



**LEGISLATIVE ASSEMBLY**  
FOR THE AUSTRALIAN CAPITAL TERRITORY

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SELECT COMMITTEE ON VOLUNTARY ASSISTED DYING BILL  
Ms Suzanne Orr MLA (Chair), Ms Leanne Castley (Deputy Chair),  
Mr Andrew Braddock MLA, Mr Ed Cocks MLA, Dr Marisa Paterson MLA

## Submission Cover Sheet

Inquiry into the Voluntary Assisted Dying Bill 2023

**Submission Number: 073**

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Voluntary Assisted Dying Committee,  
ACT Legislative Assembly  
By email to: [LACommitteeVAD@parliament.act.gov.au](mailto:LACommitteeVAD@parliament.act.gov.au)

13 December 2023

Dear Committee Secretary,

**Inquiry into the Voluntary Assisted Dying Bill 2023**

The ACT Human Rights Commission welcomes the opportunity to make a submission to this Inquiry into the *Voluntary Assisted Dying Bill 2023*.

This submission is made on behalf of the President and Human Rights Commissioner, Dr Penelope Mathew, the Public Advocate and Children and Young People Commissioner, Jodie Griffiths-Cook and the Discrimination, Disability, Health and Community Services Commissioner, Karen Toohey.

Should you wish to discuss this matter further or provide feedback regarding our advice, contact in my office.

Yours sincerely

Dr Penelope Mathew  
President and Human  
Rights Commissioner

Jodie Griffiths-Cook  
Public Advocate and  
Children and Young  
People Commissioner

Karen Toohey  
Discrimination, Health  
Services, and Disability  
and Community Services  
Commissioner

## The ACT Human Rights Commission

The ACT Human Rights Commission is an independent agency established by the *Human Rights Commission Act 2005 (HRC Act)*. Its main object is to promote the human rights and welfare of people in the ACT. The HRC Act became effective on 1 November 2006 and the Commission commenced operation on that date. Since 1 April 2016, a restructured Commission has included:

- the President and Human Rights Commissioner,
- the Discrimination, Health Services, Disability and Community Services Commissioner,
- the Public Advocate and Children and Young People Commissioner and
- the Victims of Crime Commissioner.

As independent statutory office holders with key oversight responsibilities for promotion of human rights and the welfare of people in the ACT, the Commission is engaged in ongoing law reform work, particularly in areas such as the subject matter of this inquiry which require a delicate balancing of human rights protected by the *Human Rights Act 2004 (HR Act)*. The balance to be considered in relation to the current inquiry touches on the foundational concepts underpinning human rights protected by the HR Act, including those of human dignity, liberty and equality.

The Commission supports human rights compatible legislation to enable access to appropriate and adequate health care to assist a person to die with dignity in circumstances where other health interventions are futile or intolerable to the suffering person. This submission considers the particulars proposed by the *Voluntary Assisted Dying Bill 2023 (the Bill)* using a human rights framework.

### A human rights approach to Voluntary Assisted Dying

The Commission supports the introduction of a Voluntary Assisted Dying (**VAD**) scheme that appropriately considers and upholds the principles underlying the HR Act. The HR Act provides an important framework for analysing the Bill including consideration of human rights engaged, whether any such rights have been limited and, if so, whether such limitation is justified.

While VAD legislation may better promote certain human rights (such as the right to privacy, including personal autonomy) by giving individuals who are suffering from terminal conditions greater choice and agency at the end of their life, such legislation also has the potential to be incompatible with other protected rights. The UN Human Rights Committee has commented:

States parties that allow medical professionals to provide medical treatment or the medical means to facilitate the termination of life of afflicted adults, such as the terminally ill, who experience severe physical or mental pain and suffering and wish to die with dignity, must ensure the existence of robust legal and institutional safeguards to verify that medical professionals are complying with the free, informed, explicit and unambiguous decision of their patients, with a view to protecting patients from pressure and abuse<sup>1</sup>.

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<sup>1</sup> UN Human Rights Committee, *General Comment No. 36, Article 6: right to life*, (2018) CCPR/C/GC/36

The balancing of the human rights promoted and limited when considering introduction of a VAD scheme is not straight forward.<sup>2</sup> We refer the Committee to our earlier submissions that more fully articulate the human rights engaged when introducing a VAD scheme.<sup>3</sup>

Given our previous submissions addressed our support for the introduction of an appropriately regulated VAD scheme, this submission focuses on the operation of the VAD scheme proposed Bill. Our concern is that the Bill contains safeguards to prevent any unreasonable limitations on human rights, both in terms of ensuring protections for the vulnerable but also including consideration of a range of other human rights, including those that ensure equality of access to the scheme.

Relevant rights protected by the HR Act that the Commission considers are engaged by the Bill include the right to recognition and equality before the law (s 8), the right to life (s 9), the right to protection from torture and cruel, inhuman or degrading treatment (s 10), the right of children to protection needed by the child (s11(2)), the right to privacy (s 12(a)), the right to freedom of thought, conscience, religion and belief (s 14) and the right to liberty and security of person (s 18).

Section 28 of the HR Act provides a framework for consideration of the reasonableness, necessity and proportionality of any limit on rights recognised under the HR Act. It is the task of policy makers to justify such limitations in the design of the legislative scheme.

It is the Commission's view that the identification of human rights engaged by the Bill and the limitation of human rights engaged appear to have been appropriately explained and justified in the Explanatory Statement (ES) to the Bill.

We agree that, for the most part, the Bill contains appropriate safeguards to provide equal access to VAD and to protect against the exploitation of people experiencing vulnerability because of terminal illness, loss of capacity, old age, emotional distress and suffering. We are also of the view that the Bill appropriately balances facilitating access to the scheme with the rights of health practitioners who conscientiously object to being involved in the provision of VAD.

Under the heading below we outline where we see that the Bill may fall short. These concerns relate both to questions of human rights compatibility but also to operational concerns informed by the experience of our Health Services Commissioner. We are comforted by section 159 of the Bill which proposes a statutory review of the scheme as soon as practicable 3 years after commencement. We acknowledge that certain of the issues outlined below have already been incorporated into the requirements of the future review. We recommend that the review be expanded to also include the other issues we have highlighted.

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<sup>2</sup> For the purpose of determining human rights compatibility, the HR Act expressly allows consideration of relevant international law and decisions of foreign and international courts. The question as to whether a prohibition on VAD is inconsistent with human rights has been considered by the European Court of Human Rights, and courts in the United Kingdom, Canada and New Zealand with differing outcomes as to which human rights are engaged and (if engaged) whether limitations on such rights are justifiable. An overview of the differing approaches to the question of whether a prohibition on VAD is compatible with human rights can be found in Willmott, White & Del Villar "Voluntary Assisted Dying: Human Rights Implications for Australia" in Gerber & Castan (eds.) *Critical Perspectives on Human Rights Law in Australia* (Vol 2), 2021.

<sup>3</sup> See ACT Human Rights Commission submission to the Consultation by the Justice and Community Safety Directorate into Voluntary Assisted Dying, 6 April 2023; and ACT Human Rights Commission submission to the Inquiry by the Select Committee on End of Life Choices in the ACT, 26 March 2018.

## Improvements to the proposed scheme

We detail below certain of our earlier recommendations that have not been incorporated into the Bill.

- 1. Access for Children and Young People under 18:** the current scheme is limited to individuals over the age of 18 years old. Human rights principles require due consideration for the rights of children and young people, including their right to access health care without discrimination (s 8 of the HR Act) and their right to have their views taken into account.<sup>4</sup> It is the Commission's view that this extends to decisions for a child or young person to voluntarily end their life with dignity in the same circumstances as adults: namely where they have a condition that is advanced, progressive and expected to cause their death, where they are suffering intolerably, where they are acting voluntarily, and where they have demonstrated maturity and capacity to make such a decision. We recognise that there may need to be additional steps and safeguards for children and young people, particularly where the views of parents and carers differ from the young person or from each other.
- 2. Advance care directives:** the Commission is of the view that a model should not be ruled out that enables a person to access VAD even in circumstances where there has been loss of capacity or an inability to communicate, but where there has been a prior voluntary directive established when the individual had capacity indicating that an individual wished to access VAD. This might be through the mechanism of an advanced health care directive, so long as accompanied by appropriate safeguards. The inability of those facing a painful or prolonged death to determine their own future care once they lose capacity may engage the rights to equality and non-discrimination and the right to privacy, due to the lack of autonomy. The lack of such an option may also engage the right to life as certain people suffering intolerably may access VAD at an earlier point in time than they might otherwise have chosen for fear of losing capacity. We see the balance as one that promotes individual autonomy by enabling the making of decisions about a person's own future.

We recognise that enabling VAD through advance care directives or their equivalent involves fraught ethical issues regarding administering VAD to individuals who cannot consent at the time of administration. It is worthwhile noting, however, that this was a core issue of concern from community in the consultation process leading to the development of the Bill.<sup>5</sup> Including this possibility will therefore both further promote and limit human rights but nevertheless deserves consideration. We are encouraged by the commitment to revisit this question through the statutory review process once the scheme has been in operation for three years.

- 3. Oversight, reporting and compliance mechanisms:** the Commission supports robust safeguards to ensure that the VAD scheme is protective of the most vulnerable members of our community. In our view the scheme contains such safeguards and appropriate checks. Our concern is rather that the oversight mechanisms should not unnecessarily become a barrier to

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<sup>4</sup> Section 11(2) of the HR Act. In addition, it is important to consider the best interests of the child as protected by the *Convention on the Right of the Child*.

<sup>5</sup> See ACT Your Say [Listening report](#): *Voluntary assisted dying in the ACT: report on what we heard*, June 2023.

access. We note the Bill includes appropriate eligibility requirements for the health professionals involved, plus the following requirements:

- a first request by an individual wishing to access VAD, including involvement by a health practitioner as a coordinating practitioner and referral to a consulting practitioner;
- a second request to the coordinating practitioner and a written request witnessed by two witnesses (and potentially signed by a third person as an agent if the person cannot sign), all of whom must not be the coordinating or consulting practitioner nor someone who may be a beneficiary under the will nor benefit financially from the death of the person, nor the manager or owner of a facility in which the person is residing. The witnesses and any agent who signs must all sign certifications as to the voluntariness of the request and lack of coercion;
- a final request that is clear and unambiguous made personally by the individual followed by a final assessment by the coordinating practitioner to ensure the individual retains decision-making capacity and is making the decision voluntarily and without coercion; and
- an administration decision that is clear and unambiguous made personally by the individual that is communicated to the individual's coordinating practitioner.

In addition to these steps, there are also further stringent safeguards with regards to the administration process, the appointment of a contact person for those who elect to self-administer, in relation to any translator used, and in prescribing and dealing with approved substances.

Given the numerous steps, and consistent with our previous submission, we propose that the statutory review of the scheme be required to consider a model of oversight which occurs at the conclusion of the process rather than for the board to be notified at each step along the way.<sup>6</sup>

A scheme whose purpose is to facilitate access to VAD in order to help individuals end their lives with dignity, and to ensure that intolerable suffering is not unnecessarily prolonged, should avoid unnecessarily delays that may frustrate its purpose.

We are concerned that the Bill may unintentionally create such delays due to the requirement for the board to be notified of each step in the process including as required by sections 18, 22, 25, 30, 42, 44, 51 and 59 of the Bill plus more if there are any changes in the practitioners involved.

These notification provisions impose strict liability offences on health practitioners if not complied with, including notification within a 2-day period. We are concerned that the level of paperwork combined with the penalty regime for late notifications may serve as a disincentive for health practitioners to be involved with the scheme. On a preliminary reading of the Bill, eight (and in some cases many more) separate notifications are required to the Board before a person is able to move on to the final stage of the VAD process. There are then additional requirements to notify the Board on completion of the VAD process or if the person dies otherwise than through VAD – examples being found at sections 74 or 78.

Although there is no requirement for the Board to actually approve each of these steps, the Commission considers that the impact of this iterative notification scheme to the Board should

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<sup>6</sup> ACT Human Right Commission submission to the Voluntary Assisted Dying Consultation, 6 April 2023 at [59]

be closely monitored and that its operation and impact be reviewed for any unintended barriers it creates.

We are also concerned with the requirement outlined above to have numerous independent individuals involved for the second request including: the person making the request, an agent for those who cannot sign for themselves, the health practitioner, and two witnesses. Noting none of these may be a beneficiary (which may have the effect of ruling out close relatives or friends) and none may be responsible for the management of the facility, this requirement may be unduly onerous for certain people in institutional settings to comply with or for those who are isolated in the community. While we understand the need for robust witnessing requirements, the practical effect may serve as an unnecessary barrier, one that requires careful consideration of its engagement of s8 of the HR Act given the potential to limit access to the VAD scheme.

- 4. Review rights when denied access to VAD:** the Commission strongly supports a process for review of decisions by the ACT Civil and Administrative Tribunal (**ACAT**) in relation to access to VAD. The Commission also strongly supports the tight 5-day limit imposed at section 133(2) where a review is sought in circumstances where a decision has been made for facilitating access to VAD. However, we only agree with such a tight time limit to ensure that there is not undue delay to a person who is suffering intolerably from accessing VAD because of a request for review by an affected person other than the individual about whom the reviewable decision was made.

The Commission is of the view that this 5-day period is inappropriate when a request for VAD has been denied and a request for review is being made by the individual wanting to access VAD. If a decision is made that a person does not have the requisite capacity or is not voluntarily choosing VAD or does not have a substantial connection with the ACT, or for any other decision that leads to VAD not proceeding, then it is our view that the person should have the usual 28 days to request a review and that ACAT should have the usual discretion to extend that time period in certain limited circumstances, as is the case for most reviewable decisions. Although in many cases a person will wish the decision reviewed urgently, in order to bring an end to their suffering, a longer time period is essential for those who are very unwell or terminally ill to enable them time to learn about their review rights and to action them – including allowing time to potentially seek legal advice. We cannot see the justification for limiting the time period for review so dramatically in such circumstances and are concerned it may limit section 21(1) of the HR Act if it prevents a person from being able to challenge a decision to deny them access to VAD in an accessible forum.