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Decision-making capacity following final approval for voluntary assisted dying (VAD) – an exploration of issues and feedback.

A report by ACTHD

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Introduction

The ACT Legislative Assembly passed the *Voluntary Assisted Dying Act 2024* (the Act) on 5 June 2024. The Act comes into effect on 3 November 2025 and includes elements that have not previously been established in Australia, including the use of nurse practitioners and not specifying a maximum estimated time to death for eligibility.

On 6 June 2024, the Legislative Assembly passed a resolution to address the issue of individuals who had been found eligible for VAD becoming ineligible to die by VAD due to a loss of decision-making capacity.

The resolution requires the ACT Government to

a. Explore the issue as experienced in other VAD jurisdictions of ineligibility due to loss of capacity after the final approval for VAD access, and through this work:

   i. Engage a broad range of stakeholders to develop a pathway in the ACT to address this issue;

   ii. Explore models to address where an individual has lost capacity following the final assessment report, this may include Enduring Power of Attorney or Advance Care Directives.

b. Report back to the Assembly at the end of May 2025.

Between November 2024 and February 2025, the ACT Government engaged a broad range of stakeholders to explore the emerging issue of loss of decision-making capacity after final approval for voluntary assisted dying. Led by the ACT Health Directorate, the consultation sought views from over 100 stakeholders in Australia and internationally. There was engagement with health and medical professionals, including current VAD practitioners and palliative care specialists, legal and policy experts, government officials, Australian and New Zealand VAD board and policy teams, academic and clinical researchers, and selected community and non-government organisations.

- 102 individuals, including:
  - 23 clinicians, including 7 authorised VAD practitioners, and palliative care specialists
  - 4 international VAD jurisdictions
  - 12 VAD law and policy experts and researchers
  - 16 bioethicists

- 14 non-government organisations
- Representatives from Australian VAD boards and policy teams

While the concept of VAD is increasingly accepted in Australia, access for individuals who have lost capacity following final approval is sensitive, complex and nuanced. Very few organisations have agreed policy positions on the concept, and many are reluctant to publicly state a position while policy discussions are nascent and research in the Australian context almost non-existent. Most individuals and organisations consulted by the ACT Health Directorate agreed to do so on the condition that their opinions were not publicly attributable to them. This report summarises what the Directorate heard during this engagement, organised around specific themes and concepts. No specific positions or opinions have been attributed to any individual or organisation.

The ACT Government is grateful to all the stakeholders who participated in this process, contributing their experiences and providing honest, considered and valuable information.

What is the situation now?

As of December 2024, all Australian States provide access to VAD services. The ACT's Act aligns with all VAD legislation in Australia and New Zealand in requiring an individual to have decision-making capacity ("capacity") at every stage of the VAD process. This was considered a central safeguard to ensure all decisions to request and access VAD are made voluntarily and without coercion. For the purposes of the Act, an individual has capacity in relation to VAD if they can (12(1)):

a. understand the facts that relate to a decision about accessing voluntary assisted dying; and

b. understand the main choices available to them in relation to the decision; and

c. weigh up the consequences of the main choices; and

d. understand how the consequences affect them; and

e. on the basis of paragraphs (a) to (d), make the decision; and

f. communicate the decision in whatever way they can.

Access to VAD requires an individual to have capacity at four time points across the VAD process: first assessment, consulting assessment, final assessment (or approval in some Australian jurisdictions) and administration of the VAD substance.

However, we know that some people will lose capacity as they approach their death. This means that some people who have been found eligible for VAD may become ineligible for the last step – to receive the VAD substance. The ACT Legislative Assembly has asked the Government to explore possible legislative responses so that an individual in this situation could still access VAD as their end-of-life choice.

What We Heard

Many people lose capacity at end of life … but few are unable to access VAD as a result

During the consultation, medical professionals told us that loss of capacity is a common occurrence when a person is very close to dying. There are several factors that contribute to the likelihood of someone losing capacity at the end-of-life, including:

- as a consequence of some progressive disease processes;
- due to the effects of medications (which may or may not be reversible);
- acute illnesses and infections (which may or may not resolve); and
- as a pre-terminal event as an individual approaches their death.

From other Australian VAD jurisdictions, we heard that many people access VAD late in their disease trajectory – for a variety and combination of reasons. In other jurisdictions, this includes legislative requirements and safeguards that may act as a barrier to timely access to VAD, such as legislated timeframe to death of 6 months, or restrictions on medical practitioners initiating conversations about VAD with their patients.[1] Many medical professionals also communicated the view that individuals will often access VAD late in their disease trajectory because addressing the administrative realities of death go against an intrinsic desire to live.

To help understand experience of this issue in Australian and New Zealand VAD jurisdictions, the ACT Health Directorate made formal requests to all Australasian VAD Boards for any data points that could support quantification of the possible prevalence of this issue.

Broadly, Australian VAD laws require the collection of statistical information on persons approved for VAD and people who have died as a result of the VAD substance. No Australian VAD jurisdiction requires the collection of data on an individual's loss of decision-making capacity after the final assessment or approval for VAD. This is to preserve the low-intervention, person-centred approach of Australasian VAD models. There is concern that compelling individuals, family members or carers at this juncture to provide information could be perceived as a form of coercion or be disruptive. Moreover, jurisdictions have also carefully considered the data collection onus and burden already on VAD practitioners.

Based on the Board responses received, there is limited data currently collected, published or available relating to the specific issue of loss of capacity for a VAD applicant following final approval for VAD. Data available on loss of capacity at earlier stages of the VAD process does exist in some jurisdictions, albeit in a varied and patchwork way. However, the differences in disaggregation and

[1] In early 2025, following the Victorian VAD Act legislated 5-year review, the Victoria Government has introduced amendments to remove the restriction of practitioners raising VAD with individuals after the review found it was a barrier to access to VAD. "Voluntary Assisted Dying Five-Year Review," p. 43. https://www.health.vic.gov.au/voluntary-assisted-dying/five-year-review

definitions in this data make it impossible to compare and develop a clear, consistent national picture of the issue.

In the absence of clear data, anecdotal accounts by VAD practitioners across Australia indicate that the loss of capacity after final approval occurs within the Australian model, although in a small minority of cases.

Seven international jurisdictions have a legal mechanism to permit voluntary assisted dying for people who have lost capacity – the Netherlands, Luxembourg, Belgium, Canada, Spain, Colombia and Ecuador.[2] The ACT Health Directorate consulted with academics, patient advocates, clinicians and clinician researchers in Canada, the Netherlands and Spain, and Australian VAD researchers whose work has focused on Canada and Belgium.

In the Netherlands, in 2024, only 8 out of 9,000 euthanasia cases were carried out via its mechanism of an Advance Euthanasia Directive. In Canada, 3.87 per cent of patients who received Medical Assistance in Dying (MAiD) used Canada's Waiver of Final Consent due to loss of capacity in 2023.[3] Spain identified that roughly 4 per cent of euthanasia requests were made through its advance directive mechanism, although there is no data on how many individuals accessed assisted dying in this way.

How is this currently addressed in the Australian model?

Both palliative care and VAD clinicians discussed that the identification and anticipation of, and response to, issues of declining capacity in patients with a terminal diagnosis is core to person-centred care and practice at end of life. Several approaches are currently used by Australian VAD practitioners to address this issue.

Establishing Expectations

We heard that open and clear communication from early in the individual's VAD journey is critically important. Clinicians reported that establishing expectations about potentially losing eligibility was an effective way to allay potential distress. As part of this open communication, clinicians underline that VAD does not exist in isolation. It is one component of a broader suite of end-of-life care options, including palliative care.

Expediting Requests

A few Australian VAD jurisdictions allow VAD requests to be expedited by waiving "cooling off periods" (minimum timeframes). Applying to expedite a request is relied on heavily by clinicians when an individual is expected to either lose capacity or die within the "cooling off period." Practitioners told us that expediting cases when individuals are expected to lose decision-making capacity is important person-centred care but adds significant pressure to the VAD workforce. We heard from stakeholders that reducing barriers to access will allow people to interact with the VAD process in a way that supports more timely access.

The ACT's VAD laws have some unique differences which drew from the experiences of other jurisdictions. These differences have the potential to minimise the extent to which people lose capacity during the VAD process. Though it will take a period of implementation to determine whether the lack of a set timeframe to death will impact the issue of late loss of capacity.

The case for change? Balancing access with appropriate safeguards

During the consultation we heard some compelling reasons to consider legislative reform in this area:

- determining how long someone has to live is extremely difficult, as is predicting the timing of an expected loss of capacity
- for some individuals and their families, the prospect of losing capacity, and therefore VAD eligibility, can be a constant source of anxiety throughout the VAD process
- there are reports of instances where individuals opt out of taking palliative care medicines to ensure they retain capacity for VAD
- For some individuals, not being able to die by VAD as their end-of-life choice is a source of suffering in itself
- If an individual becomes ineligible and unable to access voluntary assisted dying due to loss of capacity, family members can experience feelings of distress and guilt at not being able to help their loved ones to end their suffering and access VAD as their end of life choice.

The consultation also revealed challenging ethical, legal and medical concerns with legislatively addressing this issue, and a broad spectrum of views across stakeholders.

Consultation showed the difficulties in balancing reasonable access to VAD with appropriate safeguards for individuals, practitioners and the community. Some stakeholders held the view that expanding access to VAD for people who lose capacity after final approval was important for end-of-life autonomy, choice and control. Others were of the view that creating an exception to the capacity requirement at the point of administration compromises the integrity of decision-making capacity as a core principle and safeguard.

Consultation also revealed the difficulties in balancing reasonable access to VAD with appropriate safeguards for individuals, practitioners and the community. For example, a key safeguard of the ACT model is that individuals are under no obligation to continue with the process and can withdraw at any time. One prominent concern around allowing access to individuals who lose decision-making capacity is allowing for a change of mind. We heard that individuals do reconsider their decisions about VAD. Current data shows approximately 30 per cent of individuals who are found eligible for VAD do not die from administration of the VAD substance.[2] While, this is due to a range of reasons, for many people, simply having VAD as an option provides relief from the anxiety caused by the potential of future suffering. A model which loosens the capacity requirement at administration introduces the possibility that a change of mind cannot be factored in or accounted for adequately.

[2] In the 2023/24 reporting period, QLD reported that 36.2% of substances were not administered. See p. 10 of "Queensland Voluntary Assisted Dying Review Board Annual Report 2023-2024. Available at: https://www.health.qld.gov.au/research-reports/reports/departmental/voluntary-assisted-dying-review-board-annual-report/2023-2024

On the other hand, the fear of losing capacity has been reported to compel some individuals into accessing VAD earlier than they otherwise would – fundamentally undermining the VAD principles of voluntariness and choice. One Australian study identified that the fear of "missing the boat" or being in a "race against time" to access VAD before losing capacity can play into people's experiences of the VAD process.[3] However, this same study also found that the perception of time and experiences in the VAD process were highly subjective and individual.

Workforce considerations

Many current VAD practitioners indicated in-principle support for legislative changes to provide VAD access to individuals who lose capacity after final assessment. However, this support tended to be caveated to specific and/or exceptional circumstances. Others said they would be unlikely to practice in this space for a variety of personal, ethical and medico-legal reasons, even if it were legislated. The main issues raised by clinicians during the consultation were:

- the moral and ethical issues of administering VAD to someone without decision-making capacity, which goes against usual medical practice of seeking consent for interventions
- concerns around disagreement between and among family members about how to proceed
- risk of litigation
- the potential for burn out from working on complex and challenging cases

Some clinicians felt removing the requirement for capacity at administration of the VAD substance increased their risk of moral injury. On the flipside, it was suggested that not being able to fulfil a clear and enduring wish of a patient can cause moral injury. Many VAD practitioners stated they would only feel comfortable administering the substance to an individual with whom they already have an existing clinical relationship.

VAD practitioners reflected that care at the end of life is invariably shaped and influenced by family dynamics. Difficult situations can arise where family disagreement about an individual's VAD choice adds layers of complexity to the process. This was also tied to concerns about the potential risk of litigation for practitioners and the need for robust legal protections.

There were also general comments on the complexity of capacity assessments and the need to balance an approach that is consistent across the board and yet responsive and flexible to the individual.

[3] See White et al., "Access to voluntary assisted dying in Victoria: a qualitative study of family caregivers' perceptions of barriers and facilitator," MJA, 2023. Available at https://onlinelibrary.wiley.com/doi/10.5694/mja2.52004

International models

Seven countries have national legal frameworks allowing access to assisted dying for people who lose capacity – Spain, the Netherlands, Belgium, Luxembourg, Canada, Colombia and Ecuador. The ACT Health Directorate conducted desktop research and met with researchers, clinicians and advocates from Canada, the Netherlands and Spain to learn more about the two international models already in practice – advance requests and waiver of final consent – and their potential applicability to the ACT context.

Advance requests

- **Belgium and Luxembourg** – Both country's assisted dying legislation recognise the authority of advance request in the event that someone is in an irreversible coma. Both countries have standalone advance directive documents for assisted dying which can only be enacted in this specific circumstance.
- **The Netherlands** – allows access to assisted dying through an Advance Euthanasia Directive (AED). Although AEDs have been in place in The Netherlands since the early 2000s, their use is controversial and generally not favoured by practitioners. Determining the point at which to initiate the assisted dying process based on an AED is a challenge for practitioners and is a key factor in their hesitation to carry them out. In the Netherlands, decades-long social acceptance of euthanasia has characterised the development of AED legislation and practice.
- **Spain** – allows access to people who have lost decision making capacity through the country's usual advance care directive mechanism. 30 per cent of people in Spain have a registered advance care directive. Spain's assisted dying laws commenced in 2021 and, as such, there is less experience to draw on.

Waiver of Final Consent

Canada introduced a Waiver of Final Consent (the Waiver) in 2021 to address the specific issue of loss of capacity following final approval. The Waiver works similarly to an advance request by allowing an individual to waive the requirement for their final consent at administration *in advance*. Unlike other international systems that link advance directive laws to assisted dying laws, the Waiver was developed to operate specifically within the MAiD legislation and process. Canadian stakeholders told us that this model provides peace of mind for individuals who are at risk of losing capacity. It also addresses some clinician concerns by reflecting a recent statement of a person's wish to access MAiD and setting a specific date for the practitioner to provide MAiD if capacity is lost. However, stakeholders also told us that some practitioners felt at risk of moral injury when an individual had lost capacity but appeared otherwise comfortable and content. This is reflected in the low rates of use. In 2023, 3.87 per cent of individuals who received MAiD accessed it via a Waiver of Final Consent. On this note, research shows that some patients seek access to a Waiver because, for them, losing capacity in and of itself is a form of intolerable suffering.[4]

[4] Variath C, Peter E, Cranley L, Godkin D. Experiences of healthcare providers with eligible patients' loss of decision-making capacity while awaiting medical assistance in dying. *Palliative Care and Social Practice*. 2022;16. doi:10.1177/26323524221128839

The VAD Attorney Model

The consultation also included consideration of a VAD Attorney model. This novel model would allow an individual to appoint a substitute decision-maker, who would be empowered to make VAD decisions, including whether to proceed with VAD, in the event the individual loses capacity.[5] Some VAD practitioners were drawn to this model as they felt it may be simple to put into practice, and would provide shared and real-time decision making between the VAD Attorney and the VAD practitioner. However, other stakeholders were concerned about a model that relied solely on substitute decision making due to potential for coercion, and that it potentially conflicts with the person-centred nature of Australia's VAD model. Carers expressed concerns about the significant moral, emotional and administrative burden of being asked to act as a substitute decision maker.

There is no one-size-fits-all solution

As with all aspects of this complex issue, views on an appropriate legislative model to allow access in the event of a loss of capacity after final approval were diverse and contested. Based on information gathered to date, none of the international models are easily transferable to the ACT's unique social and legal setting. The proposal of a substitute decision-making model poses many unresolved challenges. Despite this, stakeholders felt that particular elements of each model should be considered in the development of an ACT model, and that this model should be designed with local stakeholders and workforce to adequately reflect our unique and local needs and values. Furthermore, many experts advised that any changes to VAD systems should not unduly complicate the system – a sentiment echoed by practitioners.

What's Next?

The concept of changing the VAD process to legally allow administration of the VAD substance to an individual without capacity raises profound ethical, legal and clinical concerns. Such a change would be unprecedented in an Australasian context and there are few existing precedents overseas. Continuity and stability in safeguards and process is critical for public and community trust in VAD, workforce confidence and health system capabilities.

The consultation revealed these key and recurring themes:

- More data in this area is necessary to develop a policy position.
- Where other models exist, they have been developed in legal and cultural contexts that are different to the ACT.
- There is no consensus on the most appropriate alternative model.
- Significant further consultation needs to be undertaken to understand views of patients and their families, the health and community sector and the broader public.

[5] See Marisa Paterson, MLA. "Community Consultation on VAD Amendments. Available at https://marisapaterson.com.au/campaigns/community-consultation-on-vad-amendments/

Stakeholders made it clear that any approach needs to engage the community and workforce without undermining existing strong support for VAD and supporting the workforce that delivers it. It will also be important to understand how the ACT's unique VAD scheme is progressing and the impact of the ACT's eligibility criteria. This will require ongoing data collection and analysis, and further, broader consultation in the years after VAD implementation.

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