

**Submission
No 105**

**INQUIRY INTO PROVISIONS OF THE VOLUNTARY
ASSISTED DYING BILL 2021**

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HammondCare Submission

Voluntary Assisted Dying Bill 2021 (NSW)
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Executive Summary

When we or someone we love experience terminal suffering, it can push us to the very edge of what it means to be human. We would do anything to prevent this – including allowing or taking actions not normally countenanced. In the midst of this anguish, voluntary assisted dying may be presented as a painless and tidy end compared with the messiness and struggle of what is assumed will be a natural journey to a terrible death. But, as is shown in these pages, it is never neat and easy to end a human life.

The context is society's growing unfamiliarity and inability to deal with the reality of the journey of death, assuming something so shocking is devoid of hope and meaning – like the HammondCare patient who could not reconcile with his impending death, deteriorating rapidly and asking to have his life ended. It was not until he was surrounded with holistic palliative care that he learned that in this season, his role was to receive and rest in the love and care of those supporting. Before long, he was out of bed again, sharing precious moments in nature with family: moments that will be remembered forever but that would have been lost.

This highlights two key factors – the drive to choose our destiny is often misdirected by inability to comprehend the last great mystery of life. Secondly, we simply do not know what palliative care is, what it can do, how it can minimise symptoms and importantly, that the very worst suffering it addresses (in our clinical experience) is often not physical but existential. Such suffering is not even discerned in the advocacy for a 'dignified' assisted death. This is why HammondCare cannot support the Voluntary Assisted Dying Bill 2021 (NSW) because there is another way – the provision of quality palliative care for every person at the end of life.

About HammondCare

Established in the 1930s, HammondCare is an independent Christian charity specialising in palliative care, dementia care, rehabilitation and older persons' mental health services. Caring for people at the end of life and improving the quality of life for people in need, regardless of their circumstances, is an integral part of HammondCare's mission.

As an organisation, we care for people at the end of life in various settings: in our palliative care units at Greenwich, Neringah and Braeside hospitals, in our residential aged care homes (including the specialist Lavender Palliative Care Suite), and in clients' homes through the Palliative Extended Aged Care in the Home (PEACH) Program. We employ a number of experts in palliative care, including Professor Josephine Clayton (Professor of Palliative Care; Director, Centre for Learning & Research in Palliative Care), Professor Melanie Lovell (Senior Staff Specialist in Palliative Care and Centre for Learning & Research in Palliative Care) and Professor Roderick MacLeod (HammondCare Associate). In addition, HammondCare recently launched The Palliative Centre – a central hub for a wide range of services, education and resources.

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Definitions

There is no universal consensus around the definition of assisted dying or voluntary assisted dying (VAD). HammondCare prefers to use other terms, such as physician-assisted suicide and euthanasia, as defined in the European Association for Palliative Care White Paper, in order to distinguish between the self-administration and practitioner-administration of a prescribed substance.¹

However, for the purposes of this paper and consistency with the terminology of the Bill, we will refer to both practices as VAD hereafter.

Position on Voluntary Assisted Dying

The following section outlines HammondCare's principled rejection of VAD, as well as our rationale in calling upon Parliament to dismiss the Voluntary Assisted Dying Bill 2021 (NSW).

HammondCare is a Christian organisation whose mission is to improve the quality of life for people in need. This includes caring for people who are dying. We believe in the value of all people as made in the image of God and as loved by God. The Christian belief in the 'image of God' affirms that each person has inherent worth regardless of race, religion or capacity. This belief motivates us to show love, compassion and respect for all people regardless of stage of life.

HammondCare opposes all legalisation of VAD and endorses palliative care as the appropriate service for people who are nearing the end of life.

We believe that each human life is valuable to the end. While we acknowledge that there may be suffering at the end of life, there is also opportunity for quality of life. This is the goal that HammondCare's palliative care services strive toward.

Principles

1. Commitment to care

It is HammondCare's mission to improve quality of life for people in need and to care for those that others won't or can't – especially for those with complex needs. Therefore, regardless of the outcome of the Bill, HammondCare will not withdraw our services nor abandon people at any point in the individual's ageing or palliative journey. HammondCare will continue to provide palliative, spiritual and pastoral support to our clients and their families, even if they decide to participate in the processes outlined in the Bill.

2. Every human life has equal value

HammondCare strongly supports the principle that every human life has equal value. We do not believe that this can be upheld within the Bill. Fundamentally, the creation of VAD law suggests that some lives are not worth living.² When the option for hastened death becomes available it can have a small but significant effect on public consciousness. Rather than being off limits, killing suddenly becomes a possibility. Once it is a

¹ Lukas Radbruch et al. "Euthanasia and physician-assisted suicide: a white paper from the European Association for Palliative Care", *Palliative Medicine* 30, no. 2 (2016): 108.

² Goligher et al. "Euthanasia and Physician-Assisted Suicide are Unethical Acts", 36.



possibility, it must be legally defined. When can it occur? It may be when a person is 'terminally ill'. However, as Baroness Jane Campbell of the House of Lords articulates:³

“Who decides what is terminal? If terminal illness, why not chronic and progressive conditions? And, if chronic and progressive conditions, why not seriously disabled people? I am already on the list.”

These processes distort society's perception of the value of life and damages our communal responsibility to protect the vulnerable and weak. Rather, society should support the vulnerable, providing hope, relief, care and meaning.

3. Voluntary assisted dying is antithetical to the goals of medicine

VAD is antithetical to the goals of medicine, which are concerned with care and enhancing patients' quality of life, not assisting in the ending of life. HammondCare particularly opposes VAD being undertaken by physicians, as it can be traumatic and lead to role conflicts. Hippocrates, the ancient father of medicine, stated in the 5th century BC, “I will neither give a deadly drug to anybody who asked for it, nor will I make a suggestion to this effect”. Throughout history, medicine has been concerned with care and quality of life, not assisting in prematurely ending life. HammondCare believes that this role does not end once a person is terminally ill. Rather, good quality care should be provided right up until the end of life.

Involving doctors in VAD leads to role conflicts, which the World Medical Association (WMA)⁴ outlines in the following way:

“Any society that insists on transforming suicide from a freedom to a right, should stand up a different profession with the duty to fulfill that new right, as killing does not belong in the House of Medicine.”

4. Making a prognosis is not an exact science

The end of one's life is a uniquely individual experience. Diagnosing a terminal illness and estimating life expectancy are standard medical practices. However, making a prognosis is a professional opinion based on medical experience that only produces a forecast of the likely outcome of a medical condition. By its nature, VAD is an irreversible process. HammondCare believes that in order to legislate the killing of another person, medical practitioners must be certain that the individual's life expectancy meets the relevant eligibility criteria outlined in the Bill. Since this is impossible, HammondCare rejects the premise that eligibility can be determined on the mere “balance of probabilities,”⁵ as is suggested in the Bill.

5. Protecting persons who may be subject to pressure or duress

HammondCare whole-heartedly supports the principle of protecting persons who may be subject to pressure or duress. VAD places vulnerable people at greater risk of having their lives ended without their consent. It is incredibly hard to detect coercion when people want to end their own life, as there is no real test to know if, in fact, they are seeking death of their own free will – especially when those at risk are already vulnerable.⁶ Medical practitioners are not qualified or trained to detect coercion; nor is it their responsibility to be so trained. When the outcome is death, it is essential that the process is able to guarantee that the decision is

³ Baroness Campbell of Surbiton, “It sends a shiver down my spine”, The Telegraph, March 24, 2014, accessed November 15, 2021, <http://www.telegraph.co.uk/comment/10717795/It-sends-a-shiver-down-my-spine.html>.

⁴ Ewan Goligher et al. “Euthanasia and Physician-Assisted Suicide are Unethical Acts”, World Medical Journal (2019): 36.

⁵ Voluntary Assisted Dying Bill 2021, Part 2.16.1.d.ii

⁶ Gill v Woodall and Others [2009] EWHC 834; Wharton v Bancroft and Others [2011] EWHC 3250.



completely made of the individual's free will. HammondCare proposes that, since this is not attainable, VAD should not be legalised at all.

6. Voluntary assisted dying places undue burden on others

When engaging in conversations on VAD, the burden and pressure placed on carers, appointed Powers of Attorney, fellow residents and health care practitioners is often overlooked. While arguments in favour of these processes tend to subscribe to the individual's 'right to die', they tend to forget the person who is required to authorise, enact or support that action of killing. Particularly when the language is ambiguous, such as "on the balance of probabilities" and "cannot be relieved in a way the person considers tolerable" – it becomes the responsibility of another person to interpret and act out that decision.

Furthermore, in a residential aged care context, the narrative on the 'right to die' often forgets the impact that such legislation has on other residents living in the cottage or facility. Death can be confronting for people, and even more so when it occurs in your own home. The permitting of VAD in residential aged care facilities ignores the trauma and stress that such processes may have on those living with the individual. It is unfair and unloving to force other residents to experience something potentially emotionally traumatising for another's sake. Supports and safeguards must be considered for those impacted beyond the individual requesting VAD. These should include psychological, emotional, spiritual and physical support.

7. Palliative care does not include voluntary assisted dying

The Bill is drafted on the premise that an individual should be able to access palliative care as part of their VAD journey. However, the WHO defines palliative care as:

"An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."⁷

The practice of palliative care medicine operates to affirm life but acts neither to hasten nor postpone death, thereby standing in tension with the principles of VAD.

8. Fear and free will cannot coexist

Those in favour of the Bill often cite the 'freedom to choose' and free will as driving forces to support its passage. However, HammondCare believes that free will can only exist in the absence of fear. In Oregon's *Death with Dignity Act 1997*, patients' reasons for requesting VAD were overwhelmingly associated with a fear of losing autonomy and dying. These were much more prominent characteristics than intractable pain⁸. Rather than facilitating the individual's fears through legalising VAD, HammondCare strongly believes that the individual is best cared for through an open conversation focusing on minimising distress and optimising quality of life. We argue that an empowered end of life experience can be achieved through addressing the underlying causes of fear, rather than disregarding them through the VAD process.

⁷ "WHO definition of Palliative Care", World Health Organisation, accessed September 21, 2020, <http://www.who.int/cancer/palliative/definition/en>.

⁸ Arthur Eugene Chin et al. "Oregon's Death with Dignity Act: The First Year's Experience", Department of Human Resources, Oregon Health Division, Center for Disease Prevention and Epidemiology (1999): 9.



Commentary on the Bill

Although HammondCare does not support the legalisation of VAD, we have provided feedback on the Bill, as well as proposed amendments, to ensure adequate protections for vulnerable people, provide true opportunity for informed choice and protect medical practitioners.

Of the amendments proposed below, all of which are significant, we particularly urge the Parliament to prioritise consideration of the following three:

1. Exemptions for faith-based organisations, including the requirement to provide an administering practitioner access to the person at a facility and the responsibility of the facility to transfer a patient to a place where VAD may be administered.
2. Greater safeguards to ensure that a person seeking VAD is acting voluntarily, such as the requirement for referrals to be made to an interdisciplinary medical team and for multiple psychiatric assessments to be made.
3. All assessments and consultations about VAD must be conducted face-to-face for the accurate and holistic examination of a patient.

Part 1 – Preliminary

Interpretation

Assumption of decision-making capacity and mental health (Division 3.6.2.a & b)

When considering legislating a process which allows for the killing of another person, HammondCare is wary of the presumption that the individual has decision-making capacity. This is especially troublesome as the Bill does not disqualify a person if they are diagnosed with a mental illness, such as clinical depression.⁹

People with chronic mental conditions are considered to be a vulnerable population and a wish to die could be a symptom of a mood disorder. There is tension between respecting an individual's sense of autonomy and harm prevention.¹⁰ In 2007, Switzerland legalised VAD for people with mental illness in the same way as those with physical suffering. In Belgium, the Belgian Federal Control and Evaluation Commission has on various occasions also permitted the euthanizing of patients who suffered with depression and dementia.¹¹ This is problematic because symptoms of depression and feelings of hopelessness appear strongly linked to a preference to hasten death.¹²

Thus, for people with mental illnesses, an individual's cognitive capacity to make a decision such as ending their life, may be diminished or impaired.¹³ In the case of depression, effective treatment can diminish an individual's desire to die. However, state-level surveillance data from Oregon found that only five per cent of patients who qualified for VAD were referred to a mental health assessment.¹⁴ Given that these processes are

⁹ Voluntary Assisted Dying Bill 2021, Part 2.16.2

¹⁰ Sigrid Dierickx et al. "Euthanasia for people with psychiatric disorders or dementia in Belgium: analysis of officially reported cases", *BMC* 17, no. 203 (2017): 6.

¹¹ Raphael Cohen-Almagor, "First do no harm: Euthanasia of Patients with Dementia in Belgium", *The Journal of Medicine and Philosophy* 41, (2016): 75.

¹² Ryan Holliday et al. "Depressive disorders" in *The American psychiatric association publishing textbook of suicide risk and management*, ed. L Gold & R Frierson (American Psychiatric Association Publishing, Washington, DC, 2020).

¹³ Nathan Fairman, "Physician-Assisted Dying", In *The American Psychiatric Association Publishing Textbook of Suicide Risk Assessment and Management*, ed. L Gold & R Frierson (American Psychiatric Association Publishing, Washington, DC, 2020). 335.

¹⁴ *Ibid.*



meant to be 'voluntary' decisions by those who are cognisant and mentally capable, those with mental health illnesses are left vulnerable.

Proposed amendment: HammondCare recommends that further safeguards, such as ongoing mental health assessments, be embedded into the Bill so that people are not at risk of being incorrectly assessed as having decision-making capacity when, in fact, a mental health assessment could show otherwise.

Other provisions

Suggesting voluntary assisted dying (Division 4.10.2)

HammondCare does not support any provision which allows a health care worker or medical practitioner to initiate discussions about or suggest the process of VAD to a patient, even if it is provided alongside other treatment options. HammondCare acknowledges the existential dread and fears that can be experienced when reaching the end of life. Causes of anxiety can include fear of the dying process, pain, leaving family and loved ones behind, the effect their illness will have on others and being a burden on their family, carers and society. To allow medical practitioners and health care workers to initiate a conversation regarding VAD with someone in such a vulnerable position may pressure them to initiate the process to end their life out of guilt or duress.

Though the Bill attempts to mitigate this risk by requiring the medical practitioner or health care worker to also provide information regarding their treatment options, palliative care options, as well as their likely outcomes, there is no calibre or benchmark on the quality or detail of information provided to the individual. The provision assumes that the medical practitioner or health care worker has an intimate understanding not only of the individual's medical history but also of the relevant palliative care services available. This is rarely the case. Furthermore, the provision does not take into account individuals living in rural or remote areas, who may not have many palliative care or treatment options accessible to them.

Proposed amendments:

First, HammondCare proposes an amendment to this provision, so that any discussion or engagement on VAD must only be at the request of the individual. This would be in line with other Australian jurisdictions, namely South Australia and Victoria, whose legislation renders the initiation of such a discussion by a medical practitioner unlawful without exception.¹⁵

Second, when an initial inquiry is made, the medical practitioner should be permitted to opt-out of the conversation if they conscientiously object.

Third, in order to ensure that appropriate and current information regarding treatment and palliative care options are communicated, HammondCare recommends that the consulting and coordinating practitioners must be qualified specialists in the individual's terminal illness, disease or medical condition.

¹⁵ NSW Parliamentary Research Service, "Voluntary Assisted Dying Bill 2021 (NSW): a comparison with legislation in other States", Issues Backgrounder, no. 2 (2021):13.



Part 2 – Requirements for access to voluntary assisted dying

Eligibility Criteria

“is causing suffering to the person that cannot be relieved in a way the person considers tolerable” (16.1.d.iii)

Suffering is inherently a subjective phenomenon. It is appropriate that the Bill allows the person to indicate their level of suffering, rather than requiring health professionals to make this determination. However, pain, fear and fatigue can be so severe that it impacts an individual’s capacity to make rational decisions.¹⁶ This renders any individual who identifies with such immense levels of pain, potentially unable to meet the eligibility criteria laid out in Part 2 of the Bill: “the person has decision-making capacity in relation to voluntary assisted dying”.¹⁷

Furthermore, the American Psychological Association cautions against a solely clinical-based concept of ‘suffering’.¹⁸ Suffering goes beyond the presence of physical pain and relief from pain will not always relieve suffering. Suffering, in its holistic sense, is multidimensional, complex and is not stagnant in form – it is oscillating and difficult to express or explain. It may include familial, social, financial, psychological, cultural, spiritual and legal pressures. Separating the experience of suffering as a by-product of a disease, illness or medical condition from all other factors is impossible. Therefore, the Bill unintentionally allows the killing of an individual based on a person’s perceived suffering in other areas of life.

Proposed amendment: HammondCare recommends that specific wording is included in the Bill’s definition of eligible suffering to confirm that the provision of palliative care has been unsuccessful in managing the individual’s pain in a way they consider tolerable.

“the person is acting voluntarily” (16.1.d.f)

It is impossible to determine with certainty whether a request is voluntary and made without coercion. While safeguards can be put in place to help protect those who are vulnerable, experts in the field identify that one of the most significant concerns about legalising VAD is the inability to determine who is suitable and who is unsuitable.¹⁹ No number of indicia will ever be able to provide health professionals with concrete certainty that an individual is requesting VAD voluntarily. This must be acknowledged at the outset of the Bill.

Notwithstanding this, safeguards should still be implemented to ensure that an individual is acting of their own volition. As previously mentioned, HammondCare is particularly cognisant of the other factors beyond the disease, illness or medical condition that can impact an individual’s decision to request VAD.

Proposed amendment: HammondCare therefore recommends the implementation of mandatory referrals to an interdisciplinary palliative care team before an application for VAD can be made. During the VAD process, a psychiatrist must be involved to determine the individual’s decision-making capacity, as well as a specialist in the individual’s relevant disease, illness or medical condition. Rather than the current provision of the Bill, in which only two (2) practitioners (the coordinating and consulting) are required to assess the individual, an interdisciplinary approach will provide a more holistic, independent and qualified judgement regarding eligibility.

¹⁶ RE T [1992] WLR 782; RE MB [1997] EWCA Civ 3093

¹⁷ Voluntary Assisted Dying Bill 2021, Part 2.16.1.e

¹⁸ “Resolution on Assisted Dying and Justification”, American Psychological Association, accessed November 15, 2021, <https://www.apa.org/about/policy/assisted-dying-resolution>

¹⁹ Tanya Munday & Peter Poon, “Geriatricians’ attitudes towards voluntary assisted dying: a survey of Australian and New Zealand Society for Geriatric Medicine members”, *Australasian Journal on Ageing* 39, no. 1 (2020): 43.



Lack of palliative care requirement

In most cases, pain can be managed. HammondCare's firsthand clinical experience is that people receiving palliative care very rarely persist with requests for VAD, though these may be more common at time of admission. It is important to ensure that palliative care, with adequate psychological supports, is more readily available to people considering accessing VAD. This information should be made clear to patients seeking the services outlined in the Bill.

Proposed amendments: HammondCare proposes that an individual must receive at least one (1) month of palliative care as a pre-requisite of eligibility to access VAD.

Part 3 – Requesting access to voluntary assisted dying and assessment of eligibility

Eligibility requirements for medical practitioner

“the medical practitioner has completed the approved training” (Division 1.18.b)

According to the Victorian Voluntary Assisted Dying Review Board, since its implementation in June 2019, 807 applicants were deemed eligible to use VAD, with 597 permits being issued and 331 people dying from taking the prescribed medications.²⁰ As of December 2020, more than 450 medical practitioners have registered for the online training; only five have registered as specialising in palliative medicine.²¹

HammondCare believes that education and training will be vitally important to the appropriate enacting of the legislation, and to affirm the importance of palliative care in the assessment process. While the Bill requires eligible practitioners to complete ‘approved training’, greater transparency is needed regarding what this entails.

Furthermore, the criteria for a medical practitioner to be eligible to participate in VAD processes does not require them to have experience or expertise in the individual's illness, disease or medical condition. Without this specialised knowledge of the individual, it begs the question of how well they will be able to provide a holistic assessment of the person.

Proposed amendments:

First, HammondCare recommends that in order to be the eligible consulting or coordinating practitioner, they must be a qualified specialist in the individual's terminal illness, disease or medical condition.

Second, HammondCare recommends that specialist education includes an initial component and an ongoing component covering diagnosis and prognosis, making specific reference to terminal illness/serious and incurable conditions, ethics, comprehensive overview of relevant legislation and safeguards, and an in-depth overview of current and alternative care options to VAD (such as palliative care and pain management programs).

²⁰ “Voluntary Assisted Dying Review Board report of operations: January to June 2021”, Victoria State Government (2021): 3.

²¹ “Voluntary Assisted Dying Review Board report of operations: July to December 2020”, Victoria State Government (2021): 6-7.



Requests, assessments and written declarations

Timeframes

With no 'cool down period' drafted within the Bill, an individual could potentially move from their first to final request within five (5) days. Further, the Bill encourages a quick 'turn around' of assessments, often requiring decisions to be communicated "within 5 business days"²² or "within 2 business days"²³. While the Bill includes provisions for the individual to discontinue the VAD process at any time, it does not mandate sufficient time for personal reflection on the matter. The importance of this is highlighted by HammondCare Associate and Senior Medical Specialist in Palliative Care at Hibiscus Hospice, Professor Rod MacLeod²⁴:

"Often, in my experience, the desire for death fluctuates and changes on a daily basis. On some days people with a terminal illness seem more ready to accept their dying than on others. Dying can be hard."

The decision to undergo VAD is a permanent one. People's personal preferences for this can vary significantly over time. Unfortunately, these processes do not allow for patients to change their mind. A 2020 study found that 54.4% of participants initially agreed with the euthanising and delivery of VAD to people with dementia. However, after engaging with real-world scenarios this number decreased to only 20-39%.²⁵ Seeing changes in patients' attitude towards VAD and palliative care is a common experience for palliative care clinicians working in HammondCare's frontline services. It is therefore essential that 'waiting periods' be built into the Bill, ensuring that people are given the opportunity to reflect on their choices and to consult with health care professionals, such as palliative care and mental health experts.

Proposed amendment: HammondCare proposes that a one (1) week waiting period must be observed between each 'step' of the VAD process. In other words, at least one (1) week between First Request, First Assessment, Consulting Assessment, Written Declaration, and Final Request and Final Review.

Psychiatric assessment

Although the Bill does have provisions for psychiatrists to help determine decision-making capacity, if the applicant is acting voluntarily or acting under pressure or duress, this is restricted only to referrals made by the coordinating or consulting practitioner.²⁶ HammondCare believes that an optional referral to a psychiatrist for assessment is inadequate.

The processes outlined in the Bill are such a deviation from the norm of medical practice that HammondCare recommends that a psychiatric assessment be mandatory for all people who request VAD. In addition, we recommend that each person attend multiple assessments with a psychiatrist. The individual's General Practitioner (GP) and psychiatrist should also be part of an inter-disciplinary team, which includes at least one palliative care specialist (as discussed earlier in this paper). Rather than the burden of decision falling exclusively on the coordinating and consulting practitioners, requiring a team approach would alleviate the

²² Voluntary Assisted Dying Bill 2021, Part 3.23.1

²³ Voluntary Assisted Dying Bill 2021, Part 3.32.4

²⁴ "End of Life Choice Bill – Professor Roderick MacLeod", Rod MacLeod, accessed November 15, 2021, https://www.parliament.nz/en/pb/sc/submissions-and-advice/document/52SCJU_EVI_74307_19891/professor-roderick-macleod

²⁵ Dominic Mangino et al. "Assessing Public's Attitudes towards Euthanasia and assisted suicide of persons with dementia based on their advance request: an experimental survey of US Public", American Journal of Geriatric Psychiatry 29, no. 4 (2021): 9.

²⁶ Voluntary Assisted Dying Bill 2021, Part 3.27.2.a; Voluntary Assisted Dying Bill 2021, Part 3.38.2.a



potential for a sense of isolation, which has been reported by doctors in overseas jurisdictions, and provides peer support and collaboration to ensure the most accurate assessment is made.²⁷

Proposed amendments:

First, HammondCare recommends that multiple psychiatric assessments be mandatory for all people who request VAD.

Second, we recommend that each patient should be supported by an interdisciplinary team consisting of at least the patient's GP, a psychiatrist and a palliative care specialist.

Protection of medical practitioners who conscientiously object

HammondCare queries whether the Bill can sufficiently safeguard the wellbeing of medical practitioners. Medical practitioners who conscientiously object at any point in the process outlined in the Bill must report their refusal to the Voluntary Assisted Dying Review Board within five (5) business days of making the decision and must inform the individual of their decision within two (2) business days of the request. Physicians may feel pressured to fulfill applications for VAD within such short timeframes for deliberation, especially when refusal may threaten their careers (via the requirement to inform the Board of such a decision).

Studies have described instances of emotional blackmail and threats to commit suicide if the medical practitioner did not comply with their request.²⁸ If a physician feels forced to break the Hippocratic oath, or violate their moral or ethical code, they can suffer severe distress and functional impairments; commonly known as 'moral injury'.²⁹ This may take the form of experiencing guilt, shame, spiritual-existential crisis and loss of trust in oneself and questioning their morality,³⁰ contributing to the increasing number of diagnoses of burnout and posttraumatic stress disorder in health care sector workers.³¹ The safety and welfare of medical health professionals should be taken into serious consideration.

Proposed amendments:

First, HammondCare recommends implementing more robust safeguards to support practitioners to follow their conscience regarding their decision to participate. Such protections could mirror other States' VAD laws to allow them to opt out of the process completely, as opposed to still being required to provide information on VAD and access to a person.

Second, psychological, emotional, spiritual and physical support should be extended to those beyond the person seeking VAD. This acknowledges the broader impact VAD has on those surrounding the individual and makes it incumbent on physicians choosing to provide VAD to respect others' differing convictions.

²⁷ Kenneth Stevens, "Emotional and Psychological Effects on Physician-Assisted Suicide and Euthanasia on Participating Physicians", *The Linacre Quarterly* 73, no. 3 (2006): 188.

²⁸ Marike de Boer et al., "Pressure in dealing with requests for euthanasia or assisted suicide. Experiences of general practitioners", *Journal of Medical Ethics* 45, no. 7 (2019): 422; Jaap Schurmann et al., "Euthanasia requests in dementia cases, what are experiences and needs of Dutch physicians? A qualitative interview study", *BMC Medical Ethics* 20, no. 1 (2019): 70.

²⁹ Brandon Griffin et al., "Moral Injury: An Integrative Review", *Journal of Traumatic Stress* (2019): 1.

³⁰ Mady Stovall, Lissi Hansen & Michelle van Ryn, "A Critical Review: Moral Injury in Nurses in the Aftermath of a Patient Safety Incident", *Journal of Nursing Scholarship* 52, no. 3 (2020): 322.

³¹ Wendy Dean, Simon Talbot & Austin Dean, "Reframing Clinician Distress: Moral Injury Not Burnout", *Federal Practitioner* 36, no. 9 (2019): 400.; Victoria Williamson, Sharon Stevelink & Neil Greenberg, "Occupational moral injury and mental health: systematic review and meta-analysis", *The British Journal of Psychiatry* no. 6 (2018): 339.



Data Gathering

In order to ensure the implemented safeguards are appropriate and operational, it is critical that robust and consistent data is collected and independently analysed.³² This will work to provide and track trends of those opting for VAD, as well as the outcomes or gaps that may be identified, such as barriers to palliative care or appropriate health care services. HammondCare suggests that this data be based on the criteria suggested by Donnelly et al.³³

1. Reasons people participate in VAD – grounded in the precedent set in a 2020 Canadian report, which exposed a serious lack of access to palliative care and disability support services.
2. Performance information on medical practitioners – providing colour to the contexts in which people are both requesting and receiving VAD.
3. Details about the dying process – including length of time between ingestion/delivery of the regulated drugs and death; observed side effects of the regulated drugs; what course of action was taken if the regulated drugs failed to end the person's life etc.
4. Demographic trend data – including education, diagnosis, length of relationship to medical practitioner, reasons for request, availability of palliative care, process of prognosis, nature of 'suffering' and the existence of mental health issues, disabilities, recent bereavement, loneliness or financial concerns.

Proposed amendment: That the Bill be amended to ensure the data referenced above is collected.

Part 5 – Participation

Refusal to participate

Definitions

HammondCare strongly supports the Bill's proposal to allow residential facilities and health care establishments to not participate nor deliver VAD within their own facility or establishment. However, the Bill still mandates that organisations must allow reasonable access to the person at the facility³⁴ or a health establishment³⁵ throughout the VAD process, including for the administration of the prescribed substance in residential facilities. To protect the overall right to contentiously object, we suggest further clarification regarding the definition of hindering access in the Bill, so organisations have a practical understanding of what providing "access" involves, as well as reassurance of their compliance with the legislation, if it were to pass.³⁶

Proposed amendment: That the Bill be amended to include a more specific definition of what providing access involves and what falls within the legal responsibility of the facility.

Lack of protections for religious organisations

Although initially promised prior to the Bill's introduction to NSW Parliament, there are no protections or exemptions for faith-based organisations.

Under the Bill, religious organisations, for which the process of VAD may stand in direct opposition to their values, beliefs and mission, must allow medical practitioners to access their premises for every stage of the

³² Sinead Donnelly et al. "More scrutiny needed as assisted dying becomes law" (2021): <https://www.stuff.co.nz/opinion/300446032/more-scrutiny-needed-as-assisted-dying-becomes-law>

³³ Ibid.

³⁴ Voluntary Assisted Dying Bill 2021, Part 5.93.3

³⁵ Voluntary Assisted Dying Bill 2021, Part 5.99.2b

³⁶ Voluntary Assisted Dying Bill 2021, Part 5.90.2



process, including to kill the individual on site. Essentially, the Bill prioritises VAD over the right of an organisation providing care to uphold their ethos.

While we do not object to facilitating information about VAD in conjunction with other treatment and palliative care options, given that faith-based organisations run a large number of health and residential facilities across NSW, it is crucial that such organisations are protected if they conscientiously object to allowing VAD in their facilities or by their staff.

Proposed amendments:

First, HammondCare urges that an exemption for faith-based organisations be explicitly provided for in the Bill, such that they can refuse to allow VAD to be performed at their facility due to it being contrary to the values, missions and beliefs of the organisation.

Second, this exemption should also be extended to having to “facilitate the transfer of the person to and from a place where the person’s relevant request [for VAD] may be made to.”³⁷

Part 6 – Review by Supreme Court

Transparency (117)

It is important that there is increased transparency regarding the information provided to and the running of the Supreme Court reviews. The Bill currently states that such proceedings must be held in private. However, HammondCare suggests that such privacy to protect personal information and maintain patient confidentiality should not be at the expense of the review’s transparency and accountability.

Proposed amendment: HammondCare recommends that further consideration should be given to the transparency of the review process.

Part 8 – Enforcement

Time-limits for prosecution (135)

HammondCare raises concerns regarding the two (2) year cap on the prosecution of an offence under the Bill. While allegations regarding murder and manslaughter can be prosecuted at any time, such narrow timeframes risk abuses of the process slipping through the cracks. This risk is exacerbated by the likelihood that for some, the offender may be a familial relation or close contact, and an individual may take a number of years in order to build up the courage to bring forward an allegation against them.

Proposed amendment: HammondCare recommends that, similar to murder and manslaughter, the time for prosecution of VAD-related offences should have no time limit.

Privacy (130)

HammondCare recognises the Bill’s intention behind mandating 12 months imprisonment for those who disclose personal information regarding an individual’s VAD process as protecting their privacy. However, this may create a barrier to the transparency of the process itself. To ensure that VAD is suitably safeguarded and

³⁷ Voluntary Assisted Dying Bill 2021, Part 5.92.3



that the Bill becomes an effective piece of legislation, there must be increased open communication to the appropriate authorities for purposes such as data gathering (see section above).

Part 12 – General

Telehealth (182.1&2)

HammondCare opposes the Bill's provision for telehealth or "audio-visual" communication with a participant as the basis for assessments. As discussed above, assessments should be holistic and take into consideration family pressures, socio-economic issues or untreated medical conditions, as well as the myriad of other factors which may impact the person's eligibility. These cannot be accurately nor thoroughly examined via telehealth.

Proposed amendment: HammondCare recommends that all assessments of a person wanting to participate in VAD, must be conducted face-to-face.



Proposed alternative to the Bill

HammondCare proposes an alternative to the Voluntary Assisted Dying Bill 2021 (NSW) – that the Government invest into palliative care as the appropriate service to support those at the end of their lives.

HammondCare endorses palliative care as the appropriate service for people who are dying, not VAD. Australia jeopardises the welfare of its people by providing VAD without first investing in and providing effective, quality palliative care. The Australian Association for Hospice and Palliative Care states that “public interest in voluntary active euthanasia reflects a concern about a lack of adequate support for people who are dying”.³⁸ Our country and its parliaments have the opportunity to refocus our efforts to support effective palliative care.

Palliative care medicine has advanced significantly over the past 40 years and has come into its own as a discrete area of medicine. There have been numerous advances both in the understanding and development of palliative care practice, as well as in the technologies available to help. However, as an emerging practice there is still significant scope for improvement.

In line with the National Palliative Care Strategy,³⁹ HammondCare believes the following four steps should be taken to improve palliative care throughout Australia:

1. Provide education in palliative care training for all relevant health professionals.
2. Promote the uptake of advance care planning across all sectors (primary, acute and aged care) and address any barriers to its uptake.
3. Develop and implement a national public awareness campaign encouraging people to talk about how they would like to die.
4. Ensure there is sufficient funding and resources to support palliative care initiatives and programs.

Provide education in palliative care for all relevant health professionals

There is a need for more and better education in palliative care for all health professionals. People involved in health care, and particularly those involved in care for older people, will inevitably face issues around death and dying. Doctors may find these conversations difficult and may not feel equipped to assist in palliative care – this needs to be addressed through education. As Bharmal et al. highlight:

“junior doctors frequently feel unprepared and unsupported to provide palliative and end-of-life care, with greater emotional demands than other areas of medicine. There is a pressing need for changes in undergraduate and postgraduate medical education to focus on the development of knowledge, skills and attitudes of junior doctors in this area of patient care.”⁴⁰

HammondCare supports the integration of palliative care education within all health undergraduate and relevant post-graduate curricula. The foundation for this has already been laid with the development of a core curriculum by the Australian and New Zealand Society of Palliative Medicine in 1995. While this curriculum is available, palliative care education currently remains optional and self-directed. The Government is to be commended for its investment in the Palliative Care Curriculum for Undergraduates

³⁸ “Global Statements on Euthanasia and Physician Assisted Suicide”, International Association for Hospice & Palliative Care, accessed November 15, 2021, <https://hospicecare.com/policy-and-ethics/ethical-issues/statements-on-euthanasia-and-physician-assisted-suicide/>

³⁹ “National Palliative Care Strategy 2018”, Department of Health, accessed November 15, 2021, https://www.safetyandquality.gov.au/sites/default/files/2019-06/national_palliative_care_strategy_2018.pdf

⁴⁰ Aamena Bharmal et al. “Palliative and end-of-life care and junior doctors’: a systematic review and narrative synthesis”, *BMJ Supportive & Palliative Care*, (2019): 5.



(PCC4) program. HammondCare recommends that this, or a similar curriculum, be embedded within all health care education courses. For non-university-trained health professionals, including care staff in residential care homes, HammondCare suggests that palliative care training courses be promoted to increase uptake. The Program of Experience in the Palliative Approach (PEPA), funded by the Australian Government Department of Health, provides free palliative care workshops and placements in palliative care services. This program operates in each state and territory but uptake, particularly among residential aged care staff, remains low.

Teaching styles that encourage students to draw on their own experiences and skills have been most effective in palliative care training.⁴¹ Palliative care education in Australia has often been diverse and imaginative, drawing upon multimodal approaches.⁴² These ways of teaching have been helpful in assisting students to understand that palliative care is best delivered in a person-centred approach and not according to imposed formulae.⁴³

The Commonwealth Government's 2021-22 Budget has recognised this need for increased investment into palliative care education. In their response to the 2021 Royal Commission into Aged Care Quality and Safety, it committed \$36.5 million to continue the Greater Choice for At Home Palliative Care initiative in all 31 Primary Health Networks and \$49.4 million in increased funding towards training to improve aged care workers' knowledge and practice in dementia and palliative care. HammondCare supports such investments, believing that palliative care education is paramount to the provision of good, quality care up until the end of life.

Promote the uptake of advance care planning across all sectors (primary, acute and aged care)

Advance care planning involves individuals developing a plan for their care should they become seriously ill or unable to speak for themselves. This includes outlining their treatment preferences, as well as indicating their goals, values and beliefs, so that they can be respected by health care providers, family and friends, particularly at the palliative stage.

HammondCare believes that all Australian jurisdictions should promote advance care planning in order to increase its uptake. For advance care planning to become normalised and more prevalent, it needs to be promoted across all sectors (primary, acute and aged care) and barriers to uptake need to be addressed. Currently, there are legislative differences in how advance care directives are recognised between different states and territories. HammondCare recommends that all jurisdictions work together to achieve consistency in advance care planning arrangements.

HammondCare is an industry leader in advance care planning. As part of the Commonwealth Government funded National Projects, HammondCare has led and delivered The Advance Project since 2016, in collaboration with various health organisations and universities across Australia. This national program includes training general practice nurses and GPs to initiate early discussions about advance care planning and assessment of palliative and supportive care needs. It is hoped that this will lead to earlier consideration and uptake of advance care planning. HammondCare has received additional funding to continue this program under the Government's funded 2020 National Projects.

⁴¹ Roderick MacLeod, "Approach and nature of palliative care," in *Textbook of Palliative Care*, ed. R MacLeod & L Van Den Block (Springer, 2019).

⁴² *Ibid.*

⁴³ *Ibid.*



Public awareness campaign

While death is a universal human experience, it is typically something that people are reluctant to talk about. This hesitancy is caused by a range of factors, both personal and cultural. So long as stigma about death and dying persist, the likelihood of a 'bad death', without appropriate palliative care and support is increased. HammondCare supports the development and implementation of a national public awareness campaign, encouraging people to talk about how they would like to die. A public awareness strategy of this kind would complement the promotion of advance care planning and would raise awareness about end of life care services.⁴⁴ It would also help to dispel misconceptions about palliative care and would lead to a better national dialogue around issues of VAD. Palliative Care Australia has developed the 'Dying to Talk' campaign as a prototype for this style of campaign. Then Board Chair of Palliative Care Australia, Dr Jane Fischer stated,

"We know that demand for palliative care is increasing. By having the conversation with their loved ones and health professionals as early as possible, people can ensure their treatment and care best aligns with their values and preferences regarding both the type and place of care and place of death... Knowing what is important to you will reduce their burden at a difficult time and ensure you get the care you desire."⁴⁵

Support palliative care initiatives and programs

HammondCare calls on the Commonwealth and State and Territory governments to increase support, funding and coordination of palliative care services across Australia. The Commonwealth Government is to be commended for its support of the National Palliative Care Projects⁴⁶, which cover a range of areas relevant to the continued development of palliative care in Australia. While funding new initiatives, governments should also commit to the subsidisation and expansion of existing palliative care services.

Historically, funding has been provided by the NSW Government to deliver the Palliative Care Home Support Program, which HammondCare operated in a consortium with Sacred Heart Health Services and Calvary Health Care. The program provided end of life care for patients who wished to remain at home – something that 70 per cent of Australians say they want, but only 14 per cent actually achieve. During HammondCare's provision of the program, 73 per cent of clients were able to die at home. While funding for this initiative has since concluded, HammondCare believes that there are strong opportunities for such palliative care initiatives to be re-imagined in a cost-effective way. HammondCare has since established an ongoing annual agreement with South Western Sydney Local Health District to provide the Palliative Extended Aged Care in the Home (PEACH) program. The agreement also includes inpatient and ambulatory/community palliative care, rehabilitation and older persons mental health services across the district.

HammondCare welcomes the recent increased investment by State governments in palliative care programs, including initiatives in South Australia, Queensland and South West Sydney. HammondCare encourages continued awareness, investment and support of such pilot programs in order to improve palliative care for all.

The Commonwealth Government and State/Territory Health Ministers are encouraged to continue working together to deliver consistent, accessible palliative care services in all jurisdictions across Australia.

⁴⁴ Jane Seymour, "The impact of public health awareness campaigns on the awareness and quality of palliative care", *Journal of Palliative Medicine* 21, no. 1(2018): 34.

⁴⁵ "It's time to talk about 'What matters most?'", Palliative Care Australia (2019), accessed November 15, 2021, https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2019/07/NPCW19_community-media.pdf

⁴⁶ "Evaluation of the National Palliative Care Projects – Final Report", Department of Health (2019), accessed November 15, 2021, <https://www.health.gov.au/sites/default/files/documents/2020/03/evaluation-of-the-national-palliative-care-projects-final-report.pdf>