medical practitioner (or any other person), acts in accordance with the bill or believes on reasonable grounds that they are doing so,

- They will not incur any civil or criminal liability for their actions
- The action will not be regarded as a breach of professional ethic or standards, or any other principles of conduct to their employment

Part 20 Miscellaneous - Clause 140

For the purpose of the law of this State, a person who dies as a result of the administration to the person, in accordance with this Act, of a VAD substance or a substance under section 88, or the self-administration by the person, in accordance with this Act, of a VAD substance does not die by suicide.

Tasmania also has a Voluntary Assisted Dying Commission. The Commission is an independent oversight and decision-making body with responsibility for performing the functions and exercising the powers conferred upon it by the Act. The Commission's functions include: issuing, amending and revoking VAD Substance Authorisations.

The commission has undertaken various activities to promote and fulfil its role under the VAD legislation. For instance, the commission has sponsored fact sheets exploring various stages of the process and has updated relevant documents to provide more information on eligibility. This comes with an aim to provide support to families and friends and those undertaking the voluntary assisted dying process with clear and easily digestible information.

These documents are made accessible online and in person and can be accessed in different languages, demonstrating forward-thinking accessibility measures and meeting demands being noted in other Australian VAD jurisdictions for access for multicultural communities and remote areas.

4. How could the NT monitor the process to ensure VAD is delivered safely and effectively?

All Australian jurisdictions with VAD legislation (except Tasmania) have assessed the process and have chosen a portal as the most efficient system.

A VAD portal is a secure online system used by Medical Practitioners to manage requests and ensure compliance with VAD legislation. It allows Doctors to complete and submit forms, access training and apply for permits to prescribe VAD medications.

Indeed, Tasmanian Health Practitioners have contacted me with real concerns that a lack of a VAD portal has had impacts on their professionalism, their health and, importantly, Tasmanians and families who gain so much from their support and assistance.

I am currently urging the Tasmanian Government to provide funding and support for a VAD portal. Given that the biggest issue for getting Medical Practitioners to assist in the VAD space is a non-remunerated administrative burden, a portal should be a priority and ensure our doctors spend less time filling in paperwork.

I do believe that a rather minimal outlay for a VAD Portal would be a very wise investment.

Comments Received:

Before I close, I would like to share two letters which highlight the reality of the VAD legislation.

The first letter provided to me (with permission) is to a doctor from the son of a lady who chose the VAD pathway in Tasmania.

“A year ago today you assisted my mother... to end her own life. For mum, the ability to choose when and how to end her own life and to be able to do so in a dignified and calm manner was fundamental to who she was. As you may remember, Shirley was somewhat phobic about being swept up by the medical system and being forced to spend her remaining days in a hospital ward, surrounded by strangers and feeling she had no control over her own destiny.

At the time we first came to see you, mid-2023, Mum was desperate to access VAD and she was considering travelling to Switzerland to seek out potential euthanasia options offered by Dignitas. We knew that the Tasmanian VAD laws were in place, but media coverage had given her the impression that the Tasmanian VAD laws were very difficult to navigate, so mum had dismissed VAD in Tasmania as an option. Luckily, a good friend who was the daughter of a doctor suggested the Tasmanian VAD system was actually significantly less impenetrable than the Switzerland one, as we had been led to believe. Her father also gave us your name as a potential contact.

I accompanied Mum to your surgery in Dover in June 2023 and I was immediately struck by the way that you managed to almost instantly gain my mother's trust, a woman who was very nearly paranoid in her aversion to doctors and the medical system. Within a few minutes she consented to you giving her a physical examination. I was completely floored, but perhaps the moment I remembered the most was when Mum mentioned that she would still consider going to Switzerland if necessary and you said to her, 'I promise you, you won't need to go to Switzerland, and you'll only need to go to Switzerland if you want to see the mountains'.

Even then, for Mum, it took a little while for it to sink in that she could actually access VAD in her own home here in Tasmania. She couldn't believe that the outcome she most wanted was actually going to be available to her.

So anyway, the point of the letter is....that I just wanted to say to you thank you, from the bottom of my heart. I just can't thank you enough for your professionalism, your compassion and your commitment. I will never forget the way you made Mum feel that she had control of her own destiny and how happy that made her. Of course we, her family, were sad to lose Mum, Gran, sister, et cetera, but it made her death so much easier to bear, and so much more positive knowing that she left this life in a calm, dignified manner with little or no suffering. So thank you..... I have some tears in my eyes as I'm writing this, but they're not tears of sadness. They're tears of gratitude that this world that we live in has such wonderful people like yourself living in it.

All the best to you and your family.”

The second letter I personally received earlier this year:

“Dear Mike,

My partner and I heard you speak in the lead-up to the passing of the VAD legislation in Tasmania and we were impressed by the careful thought and the work which went into your presentation.

I am contacting you now to say many thanks for that work and how pleased I am with the result. A close friend died recently with VAD and it was a sad but awesome experience, in the best sense, for his family and friends. He had terminal prostate cancer and, although showing a stiff upper lip, I understand he was suffering pretty severe pain. Once he had decided this was what he wanted the assessment process was apparently smooth and swift, much to everyone's relief. He set the date and a final farewell was held at his home with family and close friends alternately reminiscing, singing, laughing and crying.

Less than an hour after friends had left he was dead. I understand his death was supremely tranquil and now, some two weeks later, his wife is able to express her deep thanks that his suffering is over and was able to 'depart' in the way he chose, at home and surrounded by family.

So I am hereby expressing my sincere gratitude for the work you did and the fact that Tasmanian people can now, in the right circumstances, die with dignity at a time of their choosing.”

Closing Remarks

I offer this submission in the hope that it highlights that Tasmania used a different process than the other Australian states and perhaps there are some lessons to be considered about the value of authentic community consultation. I believe that there needs to be a very transparent and open process where people feel as though they are included in the conversation and each opinion is important. Obviously, with this issue there will never be consensus but I believe all Tasmanian's felt they could be involved.

I wish all members of the Legal and Constitutional Committee the very best with their deliberations.

I am more than happy to discuss this submission or provide further information if required.