

Dementia: Eligibility for Voluntary Assisted Dying in Australia and New Zealand

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Dementia: Eligibility for Voluntary Assisted Dying

Voluntary assisted dying is an end of life choice in every Australian state and New Zealand for people who meet the eligibility criteria. At public forums, in general correspondence and in conversation, the question most frequently asked, is 'can I use voluntary assisted dying if I get dementia'. The answer is usually, no. The eligibility criteria include a requirement for decision-making capacity at every stage of the request and assessment process, as well as a prognosis of less than six or 12 months (for a neurodegenerative disease in Australia). By the time a person with dementia has a prognosis of 12 months, they are usually assessed as no longer having decision-making capacity in relation to their request for voluntary assisted dying. This paper examines options to enable a person with dementia to access voluntary assisted dying.

1. Overview of Voluntary Assisted Dying in Australia

All six states in Australia now provide voluntary assisted dying (VAD) as an end of life choice for people who meet the eligibility criteria. VAD will commence in the ACT in November 2025; the NT is currently holding an inquiry. Victoria was the first state to allow voluntary assisted dying, commencing in June 2019, followed by WA (July 2021), Tasmania (October 2022), Queensland and South Australia (January 2023) and New South Wales in November 2023.

Each state has a VAD Review Board (or similar) which monitors implementation and operation of voluntary assisted dying in their state and compliance with the legislation. Regular reports are provided by each Board and posted on a public website. In the four year period between July 2019 and June 2023, 2807 people in Australia were assessed as eligible to use voluntary assisted dying, and 1673 people used the VAD substance to die, either through self administration or practitioner administration. During those four years, a further 634 people were assessed as eligible but died from their illness without using the VAD substance.¹

There are some differences in the legislation between Australian states, however the eligibility criteria defined in each state VAD Act are similar (see Table 1). Each person must be assessed by two independent doctors as meeting the criteria for voluntary assisted dying before they can make a witnessed written request, and then a final request, before the coordinating medical practitioner is able to write a prescription for the VAD substance. Assessing doctors must be VAD trained, and complete a considerable amount of paperwork.

In some states a VAD Permit (or similar) must be issued by the regulating agency prior to provision of the VAD substance. The proportion of people who self administer the VAD substance compared with using practitioner administration varies between jurisdictions. The average time from a person making a first request for VAD, to the administration of the VAD substance, is about 30 days and approximately 70% of people requesting VAD have cancer.

Assessing doctors must certify that the person was making the request voluntarily, that the request was enduring and there was no pressure to request VAD from a third party, that they had decision-making capacity in relation to VAD and understood the effect of the VAD substance, and that they had considered all possible treatment and palliative care options.

To be assessed as eligible for VAD, a person must meet four criteria (see Table 1):

¹ Note that these numbers cover 4 years of data for Victoria, 2 years for WA, 8 months for Tasmania, 6 months for Queensland, 5 months for SA and no data for NSW; differences in numbers of people assessed as eligible, those who used the VAD substance, and those who died without using the VAD substance relate to timing of each step and end of year reporting.

- Diagnosed with a disease, illness or medical condition which is incurable²
- The disease, illness or medical condition must be advanced, progressive and will cause the person's death
- The person's death is expected within six or 12 months (see below)
- The person's suffering cannot be relieved in a manner acceptable to the person.

In every state, there is a requirement to have a prognosis of no more than a defined time to live. In all states except Queensland, six months is the criterion for most illnesses or medical conditions, including cancer; while 12 months is the criterion for a neurodegenerative condition such as Motor Neurone Disease; in Queensland, all conditions require a 12-month prognosis. In the ACT there will be no requirement for a time limited prognosis: the ACT VAD Act requires that the medical condition be 'advanced, progressive and will cause death', with the explanatory memorandum stating that 'advanced' means

*a period of serious illness when functioning and quality of life decline, and treatments (other than for the primary purpose of pain relief) have lost any beneficial impact. It is not the intent that the definition of 'advanced' be limited to the final days, weeks or months of life. A person may be considered to be eligible for VAD, even if it is uncertain whether their relevant conditions will cause death within the next 12 months.*³

Table 1 Eligibility for voluntary assisted dying, Australia

VAD medical eligibility criteria	Vic	WA	Tas	SA	Qld	NSW	ACT
Diagnosed with a disease, illness or medical condition that is advanced, progressive and will cause death	✓	✓	<ul style="list-style-type: none"> • Plus injury • Advanced and irreversible 	✓	✓	✓	✓
Illness is incurable	✓	Silent	✓	✓	Silent	Silent	Silent
Causing suffering which cannot be relieved in a manner tolerable to the person	✓	✓	✓	✓	✓	✓	✓
Death is expected within six months or 12 months for a neurodegenerative condition	✓	✓	<ul style="list-style-type: none"> • Prognosis exemption through VAD Commission 	✓	12 months for all	✓	Silent
Must have decision making capacity in relation to VAD at every stage	✓	✓	✓	✓	✓	✓	✓
Decision-making capacity required and presumed unless proven otherwise	✓	✓	✓	✓	✓	✓	✓
Person is acting voluntarily and without coercion	✓	✓	✓	✓	✓	✓	✓
Mental illness not a criterion	✓	✓	✓	✓	✓	<ul style="list-style-type: none"> • Exclusion for dementia (S16(2)(b)) 	✓
Disability not a criterion	✓	✓	✓	✓	✓	✓	✓

² Three states include 'incurable' in the criteria

³ Voluntary Assisted Dying Bill 2023, Supplementary Explanatory Statement, June 3, 2024, https://www.legislation.act.gov.au/b/db_68609/

In addition to the medical criteria, each state lists residency and citizenship requirements, some of which are more flexible, such as for near border residents, or may be appealable, for example to the VAD Review Board or an administrative appeals tribunal.

2. Assisted Dying in New Zealand

New Zealand had a different pathway to Australia in legalising assisted dying. One major difference is that the End of Life Choice (EOLC) Act is national legislation. To achieve debate on assisted dying, the EOLC Bill had to first pass the hurdle of being one of the Bills drawn from the members' bills ballot, which occurred on June 8, 2017. The EOLC Act was passed on November 13, 2019, but subject to a binding referendum at the October 2020 general election. With 65% support from the referendum, assisted dying became law in New Zealand on November 7, 2021.

Of note is that the original EOLC Bill tabled by David Seymour, MP, did not include a six month prognosis but the criterion of 'a grievous and irremediable medical condition'. In evidence to the *Parliament of Ireland Joint Committee on Assisted Dying* in November 2023, (now) Minister Seymour said that 'during the legislative process I compromised and introduced the six month restriction, but that was a political compromise'⁴. Other features of the EOLC Act are

- Doctor cannot initiate discussion of assisted dying (same as Victoria and SA)
- A practitioner is always present when the VAD substance is consumed; it means the person can change from self to practitioner administration at the last minute
- Criteria of 'advanced state of irreversible decline in physical capability' and 'unbearable suffering that cannot be relieved in a manner that the person considers tolerable' (S5)
- The NZ Health Department selects the second independent assessing doctor.

3. Dementia and Assisted Dying

The focus for this paper is the difficulty for people with dementia (or other conditions causing a loss of capacity) to access VAD⁵.

Dementia is the leading cause of death for women in Australia, the second leading cause of death overall, accounting for 10% of all deaths in Australia.⁶ In 2021, there were a total of 15,800 deaths due to dementia in Australia, with more women than men dying due to the condition (around 10,100 and 5,700 deaths, respectively). With an ageing and growing population, it is predicted that the number of Australians with dementia will more than double by 2058 to 849,300 people (533,800 women and 315,500 men).

The most frequently asked question of all organisations advocating for VAD, is the question of access for a person with dementia.

There are three key aspects of state VAD legislation which make it difficult for a person with dementia to access VAD:

- Requirement for a prognosis of less than 12 months for a neurodegenerative disease
- Requirement for decision-making capacity in relation to VAD (capacity) at every stage of the request and assessment process, including when the VAD substance is delivered or administered
- Inability to nominate VAD in an Advance Care Directive (or similar).

⁴ <https://www.oireachtas.ie/en/oireachtas-tv/video-archive/committees/8698/> at 51 minutes

⁵ The VAD Act in NSW specifically prohibits dementia being a criterion for VAD (S16(2)(b)); no other state legislation precludes a person with dementia from requesting VAD

⁶ <https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/summary>

In Canada, a person living with dementia has always been eligible for their VAD equivalent, Medical Assistance in Dying (MAiD). Canada does not include a prognosis, but the criterion of ‘death is reasonably foreseeable’. Subsequent court cases and clinician developed protocols have clarified the meaning of ‘reasonable’ in relation to MAiD. Despite this, the number of people with dementia using MAiD remains low⁷. In 2022, neurological conditions were reported as a main underlying condition by 12.6% of individuals receiving MAiD in Canada, with 9% of those neurological conditions reported as dementia. Given that in 2022 there were 13,241 MAiD deaths in Canada, it appears that in the sixth year of operation of MAiD in Canada, 150 people with dementia were able to use MAiD in that year.⁸

Bill C7 in 2021 amended the Canadian law and introduced a ‘waiver of final consent’ (the waiver). The waiver allows a person who has been assessed as eligible for MAiD, who fears they may lose capacity, to waive the final consent by setting a date for the MAiD procedure with their MAiD provider. The waiver means that if a person loses capacity after they have been assessed as eligible for MAiD, MAiD can proceed on that agreed date. Alternatively, if the person retains capacity, they can choose to proceed with MAiD or set another date. Advocacy for the waiver was based on the experience of a woman with cancer who chose to use MAiD earlier than she wished to ensure she would still meet the capacity test.

The waiver provides the person with the confidence that if they lose capacity, MAiD will proceed. Anecdotal evidence suggests that the waiver provides relief for the person and their family: the person can take their pain relief medication in the knowledge that MAiD can still proceed even if this causes a loss of capacity; and patients use their remaining time in a more comfortable environment.

DWD Canada is the national NGO advocating for and supporting MAiD in Canada. It has undertaken extensive consultation and education on MAiD and dementia and provides a number of informative webinars on their website⁹. In these webinars, members of the DWD Canada Clinicians Advisory Council and MAiD providers explain their experience assessing a person with dementia.

Clinicians report that the relationship with a person with dementia who requests MAiD usually builds over several years. During that time the clinician can observe the passage of the disease and note changes in capacity. Clinicians report on the challenge of identifying when suffering is at its greatest, the difficulty in establishing the level of suffering of a person who has lost capacity, and the ethical challenge of proceeding with MAiD if the person is no longer requesting a medically assisted death. These accounts strongly suggest that the waiver of final consent rarely results in a person with dementia accessing MAiD after a loss of capacity. A 2022 study of MAiD providers reveals variations, reluctance and concerns in managing the waiver.¹⁰

Anecdotal evidence and academic research indicate that doctors (and nurse practitioners in Canada) are reluctant to administer VAD or MAiD if the person no longer has capacity. In order to proceed with MAiD, the doctor or nurse practitioner must certify at the time of the procedure that the person is suffering intolerably or unbearably. There is ongoing debate about the difficulty in assessing the suffering being experienced by a person with late stage dementia.

⁷ The figures are drawn from the Fourth Annual Report on Medical Assistance in Dying in Canada 2022 (calendar year) <https://www.canada.ca/en/health-canada/services/publications/health-system-services/annual-report-medical-assistance-dying-2022.html>

⁸ A pro rata equivalent in Australia, given the different populations, would be 100 per year.

⁹ <https://www.dyingwithdignity.ca/about-us/>; type MAiD and dementia in the search button

¹⁰ Health care providers’ ethical perspectives on waiver of final consent for Medical Assistance in Dying (MAiD): a qualitative study, Caroline Variath, Elizabeth Peter, Lisa Cranley and Dianne Godkin, BMC Medical Ethics, 2022, 23:8, <https://doi.org/10.1186/s12910-022-00745-4>

In June 2023, Quebec Province in Canada passed legislation to allow MAiD to be nominated in an advance request. The law has not yet commenced and will be the subject of further discussion. It appears that the discussion will take a number of years and require the federal government to agree to amend the national Criminal Code.

In the Netherlands and Belgium, since commencement in 2002, VAD has always been available for a person with dementia. After two decades, recent data shows that dementia is reported as the underlying condition for approximately 2% of assisted deaths.¹¹ In the Netherlands, for example, 2.5% of VAD deaths are by a person with dementia; and perhaps two or three VAD deaths a year are by a person who has lost capacity. In 2020, 170 people in the Netherlands with dementia used VAD (1.2% of dementia deaths)¹². The Netherlands, Belgium, Luxembourg and Colombia also allow a request for VAD to be nominated in an Advance Care Directive.

4. Legislative barriers to access VAD

VAD laws in Australia and New Zealand are among the safest and most strict in the world, with over 70 safeguards. Consultation with members of the public consistently highlight concern at the legislative barriers to accessing VAD for a broad range of people, including people with dementia. The barriers highlighted are:

- **The prognosis:** in some states many people report that their doctor will not provide a prognosis, so they believe they are not eligible for VAD; others report that the advice on the time left to live was vastly different from the experience of their loved one
- **Decision-making capacity:** the requirement for decision-making capacity (in relation to VAD) at every stage means that people will either endure unnecessary suffering - because a person with cancer, for example, may forego pain medication to ensure they retain capacity - or choose to take the VAD substance earlier for fear of losing capacity
- **Advance Care Directives:** many people wrongly believe they can nominate VAD in their ACD to allow their substitute decision-maker to choose VAD when their ACD comes into effect.

For a person with a neurodegenerative disease such as dementia, the difficulty of achieving a 12 month prognosis is compounded by the requirement for capacity at every stage.

4.1 The Prognosis

The six month prognosis was part of the first Voluntary Assisted Dying Act to pass in Australia, the Voluntary Assisted Dying Act (2017) in Victoria. The inclusion of the six month prognosis followed the model used in the USA state of Oregon, the first state to legalise a medically assisted death. Assisted dying became legal in Oregon as a result of a 1994 citizen referendum and Death With Dignity (DWD) commenced in Oregon in October 1997. The nomination of a six month prognosis was based on a regulation whereby people became eligible for hospice care once they had a prognosis of six months or less. The six month prognosis for hospice care was a policy response to managing the health budget.

The VAD Act in Victoria has many similarities to the Oregon law. All other state VAD laws developed from the original Victorian VAD Act. The (now) 26 years of annual reports from the Oregon Department of Health, showing compliance with their legislation and no evidence of abuse of the

¹¹ Jaap Schuurmans & Boudewijn Chabot, Springer Nature, November 2021, Euthanasia in advanced dementia

¹² Marijnissen, Radboud M; Chambaere, Kenneth; Oude Voshaar, Richard C, Euthanasia in Dementia, Frontiers in Psychiatry, 2022, p7, file:///Users/annejbunning/Library/Mobile%20Documents/com~apple~CloudDocs/Documents/1VAD/national/Dementia/Netherlands%20and%20Belgium_Dementia_2022_MarijnissenRM_FrontPsychiatry.pdf

law, provided Members of Parliament in Australia with confidence that it was possible to legislate a safe and compassionate end of life choice for people who were dying. Part of that assurance was provided by a prognosis of less than six months to live if the disease followed its natural course. The Victorian Parliament accepted an additional criterion of a 12 month prognosis for a person with a neurodegenerative disease. All states except Queensland have subsequently adopted the six and 12 month prognosis as one of their criteria, with Queensland using 12 months for all medical conditions. New Zealand has six months for all conditions.

In Canada, where Medical Assistance in Dying (MAiD) commenced in June 2016 as the result of a Supreme Court decision, the federal legislation does not include a prognosis of time to death, and since March 2021, the death is not required to be 'reasonably foreseeable'.¹³ The Canadian Department of Justice defines the eligibility criteria for MAiD in the following terms:

As of March 17, 2021, persons who wish to receive MAiD must meet the following eligibility criteria:

- be 18 years of age or older and have decision-making capacity
- be eligible for publicly funded health care services
- make a voluntary request that is not the result of external pressure
- give informed consent to receive MAiD, meaning that the person has consented to receiving MAiD after they have received all information needed to make this decision
- have a serious and incurable illness, disease or disability (excluding a mental illness for the time being)
- be in an advanced state of irreversible decline in capability
- have enduring and intolerable physical or psychological suffering that cannot be alleviated under conditions the person considers acceptable.

Annual reports on the operation of MAiD show no evidence of abuse.

Since the first assisted dying requests in Victoria in 2019, achieving a six or 12 month prognosis has emerged in every state and New Zealand as a barrier to a person requesting a medically assisted death. In some states evidence has emerged that many people do not inquire about VAD because their doctor did not provide a prognosis. Others ask their doctor about a prognosis and receive a vague or non-committal response, and assume they are not eligible. Doctors confirm that prognosis is a difficult area, generally subjective, generally overly optimistic and unreliable, with many doctors reluctant to provide advice on a prognosis. The unreliability of the prognosis is reflected in a recent UK study where, across all disease groups, the accuracy of survival estimates was found to be high for patients who were likely to live for fewer than 14 days (74% accuracy) or for more than one year (83% accuracy), but poor when predicting survival of "weeks" or "months" (32% accuracy).¹⁴

The doubt about prognosis was clearly expressed by the WA Joint Select Committee in its 2018 report entitled *My Life, My Choice*. In her Foreword, the Chair stated:

"In the course of the inquiry, the Committee found that a predicted timeframe until death as an eligibility criteria (sic) can result in some individuals being unfairly excluded, and may not be

¹³ <https://www.justice.gc.ca/eng/cj-jp/ad-am/bk-di.html>; different rules apply for people whose death is reasonably foreseeable compared with those whose death is not reasonably foreseeable, such as a person with unrelievable suffering from a neurological condition

¹⁴ Accuracy of clinical predictions of prognosis at the end of life: evidence from routinely collected data in urgent care records, Orlovic et al, BMC Palliative Care 22, Article number: 51 (2023) <https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-023-01155-y#:~:text=Overall%2C%20clinicians%20%20overestimated%20prognosis,%20in%2015%25%20of%20cases.>

clinically justified. People with progressive chronic or neurodegenerative disease may experience intractable suffering for months or years before they die. The committee has chosen not to ignore the suffering of these individuals.”¹⁵

The Select Committee did not recommend the inclusion of a time limited prognosis, favouring the ‘death is reasonably foreseeable’ criterion. The WA Parliament followed the Victorian model and included the six and 12 month prognosis.

The WA Health Department VAD Guidelines state

During the final 12 months of their life, a person with a life-limiting disease, illness or medical condition may experience rapid and severe changes and fluctuations in their condition. Predicting when the person is entering the final months of their life can be difficult. Most prognostication tools have been developed to assist in identifying a patient’s needs and to plan care and support, not for determining a predictable timescale for death. It is important that in making any such determination, the Coordinating Practitioner and Consulting Practitioner act within their scope of expertise and experience and consider seeking a further opinion where appropriate.¹⁶

The 2022-23 Annual Report of the Victorian VAD Review Board also raises doubt about the reliability of the prognosis as a safeguard, stating ‘it is recognised that prognostication is not an exact science’ (p29).

The effect of the prognosis criterion is that many people who would otherwise request VAD are denied access. This sits uncomfortably with the identified principles underpinning these laws regarding autonomy and the minimising of suffering.

4.2 Decision-Making Capacity

The requirement for decision-making capacity (capacity) at every stage of the VAD request and assessment process is aimed at ensuring that the request remains voluntary and enduring. However, the requirement for capacity in the final hours causes unintended barriers to accessing VAD for a person who has completed all previous steps while they had capacity, but due to the passage of their illness or treatment, may no longer have capacity.¹⁷ It is understood that all states have reported cases where a person was assessed as eligible for VAD, but by the time the VAD substance was delivered, the person was assessed as no longer having capacity in relation to VAD and VAD was refused.¹⁸

The difficulty with the requirement for constant assessment of capacity at every stage of the request and assessment process means that even at the final stage, when the pharmacists deliver the VAD substance in person, or the doctor is ready to administer the VAD substance (for practitioner administration), the person must be assessed as having capacity and recognise the impact of the VAD substance. The outcome is that a person who is in pain may forego pain medication in order to be confident they will still have capacity. Another outcome is that the person may choose to take the VAD substance earlier than they would prefer, while they are confident of retaining capacity.

¹⁵

[https://www.parliament.wa.gov.au/parliament/commit.nsf/\(Report+Lookup+by+Com+ID\)/71C9AFEC0FAEE6E482582F200037B37/\\$file/Joint+Select+Committee+on+the+End+of+Life+Choices+-+Report+for+Website.pdf](https://www.parliament.wa.gov.au/parliament/commit.nsf/(Report+Lookup+by+Com+ID)/71C9AFEC0FAEE6E482582F200037B37/$file/Joint+Select+Committee+on+the+End+of+Life+Choices+-+Report+for+Website.pdf)

¹⁶ Western Australian Voluntary Assisted Dying Guidelines, p35, <https://www.health.wa.gov.au/-/media/Corp/Documents/Health-for/Voluntary-assisted-dying/VAD-guidelines.pdf>

¹⁷ Note that the capacity assessment is limited to the request for VAD, and is not a broader capacity assessment.

¹⁸ Note that the state VAD Acts require capacity in relation to VAD and an understanding of the impact of the VAD substance; capacity assessments used by clinicians use a scale to determine the severity of a person’s medical condition

The question of capacity is particularly relevant for people with a neurodegenerative condition, such as Huntington's Disease or MND or dementia. A person with a neurodegenerative condition may meet the medical criteria, however, by the time the person receives a prognosis of 12 months, they may be close to losing - or have already lost - capacity. The disease trajectory for each person is unique to that person, and there is no certainty about a prognosis or at what stage a person may lose capacity.

4.3 Advance Care Directives

Most members of the public assume that VAD can be requested in an Advance Care Directive (or similar) (ACD) provided in each jurisdiction. This is incorrect. No state, territory or NZ VAD Act allows VAD to be requested in an ACD. The NSW VAD Act specifically excludes a person with dementia from requesting VAD. The substitute decision-maker nominated in an ACD manages discussion with the health team only after the person themselves is unable to provide direction, such as when the person loses capacity. Due to the requirement for capacity at every stage of the VAD process, and that VAD can only be requested by the person themselves, current legislation in Australia and NZ precludes VAD being able to be requested by a third party. Evidence from the four jurisdictions which allow VAD in an ACD – the Netherlands, Belgium, Luxembourg and Colombia – show that few people are able to use an ACD for assisted dying. There is an ongoing global debate about a suitable methodology and practice for nominating VAD in an ACD.

The related question is whether VAD can proceed for a person who has been assessed as eligible and then loses capacity. In Canada, the waiver of final consent allows a person who has been assessed as eligible for VAD to proceed with MAiD (VAD equivalent) if they lose capacity. The 2021 amendment in Canada allows a person to make an agreement with their MAiD provider for MAiD to proceed on a particular date in the event the person loses capacity. In Australia this would mean that if a person has been assessed as eligible for VAD - so they have shown that they meet all the eligibility criteria, and have personally requested VAD - but then lose capacity before the written request, or the final request, or the delivery of the VAD substance, such a mechanism would allow VAD to proceed. The person's request was clear. It was voluntary. It was enduring while they had capacity. It was their expectation. It was an evidence based choice made voluntarily and with clear intention.

The waiver of final consent, as legislated in Canada, provides a choice for people who may have a longer disease trajectory, or one where their capacity may become unreliable as their disease progresses, and allows them to be assessed for VAD while they still have capacity. Once assessed as eligible, the person can live the rest of their life in the comfort that their choice of a medically assisted death will proceed.¹⁹

In the Netherlands, where an assisted death can be nominated in an ACD, clinicians are reluctant to proceed if the person loses capacity. The provision is rarely used²⁰.

In June 2023 the Quebec provincial parliament in Canada passed legislation which would allow a person to request MAiD in an ACD. While these amendments have passed the provincial parliament, there is no indication that the Quebec Amendments will come into operation in the near future.

¹⁹ It is understood that the date set in the waiver is usually a number of months ahead; on that day, if the person retains capacity, they can proceed with MAiD or set a new date.

²⁰ It is understood that 2 or 3 VAD deaths per year proceed in the Netherlands for someone who has lost capacity – see Footnotes 11, 12.

5. Discussion

The criteria for access to VAD in all states of Australia include a prognosis: six or 12 months to live. Each person must obtain a prognosis of six or 12 months from two different VAD trained doctors. In every state of Australia and NZ, there are a small number of VAD trained doctors. A person who has a terminal illness is unlikely to have a VAD trained doctor as their treating doctor. Initial consultations will therefore be with a doctor who is unlikely to be familiar with the detailed assessment process associated with VAD, or the eligibility criteria, and may not offer advice in relation to a six or 12 month prognosis. When specifically asked, many people report that their treating doctor said they did not know how long the person had to live. The working group is aware that this was the advice offered to a terminally ill person - who would have requested VAD - who died the next day. This experience is not unique, and confirms the futility of the requirement in all state VAD laws that eligibility for VAD is dependent on a prognosis of six or 12 months.

In June 2024 the ACT Parliament passed the first VAD legislation in Australia which does not include the requirement for a specific time limited prognosis. VAD is due to commence in the ACT in November 2025.

There is considerable national and international evidence that the six or 12 month prognosis is an unreliable and inconsistent criterion for determining eligibility for VAD. There are a wide range of factors which influence a prognosis. A predetermined fixed time period to death for any disease is broadly recognised as unreliable. Medical practitioners are consistently reluctant to provide a specific prognosis. In the absence of a prognosis from their treating doctor, many people proceed no further with their request for an end to their suffering through a medically assisted death.

Priority on prognosis

The requirement for nominating a time left to live is seen as the one barrier which, if removed, would have the greatest impact on providing more equitable access to VAD and the least impact on the safety and security of the VAD request and assessment process. Removal of the prognosis would allow people with a broad range of diseases and illnesses, including dementia, to request VAD. Globally, cancer is the most frequently recorded illness underlying a request for VAD. Approximately 70% of people who request medical assistance to die have been diagnosed with a malignancy. Many people report that they are unable to get a prognosis from their doctor, or are encouraged to engage in treatments or therapies to suppress or eliminate their cancer, with no accompanying prognosis if such treatment is taken up or refused. Historical data provide a guide of time from diagnosis to death; however each person is an individual, and there is no guarantee that the historical data will apply to any one person. The person who is dying may receive a range of confusing and contradictory advice about the efficacy of future treatments and their associated prognosis.

The prognosis of six months has no compelling medical origin. The nomination of six months emerged in Oregon, USA, where funding for hospice care becomes available after the person has a prognosis of six months to live; the reliability of a prognosis of anything other than days or years – such as a prognosis of several months - has been consistently revealed as unreliable.

In Canada, where the original criteria required that ‘death is reasonably foreseeable’, there is no evidence of abuse or difficulty in managing access and assessments. There is substantial evidence of the development of considered and informed clinical practice to support a compassionate end of life choice for someone with a terminal illness.

Clinicians in Canada report that despite the waiver, the majority of people who use MAiD still have capacity. This appears to be a combination of both the person and the clinician’s preference, with evidence that clinicians may be reluctant to administer MAiD to a person who no longer has capacity.

The mythical safeguard

The prognosis of six or 12 months is considered the least evidence based safeguard, difficult to obtain, and a significant impediment to accessing VAD. Time to live is an opinion. Each person is different. The disease trajectory for each person is different. The prognosis cannot be guaranteed. Some doctors refuse to provide a prognosis. It is only after the person's death, if they die without using the VAD substance, that there can be a reconciliation between the prognosis and the actual time to death. The six or 12 month prognosis is a false safeguard; there is no way to know if the person will die earlier or live longer. Removal of the six or 12 month prognosis would not negatively impact the safety and management of VAD requests. The key determinant of when people use the VAD substance is when they determine that their suffering has become unbearable. Removing a prognosis of six or 12 months will not result in more people dying. Provided that their quality of life is acceptable, most people wish to live longer; it is only when they determine that their suffering has become unbearable that they request VAD. The requirement for a six or 12 month prognosis has the unintended consequence of people continuing to suffer, to not request VAD even though they meet the criteria, because they did not receive the required prognosis.²¹

Requiring two doctors to agree on an arbitrary time to death before a terminally ill person can request medical assistance for an end to their intolerable suffering is recognised in other jurisdictions as an uncomfortable interference in an otherwise compassionate end of life choice. The evidence is that most people request assistance to die late in their disease trajectory, that they engage in a range of end of life treatments and therapies in order to extend their life, and it is not until their suffering becomes unbearable that they request assistance to die.

The compounding effect

The requirement for a prognosis as well as decision-making capacity at every stage of the request and assessment process has emerged as a major barrier for access to VAD under current legislation, particularly for a person with a neurodegenerative disease. For people with a neurodegenerative disease, the application of the arbitrary and non evidence based eligibility criteria of a prognosis of 12 months means the person is likely to be, by then, ineligible for VAD because they have lost capacity. For example, by the time a person with Huntington's disease is assessed as having less than 12 months to live, they may also be assessed as no longer having decision-making capacity in relation to VAD.

For a person with a terminal illness, who is dying, for whom there are no further treatments acceptable to the person, but they have become ineligible for VAD because no doctor will provide a prognosis of less than 12 months, there needs to be a more compassionate legislative choice. The prognosis requirement is particularly cruel for a person diagnosed with dementia. By the time they receive a prognosis of less than 12 months, they are most likely to be assessed as no longer having capacity.

6. Summary

Dementia is the leading cause of death for women in Australia, second overall. Eligibility criteria in Australian state and New Zealand voluntary assisted dying laws make it unlikely that a person with dementia would be eligible for VAD. Given the removal of the time bound prognosis, the ACT VAD Act may facilitate more equitable access to VAD for a person with dementia, however the ACT VAD Act does not commence until November 2025. In Canada, dementia has been an eligible condition

²¹ This unintended consequence is exacerbated in Victoria and South Australia where the legislation prohibits a doctor from listing VAD in an end of life treatment plan; in the absence of both a prognosis and information from a doctor that VAD is an end of life option, some people will continue to endure unnecessary suffering.

for assisted dying since commencement of their Medical Assistance in Dying law in 2016. Eligibility for MAiD in Canada does not include a prognosis of a time to death. There is no evidence from Canada that the absence of a prognosis has led to abuse of the law.

The prognosis of six or 12 months contained in NZ and Australian state VAD legislation is widely viewed as an ineffective safeguard, and the least consequential when assessing a person's eligibility for an assisted death. Removal of the six or 12 month prognosis would enhance the equity of access to VAD and provide no challenge to the safety and security of the assisted dying assessment process. Most people wish to live longer, rather than die earlier; it is when their suffering becomes unbearable or intolerable that they seek assistance to die.

Removal of the prognosis of six or 12 months as one of the criteria for access to VAD would likely allow some people with dementia to become eligible for VAD while they still retain decision-making capacity and, given the evidence from overseas, would have no impact on the safety and security of the operation of the law. Clinicians in jurisdictions where an assisted death is possible for someone with dementia have developed clinical guidelines which ensure the safety and security of both the person requesting an assisted death and the clinician. Communities of practice in Australia would provide similar guidance. Removal of the prognosis would provide a compassionate end of life choice for at least some of a large and growing cohort of people diagnosed with dementia.

Removal of the six or 12 month prognosis would be of benefit to people with a broad range of illnesses who struggle to obtain a six or 12 month prognosis, are misinformed about their prognosis, or are reluctant to ask about a prognosis. Repeal of the prognosis criterion would leave the remaining eligibility criteria, which would be wholly adequate as an entry way to VAD, and one which has proper regard to the principles of autonomy, compassion, and minimisation of harm and suffering.