

Ensuring equitable access to VAD

Submission to the ACT Government's review of the Voluntary Assisted Dying Bill 2023

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Introduction

Thank you for the opportunity to make a submission to the review of the Voluntary Assisted Dying Bill 2023. The ACT Government and Minister for Human Rights Tara Cheyne should be commended for introducing this bill. With the passage of the *Restoring Territory Rights Act* through the Commonwealth Parliament in December 2022, the ACT at last became able to legislate on this issue. After almost 20 years – during which time every state in Australia has legalised voluntary assisted dying (VAD) – terminally ill Canberrans will soon also be able to exercise their right to choose to end their life with compassion and dignity.

The Australia Institute supported the *Restoring Territory Rights Act*,¹ and has long advocated for VAD as a human right, and for the right of the ACT and Northern Territory to legislate VAD. With this submission we add our support to the passage of the Voluntary Assisted Dying Bill 2023, and offer some suggestions for how the bill could be improved.

¹ Australia Institute (2022) *Passage of territory rights bill welcome*, <https://australiainstitute.org.au/post/passage-of-territory-rights-bill-welcome/>; for the Australia Institute's more detailed response to an earlier proposal, see Browne (2021) *Ensuring both territories' rights*, <https://australiainstitute.org.au/report/ensuring-both-territories-rights-submission-to-the-inquiry-into-the-ensuring-northern-territory-rights-bill/>

Australia Institute polling shows support for VAD

Polling conducted by the Australia Institute over recent years has consistently shown strong support for the right of Canberrans to decide their laws and their right to voluntary assisted dying. This included:

A nationally representative poll of 1,434 Australians conducted in 2021,² which asked respondents about their attitudes to voluntary assisted dying and found that:

- Three in four Australians (76%) agreed with the principle that a person experiencing unrelievable suffering who asks to die should be allowed to receive the assistance of a doctor to do so.
- Three in four Australians (76%) supported the Commonwealth allowing territory governments to legalise VAD within their jurisdictions, including 45% who strongly supported the proposal.

A nationally representative poll of 1,004 Australians conducted in August 2021,³ which asked respondents about their views on various restrictions on the rights and representation of the Australian Capital Territory (ACT). This poll found that:

- Six in ten (60%) Australians supported both the ACT and Northern Territory being allowed to legalise voluntary assisted dying.
- 8% said only the NT should be allowed, and 12% said neither territory should be allowed.⁴

A separate survey — also conducted in August 2021, but limited to residents of the ACT⁵ — which showed that, from a sample of 1057 respondents:

- 58% strongly agreed and 14% agreed that “territory governments should decide whether voluntary assisted dying is legalised within their jurisdictions”;

² The Australia Institute (2021) *Polling: Voluntary assisted dying and the territories*, <https://australiainstitute.org.au/report/polling-voluntary-assisted-dying-and-the-territories/>

³ The Australia Institute (2021) *Polling – Territory rights*, <https://australiainstitute.org.au/report/polling-territory-rights/>

⁴ This poll was conducted at a time when the Commonwealth Parliament was considering a bill that would have removed restrictions on the ability of the Northern Territory (NT) to legislate to allow voluntary assisted dying (VAD) but would have left restrictions on the ACT in place. It is for this reason that respondents were given an option to support only the NT’s right to legalise VAD. Respondents were not asked their opinion about the ACT alone legislating VAD. This helps explain why this 60% figure is lower than the polls conducted before and after it.

⁵ The Australia Institute (2021) *Polling: ACT research*, <https://australiainstitute.org.au/report/polling-act-research/>

- 54% strongly supported and 24% supported “similar laws in the ACT to legalise voluntary assisted dying [like those passed in Victoria, Tasmania, Western Australia, and South Australia].”

A nationally representative poll of 1,005 Australians conducted in July 2021, which asked respondents about their views on Territory rights and VAD⁶ and found that:

- Four in five Australians (78%) said VAD should be legal, 10% disagree.
- Over three in four (78%) Australians supported the Commonwealth allowing Territory governments to legalise VAD within their jurisdictions, 11% opposed.

Together these polls show long-term majority support for VAD to be legalised in the ACT.

POINTS FOR CLARIFICATION

While very similar in content to the laws that exist in other Australian jurisdictions, the ACT’s Voluntary Assisted Dying Bill 2023 is, in certain ways, more permissive. The *Summary of the ACT’s framework for voluntary assisted dying* makes it clear that, unlike other jurisdictions, a terminally ill person seeking to access VAD is not limited by a defined length of life expectancy.⁷ This bill also has a broader definition of the ‘health professionals’ permitted to facilitate access to VAD than the relevant NSW and Victorian laws, which means that nurse practitioners and nurses with ‘relevant specialist experience’ will be allowed to provide this service.⁸ The proposed bill will also allow health practitioners to initiate VAD conversations, which is not permitted in Victoria or South Australia.⁹ Notwithstanding these relatively liberal provisions, this submission touches on a few ways that the proposed bill could improve access to VAD.

⁶ The Australia Institute (2022) *Polling research – territory rights and voluntary assisted dying*, <https://australiainstitute.org.au/report/polling-research-territory-rights-and-voluntary-assisted-dying/>

⁷ ACT Government (2023) *Summary of the ACT’s framework for voluntary assisted dying*, p 2, https://hdp-au-prod-app-act-yoursay-files.s3.ap-southeast-2.amazonaws.com/1416/9881/6193/Summary_of_ACT_VAD_Framework_.pdf

⁸ ACT Government (2023) *Summary of the ACT’s framework for voluntary assisted dying*, p 4

⁹ Lu & Davey (2023) *What are the laws on voluntary assisted dying in each state?* <https://www.theguardian.com/australia-news/2023/oct/29/what-are-the-laws-on-voluntary-assisted-dying-in-each-state>

Dementia

The bill could provide greater clarity as to how people with dementia are able to access VAD. The proposed bill states that “an individual must not be treated as not having decision-making capacity only because they:

- (i) make an unwise decision; or
- (ii) have impaired decision-making capacity under another Act, or in relation to another decision.”

It also states that:

- (e) an individual who moves between having and not having decision-making capacity must, if practicable, be given the opportunity to consider matters requiring a decision at a time when they have decision-making capacity.”¹⁰

It is unclear how people with dementia, who may indeed have “impaired decision-making capacity” or “move between having and not having decision-making capacity”, are covered by the bill. It would benefit the increasing number of people with dementia if the bill included guidance on how these clauses should be interpreted in cases where people with dementia want to access VAD. One option could be to allow Advanced Care Directives to enable VAD if they are written within a specified time period before decision-making capacity is lost.

Promoting VAD

Assuming the bill passes into law, the ACT should learn from other states and ensure that there is wide awareness among the public that VAD has become a legal option. A recent survey of experiences of people seeking VAD in Victoria¹¹ found that “finding and making initial contact with a person who could help [with VAD] was ‘extremely difficult’ or ‘really hard’.” While the ACT bill allows for health professionals to raise VAD with patients (the survey concluded that the inability to do this was the “key problem” in Victoria) the Assembly should consider how it can effectively communicate to all Canberrans that VAD has become legal, and explain how the service can be accessed.

¹⁰ Voluntary Assisted Dying Bill 2023 (ACT), p 10, https://www.legislation.act.gov.au/b/db_68609/

¹¹ Australian Centre for Health Law Research (n.d) *Voluntary assisted dying is legal – but some people are unsure how to access it*, <https://research.qut.edu.au/voluntary-assisted-dying-regulation/wp-content/uploads/sites/292/2023/09/Some-people-are-unsure-how-to-access-VAD-family-perspectives.pdf>

THE BILL AND FEDERAL LAW

We would also like to use this submission as an opportunity to touch on issues at the Commonwealth level that affect both the ability of Canberrans to access VAD services, and the ability of the ACT Legislative Assembly to legislate on this issue. While we appreciate that these issues require legislative changes the Commonwealth level, they affect Canberrans and should be of concern to the ACT Legislative Assembly.

Medicare

Perhaps the most fundamental obstacle to accessing voluntary assisted dying services is that they are not covered by Medicare. This poses a problem for both doctors and patients. The VAD services already in operation in other states often depend on the altruistic work of doctors, who are reluctant to charge patients directly for the service. This is no basis for a sustainable service.¹² Members of the Queensland Voluntary Assisted Dying Working Group have proposed a solution that would see VAD patients responsible for an out-of-pocket fee of \$860.¹³ Adding VAD services to the Medicare Benefits Schedule (MBS) would ensure that they are affordable for all Australians and viable for health care professionals.

The need for residency requirements?

The proposed bill states that to be eligible for VAD, a person must have to have “lived in the ACT for at least the previous 12 months.”¹⁴ An exemption is available for people with a “substantial connection to the ACT”, which includes “an individual who has lived in a place close to the ACT” and anyone who works or receives medical treatment in the ACT.¹⁵ This means people who live in parts of NSW adjacent to Canberra (such as Queanbeyan, Bungendore, or Cooma) are likely to be eligible to receive VAD services in the ACT. While this deals with the immediate reality that the ACT provides health services to many people who reside in southern NSW, it raises a more fundamental question: are residency requirements now redundant given that every state has laws that permit VAD?

¹² Hunt (2023) ‘Voluntary assisted dying in Australia: emerging questions’, *Medical Journal of Australia*, <https://10.5694/mja2.52064>

¹³ Davey (2023) ‘Voluntary assisted dying costs are creating “substantial barriers” for patients, Queensland doctors say’, <https://www.theguardian.com/australia-news/2023/aug/15/voluntary-assisted-dying-costs-are-creating-substantial-barriers-for-patients-queensland-doctors-say>

¹⁴ Voluntary Assisted Dying Bill 2023 (ACT), p 7

¹⁵ Voluntary Assisted Dying Bill 2023 (ACT), p 104

The passage of Commonwealth legislation confirming the right to VAD already agreed up by every jurisdiction in Australia (except the Northern Territory) would be a logical, democratic step. It would negate the need for residency requirements and ensure all eligible Australians are able to receive VAD wherever they access health services.

Telehealth

In a trend accelerated by the COVID-19 pandemic, an increasing number of people now access medical services via telephone or internet (telehealth). However, the *Commonwealth Criminal Code Amendment (Suicide Related Material Offences) Act 2005*¹⁶ makes it a crime to use a 'carriage service' to discuss suicide-related material, this effectively makes it illegal to discuss VAD via telehealth. This could pose a problem for very sick, bedridden people, and those who might have a "connection" to the ACT but live a long way from Canberra. The bill is clear that voluntary assisted dying is not classified as suicide,¹⁷ but recent case law nonetheless suggests that VAD cannot be discussed and facilitated over telehealth.¹⁸

Given that VAD is available in every jurisdiction in Australia except the Northern Territory, state and territory governments should urge the Commonwealth government to remove the provisions in the *Commonwealth Criminal Code Amendment (Suicide Related Material Offences) Act 2005*¹⁹ that prevent Australians from accessing VAD via telehealth. This is likely to be of great benefit not only to the very ill, but to Australians in remote and regional areas.

¹⁶ https://parlinfo.aph.gov.au/parlInfo/download/legislation/ems/r2270_ems_294213b4-87e2-4cdb-9085-d9a7f9f3cffd/upload_pdf/69925.pdf;fileType=application%2Fpdf

¹⁷ Voluntary Assisted Dying Bill 2023 (ACT), p 5

¹⁸ Davey and Kolovos (2023) 'Telehealth consultations for voluntary assisted dying are illegal under Australian law, court finds', <https://www.theguardian.com/australia-news/2023/nov/30/voluntary-assisted-dying-bill-australia-telehealth-illegal>; *Carr v Attorney-General (Cth)* [2023] FCA 1500, <https://www.judgments.fedcourt.gov.au/judgments/Judgments/fca/single/2023/2023fca1500>

¹⁹ *Criminal Code Amendment (Suicide Related Material Offences) Act 2005* (Cth), <https://www.legislation.gov.au/Details/C2005A00092>