The right to die with dignity

THE CURRENT VOLUNTARY ASSISTED DYING LAWS CONTINUE TO GENERATE DEBATE AND FURTHER REFORM IS REQUIRED. BY VICTOR TSE

SNAPSHOT

- This article explains the law and practice of euthanasia in Australia and how it relates to palliative care, advance care planning and enduring powers of attorney.
- While enormous progress has been made legislating euthanasia in Australia, many shortcomings of the current laws have been identified.
- Future debate and further law reform is expected and legal practitioners should actively monitor developments and engage in the ongoing conversation.

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Voluntary assisted dying (VAD)[1] is a way for someone who is suffering from a terminal illness to legally access a substance to end their life with the support and assistance of registered health practitioners. The person can choose the time and place. It is a compassionate way for a person to die with dignity without unbearable pain and suffering for them and their loved ones.

VAD is legal in Australia

Today all six states of Australia have passed VAD laws. New South Wales (NSW) is the most recent state to legislate the law which came into effect on 28 November 2023. In 2017 Victoria was the first state to enact VAD law,[2] followed by Tasmania,[3] Western Australia,[4] South Australia[5] and Queensland[6] in 2021, and NSW[7] in 2022. Interestingly, the Northern Territory (NT) was the first jurisdiction in the world to legalise voluntary dying. *The Right of the Terminally Ill Act 1995* was passed in the Legislative Assembly on 25 May 1995 and commenced operation on 1 July 1996. In March 1997 the federal government invalidated the law and deprived the NT of the power to legislate on assisted dying in the future. However, in December 2022 the federal government passed the *Restoring Territory Rights Act 2022* removing the restrictions. The NT government has now started a community consultation process for developing a framework for VAD. And the ACT government has introduced the Voluntary Assisted Dying Bill 2023 to Parliament. It is important to note that this bill differs from other states' legislation in that it does not require a specification of time until death and nurse practitioners are able to assess patients for eligibility.

VAD debate

Opponents of VAD argue that VAD is against the sanctity of life which holds that human life is inherently valuable and intentionally ending a life goes against ethical, cultural and religious beliefs. Life should be protected and preserved at all costs regardless of circumstances. They argue that vulnerable individuals could be coerced, or they may feel they are a burden to their family or society. There is also a slippery slope argument that VAD law, once enacted, could potentially be broadened to encompass more people at lower thresholds.

Traditionally, medical professionals believed their duty was to preserve and promote life and facilitating assisted dying contradicted this principle.[8] They believed priority should be on palliative care, pain management and improving the quality of life for patients rather than actively participating in ending lives. Now, more and more medical professionals are open to VAD. The Australian Medical Association (AMA) in a 2016 Position Statement on Euthanasia and Physician Assisted Suicide[9] acknowledged that laws in relation to euthanasia and physician assisted suicide are ultimately a matter for society and government. However, it stated that any change must never compromise the provision and resourcing of end of life care and palliative care services and doctors are advised to always act within the law to help their patients achieve a dignified and comfortable death.

Proponents of VAD argue that VAD is about self-autonomy, human rights[10] and personal dignity which should all be respected. It is a compassionate response to unbearable pain allowing individuals to avoid prolonged suffering and die peacefully and on their own terms.

Further, legalisation and regulation of VAD can establish strict safeguards to prevent abuse and protect vulnerable individuals. In the end, VAD offers a choice.

Today, many societies are beginning to take an open-minded approach which seeks to balance the two competing views. Legalising VAD is becoming increasingly common in jurisdictions around the world including New Zealand, Switzerland, Austria, Germany, the Netherlands, Belgium, Luxembourg, Spain, Portugal, Colombia, Canada, and 10 states and Washington DC in the United States where it has been sanctioned in various forms, in some cases for many years.[11]

Victorian legislation

The *Voluntary Assisted Dying Act 2017* (Vic) sets out the principles and prescribes in detail the eligibility, process and safeguards of VAD.

Principles include:

- every human life has equal value
- respect to personal autonomy, culture, beliefs, values and preferences
- informed decision about treatment and care options
- minimise suffering and maximise quality of life
- protect from abuse.[12]

Eligibility criteria

- the person must be at least 18 years old, an Australian citizen or permanent resident, and have been living in Victoria for at least 12 months
- the person must have a disease or medical condition that is incurable, advanced and be expected to die within six months (12 months for neurodegenerative disease)
- the illness is causing pain and suffering that cannot be relieved in a way considered tolerable
- the person must have decision making-capacity[13] in relation to VAD
- the person must understand information relevant to the decision to access VAD, and the effect of the decision
- the person must retain that information to the extent necessary to make the decision
- the person must use or weigh the information as part of the decision-making process
- the person must communicate the decision and the person's views and needs about the decision in some way
- The person must be acting voluntarily, without pressure or duress
- the request for access to VAD must be enduring.[14]

Process

- the person must make three separate requests to specially trained medical practitioners including one in writing
- two independent medical practitioners, one coordinating and one consulting, must assess the patient's eligibility and voluntariness of the request
- a coordinating medical practitioner must oversee the process
- the VAD medication is usually self-administered by the patient or can be administered by the coordinating medical practitioner if the patient is physically unable to do so.

Safeguards

There are 68 safeguards in place including:

- the person must make the request themselves and cannot be coerced; no carer or family members can make the request
- the person must be provided with information about their diagnosis and prognosis, available treatment and palliative care options
- the person can change their mind at any time
- medical practitioners must undergo specific accredited training to participate in the VAD process
- VAD medication cannot be administered without a permit[15] authorising self-administration or practitioner administration
- there are strict penalties for breaches of the law including life imprisonment for practitioners intending to cause death and knowingly administering the substance other than in accordance with the permit[16]
- the Act requires reporting and oversight to ensure transparency and accountability
- the VAD Review Board (Board) reviews all cases to ensure compliance. The Board is responsible for monitoring, reporting, research and review of eligible decisions. The Board publishes an annual report with aggregated data on the number and nature of VAD cases. As required, the Minister for Health has caused a review of the operation of the Act to be commenced. It will review the first four years of operation[17]
- when a person is assessed ineligible for VAD because they do not meet the residency requirement or lack decision-making capacity, an application can be made to the Victorian Civil and Administrative Tribunal for a review of the decision.[18]

Being the first state to legislate VAD, Victoria in effect set a precedent for the other states. All the Acts are very similar in their eligibility and process but differ slightly in several areas.[19] For example, in Victoria and South Australia, medical practitioners are prohibited from initiating discussion about VAD with patients. They can only do so at the request of the patients to ensure their requests are voluntary. In the other states, practitioners are allowed to do so but they must inform the patients about treatment and palliative care options at the same time.

Medical practitioners who have a conscientious objection to VAD have the right to choose not to participate in VAD. However, under the laws in Tasmania, Queensland and Western Australia, medical practitioners have an obligation to provide contact details of the VAD Commission or some approved VAD information to patients who make the request. The Acts of Victoria and NSW stipulate no such obligation.

Palliative care and VAD

Palliative care and VAD are two separate concepts that both relate to end of life care. Palliative care is a holistic approach to care focused on improving the quality of life for individuals facing serious illness, particularly those near the end of their lives. It aims to manage pain and other distressing symptoms by providing emotional and psychological support, addressing spiritual and existential concerns, and offering support to the patient's family. Palliative care does not aim to hasten death but rather to provide comfort and enhance the overall wellbeing of patients during this stage of life. It is important to note that even the best palliative care cannot alleviate the pain, suffering and loss of dignity in all cases.

While palliative care and VAD are distinct concepts, they both aim to support individuals at the end of life in different ways. Palliative care focuses on providing comprehensive support, comfort and symptom management while VAD allows for the option of medical intervention to end suffering for those who meet specific legal criteria and choose to pursue this option. In the first four years of operation of VAD in Victoria, more than 80 per cent of the patients accessing VAD had or were already receiving palliative care.[20]

Advance care planning

Advance care planning[21] is a process that involves individuals thinking about, discussing and documenting their preferences for medical treatment and care when they become unable to make their own decisions. Palliative care and advance care planning are closely related and often intersect in end of life care. Advance care planning helps healthcare providers deliver care that is aligned with patients' goals and values, promoting a more patient-centred and empowering approach to end of life decision-making.

In Victoria the *Medical Treatment Planning and Decisions Act 2016* supports advance care planning in two ways. First, a person can document their values and preferences for future medical treatment or give specific instructions about future treatment the person consents to or refuses, in a legal document called an Advance Care Directive which the person's doctors are required to follow regarding their medical treatment and care when the person no longer has decision-making capability. When making these health care decisions, it is important that the person discusses them with their doctors to inform themselves of their appropriateness.

In addition, or as an alternative to an Advance Care Directive, the person can appoint one or more Medical Treatment Decision Makers who understand the preferences or values of the person and will be able to make decisions on behalf of the person in the circumstances.

It is important to emphasise that VAD cannot be a part of advance care planning. A person cannot make a VAD decision in an Advance Care Directive.

Enduring powers of attorney

In the same way that Medical Treatment Decision Makers are appointed to make medical treatment decisions on behalf of a person when they have lost their decision-making capacity, under the *Powers of Attorney Act 2014* a person can make an enduring power of attorney which allows the attorney to make either financial and/or personal decisions for the person. Financial decisions are those in relation to financial or property affairs. Personal decisions are about personal or lifestyle affairs including where and with whom the person lives, but they do not include any matter that relates to medical treatment or medical research procedures.

Impediments to VAD access and future reform

In the first four years of operation of VAD in Victoria, there were more than 2203 applications started to access the process for which 1527 permits were issued.[22] Many applicants did not complete the application process. One reason was the lengthy application period during which applicants died before permits were issued. Another reason was the deterioration of the medical conditions of the patients resulting in loss of decision-making capacity to continue the assessment process.

The *Medical Journal of Australia* published the findings of an investigation into the barriers to and facilitators of access of VAD in Victoria.[23] It indicated that people generally felt supported while navigating the application process once they found a coordinating practitioner or a navigator. However, there are still significant impediments to access. VAD supporters are advocating for changes in the existing law including the relaxation of VAD eligibility criteria.

Commonwealth Criminal Code

Commonwealth law prohibits the use of a carriage service such as telephone or telehealth for suicide related material which may include VAD. This impacts significantly on regional and rural patients. In order to access VAD, they may have to travel long distances for an in-person consultation with a medical practitioner. Recently a Federal Court application[24] was made by a Victorian GP for a judicial interpretation of suicide and whether it includes VAD. The Court concluded that taking VAD medication comes under the definition of suicide, therefore, telehealth continues to be illegal for terminally ill people seeking VAD.

Medicare benefit

At present, Medicare does not compensate medical practitioners spending clinical time to complete the often complex and time-consuming VAD assessments. Consequently, this puts a significant financial burden on VAD patients. Additionally, this lack of compensation may result in fewer practitioners available as it could be challenging for them to fully pass on their costs to the patient.

Eligibility criteria

In 2021 dementia was found to be the number one leading cause of death for females and the number two cause for males.[25] Persons with dementia are unlikely to be eligible for VAD, either because they are not expected to die within six months or because their dementia has advanced to the point that they lack decision making capacity.

Future

As more people access VAD in Australia, VAD laws will receive increasing public attention and generate further debate. The Victorian government has established a free VAD Care Navigator Service to provide information and support for the community, health practitioners and health services across Victoria. Contact vadcarenavigator@petermac.org or call (03) 8559 5823 or 0436 848 344. ■

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1. Defined in *Voluntary Assisted Dying Act 2017* (Vic) as the administration of a voluntary assisted dying substance and includes steps reasonably related to such administration
2. *Voluntary Assisted Dying Act 2017* (Vic) effective June 2019
3. *End-of-life Choices (Voluntary Assisted Dying) Act* 2021 (Tas) effective March 2021 when it passed the Upper House, commenced 23 October 2022
4. *Voluntary Assisted Dying Act 2021* (WA) effective July 2021
5. *Voluntary Assisted Dying Act 2021* (SA) effective January 2022
6. *Voluntary Assisted Dying Act 2021* (Qld) effective January 2023
7. *Voluntary Assisted Dying Act 2022* (NSW) effective November 2023
8. Hippocratic oath – "First, do no harm"
9. https://www.ama.com.au/position-statement/euthanasia-and-physician-assisted-suicide-2016
10. Australian Human Right Commission, *Euthanasia, human rights and the law, issues paper May 2016* https://humanrights.gov.au/our-work/age-discrimination/publications/euthanasia-human-rights-and-law
11. World Federation Right to Die Societies https://wfrtds.org/worldmap/
12. Note 2 above, for full list see s5 of the Act
13. A person is presumed to have decision-making capacity unless there is evidence to the contrary – *Voluntary Assisted Dying Act* 2017 (Vic), s4(2)
14. *Voluntary Assisted Dying Act* 2017 (Vic), s9
15. Part 4 *Voluntary Assisted Dying Act* 2017 (Vic)
16. Note 2 above, s83
17. Note 2 above, s116
18. Note 2 above, Part 6
19. Queensland University of Technology, End of Life Law in Australia, https://end-of-life.qut.edu.au//assisteddying
20. 2023 Annual report VAD Review Board (Vic)
21. Advance Care Planning Australia https://www.advancecareplanning.org.au/
22. VAD Review Board, Report 2022-2023
23. Australian Centre for Health Law Research, Queensland University of Technology
24. *Carr v Attorney-General (Cth)* [2023] FCA 1500
25. Australian Institute of Health and Welfare