LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON VOLUNTARY ASSISTED DYING BILL
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Submission Cover Sheet

Inquiry into the Voluntary Assisted Dying Bill 2023

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ACT INQUIRY INTO THE VOLUNTARY ASSISTED DYING BILL 2023

Submission from Dying With Dignity Victoria - January 2024

Dying With Dignity Victoria Inc.
Jane Morris, President

Introduction

Dying With Dignity Victoria welcomes the opportunity to make a submission to the Select Committee Inquiry into the ACT's *Voluntary Assisted Dying Bill 2023* (the VAD Bill).

We sincerely apologize for our late submission. We were unaware that submissions had been called for and would greatly appreciate if this submission was accepted.

About Us

Founded in 1974, Dying With Dignity Victoria (DWDV) is a law reform and educative organisation pursuing public policies and laws in the state of Victoria to enhance self-determination and dignity at the end of life. DWDV's purpose is to relieve distress, helplessness and suffering for Victorians with untreatable, painful, or terminal illnesses.

Victoria was the first Australian state to legislate voluntary assisted dying in 2017, after some 50 earlier failures to pass such legislation in the six Australian states. Victoria's *Voluntary Assisted Dying Act 2017* (the Act) passed by a very narrow margin, and only after many concessions were made to ensure its successful passage. This resulted in the inclusion of 68 safeguards in the Act. Consequently, the Act was described as the most conservative of its type in the world.

Our submission

We applaud the progressive nature of the ACT's VAD Bill and consider it to be greatly improved on the Victorian Act. To ensure the successful passage of the Victorian Act, numerous amendments were agreed to. The consequences of some of these amendments, as well as problems not envisaged at the time of the passage of legislation, were not realized until VAD became operative in Victoria in 2019.

The Victorian Act has exemplified the case of legislation so heavily safeguarded that it has resulted in denying VAD access to a large cohort of people, the very individuals whom the legislation was designed to help. Other states have been able to witness the operation of Victoria's legislation. They have observed how the process can be successfully carried out but also have been able to observe problems and impediments to the efficacy of the process that have arisen.

VAD laws need to balance accessibility and protection and the ACT VAD Bill has successfully achieved this. Below we briefly discuss the points in the ACT VAD Bill which we regard as highly commendable.

Eligibility requirements

VAD legislation needs to balance accessibility with the protection of vulnerable people. Section 11(1) of the ACT VAD Bill omits the requirement for a ‘time until death’ prognosis as an eligibility criterion. We consider this omission to be extremely valuable. Interestingly, this 6-month until death criterion (with the exception of neurodegenerative illness where a 12-month time frame is allowed) derives from the requirements of the health benefits system of the US state of Oregon.

If the purpose of the legislation is to prevent suffering at the end of life for those who are already dying, then a time-based prognostic requirement can lead to failure in many cases where the option of an expedited death is denied to those who need it most.

By their own admission, doctors are not good at delivering a prognosis. Their nervousness at facing possible criticism of an inaccurate prognosis can delay the provision of a diagnosis and consequent VAD eligibility. Often a prognosis is not delivered until death becomes imminent, and the patient has little time or energy to complete the VAD process. This restrictive and, at times, cruel eligibility requirement may result in a prolongation of intense suffering. A Victorian VAD provider has stated that due to the reluctance of doctors to provide this prognosis, in many cases the doctors wait too long and when a 6 month until death prognosis is finally delivered, that patient may have only about 6 weeks.

DWDV considers that the criteria to access VAD should be intolerable pain and suffering resulting from a medical condition that cannot be alleviated to a level acceptable to the person. We are pleased to see the expansion of the definition of “suffering” in the ACT VAD Bill to embrace both physical and mental suffering and, importantly, to adopt the inclusion of anticipatory or expectant suffering. We have seen this referred to in Tasmanian legislation and consider it to be a most welcome and critical addition to VAD legislation.

The acknowledgement that suffering may derive not only from the underlying medical condition, but from its interaction with concurrent medical conditions and associated treatments and possible side-effects, is also greatly welcomed. This may be exemplified by the case of an individual diagnosed with a slowly progressing terminal illness, with an expected 8-year prognosis until death. This individual may also suffer from multiple co-morbidities, all of which are individually and specifically treated. The resultant suffering may be unbearable, but the individual must endure it until a time when they may be considered eligible for an assisted death based solely on their anticipated life expectancy from the underlying medical condition.

It has been heartbreaking to learn that due to restrictive eligibility criteria, some people experience a sense of guilt that arises from the fact that they have been considered eligible for VAD, whilst others who suffer similar illnesses and comparable suffering are deemed ineligible.

Administration of the VAD substance

Self-administration of VAD medication is the default option in Victoria. We consider that leaving the method of VAD medication administration to the individual's discretion to be another important provision in the ACT VAD Bill.

It must be noted that in Victoria when a patient requests self-administration, some VAD providers offer to be in attendance when the patient self-administers the medication. When this is offered, a Victorian DWDV Board member and VAD provider has stated that around a third of patients accept. Patients want to know that the process will proceed effectively and are reassured by the presence of a doctor.

Role of health professionals

Access to VAD in Victoria has been impeded for many individuals, particularly in regional and rural areas, by the lack of VAD providers. In Victoria, only medical practitioners may provide VAD. Victoria's Act requires that either the co-ordinating or consulting be a 'specialist' in the underlying medical condition of the patient that initiates a VAD request. This creates significant barriers for people seeking VAD due to shortages of appropriate specialists, even in metropolitan Melbourne, but particularly in regional and rural Victoria. The problem is further compounded by the need for a second specialist opinion in the case of neurodegenerative conditions where an expanded 6-12 month until death prognosis was included. We commend the ACT VAD Bill for omitting any such burdensome requirements.

DWDV commends the ACT VAD Bill for the inclusion of nurse practitioner roles in the VAD process. In Western Australia, New South Wales, Tasmania, and Queensland nurse practitioners are permitted to administer VAD medication. The ACT VAD Bill has made further provision for nurse practitioners by allowing them to fulfil the role of either co-ordinating or consulting practitioners with the stipulation that a medical practitioner should fulfil the complementary role to the nurse practitioner. We view this as an instrumental step in reducing the burden on doctors and helping to make the VAD service more easily accessible.

The proposed bill will allow nurses and registered healthcare providers to initiate VAD conversations with patients on the condition that they provide all available treatment options, including that of palliative care. Other states have included this critical provision in their legislation. In Victorian, doctors are banned from initiating discussion of VAD with patients, and we consider this to contribute to the inequity of access to VAD for many individuals, particularly those with low health literacy.

Oversight, reporting, compliance

In Victoria an independent board, the Victorian Voluntary Assisted Dying Review Board, was established to oversee the safe operation and strict compliance to the Act. In the first 2 years of operation, reports were released at 6 monthly intervals and are now annual. These reports have been helpful to understand VAD use in Victoria.

The provision for ongoing review must respond to the reality that attitudes and approaches to societal issues evolve over time. Legislation does not dictate societal views. Therefore, it is important to acknowledge that legislation must be subject to re-evaluation, by subsequent law makers, and reflect changing public views.

The Victorian Act requires a mandatory 5-year review on the “operation” of the first four years of VAD implementation. Disappointingly, this has been interpreted by the Victorian government to exclude changes to the legislation to address problems that have arisen in the provision of equitable VAD access. Regular reviews need to be conducted to ensure these issues can be addressed. It is promising to see that the ACT VAD Bill has proposed a review on 3 years of operation. Most importantly, we see that the review is obliged to include further examination on 3 important issues, residency requirements, access for minors and the use of advance care directives for dementia patients. These are all extremely important, albeit challenging, issues. The ACT Government must be congratulated on persevering with their inclusion.

Dementia and VAD

DWDV highly commends the ACT Government for becoming the first Australian jurisdiction to broach the subject of dementia in VAD legislation. The fact that those diagnosed with dementia are deemed ineligible for VAD is of critical concern to many Victorians, Australians and citizens around the world who reside in jurisdictions where assisted dying is legal. It is the most frequently referred to issue we encounter with public inquiry.

Australia has a rapidly ageing population and the number of people living with dementia is set to rise sharply. Currently more than 450,000 Australians are living with dementia, and this number is expected to grow to over 1 million by 2050 (Brown et al., 2017). Dementia is the leading cause of death for all Australians over 85 and for women over 75 (AIHW 2023).

The purpose of DWDV is to relieve distress, helplessness and suffering for Victorians with untreatable, painful, or terminal illnesses. It is DWDV’s position that we have a moral obligation to address the critical issue of dementia and VAD. A survey conducted by DWDV in late 2022 (open to both members and non-members) indicated considerable levels of concern and frustration that VAD is not available to people with dementia. These findings have proved consistent with broader community concerns as evidenced by the overwhelming public response to recent media articles that have focused on this issue.

The late Dr Rodney Syme stated that dementia satisfies Victoria’s VAD legislative eligibility criteria that a condition be progressive, incurable, and terminal. It does not, however, meet the prognostic timeframe until death requirement, or the requirement that an individual retain decision-making capacity throughout the entire voluntary assisted dying process.

Institutional Objection

The issue of institutional conscientious objection was not addressed in the Victorian Act, nor the Western Australian legislation. Victoria sought to adopt a policy approach to manage institutional participation in VAD, an approach that has patently failed to ensure consistent, person-centred care across the system. DWDV is aware of incidents in which facilities such as hospitals and residential aged care have denied individuals access to VAD information, consultations with VAD doctors and, in one case, refusal of entry to the pharmacists delivering the VAD medication. DWDV has heard from people impacted by these actions who have, as a result of institutional objection, personally experienced or witnessed the additional suffering of a loved one.

DWDV attempted to contact all Victorian residential aged care facilities to ascertain their VAD policies. Very few responded and, as a result, many elderly people enter facilities unsure if they will be able to access VAD if required. DWDV would like to see the Victorian VAD Act amended to regulate institutional objection, including requiring facilities providing health or residential aged care services to provide a public VAD policy statement. We note that the ACT VAD Bill will allow all care facilities to decide their level of involvement and document this in a published policy. Facilities must comply with minimal standards and not deny access to VAD information, and provide patients with access to VAD health professionals either on the premises or facilitate a patient's safe transfer to another location. A legislative approach is the optimal regulatory response to institutional objection to VAD.

Conclusion

In conclusion, we commend the ACT VAD Bill for taking major steps in addressing the following issues:

- Eliminating the time until death prognosis
- Broadening the definition of suffering
- Ensuring equitable access to VAD
- Dementia and VAD ineligibility
- Addressing the shortage of VAD providers with the inclusion of Nurse Practitioners
- Addressing the issue of institutional objection.

The Federal issues which have proved problematic to VAD in Victoria are:
- The Commonwealth *Criminal Code Amendment (Suicide Related Material Offences) Act 2005* that prevents Australians from accessing VAD via telehealth
- The lack of appropriate remuneration for VAD providers due to the specific exclusion of benefits for VAD on the Medicare Benefits Schedule.

REFERENCES:

Australian Institute of Health and Welfare. *"Dementia in Australia, Deaths Due to Dementia"* February 23, 2023, https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/population-health-impacts-of-dementia/deaths-due-to-dementia

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