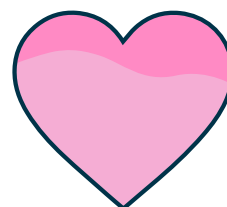


Dementia and access to Voluntary Assisted Dying



Summary



Australian states have been progressively introducing Voluntary Assisted Dying legislation (VAD), allowing terminally ill adults to request and receive medication to end their lives



Eligibility criteria in all existing legislation explicitly or implicitly excludes people living with dementia from accessing VAD due to the variability of the disease trajectory and impact on cognitive function and decision-making capacity or ability



Dementia Australia supports the right of every person, including those living with dementia, to exercise choice over end-of-life care options, which may include VAD measures

Background

Voluntary assisted dying (VAD) legislation has been passed in every State in Australia. The Australian Capital Territory's Voluntary Assisted Dying Bill 2023 is undergoing a parliamentary committee inquiry before becoming law. The Northern Territory Government has commenced a community consultation process for developing a VAD framework.

VAD laws allow terminally ill adults to request and receive medication to end their lives. The laws have specific eligibility criteria, including being over a certain age and having a terminal illness that is causing suffering and/or is expected to cause death within six to 12 months, depending on the stage and condition. Other criteria specifies that the individual must have decision-making capacity throughout the entire process and that VAD cannot be included in an Advance Care Plan or in substitute decision-making powers.

The 2008 UN Convention on the Rights of Persons with Disabilities (UNCRPD) acknowledges that people with disabilities, including those living with cognitive impairment and dementia, can have legal capacity.¹ In accordance with this position, the degree of capacity or decision-making ability depends on the individual circumstances of the person with the disability. Given the variability of the dementia trajectory, multiple assessments of decision-making ability might be required over the course of the disease. Dementia Australia supports the principles underpinning the UN-CRPD, noting that many people believe it is an appropriate and respectful framework for considering the rights of people living with dementia in relation to VAD. Dementia Australia emphasises that any decision must always be made in a way that is ethically rigorous and safeguards the interests of the individual.



I support assisted death for terminally ill people who have expressed that wish at an earlier point in their illness when they are able to do so. I don't want to creep endlessly into the night over weeks, or months or even years. ”

Person living with dementia.

Issue

It is often assumed that people with dementia, and associated cognitive decline, lack the ability to make decisions. A person with dementia will experience cognitive decline but this depends on the type of dementia they develop as well as a range of other variables which will be different for every individual. Some people living with dementia will maintain a degree of cognitive ability for a significant time post-diagnosis while others will experience a more rapid deterioration.² Given dementia is a progressive condition, there is support among people impacted by the disease for the view that individuals with dementia should be able to make the decision to access VAD while they still have the ability to do so.



My wife is seven years into her journey (with dementia) but still has the ability to make decisions and she has always stated that she wants to end it all when the quality of life has gone. ”

Partner of someone living with dementia.

Equally, people living with dementia, their families and carers have also expressed concern about the potential for people with dementia who do not have the ability to make an informed decision about VAD to be vulnerable to influence or manipulation.



Long term planning needs to be offered to people with dementia and families as early as possible to ensure no coercion is possible. ”

Carer of a person living with dementia.

The issue of the potentially negative effect of the association between dementia and VAD has also been raised by stakeholders in the community. They argue that if people with the condition were able to access VAD, this might reinforce stereotypical attitudes and beliefs about the futility of life after diagnosis with dementia and contribute to ongoing stigma and discrimination against people living with the condition.

Dementia Australia notes that people with mental illness and/or disabilities, including dementia, have been excluded from the various forms of State-based VAD legislation. We also note that most legislation stipulates that only people whose terminal disease will cause death within six months, or 12 months for neurodegenerative conditions, qualify. The limited time frame stipulated in these legislative conditions would potentially exclude many people with neurodegenerative conditions, including dementia, from qualifying for VAD. The eligibility criteria in relation to ability would also effectively prevent people living with dementia from accessing the existing VAD legislation.



Prohibiting the request from being made in an advance care directive and requiring that a medical practitioner must deem that a person is at the end of life when the request is made, would exclude persons with dementia accessing voluntary assisted dying. Those persons who would fall outside the proposed legislative framework will be left to die an excruciatingly painful death. ”

Daughter of a person with dementia

Dementia Australia's position



Dementia is a serious, progressive and life-limiting condition and VAD is a complex and challenging issue. As with the broader Australian community, people living with dementia, their family members and carers, have a range of views in relation to this issue and the associated legislation.



As the peak advocacy body for people impacted by dementia, Dementia Australia reflects this diversity of opinion in neither supporting nor rejecting the concept of voluntary assisted dying. What we advocate for is choice and a greater engagement with people impacted by dementia to understand how to best empower them to make decisions about their life and death.

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1. United Nations, Department of Economic and Social Affairs Disability. 'Convention on the Rights of Persons with Disabilities (CRPD)'; <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>
 2. J.N.Viaña, F. McInerney & H. Brodaty. 'Beyond Cognition: Psychological and Social Transformations in People Living with Dementia and Relevance for Decision-Making Capacity and Opportunity', *The American Journal of Bioethics*, 20:8, 101-104, (2020). DOI: 10.1080/15265161.2020.1781960