SUBMISSION TO THE GOVERNMENT OF THE NORTHERN TERRITORY

Introduction

Dying With Dignity Western Australia is an incorporated community group that has existed for more than 40 years. It is dedicated to the passage of legislation to permit at the end of life a choice to have assistance in dying in circumstances and at a time chosen by the person concerned.

We are pleased to be able to provide this brief submission, in the hope that it may assist in the preparation of voluntary assisted dying (VAD) legislation for the Northern Territory. We suggest that you may want to also review our primary submission made in March 2024.

The author indicates that he has read the discussion paper dated July 2025.

As you may know, the passage of the Western Australian *Voluntary Assisted Dying Act 2019* was preceded by a year-long inquiry by a cross-party parliamentary committee (Joint Select Committee) which culminated in a report entitled *My Life, My Choice* in August 2018. We strongly supported the recommendations made by the Joint Select Committee and, in the light of subsequent experience, we still do.

Unfortunately, ultimately the WA Act was drafted, and passed, in terms that fell well short of the Joint Select Committee report. In particular, it adopted the Victorian eligibility requirement that an applicant be assessed as having no more than 6 months to live (or 12 months if suffering from a neurodegenerative condition).

Nevertheless, its passage was a welcome advance. The Act is a compassionate law that included particular measures appropriate for the large and culturally diverse state of Western Australia – features which of course it shares with the Northern Territory.

We highlight below some essential concerns with the adequacy of the Western Australian VAD Act.

In our view the Northern Territory should pass VAD legislation which addresses each of these concerns; if it were to do so, it would have a world-class VAD law which admirably balanced accessibility, compassion and choice with balanced and workable safeguards.

1. **Eligibility**

In the WA Act the eligibility criteria are found in s 16. They are in terms substantially similar to the Acts of other states. In our view, experience in Australia, Canada and the Benelux countries has shown that a workable and safe VAD system, with which the public as a whole would be comfortable, can be operated with key eligibility criteria that are both *less restrictive* and *more flexible.* These would permit better access, and less suffering.

Time to death criterion

In particular, the 6-month to death criterion – which originated in Oregon and was an arbitrary choice unsupported by research or proper consideration[1] – is inappropriate as being antithetical to the objects and purposes of such legislation. It leads inevitably to unnecessary and prolonged suffering for people who are afflicted by conditions that will kill them but not within that time frame.

Victoria added the ameliorating provision of a 12-month criterion for neurological conditions. More recently Queensland adopted that criterion for all cases. However, these are only improvements at the margin. They do not assist significant numbers of people with slowly progressing but fatal conditions that may be causing unacceptable suffering.

We suggest that the remaining criteria set out in s 16 should themselves be adequate to establish eligibility Thus, a person who is diagnosed with *at least one disease, illness or medical condition* that is *advanced, progressive and will cause death,* and that is *causing suffering to the person that cannot be relieved in a manner that the person considers tolerable* should be eligible.

Such a formulation would be centred on suffering, which is the key issue and driver for VAD. A definition of *suffering intolerably* in terms similar to s 14 in the Tasmanian Act should be adopted.

It is important to note that eligibility would still be confined to those at an advanced stage of a terminal illness; the floodgates would not be opened.

The Canadian federal legislation continues to use the criterion that *death is reasonably foreseeable*, and it appears to have proved workable in that jurisdiction. Its use was recommended by the Western Australian

[1] https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care.

joint select committee, but that was not adopted when our Bill was drafted. It might be considered for inclusion in the NT Bill, alongside the other criteria, and in place of the time-to-death criterion.

The Australian Capital Territory has passed VAD legislation that omits any requirement to establish a particular length of life remaining to the individual. We strongly commend this approach.

Decision-making capacity and dementia

People who at any stage of the process have lost decision-making capacity will be unable to access VAD. This is because they will be seen as not acting voluntarily, nor with an enduring wish for VAD.

There can be no doubt that a large part of the community feels – at the very least - disquiet at the exclusion from VAD eligibility of the many who will suffer from dementia or similar conditions, who have made a clear previous request for VAD in the event that they might in the future suffer from exactly that condition. The incidence of dementia, including Alzheimer's disease, is increasing; currently it is the leading cause of death for women and the second-leading cause of death for men.

It is possible to draft safe and acceptable provisions to permit special access to VAD for such cases. Amendments to both VAD legislation and also to guardianship and administration legislation would be required. Quebec has passed detailed amendments to its MAiD legislation which appear to be well thought through. They have been in operation since late October 2024. We suggest that the Quebec model is worthy of close consideration by the Territory.

It may be desirable to have two tracks for VAD eligibility – one for those who satisfy the present capacity requirements at the time of request and persevering to the date of death, and the other for those who do not. The second track would require the jumping of a significant number of extra hurdles (safeguards). This would have some similarities to the present Canadian model.

The federal Canadian adoption of 'waiver of final consent' provisions should also be considered. It permits a person assessed as eligible to set a date for MAiD provision, which need not be followed if he retains capacity, but may be if capacity is lost in the meantime. This is reported as providing a great sense of wellbeing and reassurance.

Residence

With every Australian state now having legislated for VAD, it is neither necessary nor appropriate to require that an eligible person must be or have been resident in the particular jurisdiction – at all, let alone for any particular time. The cruel exclusion of people residing in one state or territory and having substantial connections in another, or who upon diagnosis move to another jurisdiction for support, cannot be justified.

Residence in the Territory should not be required. On a personal note, the author, a past resident of Kununurra, can attest to the frequent movements of people between the East Kimberley and the Territory (including for medical treatment).

There are occasional difficult cases of people who are not Australian permanent residents but have a substantial connection to the country, perhaps from long presence, and also cases of people unexpectedly suffering a serious deterioration in health during a planned visit. These possibilities point to the need for flexibility. We recommend adoption of an exempting provision such as is found in s 17 of the NSW VAD Act.

Age

Consideration might be given to whether mature minors (perhaps limited to those aged 16 years or more) should be eligible. In that event, it might be reasonable to require in such cases that parental support or consent be required, or that a psychologist confirm the voluntary and enduring nature of the request.

2. Other issues

The Western Australian Act has much in common with VAD laws in other states, but at several points offers advantages when compared to the Victorian model.

We strongly support WA's rejection of the following Victorian provisions:

(a) the prohibition on medical practitioners raising the topic of VAD with patients;
(b) the requirement that one of the doctors have specialised knowledge and experience in the particular condition; and
(c) the requirement for a permit to be issued by the Health Department to authorise a voluntary assisted death.

In Victoria these provisions have seriously limited people's access to VAD (especially in regional areas).

We support the inclusion of nurse practitioners (as in WA) and nurses (as in Queensland) at least as administering practitioners; and recommend consideration of authorising them to be assessing practitioners as well.

We recommend that patients be entirely free to choose between self-administration and practitioner administration. In WA, perhaps the jurisdiction that comes closest to this position, a strong majority of patients choose the latter. There is no reason why there should be even a default system that favours self-administration.

It is important to permit the coordinating and assessing practitioners jointly to truncate the usual waiting period in cases where it is likely that the patient will either die or lose capacity before it ends.

We suggest that it should be open to a patient to have the coordinating practitioner present during an intended self-administration, who could step in and effectively assist the patient or even take over the process and convert it to practitioner-administration (see the Tasmanian Act generally, in particular s 88).

Care Navigators have been a great success, and should be part of a small unit in the Health Department to assist patients, families and practitioners. However, we would recommend that this be an emergency service available at all times, rather than only during 'office hours' as in WA.

The WA Act, unlike some others, is silent on the topic of so-called institutional conscientious objection. In our view, this is a significant deficiency. While we fully support the right of *individuals* to choose not to provide VAD services we do not agree that *bodies* (such as companies, charities or trusts) providing health or care services should have such a right (one that in effect precludes individual staff members from making their own considered decisions). Alternatively, a residential or medical facility should be required to permit the provision of VAD services on their premises if such provision does not unduly interfere with other patients or residents and their care. At the very least, if the facility in effect is the residence of the patient, all such services must be permitted – especially when it would be distressing or unreasonable to force the resident to go elsewhere for the purpose (such determinations should be in the hands of the coordinating practitioner rather than the institution).

One aspect of the WA Act which in our opinion should not be adopted relates to practitioner eligibility to undertake the training. This is the requirement that the practitioner satisfy the *CEO requirements.* The Act leaves it open to the CEO (the Director General of the Health Department) to decide entirely for himself what these requirements should be. These are not subject to any scrutiny, parliamentary or otherwise. In practice they include an obligation to provide two referees, and amount to an opaque screening process, which we believe has deterred some practitioners from applying (in part because some prefer their colleagues and peers not to know of their decision to undertake VAD work). This has been one of the pressures causing a shortfall of medical and nurse practitioners willing to qualify themselves for VAD purposes.

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