

Legislative Assembly for the Australian Capital Territory

Select Committee on the Voluntary Assisted Dying Bill 2023

Inquiry into the Voluntary Assisted Dying Bill 2023

Legislative Assembly for the Australian Capital Territory Select Committee on the Voluntary Assisted Dying Bill 2023

Approved for publication

10th Assembly February 2024

About the committee

Establishing resolution

The Assembly established the *Select Committee on the Voluntary Assisted Dying Bill 2023* (the Committee) on 31 October 2023.

At its meeting on Tuesday, 31 October 2023, the Assembly passed the following resolution:

"That:

(1) a *Select Committee on the Voluntary Assisted Dying Bill 2023* be appointed to examine the bill and any other related matters;

(2) the Committee be composed of:

- (a) two Members to be nominated by ACT Labor;
- (b) two Members to be nominated by the Canberra Liberals; and
- (c) one Member to be nominated by the ACT Greens;
- to be notified in writing to the Speaker by 3pm today;
- (3) the chair of the Committee shall be an ACT Labor Member;
- (4) the Committee is to report by 29 February 2024; and
- (5) the foregoing provisions of this resolution, so far as they are inconsistent with the standing orders, have effect notwithstanding anything contained in the standing orders."

You can read the full establishing resolution on our website.

Committee members

Ms Suzanne Orr MLA, Chair Ms Leanne Castley MLA, Deputy Chair Mr Ed Cocks MLA Dr Marisa Paterson MLA Mr Andrew Braddock MLA (appointed on 30 November 2023) Mr Jonathan Davis MLA (resigned on 12 November 2023)

Secretariat

Ms Kathleen de Kleuver, Committee Secretary Ms Alicia Coupland, Assistant Secretary Ms Erin Dinneen, Assistant Secretary Mr Peter Materne, Assistant Secretary (until 23 November 2023) Mr Satyen Sharma, Administrative Officer

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Acronyms

Acronym	Long form				
ACT	Australian Capital Territory				
ACAT	ACT Civil and Administrative Tribunal				
AFI	Advocacy for Inclusion				
ANMF	Australian Midwifery and Nursing Federation				
ANZSPM	Australia and New Zealand Society of Palliative Medicine				
CEO	Chief Executive Officer				
СНА	Catholic Health Australia				
COPD	Chronic Obstructive Pulmonary Disease				
GPs	General Practitioners				
HCCA	Health Care Consumers Association				
HIV	Human Immunodeficiency Viruses				
HRA	Human Rights Act 2004				
HRC	Human Rights Commission				
LGBTQIA	Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, and Asexual				
MACM	Ministerial Advisory Council for Multiculturalism				
MLA	Member of the Legislative Assembly				
NSW	New South Wales				
NT	Northern Territory				
PCOC	Palliative Care Outcomes Collaboration				
PR	Permanent Residency				
Qld	Queensland				
QON	Question on notice				
QTON	Question taken on notice				
QVAD	Queensland Voluntary Assisted Dying				
SA	South Australia				
Tas	Tasmania				
The bill	Voluntary Assisted Dying Bill 2023				
The Commission	ACT Human Rights Commission				
The Committee	Select Committee on the Voluntary Assisted Dying Bill 2023				
The Scrutiny Committee	Standing Committee on Justice and Community Safety (Legislative Scrutiny role)				

The Territory	The Australian Capital Territory
Vic	Victoria
VADANZ	Voluntary Assisted Dying Australia and New Zealand
VAD	Voluntary assisted dying
WA	Western Australia

Recommendations

Recommendation 1

The Committee recommends that the ACT Government review and introduce amendments to the bill to more clearly define the use of the term 'advanced'.

Recommendation 2

The Committee recommends that the ACT Government review the term 'last stages of their life' and introduce amendments to the bill providing a less subjective and ambiguous definition.

Recommendation 3

The Committee recommends that the ACT Government introduce amendments to the bill to increase the timeframe from two working days to four working days for requirements to report or refer which have strict liability offence provisions attached.

Recommendation 4

The Committee recommends that the ACT Government provide plain English information about legal requirements and penalties to impacted health practitioners and health service providers who have obligations in regard to voluntary assisted dying.

Recommendation 5

The Committee recommends that the ACT Government introduce amendments to the bill to more clearly define the meaning of 'working day'.

Recommendation 6

The Committee recommends that the ACT Government ensure all strict liability provisions in the bill align with the explanatory statement, and provide an updated version of the explanatory statement Appendix 1 to the Assembly.

Recommendation 7

The Committee recommends that the ACT Government introduce amendments to the bill to make it explicitly clear who is considered a health practitioner and therefore has obligations when initiating conversations (as per subclause 152(2)).

Recommendation 8

The Committee recommends that the ACT Government introduce amendments to the bill in respect of Clause 152, to provide greater clarity on the intent and obligations of the provisions and revise the explanatory statement accordingly.

Recommendation 9

The Committee recommends that the ACT Government introduce amendments to the bill in respect of the time frame in which unused or expired approved substances are to be returned by, following the death of an individual with a view to shortening it to no more than 72 hours, and making sure individuals and families are aware of these obligations prior to the substances being dispensed.

Recommendation 10

The Committee recommends that the ACT Government develop processes to allow an individual to seek independent review when a facility operator decides that access to a facility for a relevant person is not reasonably practicable.

Recommendation 11

The Committee recommends that the ACT Government introduce amendments to the bill to require a minimum waiting period of 48 hours between first and last requests to access voluntary assisted dying, with the ability to grant exemptions where there is a compelling reason.

Recommendation 12

The Committee recommends that the ACT Government works with speech pathology practitioners and representatives to reconcile any concerns regarding communicating decisions to access voluntary assisted dying other than oral and written.

Recommendation 13

The Committee recommends that the ACT Government introduce amendments to the bill to extend the ACT Civil and Administration Tribunal (ACAT) review application time of five days where a reviewable decision has led to access to voluntary assisted dying being denied, to align with the 28 days usually available and allow ACAT members the discretion to increase this time as they can with other matters.

Recommendation 14

The Committee recommends that the ACT Government ensures the Voluntary Assisted Dying Oversight Board contains members with a range of perspectives, and consider the inclusion of members with knowledge and/or experience of:

- lived experience of disability;
- palliative care;
- healthcare consumers and carers.

Recommendation 15

The Committee recommends that the ACT Government make a statement to the Assembly regarding the provision of palliative care services in the ACT prior to debate of the Voluntary Assisted Dying Bill 2023.

Recommendation 16

The Committee recommends that the ACT Government make a statement to the Assembly regarding the provision of palliative care services in the ACT three years after the enactment of the Voluntary Assisted Dying Bill 2023.

Recommendation 17

The Committee recommends that the ACT Government consult with palliative care specialists to ensure that appropriate consideration be given to palliative care treatment options during the development of the compulsory training for voluntary assisted dying practitioners.

Recommendation 18

The Committee recommends that the ACT Government ensure that training is provided across the healthcare workforce to ensure that people who may be asked to provide assistance on voluntary assisted dying in varying capacities are aware of their obligations.

Recommendation 19

The Committee recommends that the ACT Government ensure that health practitioners are renumerated for their time spent undertaking mandatory training on voluntary assisted dying.

Recommendation 20

The Committee recommends that the ACT Government ensure that broader community education is clear that voluntary assisted dying is just one end-of-life option available and makes it clear what other options are available.

Recommendation 21

The Committee recommends that the ACT Government amend the explanatory statement to the Voluntary Assisted Dying Bill 2023 to explicitly state and further clarify that voluntary assisted dying is not to be seen as an alternative to providing supports for people with disability.

Recommendation 22

The Committee recommends that the ACT Government ensure mandatory training for voluntary assisted dying practitioners includes disability awareness training and identifying signs of coercion in respect of people with disability.

Recommendation 23

The Committee recommends that the ACT Government introduce amendments to the bill to include a definition of carer, in line with the *Carers Recognition Act 2021*, and update the Bill and explanatory statement as necessary to align with this.

Recommendation 24

The Committee recommends that the ACT Government recognise the role of carers in supporting people who may choose to access voluntary assisted dying.

Recommendation 25

The Committee recommends that the ACT Government ensure mandatory training for voluntary assisted dying practitioners includes the role of carer relationships in decision making and identifying signs of coercion.

Recommendation 26

The Committee recommends that the ACT Government consider the role of carers during the development and implementation of the Care Navigator Service to ensure that carers are appropriately supported.

Recommendation 27

The Committee recommends that the ACT Government seek input from culturally and linguistically diverse communities and Aboriginal and Torres Strait Islander people to ensure that public awareness and educational resources adequately address the needs of those groups.

1. Conduct of the inquiry

- 1.1. The Voluntary Assisted Dying Bill 2023 was presented in the Assembly on 31 October 2023.
- 1.2. The Assembly appointed the Select Committee on the Voluntary Assisted Dying Bill 2023 to examine the bill and any other related matters on 31 October 2023 and report by 29 February 2024.¹
- 1.3. On 2 November 2023, the Committee issued a media release calling for public submissions by 8 December 2023. Invitations to make submissions to the inquiry were also emailed directly to stakeholders.
- 1.4. The Committee received 83 submissions. These are listed in **Appendix A**.
- 1.5. The Committee held a public hearing in the week commencing 29 January 2024. Witnesses who appeared at the hearing are listed in **Appendix B**.
- 1.6. The Committee had nine Questions Taken on Notice from the public hearing. These are listed in **Appendix C**.
- 1.7. A breakdown of witnesses at the public hearing by gender identity is given in **Appendix D**.
- 1.8. In this report, references to *Committee Hansard* are to the *Proof Transcript* of evidence. Page numbers may vary between proof and final official transcripts.
- 1.9. Due to the sensitive nature of this inquiry, efforts were made to look at participants involved in this inquiry, especially those who gave evidence relating to their personal experience in looking after a family member.
- 1.10. Support for anyone affected by the issues raised in this inquiry is available from:
 - Lifeline: 131114 www.lifeline.org.au
 - Griefline: 1300 845 745 https://griefline.org.au/

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¹ ACT Legislative Assembly, *Minutes of Proceedings*, no 104, 31 October 2023, p 1492.

2. Introduction

Background to the bill

- 2.1. Between 1993 and 1997, five private members' bills were introduced in the ACT Legislative Assembly by independent MLA Micheal Moore in relation to voluntary assisted dying (VAD), however none of these bills passed.²
- 2.2. The first Australian jurisdiction to legalise VAD was the Northern Territory (NT) in 1995 with the *Rights of the Terminally III Act 1995.*³
- 2.3. In 1997, a federal bill, the Euthanasia Laws Bill 1996, came into effect which inserted provisions into *the Australian Capital Territory (Self-Government) Act 1988*, the *Northern Territory (Self-Government) Act 1979*, and the *Norfolk Island Act* 1979 which prevented the territories from passing legislation which would allow for VAD.⁴ This effectively overturned the recently introduced legislation in the Northern Territory, and prevented any further attempts to legalise voluntary assisted dying in NT, ACT, and Norfolk Island.
- 2.4. In 2017, the ACT Legislative Assembly established a Select Committee to review and report on end-of-life choices in the ACT. Whilst the inquiry was not specifically about voluntary assisted dying, it did seek community views on the desirability of VAD being legislated in the ACT, and the risks associated with it. The inquiry received 108 submissions in support of VAD and 160 in opposition. The report did not make any recommendations in relation to VAD but did comment that if the Assembly considered it in the future, it would need to implement significant safeguards. The report suggested further consideration would need to be given to the risks to vulnerable individuals, provisions for healthcare professionals who object, ensuring appropriate training and support to healthcare workers, establishing an independent body to record and assess data, and increasing palliative care funding.⁵
- 2.5. In December 2022, the federal government passed the Restoring Territory Rights Bill 2022, which amended the Australian Capital Territory (Self-Government) Act 1988 and the Northern Territory (Self-Government) Act 1978 to remove the prohibition on legalising euthanasia.⁶
- 2.6. In February 2023, the Justice and Community Safety Directorate, in conjunction with the ACT Health Directorate and Canberra Health Services, released a Discussion Paper⁷ on VAD. The paper identified key questions for a community consultation on what VAD should look like in the ACT.
- 2.7. Between February and April 2023, the ACT Government conducted community consultation on VAD in the ACT. The specific themes of the consultation were: eligibility,

² Voluntary and Natural Death Bill 1993; Medical Treatment Amendment Bill 1995; Euthanasia Referendum Bill 1997; Medical Treatment Amendment Bill 1997; Crimes (Assisted Suicide) Bill 1997.

³ Rights of the Terminally Act 1995 (NT).

⁴ Parliament of Australia, Restoring Territory Rights Bill 2022, Bills Digest No 5, 2022–2023.

⁵ Select Committee on End of Life Choice in the ACT, *Report*, March 2019, p 95–96.

⁶ Restoring Territory Rights Act 2022 (Cth).

⁷ ACT Government, Voluntary assisted dying discussion paper, February 2023.

the process, the role of health professionals and health services, and monitoring to ensure the process is safe and effective.⁸

- 2.8. A Listening Report was produced in June 2023, summarising the findings from the public consultation, highlighting that most contributors supported the main features of the 'Australian model' (i.e. the general approach taken in Victoria (Vic), Western Australia (WA), Queensland (Qld), South Australia (SA), Tasmania (Tas) and New South Wales (NSW)⁹:
 - strict eligibility criteria, including that a person must be suffering unbearably from a terminal illness, disease or condition;
 - thorough request process: three requests, including one in writing, with accessibility options, witnessed by independent witnesses;
 - provision of support and information through a government-run Care Navigator Service and pharmacy service;
 - two health professionals, who meet training and eligibility requirements to independently assess a person's eligibility, at least one of whom is responsible for ensuring the person is informed and supported regarding all of their end-of-life and care options;
 - strict requirements for prescription, management and administration of a VAD substance with criminal offences for mismanagement;
 - health professionals and health services may object to being actively involved in facilitating VAD, as long as they do not hinder access; and
 - an independent oversight body monitors compliance, records data, and exercises other oversight functions.
- 2.9. On 31 October 2023, the Voluntary Assisted Dying Bill 2023 was introduced in the ACT Legislative Assembly.¹⁰

Legislative scrutiny

- 2.10. The bill was considered by the Standing Committee on Justice and Community Safety (Legislative Scrutiny role) (the Scrutiny Committee) in its Scrutiny Report 37 of 21 November 2023.¹¹
- 2.11. The Scrutiny Committee noted that certain human rights can be limited due to the following features of the bill, but that these were identified in the explanatory statement with information provided as to why this was reasonable.¹²

⁸ Your Say Conversations, *Voluntary assisted dying*, <u>https://yoursayconversations.act.gov.au/voluntary-assisted-dying-in-ACT</u> (accessed 8 December 2023).

⁹ ACT Government, Voluntary assisted dying in the ACT: report on what we heard, June 2023, pp 3–4.

¹⁰ ACT Legislative Assembly, *Minutes of Proceedings,* No. 104, p 1493.

¹¹ Standing Committee on Justice and Community Safety (Legislative Scrutiny), Scrutiny Report 37, 21 November 2023, p 9.

¹² Standing Committee on Justice and Community Safety (Legislative Scrutiny), Scrutiny Report 37, 21 November 2023, p 9–11.

- 2.12. The Scrutiny Committee drew these to the attention of the Assembly but did not require a response from the minister.
- 2.13. The Scrutiny Committee further noted that the bill will introduce a large number of strict liability offences. These were brought to the attention of the Assembly.
- 2.14. The Committee also raised concerns about an offence in clause 64 of the bill that may inadvertently become a strict liability offence. The Committee asked the Minister for Human Rights to provide more information prior to the bill being debated:

Clause 64 of the bill creates two offences: subclause 64(3) requires an original contact person to comply within 2 days with a request from an individual to provide the approved substance to another contact person to be used in self-administration by the individual, subject to a maximum penalty of 100 penalty units; and subclause 64(5) requires the original contact person to tell the board within two days of providing the substance to the new contact person, subject to a maximum penalty of 20 penalty units. Subclause 64(6) provides that an offence against this section is a strict liability offence.

The Committee is concerned that subclause 64(6) will have the effect that the offence in subclause 64(3) will also be a strict liability offence, with a maximum penalty in excess of the 30 penalty units provided for in the Guide to Framing Offences. This is contrasted with the approach taken in other provisions of the bill, such as clause 101, where only one of two offences created by the clause is identified as a strict liability offence.

The Committee notes that a breach of subclause 64(3) may not have been intended to be a strict liability offence. That subclause is not described as a strict liability offence in the outline of the clause in the explanatory statement, and is not listed in the list of strict liability offences in Appendix 1 of the explanatory statement. The explanatory statement also refers to all strict liability offences having a maximum penalty of 20 or 30 penalty units.

The Committee therefore requests further information from the Minister whether it is intended that a breach of subclause 64(3) be a strict liability offence, and if so, why any limitation on the presumption of innocence by that subclause is considered necessary.¹³

- 2.15. The government responded, advising that it is not intended that subclause 64(3) will be a strict liability clause and that the government intends to make amendments to the bill to clarify this.¹⁴
- 2.16. The Scrutiny Committee also raised concerns that in discussing possible limitations to human rights relating to freedom of thought, conscience, religion and belief, the explanatory statement did not refer to the part of the bill that places obligations on facility

¹³ Standing Committee on Justice and Community Safety (Legislative Scrutiny), *Scrutiny Report 37*, 21 November 2023, p 11–12.

¹⁴ Ms Tara Cheyne, Member of the Legislative Assembly (MLA), Minister for Human Rights, *Response to Scrutiny Committee Report 37*, 14 December 2023, p 1.

operators to provide information, access and transfers relating to VAD. The minister was asked to provide further information on this prior to the bill being debated.¹⁵

2.17. The government advised that it intended to table a revised explanatory statement. It also advised that the bill may limit the right to freedom of both an individual responsible for the management of a facility, and for an individual working in a facility who may be directed to take certain actions that may conflict with their beliefs or religion.¹⁶ Further details are available in the minister's response.

Voluntary assisted dying laws across Australia

- 2.18. All Australian states currently make provision for VAD.
- 2.19. Similar to the ACT the Northern Territory has only recently received the right to legislate on this matter so is in the process of conducting its own inquiry into VAD.¹⁷
- 2.20. Across all Australian states, the following requirements are in place for a person to be eligible for VAD:
 - must be at least 18 years old;
 - must have decision making capacity;
 - must have a disease, illness or medical condition that:
 - will cause death;¹⁸
 - is causing intolerable suffering.
- 2.21. To access VAD, all Australian states require an individual to be expected to die within a certain timeframe. In all states, apart from Queensland, this is six months (unless they have a neurodegenerative condition in which case it is increased to 12 months).¹⁹ Queensland is the only state that allows individuals to access VAD if they are expected to die within 12 months.²⁰
- 2.22. In NSW, Tasmania and Queensland, individuals who are not Australian citizens or permanent residents can still access VAD if they have lived in Australia for three years. All other States only allow Australian citizens or those with permanent residency (PR) to access VAD. In all states, an individual must have lived in that jurisdiction for 12 months (Queensland and NSW allow people to apply for an exemption if they can demonstrate a close connection to that state).²¹

¹⁵ Standing Committee on Justice and Community Safety (Legislative Scrutiny), *Scrutiny Report 37*, 21 November 2023, p 12.

¹⁶ Ms Tara Cheyne MLA, Minister for Human Rights, *Response to Scrutiny Committee Report 37*, 14 December 2023, p 3. ¹⁷ Northern Territory Government, *Voluntary assisted dying (VAD) in the Northern Territory,*

https://haveyoursay.nt.gov.au/vad (accessed 5 December 2023).

¹⁸ In Tasmania, the *End-of-Life Choices (Voluntary Assisted Dying) Act 2021*, s 6(1)(b) states that the relevant medical condition is 'expected to cause death'.

¹⁹ ACT Government, Voluntary assisted dying discussion paper, February 2023, p 9.

²⁰ Voluntary Assisted Dying Act 2021 (Qld), s 10(1)(a)(ii).

²¹ Katherine Waller, Katrine Del Villar, Lindy Willmott, and Ben White, 'Voluntary assisted dying in Australia: A comparative and critical analysis of state laws', *University of New South Wales Law Journal*, vol 46, no 4, pp 1421–1470.

- 2.23. All states require a person to be assessed by two doctors as meeting the eligibility requirements.²²
- 2.24. In Victoria and South Australia, a person must self-administer the medication used to end their life. Medical practitioners can only assist if the person requesting VAD is physically unable to administer it themselves. In all other states, a person can request self-administration or practitioner administration.²³
- 2.25. Nurse practitioners can administer the medication in Western Australia, New South Wales, Tasmania, and Queensland, but are not permitted to in Victoria and South Australia.²⁴
- 2.26. In Victoria and South Australia, only the person wanting to access VAD can initiate the conversation about VAD; health practitioners are prohibited from initiating conversations with the patient. In New South Wales, Tasmania, Western Australia, and Queensland medical practitioners can initiate conversations about VAD but must also discuss possible treatments and palliative care options at the same time.²⁵
- 2.27. In Western Australia, if a health practitioner conscientiously objects to VAD, they must still provide information about it to the individual. In Tasmania, healthcare providers must give the individual the contact information to the VAD Commission if they object to assisting themselves. Similarly, in Queensland, healthcare providers with a conscientious objection must either refer the individual to a different healthcare provider who may be able to assist, or the Queensland Voluntary Assisted Dying (QVAD) Support Service. This contrasts with Victoria and South Australia, where conscientious objectors can refuse to provide any information about VAD.²⁶
- 2.28. New South Wales, Queensland and South Australia all have requirements regarding residential health care facilities and their obligations in respect of VAD.²⁷ All three states require residential care facilities to facilitate access by health professionals in relation to VAD, or transfer of the individual to a different facility, even if they object to VAD.

²² ACT Government, *Voluntary assisted dying discussion paper*, February 2023, p 14.

²³ Queensland University of Technology, End of Life Law in Australia, <u>https://end-of-life.qut.edu.au/assisteddying</u> (accessed 8 December 2023).

²⁴ ACT Government, Voluntary assisted dying discussion paper, February 2023, p 23.

²⁵ ACT Government, Voluntary assisted dying discussion paper, February 2023, p 24.

²⁶ ACT Government, Voluntary assisted dying discussion paper, February 2023, p 26 and Queensland Government, Queensland Voluntary Assisted Dying Handbook, October 2022, p 50.

²⁷ ACT Government, *Voluntary assisted dying discussion paper*, February 2023, p 29.

Table 1: Voluntary Assisted Dying Legislation in Australian jurisdictions [source: Australian Centre for Health Law Research, *QUT End of Life Law in Australia: Voluntary Assisted Dying*, <u>https://end-of-life.gut.edu.au/assitsteddying</u> (accessed 21 February 2024)

State	Applicable Legislation	Timeframe to death	Self or practitioner administration	Practitioners can initiate conversations about VAD	Must be Australian/PR	Conscientious Objectorss must refer or provide information	Date legislation commenced
NSW	Voluntary Assisted Dying Act 2022	6 months*	Choice	Yes	No	Yes	17 November 2023 ²⁸
Qld	Voluntary Assisted Dying Act 2021	12 months	Choice	Yes	No	Yes	1 January 2023 ²⁹
Vic	Voluntary Assisted Dying Act 2017	6 months*	Must self- administer (unless unable to)	No	Yes	No	19 June 2019 ³⁰
SA	Voluntary Assisted Dying Act 2021	6 months*	Must self- administer (unless unable to)	No	Yes	No	31 January 2023 ³¹
Tas	End-of-Life Choices (Voluntary Assisted Dying) Act 2021	6 months*	Choice	Yes	No	Yes	23 October 2022 ³²
WA	Voluntary Assisted Dying Act 2019	6 months*	Choice	Yes	Yes	Yes	1 July 2021 ³³

*or 12 months if the individual suffers from a neurodegenerative condition

Personal experiences

2.29. The Committee received a large number of submissions to this inquiry detailing personal experiences and appreciates the important perspective that these submissions provide.³⁴

²⁸ NSW Government, NSW Health, *Obligations of Healthcare Workers*, November 2023, <u>https://www.health.nsw.gov.au/voluntary-assisted-dying/Pages/healthcare-worker-obligations.aspx</u> (accessed 28 February 2024).

²⁹ Voluntary Assisted Dying Act 2021 (Qld), s 2.

³⁰ Voluntary Assisted Dying Act 2017 (Vic), s 2.

³¹ South Australian Government, *The South Australian Government Gazette*, 11 August 2022, no 55, p 2489.

³² Tasmanian Government, Department of Health, <u>Voluntary Assisted Dying in Tasmania</u>, p 1.

³³ Western Australian Government, Western Australian Government Gazette, 18 June 2021, no 106, p 2458.

 ³⁴ Geoffrey Kerr Williams, Submission 5, pp 2–3; name withheld, Submission 6, p 2; Susan Rockliff, Submission 13, pp 2–3; Tony Whelan, Submission 15, p 2; name withheld, Submission 18, p 2; Ian Chubb, Submission 31, pp 2–3; Mary Elizabeth Bruinink, Submission 40, pp 2–7; Susan Liebke, Submission 43, p 2; Joseph Gasendo, Submission 45, p 2;

- 2.30. The Committee would like to thank those who informed the Committee about their own, or their loved ones, experiences, and acknowledges that this may have caused considerable distress.
- 2.31. The following summarises some of the submissions made to this inquiry that detail personal experiences.
- 2.32. Geoffrey Kerr Williams detailed his mother's experience with Alzheimer's and the effect that watching her deteriorate had on their family. He expressed support for VAD being available through the use of advance care directives.³⁵
- 2.33. Ian Chubb spoke of his experience seeing his wife of 51 years being diagnosed with dementia, going into decline, and becoming unable to look after herself. He said 'she would not have conceded that the decline into indignity was acceptable had she known what was in store. Nor would she have missed an opportunity when cognitively aware to plan a dignified end-of-life on the chance that she may have developed dementia'.³⁶
- 2.34. Corrinne Vale and Jim Williams, daughter and husband of Ros Williams, shared Ros's experiencing of wanting to die with dignity at a time of her choosing. They informed the Committee that Ros took her own life as VAD wasn't available to her and urged the bill to be passed without delay, in the hope that others do not experience the same suffering.³⁷.
- 2.35. Lara Kaput detailed the experience of her partner's death from glioblastoma, describing multiple missed opportunities in his healthcare. She advised that after exhausting all options, he wanted to access VAD, but having moved to the ACT from Victoria was unable to do so.³⁸
- 2.36. Another shared with the Committee their own experiences of psychiatric illness, advising that the bill needed to go further to include psychiatric illness as an eligibility criterion for VAD.³⁹
- 2.37. Susan Rockliff also detailed her sister's experience with psychiatric illness, culminating in her sister ending her own life. She advised the Committee that discretion should be made for complex medical conditions, suggesting they be reviewed on a case-by-case basis.⁴⁰
- 2.38. Tony Whelan shared his experience of regularly visiting a friend who would have liked to die on her own terms after having a stroke. He expressed support for the absence of a time frame to death but felt that nonterminal conditions should also be included in the eligibility criteria.⁴¹

Katarina Pavkovic, *Submission 52*, pp 2–4; Dinny Lawrence, *Submission 65*, pp 2–8; Sheena Ruth Black, *Submission 68*, p 2; Lara Kaput, *Submission 81*, pp 2–13; Carole and Colin Ford, Alayne and David Richardson, *Submission 83*, pp 2–3. ³⁵ Geoffrey Kerr Williams, *Submission 5*, pp 2–3.

³⁶ Ian Chubb, *Submission 31*, p 1–2.

³⁷ Corinne Vale and Jim Williams, *Submission 70*, pp 2–17.

³⁸ Lara Kaput, *Submission 81*, pp 2–13.

³⁹ Name withheld, *Submission 6*, p 2.

⁴⁰ Susan Rockliff, *Submission 13*, pp 2–3.

⁴¹ Tony Whelan, *Submission 15*, p 2.

- 2.39. Susan Liebke told the Committee that as an octogenarian, she has witnessed the deaths of her parents, as well as many of her friends. She indicated support for VAD, stating that '[i]n my observed experience death and dying can be long and miserable'.⁴²
- 2.40. Joseph Gasendo expressed support for the Bill, sharing that both his parents and his first wide had passed away without the control they would have wanted.⁴³
- 2.41. Dinny Lawrence detailed her father's experience with asthma, resulting in him ending his own life; as well as her friends experience requesting VAD in Western Australia. As a result of these experiences, she expressed concern that the bill may be too prescriptive in its definition of 'advanced', and 'last stages of life'.⁴⁴
- 2.42. Sheena Ruth Black informed the Committee that she has chronic obstructive pulmonary disease (COPD) and would like the opportunity to die with dignity and independence should she no longer be able to breath without bottled oxygen.⁴⁵
- 2.43. Carol and Colin Ford along with Alayne and David Richardson shared their experience of watching their father pass away in hospital 'after many months of sad, painful decline'. They expressed concern that their mother is now also in decline, and 'who has on many occasions requested that she be allowed to die while still mentally capable of choosing to'.⁴⁶
- 2.44. Griefline shared that many of their members felt a stigma disclosing that their grief was as result of losing a loved one who chose VAD, and advised the Committee there is a need for VAD specific bereavement support.⁴⁷
- 2.45. The Committee notes that not all submissions that detail personal experiences have been included in this section, others have been noted throughout the report.

⁴² Susan Liebke, *Submission 43*, p 2.

⁴³ Joseph Gasendo, *Submission 45*, p 2.

⁴⁴ Dinny Lawrence, Submission 65, 2-8.

⁴⁵ Sheena Ruth Black, Submission 68, p 2.

⁴⁶ Carole and Colin Ford, Alayne and David Richardson, Submission 83, pp 2–3.

⁴⁷ Griefline, *Submission 56*, pp 2–4.

3. Operation of the bill

Eligibility criteria and timeframe to death requirements

3.1. Unlike other Australian jurisdictions, the bill does not require that there be an expected timeframe to death within six to 12 months to be eligible for voluntary assisted dying (VAD). The bill requires (along with other eligibility criteria) that a person has been 'diagnosed with a condition that either on its own or in combination with one or more other diagnosed conditions is advanced, progressive and expected to cause death'. In addition, the person must be 'suffering intolerably in relation to the relevant conditions'.⁴⁸

Concerns about the lack of a timeframe to death requirement

- 3.2. Some concerns were raised about the VAD eligibility criteria not including a requirement that a person has a finite life expectancy such as six to 12 months.
- 3.3. The Plunkett Centre for Ethics told the Committee that the lack of a timeframe to death criteria in the bill would lead to 'bracket creep'.⁴⁹
- 3.4. Calvary Health Care raised concerns about the differences between the proposed ACT model and established New South Wales (NSW) model including the lack of a timeframe requirement. They submitted that harmonising these differences is important to avoid unnecessary confusion and complexity for those accessing and navigating the ACT health system.⁵⁰
- 3.5. Advocacy for Inclusion (AFI) said that the absence of a timeframe to death in the eligibility criteria raises serious concerns for people with a disability, including unintended consequences such as coercion and inadequate disability support:

The Victorian legislation has a time frame requirement that a person needs to be within six months of their expected death. The ACT's does not, but the ACT's does have a requirement that on paper excludes disability from voluntary assisted dying. But if you take the time frame requirement away, there is nothing that distinguishes the meaning of disability within the ACT Discrimination Act—which is cited within the draft bill—from the eligible conditions that might be brought into scope for voluntary assisted dying.⁵¹

3.6. AFI told the Committee that the eligibility requirements to VAD should not be extended beyond the Victorian legislation – specifically in relation to the eligibility requirement that a person should be within six months of the expected death. Mr Wallace went on to say:

My disability will shorten my life span, but do I have a terminal illness that I would want to address by seeking voluntary assisted dying? At this point, no. But there

⁴⁸ Voluntary Assisted Dying Bill 2023, explanatory statement, p 9 and Voluntary Assisted Dying Bill 2023, cl 11(1)(b) and 11(1)(c).

⁴⁹ Dr Bernadette Tobin, Acting Director, Plunkett Centre for Ethics, *Proof Committee Hansard*, 31 January 2024, pp 114–115.

⁵⁰ Calvary Health Care, Submission 55, p 6.

⁵¹ Mr Craig Wallace, Head of Policy, Advocacy for Inclusion, *Proof Committee Hansard*, 29 January 2024, pp 55–57.

were times when that disability might have been intolerable to me and, if this legislation had been present, I might have sought voluntary assisted dying, and I would not be giving evidence to you today. That is where our problems with this lie.⁵²

- 3.7. Other witnesses disagreed with this concern that disability could be considered a condition that leads to being eligible for VAD. Dr White disagreed that the absence of a timeframe to death could lead to a person with a disability being eligible for VAD, noting that the bill specifically says disability is not one of the relevant conditions for qualifying for VAD.⁵³
- 3.8. The Minister for Human Rights told the Committee that disability is not an eligible condition for accessing VAD.⁵⁴
- 3.9. Subclause 11 (2) of the bill states that 'an individual does not meet the eligibility requirement mentioned in paragraph 11 (1) (b) [being diagnosed with a condition that is advanced, progressive and expected to cause death] only because they have a disability, mental disorder or mental illness'. See Chapter 6: Disability considerations for more detail regarding disability concerns.

Support for having no timeframe to death requirement

- 3.10. The ACT Government told the Committee that not having a timeframe to death requirement is consistent with the approach in the Netherlands, Belgium, Switzerland, Canada, Spain and Luxembourg. They advised that the combination of other eligibility requirements and safeguards is a better way to ensure that VAD is only available to those at an advanced stage of their illness where their functioning and quality of life is in decline and treatments are not providing the appropriate level of benefit.⁵⁵
- 3.11. The explanatory statement states that a timeframe to death requirement was not included because such eligibility criteria can be arbitrary and do not distinguish between the levels of intolerable suffering experienced by individuals with different timeframes to death.⁵⁶ The explanatory statement goes on to say that during consultation processes, the government was advised that timeframe to death criteria may delay eligibility to a point where the person is no longer well enough to navigate the assessment process. Further, the explanatory statement outlines a range of evidence, indicating that estimates of the timeframe to death can be inaccurate.⁵⁷
- 3.12. Many witnesses gave evidence to support this position.
- 3.13. Dr Kerstin Braun told the Committee that that a timeframe of 12 months is arbitrary. She noted that it had been adopted in other jurisdictions because it had been adopted in Victoria, and Victoria was following Oregon's lead. She went on to say that she did not see the absence of a timeframe leading to a greater risk of coercion given the assessments that

⁵² Mr Craig Wallace, Head of Policy, Advocacy for Inclusion, *Proof Committee Hansard*, 29 January 2024, p 55.

⁵³ Professor Ben White, *Proof Committee Hansard*, 1 February 2024, pp 150–151.

⁵⁴ Ms Tara Cheyne MLA, Minister for Human Rights, *Proof Committee Hansard*, 2 February 2024, p 201.

⁵⁵ ACT Government, *Submission 66*, p 18.

⁵⁶ Voluntary Assisted Dying Bill 2023, *explanatory statement*, p 9.

⁵⁷ Voluntary Assisted Dying Bill 2023, *explanatory statement*, p 10.

are required. $^{\rm 58}$ This was also noted in the submission from Dying with Dignity Western Australia. $^{\rm 59}$

- 3.14. The Health Care Consumers Association (HCCA) were supportive of the absence of a timeframe to death requirement in the eligibility criteria noting that the timeframe can be unclear in the case of neurological conditions such as motor neurone disease.⁶⁰
- 3.15. Ms Katarina Pavkovic spoke of her father's experience in suffering from Parkinson's disease and the difficulty in providing a timeframe to death:

... in terms of the time frame, for someone like my dad, who had a neurodegenerative disease, putting a time frame on something like that, particularly when Parkinson's has over 100 different expressions and 100 different ways on how it can progress, it can be really challenging to nail down a specific date, and it will be absolutely dependent on which doctor you go to. Someone will say three months and someone will say 24 months. It is inconclusive.⁶¹

- 3.16. Go Gentle Australia told the Committee that in relation to the absence of a six to 12 month timeframe to death, there were already a number of hurdles that a person had to get through to be eligible as they had to determine the condition was advanced, aggressive, expected to cause death and the person was suffering intolerably.⁶²
- 3.17. Go Gentle Australia also advised that life expectancy can be difficult to predict and can change, including in the context of motor neurone disease and some neurodegenerative diseases. They cautioned against reliance on a timeframe to death criteria:

That is some of the complexity that we have seen play out in other states around Australia, where, with the best of intentions, someone presents to their healthcare professional, and they look well. They look like they are stable on their oncology medications, or they look like they are managing well with their disease, and it looks, on the balance of probability, that they may live six months or more. Then a month later they come back, and something has happened, and they have deteriorated dramatically, and they only have a month to live. Suddenly, they have gone from a world where they were not eligible to actually now either needing to race at the very last stage of life, or tragically, cannot even get through the eligibility checks and balances at all.⁶³

3.18. The Clem Jones Group advised the Committee that in their view the VAD scheme protects vulnerable people from coercion, including the elderly and people with disabilities, even in the absence of a timeframe to death criterion, because a VAD system has safeguards in place.⁶⁴ Professor Lindy Willmott also noted that there are a number of safeguards to

⁵⁸ Dr Kerstin Braun, *Proof Committee Hansard*, 1 February 2024, pp 149–150.

⁵⁹ Dying with Dignity Western Australia, *Submission 67*, p 6.

 ⁶⁰ Dr Adele Stevens, Consumer representative, Health Care Consumers Association, *Proof Committee Hansard*, 29 January 2024, pp 20–21.

⁶¹ Ms Katarina Pavkovic, *Proof Committee Hansard*, 1 February 2024, p 166.

⁶² Dr Linda Swan, CEO, Go Gentle Australia, *Proof Committee Hansard*, 1 February 2024, p 124.

⁶³ Dr Linda Swan, CEO, Go Gentle Australia, *Proof Committee Hansard*, 1 February 2024, p 125.

⁶⁴ Mr David Muir AM, Chair, Clem Jones Group, *Proof Committee Hansard*, 1 February 2024, p 141.

ensure the 'decision is made by someone with capacity, voluntarily and without coercion' pointing to mandatory training requirements and conducting interviews with the person separately from caregivers.⁶⁵ Similar views were provided by the ACT Law Society.⁶⁶ The minister noted the protections provided include criminal offences for coercion.⁶⁷

3.19. In the public hearing the minister told the Committee that timeframes to death are a guess only and had been included in eligibility criteria in other states only for political reasons that facilitated the passage of legislation.⁶⁸

Using 'Last stages of their life' to define 'advanced'

3.20. Several witnesses raised concerns about the use of the term 'last stages of their life' used in clause 11(4) to define 'advanced' for purposes of clause 11(1)(b). This clause requires as part of the eligibility requirements for the condition to be 'advanced, progressive and expected to cause death'.

3.21. The term 'advanced' is defined as:

advanced—an individual's relevant conditions are advanced if—

- a) The individual's functioning and quality of life have declined; and
- b) Any treatments that are available and acceptable to the individual lose any beneficial impact; and
- c) The individual is in the last stages of their life.⁶⁹
- 3.22. Dr Michael Chapman told the Committee that the term 'last stages of life' could be easily misconstrued as being of advanced age.⁷⁰
- 3.23. Go Gentle Australia told the Committee that the use of the phase 'last stages of their life' was not helpful because it was not clear what it meant, and is repetitive when taken with the eligibility requirement that the condition the person is suffering from is expected to cause death. They recommended that it be removed because 'last stage' is subjective and would not make a meaningful difference if removed due to the need to meet other parts of the criteria.⁷¹
- 3.24. Go Gentle Australia provided additional information to clarify to the Committee that in their view, it runs the risk of it effectively 'reintroducing a timeframe in the VAD process as the term "last stages of life" requires the health professional to form a view about how long it will be until the person will die.'⁷²
- 3.25. The Clem Jones Group also told the Committee that removing the term 'last stages of their life' from the eligibility criteria would be 'eliminating an area of subjectivity.' They went on

⁶⁵ Professor Lindy Willmott, , Proof Committee Hansard, 1 February 2024, p 151.

⁶⁶ Ms Elsa Sengstock, Senior Policy Officer, ACT Law Society, *Proof Committee Hansard*, 2 February 2024, p 177.

⁶⁷ Ms Tara Cheyne MLA, Minister for Human Rights, *Proof Committee Hansard*, 2 February 2024, p 204.

⁶⁸ Ms Tara Cheyne MLA, Minister for Human Rights, *Proof Committee Hansard*, 2 February 2024, p 191.

⁶⁹ Voluntary Assisted Dying Bill 2023, cl 11(4).

⁷⁰ Dr Michael Chapman, Submission 59, p 2.

⁷¹ Dr Linda Swan, CEO, Go Gentle Australia, *Proof Committee Hansard*, 1 February 2024, pp 123–124.

⁷² Dr Linda Swan, CEO, Go Gentle Australia, *Clarification statement*, provided on 7 February 2024.

to say the existing requirements were adequate and were very supportive of the lack of a six to 12 month timeframe to death. $^{\rm 73}$

3.26. Professor Lindy Willmott, while supportive of the lack of a six to 12 month timeframe, said the term 'last stages of their life', will cause confusion and uncertainty for health professionals assessing eligibility who may have different views on when someone is in their last stages of life:

We anticipate that different health professionals will have different views about when someone is in the last stages of life. It could be that some doctors, or potentially nurse practitioners, think it will be last days or week or month of life. Others might think, "Well, maybe they are meaning six months. They have to be in the final six months." So we think it has potential for confusion, and that is undesirable. Indeed, it might mean that the ACT model becomes even narrower than currently exists in other jurisdictions. ⁷⁴

- 3.27. Professor Willmott raised the concern that while she did not think that the term being excluded from the bill would change the eligibility requirements, including the term would mean that people would have to start the process later and possibly lose capacity or die in the process.⁷⁵
- 3.28. Concerns about the subjectivity of the term 'last stages of their life' were also shared by the ACT Law Society. They told the Committee that it could be open to interpretation and would need to be supported by guidance materials and would likely be subject to judicial consideration.⁷⁶
- 3.29. In their submission, Voluntary Assisted Dying Australia and New Zealand (VADANZ) also echoed concerns that the wording was vague and open to interpretation. VADANZ suggested that the definitions used by the Palliative Care Outcomes Collaboration (PCOC) offer more standardised definitions that have been adopted by the Australian Institute of Health and Welfare. In addition, VADANZ suggested to the Committee that the word 'progressive' in clause 11(1)(b) should be replaced by alternative words such as 'unlikely to improve'. According to VADANZ, this would assist patients with conditions such as a stroke who have had their quality of life severely impacted and incur significant suffering despite it not being a progressive disease.⁷⁷
- 3.30. The minister acknowledged the numbers of submissions particularly from practitioners concerning the potential ambiguity and duplicative nature of the use of the 'last stage of life' in the eligibility criterion. She advised the Committee that she intended to consider this further.⁷⁸

⁷³ Mr David Muir AM, Chair, Clem Jones Group, *Proof Committee Hansard*, 1 February 2024, p 140.

⁷⁴ Professor Lindy Willmott, *Proof Committee Hansard*, 1 February 2024, pp 148–149.

⁷⁵ Professor Lindy Willmott, *Proof Committee Hansard*, 1 February 2024, p149.

⁷⁶ Ms Elsa Sengstock, Senior Policy Officer, ACT Law Society, *Proof Committee Hansard*, 2 February 2024, p 177.

⁷⁷ Voluntary Assisted Dying Australia and New Zealand (VADANZ), Submission 32, p 3.

⁷⁸ Ms Tara Cheyne MLA, Minister for Human Rights, *Proof Committee Hansard*, 2 February 2024, p 191.

Committee comment

3.31. The Committee notes the concerns raised by the terminology used in describing the condition in the eligibility requirements, in particular the use of the phrase 'last stages of their life' in the definition of 'advanced', and notes that the minister has acknowledged that clearer terminology is required.

Recommendation 1

The Committee recommends that the ACT Government review and introduce amendments to the bill to more clearly define the use of the term 'advanced'.

Recommendation 2

The Committee recommends that the ACT Government review the term 'last stages of their life' and introduce amendments to the bill providing a less subjective and ambiguous definition.

Strict liability offences

- 3.32. The Committee heard a range of concerns about the use of strict liability offences. Many of these related to the strict liability offence where a health practitioner or health service provider must refer or provide something within two working days (discussed in more detail below). An explanation of what is a strict liability offence is provided at the end of this section in addition to some issues in the bill that may require some clarification.
- 3.33. The explanatory statement specified that the strict liability offences were designed to regulate 'compliance requirements', and fall into three broad categories:
 - reporting to and notifying the Voluntary Assisted Dying Oversight Board (the board) of key events;
 - providing details of the Care Navigator Service to individuals; and
 - providing the VAD policy of a facility to an individual.⁷⁹
- 3.34. This following section will address the evidence received by the Committee in relation to each of the three broad categories.

Definition of a strict liability offence

- 3.35. The bill contains 34 strict liability offences.⁸⁰
- 3.36. Clause 5 provides that the *Criminal Code 2002* 'applies to all offences against this Act'.⁸¹ This means that the *Criminal Code 2002* will provide the definition of a 'strict liability offence' as relevant to the bill.

⁷⁹ Voluntary Assisted Dying Bill 2023, *explanatory statement*, p 37.

⁸⁰ Voluntary Assisted Dying Bill 2023, *explanatory statement*, p 37.

⁸¹ Voluntary Assisted Dying Bill 2023, cl 5.

- 3.37. Section 23 of the *Criminal Code 2002* sets out the definition of strict liability. It states that for a strict liability offence:
 - there are no 'fault elements';⁸² and
 - the defence of 'mistake of fact' remains available.⁸³
- 3.38. Section 17 describes fault elements as intention, knowledge, recklessness, or negligence. There is no need to prove fault via one of these elements for a strict liability offence.⁸⁴
- 3.39. The explanatory statement to the Voluntary Assisted Dying Bill 2023 notes that:
 - strict liability offences 'allow for the imposition of criminal liability without the need to prove fault';⁸⁵ and
 - the intent of including this offence type in the bill is to 'support an effective regulatory scheme and deter unauthorised behaviour'.⁸⁶
- 3.40. At the public hearing, the Justice and Community Safety Directorate expanded on the reasoning behind the inclusion of strict liability for some offences:

...decisions were guided by a policy document called the guide for framing offences. That sets out some general criteria about when offences are characterised as strict liability and the obligation to explicitly say so is in the legislation. In this circumstance—and probably just vis-a-vis the general policy principles—they are generally amenable in circumstances where individuals who will be subject to the offence should know or ought to know their obligations in this space and they are applicable in circumstances such as where it is necessary to ensure the integrity of a regulatory scheme, for example.⁸⁷

Board reports and notifications

- 3.41. The board is provided for in clauses 105–122 of the bill. The explanatory statement sets out that the board will be 'an important oversight mechanism to monitor compliance, recommend improvements to the scheme and provide for the safe and transparent operation of VAD legislation'. It also notes that the board will be independent, and must prepare annual reports as provided by the *Annual Reports (Government Agencies) Act 2004*.⁸⁸
- 3.42. Thirty-one of the 34 strict liability offences in the bill relate to the requirement to:

⁸² Criminal Code 2002, para 23(1)(a).

⁸³ Criminal Code 2002, para 23(1)(b) and s 36: Mistake of fact- strict liability: A person is not criminally responsible for an offence that has a physical element for which there is no fault element if a) when carrying out the conduct making up the physical element, the person considered whether or not facts existed, and was under a mistaken but reasonable belief about the facts; and b) had the facts existed, the conduct would not have been an offence.

⁸⁴ Criminal Code 2002, s 17.

⁸⁵ Voluntary Assisted Dying Bill 2023, explanatory statement, p 37.

⁸⁶ Voluntary Assisted Dying Bill 2023, *explanatory statement*, p 38.

 ⁸⁷ Daniel Ng, Acting Executive Group Manager, Justice and Community Safety Directorate, *Proof Committee Hansard*, 2 February 2024, p 215.

⁸⁸ Voluntary Assisted Dying Bill 2023, *explanatory statement*, pp 87–91.

- provide written notice to the board of practitioner appointments and transfers, deaths, and other matters within two working days;
- provide written notice or records to the board in relation to an approved substance within two working days; and
- provide the board with copies of assessment reports, requests, and other documents within two working days.⁸⁹
- 3.43. The Committee received evidence from several organisations about the practical reality of completing these administrative tasks which suggested that the two-day timeframe was very short. Concerns were raised given that not meeting the time requirement is a strict liability offence:
 - VADANZ cautioned that 'if coordinating or consulting doctors undergo an accident, personal or family trauma, or telecommunications disturbance' that resulted in a delay, they would be held liable regardless;⁹⁰
 - the Australia and New Zealand Society of Palliative Medicine (ANZSPM) were concerned about 'the capacity of the profession to comply with the administrative burden falling on the professionals';⁹¹
 - the Australian Midwifery and Nursing Federation (ANMF) pointed out that 'nursing and midwifery workforces (among other health professions) in the ACT continue to grapple with severe staffing issues', and as such may not be able to meet the deadline 'due to circumstances beyond their control';⁹² and
 - the ACT Law Society was critical about 'short timeframes (two working days) for meeting certain requirements under the bill (including making assessments and writing reports), given that a person will be subject to a strict liability offence for noncompliance...these offences generally carry a penalty of 20 penalty units (which equates to \$3,200 for an individual, and \$16,000 for a corporation).'⁹³
- 3.44. The ACT Human Rights Commission shared these concerns about two days being a short period to complete significant paperwork. They suggested that the combination of this and strict penalties especially given that there is no need to prove fault 'may serve as a disincentive for health practitioners to be involved with the scheme.'⁹⁴
- 3.45. ANMF agreed, submitting that the strict penalties may deter health practitioners from engaging in the scheme: 'the introduction of strict liability offences may be contrary to the public interest as it has the potential to render health professionals unwilling to obtain authorisation, impeding access to VAD in the ACT'.⁹⁵

⁸⁹ Voluntary Assisted Dying Bill 2023, *explanatory statement*, pp 107–109.

⁹⁰ Voluntary Assisted Dying Australia and New Zealand (VADANZ), Submission 32, p 3.

⁹¹ Australia and New Zealand Society of Palliative Medicine (ANZSPM), Submission 71, p 5.

⁹² The Australian Midwifery and Nursing Federation (ANMF), *Submission 36*, p 4.

⁹³ ACT Law Society, Submission 79, p 10.

⁹⁴ ACT Human Rights Commission, Submission 73, p 6.

⁹⁵ The Australian Midwifery and Nursing Federation (ANMF), Submission 36, p 4.

3.46. Carers ACT raised concerns about the application of strict liability to carers who are appointed as a contact person.⁹⁶ The contact persons role is to give the approved substance to the individual, and then give notice to the board within two working days under strict liability.⁹⁷

3.47. They argued that the bill should also protect contact persons:

Given the significant responsibilities of someone appointed as a contact person and the presence of liability offences if they fail in their duties, the objects of the Act must not only include protections for health practitioners but contact persons also.⁹⁸

- 3.48. During the public hearing, Carers ACT stated 'I think that we can all assume that when selfadministration has been chosen as the process for VAD, the carer is most likely to be the contact person.'⁹⁹
- 3.49. Carers ACT also raised concerns during the hearing about the two business day timeframe within which a contact person must notify the coordinating practitioner of a death.¹⁰⁰ As outlined in clause 73, the Committee notes that a strict liability offence does not apply to this notification¹⁰¹.
- 3.50. The Australian College of Nursing underlined the need for the Committee to consider the practical implications of the timeframe, saying that 'two days in the life of a nurse is very different than two days in the life of society, because we work 24/7'.¹⁰²

Referral timeframes to the care navigator service

- 3.51. There are two strict liability offences in the bill relating to referral of individuals to the Care Navigator Service:
 - clause 95 requires a health practitioner who refuses to do something because they conscientiously object to give an individual, in writing, the contact details of the Care Navigator Service within two working days; and
 - clause 99 requires a facility operator to give an individual who has requested VAD, in writing, the contact details of the Care Navigator Service within two working days.
- 3.52. Go Gentle Australia indicated their support relating to the referral of a person to the Care Navigator Service within two days.¹⁰³
- 3.53. During the public hearing, the Pharmacy Guild of Australia ACT Branch stated that there are no concerns about meeting the two-day timeframe for referral for pharmacists:

⁹⁶ Carers ACT, Submission 42, p 5.

⁹⁷ Voluntary Assisted Dying Bill 2023, cl 51 and subcl 61(4) and(5).

⁹⁸ Carers ACT, Submission 42, p 5.

⁹⁹ Ms Jessica Johnson, Policy Officer, Carers ACT, *Proof Committee Hansard*, 29 January 2024, p 47.

¹⁰⁰ Ms Lisa Kelly, CEO, Carers ACT, *Proof Committee Hansard*, 29 January 2024, p 47.

¹⁰¹ Voluntary Assisted Dying Bill 2023, cl 73.

¹⁰² Ms Kylie Yates, CEO, Australian College of Nursing, *Proof Committee Hansard*, 29 January 2024, p 36.

¹⁰³ Go Gentle Australia, *Submission 44*, p 11.

In pharmacies quite often there are several pharmacists, so if a particular one may not wish to have that conversation it could be passed immediately on to another. In pharmacies that may not have that option, we would usually have a buddy pharmacy that we refer them on to straightaway, because we already have that issue with the morning-after pill and some of those things. We are already set up for that, and we acknowledge that. With the pharmacists on our team that have that, we are very aware of who is able and who is not able. The community pharmacy network is very strong, and we would refer to our neighbouring pharmacists or refer the client on straightaway.¹⁰⁴

3.54. The minister outlined the reason the government sought to include strict liability provisions for the referral clauses:

It is about providing certainty to everyone. When you are making these sorts of requests, you are in a vulnerable state that is exacerbated by making the request. To make a request and then for the person to in their absolute right to object but to still be obligated to refer you and then not do that only exacerbates their vulnerability and the distress when someone is at that stage of their life. That is the balance we were looking to strike there.¹⁰⁵

Requirement for facility operator to have a VAD policy

3.55. Clause 103 requires a facility operator to:

- have a policy about VAD;
- publish said policy in an easily accessible way; and
- give an individual a copy of the policy, when requested, within two working days.¹⁰⁶
- 3.56. Go Gentle Australia stated that the VAD policy of a facility should be 'readily available', and it was appropriate that strict liability applied to a facility which does not publish it or provide it within two working days on request.¹⁰⁷
- 3.57. Whilst not directly addressing the requirement to provide a policy within two working days, at the public hearing, the Catholic Archdiocese of Canberra and Goulburn noted that 'we do not leave people ignorant of our ethical stance', and emphasised that '[we] do not think anybody accessing a Catholic healthcare service would be surprised that we do not engage in life-ending activity'.¹⁰⁸

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¹⁰⁴ Sandra Ferrington, Committee member, Pharmacy Guild of Australia ACT Branch, *Proof Committee Hansard*, 29 January 2024, pp 11–12.

¹⁰⁵ Ms Tara Cheyne MLA, Minister for Human Rights, *Proof Committee Hansard*, 2 February 2024, p 215.

¹⁰⁶ Voluntary Assisted Dying Bill 2023, cl 103.

¹⁰⁷ Go Gentle Australia, *Submission 44*, p 11.

¹⁰⁸ Archbishop Christopher Prowse and Dr Patrick McArdle, Catholic Archdiocese of Canberra and Goulburn, Proof Committee Hansard, 29 January 2024, p 73 and p 83.

3.58. The ACT Government submission pointed out although required to have an available policy, 'facility operators may decide their level of involvement with voluntary assisted dying'. The policy must simply describe how the minimum standards will be addressed.¹⁰⁹

Committee comment

3.59. The Committee notes the most frequent concerns in respect of the strict liability offences were raised in relation to the practical difficulties involved with meeting the two working day timeframe requirement. Options to avoid this situation would be either to change the offence from being a strict liability offence or to increase the timeframe of the strict liability offence. The latter maintains the protections of the legislation, but in a more reasonable manner.

Recommendation 3

The Committee recommends that the ACT Government introduce amendments to the bill to increase the timeframe from two working days to four working days for requirements to report or refer which have strict liability offence provisions attached.

3.60. The ACT Law society stated that, given the penalties associated with the legal requirements in the scheme, there should be clear provision of information:

...as part of the process of authorising practitioners (under Division 5.2 of the bill), the Director-General be required to provide information about the legal requirements under the scheme, drawing attention to the criminal sanctions which apply for non-compliance.¹¹⁰

Recommendation 4

The Committee recommends that the ACT Government provide plain English information about legal requirements and penalties to impacted health practitioners and health service providers who have obligations in regard to voluntary assisted dying.

Definition of a 'working day'

3.61. The bill provides the following definition of a working day:

working day, for a person, means a day when the person is working.¹¹¹

3.62. This differs from the definition of working day provided in the *Legislation Act 2001*, which provides that:

¹⁰⁹ ACT Government, *Submission 66*, p 16.

¹¹⁰ ACT Law Society, *Submission 79*, p 10.

¹¹¹ Voluntary Assisted Dying Bill 2023, Dictionary, working day.

working day means a day that is not-

- (a) a Saturday or Sunday; or
- (b) a public holiday in the ACT.¹¹²

3.63. The explanatory statement elaborates on the reasoning behind the definition of a working day provided in the bill:

In any case, the provisions attaching to health practitioners require practitioners to do things within 'working days', meaning days when that practitioner is working. This is a deliberately less rights-restricting approach than requiring practitioners to comply outside of their work hours, to reflect the significant burden these provisions place on practitioners.¹¹³

Business day

- 3.64. The bill also uses the phrase 'business days' in place of working days in three clauses relating to obligations for contact persons in subclauses 61(4), 64(5) and 73(2).
- 3.65. The bill provides no definition of 'business days'. The definition from the Legislation Act 2001 states:

business day means a day that is not—

(a) a Saturday or Sunday; or

(b) a public holiday or bank holiday in the ACT.¹¹⁴

3.66. No explanation is provided in the explanatory statement as to why the 'business days' definition should apply to these three clauses, as distinct from the remaining clauses which use 'working days'.

The need for clarity

3.67. The Clem Jones group raised concerns in their submission and at the public hearing in relation to the definition of working days provided for in the bill, particularly where a person is required to refer an individual in cases of conscientious objection. They argued that the bills definition could result in an individual waiting for an extended period, if the practitioner went on leave for example.¹¹⁵

Committee comment

3.68. The Committee notes that the definition of a working day needs to be clear because the clauses which use the phrase 'working days' are in relation to the obligations of various individuals and strict liability applies to many of these clauses.

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¹¹² Legislation Act 2001, ss 144(1) and Dictionary part one, working day.

¹¹³ Voluntary Assisted Dying Bill 2023, *explanatory statement*, p 40.

¹¹⁴ Legislation Act 2001, ss 144(1) and Dictionary part one, business day.

¹¹⁵ Clem Jones Group, *Submission 34*, p 11 and David Muir AM, Chair, Clem Jones Group, *Proof Committee Hansard*, 1 February 2024, p 143.

Recommendation 5

The Committee recommends that the ACT Government introduce amendments to the bill to more clearly define the meaning of 'working day'.

- 3.69. Appendix 1 to the explanatory statement is a list of strict liability offences.¹¹⁶ Several areas of the appendix are unclear. For example:
 - in the bill, paragraph 36(4)(b) does not match the text provided in the table. The table refers to providing the board a copy of the final assessment report within two working days, but in the bill refers to giving it to 'the individual as soon as practicable after preparing it;¹¹⁷
 - in the bill, paragraph 74(2)(b) refers only to the director-general, but the text in the table refers to the board;¹¹⁸ and
 - several other errors of correlation between clause numbers and the bill text.¹¹⁹

Recommendation 6

The Committee recommends that the ACT Government ensure all strict liability provisions in the bill align with the explanatory statement, and provide an updated version of the explanatory statement Appendix 1 to the Assembly.

Initiation of a conversation about VAD

- 3.70. The Committee heard several concerns about which health practitioners would be subject to the requirements in clause 152 for initiating conversations with an individual about VAD.
- 3.71. Subclause 152(2) allows relevant health professionals to initiate conversations about VAD, provided:
 - the person meets the required eligibility criteria; and
 - the health professional mentions the treatment and palliative care options available, and advises the person to speak to their treating doctor.¹²⁰
- 3.72. Subclause 152(3) defines 'relevant health professional' to mean a counsellor, social worker, or health practitioner.¹²¹

¹¹⁶ Voluntary Assisted Dying Bill 2023, *explanatory statement*, pp 107–109.

¹¹⁷ Voluntary Assisted Dying Bill 2023, para 36(4)(b).

¹¹⁸ Voluntary Assisted Dying Bill 2023, para 74(2)(b).

¹¹⁹ See, for example, 25(1)(c) and 58(3), Voluntary Assisted Dying Bill 2023, *explanatory statement*, pp 107–109.

¹²⁰ Voluntary Assisted Dying Bill 2023, subcl 152(2).

¹²¹ Voluntary Assisted Dying Bill 2023, subcl 152(3).

- 3.73. The Committee notes that clarification of the phrase 'health practitioner' was sought by some, including the Pharmacy Guild of Australian ACT Branch and Speech Pathology Australia.¹²²
- 3.74. The Committee also sought clarification from the minister regarding the intent of clause 152 in respect of whether it places obligations on any professional who is in initiating a discussion on VAD or defines who may initiate a discussion and what might be covered. The minister's response stated that the bill 'does not prohibit any person, including health professionals, from initiating a discussion about Voluntary Assisted Dying (VAD). Rather it establishes minimum requirements for health professionals who initiate these conversations'.¹²³
- 3.75. Several organisations raised their concerns in relation to the initiation of conversations about VAD by health practitioners. These concerns will be addressed below, and fell into two categories:
 - concern about the lack of clarity surrounding the definition of a health practitioner and who is impacted by the provisions; and
 - general concerns about the impact of a health practitioner initiating a conversation with an individual.

Definition of a health practitioner

- 3.76. The bill contains a dictionary of relevant terms.
- 3.77. The dictionary notes that several definitions, including the definition of 'health practitioner', are contained within the *Legislation Act 2001*.¹²⁴
- 3.78. The *Legislation Act 2001* provides the following definition of a health practitioner:

...health practitioner means a person registered under the Health Practitioner Regulation National Law (ACT) to practise a health profession (other than as a student).¹²⁵

- 3.79. Section 6 of the *Health Practitioner Regulation National Law (ACT) Act 2010* states that the schedule set out in the Queensland Act the *Health Practitioner Regulation National Law Act 2009 (Qld)* 'applies as a territory law'.¹²⁶
- 3.80. The *Health Practitioner Regulation National Law Act 2009 (Qld)* section five Definitions, sets out the following definition of a health care practitioner, and a health profession:¹²⁷
 - 'health practitioner means an individual who practises a health profession'.

¹²² Pharmacy Guild of Australia, Submission 24, p 2; Speech Pathology Australia, Submission 52, p 4.

¹²³ Ms Tara Cheyne MLA, Minister for Human Rights, *correspondence received 19 February 2024*.

¹²⁴ Dictionary, Voluntary Assisted Dying Bill 2023.

¹²⁵ Dictionary, *Legislation Act 2001*.

¹²⁶ Health Practitioner Regulation National Law (ACT) Act 2010, s 6.

¹²⁷ Health Practitioner Regulation National Law (Queensland) 2009, s 5.

- health profession means the following professions, and includes a recognised specialty in any of the following professions—
 - Aboriginal and Torres Strait Islander health practice;
 - Chinese medicine;
 - chiropractic;
 - dental (including the profession of a dentist, dental therapist, dental hygienist, dental prosthetist and oral health therapist);
 - medical;
 - medical radiation practice;
 - midwifery;
 - nursing;
 - occupational therapy;
 - optometry;
 - osteopathy;
 - paramedicine;
 - pharmacy;
 - physiotherapy;
 - podiatry;
 - psychology.

Concerns about the definition of health practitioner

- 3.81. Both the Pharmacy Guild of Australia ACT Branch and Speech Pathology Australia were unsure as to whether their practitioners would be considered health practitioners under the bill.¹²⁸
- 3.82. The list provided earlier from the *Health Practitioner Regulation National Law Act 2009* (*Qld*) does include pharmacists, but not speech pathologists.
- 3.83. Speech Pathology Australia advocated for speech pathologists to be recognised as 'relevant health professionals' for the purposes outlined in the bill, arguing:
 - speech pathologists often support people experiencing communication difficulties in conversations with other medical professionals; and

¹²⁸ Pharmacy Guild of Australia ACT Branch, *Submission 24*, p 3; Speech Pathology Australia, *Submission 52*, p 3.

- as part of a multidisciplinary team, protection from liability for speech pathologists was important: 'we are just asking for that [clause 152 of the bill] to also acknowledge the self-regulating health professions like speech pathology'.¹²⁹
- 3.84. Speech Pathology Australia also raised other concerns, which are covered under 'communication of decision' in this chapter, under the heading 'Communication of decision'.

3.85. The Pharmacy Guild of Australia ACT Branch also sought clarity on whether pharmacists were subject to the provision:

For our members, clarity is really important, regarding what they can and cannot say. We want them to know what is the right thing to say, and whether they can initiate it or not. We need to have that made fairly clear so that members do the right thing. Community pharmacists should know whether they can suggest it at all, and whether they can discuss it; otherwise they might say, "No, we can't do anything for you," and that person will not get the help they need.¹³⁰

3.86. The Committee raised the concerns that had been put to them regarding which health practitioners are affected by the provisions. The minister told the Committee that clause 125 (regarding people assisting access to VAD or witnessing administration of approved substance) and clause 126 (people engaging in conduct under the Act) are protections for people in such situations:

That is deliberately a broad protection that includes health professionals but also family, friends and carers, to the extent that they are performing a statutory function.¹³¹

Committee comment

- 3.87. The Committee recognises the concerns raised in evidence by witnesses about the lack of clarity concerning the definition of a health practitioner. To determine who is a health practitioner, it is necessary to consult the dictionary section of the bill, then the *Legislation Act 2001,* then the *Health Practitioner Regulation National Law (ACT) Act 2010,* then the *Health Practitioner Regulation National Law Act 2009 (Qld).*
- 3.88. Given the importance of the obligations outlined in this clause, the Committee is of the view that it should be made as easy as possible for people to understand who it applies to.

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 ¹²⁹ Ms Kym Torresi, Senior Adviser, Aged Care, Speech Pathology Australia, *Proof Committee Hansard*,
29 January 2024, pp 51–52.

 ¹³⁰ Ms Sandra Ferrington, Committee member, Pharmacy Guild of Australia ACT Branch, *Proof Committee Hansard*,
29 January 2024, p 10.

¹³¹ Ms Tara Cheyne MLA, Minister for Human Rights, *Proof Committee Hansard*, 2 February 2024, p 197.

Recommendation 7

The Committee recommends that the ACT Government introduce amendments to the bill to make it explicitly clear who is considered a health practitioner and therefore has obligations when initiating conversations (as per subclause 152(2)).

Initiation of conversations

Support for the bill

- 3.89. Dying with Dignity NSW considered the bill took a 'compassionate and common sense approach' to initiating conversations, noting that problems had occurred in Victoria where practitioners cannot mention VAD when discussing options.¹³²
- 3.90. During the public hearings, the Clem Jones Group reiterated this point, stating:

you are putting a medical practitioner in a circumstance where they are aware of other options for their patients, but they are not allowed to talk about them or discuss them. I think that is an unnecessary restriction on the professional duty of a medical practitioner.¹³³

- 3.91. Go Gentle Australia also expressed support for the proposal, advocating for an individual's right to be provided with all available health and treatment options by their healthcare professional.¹³⁴
- 3.92. During the hearings, the minister told the Committee that the ability of health practitioners to initiate conversations was a deliberate feature of the bill.¹³⁵ In addressing concerns about the risks involved, the minister stated:

...there are many safeguards that then follow a discussion. First of all, a person who considers what has been raised with them then needs to be acting voluntarily. They need to meet all of the eligibility criteria, not just one. They need to make repeated requests. There needs to be a coordinating and a consulting practitioner who both need to independently verify that this person does not feel coerced or whatever it may be. There are significant penalties for coercing someone to participate in voluntary assisted dying. I think all of these protections really do mitigate the risk that you are talking about.¹³⁶

3.93. Clause 92 provides that a person can only act as a coordinating, consulting, or administering practitioner if they are authorised to do so by the Director-General.¹³⁷ The combination of this requirement and proposed section 152 means that in practice:

¹³² Dying with Dignity NSW, Submission 77, p 4.

¹³³ Mr David Muir AM, Chair, The Clem Jones Group, Proof Committee Hansard, 1 February 2024, p 146.

¹³⁴ Dr Linda Swan, CEO, Go Gentle Australia, *Proof Committee Hansard*, 1 February 2024, p 126.

¹³⁵ Ms Tara Cheyne MLA, Minister for Human Rights, *Proof Committee Hansard*, 2 February 2024, p 198.

¹³⁶ Ms Tara Cheyne MLA, Minister for Human Rights, *Proof Committee Hansard*, 2 February 2024, p 199.

¹³⁷ Voluntary Assisted Dying Bill 2023, cl 92.

- a health practitioner listed in the *Health Practitioner Regulation National Law Act* 2009 (Qld) can initiate a conversation about VAD, but
- only practitioners authorised by the director-general can undertake the various functions relating to the acceptance of requests and assessments of eligibility.

Concerns

- 3.94. Several submitters cautioned that if a health practitioner can initiate a conversation, this could influence a patient's decision.¹³⁸
- 3.95. Family Voice Australia concurred, and illustrated their concerns about the power imbalance between a patient and health practitioner, particularly in relation to vulnerable people.¹³⁹
- 3.96. HOPE (Preventing Euthanasia and Assisted Suicide) were of the view that prohibiting health practitioners from initiating conversations was a 'crucial safeguard'.¹⁴⁰
- 3.97. ANZSPM suggested that the initiation of a discussion by a practitioner with limited knowledge of palliative care may be a concern, given the requirement to mention available palliative care options:

People not working in palliative care but getting involved in VAD will not have the equal knowledge of palliative care and all the options and the current treatments et cetera. So there is a tension there which we wish to highlight for the committee.¹⁴¹

- 3.98. These concerns are discussed further in Chapter 4: Palliative care considerations, under the heading 'palliative care training for VAD practitioners.
- 3.99. The Committee noted confusion around the operation of clause 152, and in particular subclause 152(2).
- 3.100. The committee heard from a range of witnesses that the scope of who was covered by this clause was unclear, and the obligations of this clause difficult to follow.
- 3.101. The Committee notes the evidence from groups such as the Pharmacy Guild of Australia ACT Branch, as referred to in paragraph 3.85, who stated they will receive questions on VAD, and would like clarity on what they can and can't discuss so they are not unintentionally breaking any laws.¹⁴²

Committee comment

3.102. The Committee is of the view that there should be clear expectations and guidance on having conversations about VAD for health professionals, and other associated

¹³⁸ See, for example, Andrew Donnellan, *Submission 60*, p 2; Jennifer Hobson, *Submission 80*, p 2.

¹³⁹ Family Voice Australia, Submission 69, p 6.

¹⁴⁰ HOPE (Preventing Euthanasia and Assisted Suicide), *Submission 72*, p 7.

¹⁴¹ Mr Joe Hooper, Chief Executive Officer, Australia and New Zealand Society of Palliative Medicine (ANZSPM), Proof Committee Hansard, 31 January 2024, p 98.

 ¹⁴² Ms Sandra Ferrington, Committee member, Pharmacy Guild of Australia ACT Branch, *Proof Committee Hansard*, 29 January 2024, p 10.

professionals. In this regard, while the Committee supports the intent of clause 152, it is of the view that the clause needs revision to meet that intent.

Recommendation 8

The Committee recommends that the ACT Government introduce amendments to the bill in respect of Clause 152, to provide greater clarity on the intent and obligations of the provisions and revise the explanatory statement accordingly.

Clarity of definitions

- 3.103. During the public hearings, the Committee asked Speech Pathology Australia, about their views on clause 94 on conscientious objection as it relates to speech pathologists. They responded that they believed speech pathologists would be 'covered' by clause 94, but not necessarily by clause 152.¹⁴³
- 3.104. The Committee notes that the explanatory statement refers to subclause 94(5), which does not exist in the bill.¹⁴⁴
- 3.105. Subclause 94(3) in relation to conscientious objection, provides the following definitions:
 - a) A health service is as defined in the *Health Act 1993*, section 5; and
 - b) A health service provider is as defined in the *Health Act 1993* section 7 (or is prescribed by regulation).¹⁴⁵
- 3.106. The definition referred to in the explanatory statement provides the following explanation in respect of a health practitioner:

A health practitioner is defined in the *Legislation Act 2001* (ACT) as a person registered under the *Health Practitioner Regulation National Law* (ACT) to practise a health profession (other than as a student). A health profession includes medicine, nursing, occupational therapy, pharmacy, physiotherapy, and psychology.¹⁴⁶

Procedural matters

3.107. A number of procedural issues were raised with the Committee about the operation of the VAD scheme under the bill. These concerns related to disposing of approved substances, the role of general practitioners (GPs), access to facilities, certification of witnesses and time between requests to access VAD.

¹⁴³ Kym Torresi, Senior Advisor Aged Care, Speech Pathology Australia, *Proof Committee Hansard*, 29 January 2024, p 50; Kym Torresi, Senior Advisor Aged Care, Speech Pathology Australia, *answer to QTON 3: conscientious objection referrals*, 29 January 2024 (received 6 February 2024), p 2.

¹⁴⁴ Voluntary Assisted Dying Bill 2023, *explanatory statement*, p 81.

¹⁴⁵ Voluntary Assisted Dying Bill 2023, subcl 94(3).

¹⁴⁶ Voluntary Assisted Dying Bill 2023, *explanatory statement*, p 81.

Disposing of approved substances

- 3.108. Division 4.3 of the bill outlines the processes for dealing with approved substances for the purposes of causing an individual's death under the VAD Scheme.¹⁴⁷
- 3.109. The bill proposes that contact persons, individuals, and other persons in possession of a controlled substance must return it to an 'approved disposer' no later than 14 days after the substance is deemed unusable or not required.¹⁴⁸
- 3.110. The bill's explanatory statement notes the lack of timeframe for clause 66 (which is for administering practitioners), suggesting that 'while it is expected this would occur as soon as practicable, given the administering practitioner is a health professional it is not considered necessary to impose a statutory timeframe to return the substance'.¹⁴⁹
- 3.111. A single centralised pharmacy service will be used for provision and disposal of approved substances, as is the case in other Australian jurisdictions.¹⁵⁰

Support for the bill

- 3.112. The ACT Government notes that the disposal of the approved substance is 'tightly regulated' in the bill, and in addition by the existing *Medicines, Poisons and Therapeutic Goods Act 2008.*¹⁵¹
- 3.113. The Clem Jones Group indicated their support for the provisions, commenting that the proposed processes would provide a 'secure' system without being 'overly onerous'.¹⁵²
- 3.114. The minister noted that the 14 day timeframe for return of substances was developed using the experience of other jurisdictions, and attempts to balance the burden on an individual's family with risk to the community.¹⁵³

Risks of the substance to the community

- 3.115. The Committee received evidence that raised concerns about the risks and responsibilities attached to these substances being in the community, including:
 - The Australian Lawyer's Alliance, who suggested that all relevant regulations in relation to storage of the substance must be clear and made public given the inherent risk;¹⁵⁴
 - The Australian Care Alliance, who noted their concern that the substance, once provided for self-administration, could be in the community for 'an indefinite time';¹⁵⁵

¹⁴⁷ Voluntary Assisted Dying Bill 2023, Division 4.3.

¹⁴⁸ Voluntary Assisted Dying Bill 2023, cl 65 and 67.

¹⁴⁹ Voluntary Assisted Dying Bill 2023, *explanatory statement*, p 73.

¹⁵⁰ Voluntary Assisted Dying Bill 2023, *explanatory statement*, p 5.

¹⁵¹ ACT Government, Submission 66, pp 9–10.

¹⁵² Clem Jones Group, *Submission 34*, p 10.

¹⁵³ Ms Tara Cheyne MLA, Minister for Human Rights, *Proof Committee Hansard*, 2 February 2024, p 213–214.

¹⁵⁴ Australian Lawyers Alliance, *Submission 41*, pp 12–13.

¹⁵⁵ Australian Care Alliance, *Submission 26*, p 12.

- The Pharmacy Guild of Australia ACT Branch, who agreed that the substance is dangerous, but pointed out many medications in the community can be;¹⁵⁶
- Carers ACT, who argue that carers are likely to fulfill the role of 'contact person', and therefore carry responsibilities in relation to clauses 64 and 65.¹⁵⁷

3.116. The Pharmacy Guild of Australia ACT Branch highlighted their concerns about the practical application of a single centralised pharmacy service, stating:

'It is common for family members to return all of a person's unused medicines to a local community pharmacy after a person dies for disposal by the Federal Government's Return of Unwanted Medicines (RUM) Program. We wish to highlight that there might be potential for unused VAD medicines to be returned to a community pharmacy for disposal as part of the general collection of unused medicines.'¹⁵⁸

3.117. The Pharmacy Guild of Australia ACT Branch reiterated this concern during their appearance at the public hearings, suggesting that a community pharmacy may receive such a substance for disposal, and clear procedures must be in place.¹⁵⁹

Committee comment

- 3.118. The Committee considers 14 days to be a lengthy period of time for people to return an unused or expired substance of this nature for disposal.
- 3.119. Notwithstanding this, the Committee understands the need to balance the provision of adequate time to meet disposal obligations with community safety.

Recommendation 9

The Committee recommends that the ACT Government introduce amendments to the bill in respect of the time frame in which unused or expired approved substances are to be returned by, following the death of an individual with a view to shortening it to no more than 72 hours, and making sure individuals and families are aware of these obligations prior to the substances being dispensed.

The role of General Practitioners

3.120. The Committee received evidence that General Practitioners (GPs) play an essential role in the care of individuals who may be seeking access to the scheme:

 ¹⁵⁶ Mr Simon Blacker, Branch President, Pharmacy Guild of Australia ACT Branch, *Proof Committee Hansard*, 29 January 2024, p 13.

¹⁵⁷ Carers ACT, Submission 42, p 5.

¹⁵⁸ Pharmacy Guild of Australia, *Submission 24*, p 4.

 ¹⁵⁹ Ms Sandra Ferrington, Committee member, Pharmacy Guild of Australia ACT Branch, *Proof Committee Hansard*,
29 January 2024, pp 12–13.

- The Pharmacy Guild of Australia ACT Branch explained that collaborative care was crucial, with an individual's GP is often being a central figure from whom to seek information;¹⁶⁰
- In many instances, palliative care is provided by GPs;¹⁶¹
- GPs are well placed to be approved practitioners for the voluntary assisted dying process.¹⁶²
- 3.121. Concerns about the possibility of vulnerable people being coerced into accessing VAD were raised in some submissions:¹⁶³
 - The Hon. Greg Smith SC noted that 'there is no requirement under the bill that they have previously seen a treating doctor of the patient and/or his/her family';¹⁶⁴ and
 - The Australian Care Alliance raised concerns about this, suggesting it may be difficult for a doctor to accurately assess decision-making capacity in a person they 'do not have an established relationship with'.¹⁶⁵
- 3.122. During the public hearings, The Plunkett Centre for Ethics indicated that although they did not support the bill, 'some kind of involvement of the person's GP—someone who has known the person—might provide the ingredients for you to ensure that the proper protections are in place' for those individuals at risk of coercion.¹⁶⁶
- 3.123. At the public hearing, the Clem Jones group suggested that GPs may well be the first professional an individual approaches with a request for VAD. They commented that in these cases, the existing relationship and rapport between the individual and GP would act as a safeguard, given the GP would be well placed to consider issues such as coercion.¹⁶⁷
- 3.124. Paragraph 7(f) of the bill states 'individuals should be protected from coercion and exploitation'¹⁶⁸ and includes offences for coercive actions.¹⁶⁹

Committee comment

3.125. The Committee notes that during the course of this inquiry, no submissions or evidence were received from GPs or their representative bodies.

Reasonable access to facilities

3.126. Amongst the range of obligations that apply to facility operators (i.e., entities responsible for the management of a facility such as a hospital, hospice, nursing home or residential

¹⁶⁰ Mr Simon Blacker, Branch President, Pharmacy Guild of Australia ACT Branch, *Proof Committee Hansard*, 29 January 2024, p 10.

¹⁶¹ Dr Michelle Gold, Australia and New Zealand Society of Palliative Medicine (ANZSPM), *Proof Committee Hansard*, 31 January 2024, p 94.

¹⁶² Name withheld, *Submission 57*, p 9; ACT Government, *Submission 66*, p 13.

¹⁶³ See, for example, Beverley Cains (former MLA), *Submission 50*, p 2; Hon. Greg Smith SC, *Submission 62*, p 15.

¹⁶⁴ Hon Greg Smith SC, Submission 62, p 16.

¹⁶⁵ Australian Care Alliance, *Submission 26*, p 12.

¹⁶⁶ Dr Bernadette Tobin, Acting Director, Plunkett Centre for Ethics, Proof Committee Hansard, 31 January 2024, p 113.

¹⁶⁷ Mr David Muir AM, Chair, The Clem Jones Group, *Proof Committee Hansard*, 1 February 2024, p 145.

¹⁶⁸ Voluntary Assisted Dying Bill 2023, para 7(f).

¹⁶⁹ Voluntary Assisted Dying Bill 2023, cl 40.

care facility)¹⁷⁰, a facility operator must, with the consent of the individual, allow a relevant person reasonable access to a person at the facility.¹⁷¹ A relevant person is a person providing information about VAD, or a person assisting in the VAD assessment process or a request for access to VAD.¹⁷²

3.127. Calvary Health Care stated that they do not credential external health practitioners to enter Calvary facilities to provide services beyond their expertise, citing concerns that they would not be able to ensure the appropriate standard of clinical care.¹⁷³

3.128. This was also noted by ANZSPM, who stated:

Allowing medical practitioners to enter and perform a procedure on a patient in an institution without any oversight, credentialling or governance of that institution is not accepted medical practice nor accepted patient care. This is not done in any other part of medicine, nor is it accepted by any institution. In this situation, it is important to ask who would be ultimately responsible for an adverse outcome, and to firmly reject the possibility of procedures being performed outside of the governance and staffing arrangements of the patient's hospital or care facility.¹⁷⁴

- 3.129. Calvary Health Care advised the Committee that the credentialing requirements for clinicians on hospital grounds are different to those for aged care facilities. They suggested the bill as written does not fully acknowledge these differences, and that closer alignment with NSW or South Australia (SA) would be beneficial.¹⁷⁵
- 3.130. Subclause 100(2) provides that access is not required if the facility operator decides it is not reasonably practicable to do so.

3.131. Professors Ben White and Lindy Willmott cautioned that the term 'not reasonably practicable' was difficult to define:

The circumstances in which it would be regarded as 'not reasonably practicable' to allow a relevant person to access the facility is therefore unclear, and amenable to a subjective assessment by the facility operator. This means that it is possible that an institution that has an objection to VAD may make this assessment differently to an institution that does not hold objections to VAD. This subjectivity is undesirable.¹⁷⁶

3.132. The Clem Jones Group submitted that a facility operator should not be deciding what is 'reasonable practicable'. They advised that a better approach would be that used in

¹⁷⁰ Voluntary Assisted Dying Bill 2023, subcl 96(1).

¹⁷¹ Voluntary Assisted Dying Bill 2023, para 102(1).

¹⁷² Voluntary Assisted Dying Bill 2023, subcl 98 (1).

¹⁷³ Calvary Health Care, Submission 55, p 9.

¹⁷⁴ Australia and New Zealand Society of Palliative Medicine (ANZSPM) Submission 71, p 6.

¹⁷⁵ Calvary Health Care, answer to QTON 5: information on hospital vs aged care facility obligations, 1 January 2024 (received 8 January 2024).

¹⁷⁶ Professor Lindy Willmott and Professor Ben White, Submission 27, p 12.

Queensland, where the facility operator does not have the discretion to decide what is reasonably practicable'.¹⁷⁷

3.133. Catholic Health Australia (CHA) also suggested that the definition of 'reasonably practicable' lacked clarity, and could be interpreted in a range of ways:

...although CHA members consider ethical objections as reasonably practicable, there is enough evidence to suggest that others may not at any given time, and no further clarity is provided within the bill to safeguard this outside of a few select areas outlined regarding assessment, and consultation.¹⁷⁸

3.134. The ACT Government advised the Committee that clause 103 of the bill requires facility operators to have policies on issues such as providing reasonable access.¹⁷⁹

Committee comment

3.135. The Committee notes the evidence raised about the difficulties in defining 'not reasonably practicable' and that this has the potential to cause inconsistent application of the law.

Recommendation 10

The Committee recommends that the ACT Government develop processes to allow an individual to seek independent review when a facility operator decides that access to a facility for a relevant person is not reasonably practicable.

Witnesses

- 3.136. The bill sets out a process for a person to access VAD, which involves a first request to access VAD, a second request and then a final request.¹⁸⁰ The second request must be signed in the presence of two eligible witnesses who certify that that it was signed voluntarily (or the individual voluntarily asked their agent to sign it).¹⁸¹ A witness must be an adult who:
 - will not benefit in any way from the death of the individual;
 - is not the owner of the facility the person lives in (if relevant); and
 - is not the person's coordinating or consulting practitioner.¹⁸²

Issues raised in evidence

3.137. The ACT Human Rights Commission noted that 'numerous independent individuals' need to be involved in the second request. The Commission submitted that needing up to three independent individuals present to make a second request was challenging for those who

¹⁷⁷ Clem Jones Group, *Submission 34*, p 10.

¹⁷⁸ Catholic Health Australia (CHA), *Submission 46*, p 9.

¹⁷⁹ Mr Daniel Ng, Acting Executive Group Manager, Justice and Community Safety Directorate, *Proof Committee Hansard*, 2 February 2024, p 210.

¹⁸⁰ ACT Government, *Submission 66*, pp 8–9.

¹⁸¹ Voluntary Assisted Dying Bill 2023, subcl 27(3).

¹⁸² Voluntary Assisted Dying Bill 2023, subcl 27(6).

may be living in a health facility or isolated in the community. They warned that 'while we understand the need for robust witnessing requirements, the practical effect may serve as an unnecessary barrier'.¹⁸³

- 3.138. Go Gentle Australia also shared these concerns and suggested that one witness rather than two would be sufficient.¹⁸⁴
- 3.139. Conversely, the ACT Law Society pointed out that witness capability is crucial, given that the witness must be confident that the request is being made free from any coercion. Their submission suggested consideration be given to mandating witness qualifications (such as those required for witnessing statutory declarations).¹⁸⁵
- 3.140. In evidence provided at the public hearing, the Society noted that:
 - having a qualified witness has a 'degree of solemnity that can be relied upon by court or tribunal in the future';¹⁸⁶ and
 - there may be situations where judging whether or not coercion has taken place is 'open to interpretation';¹⁸⁷ however
 - they appreciate the need to balance 'the availability of witnesses with also making sure the witnesses who are present are appropriate'.¹⁸⁸
- 3.141. The ACT Law Society provided several examples in their submission of what a certified witness may look like in practice, including solicitors, Justice of the Peace, and persons able to witness statutory declarations.¹⁸⁹
- 3.142. The ACT Human Rights Commission considered the evidence provided at the hearing by the ACT Law Society, and suggested it was too restrictive:

it would be adding complexity: who is a certified witness; where can we find them; is it a public holiday in Canberra; is it over Christmas, when there is no-one here? You know, there is a whole range of factors that go into that, particularly in a small jurisdiction.¹⁹⁰

3.143. In their joint submission, Exit International ACT (Exit ACT) and Ethical Rights were generally supportive of the proposed witnessing requirements as they stand in the bill, submitting that the scheme should adopt 'best regulatory practice': two witnesses would suffice; and carers, and anyone set to benefit from the individual's death, should be ineligible.¹⁹¹

¹⁸⁹ ACT Law Society, *Submission 79*, p 6.

¹⁸³ ACT Human Rights Commission, Submission 73, p 7.

¹⁸⁴ Go Gentle Australia, *Submission 44*, p 9.

¹⁸⁵ ACT Law Society, *Submission 79*, p 5.

 ¹⁸⁶ Mr Timothy Morton, Co-Chair, Elder Law and Succession Committee, ACT Law Society, *Proof Committee Hansard*, 2 February 2024, p 179.

¹⁸⁷ Ms Elsa Sengstock, Senior Policy Officer, ACT Law Society, *Proof Committee Hansard*, 2 February 2024, p 179.

¹⁸⁸ Ms Elsa Sengstock, Senior Policy Officer, ACT Law Society, *Proof Committee Hansard*, 2 February 2024, p 179.

¹⁹⁰ Ms Karen Toohey, Discrimination, Health Services, Disability and Community Services Commissioner, ACT Human Rights Commission, *Proof Committee Hansard*, 2 February 2024, p 185.

¹⁹¹ Exit ACT and Ethical Rights, Submission 29, p 69.

In addition to their concerns about witness qualifications, the ACT Law society also 3.144. cautioned that 'under the Victorian scheme, no more than one witness can be a family member'.¹⁹² The Committee notes that, although paragraph 27(6)(c) stipulates that a person set to benefit in any way from a death cannot be a witness, family members are not specifically excluded.

Time between requests to access VAD

- 3.145. The bill does not provide a minimum waiting period that must elapse between the first and final request for VAD. Several submissions offered support for this lack of 'cooling off' period.193
- In their submission, Professors Lindy Willmott and Ben White pointed out that requesting 3.146. and being assessed for eligibility already take a significant period of time. They reported, for example, that the median number of days between the first and final request in Western Australia was 13 (despite that jurisdiction having a 9 day cooling off period).¹⁹⁴
- 3.147. Although Go Gentle Australia generally concurred with the view that the time the process takes in itself acts as a cooling off period, they did raise some concerns:
 - it is not impossible that a person could 'move through the process very rapidly';¹⁹⁵ and
 - voluntary assisted dying should never be considered as an 'emergency situation' to be dealt with entirely within a single day.¹⁹⁶
- 3.148. Given these concerns, they suggest in their submission the inclusion of a minimum 48-hour period between the first and last requests.¹⁹⁷
- 3.149. At the public hearing, Dr Linda Swan from Go Gentle Australia provided further context for the organisation's position:

In reality, we think that the process is much longer than 48 hours, but it is possible, if you do not have anything in there, that you are going to open up the bill to criticism, because perhaps, theoretically, there is some way someone could be raced through the process in fewer than 24 hours. If you at least have that which says no-one will ever be able to get through in fewer than two days, it is just another safeguard. In practicality, that is not the way the system works; it is very complicated. There are a lot of different steps involved. I cannot even think of a case that we have heard of where someone got through in anywhere near 48 hours.198

3.150. This issue was also discussed with Professor Ben White at the public hearing, who argued that the goal was that an individual makes 'a considered, careful decision' and this was

¹⁹² ACT Law Society, Submission 79, p 6.

¹⁹³ See, for example, Marshall Perron, *Submission 19*, p 3; Lindy Willmott and Ben White, *Submission 27*, p 11.

¹⁹⁴ Professor Lindy Willmott and Professor Ben White, *Submission 27*, p 11.

¹⁹⁵ Go Gentle Australia, *Submission* 44, p 9.

¹⁹⁶ Go Gentle Australia, *Submission* 44, p 9.

¹⁹⁷ Go Gentle Australia, *Submission* 44, p 9.

¹⁹⁸ Dr Linda Swan, CEO, Go Gentle Australia, Proof Committee Hansard, 1 February 2024, p 127.

achieved by the process requirements. The Professor also noted, however, that in jurisdictions that do have cooling off provisions, exemptions can be granted and waiting periods can be shortened.¹⁹⁹

- 3.151. Exit ACT and Ethical Rights argued that there should be exemptions available to any legislated timeframe, noting that those receiving palliative care or of advanced age may not be able to wait.²⁰⁰
- 3.152. In their submission, the ACT Government stated that a 'significant number' of exemptions are being granted in other Australian jurisdictions where these is a minimum waiting period, highlighting the need for flexibility in some cases.²⁰¹
- 3.153. Despite their suggestion of adding a minimum waiting period, Go Gentle Australia also advocated strongly for an exemption to be included where a person may either die or lose capacity within a short time.²⁰²

Committee comment

3.154. The Committee would like to seek assurance that the VAD process achieves a balance, and is not unduly rushed. It therefore considers that a mandated 48 hour gap in most cases will help achieve this.

Recommendation 11

The Committee recommends that the ACT Government introduce amendments to the bill to require a minimum waiting period of 48 hours between first and last requests to access voluntary assisted dying, with the ability to grant exemptions where there is a compelling reason.

Communication of decision

- 3.155. The bill permits individuals seeking access to VAD to communicate decisions 'in what ever way they can' in relation to:
 - determining decision-making capacity;
 - making the first and final request (to a health practitioner); and
 - making or changing administration decisions.²⁰³
- 3.156. The explanatory statement notes that the bill allows decisions to be communicated 'in what ever way they can' because sometimes individuals may have conditions that prevent the decisions being made in writing or orally:

¹⁹⁹ Professor Ben White, *Proof Committee Hansard*, 1 February 2024, p 148.

²⁰⁰ Exit ACT and Ethical Rights, *Submission 29*, p 69.

²⁰¹ ACT Government, Submission 66, p 24.

²⁰² Go Gentle Australia, *Submission* 44, p 9.

²⁰³ Voluntary Assisted Dying Bill 2023, subcl 12(1), 13(3), 32(3), 42(3), 43(3), and 45(2).

Provisions such as these ensure that an individual is not precluded from accessing VAD simply because they have a disability or condition which involves fluctuating decision-making capacity, or which affects their ability to communicate without support. This is particularly important in the context of VAD. Many individuals seeking to access VAD may, due to the advanced progression of their condition, have lost the ability to speak or write. Others may be taking medication that affects their decision-making capacity from time to time. Providing safeguarded yet flexible avenues for accessing VAD promotes the right to equality and non-discrimination.²⁰⁴

- 3.157. The second request, unlike the first and final, must be made in writing; however, provision is made for an agent to sign a request on behalf of an individual who has decision making capacity but is unable to physically sign.²⁰⁵
- 3.158. The ACT Law Society highlighted the importance of considering potential impediments to a person demonstrating their understanding and decision-making capacity. These impediments included factors 'such as language barriers, communication methods, the extent of any physical or mental impairment (as distinct from having no legal capacity) and the vulnerability of the person's situation'.²⁰⁶
- 3.159. Speech Pathology Australia advised that the requirement for the second request to be in writing may also present difficulties to those with limited literacy skills (which may be a result of illness, education, or English language proficiency). They were of the view that a proforma being available for the request may be beneficial.²⁰⁷
- 3.160. Speech Pathology Australia presented evidence on the importance of considering communication methods, particularly in relation to a person's ability to demonstrate decision-making capacity, including:
 - that the 'communication accessibility' of the process must be considered to ensure individuals with communication difficulties can access the scheme if they wish;²⁰⁸
 - that 'it is a common misconception, even amongst some medical practitioners, that people without speech cannot have legal capacity';²⁰⁹
 - that communication accessibility would be improved if additional supporting information about aids and strategies was included in the bill;²¹⁰ and
 - speech pathologists are an essential part of a care team in some circumstances.²¹¹
- 3.161. Speech Pathology Australia elaborated on the reasons for speech pathologists being essential:

²⁰⁴ Voluntary Assisted Dying Bill 2023, *explanatory statement*, p 9.

 $^{^{\}rm 205}$ Voluntary Assisted Dying Bill 2023, subcl 27(3) and 27(4).

²⁰⁶ ACT Law Society, *Submission 79*, p 5.

²⁰⁷ Speech Pathology Australia, *Submission 52*, p 3.

²⁰⁸ Speech Pathology Australia, *Submission 52*, p 2.

²⁰⁹ Speech Pathology Australia, *Submission 52*, p 3.

²¹⁰ Speech Pathology Australia, *Submission 52*, p 3.

²¹¹ Ms Kym Torresi, Senior Adviser Aged Care, Speech Pathology Australia, *Proof Committee Hansard*, 29 January 2024, p 49.

Typically, if we are then supporting that person with a communication aid, for example, it is the speech pathologist who needs to program the vocabulary into the communication device. Without that communication device, the person may not be able to clearly make their wishes known to the medical practitioner to seek voluntary assisted dying.²¹²

Committee comment

3.162. The Committee notes that Speech Pathology Australia suggested that clause 12 (the meaning of decision-making capacity) could be improved with the inclusion of examples of communication support, such as those found in the *South Australian Voluntary Assisted Dying Act 2021*.²¹³

Recommendation 12

The Committee recommends that the ACT Government works with speech pathology practitioners and representatives to reconcile any concerns regarding communicating decisions to access voluntary assisted dying other than oral and written.

Period to apply for a review by the ACT Civil and Administration Tribunal

- 3.163. The bill gives the ACT Civil and Administrative Tribunal (ACAT) jurisdiction to review decisions made about whether a person has decision making capacity, is acting voluntarily and without coercion, and has lived in the ACT for at least the previous 12 months.²¹⁴
- 3.164. Clause 133 of the bill allows a person subject to a 'reviewable decision' (or another person with sufficient or genuine interest in the rights of this person) to make an application to the ACAT for review. The application must be made within five days of the individual being given a copy of the first assessment report, consulting assessment report or final assessment report or becoming aware of the reviewable decision.²¹⁵
- 3.165. The explanatory statement states that while five days is shorter than usual 28 days, a person's need to access VAD can be time critical and delay might prolong suffering. The explanatory statement goes on to say that under section 151C of the *Legislation Act 2001* (ACT) the ACAT can extend this timeframe even after the it has elapsed.²¹⁶
- 3.166. The ACT Law Society raised concerns in their submission that five days was a very short time frame and could be a barrier to accessing review rights, especially if the individual

²¹² Ms Kym Torresi, Senior Adviser Aged Care, Speech Pathology Australia, *Proof Committee Hansard*, 29 January 2024, p 49.

²¹³ Speech Pathology Australia, *Submission 52*, p 3 and the *South Australian Voluntary Assisted Dying Act 2021* subsections 4(1) and 4(3).

²¹⁴ Voluntary Assisted Dying Bill 2023, *explanatory statement*, p 93.

²¹⁵ Voluntary Assisted Dying Act 2023, subcl 133(1) and (2).

²¹⁶ Voluntary Assisted Dying Bill 2023, *explanatory statement*, p 95.

wishes to seek legal advice. They suggested that the bill allow the ACAT the discretion to allow applications outside the five-day period.²¹⁷

3.167. The Human Rights Commission also raised concerns about the five-day period in cases where the request to access VAD has been denied. They recommended that the usual 28 days should apply in these cases with the ACAT having their usual discretion to extend that time period in limited circumstances. This will enable the person to learn about and act on their review rights, including by seeking legal advice where necessary. In cases where the request to access VAD has been agreed to, the Human Rights Commission were supportive of the five day timeframe in order to prevent undue intolerable suffering.²¹⁸

Committee comment

3.168. The Committee notes the concerns raised by the ACT Law Society and the ACT Human Rights Commission regarding the five day timeframe for making an application for a review of a reviewable decision, particularly for a person who has had their application denied and that this could be a barrier to accessing review rights. The Committee notes that the explanatory statement has indicated some scope to extend this timeframe already exists under the *Legislation Act 2001*, but it is not clear if this can be easily accessed and if there is adequate awareness of it. Having it expressly included in the Voluntary Assisted Dying bill would make this clearer.

Recommendation 13

The Committee recommends that the ACT Government introduce amendments to the bill to extend the ACT Civil and Administration Tribunal (ACAT) review application time of five days where a reviewable decision has led to access to voluntary assisted dying being denied, to align with the 28 days usually available and allow ACAT members the discretion to increase this time as they can with other matters.

Voluntary Assisted Dying Oversight Board membership

- 3.169. Division 8.2 of the bill concerns the membership of the board. It stipulates that the board must consist of at least four, but no more than seven members, including the chair and deputy chair.²¹⁹
- 3.170. A number of submitters made suggestions in regard to the membership of the VAD Oversight Board.²²⁰
- 3.171. Advocacy for Inclusion sought the inclusion of a person with a disability on the VAD Oversight Board who could 'apply a critical and inquiring lens on end-of-life issues working

²¹⁷ ACT Law Society, *Submission 79*, p 7.

²¹⁸ Human Rights Commission, *Submission 73*, p 6.

²¹⁹ Voluntary Assisted Dying Bill 2023, cl 106.

²²⁰ See, for example: Health Care Consumers Association (HCCA), Submission 28, p 8; Advocacy for Inclusion (AFI), Submission 61, p 6; Palliative Care ACT, Submission 58, p 3.

from a disability rights perspective'. They suggested this board member be nominated by a peak Disabled Peoples Organisation.²²¹

3.172. During the public hearing, they further elaborated on the need for the board to include someone with lived experience of disability, stating:

I think you need someone on there with a critical eye—somebody who can look over this and say, "Actually, that was a person with a disability. If we provided that person with the right interventions at the right time, that might not have been necessary or appropriate for them. What can we do, as we move forward with this, to prevent more adverse outcomes like this?" It needs to be somebody from the disability rights community with a strong understanding of the social model and CRPD who can cast a critical eye over all of them.²²²

- 3.173. Palliative Care ACT suggested that it would be beneficial for the board to include a palliative care professional, considering the importance of VAD being implemented alongside quality end-of-life care.²²³
- 3.174. HCCA advocated for the inclusion of a consumer member on the board; an individual who could represent the perspective of a person seeking VAD.

3.175. They told the Committee this was needed because:

...other people on that board will be there to perhaps represent what it is like to be the medical practitioner, the pharmacist and the care facility. There will be other people with other views that have a primary reason for being there. Somebody needs to be on that board whose primary reason is to take care of the people and their families who are seeking VAD.²²⁴

- 3.176. Subclause 107(2) stipulates that the board needs to include people with a 'range of experience, knowledge and skills relevant to the work of the board', and take into consideration 'the social, cultural and geographic characteristics of the ACT community and people who work or receive medical treatment in the ACT'.²²⁵
- 3.177. Subclause 107(5) asserts that a relevant area for admission to the board includes:
 - (a) medicine;
 - (b) nursing;
 - (c) pharmacy;
 - (d) psychology;
 - (e) social work;

²²³ Palliative Care ACT, *Submission 58*, p 3.

²²¹ Advocacy for Inclusion (AFI), *Submission 61*, p 6.

²²² Mr Craig Wallace, head of Policy, Advocacy for Inclusion (AFI), *Proof Committee Hansard*, 29 January 2024, p 62.

 ²²⁴ Ms Kate Gorman, Deputy Director, Health Care Consumers Association (HCCA), *Proof Committee Hansard*,
29 January 2024, p 18.

²²⁵ Voluntary Assisted Dying Bill 2023, subcl 107(2).

- (f) ethics;
- (g) law;
- (h) another area the Minister considers relevant to the performance of the board's functions.²²⁶

Committee comment

3.178. The Committee recognises the need for the board to include a variety of relevant perspectives, knowledge, and experience, whilst also being made up of a manageable number of members.

Recommendation 14

The Committee recommends that the ACT Government ensures the Voluntary Assisted Dying Oversight Board contains members with a range of perspectives, and consider the inclusion of members with knowledge and/or experience of:

- lived experience of disability;
- palliative care;
- healthcare consumers and carers.

Statutory review of the Act

- 3.179. Subclause 159(1) of the bill requires the minister to conduct a review of the Act three years after commencement, and every five years thereafter.²²⁷
- 3.180. Subclause 159(2) states that the first review must consider the following eligibility matters:
 - residency status;
 - children and their decision-making capacity; and
 - the use of an advanced care plan to request VAD.²²⁸
- 3.181. Many submissions addressed this aspect of the review.²²⁹ The Committee notes there was a range of views in relation to the requirement to consider these specific eligibility matters, in particular relating to children and advanced care plans.

²²⁶ Voluntary Assisted Dying Bill 2023, subcl 107(5).

²²⁷ Voluntary Assisted Dying Bill 2023, subcl 159(1).

²²⁸ Voluntary Assisted Dying Bill 2023, subcl, 159(2).

²²⁹ See, for example, Catholic Health Australia (CHA), *Submission 46*, p 11; Name Withheld, *Submission 57*, p 4; Roy Harvey, *Submission 76*, p 9.

Children with decision-making capacity

Support

- 3.182. Former MLA Mary Porter noted that the review should seek the voices of those affected: 'When this legislation is reviewed at a later date, it is important that terminally ill young people are given a voice in the consultation'.²³⁰
- 3.183. The ACT Human Rights Commission said that children and young people should have access to the scheme, in line with their rights to access health care and have their views considered. The Commission acknowledged that 'there may need to be additional steps and safeguards', and that the issue has 'already been incorporated into the requirements of the future review.'²³¹
- 3.184. Exit ACT and Ethical Rights pointed out in their submission that waiting until the inclusion of children in the scheme had been considered in the review ensured that 'no changes would be effective until at least 2030'.²³² At the public hearing, Dr David Swanton argued that the exclusion of children from the scheme is discrimination on the basis of age.²³³
- 3.185. The minister noted that during its consultation on the bill, the government 'did hear some strong support, of course, and I think the view that was generally put forward as a theme was that an age as a limit is arbitrary and it really should be about someone's decision-making capacity'.²³⁴
- 3.186. However, the minister suggested that this issue was best addressed in the first review because of the 'significant policy complexities' involved in implementing access for young people, and the need to balance human rights obligations with the practicalities of rolling out the scheme in a timely manner.²³⁵

Concerns

- 3.187. Several witnesses and submissions argued that children must never be eligible for VAD, and therefore this aspect of the review should be removed.²³⁶
- 3.188. During the public hearings, ACT Right to Life were critical of the inclusion of children's eligibility in the review clause, arguing that it did not uphold the right to life and was unjust.²³⁷
- 3.189. Others raised concerns that by listing certain items to be included in the review the provision might lead to these issues being considered over others or influence a certain outcome. In his submission, Andrew Donnellan asserted that the review clause as it stands

²³⁰ Mary Porter, Submission 25, p 7.

²³¹ ACT Human Rights Commission, *Submission 73*, p 5.

²³² Exit ACT and Ethical Rights, *Submission 29*, p 9.

²³³ Dr David Swanton, Chapter Leader, Exit International ACT Chapter, *Proof Committee Hansard*, 1 February 2024, p 133.

²³⁴ Ms Tara Cheyne MLA, Minister for Human Rights, *Proof Committee Hansard*, 2 February 2024, p 189.

²³⁵ Proof Committee Hansard, 2 February 2024, p 189.

²³⁶ See, for example, Rita Joseph, Submission 37, p 2; and ACT Right to Life, Submission 17, p 4.

²³⁷ Mr John Kennedy, President, ACT Right to Life, Proof Committee Hansard, 31 January 2024, pp 88–89.

is anticipatory and should be amended so that a future Government is not required to consider extending the scheme to children and young people.²³⁸

- 3.190. The Plunkett Centre for Ethics was critical of the specific inclusion of children in the review, stating that they viewed such inclusions as 'de facto promises for how eligibility should be widened to make it available to children'.²³⁹
- 3.191. CHA stated that the explicit instruction to consider children in the review gives 'weighting to the importance of this over other matters that may need to be considered in any review'.²⁴⁰
- 3.192. Calvary Health Care indicated their disappointment about the ACT Government's apparent intent 'to widen the eligibility criteria for access to VAD' upon review. They suggested that the review should, instead, be similar to the NSW *Voluntary Assisted Dying Act 2022* provisions which require the relevant minister to consider only the 'operations and effectiveness' of the Act and geographical access considerations.²⁴¹
- 3.193. The ACT Law Society, while not providing a view on ethical issues on eligibility of children, cautioned that including children and young people in the eligibility criteria for the scheme would result in complexities due to the interaction between territory and federal law:

The complication that it will have is, if we move into that space, you will immediately attract the application of federal legislation with the best interests of the child being covered under the Family Law Act. That is a more complicated issue and appropriate that it be discussed as part of the review in three years.²⁴²

Advanced care planning

Support

- 3.194. The Committee notes there was significant support for amendments to the bill to allow the inclusion of advance care planning provisions.²⁴³
- 3.195. HCCA told the Committee that many of their members have said that they would not like to be excluded from being eligible for VAD if they have dementia, noting that the Netherlands has arrangements in place for people with advance directives (a living will).²⁴⁴
- 3.196. Roy Harvey submitted that consideration of advance care directives as part of the VAD regime has merit, arguing they are used in most jurisdictions.²⁴⁵ In his additional submission, he raised the need to consider amendments to the bill to allow access to VAD

²³⁸ Andrew Donnellan, *Submission 60*, pp 2–3.

²³⁹ Dr Bernadette Tobin, Plunkett Centre for Ethics, *Submission* 75, p 3.

²⁴⁰ Catholic Health Australia (CHA), *Submission 46*, p 11.

²⁴¹ Calvary Health Care, Submission 55, p 7.

 ²⁴² Mr Timothy Morton, Co-Chair, Elder Law and Succession Committee, ACT Law Society, *Proof Committee Hansard*,
2 February 2024, p 178.

²⁴³ See, for example, Frances Coombe, Submission 4, p 2; Ian Chubb, Submission 31, p 2; and The Australia Institute, Submission 78, p 5.

 ²⁴⁴ Dr Adele Stevens, Consumer representative, Health Care Consumers Association (HCCA), *Proof Committee Hansard*, 29 January 2024, p 17.

²⁴⁵ Roy Harvey, Submission 76, p 9.

for people with dementia, primarily through advanced care directives. He noted that many submissions suggested advanced care directives would allow people to request access to VAD while they still can, before they become ineligible because of reduced decision-making capacity. He noted that delaying this until it might be addressed (as late as 2030) might mean that people could make their own 'alternative, "illegal" arrangements', adding that he is aware of people who have made these plans.²⁴⁶

- 3.197. Dying with Dignity Victoria also noted that the use of advance care directives for dementia patients was an important but challenging issue that should be considered in the future.²⁴⁷
- 3.198. Michael Boesen said in his submission on behalf of 14 ACT residents that they supported consideration of advance care plans in a future review to assist those that have lost their decision-making capability.²⁴⁸
- 3.199. The ACT Human Rights Commission expressed their support for the inclusion of this issue in terms of the first review, noting that:
 - There are overseas jurisdictions with provisions for advanced care plans; and
 - while it is a complex issue, 'it should be possible to have an advanced care directive. There are parallels with not resuscitating, for example'.²⁴⁹
- 3.200. Exit ACT and Ethical Rights endorsed the inclusion of advanced care planning in the review clause.²⁵⁰ However, they expressed concern that any change that resulted from the review would not take place for many years. This concern was also shared by other submitters.²⁵¹
- 3.201. In its submission, the ACT Government told the Committee that its consultation heard that excluding people without decision making capability would mean many people would not be eligible for VAD, noting that dementia is a leading cause of death in Australia and produces intolerable suffering. However, consultation also found that a decision to supply an approved substance to a person who lacks capacity is highly subjective, ethically challenging and without precedent in medical practice in Australia. According to the ACT Government, this issue has not been properly researched and considered in Australia at this time.²⁵²

Concerns

3.202. The Plunkett Centre for Ethics told the Committee that advanced care plans should be removed from the review terms, arguing that if a person has lost capacity the assisted dying can no longer be voluntary.²⁵³

²⁴⁶ Roy Harvey, Submission 76.1 p 2.

²⁴⁷ Dying with Dignity Victoria, *Submission 82*, p 5.

²⁴⁸ Mr Michael Boesen, *Submission 20*, p 3.

²⁴⁹ Dr Penelope Mathew, President and Human Rights Commissioner, ACT Human Rights Commission, Proof Committee Hansard, 2 February 2024, p 185.

²⁵⁰ Exit ACT and Ethical Rights, *Submission 29*, p 9.

²⁵¹ See, for example, name withheld, *Submission 57*, p 4; Roy Harvey, *Submission 76*, p 3.

²⁵² ACT Government, *Submission 66*, p 7.

²⁵³ Dr Bernadette Tobin, Acting Director, Plunkett Centre for Ethics, *Proof Committee Hansard*, 31 January 2024, pp 115–116.

- 3.203. HOPE (Preventing Euthanasia and Assisted Suicide) indicated their concern about the first review specifically including consideration of advanced care planning. According to HOPE 'it is not unreasonable to presume that the ACT will follow Canada's trajectory, where there has been a considerable increase in the numbers of people dying by euthanasia and assisted suicide in every year of its operation'.²⁵⁴
- 3.204. Calvary Health Care argued that the future government should be able to conduct the review as they see fit, rather than as 'prescribed by legislation'. As a result, Calvary Health Care argued that reference to advanced care plans and children should both be removed.²⁵⁵
- 3.205. CHA concurred, warning that 'such an inclusion implies a view to expanding these laws, before the initial bill has even passed the Parliament'.²⁵⁶

²⁵⁴ HOPE (Preventing Euthanasia and Assisted Suicide), Submission 72, p 5.

²⁵⁵ Calvary Health Care, Submission 55, p 13.

²⁵⁶ Catholic Health Australia (CHA), *Submission 46*, p 11.

4. Palliative care considerations

Relationship between VAD and palliative care

- 4.1. The Committee received a number of submissions regarding the role of palliative care, and how this would interact with the introduction of voluntary assisted dying (VAD).²⁵⁷
- 4.2. The Australia New Zealand Society of Palliative Medicine (ANZSPM) emphasised the importance of ensuring that the general public understand the difference between palliative care services and VAD, noting that misunderstandings exist among health professionals as well as the wider community.²⁵⁸
- 4.3. ANZSPM highlighted that the role of palliative care is to 'provide comfort, physically, emotionally and spiritually to a patient up to and including their natural death' and not to 'prematurely end the life of a patient'.²⁵⁹
- 4.4. In its submission, the ACT Government highlighted that VAD should be considered as 'one of several end-of-life options, and not simply as an alternative to palliative care'.²⁶⁰
- 4.5. The Minister for Human Rights reiterated to the Committee that palliative care and VAD are 'part of the continuum of care, that it is not either/or; they absolutely exist together'.²⁶¹
- 4.6. Dr Michael Chapman, palliative care specialist and member of ANZSPM, summarised the intersection of VAD and palliative care as follows:

My personal view is that VAD is best understood as an end of life choice. In the context of people with advanced illness who are in the process of making end of life choices, all people should have access to palliative care and that should be a routine part of the specific care that is provided within that space.²⁶²

4.7. Clause 152 of the bill (requirements for health professionals when initiating conversations about VAD) requires that reasonable steps are taken to ensure that the individual is aware of palliative care options. This is discussed further in Chapter 3: Operation of the bill – under the heading 'initiation of conversations', and further in this chapter, under the heading 'palliative care training for VAD practitioners'.

Committee comment

4.8. The Committee recognises that seeking access to VAD does not preclude a person from also receiving palliative care, and nor does palliative care preclude someone from going on to choose VAD.

 ²⁵⁷ See for example, Ministerial Council for Multiculturalism, *Submission 39*, pp 3–4; Catholic Health Australia, *Submission 46*, pp 3–7; Beverly Cains, *Submission 50*, p 3–4; Mary Porter, Submission 25, pp 4–8.

²⁵⁸ Australia and New Zealand Society of Palliative Medicine (ANZSPM), Submission 71, pp 2–3.

²⁵⁹ Australia and New Zealand Society of Palliative Medicine (ANZSPM), Submission 71, p 4.

²⁶⁰ ACT Government, *Submission 66*, p 14.

²⁶¹ Ms Tara Cheyne MLA, Minister for Human Rights, *Proof Committee Hansard*, 2 February 20204, p 216.

²⁶² Dr Michael Chapman, palliative care specialist and member of Australia and New Zealand Society of Palliative Medicine (ANZSPM), *Proof Committee Hansard*, 31 January 2024, p 94.

Palliative care provision in the ACT

- 4.9. Several submitters highlighted the need to ensure that there is adequate provision and availability of palliative care in the ACT²⁶³ to ensure that people do not choose to access VAD simply because palliative care is not available to them.²⁶⁴
- 4.10. For example, Calvary Health Care told the Committee that '[i]n order to ensure choice is not just a principle but a reality, high quality palliative and end-of-life care must be easily accessible to all.'²⁶⁵
- 4.11. The Catholic Archdiocese of Canberra and Goulburn advocated for adequate funding for the following end-of-life choices in the ACT:
 - Clare Holland House;
 - a palliative care facility in South Canberra; and
 - the provision of palliative care in the home.²⁶⁶
- 4.12. Catholic Health Australia (CHA) drew the Committee's attention to the final report of the Palliative Care Services Function Review 2023,²⁶⁷ which found gaps in the provision of palliative care services in the community setting. This review also anticipated an increasing demand for these services due to an aging population.²⁶⁸ The Committee was advised by some submitters that the recommendations from this review should be adopted in full.²⁶⁹
- 4.13. There were also a number of concerns raised that palliative care spending would decrease as result of VAD being introduced.²⁷⁰
- 4.14. Calvary Health Care suggested that the bill include a requirement that the VAD Oversight Board (the board) produce an annual report which includes data on palliative care spending. According to Calvary Health Care, this reporting would bring the ACT in line with NSW. If palliative care spending was found to have decreased since the prior report, they suggested a review of the Act should be conducted, similar to the provisions in the South Australian legislation.²⁷¹
- 4.15. During the public hearing, the minister told the Committee that: 'there is no evidence in Australia that palliative care funding has been withdrawn or that bucket [of funding] has gone to pay for VAD.'²⁷²

²⁶³ Vicki Dunne, Submission 64, p 7; Calvary Health Care, Submission 55, p 6. Paul Burt, Submission 38, p 2; Mary Porter, Submission 25, p 7.

²⁶⁴ See for example, Chris and Maree Rule, Submission 23, p 2; Catholic Health Australia (CHA), Submission 46, p 3. Calvary Health Care, Submission 55, p 12; Australia and New Zealand Society of Palliative Medicine (ANZSPM), Submission 71, p 2.

²⁶⁵ Calvary Health Care, Submission 55, p 12.

²⁶⁶ Catholic Archdiocese of Canberra and Goulburn, *Submission* 47, p 10.

²⁶⁷ Abt Associates, Bold Delivers: Australian Capital Territory, Palliative Care Service Function Review Final Report, June 2023, p 5.

²⁶⁸ Catholic Health Australia (CHA), *Submission 46*, p 6.

²⁶⁹ Catholic Health Australia (CHA), Submission 46, p 6; Name withheld, Submission 18, p 2.

²⁷⁰ Andrew Donnellan, *Submission 60*, p 2; Chris and Maree Rule, Submission 23, p 2.

²⁷¹ Calvary Health Care, *Submission 55*, p 13.

²⁷² Ms Tara Cheyne MLA, Minister for Human Rights, *Proof Committee Hansard*, 2 February 2024, p 216.

4.16. Furthermore, the minister informed the Committee of recent spending commitments for the provision of palliative care in the ACT:

You may know that there has been a pretty significant investment in palliative care recently as well as annually. There is a significant investment each year in non-clinical palliative care services. You might recall that Cleo's Place was established as a trial and now is a permanent place for respite, and there is funding to expand the capacity at Clare Holland House.²⁷³

Committee comment

4.17. The Committee acknowledges the need to adequately provide palliative care services in the ACT to ensure all Canberrans have access to quality end of life care that aligns with their values and preferences.

Recommendation 15

The Committee recommends that the ACT Government make a statement to the Assembly regarding the provision of palliative care services in the ACT prior to debate of the Voluntary Assisted Dying Bill 2023.

Recommendation 16

The Committee recommends that the ACT Government make a statement to the Assembly regarding the provision of palliative care services in the ACT three years after the enactment of the Voluntary Assisted Dying Bill 2023.

Palliative care training for VAD practitioners

- 4.18. Subclause 152(1) requires health practitioners to discuss palliative care options when initiating a conversation about VAD.
- 4.19. Several submitters were concerned that a lack of palliative care training among health professionals could inhibit an individual from receiving the appropriate level of information to enable them to make a fully informed decision.²⁷⁴
- 4.20. This concern was expressed by ANZSPM, who indicated that the level of training on palliative and end of life care in medical schools is inadequate, and that '[p]alliative care options are, again, not well understood by a lot of non-palliative care specialists.'²⁷⁵
- 4.21. The ACT Government submission to this inquiry explained that 'clinical guidelines will be developed during the implementation period' for end-of-life discussions. They emphasised

²⁷³ Ms Tara Cheyne MLA, Minister for Human Rights, *Proof Committee Hansard*, 2 February 2024, p 216.

²⁷⁴ Australia and New Zealand Society of Palliative Medicine (ANZSPM), *Submission 71*, p 4; Palliative Care ACT, *Submission 58*, p 3.

²⁷⁵ Dr Michelle Gold, President of Australia and New Zealand Society of Palliative Medicine (ANZSPM), *Proof Committee Hansard*, 31 January 2024, p 98.

that these guidelines would include information on treatment options, palliative care, and VAD. $^{\rm 276}$

Committee comment

- 4.22. The Committee notes the importance of health practitioners having an adequate understanding of palliative care in order to meet the legislative requirements in subclause 152(1) of the bill and considers this is an important safeguard for individuals.
- 4.23. The Committee also notes that a health practitioner who does not meet the level of expertise required in subclause 152(1) must still take reasonable steps to ensure that an individual knows that 'treatment and palliative care options are available to the individual;' and 'the individual should discuss the options with their treating doctor' as per paragraph 152(2)(b).²⁷⁷
- 4.24. The Committee believes that appropriate consideration should be given to palliative care within the compulsory training for VAD practitioners so that individuals are informed of their palliative care options during the initiation of a discussion about VAD by a health practitioner.

Recommendation 17

The Committee recommends that the ACT Government consult with palliative care specialists to ensure that appropriate consideration be given to palliative care treatment options during the development of the compulsory training for voluntary assisted dying practitioners.

²⁷⁶ ACT Government, *Submission 66*, p 14.

²⁷⁷ Voluntary Assisted Dying Bill 2023, para 152(2)(b).

5. Education and training considerations

Training for the healthcare workforce

- 5.1. Several submitters raised the importance of ensuring that healthcare professionals receive adequate training, resourcing, and upskilling in order for voluntary assisted dying (VAD) to be successfully implemented.²⁷⁸
- 5.2. The Australian College of Nursing, along with the Pharmacy Guild of Australia noted the 18 month implementation period would provide time for education and training of the healthcare community.²⁷⁹
- 5.3. The Pharmacy Guild of Australia noted that while pharmacists at the centralised pharmacy service will have a specific role, it is likely that community pharmacists will be asked to provide information about VAD and they needed to be able to assist:

From our perspective, it is about making sure that we can assist, because the queries will come our way. We do not want to do the wrong thing. We want to provide the right information and advice when we are asked.²⁸⁰

It is very much about having collaborative care, but we do field a lot of questions because people can just walk in. They can walk in at any time, such as over the weekend, when the doctors' surgeries are closed. It is really important that we know what the guidelines are and that we are involved in that process so that we can, as Simon said, ask, "Who have you spoken to? If you can't get in contact with your GP, who is the next person you can speak to about this?"²⁸¹

- 5.4. Speech Pathology Australia also said they would welcome clarification on their obligations when assisting patients seeking to access VAD.²⁸²
- 5.5. Professor White suggested that two streams of training might be required for practitioners involved in assessing eligibility or providing VAD and more general short training available to all health practitioners.²⁸³
- 5.6. Professor White also told the Committee that health practitioners may need to have a knowledge of both the ACT and New South Wales (NSW) VAD legislation given that practitioners or individual patients can live on either side of the border, because for example, duties of doctors and nurses might be different in the ACT than NSW.²⁸⁴ The ACT

²⁷⁸ Meridian, Submission 7, p 3; Mary Porter, Submission 25, p 8; Tamra Mcleod, Submission 48, p 2; Name withheld, Submission 57, p 9.

²⁷⁹ Australian College of Nursing, *Submission 16*, p 4; Pharmacy Guild of Australia, *Submission 24*, p 4;

 ²⁸⁰ Mr Simon Blacker, Branch President, Pharmacy Guild of Australia ACT Branch, *Proof Committee Hansard*,
29 January 2024, p 9.

 ²⁸¹ Ms Sandra Ferrington, Committee member, Pharmacy Guild of Australia ACT Branch, *Proof Committee Hansard*,
29 January 2024, p 10.

²⁸² Ms Torresi, Senior Adviser, Aged Care, Speech Pathology Australia, *Proof Committee Hansard*, 29 January 2024, p 53.

²⁸³ Professor Ben White, *Proof Committee Hansard*, 1 February 2024, p 153.

²⁸⁴ Professor Ben White, *Proof Committee Hansard*, 1 February 2024, p 155.

Government confirmed that VAD practitioners will have to undertake ACT VAD training even if they have done VAD training in another state.²⁸⁵

- 5.7. Meridian, a Canberra based Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, and Asexual (LGBTQIA) and HIV community organisation, highlighted that non-clinical support workers and in-home care workers would also need access to training around VAD.²⁸⁶
- 5.8. The Committee heard views about the amount and type of training that is provided, and that the six hours of on-line training generally provided in other jurisdictions is inadequate to provide holistic care.²⁸⁷ At the hearing, it was explained that this training was focused on processes and legalities but also needed to focus on communication skills and a knowledge of palliative care support.²⁸⁸
- 5.9. Australia and New Zealand Society of Palliative Medicine (ANZSPM) recommended that VAD training include the following components:
 - palliative care²⁸⁹
 - exploring the reasons a person may be seeking access to VAD²⁹⁰
 - practicing clinical neutrality²⁹¹
 - detecting signs of coercion²⁹²
 - capacity assessments²⁹³
 - communication skills²⁹⁴
 - management of grief and bereavement²⁹⁵
- 5.10. The ACT Government stated that there will be compulsory training for health practitioners who wish to play a role in VAD.²⁹⁶
- 5.11. During the public hearings, Canberra Health Services advised the Committee that training for the wider healthcare workforce would be developed during the implementation phase:

Whilst it is subject to implementation, planning and development, clearly there are multiple layers of education that will be produced, which will include that fundamental level which will be accessible by more than just a clinical workforce

²⁸⁵ Ms Rebecca Cross, Director-General, ACT Health, *Proof Committee Hansard*, 2 February 2024, p 197.

²⁸⁶ Meridian, *Submission* 7, p 3.

²⁸⁷ Australia and New Zealand Society of Palliative Medicine (ANZSPM), Submission 71, p 2.

 ²⁸⁸ Dr Michelle Gold, President, Australia New Zealand Society of Palliative Medicine, *Proof Committee Hansard*, 31 January 2024, p 98.

²⁸⁹ Dr Michelle Gold, President of ANZSPM, *Proof Committee Hansard*, 31 January 2024, p 98.

²⁹⁰ Australia and New Zealand Society of Palliative Medicine (ANZSPM), Submission 71, p 3.

²⁹¹ Australia and New Zealand Society of Palliative Medicine (ANZSPM), Submission 71, p 3.

²⁹² Australia and New Zealand Society of Palliative Medicine (ANZSPM), Submission 71, p 3.

²⁹³ Dr Michael Chapman, Palliative care specialist and member of Australia and New Zealand Society of Palliative Medicine (ANZSPM), *Proof Committee Hansard*, 31 January 2024, p 99.

²⁹⁴ Dr Michelle Gold, President of Australia and New Zealand Society of Palliative Medicine (ANZSPM), Proof Committee Hansard, 31 January 2024, p 98.

²⁹⁵ Dr Michael Chapman, Palliative care specialist and member of Australia and New Zealand Society of Palliative Medicine (ANZSPM), *Proof Committee Hansard*, 31 January 2024, p 99.

²⁹⁶ ACT Government, *Submission 66*, p 12.

... and will be suitable for what we term "health professionals" ... So, absolutely, a base-level of education would be available to all people working in health, with the greatest breadth of description, is what we would anticipate.²⁹⁷

Committee comments

- 5.12. The Committee considers that a wide range of healthcare workers will need access to educational resources, advice, and training. The Committee acknowledges the evidence that the level of training required is usually under-estimated.
- 5.13. The Committee notes the ACT Government's commitment to implementing compulsory training for health practitioners, and the development of educational resources for the wider healthcare workforce.

Recommendation 18

The Committee recommends that the ACT Government ensure that training is provided across the healthcare workforce to ensure that people who may be asked to provide assistance on voluntary assisted dying in varying capacities are aware of their obligations.

Training and education resourcing considerations

- 5.14. Several submitters raised the importance of ensuring that there are enough practitioners participating in VAD in ACT, should the bill pass.²⁹⁸
- 5.15. The Clem Jones Group stated that '[i]nadequate remuneration can adversely impact the availability of practitioners willing to be involved in the VAD process.'²⁹⁹
- 5.16. Go Gentle Australia suggested the possibility of paying practitioners for undertaking the mandatory VAD training, which may encourage more practitioners to participate.³⁰⁰
- 5.17. Dr Linda Swan, CEO of Go Gentle Australia, reiterated this during the public hearing, telling the Committee:

I would love a world where the training is paid so that, if people take eight hours out of their day, they at least get some coverage for that time.³⁰¹

Committee Comment

5.18. Considering that the ACT is a small jurisdiction, the Committee notes the importance of ensuring there are adequate VAD practitioners within the territory.

²⁹⁷ Ms Janet Zagari, Chief Executive Officer, Canberra Health Services, *Proof Committee Hansard*, 2 February 2024, p 198.

²⁹⁸ Health Care Consumers Association (HCCA), Submission 28, p 8; Ministerial Council for Multiculturalism (MACM), Submission 39, p 6; Australian Lawyers Alliance, Submission 41, p 7; Professor Lindy Willmott and Professor Ben White, Submission 27,pp 10–11.

²⁹⁹ Clem Jones Group, *Submission 34*, p 16.

³⁰⁰ Go Gentle Australia, *Submission 44*, p 15.

³⁰¹ Dr Linda Swan, CEO, Go Gentle Australia, *Proof Committee Hansard*, 1 February 2024, p 131.

Recommendation 19

The Committee recommends that the ACT Government ensure that health practitioners are renumerated for their time spent undertaking mandatory training on voluntary assisted dying.

Community education and awareness

- 5.19. Both the Clem Jones Group and the Australia Institute emphasized the importance of ensuring that the public are made aware of VAD, as this has been identified by VAD practitioners as an issue in other jurisdictions.³⁰²
- 5.20. The explanatory statement asserts that the 18-month implementation period will allow for the 'development of public communications for consumers, carers, stakeholders and community'.³⁰³
- 5.21. ANZSPM highlighted that there is a poor understanding amongst the general population about what palliative care is, and that educating the public on VAD, as well as other end of life options, must be a priority.³⁰⁴
- 5.22. This sentiment was echoed by Palliative Care ACT, who recommended that 'resources are committed to awareness raising in the general community and among health professionals on the benefits and role of palliative care'.³⁰⁵
- 5.23. Ms Kui Foon Wong, a council member of the Ministerial Advisory Council for Multiculturalism (MACM), told the Committee there were a lot of misconceptions about palliative care within multicultural communities:

When we talk about palliative care, the reluctance is mainly because of the fear of going into hospital and never coming out again. Certainly, whether you are ill or not ill, some communities interpret palliative care as being a place where you go to die ... We know that this misconception needs to be changed. Instead we have a hesitance regarding the community taking up palliative care.³⁰⁶

5.24. The Committee heard additional advice from MACM regarding the need to ensure the multicultural community is included in community education about VAD. This is discussed further in Chapter 8: Multicultural community considerations under the heading 'community education'.

³⁰² Australia Institute, *Submission 78*, p 5; Clem Jones Group, *Submission 34*, pp 15–16.

³⁰³ Voluntary Assisted Dying Bill 2023, *explanatory statement*, p 47.

³⁰⁴ Australia and New Zealand Society of Palliative Medicine (ANZSPM), Submission 71, p 4.

³⁰⁵ Palliative Care ACT, *Submission 58*, p 3.

³⁰⁶ Ms Kui Foon Wong, Council Member, ACT Ministerial Advisory Council for Multiculturalism (MACM), *Proof Committee Hansard*, 29 January 2024, p 69.

Committee comment

- 5.25. The Committee notes the importance of ensuring that the public are adequately informed about end-of-life care options.
- 5.26. The Committee also notes that not all Canberrans will be aware of their end-of-life choices, such as palliative care in the hospital, the community, or the home. Consideration should be given to ensuring that public communications about voluntary assisted dying include reference to all end-of-life healthcare options.

Recommendation 20

The Committee recommends that the ACT Government ensure that broader community education is clear that voluntary assisted dying is just one end-of-life option available and makes it clear what other options are available.

Disability training for the healthcare workforce

5.27. Advocacy for Inclusion called for the healthcare workforce to be adequately trained on the social model of disability and diagnostic overshadowing.³⁰⁷ This is discussed in the following chapter.

Palliative care training for VAD practitioners

5.28. Some submitters raised concerns about a lack of palliative care training among health professionals and were concerned about the impact this could have on an individual from receiving the appropriate level of information.³⁰⁸ This is discussed further in the previous chapter on palliative care, under the heading 'palliative care training for VAD practitioners'.

³⁰⁷ Advocacy for Inclusion *Submission 42*, p 5.

³⁰⁸ Australia and New Zealand Society of Palliative Medicine Submission 71, p 4; Palliative Care ACT, Submission 58, p 3.

6. Disability considerations

Support offered to people with disability seeking VAD

- 6.1. The Australian Care Alliance suggested that ableist attitudes among health practitioners puts people with disabilities at a greater risk in the context of voluntary assisted dying (VAD).³⁰⁹
- 6.2. Advocacy for Inclusion (AFI) told the Committee that people with disabilities considering VAD should be offered 'disability, mental health, psychosocial supports or suicide counselling assistance to avert that decision' as a legal requirement. He cautioned that this could lead to health practitioners suggesting VAD rather than offering additional supports, pointing to instances in Canada where allegations of this have been reported.³¹⁰ This concern was shared by the Knights of the Southern Cross.³¹¹ AFI said that people with disability often encounter negative assumptions from health professionals regarding their quality of life. This can lead to them not being offered adequate health treatment:

...people with disabilities who go into hospital are often confronted by doctors who believe that they have minimal life chances, and that it is not worth attempting surgery on them because their quality of life is too low. People are offered "do not resuscitate" orders when they have not asked for "do not resuscitate" orders. There is an assumption that someone with a disability will have poor quality of life. If you add that to legalising physician-assisted suicide, we see a danger there, and we see that there needs to be an intense program of work on a disability health strategy before a bill like this is enacted.³¹²

6.3. AFI also proposed that there be a criminal offence where an entity who funds a person's disability supports denies that support, and then suggests they apply for VAD.³¹³

Committee comment

6.4. The Committee considers that it should be made very clear that VAD should not be an alternative to ensuring the right disability supports are available to prevent potential coercion.

³⁰⁹ Australian Care Alliance, Submission 26, pp 8–9.

³¹⁰ Advocacy for Inclusion (AFI), Answer to QTON 4: VAD offered instead of supports, 29 January 2024, (received 8 January 2024), pp 1–2.

³¹¹ Knights of the Southern Cross, *Submission 74*, pp 20–21.

³¹² Mr Craig Wallace, Head of Policy, Advocacy for Inclusion (AFI), *Proof Committee Hansard*, 29 January 2024, p 58.

 ³¹³ Advocacy for Inclusion (AFI), Answer to QTON 4: VAD offered instead of supports, 29 January 2024, (received 8 January 2024), p 3.

Recommendation 21

The Committee recommends that the ACT Government amend the explanatory statement to the Voluntary Assisted Dying Bill 2023 to explicitly state and further clarify that voluntary assisted dying is not to be seen as an alternative to providing supports for people with disability.

Disability training for the healthcare workforce

6.5. In their submission and during the public hearing, AFI highlighted a need for health practitioners to have training in diagnostic overshadowing and the social model of disability as a way to safeguard people with disabilities. AFI told the Committee:

One of the things that we said in our submission is that all of the health practitioners who are prescribing voluntary assisted dying should have some training on the social model of disability. That is because people with disabilities who go into hospital are often confronted by doctors who believe that they have minimal life chances, and that it is not worth attempting surgery on them because their quality of life is too low.³¹⁴

Committee comment

- 6.6. The Committee notes that the Disability Health Strategy: First Action Plan 2024-2026 was recently published by the government. It aims to 'ensure people with disability have equitable and appropriate access to healthcare in the ACT and improved health outcomes'.³¹⁵
- 6.7. The action plan includes a focus on training, including to 'develop disability health training for frontline employees across the healthcare system in the ACT'.³¹⁶
- 6.8. The Committee acknowledges the importance of ensuring that the healthcare workforce has an adequate understanding of disability and notes the concerns of AFI in regard to the specific risks relating to VAD.

Recommendation 22

The Committee recommends that the ACT Government ensure mandatory training for voluntary assisted dying practitioners includes disability awareness training and identifying signs of coercion in respect of people with disability.

³¹⁴ Mr Craig Wallace, Head of Policy, Advocacy for Inclusion, *Proof Committee Hansard*, 29 January 2024, p 58.

 ³¹⁵ ACT Government, <u>Disability Health Strategy: First Action Plan 2024 – 2026</u>, December 2023, p 1.
³¹⁶ ACT Government, <u>Disability Health Strategy: First Action Plan 2024 – 2026</u>, December 2023, p 10.

Timeframe to death

6.9. AFI expressed significant concern that the lack of 'timeframe to death' requirement would effectively mean that people with a disability alone would be eligible for VAD.³¹⁷ This is discussed further in Chapter 3: Operation of the bill, under the heading 'eligibility criteria and timeframe to death requirements'.

Representation on the Voluntary Assisted Dying Oversight Board

- 6.10. AFI told the Committee that the Voluntary Assisted Dying Oversight Board (the board) should include a mix of medical professionals and others with expertise and knowledge on end-of-life issues and ethical issues as well as disability rights. They spoke to the benefits of having a person with disability being able to provide a critical and inquiring lens. This person could be nominated by a peak Disabled Persons Organisation.³¹⁸
- 6.11. This report discussed membership of the Voluntary Assisted Dying Oversight Board in Chapter 3: Operation of the Bill, under the heading 'Voluntary Assisted Dying Oversight Board membership'.

 $^{^{\}rm 317}$ Advocacy for Inclusion (AFI), Submission 61, p 4.

³¹⁸ Advocacy for Inclusion (AFI), Submission 61, p 6.

7. Carers considerations

- 7.1. The Committee heard from Carers ACT regarding the vital role that carers play in supporting people dealing with a condition that could cause them to consider voluntary assisted dying (VAD).³¹⁹
- 7.2. In their written submission, Carers ACT expanded on the type of supports a carer might provide to a person seeking to access VAD. This included:
 - arranging appointments and transportation;
 - facilitating discussions with healthcare professionals;
 - supporting the person they care for to understand and complete paperwork; and
 - continuing to tend to the person's wellbeing and daily care.³²⁰
- 7.3. Carers ACT posited that it would be reasonable to assume the 'vast majority of individuals at the point of accessing VAD will have people in their lives providing care for them who are not paid professionals',³²¹ and that this constitutes a care relationship as defined by the *Carers Recognition Act 2021*.³²²
- 7.4. Specifically, Carers ACT pointed to section 8 of the *Carers Recognition Act 2021* which states that carers should be respected and recognised as 'someone with knowledge of the person receiving care'.³²³ Additionally, according to the Federal Statement for Australia's Carers '[c]arers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.'³²⁴
- 7.5. The importance of the knowledge and expertise that carers can provide to health professionals was further emphasised by Carers ACT who stated:

Carers often possess crucial information about the individual's care, preferences, medical needs and daily routines, making their involvement and insight essential for continuity of care. As such, carers must be treated as an integral part of the care relationship at a time when an individual is considering the choice to end their life.³²⁵

- 7.6. Whilst Carers ACT acknowledged that the decision to access VAD lies with the individual, they advised that carers are likely to be involved in that decision making process.³²⁶
- 7.7. This was echoed by the Ministerial Council for Multiculturalism(MACM), who informed the Committee that intergenerational living and collective decision making was a prominent

³¹⁹ Ms Lisa Kelly, CEO, Carers ACT, *Proof Committee Hansard*, 29 January 2024, pp 47–54.

³²⁰ Carers ACT, Submission 42, p 5.

³²¹ Carers ACT, Submission 42, p 5.

³²² Carers Recognition Act, 2021.

³²³ Carers Recognition Act 2021, s 8(1(a)(iii).

³²⁴ Carers Recognition Act 2010 (Cth), Schedule 1(7).

³²⁵ Carers ACT, Submission 42, p 6.

³²⁶ Carers ACT, *Submission 42*, p 6.

feature of multicultural communities, meaning the involvement of carers would also be likely.³²⁷

- 7.8. Carers ACT felt that the bill should recognise the role of carers in the decision-making process by legislating that health professionals consider the care dyad³²⁸ 'where the carer and the person they care for are treated and seen as a unit'.³²⁹
- 7.9. Overall, they felt that the bill did not sufficiently acknowledge the significant role carers are likely to play in supporting an individual to access VAD and suggested that section 7 Principles of the Act should include a statement recognising the contribution of carers.³³⁰
- 7.10. They also highlighted that the bill does not provide a definition of the word 'carer' and suggested this be included in line with the *Carers Recognition Act 2021*.³³¹

Committee comment

- 7.11. The Committee notes that the role of carers was also acknowledged by several other submitters.³³²
- 7.12. The Committee recognises the important role of carers and acknowledges the likelihood that people seeking access to VAD may be receiving care from a carer.
- 7.13. The Committee believes the bill and explanatory statement would be strengthened by further acknowledgement of the role carers are likely to play in supporting their care recipients to access VAD.

Recommendation 23

The Committee recommends that the ACT Government introduce amendments to the bill to include a definition of carer, in line with the *Carers Recognition Act 2021*, and update the Bill and explanatory statement as necessary to align with this.

Recommendation 24

The Committee recommends that the ACT Government recognise the role of carers in supporting people who may choose to access voluntary assisted dying.

Protections for carers

7.14. During the public hearing, Carers ACT indicated that they would like to see better protections for carers in the bill. Of specific concern was that a person seeking VAD may change their mind and that this could be seen by some as coercion from the carer.³³³

³²⁷ Ministerial Advisory Council for Multiculturalism (MACM), Submission 39, p 5.

³²⁸ Interaction of the pair (of carer and patient)

³²⁹ Carers ACT, Submission 42, pp 6–7.

³³⁰ Carers ACT, Submission 42, p 6.

³³¹ Carers ACT, Submission 42, p 6.

³³² Pharmacy Guild of Australia, Submission 24, pp 2–4; Ian Chubb, Submission 31, p 2; Australia and New Zealand Society of Palliative Medicine (ANZSPM), Submission 71, p 3; Lara Kaput, Submission 81, pp 6–13.

³³³ Ms Lisa Kelly, CEO, Carers ACT, Proof Committee Hansard, 29 January 2024, p 43.

7.15. Carers ACT reminded the Committee that carers are often also family members and friends, who are likely to have strong feelings towards their care recipients:

We forget that, despite them being a carer and somebody who is dying, they are spouses, they are parents and children, and they are brothers and sisters. There is a whole range of other relationships that happen within that space as well.³³⁴

- 7.16. Carers ACT highlighted the importance of health practitioners being trained in relation to both the role of carers and identifying coercion. They also argued that adequate training in these areas it would provide a layer of protection for the carer, given practitioners are often present for conversations about VAD.³³⁵
- 7.17. Carers ACT also saw the need for the inclusion of a protection statement for carers in the bill, similar to subclause 6(d) which states that an object of the Act is to 'provide protection for health practitioners who choose to assist, or not assist, individuals to exercise the option of ending their lives in accordance with this Act'.³³⁶
- 7.18. They highlighted this was particularly important given the likelihood that a carer would be appointed as a 'contact person' by an individual seeking VAD, and the associated responsibilities and strict liability offences attached to the status of the contact person.³³⁷
- 7.19. During the public hearings, the Minister for Human Rights told the Committee that the bill provides protection for carers, specifically:

Sections 125 and 126 make it abundantly clear that, as long as a person is acting honestly and without recklessness, that person is not criminally or civilly liable for conduct under the bill, including conduct that assists an individual to access voluntary assisted dying in accordance with the bill.³³⁸

- 7.20. The criminal offence in clause 49 of inducing an individual to make or revoke a decision also requires that a person be 'acting dishonestly or by coercion'.³³⁹
- 7.21. Paragraph 51(2)(b) stipulates that a person can only be appointed as a contact person if that person 'consents to being appointed as the contact person for the individual'.³⁴⁰

Committee comment

7.22. The Committee acknowledges that health practitioners will play a crucial role in ensuring that patients seeking access to VAD are doing so without coercion from carers, family members and friends, and recognises the need for VAD practitioners to be adequately trained about the role of carers in this area.

³³⁴ Ms Lisa Kelly, CEO, Carers ACT, *Proof Committee Hansard*, 29 January 2024, p 43.

³³⁵ Ms Jessica Johnson, Policy Officer, Carers ACT, Proof Committee Hansard, 29 January 2024, p 43.

³³⁶ Carers ACT, Submission 42, p 5; Voluntary Assisted Dying Bill 2023, subcl 6(d).

³³⁷ Carers ACT, Submission 42, p 5.

³³⁸ Ms Tara Cheyne MLA, Minister for Human Rights, *Proof Committee Hansard*, p 197.

³³⁹ Voluntary Assisted Dying Bill 2023, cl 49.

³⁴⁰ Voluntary Assisted Dying Bill 2023, para 51(2)(b).

Recommendation 25

The Committee recommends that the ACT Government ensure mandatory training for voluntary assisted dying practitioners includes the role of carer relationships in decision making and identifying signs of coercion.

Support for carers through the Care Navigator Service

- 7.23. The bill establishes a Care Navigator Service to 'provide multidisciplinary support to individuals, their carers and families, health practitioners and health or care services seeking information and pathways regarding VAD'.³⁴¹
- 7.24. Subclause 155(3) specifies that "[t]he purpose of the approved care navigator service is to provide support, assistance and information to people relating to VAD.'³⁴²
- 7.25. In recognition of the significant role carers are likely to play in supporting a person to access VAD, as well as the likelihood of a carer taking on the role of a contact person, Carers ACT reasoned that the Care Navigator Service should also provide support to carers as well as the individual seeking VAD.³⁴³
- 7.26. According to Carers ACT, the Care Navigator Service should be implemented in line with the principals of the *Carers Recognition Act 2021*, specifically that a carer 'be provided with support that is timely, responsive, appropriate, respectful and accessible'.³⁴⁴ Carers ACT also proposed that staff of the service undertake mandatory carer awareness training.³⁴⁵
- 7.27. The explanatory statement indicates that the Care Navigator Service will provide support to a contact person, specifying that the Care Navigator Service 'can provide tailored information and support to a contact person to help them understand how to handle an approved substance and when to report to the board'.³⁴⁶

7.28. Additionally, during the public hearings, the minister stated that:

The care navigator service is that central point, so it will be able to provide generalised support and explanations and assist people to understand the process as well as individualised support to people, and that will include providing support to carers about what they need to do to support their person through the process.³⁴⁷

7.29. Further to this, Canberra Health Services told the Committee that they would take on board evidence from the inquiry.³⁴⁸

³⁴¹ ACT Government, Submission 66, p 13.

³⁴² Voluntary Assisted Dying Bill 2023, subcl, 155(3).

³⁴³ Carers ACT, Submission 42, p 7.

³⁴⁴ Carers Recognition Act 2021, s 8(g).

³⁴⁵ Carers ACT, Submission 42, p 7.

³⁴⁶ Voluntary Assisted Dying Bill 2023, *explanatory statement*, p 40.

³⁴⁷ Ms Tara Cheyne MLA, Minister of Human Rights, *Proof Committee Hansard*, 2 February 2024, p 207.

³⁴⁸ Ms Janet Zagari, Deputy CEO, Canberra Health Service, *Proof Committee Hansard*, 2 February 2024, p 207.

Committee comment

7.30. The Committee is of the view that carers will need to be supported throughout the VAD process and therefore seeks assurance from the ACT Government that the Care Navigator Service will continue to consider the needs of this group.

Recommendation 26

The Committee recommends that the ACT Government consider the role of carers during the development and implementation of the Care Navigator Service to ensure that carers are appropriately supported.

8. Multicultural community considerations

- 8.1. The Committee heard from the Ministerial Advisory Council for Multiculturalism (MACM) about the considerations needed in regard to culturally and linguistically diverse communities, noting however, 'the multicultural community is not a unilateral body or one that shares the same experiences and challenges'.³⁴⁹ The Committee also heard of some of the barriers for the multi-cultural community (see below).
- 8.2. MACM indicated overall support for the bill,³⁵⁰ and also supported provisions allowing health professionals to abstain from participating in voluntary assisted dying (VAD) due to their personal or religious beliefs.³⁵¹

Barriers to healthcare

8.3. The Committee heard from Katarina Pavkovic, who described herself as a first generation Australian whose parents came to Australia in early adulthood from Serbia. She highlighted the need for information about health care services to be available to people from multicultural backgrounds:

I think it was a challenge for them, coming from a culturally and linguistically diverse background, to seek the support and services that they needed ... I remember growing up and saying to my mum, "Hey, I have a question about this thing" and she would say, "No, do not ask that; we can handle this ourselves". That sort of stuff is a deeply rooted cultural thing with the families, and it takes a lot of deep behavioural change to try and combat that. Culturally, in seeking support before the palliative care stage, I would say you would benefit if you were more educated and were able to understand the information that was being relayed.³⁵²

8.4. Misconceptions about healthcare services were also acknowledged by the MACM, who told the Committee there is a reluctance in multicultural communities to seek palliative care.

When we talk about palliative care, the reluctance is mainly because of the fear of going into hospital and never coming out again. Certainly, whether you are ill or not ill, some communities interpret palliative care as being a place where you go to die.³⁵³

 ³⁴⁹ Ms Izabela Barakovska, Chair, Ministerial Advisory Council for Multiculturalism (MACM), *Proof Committee Hansard*, 29 January 2024, p 64.

³⁵⁰ Ministerial Advisory Council for Multiculturalism (MACM), Submission 39, p 3.

³⁵¹ Ministerial Advisory Council for Multiculturalism (MACM), *Submission 39*, p 4.

³⁵² Ms Katarina Pavkovic, Proof Committee Hansard, 1 February 2024, p 166–167.

³⁵³ Ms Kui Foon Wong, Council Member, Ministerial Advisory Council for Multiculturalism (MACM), *Proof Committee Hansard*, 29 January 2024, p 69.

8.5. Ms Katarina Pavkovic acknowledged that the Care Navigator Service would likely be a useful service in assisting families from culturally and linguistically diverse backgrounds to navigate the VAD process.³⁵⁴

Death certificate

8.6. Clause 77(2) of the bill requires that a person's underlying condition be recorded on their death certificate, rather than VAD. As per the explanatory statement, the reason for this is:

to promote the individual's right to privacy and avoid any unintended implications relating to insurance or other personal matters arising after an individual's death.³⁵⁵

8.7. MACM endorsed this provision, highlighting the importance of respecting an individual's privacy. Additionally, they emphasised the importance of this being communicated to the individual so they are aware that VAD would not be recorded on their death certificate.³⁵⁶

Interpreters and translators

- 8.8. The bill recognises that interpreters may need to be involved in the VAD process so that an individual can fully participate in discussions with their health practitioner.
- 8.9. Paragraph 153(1)(a) stipulates that an interpreter must not be a family member of the individual. However, this can be dispensed with by the director-general if no other interpreter is reasonably available or there are exceptional circumstances.³⁵⁷
- 8.10. In their submission, MACM said that the use of a professional translator could protect an individual from interference by family members and urged the use of a professional translator where possible.³⁵⁸
- 8.11. During the public hearing, MACM further noted that privacy is often very important to people, and that in the case of minority languages, this could cause an issue:

There are minority languages, and translators are often typically part of the community as well, and that can create some real difficulties with people wanting to have a bit more privacy, a private experience, when they are discussing really personal matters like this—wanting them to stay confidential and not go back to a community.³⁵⁹

³⁵⁴ Ms Katarina Pavkovic, *Proof Committee Hansard*, 1 February 2024, p 167.

³⁵⁵ Voluntary Assisted Dying Bill 2023, *explanatory statement*, p 76.

³⁵⁶ Ministerial Advisory Council for Multiculturalism (MACM), *Submission 39*, pp 5–6.

³⁵⁷ Voluntary Assisted Dying Bill, 2023, s 153(2).

³⁵⁸ Ministerial Advisory Council for Multiculturalism (MACM), *Submission 39*, p 4.

 ³⁵⁹ Ms Izabela Barakovska, Chair, Ministerial Advisory Council for Multiculturalism (MACM), *Proof Committee Hansard*,
29 January 2024, p 64.

8.12. The Australian Lawyers Alliance emphasised the need to ensure that interpreters are trained and adequately renumerated to ensure sufficient availability of interpreters to assist individuals in the ACT to access VAD.³⁶⁰

Community education

- 8.13. During the public hearing, members of MACM reiterated the importance of ensuring that community education on VAD extended to all multicultural communities.³⁶¹
- 8.14. In their submission, MACM indicated that community education on VAD should emphasise that there are eligibility criteria an individual must meet, and that it is only an end-of-life choice for individuals who are suffering intolerably.³⁶²
- 8.15. MACM told the committee it would also be beneficial to include case studies as part of educational materials, particularly in regard to what coercion can look like:

In conversations and in training materials, that community understanding needs to be supported. Case studies would probably be really valuable in order to have those more defining parameters of what is coercion, what are the consequences of it, and what that looks like ... The concept of case studies and that kind of storytelling element of the explainers and the real simplicity of it would be really great. People who are choosing it as a service need to understand the focus of self-advocacy and autonomy; and the surrounding family or community need to understand the rights and responsibilities of that individual, and the people around the individual need to respect that process as well.³⁶³

8.16. Other suggestions for engaging with multicultural communities included:

- creating handbooks for both communities and health professionals;
- holding in person information sessions; and
- producing educational resources in as many languages as possible.³⁶⁴
- 8.17. MACM also encouraged the use of roundtable discussions with multicultural communities for any further consultation on the implementation of VAD, to ensure continued community engagement with policymakers.³⁶⁵

8.18. ACT Health informed the Committee that there would be continued consultation throughout the 18-month implementation period:

As we said, during the 18-month implementation period, we will be consulting with all stakeholders and making sure that information about the scheme,

³⁶⁰ Australian Lawyers Alliance, Submission 41, p 14.

 ³⁶¹ Ms Izabela Barakovska, Chair, Ministerial Advisory Council for Multiculturalism (MACM), *Proof Committee Hansard*, 29 January 2024, p 68.

³⁶² Ministerial Advisory Council for Multiculturalism (MACM) , Submission 39, p 6.

 ³⁶³ Ms Izabela Barakovska, Chair, Ministerial Advisory Council for Multiculturalism (MACM), *Proof Committee Hansard*,
29 January 2024, p 68.

³⁶⁴ Ministerial Advisory Council for Multiculturalism (MACM), *Submission 39*, p 6.

³⁶⁵ Ministerial Advisory Council for Multiculturalism (MACM), *Submission 39*, p 7.

including that you cannot have reverse coercion, is available in a simple way. For the multicultural community, that will be in a way that is suitable for that community. It may be that we provide some of that information through trusted leaders of the community rather than just social media. We have that 18-month implementation period to work through that, and the aim is to make sure that it is all culturally appropriate and simple.³⁶⁶

- 8.19. The ACT Law society stated that 'international jurisdictions have also benefitted from consultation with indigenous communities to ensure cultural practices are appropriately respected.'³⁶⁷
- 8.20. Lack of community consultation was raised by the Knights of the Southern Cross who were concerned that the indigenous community has not been properly consulted.³⁶⁸
- 8.21. The explanatory statement states the ACT Government worked closely with the Office for Aboriginal and Torres Strait Islander Affairs, and the Aboriginal and Torres Strait Islander Elected Body in the development of the bill.³⁶⁹
- 8.22. Further, the Minister for Human Rights advised the Committee that a taskforce has been established to implement VAD in the ACT, which will:

...work closely with representatives from stakeholder groups, agencies and the wider community to develop community information, resources and support materials. Community representatives will be invited to participate in the implementation process where appropriate.³⁷⁰

Committee comment

8.23. The Committee notes the importance of continuous community consultation during the implementation stage of VAD to ensure that educational resources and materials meet the needs of Canberra's diverse and multicultural communities, including Aboriginal and Torres Strait Islander peoples.

Recommendation 27

The Committee recommends that the ACT Government seek input from culturally and linguistically diverse communities and Aboriginal and Torres Strait Islander people to ensure that public awareness and educational resources adequately address the needs of those groups.

³⁶⁶ Ms Rebecca Cross, Director-General, ACT Health, Proof Committee Hansard, 2 February 2024, p 205.

³⁶⁷ ACT Law Society, Submission 79, 9.

³⁶⁸ Knights of the Southern Cross, *Submission 74*, p 17.

³⁶⁹ Voluntary Assisted Dying Bill 2023, *explanatory statement*, p 4.

³⁷⁰ Ms Tara Cheyne MLA, answer to QTON 8: implementation phase, 2 February 2023 (received 14 February 2024).

9. Matters of conscientious objection

- 9.1. The Committee received a wide variety of submissions expressing a range of views on conscientious objection provisions for health care workers and facility operators.³⁷¹
- 9.2. The bill includes provisions enabling health practitioners and health service providers who conscientiously object to refuse to be involved in voluntary assisted dying. If a practitioner or provider refuses, they are required to refer the individual to the approved care navigator service.³⁷²
- 9.3. The bill also stipulates a number of obligations for facility operators that aim to assist an individual seeking access to VAD where the facility operator does not provide the service.³⁷³

Committee comment

9.4. The Committee notes that conscientious objection is a considerably personal issue related to one's own morals, ethics, and values. Therefore, members of the Committee have been provided with the opportunity to express their own views in an appendix to this report. The Committee does not seek to make any specific recommendations in relation to this matter and asks members of the Assembly to reflect on their own views, as well as the views of the Committee in the Appendices, and evidence provided to this inquiry.

³⁷¹ See for example, Rod Pitcher, Submission 2, p 3; Name withheld, Submission 3, p 2; Frances Coombe, Submission 4, p 2; Clem Jones Group, Submission 34, p 12; Paul Burt, Submission 38, p 2; Ministerial Council for Multiculturalism (MACM), Submission 39, pp 4–5; Australian Lawyers Alliance, Submission 41, p 13; Go Gentle Australia, Submission 44, p 11; Catholic Health Australia (CHA), Submission 46, p 9; Catholic Archdiocese of Canberra and Goulburn, Submission 47, pp 7–8; Anglican Diocese of Canberra and Goulburn, Submission 49, p 5; Calvary Health Care, Submission 55, p 9; Andrew Donnellan, Submission 60, p 3; Vicki Dunne, Submission 64, pp 3–4; Family Voice Australia, Submission 69 p 11; Australia and New Zealand Society of Palliative Medicine (ANZSPM), Submission 71, p 6; HOPE Preventing Euthanasia and Assisted Suicide, Submission 72, p 6; Knights of the Southern Cross, Submission 74, pp 9–10; Dr Bernadette Tobin, Plunkett Centre for Ethics, Submission 75, p 3; Dying with Dignity NSW, Submission 77, p 5; ACT Law Society, Submission 79, p 11; Dying with Dignity Victoria, Submission 82, p 3.

³⁷² Voluntary Assisted Dying Bill 2023, cl 94, 95.

³⁷³ Voluntary Assisted Dying Bill 2024, cl 96-104.

10. Conclusion

- 10.1. The Committee has made 27 recommendations in its *Inquiry into the Voluntary Assisted Dying Bill 2023*.
- 10.2. The Committee acknowledges that voluntary assisted dying is a sensitive topic and that different people will have different views on it. It was important to explore the views of a range of stakeholders with varying perspectives and expertise in different areas to inform this inquiry. The Committee would like to thank those who contributed to the inquiry through submissions and appearing at the public hearings which has assisted the Committee in gaining a deeper understanding of the topic.
- 10.3. The Committee thanks those who have contributed to the inquiry offering their personal experiences regarding people that have died or who are dying.

Suzanne Orr MLA Chair February 2024

Appendix A: Submissions

No.	Submission by	Received	Published
1	Confidential	03/11/2023	14/12/2023
2	Rod Pitcher	05/11/2023	28/11/2023
3	Name withheld	07/11/2023	14/12/2023
4	Frances Coombe	08/11/2023	28/11/2023
5	Geoffrey Kerr Williams	14/11/2023	14/12/2023
6	Name withheld	16/11/2023	14/12/2023
7	Meridian	16/11/2023	28/11/2023
8	lan Wood	22/11/2023	28/11/2023
9	Carmen Homaei	24/11/2023	28/11/2023
10	Yvonne Hall	24/11/2023	04/12/2023
11	Susan Garrick Leggo	27/11/2023	28/11/2023
12	Kerstin Braun	28/11/2023	04/12/2023
13	Susan Rockliff	28/11/2023	04/12/2023
14	Australian Christian Lobby	01/12/2023	04/12/2023
15	Tony Whelan	01/12/2023	04/12/2023
16	Australian College of Nursing	04/12/2023	05/12/2023
17	President Right to Life Association	04/12/2023	05/12/2023
18	Name withheld	04/12/2023	14/12/2023
19	Marshall Perron	04/12/2023	06/12/2023
20	Michael Boesen (on behalf of 14 Senior citizens from the ACT)	04/12/2026	06/12/2023
21	Doctors for Assisted Dying Choice	04/12/2023	06/12/2023
22	Australian Federal Police Association	05/12/2023	06/12/2023
23	Chris and Maree Rule	05/12/2023	06/12/2023
24	The Pharmacy Guild of Australia - ACT Branch	06/12/2023	08/12/2023
25	Mary Porter	06/12/2023	08/12/2023
26	Australian Care Alliance	07/12/2023	08/12/2023
27	Professor Lindy Wilmott and Professor Ben White	07/12/2023	14/12/2023
28	Health Care Consumer Association (HCCA)	07/12/2023	08/12/2023
29	Exit ACT and Ethical Rights	07/12/2023	08/12/2023
30	National Seniors Australia	07/12/2023	08/12/2023

31	lan Chubb	07/12/2023	08/12/2023
32	Voluntary Assisted Dying Australia and New Zealand	07/12/2023	08/12/2023
33	Dr Sid Finnigan	07/12/2023	08/12/2023
34	Clem Jones Group – Lindsay Marshall	07/12/2023	08/12/2023
35	Barbie Kelsall	07/12/2023	08/12/2023
36	Australian Nursing and Midwifery Association	07/12/2023	08/12/2023
37	Rita Joseph	07/12/2023	11/12/2023
38	Paul Burt	07/12/2023	11/12/2023
39	Ministerial Advisory Council for Multiculturalism	07/12/2023	11/12/2023
40	Mary Bruinink	07/12/2023	14/12/2023
41	Australian Lawyers Alliance	08/12/2023	11/12/2023
42	Carers ACT	08/12/2023	11/12/2023
43	Susan Liebke	08/12/2023	11/12/2023
44	Go Gentle Australia	08/12/2023	11/12/2023
45	Joseph Gasendo	08/12/2023	08/12/2023
46	Catholic Health Australia	08/12/2023	11/12/2023
47	Catholic Archdiocese of Canberra and Goulburn	08/12/2023	11/12/2023
48	Tamra Macleod	08/12/2023	11/12/2023
49	Anglican Diocese of Canberra and Goulburn	08/12/2023	11/12/2023
50	Beverley Cains	08/12/2023	11/12/2023
51	Katarina Pavkovic	08/12/2023	11/12/2023
52	Speech Pathology Australia	08/12/2023	11/12/2023
53	Hannah Mcleod-Boyle	08/12/2023	12/12/2023
54	Australian Care Alliance	08/12/2023	12/12/2023
55	Calvary Health Care	08/12/2023	12/12/2023
56	Griefline	08/12/2023	12/12/2023
57	Name withheld	08/12/2023	14/12/2023
58	Palliative Care ACT	08/12/2023	12/12/2023
59	Michael Chapman	08/12/2023	12/12/2023
60	Andrew Donnellan	08/12/2023	12/12/2023
61	Advocacy for Inclusion	08/12/2023	12/12/2023
62	Hon Greg Smith SC	09/12/2023	12/12/2023
63	John Arthur Harvey, AM	09/12/2023	12/12/2023
64	Vicki Dunne	10/12/2023	12/12/2023

65	Dinny Laurence	11/12/2023	12/12/2023
66	ACT Government	11/12/2023	12/12/2023
67	Dying with Dignity Western Australia	11/12/2023	13/12/2023
68	Sheena Ruth Black	13/12/2023	14/12/2023
69	Family Voice Australia	13/12/2023	14/12/2023
70	Corinne Vale and Jim Williams	13/12/2023	27/02/2024
70.1	Letter from Calvary Health Care	25/01/2024	27/02/2024
70.2	Letter from ACT Policing	25/01/2024	27/02/2024
71	ANZSPM	13/12/2023	14/12/2023
72	НОРЕ	13/12/2023	14/12/2023
73	ACT Human Rights Commission	13/12/2023	14/12/2023
74	Knights of the Southern Cross	13/12/2023	14/12/2023
75	Bernadette Tobin AO	13/12/2023	14/12/2023
76	Roy Harvey	14/12/2023	14/12/2023
76.1	Roy Harvey	31/01/2024	05/02/2024
77	Dying with Dignity New South Wales	14/12/2023	14/12/2023
78	Australia Institute	14/12/2023	14/12/2023
79	ACT Law Society	14/12/2023	18/12/2023
80	Jennifer Hobson	03/01/2024	04/01/2024
81	Lara Kaput	02/01/2024	15/01/2024
82	Dying with Dignity Victoria	17/01/2024	18/01/2024
83	Carole and Colin Ford, Alayne and David Richardson	31/01/2024	05/02/2024

Appendix B: Witnesses

Monday 29 January 2024

Australia Federal Police Association

• Troy Roberts, Media and Government Relations Manager

Pharmacy Guild of Australia ACT Branch

- Simon Blacker, ACT Branch President
- Sandra Ferrington, ACT Branch Committee Member

Health Care Consumers Association

- Kate Gorman, Deputy Director
- Dr Adele Stevens, Consumer Representative

National Seniors Australia ACT Branch

• Michael Boesen, ACT Policy Advisory Group, National Seniors Australia

Australian College of Nursing

- Kylie Ward, CEO
- Patsy Yates, Executive Dean, Faculty of Health at QUT

Carers ACT

- Lisa Kelly, CEO
- Jessica Johnson, Policy Officer

Speech Pathology Australia

• Kym Torresi, Senior Advisor, Aged Care

Advocacy for Inclusion

• Craig Wallace, Head of Policy

ACT Ministerial Advisory Council for Multiculturalism

- Izabela Barakovska, Chair
- Dr. Shanti Reddy Chintalaphani, Co-Chair
- Kui Foon Wong, Council Member

Catholic Archdiocese of Canberra and Goulburn

- Dr Patrick McArdle, Chancellor, Catholic Archdiocese of Canberra and Goulburn
- Archbishop Christopher Prowse, Catholic Archdiocese of Canberra and Goulburn

Anglican Diocese of Canberra and Goulburn

• Bishop Mark Short, Anglican Diocese of Canberra and Goulburn

Australian Christian Lobby

• Joshua Rowe, State Director NSW/ACT

Wednesday 31 January 2024

ACT Right to Life

- John Kennedy, President
- Moya Homan, Council Member

Australia New Zealand Society of Palliative Medicine

- Joseph Hooper, Chief Executive
- Dr Michelle Gold, President
- Michael Chapman, ANZSPM member

Calvary Health Care

- Mark Green, National Director Mission and People
- Ross Hawkins, Southern NSW and ACT Regional CEO
- Dr Frank Brennan AM, Palliative Care Physician

Plunkett Centre for Ethics

• Dr Bernadette Tobin AO, Acting Director

In individual capacity

• Andrew Donnellan, private capacity

Thursday 1 February 2024

Go Gentle Australia

• Dr Linda Swan, CEO

Exit International ACT Chapter

- Dr David Swanton, Chapter Leader
- Jennifer Lee Roberts, Executive Committee member
- Janet Clifford, Committee member

Clem Jones Group

• David Muir AO, Chair of Clem Jones Group

Palliative Care ACT

• Linda Hansen, CEO

in individual capacity

- Professor Kirstin Braun, School of Law and Justice, University of Southern Queensland
- **Professor Ben White,** Australian Centre for Health Law Research, Faculty of Business and Law, Queensland University of Technology
- **Professor Lindy Willmott,** Australian Centre for Health Law Research, Faculty of Business and Law, Queensland University of Technology
- Katerina Pavkovic, private capacity
- Roy Harvey, private capacity

Friday 2 February 2024

in individual capacity

- Corinne Vale, private capacity
- Jim Williams, private capacity
- Jacky Ryles, private capacity

ACT Law Society

- Elsa Sengstock, Senior Policy Officer
- Timothy Morton, Co-Chair
- Thomas Fischer, Committee Member

ACT Human Rights Commission

- Dr Penelope Mathew, President and Human Rights Commissioner
- Karen Toohey, Discrimination, Health Services, Disability and Community Services Commissioner
- Jodie Griffiths-Cook, Public Advocate and Children and Young People Commissioner

ACT Government

- Tara Cheyne MLA, Minister for Human Rights
- Daniel Ng, A/g Executive Group Manager, Justice and Community Safety Directorate
- Rebecca Cross, Director-General, ACT Health Directorate

- **Tania Browne,** A/g Executive Branch Manager, Health Policy and Strategy Branch, ACT Health Directorate
- **Chadia Rad,** Senior Director, End of Life Policy, (Voluntary Assisted Dying & Palliative Care), ACT Health Directorate
- Janet Zagari, Deputy Chief Executive Officer, Canberra Health Services

Appendix C: Questions taken on notice

Questions taken on notice

No.	Date	Asked of	Subject	Response received
1	29/01/2024	Australian Federal Police Association	Mental health impact of suicides on Police	07/02/2024
2	29/01/2024	Health Care Consumers Association	Age 14 and over for VAD eligibility	08/02/2024
3	29/01/2024	Speech Pathology Australia	Views on conscientious objection and two-day referral period	06/02/2024
4	29/01/2024	Advocacy for Inclusion	Evidence of people with a disability being offered VAD instead of disability support I other jurisdictions	08/02/2024
5	31/01/2024	Calvary Health	Further information on hospital/aged care facility obligations	08/02/2024
6	02/02/2024	Minister for Human Rights	Intersection of disability and other eligibility criteria for accessing VAD	09/02/2024
7	02/02/2024	Minister for Human Rights	Further information regarding the substance	14/02/2024
8	02/02/2024	Minister for Human Rights	Implementation phase plan documentation	14/02/2024
9	02/02/2024	Minister for Human Rights	Wording of 'takes reasonable steps to ensure' vs 'ensures' in proposed section 152	09/02/2024

Appendix D: Gender distribution of witnesses

Beginning in April 2023, in response to an audit by the Commonwealth Parliamentary Association, Committees are collecting information on the gender of witnesses. The aim is to determine whether committee inquiries are meeting the needs, and allowing the participation of, a range of genders in the community. Participation is voluntary and there are no set responses.

Gender indication	Total
Female	30
Male	21
Non-binary	0
Gender neutral	0
No data	3

Appendix E: Additional Comments by Mr Andrew Braddock MLA

Voluntary Assisted Dying (VAD) is already happening here in the ACT.

It happens in a myriad of different ways. Sometimes peacefully, sometimes traumatically, sometimes successfully, sometimes unsuccessfully, but the one consistent element is that it all happens in secret.

This secrecy means access is restricted and inconsistent. It places a heavy burden on our medical system, our police, and our coronial system. This bill simply brings VAD out of the shadows, to make it safer, and reduces the trauma for all involved, ultimately to the benefit of both the individual and the community.

This is an issue of which I, and many in our community, have personal experience. I have watched a family member whither away due to dementia. It haunts me, and creates fears of the future for myself and my loved ones. As it does for many in our community.

I won't pretend that the bill, or the committee's recommendations which I support, have the balance perfectly right. This will be an evolving policy space that will take years to resolve complex contradictory rights, ethics, and societal viewpoints into the black and white of legislation.

Is the Bill a good step? Yes. The benefit of moving last is that the Territory has had the opportunity to learn from other jurisdictions and adopt best practice.

"Like all legislation, the Bill may not be perfect. But it is a perfect next step to enabling our people the right to die with dignity and not suffer intolerably at the end of their lives." Katarina Pavkovic

Does the bill go far enough? No. The bill itself recognises that significant questions remain outstanding. These were not able to be resolved due to the need to get something in place in the time required. I support this approach of getting VAD in place whilst providing more time for other more complicated matters to be resolved. But I can't help but lament the lack of ambition to meet the community where it is at. Particularly as it relates to the loss of capacity.

Loss of Capacity

Dementia is a grievous disease, the leading cause of death in Australia, and will only increase in prevalence as people are kept alive for longer but with low quality of life.

The ACT Government's reluctance to engage this question in this tranche of VAD reform appears to be founded on three arguments.

The ethics of requiring medical professionals to administer VAD when the patient is not able to provide their consent (at the time of administration of VAD).

I found this argument challenging given the range of activities that are already covered via advanced health care directives. These include forced feeding, intubation, stopping life support systems, stopping feeding (ie starvation), preventing medical resuscitation or intervention plus others. There is clearly scope here for consideration of how such a scheme could include a formally registered advance care plan stating a desire to access VAD and a consistently expressed desire to undertake it.

I recognise there is an ethical grey zone of those who have lost capacity but may retain some level or form of awareness or may even deny or withdraw consent. But I also draw attention to how other international jurisdictions have successfully worked through this ethical challenge for a number of decades. The criterion proposed by National Seniors in their submission is likely to address this (reproduced below):

In our April submission, we proposed if a person does not have decision-making capacity, they should not be precluded from access to provisions for VAD providing these preconditions are satisfied:

(i) the desire to access VAD was stated in an advance care plan or other legally recognised document that was formally registered prior to them losing capacity;

(ii) while they no longer have decision-making capacity, they continue to consistently and repeatedly express their desire to undertake VAD.

That it was subjective

A core principle for VAD reform centres the decision on the dying person and their wishes. Such a principle means there will always be a degree of subjectivity inherent in the process.

That no other jurisdiction in Australia had done it

Welcome to the ACT – Australia's most progressive jurisdiction as long as someone else has gone first. Despite the community overwhelmingly stating that this is what they wanted to see included in VAD we as a committee, had to turn to models from Netherlands and Canada for inspiration. But ultimately as a committee, similar to the Government, our nemesis was time. However I don't believe the ACT needs to wait until the statutory review before it examines this question further, meanwhile condemning some vulnerable members of our community to intolerable suffering over extended periods of time before dying in an undignified, painful, and fearful manner.

Recommendation 1

That the ACT Government implement VAD for those who lose capacity prior to when the statutory review is scheduled.

Observance of the legislation in operation does not need to be a precondition to undertaking the policy and legislative work to expand the operation of the Act to those who lack capacity. There is demonstrated strong community demand for this to occur and it is the responsibility of the ACT Government and Legislative Assembly to continue to work on this issue without waiting for the review.

Conscientious objection by facility operators

An individual's right to conscientiously object to participating in VAD is enshrined in the Bill, is a cornerstone of the Australian model, and was not questioned during the committee process except for the administration of the Bill. A key question that arose before the committee is whether this same right should apply to institutions. Sadly, the Committee was unable to reach consensus on this aspect of the Bill.

Institutions are enduring collection of individuals who may vary over time. Each of those individuals who make up the Institution have an individual conscience and may suffer personal moral injury. But this should not be conflated onto the Institution. Institutions do not have a 'conscience', institutions do not suffer in the way an individual can, institutions do not have human rights.

Therefore an argument to grant conscientious objection rights to an institution is flawed and should be seen as an attempt to grant rights to a collection of individuals of similar conscience. Ideally this would be covered by individual conscientious objection rights, and in balancing with the rights of the vulnerable person seeking VAD.

I note some faith-based institutions put forward the view that conscientious objection by facility operators is in accordance with achieving a pluralistic society. Whilst an admirable goal, if implemented this would amount to obstruction to VAD.

- he power imbalance between powerful institutions and vulnerable individuals.
- The fact that people should be able to access VAD in the comfort and security of their home – which these facilities have become for a large number of residents over an extended period of time.
- The residential aged care market domination by faith based institutions in Canberra means choice is extremely difficult to access in practice.
- There are a large number of people who entered these facilities prior VAD becoming available.

The committee heard evidence from Go Gentle that: "There is a distinct difference between conscientious objection and obstruction. Enough evidence now exists from around Australia to show that a blanket right for institutions to conscientiously object to VAD leads to distress and suffering for some who are eligible for VAD, yet blocked in their efforts to pursue this legal medical care.to show that a blanket right for institutions to conscientious to conscientiously object to VAD leads to distress and suffering for some who are eligible for VAD, yet blocked in their efforts to pursue this legal medical care.to show that a blanket right for institutions to conscientiously object to VAD leads to distress and suffering for some who are eligible for VAD, yet blocked in their efforts to pursue this legal medical care"

The Clem Jones group submitted that a facility operator should not be deciding what is 'reasonable practicable'. They advised that a better approach would be that used in

Queensland, where the facility operator does not have the discretion to decide what is reasonably practicable'. 374

This was discussed in Chapter 3 of this report and partially addressed by Recommendation 10.

Recommendation 2

If Recommendation 10 of the main report is not adopted I recommend that the Bill be amended that subclause 100(2) 'be amended to remove the discretion it currently offers facility operators to decide that it is not reasonably practicable to provide access individual involved in a patient's VAD process'.

Andrew Braddock MLA

February 2024

³⁷⁴ Clem Jones Group, *Submission 34*, p 10.

Appendix F: Dissenting Report by Ms Leanne Castley MLA and Mr Ed Cocks MLA

Inquiry into the Voluntary Assisted Dying Bill 2023

Dissenting Report

Ms Leanne Castley & Mr Ed Cocks

Leanne Castley MLA Member for Yerrabi

28 February 2024

Ed Cocks MLA Member for Murrumbidgee

28 February 2024

Introductory Statement:

Legalisation of voluntary assisted dying is complex and often controversial. The diversity of evidence received through the inquiry highlighted that views and opinions on voluntary assisted dying, and the many practical, ethical and moral issues it raises, are far from unanimous. There are significant differences and nuances in opinions and perspectives across the community, across the Legislative Assembly, in the Committee established to examine the Government's Bill, and indeed for us as authors of this dissenting report.

In the context of this diversity of opinion, it is notable and commendable that all members of the Select Committee sought to find a consensus position to form the main report. For the most part, the main report reflects that objective and we support those consensus recommendations.

However, the main report fails to grapple with important issues which should be considered by the ACT Legislative Assembly in its debate of the legislation, by the Government in its implementation and future directions should legislation be passed, and by the community in considering the current and future direction for voluntary assisted dying. These were important issues and perspectives which were raised during the inquiry but have been excluded from or inadequately addressed in the main report, including:

- Inadequate safeguards;
- Risks to vulnerable people;
- Expansion to children, and people without decision making capacity; and
- Barriers to conscientious objection

None of these issues are new. Each has been comprehensively examined and discussed in other Australian jurisdictions.

Therefore, while we were able to agree to the content of the main report, we consider it necessary to dissent on the basis of the information and issues excluded from that report and committee deliberations. It is important that, to the greatest extent possible, the important potential risks of the Government's approach to voluntary assisted dying be highlighted to ensure robust debate and informed discussion of the Bill.

In developing this dissenting report, and throughout the inquiry, we have each put aside our individual opinions on whether voluntary assisted dying should be legalised in the ACT. We have instead focussed our efforts on how the Bill would operate if it came into effect; and how it compares with the legislation now in place in other Australian jurisdictions, and whether it adequately protects against potential risks to individuals and the community.

Comparison with other Australian Jurisdictions

Legalisation of any form of voluntary assisted dying is very new in Australia, and there has been no comprehensive review of any of the States' models. The earliest scheme has only been operational in Victoria since June 2019, has not yet been reviewed, and the review is only expected to be an operational review which will not consider the Act itself. Other jurisdictions have legislated for voluntary assisted dying far more recently, with the Western Australian Act becoming operational in July 2021 and the Tasmanian Act becoming operational in 2022. The South Australian, Queensland and New South Wales Acts all came into effect in 2023, with the most recent (NSW) only in effect since November – after the ACT legislation had been introduced.

So while it is the case that the ACT's voluntary assisted dying legislation has not been developed or implemented before most other jurisdictions, it is clear there is very limited information or data available from the voluntary assisted dying programs of most Australian jurisdictions, and there has been minimal opportunity to evaluate or learn from most other jurisdictions prior to the development of the ACT legislation.

We cannot, therefore, accept the Minister's suggestion that the experience of all other Australian jurisdictions has been, or could have been adequately considered in developing this Bill.

This is particularly important because the proposed ACT legislation departs from the *Australian Model* of voluntary assisted dying in important ways. Evidence was received through the committee process that indicates, in contrast to the approach of other jurisdictions, the Government's Bill is more ideological, and closer to the model advocated by the more extreme and ideological advocacy organisations. Exit ACT, for example, states – *"The ACT is fortunate that Ms Cheyne has long been a very strong supporter of [Voluntary Assisted Dying]"* and argues that there should be no pressure on the Minister to propose a medical model.

The approach to voluntary assisted dying proposed by groups such as Exit International, and which seem to have underpinned the deviations from the Australian Model, appear to be largely ideological, and seem to be based on the premise that minimising the amount of time an individual suffers should override any other concern.

This ideological position was highlighted most starkly by an Exit ACT representative who, amongst other points, argued that there should be no limits to voluntary assisted dying, including limits on age or decision making ability, using the example of a two-year-old child.

It is concerning that the Bill has been described as prioritising access over safety, and removes or waters down important practical safeguards such as the requirement for a prognosis period. It also adopts harsh penalties for those who conscientiously object to participating in or facilitating an individual's death by voluntary assisted dying.

Furthermore, the Bill also embeds a worrying roadmap for expansion into highly controversial areas including voluntary assisted dying for children, and for individuals who have lost decision making capacity.

On reflection, and after considering all of the evidence presented to the Committee, we consider the Bill presented by the Minister represents the most ideological and extreme assisted dying legislation in the country.

It is also important to note that a small number of community groups and some Members of the Legislative Assembly advocate for even more extreme positions on voluntary assisted dying than those presented in the current Bill. However, the existence of, and advocacy for fringe positions does not make the current Bill any more reasonable. Nor does it indicate an appropriate compromise has been struck.

For this reason, we cannot recommend the Legislative Assembly pass the Bill in its current form, and we consider there would be benefit in the Government amending the Bill to be more consistent with the legislation which has been accepted in other jurisdictions. We consider this would increase the likelihood of acceptance and support by a greater proportion of the community, and by more members of the Legislative Assembly who may be uncomfortable with the current model.

RECOMMENDATIONS

Recommendation 1: That the Legislative Assembly not pass the Bill in its current form.

Recommendation 2: That the Government amend the Bill to be more consistent with the provisions of other jurisdictions to increase the likelihood of support from a greater proportion of the community and Members who are unable to support the current model.

Controversial Expansion Roadmap.

The provisions relating to the statutory review, and the potential future direction for voluntary assisted dying were the subject of extensive discussion during hearings, and during media coverage prior to tabling of the bill.

While the Minister's most extreme proposals were removed prior to presentation of the Bill, we remain deeply concerned that the Minister may have elected to remove those controversial provisions only because they are electorally unpopular. We are also concerned the Minister may intend to introduce those same expansion provisions after the threat of an imminent election has passed. We would be less concerned about this risk were it not for the seemingly dishonest use of the same tactics in relation to the decriminalisation of heroin and methamphetamine after the 2020 election.

It is our view that it is imperative that the Minister is up front with Canberrans about her intentions for the future of the Bill because the statutory review provisions seem to establish a clear roadmap for the Government to proceed toward even more extreme positions.

The Committee heard significant concerns that the review criteria set out for the Bill establish a roadmap toward expanding voluntary assisted dying into areas advocated by the most extreme submissions to this inquiry, specifically consideration of making death by voluntary assisted dying available to children, and those who no longer have decision making capacity.

Furthermore, this approach to reviewing the Bill represents a significant contrast to the reviews being undertaken in other jurisdictions which will focus on the operation of the

Bills. A refocussed operational review would likely enable the benefits suggested by the AFP Association.

RECOMMENDATIONS

Recommendation 3: That the Government revise clauses related to the statutory review of the Bill to remove all reference, implication and expectation of future expansion of eligibility criteria.

Recommendation 4: That the Government refocus the review on the operation of the Bill, including for example, reporting of numbers of deaths by voluntary assisted dying, reporting on proportion of people who proceed with voluntary assisted dying after being approved, and handling and timeframes for return of voluntary assisted dying substances.

Safeguards

If voluntary assisted dying legislation is to pass in the ACT, the most critical, and fundamental hurdle which must be cleared is to guarantee that each and every instance is completely voluntary and according to the genuine intent and willing consent of the individual whose life is taken.

There must never be any question as to whether someone was persuaded, convinced, or influenced by another person to end their life. Similarly, there must never be any question of whether a government official, medical practitioner, or even significant other has convinced an individual that their life is worth less, or that they are a burden due to their condition.

To be a truly personal, voluntary decision, the intent must arise from the individual, and the decision must be free from any form of coercion or external influence.

The evidence presented to the committee highlighted the presence of clear risks that an individual could be influenced toward participating in voluntary assisted dying when they would not otherwise have done so. This evidence is strongly supported by work undertaken in other jurisdictions in the course of developing voluntary assisted dying legislation.

Some safeguards utilised in other Australian jurisdictions include:

- Limiting voluntary assisted dying to people with 6 months to live (or 12 months for people with a neuro-degenerative condition);
- Requiring that health practitioners not propose or suggest voluntary assisted dying without the topic first being raised by the individual;
- A proactive review board with responsibility for the final approval of applications, and authorisation of the substances used for voluntary assisted dying;
- Strict controls on the handling and return of VAD substances.

In each of these examples, the ACT Bill has watered down the protections afforded in other jurisdictions, and it is deeply concerning that, as starkly pointed out by one witness, the current Bill prioritises access [to voluntary assisted dying] over safeguards. This means that while the Bill contains some provisions that appear designed to offset concerns, those

provisions do not provide adequate protections or safeguards to ensure the decision to end a person's life is truly self-initiated and free from influence.

We therefore recommend that the Government amend the Bill to introduce stronger safeguards, consistent with other jurisdictions; including introduction of a prognosis period, stronger and clearer regulation of risky conversations about voluntary assisted dying; and strict controls on the handling and return of VAD substances.

RECOMMENDATIONS

Recommendation 5: That the ACT Government amend the Bill to introduce a prognosis requirement to ensure voluntary assisted dying is only used during a defined end of life period.

Recommendation 6: That the ACT Government amend the bill to strengthen provisions related to how, and under what conditions voluntary assisted dying may be raised with an individual, including tightening of when a discussion may be initiated, and what training and qualifications are required to have an unbiased and sensitive discussion of voluntary assisted dying.

Recommendation 7: That the Government amend the Bill to require any unused VAD substance, and associated containers or instruments, to be retrieved and returned within 48 hours after an individual has died.

It should also be acknowledged that a critical safeguard can also arise from the direct involvement of a person's usual medical practitioner (most frequently this would be their GP). While the main report references this relationship and notes that no submissions were received from the professional groups, it was disappointing that the Committee majority chose not to seek further information from medical practitioners or GPs through a representative body once that information gap was identified.

General Practitioners are on the front line of healthcare in the ACT. We consider their perspective is essential to consideration of this Bill, and suggest that Members of the Legislative Assembly may wish to independently seek information in this regard.

Vulnerable people.

We also note the evidence presented to the Committee that safeguards are even more important in relation to vulnerable people, and situations where there is a power imbalance. Advocacy for Inclusion highlighted this in their submission on the development of the Bill which quoted Dr George Taleporos, Chair, Victorian Disability Advisory Council:

"The right of every person to live a life free from coercion and undue burden is an inalienable one. As the debate on VAD continues, it is essential that we ensure that people are kept safe and not subjected to any form of coercion or exploitation.

We must take all necessary steps to ensure that VAD decisions are made without duress and with full knowledge of all available options. This includes providing support services, legal advice, and counselling for those contemplating end-of-life decisions. It also involves taking measures to protect vulnerable individuals from exploitation or abuse, including those who may be at risk of coerced VAD."

While this statement was made in the context of the risks to people with disabilities, the risk is conceivably far broader, including anyone who is vulnerable or dealing with a power imbalance, including older people and people in domestic violence situations. For example a previous Legislative Assembly Select Committee considered there were clear risks in relation to elder abuse.

Furthermore, on reviewing the provisions of the Bill, we could not conclude that the coercion and dishonesty provisions of the Bill, would be sufficient to address the full range of risks, particularly in the face of manipulative psychological abuse. The nature of this type of abuse, including instances of elder abuse, domestic violence, and workplace psychosocial violence, means that it is possible to act outside the definition of coercion and misuse statements which are not technically dishonest to persuade a vulnerable person that their life is of lower value, or that they should use voluntary assisted dying to end their life.

In this context, we consider it is essential to acknowledge the value of every individual in our community, and to recognise that an individual's value and importance is not diminished by disability, age or frailty.

RECOMMENDATIONS

Recommendation 8: That the ACT Government amend the Bill to incorporate stronger protections for vulnerable people including people with disabilities, older people, those in a vulnerable state of mind, and people who may be experiencing domestic violence.

Conscientious Objection

One of the most glaring gaps in the main committee report is absence of any significant information on or discussion of matters of conscientious objection. We are deeply disappointed that the Committee could not reach a consensus that would allow the perspectives presented to the inquiry to be summarised or considered. We have therefore attempted to provide a balanced summary of the positions put forward in Attachment 1 to this report.

The right to conscientious objection in controversial spheres is longstanding in Australia, and across the western world. It is not restricted to religious belief, and has strong humanist roots; particularly in relation to participation in taking lives through war.

In addition, it is broadly recognised that conscientious objection can occur at a variety of levels, and to differing degrees for different individuals and institutions. For example, during the First World War, some conscientious objectors chose to participate in non-combat roles, while others objected to any role that would see them actively facilitate the military efforts, instead taking on other services important to the ongoing functioning of the country. A small minority objected to such an extent that they refused any form of service.

It is also important to recognise that conscientious objection in respect of voluntary assisted dying involves competing rights. While the Bill would establish a right to voluntary assisted dying, any health practitioner has both a right and responsibility to act in accordance with their conscience. Of direct relevance to this issue, the Victorian Advisory Council stated that:

"All people, including health practitioners, have the right to be shown respect for their culture, beliefs, values and personal characteristics."

The current Bill allows only for a very limited approach to conscientious objection and requires individuals and institutions to facilitate access, and make referrals – active steps which will conflict with the moral convictions of some. We are concerned that the extremely limited approach will cause moral injury for those people, and contravenes the principle above.

Furthermore, we note the proposition put by Mr Andrew Donnellan that "Patients, particularly those who consider themselves vulnerable, should have the option of choosing a facility where VAD will not be offered under any circumstances even by external providers.", and his suggestion that facility operators should be required to make their policy clear to all prospective patients in order to be "completely opt-out of the VAD scheme and provide no support for VAD-related activities on their premises".

Notably, Mr Donnellan's suggested approach seems to align well with the conscientious objection provisions of the South Australian legislation. Indeed, the South Australian provisions provide a strong framework for conscientious objection, and we recommend Government adapt those provisions for the ACT Bill.

RECOMMENDATIONS

Recommendation 9: That the Government recognise the right of individuals and organisations to full conscientious objection

Recommendation 10: That the Government amend the Bill in line with the conscientious objection provisions of the South Australian Voluntary Assisted Dying Act 2021.

Strict Liability Offences

The Committee also heard significant evidence of concern with the current Bill's use of strict liability offences within the Bill. As described in both the explanatory statement, and the main report, these offenses allow for the "imposition of criminal liability without the need to prove fault".

In addition to the unrealistic timeframes that would apply to the offences carrying strict liability, there was also concern that strict liability was inappropriate for those offences, and particularly in the context of the significant penalties which would apply (\$3,200 for an individual and \$16,000 for a corporation).

We acknowledge that strict liability offences are not an unusual feature of regulatory systems. Indeed, a 2002 inquiry by the Commonwealth Standing Committee for the Scrutiny of Bills comprehensively examined the application of already longstanding strict liability

offences and when and how they ought to apply. Yet it is notable that, in setting out the basic principles of strict liability, the Commonwealth inquiry report stated:

- *"fault liability is one of the most fundamental protections of criminal law. To exclude this protection is a serious matter";*
- "strict liability should be introduced only after careful consideration on a case-bycase basis of all available options. It would not be proper to base strict liability on mere administrative convenience or on a rigid formula"; and
- "strict liability offences should, if possible, be applied only where there appears to be general public support and acceptance both for the measure and the penalty"

The ACT's guide for framing offences also specifies that:

"There must be a demonstrable and legitimate aim for creating a strict liability offence."

In this light, it was concerning that, when questioned on the purpose of applying strict liability to offences within the Bill, the advice from the Justice and Community Safety Directorate pointed only to the general and formulaic criteria from the guide for framing offences. There was no indication that alternatives to strict liability offences had been considered, no evidence of public support and acceptance for the measure and the penalty, and no sign of any consideration regarding whether there was a demonstrable and legitimate aim for the application of strict liability.

We therefore do not consider that the benchmark for applying strict liability has been met, and recommend that strict liability is removed from the Bill, and the regulatory scheme.

RECOMMENDATIONS

Recommendation 11: That the Government amend the Bill to remove strict liability.

Attachment 1 – Summary of Views on Conscientious Objection Raised During Hearings

Concerns raised in evidence

Strengthening conscientious objection provisions

- A considerable number of submitters raised concerns that the current conscientious objection provisions in the Bill are insufficient to protect the rights of individuals and service providers to act in accordance with their conscience. Many of these submissions indicated that conscientious objection protections should extend to those who fully object, and should not require a conscientious objector to undertake any action that would facilitate voluntary assisted dying (for example referral to a voluntary assisted dying practitioner, or allowing voluntary assisted dying to be provided in their facility).³⁷⁵
- The Catholic Archdiocese of Canberra and Goulburn also remarked that the provisions for conscientious objection were undermined by the inclusion of clause 95 which requires a person to refer the individual seeking voluntary assisted dying to the care navigator service within two days.³⁷⁶
- Sharing a similar sentiment, the Anglican Diocese of Canberra and Goulburn said that the conscientious objection provisions did not allow for complete non-participation.³⁷⁷
- Several submitters indicated that the referral of an individual to another provider is still taking part in voluntary assisted dying, meaning they cannot fully conscientiously object under the current provisions of the bill. ³⁷⁸
- Some submitters suggested that there is value in having facilities that do not participate in any way with voluntary assisted dying, as this allows people to choose a facility that aligns with their values.³⁷⁹
- Further, Calvary Health Care stated that they do not allow credential external health practitioners to enter Calvary facilities to provide services beyond their expertise, citing concerns that they would not be able to ensure the appropriate standard of clinical care.³⁸⁰

This was also noted by ANZSPM, who stated:

Allowing medical practitioners to enter and perform a procedure on a patient in an institution without any oversight, credentialling or governance of that

³⁷⁵ Paul Burt, Submission 38, p 2; Vicki Dunne, Submission 64, pp 3–4; Family Voice Australia, Submission 69 p 11.

³⁷⁶ Catholic Archdiocese of Canberra and Goulburn, *Submission* 47, pp 7–8.

³⁷⁷ Anglican Diocese of Canberra and Goulburn, Submission 49, p 5.

³⁷⁸ HOPE, Submission 72, p 6; Knights of the Southern Cross, Submission 74, pp 9–10.

³⁷⁹ Bernadette Tobin, *Submission 75*, p 3; Anglican Diocese of Canberra and Goulburn, *Submission 49*, p 6; Andrew Donnellan, *Submission 60*, p 3.

³⁸⁰ Calvary Health Care, Submission 55, p 9.

institution is not accepted medical practice nor accepted patient care. This is not done in any other part of medicine, nor is it accepted by any institution. In this situation, it is important to ask who would be ultimately responsible for an adverse outcome, and to firmly reject the possibility of procedures being performed outside of the governance and staffing arrangements of the patient's hospital or care facility.³⁸¹

- Catholic Health Australia shared this concern about who would be responsible for the credentialing and liability of external health practitioners, as well as expressing that this requirement 'would amount to a form of participation that is fundamentally at odds with our ethics'.³⁸²
- Calvary Health Care advised the Committee that the credentialing requirements for clinicians on hospital grounds are different to those for aged care facilities. They suggested the bill as written does not fully acknowledge these differences, and that closer alignment with NSW or SA would be beneficial.³⁸³
- Additionally, ANZSPM expressed concern that individual conscientious objectors may experience subtle forms of coercion from their employer to participate in VAD.³⁸⁴
- A similar concern was shared by the ACT Law Society, who cautioned 'because there are criminal sanctions for non-compliance with requirements in Part 7 of the bill, there is a risk that facility operators might take adverse action towards a person who holds a conscientious objection.' They suggested the bill draw attention to the legislative protection against unfair dismissal ((*Fair Work Act 2009* (Cth) and the *Discrimination Act 1991* (ACT)).³⁸⁵

Conflict between the right to conscientiously object and access to Voluntary Assisted Dying

- Some submitters expressed the view that a person seeking access to voluntary assisted dying should not have that access hindered by someone who conscientiously objects.³⁸⁶
- Clem Jones Group suggested that subclause 100(2) 'be amended to remove the discretion it currently offers facility operators to decide that it is not reasonably practicable to provide access individual involved in a patient's VAD process'. They suggested further alignment with Queensland, which does not offer this discretion.³⁸⁷

³⁸¹ ANZSPM, Submission 71, p 6.

³⁸² Catholic Health Australia, Submission 46, p 9.

³⁸³ Calvary Health Care, answer to QTON 5: information on hospital vs aged care facility obligations, 1 January 2024 (received 8 January 2024).

³⁸⁴ ANZSPM, Submission 71, p 6.

³⁸⁵ ACT Law Society, *Submission 79*, p 11.

³⁸⁶ Rod Pitcher, Submission 2, p 3; Go Gentle, Submission 44, p 11; Frances Coombe, Submission 4, p 2; Name withheld, Submission 3, p 2.

³⁸⁷ Clem Jones Group, *Submission 34*, p 12.

This view was shared by Dying with Dignity NSW, who indicated that overall, the rights of conscientious objectors and individuals seeking VAD was balanced.³⁸⁸

The Australian Lawyers Alliance (ALA) stated that in Queensland, a health practitioner who conscientiously objects must provide an individual with the details of another provider at the time of informing the individual of the practitioner's decision. The ALA indicates this would be their preferred timeframe, so as not to delay a person's access to VAD.³⁸⁹

Support for balance of provisions in the bill

- The third perspective outlined in submissions was that the provisions for conscientious objectors in the bill were overall sufficiently well balanced with the rights of the individual seeking VAD, while others provided neutral commentary on the importance of achieving a reasonable balance.³⁹⁰
- Go Gentle highlighted that the right of individuals to conscientiously object is a cornerstone of voluntary assisted dying across Australia, but did not consider that this should not extend to institutions; they therefore commended the bill for requiring facilities not to hinder access.³⁹¹
- The Ministerial Council for Multiculturalism indicated strong support for the provisions that allow a health professional of care facility to abstain from participating, whilst recognising the need for an individual to seek VAD if they so wish³⁹²

The ACT Government submitted that:

The bill seeks to balance a conscientious objector's rights to freedom of belief, with an eligible individual's fundamental rights and freedoms to choose voluntary assisted dying. As such, the bill outlines minimum standards that must be followed by a health practitioner or health service provider who is unwilling or unable to assist with voluntary assisted dying.³⁹³

³⁸⁸ Dying with Dignity NSW, *Submission* 77, p 5.

³⁸⁹ Australian Lawyers Alliance, Submission 41, p 13.

³⁹⁰ Clem Jones Group, Submission 34, p 5; Go Gentle, Submission 44, p 11; Dying with Dignity Victoria, Submission 82, p 3.

³⁹¹ Go Gentle, *Submission 44*, p 11.

³⁹² Ministerial Council for Multiculturalism, Submission 39, pp 4–5.

³⁹³ ACT Government, *Submission 66*, p 13.

Appendix G: Dissenting Report by Dr Marisa Paterson MLA

I believe that all Canberrans should have access to a range of end-of-life choices that align with their preferences and values, and that Voluntary Assisted Dying (VAD) should be one choice available to Canberrans with an advanced condition, illness, or disease, experiencing suffering near the end of their lives.

Ultimately, the Bill, as it stands, provides the appropriate safeguards and protections, while attempting to provide a smooth and succinct process for people when they are at the end of their life.

I fundamentally believe that access to voluntary assisted dying is a human right.

I respect people's right to conscientiously object, and those people whose values do not align with concept of voluntary assisted dying, however, this must be about choice. VAD is not a choice between life or death, it is an additional option that can be provided to an eligible individual allowing them to have greater autonomy in how their life ends.

Until this bill passes, people in the ACT will continue to experience intolerable suffering. I think it is important to highlight some of the voices through the inquiry of people who have watched their loved ones suffer. It is these voices that drive me to see that this choice is available to ACT residents at the end of their lives.

Ian Chubb – Submission 31

To her dignity was an essential characteristic of life. Quality of life was important. She would say sanctity of life – professed by some – is ok for them but not for her. Yet she lost all dignity, all quality, in her final years.

Her last days were terrible. She was writhing in her bed, eyes closed and moaning. Her pain was treated by her carers.

Carole and Colin Ford, Alayne and David Richardson – Submission 83

'Our father'... spent his last two weeks hospitalised, falling over, falling out of bed at night, having nightmares, struggling to breathe, and unable to accept sustenance. He lost any connection to reality in his last days.

We are witnessing the same kind of decline in our mother, (95 this year), who has on many occasions requested that she be allowed to die while still mentally capable of choosing to.

Being able to say goodbye, while her true character and personality are still intact, is a precious gift that she and our family would be extremely grateful to receive.

Susan Rockliff – Submission 13

'Finally, Jeff took her home for the weekend in April 2021, and they took their own lives with the use of ether. Jeff left a suicide note for the Coroner, which read in part, "... As she has attempted several times to end her life without success, I feel that it is now my job to help her achieve this. The alternative is for her to rot away in an institution for years, unhappy and assailed by anxiety. As we both have incurable conditions [Jeff had chronic fatigue syndrome], and are unhappy with our lives which have no prospect of improvement, it seems stupid to "soldier on". By going now, we can avoid the pain and indignities likely to further besiege us as we grow older.'

Joseph Gasendo – Submission 45

Both my father and my mother, in my opinion, had gone on far too long in bed – in pain and loneliness – before their ultimate release. During our terrifying family journey, my siblings and I could only watch our parents shrink before our eyes, even though they expressed a will to die before reaching the level of non-control where we had to feed them through the nose. In addition, my first wife died of cancer in Clare Holland House, in 2003, without being afforded the morphinefree chance to take control of her life when she could no longer stand the pain.

Corrine Vale and Jim Williams – Submission 70

These laws were too late for our dearly loved mum/wife Ros Williams, who took her own life in April 2023 because voluntary assisted dying was not accessible to her. She was dying of motor neurone disease (MND) and after rationally considering all the end-of-life options available to her in the ACT, she decided that suicide was her 'least-worst option'. No-one should have to make this terrible choice.

Katarina Pavkovic – Submission 51

If my father has access to VAD, the last few weeks of his life would have been completely different. Instead of fear, anxiety, and apprehension for each day of his hospital visit, it would have been filled with love and appreciation, despite the sadness. Family would have had the opportunity to be present, and more importantly, my dad would have felt like he was in control and independent to the end.

I would also like to acknowledge **Mr Roy Harvey (Submission 76)** for his advocacy to see that VAD is legalised in the ACT so that people in circumstances like his late wife, Anne, do not have to suffer and can choose to die with dignity, on their own terms.

I dissent from three recommendations:

a) Recommendation 3

I dissent from the Select Committee's recommendation to see an extension of time (from 2 days to 4 days) for the strict liability offence for a health practitioner or health service provider to refer a patient if they conscientiously object.

While I respect the right of an individual health practitioner to conscientiously object, they should not in any way obstruct or delay an individual's right to access VAD. I believe 2 days, as outlined in the bill, is an appropriate timeframe for referral. The committee heard significant evidence from individuals whose loved ones were suffering terribly at the end stages of their life and it was clear from their evidence that time becomes critically important. Unnecessary delays due to a practitioner or a health service provider's objection to VAD should not be provided for in the legislation. I believe the strict liability offence for contentious objection referral by a health practitioner, or a health service provider should remain at 2 days.

Conscientious objection to VAD is not a belief that has arrived overnight, and it is not a stance that would change from patient to patient, in line with that reasoning health practitioners in the ACT who conscientiously object should be well prepared in knowledge of referral pathways for the circumstance that a person initiates a VAD discussion or request.

I also note the discussion in the report at part 3.55. I stress the importance of clause 103 (2) that requires a facility operator to publish its policy on VAD in a way that is likely to come to the attention of a resident of the facility, or an individual who may wish to become a resident of the facility in the future. This should remain a strict liability offence.

b) Recommendation 10

My dissent from this recommendation stems from my belief that an institution should not be able to 'conscientiously object'. There is evidence from other states that suggests that health facilities have denied patients access to VAD. Dying with Dignity Victoria (DWDV)³⁹⁴ highlights incidents "*in which facilities such as hospitals and residential aged care have denied individuals access to VAD information, consultations with VAD doctors and, in one case, refusal of entry to the pharmacists delivering the VAD medication. DWDV has heard from people impacted by these actions who have, as a result of institutional objection, personally experienced or witnessed the additional suffering of a loved one."*

³⁹⁴ Dying with Dignity Victoria, Submission 82, p 7

The evidence the committee received from Catholic Health Australia³⁹⁵ expressed that this requirement of allowing VAD practitioners into their facilities 'would amount to a form of participation that is fundamentally at odds with our ethics'.

Evidence from Calvery Health³⁹⁶ in the hearing and in their submission (Submission 55) clearly outlines their objection to facilities, such as hospitals and hospices, providing VAD information and services (even if provided by an external practitioner) to patients.

In their own words Calvery Health Care³ (Submission 55) suggest recommendations that:

- A) Do not force non-participating facilities to allow external practitioners, who are not credentialed by the facility's operator, to enter the facility and provide VAD services, which are outside the facility's scope of practice.
- *B)* Remove the requirement for the facility operator to provide the person with the contact details for the VAD navigator service in writing and align requirements regarding access to information about VAD with Sections 90 and 99 of the NSW legislation.

From my perspective this poses an unacceptable risk that VAD will not be equally accessible across the ACT. I strongly believe that if VAD is to become a legal service - all residents, regardless of the health or aged care facility they are in, should have access to VAD as an end-of-life choice.

I do not believe the ACT bill goes far enough as clause 100 (2) gives operators the discretion and the grounds to refuse access to information and relevant VAD practitioners if it is not "reasonably practicable."

As many submissions to the inquiry suggested, the ACT bill should mirror Queensland's legislation to ensure that a facility operator cannot impede access to VAD.

For example: The *Qld Voluntary Assisted Dying Act 2021* removes the facility operator's discretion to refuse access to information in Subdivision 2, Clause 90(2), (a) and (b)(i): "The relevant entity and any other entity that owns or occupies the facility – must not hinder the person's access at the facility to information about voluntary assisted dying" and "must allow reasonable access at the facility by each person who is a registered health practitioner..."

I note the Select Committee's Recommendation 10 attempts to address this issue of access with an independent review process, however, I consider an independent review process an unnecessarily, time-consuming, and potentially distressing impost on a patient that is intolerably suffering.

³⁹⁵ Catholic Health Australia, Submission 46, p 9.

³⁹⁶ Calvary Health Care, Submission 55, p 8-9

If VAD is to become law, all ACT residents who qualify for VAD should have equal access. This is a right of ACT residents that should not be compromised by the religious views of a health institution, as has been seen to occur in other jurisdictions.

c) Recommendation 11

I dissent from the Select Committee's recommendation to provide a minimum 48 hour waiting period from first request and last request. I view the bill in its current form as providing sufficient safeguards in access to VAD. I view the addition of a minimum 48 hour waiting period as providing barriers to access. I argue that if an individual is seeking access to VAD and medical professionals are processing VAD requests and assessments with that level of urgency, then arbitrary timeframes and additional barriers should not be imposed. I also view the 'ability to grant exemptions where there is compelling reason' as adding significant barriers to access when a person is intolerably suffering.

Conclusion:

I view this bill as a very important piece of legislation. I acknowledge that many people who gave evidence to the inquiry argued that the bill did not go far enough in that it did not legislate for advanced care directives or for young people with decision-making capacity to access to VAD. I believe that these are important aspects of the VAD discussion that I am glad to see are incorporated in the review of the ACT.