



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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Catholic
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Catholic Health Australia Submission

Voluntary Assisted Dying Bill 2023

Catholic Health Australia (CHA) is the largest non-government grouping of hospitals, aged and community care services in Australia.

CHA members operate in every Australian state as well as the ACT and provide approximately 25 per cent of private hospital care and 5 per cent of public hospital care in addition to extensive community and residential aged care.

CHA not-for-profit providers are a dedicated voice for the disadvantaged which advocates for an equitable, compassionate, best practice and secure health system that is person-centred in its delivery of care.

December 2023
Catholic Health Australia

Executive Summary

Catholic Health Australia (CHA) is grateful for the opportunity to comment on the *Voluntary Assisted Dying Bill* (ACT) (the Bill) as part of the two year review. We represent the largest grouping of non-government health and aged care services in Australia.

When our patients are dying, we strive to ensure that they die in comfort and with dignity. Consistent with this ethic of care, the Catholic health and aged sector do not participate in voluntary assisted dying (VAD).

Our stance has a strong ethical basis. Participation in VAD fundamentally undermines the role of our clinicians to heal and not to harm. We fear the accessibility of VAD steers vulnerable people away from seeking support and other treatment options. CHA's concerns about the availability of VAD, compared to the accessibility of palliative care options, remains. Individuals in the ACT must have a genuine choice about their end-of-life care. Ongoing service, workforce and systems barriers, many people still do not have access to a suitable standard of palliative care and instead under this Bill, have the 'option' of ending their lives. The genuinely compassionate choice would be to address barriers to universal palliative care, so that every person who wants and needs it can access it.

Catholic health services are concerned about the Bill's imposition on the institutional objection of providers who have decided not to participate in VAD. The rights of facilities to participate or not participate in specific services, whether they be due to resourcing constraints, specialist availability, or importantly, ethical objection must be maintained as a core tenant of our health care system and our society. While the needs of the terminally ill person are at the centre, VAD also affects the rights of other people. The community of care within each of our hospitals and aged care facilities is centred on the inherent dignity of the human person. This Bill has the potential to impact the experiences of people who have purposefully chosen to work with Catholic facilities or join as a patient or resident, because of our ethical stance.

While Catholic services remain opposed to VAD, we ask the Parliament to, at minimum consider some of the threats that it poses to mission-based institutions and the people they care for. We propose recommendations that, if adopted, would offer better protection to vulnerable people, and protect the rights of hospitals and aged care residences to provide compassionate care, free of any exposure to VAD.

Furthermore, the expansion of VAD practices to Nurse Practitioners requires further clarity. Although Regulations stipulate the role of Nurse Practitioners in this process, the Bill only notes health professionals, leaving this open to amendment by regulation later to further expand these practices to other health professionals. If the Government is genuine in its intent to limit these practices to medical and nurse practitioners, it should be outlined with more clarity in the Bill.

We believe terminally ill people deserve more protection and choice than that offered by the laws proposed for the ACT. Our commitment to caring for the vulnerable, including the terminally ill, will never waver.

Recommendations

Summary of recommendations

1. Fund universal access to quality palliative care for all people in the ACT and the adoption of recommendations from the Palliative Care Services Function Review 2023.
2. Require:
 - a. either the consulting or coordinating practitioner to hold specialist expertise and formal qualifications in the person's underlying disease, or
 - b. the consulting and/or coordinating practitioner to refer the person to a specialist with training in their underlying disease
3. Require that practitioners submit evidence of the person's diagnosis and prognosis to the Voluntary Assisted Dying Review Board
4. Require the consulting and/or coordinating practitioner to:
 - a. conduct a focussed VAD capacity assessment; and
 - b. In the case of a person with a condition that could affect capacity, obtain an independent assessment by a relevant specialist
 - c. request and provide reasonable support for persons with issues that may affect capacity
5. Require coordinating and consulting practitioners to provide evidence of capacity to the Review Board, as well as whether reporting on translation services utilised.
6. Permit non-residential facilities to make and be included on decisions concerning patient transfer at each stage of the VAD process
7. Require a person in a non-residential facility, or their practitioner, to inform the facility of any intention to seek VAD
8. Require a person in a residential facility, or their practitioner, to inform a residential facility of their intention to seek VAD
9. Safeguard the right of institutions to operate in line with their ethics, but substantiating what is meant by 'reasonably practicable', or remove presumption altogether.
10. Specify the eligibility criteria of practitioners within legislation, to alleviate concerns regarding expansion of VAD services to other health professionals beyond nurse practitioners and medical practitioners.
11. Give due consideration to the responsibility of government in relation to credentialing of practitioners and their liability on site, so as to not further erode the right of institutional objection.
12. Remove the prescription of the 3 year review to consider the extension of VAD to those under 18, and the utilisation of advance care directives.

Our Commitment to End of Life Care

The work of Catholic health and aged care services rests on a compassionate and courageous ethic of care, which is centred on recognition of the dignity of each person. This means that we honour each person whose care our services are entrusted with. It also challenges us to consider how we contribute to caring for the sick and vulnerable in our society, with so many people without access to adequate health or aged care, especially near the end of their life.

Australian history bears witness to our ethic of care in action: for almost two centuries our services have been responding to the suffering of those we serve at all stages of life, often with a special focus on those who are forgotten or cast aside by others. The reputation of Catholic services as places of hospitality and healing is testament to this. All this rests on a long tradition of care that it is at the heart of our tradition: the very first hospitals were places of healing and hospitality, established in the first centuries by communities who took up the challenge to “heal the sick” with courage and vision. We share a commitment to these values of healing and hospitality with the Hippocratic tradition of medical practice, which has its beginnings over 2,000 years ago, and continues today in the many practitioners and providers – secular and religious – who direct their efforts to the provision and advancement of health and aged care that is orientated to the goals of healing and hospitality.

These traditions of care place special emphasis on serving those who have a life-limiting illness and/or are nearing the end of their lives. Our Ethical Standards in Australia guide us: to heal and never to harm; to relieve pain and other physical and psycho-social symptoms of illness and frailty; to withdraw life-prolonging treatments when they are ineffective or overly burdensome or when a person wants them withdrawn; and to never abandon patients.

We continue our long commitment to improving this care through research and advancement, and we endeavour to do whatever we can to ensure that it is available to all people who need it. Though our services always strive to ensure that those in our care die in comfort and with dignity, a consistent feature of our ethic of care is that we do not assist them to end their own lives or do that for them. Our position is consistent with the Hippocratic ethic and is shared by the Australian Medical Association and the World Medical Association. ³

The passing of this Voluntary Assisted Dying Bill (VAD) in the ACT will require our services to refresh our ethic of care in the context of newly legal possibilities that do not align with it. Responding to these challenges will be a collaborative effort among our members. Our main focus is not on this legislation, but rather on ensuring that our ethic of care continues to serve those who need it

Providing a real choice: The provision of palliative care in the ACT

No amendment will resolve a fundamental problem: that the ACT still does not have universal, high quality palliative care. While this remains, the Bill will continue to fail in offering real options to people approaching the end of life.

Palliative care provides a person living with a life-limiting illness to have the best possible quality of life. This outcome is achieved through a network of clinicians and care options which can include (but are not limited to) help with managing physical symptoms, psychological support, personal care, familial support, respite, and support for family members¹.

Ongoing service, workforce and systems barriers as outlined in the Palliative Care Services Function Review 2023², indicate that many individuals within the ACT still do not have access to high quality palliative care when required. Furthermore, the review anticipated significant growth in the number of individuals needing palliative care in the Territory, with reports also indicating that this growth currently facing foreseeable barriers, seems to have already begun³.

This is even more concerning given how many of the recommendations relating to palliative care provision outlines in the ACT End of Life Choices Inquiry⁴ are yet to be adequately addressed four years later, as subsequently shown in the Palliative Care Services Function Review 2023.

The Bill emphasises choice and states that a person requesting VAD should, as a matter of principle, have access to a variety of care options, including palliative care⁵. The underlying assumption is that palliative care is an option for all Territorians. This assumption is not accurate.

The ACT must deliver universal access to palliative care. Only then can the Bill deliver on its promise to provide a genuine choice to terminally ill people.

Recommendation

- 1. Fund universal access to quality palliative care for all people in the ACT and the adoption of recommendations from the Palliative Care Services Function Review 2023**

Diagnosis

One of the underlying criteria for selecting the VAD pathway is that the patient has a condition ‘likely to cause death’⁶. Despite this requirement, neither of the two practitioners involved in assessing a person’s eligibility to access VAD must possess specialist expertise in the patient’s underlying condition/s and are only required to consult if there is ambiguity as determined by the practitioner themselves. The practitioner must refer to a consultant with “appropriate skills and training” should they be unsure, but mandating this referral to a clinician with knowledge of the individual’s prognosis and underlying condition should be included in the Bill. This means the decision to refer

¹ Department of Health. (2021). *What is palliative care?*, online article, accessed at < <https://www.health.gov.au/health-topics/palliative-care/about-palliative-care/what-is-palliative-care#:~:text=Palliative%20care%20is%20treatment%2C%20care,re%20likely%20to%20die%20from>>.

² ACT Government (2023). *Bold Delivers: Palliative Care Service Function Review*

³ Australian Institute of Health and Welfare (2023). *Palliative Care Services in Australia*, <https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/summary>

⁴ ACT Government (2019). *Inquiry into End-of-Life choices in the ACT*. <https://www.parliament.act.gov.au/parliamentary-business/in-committees/previous-assemblies/select-committees-ninth-assembly/end-of-life-choices/inquiry-into-end-of-life-choices-in-the-act#tab1143329-5id>

⁵ Voluntary Assisted Dying Bill 2023 (ACT), 7

⁶ *Ibid*, 11

to a specialist or not is at the physician's discretion and a specialist trained in the patient's disease will be involved in the VAD assessment.

While both practitioners are expected to submit records to the Voluntary Assisted Dying Review Board, the Bill does not require that this information include evidence of the patient's diagnosis and the likely outcome of their condition but rather generally stipulates a level of record keeping to be decided by regulations. Ensuring in legislation that the journey and challenges individuals are experiencing is recorded effectively, will ensure that subsequent reviews of the legislation can be conducted with greater transparency.

These are significant omissions. Without the benefit of an assessment by an appropriate specialist, a person considering VAD may not be fully informed of their potential alternative treatment options. The prognosis itself may also be inaccurate. A patient with end stage cardiovascular disease should, for example, receive their prognosis and information about their treatment options from a cardiologist specialising in their condition. The Bill would allow doctors without this specialist expertise (notwithstanding their training in VAD) to assess the likely outcome of a patient's disease. As such, the Bill should be amended to involve relevant specialists and for all practitioners involved in VAD to provide evidence of a patient's terminal diagnosis.

Recommendations

1. **Require:**
 - a. **either the consulting or coordinating practitioner to hold specialist expertise and formal qualifications in the person's underlying disease, or**
 - b. **the consulting and/or coordinating practitioner to refer the person to a specialist with training in their underlying disease**
2. **Require that practitioners submit evidence of the person's diagnosis and prognosis to the Voluntary Assisted Dying Review Board**

Stronger safeguards for the vulnerable

The Bill currently lacks the requirement for independent, rigorous assessment of capacity, and lacks specific protections for groups vulnerable to coercion or misinterpretation of their final wishes.

Part 2, Section 11 provides for a presumption in favour of capacity to make decisions about VAD⁷. Characteristics such as language skills or a disability do not affect this presumption. While this presumption might align with existing legislation, it fails to consider a key difference: the fact that VAD results in death. Determining a person's capacity to request VAD should not be treated in the same way as any other assessment about capacity. Assessing a person's capacity to end their life (and understand all the steps involved and their potential consequences) should have a higher bar than, for example, assessing their ability to enter a commercial transaction.

The capacity assessment requirements of Netherland's VAD⁸ scheme are similarly unspecific. A recent analysis of the scheme found more than half (55) of all assessments relied on 'global'

⁷ Ibid. 12 (2)

⁸ Assisted suicide refers to a doctor assisting a patient to end their life. Euthanasia refers to a doctor ending a patient's life with their consent and/or the consent of their family.

judgements of a patient's capacity⁹. Under a third (32%) relied on any evidence that a person demonstrated the four aspects of capacity¹⁰.

The lack of strong checks and balances within draft VAD laws should be a concern given the ACT's rapidly ageing population. Dementia is the second most common cause of death for those in the Territory¹¹. It is also a condition that can significantly affect capacity to make decisions. The training offered to medical students and General Practitioners (GP) in managing dementia is, however, severely limited: with the Royal Commission into Aged Care Quality and Safety hearing that the focus continues to be on acute and primary care¹².

Regardless of general or episodic capacity for decision making, the complex, multi-step and terminal nature of VAD requires a rigorous assessment of capacity. This assessment should focus on the ability of the person not just of a person to understand but retain the information necessary for the decisions involved in VAD and their consequences.

At minimum, the Bill should include further safeguards, requiring the consulting practitioner to possess formal training and diagnostic tools to support capacity assessment. In the case of a person with an established condition affecting capacity (for example, dementia), the consulting and/or coordinating practitioner should obtain an independent assessment of capacity by a relevant specialist. The consulting and coordinating practitioners should report the results of either assessment to the Review Board and whether a translation service was utilised, particularly given the exemptions allowed within the Bill for family members and other related persons to act as translators in certain circumstances.

Recommendations

1. **Require the consulting and/or coordinating practitioner to:**
 - a. **conduct a focussed VAD capacity assessment; and**
 - b. **In the case of a person with a condition that could affect capacity, obtain an independent assessment by a relevant specialist**
 - c. **request and provide reasonable support for persons with issues that may affect capacity**
 - d. **Require coordinating and consulting practitioners to provide evidence of capacity to the Review Board, as well as whether reporting on translation services utilised.**

The role of conscience must be preserved.

If the ACT Parliament is intent on legalising VAD it must respect the rights of institutions to take no part in it. Yet, the current wording of the Bill in contrast to other legislations around the country,

⁹ Doernberg, S. N., Peteet, J. R., & Kim, S. Y. (2016). Capacity Evaluations of Psychiatric Patients Requesting Assisted Death in the Netherlands. *Psychosomatics*, 57(6), 556–565, available at < <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5097685/>>.

¹⁰ Ibid.

¹¹ AIHW (2023). Deaths Due to Dementia. <https://www.aihw.gov.au/reports/dementia/dementia-in-aus/contents/population-health-impacts-of-dementia/deaths-due-to-dementia>

¹² Counsel Assisting the Royal Commission. (2020). *Counsel Assisting's submissions on workforce*, Royal Commission into Aged Care Quality & Safety, February, accessed at < [Counsel Assisting's submissions on workforce | Royal Commission into Aged Care Quality and Safety](#)>.

presumes access unless ‘reasonably practicable’¹³, watering down the important place of providers to continue delivering the exceptional level of care they have for decades in the ACT, underpinned by their ethics. This is not only out of step with other similar legislations across the country who have not sought to erode the importance of plurality in our healthcare system to this extent, and the ethical motivations that might underpin these, but it is out of step with the provision of other services within the ACT, whether they be oncology or maternity, for which no such requirement is imposed on facilities. 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 consultation¹⁴.

The current Bill under consideration also requires hospitals to allow access to VAD practitioners from the first assessment right up to administration of a lethal substance. While a patient may be transferred at any stage of the process, the decision to permit or deny transfer rests with the VAD practitioner and not with the institution. In practice, this allows VAD doctors, unlike other clinicians, to have access to Catholic facilities. Similarly, aged care facilities (‘residential facilities’) must allow access to VAD practitioners and facilitate patient contact to and from a VAD practitioner. This is required from the first assessment right up to administration of a lethal substance. This would expose our members and residents to VAD occurring on premises, without any other option. This can occur whether an individual is a permanent resident or not, and occur completely without the knowledge of the facility in question, despite the need and desire to continue all other aspects of comprehensive care outside of VAD. For the purpose of continuity of care, the facility should be made aware of patient decisions in relation to VAD, and any consultations, assessments of administrations that occur on site.

Given the provision is VAD is at its core a journey, not just a decision that can be limited to a few select interactions, the presumed availability erodes the right of institutions to object to VAD at a number of stages outside of the three outlined in the Bill¹⁵. For instance it poses significant issues for providers who may choose not to participate in VAD with the credentialing of practitioners. It is not reasonable to expect facilities to credential and manage the liability of practices not offered at that facility. Credentialing practitioners within our hospital facilities for VAD would amount to a form of participation that is fundamentally at odds with our ethics. Due consideration should therefore be given to how the Government will assume this responsibility for credentialing and liability for practitioners who will be operating within facilities that are not participating in the scheme. Although Catholic facilities will not participate in VAD, Catholic facilities would not hinder an individual’s choice to pursue VAD as an option and have proven this in other states where similar legislation exists. However, the presumption of access and terminology used gives rise to serious practical concerns.

Furthermore, the attachment of penalties to specific activities, neglects the evidence of facilities and medical practitioners acting in good faith for the care of individuals, treating coercing an individual to pursue VAD, in the same manner as facilities and medical professionals who are working to care

¹³ Voluntary Assisted Dying Bill 2023 (ACT), 100 (2)

¹⁴ Ibid. 94(2)

¹⁵ Ibid 94(2)

for individuals, when there is little evidence that such a requirement is necessary. This conveys a negative expectation of providers and practitioners in the ACT relating to VAD.

Recommendations

- 1. Permit non-residential facilities to make and be included on decisions concerning patient transfer at each stage of the VAD process**
- 2. Require a person in a non-residential facility, or their practitioner, to inform the facility of any intention to seek VAD**
- 3. Require a person in a residential facility, or their practitioner, to inform a residential facility of their intention to seek VAD**
- 4. Safeguard the right of institutions to operate in line with their ethics, but substantiating what is meant by reasonably practicable, or remove presumption altogether.**
- 5. Give due consideration to the responsibility of government in relation to credentialing of practitioners and their liability on site, so as to not further erode the right of institutional objection.**

Nurse Practitioners

The intent of the ACT to extend VAD Practitioner eligibility to nurse practitioners does not come as a surprise, given the large role such practitioners play in the provision of other health services in the ACT. The Summary of the ACT VAD Framework states the certain requirements for nurse practitioners or medical practitioners in their role as co-ordinating or consulting VAD practitioners. However, this intent if genuine, does not appear to be adequately reflected in the Bill itself. The Bill stipulates that the coordinating practitioner and the consulting practitioner for an individual must not both be nurse practitioners¹⁶ however there are no other eligibility requirements noted. Instead, the Bill states that a health practitioner must meet “the requirements prescribed by regulation”¹⁷ to be eligible to act as a coordinating, consulting or administering practitioner. According to the Bill, a health practitioner is a person registered under the *Health Practitioner Regulation National Law (ACT)*, which details various health practitioners who although health professionals in their own relevant fields, should not have the responsibility or obligations relating to the prescription of VAD services.

This omission in the legislation, leaves the administration of VAD services open to expansion by regulation rather than legislation. By explicitly stating the eligibility requirements in the Bill more comprehensively, individuals in the ACT can be sure that the individuals providing VAD now and into the future, will indeed be medical practitioners and nurse practitioners, as the Government has stated its intention to be.

¹⁶ Ibid. 92 (3)

¹⁷ Ibid. 84

Recommendations

- 1. Specify the eligibility criteria of practitioners within legislation, to alleviate concerns regarding expansion of VAD services to other health professionals beyond nurse practitioners and medical practitioners.**

Three-year review concerns

The ACT Government backed away from extending VAD to those under 18 years of age, noting the complexities around decision making capacity. Yet the mandated review to be conducted after three years¹⁸, explicitly includes this as a consideration giving weighting to the importance of this over other matters that may need to be considered in any review. Such an inclusion implies a view to expanding these laws, before the initial Bill has even passed the Parliament.

This three-year review also includes a pathway to expanding laws to include advanced care planning, assumingly to include those without decision making capacity at the time of death. This is a move that would be completely out of step with other similar legislations pertaining to VAD, and the care and protection that should be afforded to individuals when cognitive ability declines. In Victoria, where these laws have been in place the longest, current reporting outlines that approximately 32 per cent¹⁹ of individuals who are provided with the VAD substance, do not actually take the substance. This is no small proportion, and yet, under any expansion would have been subject to VAD with no ability to reassess their decision at a later date. The specific outlining of these measures as part of the review in the Bill, suggest that the current safeguards of the Bill are not genuinely sought.

Recommendations

- 1. Remove the prescription within the Bill of the 3-year review to consider the extension of VAD to those under 18, and the utilisation of advance care directives.**

¹⁸ Ibid, 159(2)

¹⁹ Voluntary Assisted Dying Review Board, (2023) Annual Report, <https://www.safercare.vic.gov.au/reports-and-publications/voluntary-assisted-dying-review-board-annual-report-july-2022-to-june-2023>