LEGISLATIVE ASSEMBLY
FOR THE AUSTRALIAN CAPITAL TERRITORY

SELECT COMMITTEE ON VOLUNTARY ASSISTED DYING BILL
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Submission Cover Sheet

Inquiry into the Voluntary Assisted Dying Bill 2023

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Our ref: PRO23/4486

Secretariat
Voluntary Assisted Dying Committee
ACT Legislative Assembly
By email: lacommitteeVAD@parliament.act.gov.au

8 December 2023

Dear Secretariat

We enclose the ACT Government's submission to the Select Committee inquiry into the Voluntary Assisted Dying Bill 2023. For any questions relating to the ACT Government's submission, please contact the relevant officials in the Justice and Community Safety Directorate and ACT Health Directorate by email at VADPolicy@act.gov.au and ACTHD-VAD@act.gov.au.

Sincerely

Tara Cheyne MLA

Rachel Stephen-Smith MLA

Encl. ACT Government submission to the Select Committee inquiry into the Voluntary Assisted Dying Bill 2023.

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Submission to the Select Committee inquiry into the Voluntary Assisted Dying Bill 2023

December 2023

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The ACT Government acknowledges the many Canberrans who have experienced, or are experiencing, suffering in the face of illness, disease, and medical conditions. We also acknowledge the hardships and grief experienced by their loved ones and carers.

This submission contains information that may be distressing or uncomfortable. If you need support, contact Lifeline on 13 11 14 or Griefline on 1300 845 745.

Submission to the Select Committee inquiry into the Voluntary Assisted Dying Bill 2023

December 2023

Background

Context for reform

The ACT Government welcomes the opportunity to make a submission to the Select Committee Inquiry into the Voluntary Assisted Dying Bill 2023 (**the Bill**).

The ACT Government believes all Canberrans should have end of life choices that align with their rights, preferences and values. Canberrans should have access to quality health care, including end of life care, when they need it. However, the ACT Government knows that even with the best end of life care, some Canberrans with an advanced condition, illness or disease experience suffering near the end of their lives. Eligible people should be able to make informed choices about the end of their lives, with the support of health professionals and services.

To promote the autonomy and dignity of those people, the ACT Government has considered how to legalise and regulate access to voluntary assisted dying, as all states in Australia have done.

The ACT Government has long advocated for the ability of the ACT to introduce voluntary assisted dying. In 1997, the Federal parliament placed a ban on the Territories making laws about this important matter. For 25 years, the Canberra community and ACT Legislative Assembly were prevented from considering an issue that deeply matters to them. In the meantime, all six Australian states progressively legislated for voluntary assisted dying.

In December 2022, the Federal parliament passed the *Restoring Territory Rights Act 2022*. This enabled the ACT Government and Legislative Assembly to consider how voluntary assisted dying should work in the ACT.

Consultation on proposed approach

From 7 February to 6 April 2023, the ACT Government undertook public consultation to understand how the Canberra community would like to see voluntary assisted dying delivered in the ACT. Knowing that the majority of Canberrans and Australians more broadly support voluntary assisted dying with appropriate safeguards in place, the consultation focused on what model should be adopted rather than whether voluntary assisted dying should be lawful.[1]

To ensure an inclusive and accessible consultation process was delivered, the ACT Government worked closely with the ACT Office for Disability, Disability Reference Group, Office for Aboriginal and Torres Strait Islander Affairs, and Aboriginal and Torres Strait Islander Elected Body. To shape consultation from lived experience within the health system, the ACT Government also worked closely with organisations representing a wide variety of health consumers in the ACT, and internally with a voluntary assisted dying Clinical Reference Group comprising ACT Health Directorate and Canberra Health Services clinical leads and experienced health professionals.

[1] The Australia Institute (2021) *Polling – Voluntary assisted dying and the territories,* available at: https://australiainstitute.org.au/report/polling-research-territory-rights-and-voluntary-assisted-dying/.

Our starting point for consultation was that voluntary assisted dying in the ACT would be usefully informed by the 'Australian model'. The Australian model refers to the general approach to voluntary assisted dying regulation taken in Victoria, Western Australia, Queensland, South Australia, Tasmania, and New South Wales. More information about the Australian model, and the varying approaches taken in each Australian state, is available in the ACT Government's February 2023 *Voluntary Assisted Dying Discussion Paper*.[2]

During consultation, the YourSay Conversations website provided the community with information about the voluntary assisted dying initiative including the detailed Discussion Paper which containing 36 questions for comment, a series of shorter Discussion Guides translated into Easy English and five common languages for the ACT community, and an invitation for people to have their say. The Discussion Paper was also available in ACT libraries, and by mail on request. Community members were able to have their say by making a submission on the YourSay Conversations website, posting their submission by mail, sending us an email, or leaving a voicemail.

The ACT Government received 366 'short answer' submissions from individuals wanting to share their own experience and views. Formal submissions from 106 individuals and organisations were received, including voluntary assisted dying academics and advocates, health, disability and social services, legal and religious bodies. In addition, 2,937 Canberrans who were part of the ACT Government's YourSay Panel completed a survey on voluntary assisted dying. The survey results are available on the YourSay Panel website.[3]

The ACT Government has reached out to 200+ stakeholders to learn from their expertise and experience to help us design a voluntary assisted dying model. More than 30 meetings with stakeholders were held to hear their views, including eight roundtables and workshops with key organisations representing health professionals, health consumers, residential aged care, disability, mental health, and First Nations communities. Meetings were undertaken with the Disability Reference Group, Ministerial Council on Ageing, Multicultural Advisory Council, Youth Advisory Council, LGBTIQ+ Advisory Council, and members of the Aboriginal and Torres Strait Islander Elected Body to hear from Canberrans with lived experience. Extensive consultation was undertaken with the Clinical Reference Group and, a workshop about clinical considerations was attended by over 150 health professionals at Canberra Health Services.

The ACT Government also consulted closely with officials in each of the six Australian jurisdictions that have legalised voluntary assisted dying. The ACT Government joined the Trans-Tasman Voluntary Assisted Dying Policy Group, a group of officials from Australia and New Zealand responsible for implementing their jurisdiction's voluntary assisted dying legislation. This enabled direct learnings from the experiences of Australian jurisdictions on which the ACT's model for voluntary assisted dying is based.

Overall, most public consultation contributors supported the ACT adopting the main features of the Australian model, with adjustments to this model to build on the experiences of other jurisdictions and meet the unique needs of the ACT. Further detail on the consultation outcomes for key topics is available in the ACT Government's June 2023 listening report, *Voluntary assisted dying: Report on what we heard*.[4]

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[2] ACT Government (2023) *Voluntary Assisted Dying Discussion Paper*, February 2023, available at: https://hdp-au-prod-app-act-yoursay-files.s3.ap-southeast-2.amazonaws.com/8416/7567/8207/Voluntary_assisted_dying_Discussion_Paper_PDF_version.pdf
[3] ACT Government (2023) *YourSay Panel: Voluntary Assisted Dying survey*, available at: https://www.yoursay.act.gov.au/yoursay-panel/research-articles/voluntary-assisted-dying-survey
[4] ACT Government (2023) *Voluntary assisted dying: Report on what we heard*, June 2023, https://hdp-au-prod-app-act-yoursay-files.s3.ap-southeast-2.amazonaws.com/5016/8791/2515/FINAL_Listening_Report_voluntary assisted dying_for_publication_on_YourSay_-_27.06.23.pdf

In order to ensure the ACT model would accommodate the ACT's unique circumstances the model has been developed in consultation with key stakeholders including ACT Policing, ACT Human Rights Commission, ACT Courts and Tribunal, Access Canberra, Capital Health Network, Aged & Community Care Providers Association, ACT Law Society, the Office of the Director of Public Prosecutions, Legal Aid ACT and international experts in end of life law Professors Ben White and Lindy Willmott of the Australian Centre for Health Law Research. Consultation on parts of the Bill affecting health consumers was also undertaken with ACT Disability, Aged and Carer Advocacy Service (ADACAS), Health Care Consumers' Association, Carers ACT, and Women With Disabilities ACT. Feedback from these stakeholders informed the final version of the Bill presented in the Legislative Assembly.

Further detail on the ACT Government's consultation is available in the June 2023 listening report, *Voluntary assisted dying in the ACT: Report on What We Heard*.

Summary of the Bill's framework for voluntary assisted dying

Below is a summary of the framework for access to voluntary assisted dying set out in the Bill. This summary is for reference only and does not represent a full statement of the proposed law or its justifications. Overall, the Bill adopts the key features of the Australian model but differs in several significant ways, as outlined in this submission.

The Bill will be accompanied by regulations which detail technical and regulatory aspects of the voluntary assisted dying framework, and guidelines which provide interpretive practical guidance about obligations arising under the Bill. These will be developed during the 18-month implementation period following passage of the Bill and before the operation of voluntary assisted dying in the ACT.

Designing and evaluating each section of voluntary assisted dying legislation has been based on how the model will work as a whole. Eligibility criteria, for example, need to be considered in relation to each other.[5] For instance, as outlined later in this submission, the eligibility criteria of 'advanced' and 'progressive' were given specific definitions in the Bill, rather than be left to their ordinary meaning as was done in other jurisdictions. This makes it clear that voluntary assisted dying is only available in the last stages of an individual's life as the Bill does not include a specific timeframe to death. This allows practitioners to have a clear test to determine whether a condition meets the eligibility criteria without needing to decide on an uncertain metric such as timeframe to death.

Further detail on the Bill's framework and its justifications, including aspects that may limit human rights, are available in the Bill's Explanatory Statement.

[5] White and Willmott (2021) *Voluntary assisted dying: A policy briefing*, Australian Centre for Health Law Research, Faculty of Business and Law, Queensland University of Technology, p 1, available at: https://research.qut.edu.au/voluntary-assisted-dying-regulation/wp-content/uploads/sites/292/2021/08/Voluntary-assisted-dying-research-Policy-briefing-web-version.pdf.

Objects and principles

Part 2 of the Bill sets out the objects (purposes and objectives) of the Bill. In summary, these are to give eligible individuals the option to access voluntary assisted dying, establish a process for access, protect individuals from coercion and exploitation, protect health practitioners from liability if they choose to assist, and provide for the monitoring and enforcement of compliance with the Bill.

Part 2 of the Bill also establishes the following principles to be taken into account by an individual who exercises any function under the Bill:

- human life is of fundamental importance;
- every individual has inherent dignity and should be treated with compassion and respect;
- an individual's autonomy, including autonomy in relation to end of life choices, should be respected;
- every individual approaching the end of their life should be provided with high quality, individual-centred care and treatment, including palliative care, to minimise their suffering and maximise their quality of life;
- an individual should be supported in making informed decisions about treatment and end of life choices;
- individuals should be protected from coercion and exploitation; and
- an individual's personal, cultural and religious beliefs and values should be respected.

Eligibility requirements

Part 2 of the Bill sets out when an individual may access voluntary assisted dying. The eligibility requirements for access are listed below.

Relevant condition

The individual must have been diagnosed with at least one relevant condition that, either on its own or in combination with one or more other diagnosed conditions, is:

- Advanced: an individual's relevant condition(s) is advanced if the individual's functioning and quality of life decline, and any treatments that are available and acceptable to the individual lose any beneficial impact, and the individual is in the last stages of their life; and
- Progressive: an individual's relevant condition(s) is progressive if their condition is deteriorating and will continue to deteriorate, and
- Expected to cause the individual's death.

Intolerable suffering

The individual must be suffering intolerably in relation to their relevant condition/s. This means persistent suffering (whether physical, mental or both) that is, in the opinion of the individual, intolerable is being caused to the individual by:

- One or more of: the relevant condition/s; the combination of the relevant conditions and any other condition or conditions they have been diagnosed with (the other conditions); treatment they have received for the relevant conditions; the combination of treatments they have received for the relevant conditions and the other conditions; or
- The anticipation or expectation, based on medical advice, of suffering that will or might be caused by a matter mentioned above; or
- A medical complication that will or might result from, or be related to, a matter mentioned above.

Residency

The individual must have lived in the ACT for at least the previous 12 months.

An exemption from this eligibility requirement is available for individuals who can demonstrate a substantial connection to the ACT, as assessed by the ACT Health Directorate on application. Examples of what might constitute a substantial connection to the ACT include:

- an individual who has lived close to the ACT border for at least the previous 12 months and who works or receives medical treatment in the ACT;
- an individual who has moved to the ACT so that family, friends or carers in the ACT can provide them with care and support;
- an individual who previously lived in the ACT and whose family, friends or carers live in the ACT;
- an Aboriginal or Torres Strait Islander individual who has substantial connections with the ACT community and wishes to die on Country;
- an individual who has lived in the ACT for less than 12 months but who was diagnosed with a relevant condition after moving to the ACT.

This eligibility requirement will be reviewed as part of the mandatory review of the Bill after three years of operation.

Decision-making capacity

As in all Australian jurisdictions, an individual must have decision-making capacity in relation to voluntary assisted dying. This means at all stages of the request, assessment and substance administration process the individual must (including with appropriate support if needed):

- Understand the facts that relate to a decision about accessing voluntary assisted dying;
- Understand the main choices available to them in relation to the decision;
- Weigh up the consequences of the main choices;
- Understand how the consequences affect them;
- On the basis of the above, make the decision; and
- Communicate the decision in whatever way they can.

In practice, this means that voluntary assisted dying will not be available to individuals who may meet all the other eligibility requirements, but lose decision-making capacity near their end of their life because of their relevant conditions or their treatment.

This situation presents significant complexity in the context of voluntary assisted dying, because some terminal conditions, such as advanced dementia, can impair an individual's decision-making capacity while the individual is experiencing intolerable suffering. Many contributors to the ACT Government's public consultation pointed out that as dementia causes intolerable suffering as well as being a leading cause of death in Australia, restricting voluntary assisted dying to people with decision-making capacity at all stages of the voluntary assisted dying process would exclude a large proportion of people near the end of their lives who may be suffering intolerably.

The ACT Government's public consultation also heard concerns from some health professionals that a decision to administer an approved substance to an individual who lacks capacity is highly subjective, ethically challenging, and without precedent in current medical practice in Australia. Health professionals shared the challenges posed by, among other things, potentially having to administer an approved substance to an individual who has lost the capacity to understand and agree that this substance would end their life (i.e. the decision to have the approved substance administered would be made by someone else, and would not be voluntary). The consultation also heard from voluntary assisted dying legal experts who considered this issue had not yet been sufficiently researched and considered in Australia, particularly as no Australian voluntary assisted dying laws currently deal with this matter.

Given these challenges, and the absence of an appropriately developed framework and safeguards for these decisions, the Bill's restrictions on access to only individuals with capacity seek to protect the rights of people who do not have decision-making capacity and protect health practitioners from unknown or unreasonable civil, criminal and professional consequences.

The Explanatory Statement provides further details on how this eligibility requirement both promotes and limits an individual's human rights, and how this limitation is demonstrably justified.

This eligibility requirement will be reviewed as part of the mandatory review of the Bill after three years of operation.

Minimum age for eligibility

As in all Australian jurisdictions, an individual must be aged 18 years or over to access voluntary assisted dying.

Public consultation indicated some strong support for the view that that mature young people suffering intolerably near the end of their lives should have the same end of life choices as adults. Many contributors with views on this issue felt that imposing an age restriction of over 18 years old is arbitrary and ignores the reality that mature minors who are suffering intolerably from terminal illness may have decision-making capacity. Some contributors felt strongly that there should be additional, tailored safeguards and supports for young people to allow them to seek to access voluntary assisted dying.

Extensive consultation with health professionals during the development of this Bill demonstrated significant policy complexities in determining the most appropriate, safeguarded and evidence-based mechanism for assessing decision-making capacity in young people in relation to voluntary assisted dying. No jurisdiction in Australia has developed such a mechanism. While the concept of Gillick competency is recognised for assessing capacity in young people's health decisions, its application in the context of voluntary assisted

dying is untested. There are still gaps in the evidence regarding the capacity of minors to give voluntary and informed consent to voluntary assisted dying.[6] The voluntary assisted dying Clinical Reference Group raised concerns that working with young people was inherently complex, particularly in relation to assessing their decision-making capacity in the context of their emerging capacity and autonomy. Additional safeguards would be needed as there are complexities around treating and caring for terminally ill young people and the involvement of parents/guardians and families.

Further, as the ACT is a very small jurisdiction, specialist paediatric treatment and palliative care for young people with complex and terminal illnesses is often provided interstate by the Sydney Children's Hospital and Network. Clinicians in the Clinical Reference Group advised that in their experience, those young people resident in the ACT who might otherwise meet the eligibility requirements for voluntary assisted dying would generally receive treatment and care outside the ACT due to the limited availability and capacity of specialised paediatric care in the ACT. As practitioners would not be regularly providing the specific services associated with voluntary assisted dying for minors, this would limit the ACT's ability to ensure these health services were provided with the necessary quality. The ACT does not provide every medical or specialist services where there is limited demand for this reason.

It is therefore not yet possible for the ACT Government to ensure the quality and safety of the provision of highly specialised voluntary assisted dying services and safeguards for young people without significant further research and, from that, capacity-building and training for ACT voluntary assisted dying clinicians and the ACT health system. Allowing access to voluntary assisted dying to young people at this time without workable safeguards would unreasonably limit the rights of young people to protection. This is due to the complexities of developing a mechanism for assessing decision-making capacity in young people in relation to voluntary assisted dying and the particular circumstances of the paediatric healthcare system in the ACT.

The Explanatory Statement provides further details on how this eligibility requirement both promotes and limits a mature young individual's human rights, and how this limitation is demonstrably justified.

This eligibility requirement will be reviewed as part of the mandatory review of the Bill after three years of operation.

Process for voluntary assisted dying request and assessment

Part 3 of the Bill prescribes a process for an individual to request access to voluntary assisted dying, and health practitioners to assess whether the individual meets the eligibility requirements.

The overall process for requesting voluntary assisted dying and assessment of eligibility generally reflects the Australian model, including:

- An individual makes a first request to access voluntary assisted dying;
- A qualified health practitioner accepts the first request, becomes the coordinating practitioner, and undertakes the first assessment;
- If the coordinating practitioner finds the individual eligible, they refer individual for a second, independent assessment by a consulting practitioner;

[6] Queensland Law Reform Commission, *A Legal Framework for Voluntary Assisted Dying* (Report No 79, May 2021), 148 [7.368]-[7.369].

- The consulting practitioner accepts the referral and undertakes the consulting assessment;
- If the consulting practitioner finds the individual eligible, the individual may make a second formal request to the coordinating practitioner in writing with two independent witnesses;
- The coordinating practitioner and consulting practitioner can refer to a third party practitioner if they are unable to assess whether the individual meets the eligibility requirements;
- The individual may make a final request to the coordinating practitioner, who certifies that the individual is acting voluntary and has decision-making capacity.
- An individual can pause or stop the voluntary assisted dying request and assessment process at any time.

Key steps in the process must be reported to the voluntary assisted dying Oversight Board, and recorded in the individual's health record within two working days, with penalties for non-compliance.

If a practitioner is unable or unwilling to continue as coordinating or consulting practitioner, they may transfer their role to another qualified voluntary assisted dying practitioner to ensure the individual's access to voluntary assisted dying is not unduly hindered.

It is an offence to induce the making or revocation of a request to access voluntary assisted dying.

Accessing the substance

Process and safeguards

Part 4 of the Bill sets out a process for accessing an approved substance, once the request and assessment process are complete.

Following the final assessment an individual may choose to proceed with self-administration or practitioner administration of the approved substance. There is no default mode of administration specified in the legislation; rather the individual and their coordinating practitioner should discuss the best option for the individual. Once they have made that decision, the coordinating practitioner is authorised to prescribe an approved substance.

An individual can choose to pause or stop the process, not take the substance, or change from self-administration to practitioner administration (or vice versa) at any time.

A contact person must be appointed for self-administration of an approved substance. This can be any eligible adult, including carers, friends or family members, or the coordinating or consulting practitioner. The contact person is authorised to handle the approved substance on the individual's behalf if the individual cannot.

An eligible witness is required for practitioner administration, but not self-administration.

It will be an offence to induce the making or revocation of a decision to proceed with administration, to administer an approved substance otherwise than in accordance with the Act, and to induce self-administration of an approved substance.

Handling the substance

Prescription, handling, storage and disposal of the approved substance is tightly regulated by both the Bill and the ACT's existing *Medicines, Poisons and Therapeutic Goods Act 2008*, and is based on the Australian model including:

- The coordinating practitioner prescribing the voluntary assisted dying substance must include a statement that the substance is for voluntary assisted dying, that an assessment process has been conducted in accordance with legislation, the mode of administration, contact details for the individual, and details of the substance, including the amount prescribed.
- The coordinating practitioner must provide the prescription directly to the authorised supplier and notify the voluntary assisted dying Oversight Board within 48 hours of providing the prescription to the supplier.
- The authorised supplier must supply the substance to either the administering practitioner for practitioner administration, or after confirming their identify, to the individual or their nominated contact person for self-administration.
- The contact person must return any unused or remaining substance to an authorised disposer within 14 days after the individual dies.
- If the individual changes their mind and chooses to not take the substance, they or their contact person must return the substance to the authorised supplier for disposal.
- The Register of Births, Deaths and Marriages will record both the cause and manner of death. The cause of death will be the relevant condition, with the manner of death recorded as 'voluntary assisted dying'. The death certificate will only record the relevant condition.

Role of health professionals

Qualification requirements

Part 5 of the Bill sets out the authorisation, qualification and experience requirements for health practitioners who wish to be involved in the voluntary assisted dying process.

Health practitioners wishing to play a role in voluntary assisted dying will be required to undertake compulsory voluntary assisted dying training based on the final ACT legislation, which will include options for self-paced online and in-person delivery.

Only health practitioners who meet qualification and experience requirements will be able to undertake the compulsory training. These will be set out in regulations, rather than in the Bill. This is to allow for flexibility and adaptation to change these requirements, if needed, to ensure the effective operation of the Bill. It is anticipated that regulations will be presented to the Legislative Assembly proposing the following requirements for a health practitioner's qualifications and experience:

Types of health practitioners	**Can apply to be an authorised…**		
	Coordinating practitioner	Consulting practitioner	Administering practitioner
A medical practitioner who holds specialist registration (including general practitioners) and has practised for at least one year	✓	✓	✓

A nurse practitioner with relevant experience[7] of at least one year post-nurse practitioner endorsement	✓ (if the consulting practitioner is a medical practitioner)	✓ (if the coordinating practitioner is a medical practitioner)	✓
A nurse practitioner with relevant experience	✗	✗	✓
A registered nurse with relevant specialist experience and qualifications (working at a minimum Australian Qualification Framework level 8-9)	✗	✗	✓

There is no requirement for a practitioner to hold specialist expertise or experience in the disease, illness or condition the individual seeking voluntary assisted dying is dying from.

Initiating conversations about voluntary assisted dying

The ACT Government held targeted consultations with people with disability organisations and health care consumer organisations to ensure the final version of the Bill has the necessary safeguards to protect individuals from coercion, while supporting and enabling voluntary assisted dying access for eligible individuals.

Clause 152 of the Bill provides that if certain health professionals want to initiate a conversation about voluntary assisted dying with an individual, they must comply with the following requirements that support the individual to make informed and voluntary end of life choices:

[7] Examples of relevant experience for nurse practitioners may include palliative care, terminal cancer care, neurodegenerative disease management and aged care.

	A medical practitioner or nurse practitioner who considers that they have the expertise to appropriately discuss treatment and palliative care options	All other medical practitioners, registered health practitioners, social workers, and counsellors
May only initiate a conversation about voluntary assisted dying if they ensure the individual knows:	• the treatment options available to the individual and the likely outcomes of the treatment options available to the individual; and • the palliative care and treatment options available to the individual and the likely outcomes of those care and treatment options.	• that the individual has palliative care and treatment options available; and • that the individual should discuss the palliative care and treatment options with their treating doctor.

In addition to medical practitioners and registered health professionals (e.g. registered nurses, psychologists, occupational therapists) being permitted to initiate conversations about voluntary assisted dying under the above conditions, the Bill allows the self-regulated allied health professions of counselling and social work to initiate voluntary assisted dying discussions as end of life and goals of care discussions are included in their scope of practice. Having a broader range of health professionals able to raise voluntary assisted dying under the conditions above will help to increase access to information about voluntary assisted dying while ensuring vulnerable members of the community are supported by being given appropriate context and information for these discussions. The requirements are not considered onerous and will support voluntary assisted dying being considered as one of several end-of-life options, and not simply as an alternative to palliative care, or a decision to decline treatment.

Clinical guidelines will be developed during the implementation period to support health professionals to engage in considered end-of-life discussions, including providing information on palliative care and treatment options as well as voluntary assisted dying.

Conscientious objection

Conscientious objection for health professionals is a well-recognised concept with protections in law and policy. 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. A health practitioner or health service provider who conscientiously objects to voluntary assisted dying or is unable to assist with a voluntary assisted dying request for any reason must:

- Advise they are unable to assist as soon as practicable to ensure the patient's access to care is not impeded; and
- Provide the individual requesting voluntary assisted dying with information directing them to the Care Navigator Service.

Protections from liability

Part 9 of the Bill provides people, including health professionals, with protections from liability for acting in accordance with the Bill honestly and without recklessness.

Role of the health system

The ACT will implement a mixed-service delivery model for voluntary assisted dying within the ACT health system. Voluntary assisted dying services will be delivered in the primary and private health sectors, and within the network of public hospitals and health services.

It is anticipated that a voluntary assisted dying Pharmacy Service will be established within the Canberra Hospital Pharmacy to perform the following functions:

- Provide information about the substance for people accessing voluntary assisted dying, their families and carers, and voluntary assisted dying practitioners, including information on prescribing, preparation, administration and disposal of the substance;
- Validate prescriptions and dispense the voluntary assisted dying substance/s plus adjunct medication;
- Deliver the voluntary assisted dying substance within the ACT to people who have elected self-administration and are unable to travel, and dispose of any unused voluntary assisted dying substance; and
- Attract, recruit and retain the right pharmacists with the blend of technical and relational people skills which will be critical to success. The details of this engagement strategy would be developed as part of the implementation process.

The Bill also provides for the establishment of a voluntary assisted dying Care Navigator Service. The Care Navigator Service will be established and managed by CHS and staffed by appropriately skilled nursing and allied health professionals. The service will provide multidisciplinary support to individuals, their carers and families, health practitioners and health or care services seeking information and pathways regarding voluntary assisted dying.

Role of facility operators

Part 7 of the Bill imposes new obligations on entities responsible for the management of a facility. A facility means a place (other than an individual's private residence) where a health, aged care or personal care service is provided to a 'resident', meaning an individual who lives or stays at the facility.

All facility operators may decide their level of involvement with voluntary assisted dying. However, if a resident wishes to see a relevant person in relation to voluntary assisted dying (such as their coordinating practitioner, contact person or a witness), and a relevant person is not available at the facility, the facility operator must:

- Provide the contact details of the Care Navigator Service; and
- Allow a relevant person access to the resident at the facility; and

- If it is **not** reasonably practicable to allow a relevant person access to the resident at the facility, the facility operator must ask the resident's coordinating practitioner or treating doctor to decide whether it is reasonable for the individual to be transferred elsewhere to see a relevant person:
  - If it is reasonable for the individual to be transferred, the facility operator must facilitate the transfer with the individual's consent as soon as reasonably practicable; and
  - If it is **not** reasonable for the individual to be transferred, the facility operator must take reasonable steps to make it reasonably practicable for the relevant person to have access to the individual at the facility.

A facility operator must publish a policy outlining how it complies with these minimum standards, and make that information available to prospective and current residents and on request.

A facility operator must not hinder access to voluntary assisted dying by withdrawing a care service because the operator knows that the individual has asked, or is likely to ask, for information about voluntary assisted dying; or has made, or is likely to make, a request to access voluntary assisted dying.

Breach of these obligations is a criminal offence. ACT law provides that corporations that break the law must pay a higher penalty than individuals.[8] At law, the concept of vicarious liability means that the acts or omissions of a facility operator include the acts or omissions of the facility operator's agents, including their employees, contractors and owners.

Oversight, reporting & compliance

Voluntary Assisted Dying Oversight Board

Part 8 of the Bill establishes the Voluntary Assisted Dying Oversight Board. The Board is an independent statutory board, appointed by and subject to direction of the Minister for Health. The Board's functions are to:

- Monitor the operation of the Act;
- Monitor requests for voluntary assisted dying;
- Refer issues identified by the Board to relevant regulatory agencies;
- Record and keep any information prescribed by regulation in relation to a request for or access to voluntary assisted dying;
- Analyse information given to the Board and research matters relating to the operation of the Act;
- Give the Minister advice in relation to the operation of the Act, the Board's functions, the improvement of the processes and safeguards for voluntary assisted dying; and
- Any other function given to the board under the Act or another territory law.

[8] See section 133 of the *Legislation Act 2001* (ACT).

The Board will not prospectively approve, intervene in, or make decisions about an individual's access to voluntary assisted dying requests, unlike some Australian jurisdictions. Instead, it is anticipated that the Board will take a proactive role in enhancing compliance, and undertake periodic review of requests and reports, particularly during the early operation of the Act.

Membership and procedure of the board will largely be dealt with by flexible regulations, though the Bill specifies that the body must have a minimum of four, and up to seven members with relevant skills and expertise, with a quorum of three for decisions.

The ACT Health Directorate will provide secretariat support to the board and be responsible for approving exemptions to ACT residency requirements, assessing health professional applications to become a voluntary assisted dying practitioner, managing board recruitment, and other functions to be determined during the implementation period.

Review of decisions

Part 10 and 11 of the Bill establish review rights for key decisions made under the Bill. The ACT Civil and Administrative Tribunal (ACAT) will have jurisdiction to review decisions by health practitioners about whether an individual has capacity, meets the residency requirements, or is acting voluntarily. The Tribunal will also have jurisdiction to review decisions by the ACT Health Directorate to refuse to grant a 'substantial connection' exemption to ACT residency requirements, refuse to authorise a health practitioner, or decision to revoke a health practitioner's authorisation.

Offences for non-compliance

Throughout the Bill there are several offences for non-compliance with the Bill, ranging from minor penalties for non-compliance with reporting requirements to significant penalties for conduct that may result in deaths otherwise than in accordance with the Bill.

Review of the Act

Clause 159 of the Bill requires that the Minister for Health must review the operation and effectiveness of the Act as soon as practicable after three years of operation, and in five-year intervals after that. The first review must include a review of minimum age requirements, advanced care planning, and residency requirements.

Other matters

Parts 1 (Preliminary), 12 (Miscellaneous) and 13 (Consequential amendments) of the Bill provide for other matters necessary for the operation of the Bill. This includes amendments to the *Births, Deaths and Marriages Registration Act 1997* and regulation, *Coroners Act 1997*, *Guardianship and Management of Property Act 1991*, and *Powers of Attorney Act 2006* to clarify the relationship between the Bill and those Acts.

Key differences from the Australian model

The below discusses four areas in which the Bill significantly differs from the approach taken by other Australian jurisdictions, and summarises the evidence base for these differences.

No timeframe to death requirement

Unlike other Australian jurisdictions, the Bill imposes no eligibility requirement that the individual's relevant conditions must be expected to cause their death with 6 or 12 months to access voluntary assisted dying (**'timeframe to death requirement'**).

This is intended to promote the right to equality and non-discrimination under section 8 of the HRA by enabling individuals to choose to access voluntary assisted dying if they meet all eligibility requirements, regardless of how soon their condition is expected to cause their death. In practice, this reduces the Bill's ability to discriminate between individuals based on the nature of their condition and prognosis. In turn, promoting the right to equality and non-discrimination regardless of timeframe to death also facilitates the enjoyment of the rights promoted by access to voluntary assisted dying discussed above.

These rights-promoting purposes of excluding a timeframe to death requirement are supported by evidence:

- **Limits access to voluntary assisted dying:** A timeframe to death requirement risks preventing people who would otherwise be eligible from accessing voluntary assisted dying if the delay until they meet the timeframe means they are no longer well enough to navigate the assessment process.[9] The requirement would mean that individuals are unable to begin the voluntary assisted dying process at a time that suits their circumstances. For example, the ACT Government's consultation heard from health professionals that the Bill must allow enough time for people to go through the process and make a decision while people still have decision-making capacity, and that if the timeframe to death requirement is too restrictive then this can become a problem.

- **Estimating timeframe to death can be inaccurate:** There is growing evidence that estimating a timeframe to death is inherently uncertain and imprecise.[10] According to a survey of members of the Australian and New Zealand Society for Geriatric Medicine in response to the (then) newly enacted Victorian voluntary assisted dying law, one third of respondents did not feel comfortable estimating a patient's prognosis, despite 95% having experience treating patients with terminal diagnoses.[11] Research has found that prognostic tools have greater accuracy predicting shorter prognoses, such as weeks to months, rather than 6 months, and clinicians may opt out of participating in voluntary assisted dying because they feel unable to make precise prognostic judgements.[12] The variability across Australian jurisdictions in wording about the level of certainty a doctor must have, or the 'standard of proof' that they must apply, in determining a timeframe to death further exacerbates uncertainty in this area. For example,

[9] White at al, 'Who is Eligible for Voluntary Assisted Dying? Nine Medical Conditions Assessed Against Five Legal Frameworks' (2022) 45 *UNSW Law Journal,* 1.
[10] Nahm, S.H., Stockler, M.R. and Kiely, B.E. (2022), "Voluntary assisted dying: estimating life expectancy to determine eligibility" *Med J Aust*, 217: 178-179. https://doi.org/10.5694/mja2.51648.
[11] Treleaven et al, 'A review of the utility of prognostic tools in predicting 6-month mortality in cancer patients, conducted in the context of voluntary assisted dying' (2023) 1 *Internal Medicine Journal* 18.
[12] Ibid.

judgements about timeframe death need to be made on what is 'expected' (Victoria) or estimated to occur on 'the balance of probabilities' (Western Australia). These challenges were echoed by many health professionals during the ACT Government's public consultation.

- **Arbitrary outcomes:** Because of the above, timeframe to death requirements can operate arbitrarily, in that there may be very little to distinguish between the intolerable suffering of an individual who is expected to die within the specified time limit, and those with similar conditions whose prognosis is slightly longer. This is exacerbated by the fact that different health professionals may assess timeframes to death in different ways, with different outcomes. The HRA requires that any limitations on human rights arising from the Bill are reasonable and justifiable, rather than arbitrary. The timeframe to death requirement in Queensland, another Australian human rights jurisdiction, has been criticised as disproportionate and arbitrary when considering the severe impact on individuals caused by timeframe restrictions and the existing limitation that individuals without a terminal illness cannot access voluntary assisted dying.[13]

- **Exacerbating suffering:** Timeframe to death requirements can create a situation where terminally ill individuals are intolerably suffering, but are forced to continue to suffer until they are close enough to death to meet the timeframe requirement.[14] For example, individuals with a terminal illness who are suffering intolerably but are not expected to die within the timeframe may be forced to consider the cruel choice between continuing to intolerably suffer until they meet the timeframe, or ending their own life outside of the voluntary assisted dying framework.[15] This was reflected by the ACT Government's consultation with individuals with lived experience. This outcome would directly contradict the objects of the Bill.

- **No support for a six-month timeframe:** There is particularly strong evidence that a six-month timeframe to death requirement would not be consistent with the Bill's objectives. The Victorian Ministerial Advisory Panel on Voluntary Assisted Dying recommended that a six-month timeframe to death requirement should not be adopted, as it is an 'arbitrary time limit based on factors that are not applicable to the Victorian context'.[16] The ACT Government's public consultation also heard strong support not to include a six-month timeframe to death requirement. Contributors were concerned that a short timeframe would, in practice, require an individual to continue to suffer until they are close to death, and within that six-month window may die or lose decision-making capacity before they can access voluntary assisted dying.

- **Supported in public consultation**: Overall, the ACT Government's public consultation on voluntary assisted dying demonstrated that most contributors with views on this matter felt that voluntary assisted dying in the ACT should not be restricted by a timeframe to death requirement.

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[13] Willmott, Lindy & White, Ben (2017) "Assisted dying in Australia: A values-based model for reform" In Petersen, K & Freckelton, I (Eds.) *Tensions and traumas in health law.* The Federation Press, Australia, 503.
[14] White at al, 'Comparative and Critical analysis of key Eligibility Criteria for Voluntary Assisted Dying under Five Legal Frameworks' (2021) 44 *UNSW Law Journal* 4.
[15] Braun, 'When ill is not ill enough – timeframe until expected death restrictions in Australian Voluntary Assisted Dying laws and human rights compatibility' (2022) 28 *Australian Journal of Human Rights* 1.
[16] Parliament of Victoria, Legislative Council, Legal and Social Issues Committee, *Inquiry into end of life choices: final report,* Session 2014-16, no. 174, 223, available at: https://vgls.sdp.sirsidynix.net.au/client/search/asset/1288816. That Committee, as well as Victoria's Ministerial Advisory Panel on voluntary assisted dying, responsible for considering Australia's first voluntary assisted dying law, found that such a requirement was introduced in Oregon (and subsequently other US states) because that is when funding for hospice care was available in that jurisdiction – a factor that is irrelevant in Australia. See Ministerial Advisory Panel on Voluntary Assisted Dying, *Final Report*, Department of Health and Human Services, July 2017, 72 available at: https://www.health.vic.gov.au/publications/ministerial-advisory-panel-on-voluntary-assisted-dying-final-report.

- **Consistency with international jurisdictions**: Not having a timeframe to death requirement in the ACT is consistent with the approach in the Netherlands, Belgium, Switzerland, Canada, Colombia, Spain and Luxembourg.[17]

It is arguable that a timeframe to death requirement is necessary to 'maintain the principle that [voluntary assisted dying] is not a choice between life and death but a choice for those who are in the process of dying and wish to choose the time and circumstances of their death'.[18] Some contributors to the ACT Government's consultation supported the inclusion of a 12-month timeframe to death requirement on the basis of ensuring the option was only available for people towards the end of their lives, as well as to provide clarity to health practitioners and consumers.

However, the Bill's careful combination of eligibility requirements and safeguards ensures that this purpose is achieved through less rights-restrictive means than imposing a timeframe to death requirement. A key safeguard is the eligibility requirements that an individual's condition be expected to cause their death, causes intolerable suffering, and is advanced and progressive. This means that voluntary assisted dying will still only be available to those who are in the advanced stage of illness, that is, when an individual's functioning and quality of life decline, and any treatments that are available and acceptable to the individual lose any beneficial impact, and the individual is in the last stages of their life. Requiring that an individual's condition is advanced, progressive and terminal provides flexibility for an assessing health professional, while ensuring that voluntary assisted dying is only an option for those near the end of life who wish for an end to intolerable suffering.

Prominent Australian voluntary assisted dying academics have found that not only do time-based approaches have a number of undesirable outcomes but are largely redundant given other, determinative, eligibility requirements which work together to provide strong safeguards.[19] White and Willmott's research found that removing timeframes would have no impact on restricting the medical conditions that would permit access to voluntary assisted dying because the requirement for an individual's medical condition to be 'advanced' similarly constrains access to voluntary assisted dying.[20]

Nurse practitioners as coordinating or consulting practitioners

Every jurisdiction in Australia requires that an individual's coordinating practitioner and consulting practitioner both be medical practitioners.

Following the Australian model's reliance on medical practitioners would have direct implications for access to voluntary assisted dying in the ACT, as a small jurisdiction with limited health resources and a small health workforce. The Australian model for voluntary assisted dying largely depends on medical practitioners who hold general and/or specialist registration being willing to devote time and resources to completing training, supporting an individual through voluntary assisted dying, and complying with onerous reporting requirements.

[17] Treleaven et al, 'A review of the utility of prognostic tools in predicting 6-month mortality in cancer patients, conducted in the context of voluntary assisted dying' (2023) 1 Internal Medicine Journal 18.
[18] Above n 15.
[19] White at al, 'Who is Eligible for Voluntary Assisted Dying? Nine Medical Conditions Assessed Against Five Legal Frameworks' (2022) 45 *UNSW Law Journal*, 1.
[20] Ibid.

This was a key concern raised in consultation, as was resourcing voluntary assisted dying in the healthcare system, due to limited resources and known workforce pressures in the ACT health sector.

The Bill takes a new approach: if a qualified and trained medical practitioner acts as an individual's coordinating practitioner or consulting practitioner, the other role can be undertaken by a qualified, suitably experienced and trained nurse practitioner who meets the requirements outlined at pages 10 and 11 of this submission.

Nurse practitioners are highly trained and autonomous health professionals, who integrate clinical skills associated with nursing and medicine to assess, diagnose, and manage patients in primary, secondary, and tertiary healthcare settings.[21] It is within a nurse practitioner's scope of practice to assess and diagnose health problems, order and interpret diagnostic investigations, formulate and assess response to treatment plans, prescribe some medicines (which may include voluntary assisted dying substances, being Schedule 4 and Schedule 8 medicines) and refer to other health professionals, within their individual levels of competence.[22]

Nurse practitioners with endorsement to practice in areas relevant to voluntary assisted dying, for example in palliative care, terminal cancer care, neurodegenerative disease management and aged care, are well suited to be assessing an individual's eligibility for voluntary assisted dying due to their ability to assess the key eligibility requirements:

- **Intolerable suffering**: Determining intolerable suffering is a subjective assessment which requires active listening, good communication skills and empathy.[23] With their holistic approach to health care, nurse practitioners are as well placed to explore the extent of an individual's suffering as any other medical professional. The importance of nurse practitioners in providing high quality end-of-life and palliative care was described in many submissions; many contributors felt the proximity and relationship nurse practitioners have with patients makes them well suited to perform the voluntary assisted dying assessment process.

- **Decision-making capacity**: Consultation demonstrated that assessing decision-making capacity is an area where medical practitioners would prefer voluntary assisted dying-specific training and supports. As with medical practitioners, with appropriate training and support nurse practitioners could build on their foundational assessment capabilities to assess a patient's decision-making capacity for voluntary assisted dying.

- **Voluntariness**: The Australian College of Nurse Practitioners considers that nurse practitioners would have the skills to determine whether an individual is acting voluntarily and without coercion.[24]

[21] Queensland Law reform Commission, (2021) *A legal framework for voluntary assisted dying*, 386-387 https://www.qlrc.qld.gov.au/__data/assets/pdf_file/0020/681131/qlrc-report-79-a-legal-framework-for-voluntary-assisted-dying.pdf
[22] Australian College of Nurse Practitioners, (2023 May) *Nurse Practitioner's Scope of Practice*. NP Fact Sheets (acnp.org.au)
[23] Collins, & Small, S. P. (2019). The nurse practitioner role is ideally suited for palliative care practice: A qualitative descriptive study. *Canadian Oncology Nursing Journal*, *29*(1), 4–9; Hewitt, Grealish, L., & Bonner, A. (2023). Voluntary assisted dying in Australia and New Zealand: Exploring the potential for nurse practitioners to assess eligibility. *Collegian (Royal College of Nursing, Australia)*, *30*(1), 198–205.
[24] Queensland Law reform Commission, (2021) *A legal framework for voluntary assisted dying*, 215 https://www.qlrc.qld.gov.au/__data/assets/pdf_file/0020/681131/qlrc-report-79-a-legal-framework-for-voluntary-assisted-dying.pdf

Our public consultation demonstrated support for this approach, including consultation with registered nurses and nurse practitioners and their representative organisations. Evidence also suggests that nurse practitioners are generally more willing to assist with voluntary assisted dying than medical practitioners.[25] A similar approach has been adopted in Canada that appears to be reducing barriers in communities with limited viability of medical practitioners. For example, while nurse practitioners represent less than 6% of voluntary assisted dying practitioners in Canada, in some rural provinces they deliver more than 30% of all voluntary assisted dying services.[26]

Some Australian jurisdictions have already allowed nurse practitioners and/or appropriately experienced registered nurses to act as administering practitioners. However, the ACT Government heard during consultation that it can be ethically and emotionally difficult for registered nurses and nurse practitioners to agree to administer a voluntary assisted dying substance for a patient if they have not had any role in that patient's voluntary assisted dying process to date. Allowing nurse practitioners to act as both the coordinating health professional and the health professional that administers the substances enhances continuity of care.

Obligations on facility operators

One of the strongest concerns arising from the public consultation was how an individual might access voluntary assisted dying if they rely on health services, residential aged care facilities, or accommodation providers that object to or oppose to voluntary assisted dying, for example on faith-based grounds.

We heard that there is significant apprehension in the Canberra community, particularly organisations representing health consumers, that faith-based service providers might obstruct or hinder access to voluntary assisted dying. We also heard both academic and anecdotal evidence from Australian states that eligible people have experienced challenges in accessing voluntary assisted dying if they are living or staying in the care of faith-based health services. In particular, the ACT Government heard concerns about the distress caused if people living in residential facilities needed to be transferred to other premises, away from their home, to access voluntary assisted dying.

Accordingly, the Bill adopts an approach that seeks to strike a balance between the rights of the individual seeking access to voluntary assisted dying and the interests of facility operators, particularly those that operate a facility in accordance with an ethos or faith that opposes voluntary assisted dying. [27] If those rights and interests conflict, the Bill's intention is to require that facility operators accommodate the rights of the individual seeking access to voluntary assisted dying.

Australian jurisdictions have taken varying approaches to dealing with that conflict. In Victoria, Western Australia and Tasmania, facility operators have no legislative obligations to facilitate access, and conduct is regulated through guidance. In Victoria, the longest-standing voluntary assisted dying jurisdiction in Australia,

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[25] Sellars, Marcus et al, (2021) 'Support for and Willingness to Be Involved in Voluntary Assisted Dying: a Multisite, Cross-sectional Survey Study of Clinicians in Victoria, Australia' *Internal medicine journal* 51(10), 1619–1628. Web; Oliver P, Wilson M, Malpas P., (2017) New Zealand doctors' and nurses' views on legalising assisted dying in New Zealand. New Zealand Medical Journal 130, 10–26; Jansky M, Jaspers B, Radbruch L, Nauck F., (2017) Attitudes and experiences regarding physician assisted suicide: a survey among members of the German Association for Palliative Medicine. Bundesgesundheitsblatt Gesundheitsforschung Gesundheitsschutz 60, 89–98.
[26] Hewitt, Grealish, L., & Bonner, A. (2023). Voluntary assisted dying in Australia and New Zealand: Exploring the potential for nurse practitioners to assess eligibility. *Collegian (Royal College of Nursing, Australia)*, *30*(1), 199.
[27] See Waller, K, Del Villar, K, Willmott, L and White, B, "Voluntary Assisted Dying in Australia : A Comparative and Critical Analysis of State Laws" *University of New South Wales Law Journal*, Vol. 46, No. 4 (2023), available at SSRN: https://ssrn.com/abstract=4394798, p 38.

this approach has been found to be "not effective in achieving the objectives of respecting institutional positions while promoting patient access" and "appears to have allowed existing power, resource, and information asymmetry to prioritise institutions' positions over patient choice.[28]

Objections in Victoria have included refusing to allow the voluntary assisted dying substance into a facility, not allowing outside health professionals to undertake eligibility assessments at a facility and preventing staff from discussing voluntary assisted dying at all. In some cases, objections resulted in forced transfers out of facilities to access voluntary assisted dying, which caused additional pain, suffering and stress for patients and caregivers. In other cases, institutional objection precluded access to voluntary assisted dying because a transfer was not available or physically possible.[29]

Patients described being admitted to a facility to manage their pain and symptoms, knowing that the facility will block their access to voluntary assisted dying. Patients also described the impact of transfers that meant moving away from staff who had been caring for them. Not only did they describe the emotional and relationship cost to them (as well as their families and carers) in not being able to die in their "home", but also the delays involved, including waiting until a bed was available in the transferring facility. The family of one patient described the frantic rush to get their mother to a facility and the resulting stress and distress having to move her out of her home on her last day alive.[30]

Institutional objection also undermines some of the crucial factors in a "good" or "successful" death from the perspective of the individual, including choice and control in the dying process, receiving integrated end-of-life care, and a pain free death which supports dignity and emotional well-being.[31] As was reflected to us in community consultation, institutional objection is also a risk factor for complex grief for family and carers.[32]

The ACT Government considered that there was a need for a different approach to managing the interests of individuals and faith-based health service providers, to prevent eligible people, and their friends, family and carers, from experiencing unnecessary suffering. Accordingly, this Bill adopts an approach more closely informed by the approach in Queensland, New South Wales and South Australia, but learning from the access challenges experienced in those jurisdictions.

Accordingly, the Bill imposes three obligations on facility operators arising under certain circumstances: giving an individual the contact details for the Care Navigator Service, granting access to a relevant person (e.g., coordinating or consulting practitioner) at the facility unless not reasonably practicable, and facilitating the transfer of an individual to another place to see a relevant person unless the transfer is unreasonable. Further details are at pages 13 and 14 of this submission.

The 18-month implementation period between passage and commencement of the Bill will facilitate further consultation with facility operators on how to meet their obligations.

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[28] White, B, Jeanneret, R., Close, E. *et al.* "The impact on patients of objections by institutions to assisted dying: a qualitative study of family caregivers' perceptions" *BMC Med Ethics* 24, 22 (2023), available at: https://doi.org/10.1186/s12910-023-00902-3p, p 11.
[29] Ibid.
[30] Ibid at p 7.
[31] Emily Meier et al, 'Defining a good death (successful dying): literature review and a call for research and public dialogue (MAID) – a qualitative study 24 *American Journal of Geriatric Psychiatry* 4 (2022).
[32] Narges Hashemi et al, "Quality of bereavement for caregivers of patients who died by medical assistance in dying at home and the factors impacting their experience: a qualitative study" 24 *Journal of Palliative Medicine* 9 (2021).

No specified minimum duration between first and final request

The Bill contains no mandatory requirement for an individual's voluntary assisted dying process to take a certain minimum number of days between the first and final request. This contrasts to other Australian jurisdictions, which impose a 'cooling off' period of between five and nine days between an individual's first and final request for voluntary assisted dying, with exemptions available when an individual is likely to die or lose capacity in that period. The intent of these jurisdictions was to ensure that decisions are not rushed and to ensure there is a period of time for the individual to reflect on their choices.[33]

Overall, the public consultation heard that a specified period was not necessary. Those with strong views on this matter felt that the voluntary assisted dying process already required enduring, repeated requests made over a number of days, such that a formal requirement to wait was not necessary; and that the five to nine days 'cooling off' period imposed by Australian states was arbitrary. We heard from some health professionals involved with voluntary assisted dying around Australia that patients rarely, if ever, change their mind during this period.

During consultation with voluntary assisted dying officials across Australian jurisdictions, there was no clear justification for selecting the length of the 'cooling off' period as five days, nine days, or some other duration. We also heard there are a significant number of 'cooling off' period exemptions being granted for people who are likely to die or lose capacity in that period, and community expectations that voluntary assisted dying should be quickly accessible to those who have chosen to access it.

Accordingly, the lack of community and stakeholder support combined with a weak evidence base justified not including a specified minimum period between first and final request being mandated by the Bill.

Conclusion

The Bill will enable eligible individuals to have access to end-of-life choices that align with their rights, values and preferences. It aims to reduce end of life suffering, enhance autonomy and dignity, and help carers, families and friends to support people who are suffering intolerably in the last stages of their lives.

The systems and safeguards introduced by the Bill are comprehensive. They have been developed and informed by research, evidence and community views on what is fair and appropriate. Any limitations on human rights arising from these safeguards can be reasonably and demonstrably justified.

It is important to understand that while the Bill's voluntary assisted dying process comprises many components, these are interconnected and related. Any amendments to one element of the Bill would need to consider the resulting impact on other elements. For instance, as noted earlier in the submission, a legislated timeframe to death was not included due to the inherent uncertainty in making that assessment; instead, the eligibility criteria of 'advanced' and 'progressive' were given specific definitions in the Bill to support practitioners.

Adding more onerous safeguards could create barriers to an individual's access to voluntary assisted dying, and in doing so could limit the ability of the Bill to achieve its objectives. Alternatively, reducing the safeguards

[33] Queensland Law reform Commission, (2021) *A legal framework for voluntary assisted dying*, 248.

to access voluntary assisted dying could increase the risk of vulnerable members of the community being coerced or exploited. Research has shown that 'piling on' ad hoc safeguards to already sound voluntary assisted dying laws does not make laws safer and can make them worse. Ad hoc safeguards that have been added during parliamentary processes in other Australian jurisdictions have led to inconsistency and incoherence in those laws without improving patient or community safety.[34]

The Bill will be complemented by a suite of policy and guidance as part of the 18-month post-passage implementation process. As demonstrated by other Australian jurisdictions, establishing and operationalising voluntary assisted dying with appropriate safeguards and processes is crucial to ensure health system readiness and workforce capability to deliver voluntary assisted dying. Key to implementation is the establishment of system-wide care and referral pathways for voluntary assisted dying, including a Care Navigator Service and pharmacy service. The implementation period is necessary to enable research, development, and delivery of functions to support effective implementation. These services, guidelines and systems are critical to ensure there is support for clinicians wishing to provide voluntary assisted dying as well as for people, their families and carers looking to access voluntary assisted dying.

[34] White and Willmott (2021) *Voluntary assisted dying: A policy briefing*, Australian Centre for Health Law Research, Faculty of Business and Law, Queensland University of Technology, p 1, available at: https://research.qut.edu.au/voluntary-assisted-dying-regulation/wp-content/uploads/sites/292/2021/08/Voluntary-assisted-dying-research-Policy-briefing-web-version.pdf.