Submission No 77

INQUIRY INTO PROVISIONS OF THE VOLUNTARY ASSISTED DYING BILL 2021

Organisation: Catholic Health Australia

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Catholic Health Australia

Submission to the Legislative Council Law & Justice Committee *Voluntary Assisted Dying Bill 2021* (NSW)

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Executive summary

Catholic Health Australia (CHA) is grateful for the opportunity to comment on the provisions of the *2021 Voluntary Assisted Dying Bill (NSW) (the Bill).*

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 will not take part in assisted suicide, or voluntary assisted dying (VAD).

Our stance has a strong ethical basis. Legalising VAD fundamentally undermines the role of clinicians to heal and not to harm. We fear the availability of VAD may steer vulnerable people away from seeking support and other treatment options.

While the needs of the terminally ill person are at the centre of our work, 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.

Passing the laws proposed for NSW would expose people who have purposefully chosen to work with us because of our ethical stance to a practice that goes against their values, as well as the patients and residents who seek our care knowing that we will not offer VAD.

The Bill itself is founded on a flawed premise: that the people of NSW have genuine choice about their end-of-life care. Thousands of people in this state cannot choose palliative care and, if VAD becomes law, will instead have the 'option' of ending their lives before time. The genuinely compassionate choice would be to fund universal palliative care, so that every person who wants and needs it can access it.

While we oppose this Bill in any form, we ask the Committee to, at minimum, recommend amending it. We have proposed changes that, if adopted, would offer better protection to vulnerable people, strengthen the accountability of practitioners, and protect the rights of hospitals and aged care residences to provide compassionate care, free of any exposure to VAD.

We believe terminally ill people deserve more protection than that offered by the laws proposed for NSW. Our commitment to caring for the vulnerable, including the terminally ill, will never waver. We ask the Committee to offer the people of NSW a better choice.

Summary of recommendations

1. **Fund universal access to quality palliative care, ensuring regional and rural NSW has equal access to the right care as those in metropolitan areas**
2. **Uphold and support the rights of doctors who do not wish to participate in voluntary assisted dying**
3. **Curtail the ability for health care workers to initiate discussions around voluntary assisted dying**
4. **Require the coordinating and consulting practitioners to:**
   a) **conduct a focussed VAD capacity assessment**
   b) **form an opinion that palliative care is unable to alleviate the suffering of the patient**
   c) **inform the specialist to whom a referral is made that the patient is requesting voluntary assisted dying**
   d) **consult with the patient's doctor**
   e) **provide a clinical report on the treatment options available to the patient**
   f) **obtain an assessment by a psychologist if the patient is suspected of having a cognitive or mental health impairment**
5. **Put in place greater protections around:**
   - the certification of a witness to the signing of a written declaration
   - the revocation of a decision to administer the lethal substance
6. **Remove any obligation on non-residential facilities to provide access to a VAD practitioner**
7. **Permit non-residential facilities to made decisions concerning patient transfer at each stage of the VAD process**
8. **Require a person in a non-residential facility, or their practitioner, to inform the facility of any intention to seek VAD**
9. **Require a person in a residential facility, or their practitioner, to inform a residential facility of their intention to seek VAD**
10. **Allow residential facilities to provide the option of transfer, in consultation with the person**
11. **Protect the requirement that requests for VAD are the current and voluntary wishes of the patient by removing any doubt that request for VAD can be documented in advance directives**

Who we are?

CHA is Australia's largest non-government grouping of health, community, and aged care services providing approximately 10 percent of hospital and aged care services in Australia.

We promote the ministry of health as an integral element of our mission and work to provide compassionate care to the sick, the aged and the dying.

In New South Wales our members include St Vincent's Health Australia, Calvary Health Care, Catholic Care, Catholic Healthcare, Southern Cross Care, St Vincent de Paul Society, and Cardinal Stepinac Village.

Between them our NSW members provide about 8,000 residential aged care beds, 1,800 public and private hospital beds and care for 14,000 home care consumers.

Why we oppose VAD

In every health, aged care, and community facility, the people we care for and the people who provide care know our services will never take part in VAD. We know that people will continue to seek us out because of this. Our mission is to always care, never abandon, and never kill.

Consistent with this ethic of care, the Catholic health and aged sector will not provide, facilitate, or authorise anyone to support a person in our care to undertake VAD. This position is consistent with the Hippocratic Oath and is shared by the Australian Medical Association and the World Medical Association. There is a strong basis for our opposition to VAD.

- **The lawful practice of assisted suicide fundamentally undermines the role of physicians to heal and not to harm.** It erodes the trust between doctor and patient, as the patient may not be confident their doctor is acting in their best interests or pursuing every treatment avenue available. This is already the case in The Netherlands, where elderly people engage in independent measures to ensure their doctors cannot coerce them into assisted dying or euthanasia.

- **The availability of VAD, in and of itself, is subtly coercive**. People who may otherwise have enjoyed more time with their loved ones may see VAD as a mechanism of easing a burden on their families. People who lack family support or suffer from depression connected with their prognosis may seek out VAD instead of requesting and obtaining support to alleviate distress during their final days.

This possibility is borne out by the experience in other jurisdictions where VAD is already lawful. Canada introduced VAD and euthanasia in 2016 and has published its first national report on the scheme[1]. More than a third of people dying by VAD or euthanasia in Canada cited a desire to not to be a burden as a reason for their choice, while a further 13% cited loneliness and the lack of social support as a factor[2]. Similarly, a systematic review found self-perceived burden was a problem for up to 65% of terminally ill people, and a contributing factor in the selection of death hastening pathways[3].

At a time when mental ill health, social isolation and loneliness are on the rise, the Bill may have the unintended consequence of pushing people down the path of VAD. As with the experience in jurisdictions where VAD is available, many people accessing the scheme may do so for psychosocial factors unconnected with their comfort, pain or prognosis and which they should instead be supported through.

- **VAD affects the rights of others, not only the rights of the person seeking it.** In a hospital or aged care setting every patient or resident is part of a community of care. In the context of a Catholic run hospital or aged care facility, a value shared by this community of care is respect for the dignity of the human person. We offer terminally ill people a meaningful choice to be treated, live and die in a place where they know they will be cared for compassionately, without any coercion to opt for VAD. The *2021 Voluntary Assisted Dying Bill (NSW),* as it stands, would undermine this ethic and force our hospitals and aged care organisations to facilitate VAD. In doing this, the Bill would force those thousands of individuals

[1] Health Canada. (2019). *First annual report on medical assistance in dying in Canada*, report, accessed at https://www.canada.ca/content/dam/hc-sc/documents/services/medical-assistance-dying-annual-report-2019/maid-annual-report-eng.pdf.
[2] Ibid.
[3] McPherson, C. J., Wilson, K. G., & Murray, M. A. (2007). 'Feeling like a burden to others: a systematic review focusing on the end of life'. *Palliative Medicine*, *21*(2), pp. 115–128, accessed at <https://journals.sagepub.com/doi/abs/10.1177/0269216307076345>.

and their families, who have specifically chosen a Catholic facility because of its ethic of care, to live and die in a place where the practice of VAD may occur.

- In jurisdictions where assisted suicide is legal, eligibility criteria have expanded over time:
- **Canada:** Medically assisted dying was introduced in 2016[4]. The scheme was strictly confined to those with an established terminal illness. The passage of Bill C-7 in 2020 expanded the medical assistance in dying regime to any person experiencing a serious condition, including a psychiatric condition, which causes irremediable suffering[5].
- **The Netherlands:** The Netherlands was the first jurisdiction to legalise physician assisted suicide and euthanasia[6]. The laws have been progressively widened to people with mental ill health, patients with dementia who have previously provided consent, and children over one year of age[7].
- **Victoria:** Victoria was the first Australian jurisdiction to introduce VAD laws and eligibility is limited to people with a terminal illness[8]. While 224 people had died and 405 people had been issued permits under the scheme[9] by December 2020, by May 2021 assisted dying advocates were already campaigning to broaden access. The Chair of Victoria's Voluntary Assisted Dying Review Board has also argued that people diagnosed with a terminal illness should be proactively informed that VAD is an option for their treatment[10].

The Committee should consider the risk of 'scope creep' when introducing the proposed VAD Bill for NSW. This is a genuine prospect when existing assisted suicide regimes have shifted the goalposts despite initially confining access to the terminally ill.

Shortcomings of the Bill

Catholic Health Australia opposes the *2021 Voluntary Assisted Dying Bill (NSW)* in any form.

Our submission, however, also contends with the aspects of the Bill that are the most troubling to the rights of vulnerable people, our members, and the communities they support. We have highlighted these aspects below with proposals for amendment.

A real choice: the need for universal access to palliative care

No law will resolve our fundamental problem: that NSW does not have universal, high quality palliative care. This means the Bill fails to offer 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

[4] *Criminal Code*, RSC (1985), c C-46 s 241.2.
[5] Ibid.
[6] *The Dutch Termination of Life on Request and Assisted Suicide (Review Procedures) Act* (2001).
[7] Government of the Netherlands. (2021). *Euthanasia, assisted suicide and non-resuscitation on request,* online article, accessed at <https://www.government.nl/topics/euthanasia/euthanasia-assisted-suicide-and-non-resuscitation-on-request>.
[8] *Voluntary Assisted Dying Act 2017* (Vic) s 9
[9] Victorian Agency for Health Information. (2020). *Voluntary Assisted Dying report of operations*, report, accessed at <https://www.bettersafercare.vic.gov.au/reports-and-publications/voluntary-assisted-dying-report-of-operations-july-to-december-2020>
[10] Kelsey-Sugg, A. and Barclay, P. (2021). 'It's been two years since Victoria introduced assisted dying laws, so how well are they working?', *ABC News*, online article, accessed at <https://www.abc.net.au/news/2021-05-07/voluntary-euthanasia-laws-how-well-are-they-working/100117058>

limited to) help with managing physical symptoms, psychological support, personal care, familial support, respite and support for family members[11].

Many in this state, however, do not have access to high quality palliative care in their area or due to their age or condition.

The Bill emphasises choice and states that a person requesting VAD must be informed of their options for palliative care[12]. The underlying assumption is that palliative care is an option for everyone in this state. This assumption is not accurate.

The NSW Premier himself has acknowledged that palliative care in this state has been underfunded, leaving many to face the impossible choice of dying in pain because they don't have access to the right care or choosing an early death through VAD.

Ensuring accurate prognosis and availability of treatment options

One of the underlying criteria for selecting the VAD pathway is that the patient has a terminal illness[13]. 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.

The practitioner 'may' refer to a consultant with specialist expertise but there are no criteria specifying when referral is required. This means the decision to refer to a specialist or not is at the VAD physician's discretion and a specialist trained in the patient's disease may never be involved in the VAD assessment.

While both practitioners are expected to keep and submit records to the Voluntary Assisted Dying Review Board, the *2021 Voluntary Assisted Dying Bill (NSW)* does not require that this information include evidence of the patient's diagnosis and the likely outcome of their condition.

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.

Protecting the vulnerable

Our members have grave concerns around the lack of safeguards in the Bill, in particular around the very real threat of coercion, as well as the person's capacity to undertake such a decision.

Division Three provides for a presumption in favour of capacity to make decisions about VAD[14]. Characteristics such as language skills or a disability do not affect this presumption. 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

[11] 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>.
[12] Voluntary Assisted Dying Bill 2021 (NSW) (s10)
[13] Ibid s 10(1)(a)
[14][14] Voluntary Assisted Dying Bill 2021 (NSW) Division 3

potential consequences) should have a higher bar than, for example, assessing their ability to enter a commercial transaction.

The process outlined for assessing capacity also exposes the **vulnerable to risk**. As mentioned earlier in this submission, two practitioners are involved in the assessment of a person's eligibility to access VAD. At various stages of this assessment, the practitioners must determine the person has the capacity to make decisions. The *2021 Voluntary Assisted Dying Bill (NSW)* does not specify how VAD practitioners would make this assessment and does not require them to have any specialist ability in making these assessments**.**

It is because of this presumption of capacity that there is no requirement for either doctor to undertake any cognitive testing of the patient. Furthermore, the **presumptive nature** of the Bill[15] is further compounded by the provision that the patient must only "reasonably appear" to the doctors to understand the consequences of the decision.

When it comes to **duress** or **undue pressure** the Bill once again fails to promote a culture of inquiry. Provided there is no evidence or circumstances of pressure or duress then they can conclude that the patient is acting voluntarily. The Bill fails to provide any guidance on how to determine whether the person is acting voluntarily or is doing so under **coercion**. The risk of coercion is exacerbated by the fact that the person's interactions can occur by audio visual means and the patient's signature on the written declaration can be made electronically.

The risk of coercion and any ability to detect, which is difficult at the best of times, is further exacerbated by the fact that that the time between the first and last request can be as short as **five days**, which is almost half of that of other jurisdictions.

Our society is aware of the prevalence of **elder abuse**; almost 40 per cent of people living in residential aged care experienced some form of abuse or neglect, according to the Royal Commission into Aged Care Quality and Safety[16]. This law will only heighten the risk of such elder abuse.

The problems with such an approach are illustrated with reference to the capacity assessment requirements of **Netherland's** assisted suicide and euthanasia[17] scheme, which is similarly unspecific. A recent analysis of the scheme found more than half (55) of all assessments relied on 'global' judgements of a patient's capacity[18]. Under a third (32%) relied on any evidence that a person demonstrated the four aspects of capacity[19].

The **lack of strong checks and balances** within draft VAD laws should be a concern given Australia's rapidly ageing population. Dementia is the second most common cause of death for Australians[20]. It is also a condition that can significantly affect capacity to make decisions. The training offered to medical

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[15] Ibid (s6 2)

[16] https://agedcare.royalcommission.gov.au/publications/research-paper-17-experimental-estimates-prevalence-elder-abuse-australian-aged-care-facilities

[17] 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.

[18] 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

[19] Ibid.

[20] Australian Institute of Health and Welfare. (2021). *Deaths in Australia,* accessed at < https://www.aihw.gov.au/reports/life-expectancy-death/deaths-in-australia/contents/leading-causes-of-death

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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 care[21].

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 to understand, retain and process the information necessary for the decisions involved in VAD and their consequences.

At minimum, the *2021 Voluntary Assisted Dying Bill (NSW)* 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 assessment should also include access to translation support where required.

The consulting and coordinating practitioners should report the results of either assessment to the Review Board.

Additionally, while the Bill contemplates that requests for voluntary assisted dying are, and should be, (a) clear and unambiguous, (b) voluntary i.e. free from coercion and (c) current , without amendment, the Bill could leave open the possibility that past advance directives are used to support voluntary assisted dying, particularly in circumstances where the patient is unable to express their wishes verbally.

Members of Catholic Health Australia oppose the use of advance directives as a mechanism to support future access to voluntary assisted dying and urge Parliamentarians to put this beyond any doubt by amendment to the Bill. In our experience, patients can and do change their wishes about their end-of-life care and plans including, at times, at the last minute. Patients should not be denied this ability by having past directives utilized as evidence of current intentions.

Protecting the rights of institutions to opt out of VAD

- Aged care facilities ('non-residential facilities'). Even though the Bill ascribes the right for residential aged care facilities to opt out of providing voluntary assisted dying at the facility they must still allow access to VAD practitioners from the first assessment right up to administration of a lethal substance. This imposition infringes the rights of the people working, living and being treated at our members' facilities. People who have intentionally sought to join a community providing compassionate care, free from any intentional taking of life, would be exposed to VAD. This exposure could be as a bystander (for example, witnessing someone undertaking VAD) or by unintentional participation in the practice (for example, through being handed a lethal substance).

- The *2021 Voluntary Assisted Dying Bill (NSW)* leaves the duty to inform the aged care facility that one of its residents is participating in VAD solely at the discretion of that person. It simply says the patient/resident *should* inform the facility manager of their decision. While our aged care members absolutely respect the privacy of their residents, it means that the first time that the centre might be made aware of the resident's death is on the discovery of the body. This could mean a staff

[21] 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>.

member, or another resident, especially one that shares a room with another resident, could undergo great anguish, leaving it to the facility to liaise with the authorities in the aftermath (ss90-96).