Submission
No 75

INQUIRY INTO PROVISIONS OF THE VOLUNTARY ASSISTED DYING BILL 2021

Organisation: St Vincent's Health Australia

Date Received: 22 November 2021

ST VINCENT'S HEALTH AUSTRALIA
UNDER THE STEWARDSHIP OF MARY AIKENHEAD MINISTRIES

SVHA Submission: *NSW Standing Committee on Law and Justice Inquiry into the Provisions of the Voluntary Assisted Dying Bill 2021*

Date FINAL

19 November 2021

St Vincent’s Health Australia Ltd
ABN 75 073 503 536

Level 22, 100 William Street
East Sydney NSW 2011

www.svha.org.au

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1. Introduction

1.1 Background

St Vincent’s Health Australia

St Vincent’s Health Australia (SVHA) is the nation’s largest not-for-profit health and aged care provider. We operate six public hospitals, 10 private hospitals and 23 aged care facilities in New South Wales, Queensland and Victoria. Along with three co-located research institutes – the Victor Chang Cardiac Research Institute, the Garvan Institute of Medical Research and St Vincent’s Institute of Medical Research – we work in close partnership with other research bodies, universities, and health care providers.

SVHA has been providing health care in Australia for 160 years, since our first hospital was established in Sydney in 1857 by the Sisters of Charity. When the first five Sisters arrived in Australia in 1838 they carried with them the vision of their Founder, Mary Aikenhead, to reach out to all in need of care and particularly to the poor and vulnerable. It is the legacy entrusted to us by the Sisters of Charity that continues to inspire St Vincent’s Health Australia to strengthen and grow our mission.

SVHA employs over 22,000 staff and operates more than 2,853 hospital beds and 2,039 residential aged care places. In our hospitals, we provide more than 1 million episodes of care for patients each year.

We are a clinical and education leader with a national and international reputation in medical research. Our areas of expertise include mental health; drug and alcohol services; homeless health; prisoner health; heart lung transplantation; bone marrow transplantation; cardiology; orthopaedics; neurosurgery; cancer; clinical genomics; HIV medicine; geriatric psychiatry; and palliative care.

In New South Wales, our Sacred Heart Health Service (Sacred Heart) is a leading provider of Palliative Care and Rehabilitation services. Opened by the Sisters of Charity in 1890 as a dedicated Hospice for the terminally ill, it has grown from a small palliative care cottage to a facility offering comprehensive rehabilitation services as well as specialist supportive and palliative care.

Our team provides palliative care services to patients with life-limiting illness. A consultation service is provided to St Vincent’s Hospital Sydney with patients and carers supported by:

- A 12 bed inpatient unit
- A 24 hour community and outpatient consultative service in Eastern Sydney
- Community/respite programs

Our services support patients undergoing anti-cancer treatments, and provide pain control and symptom management, nursing and psychosocial and pastoral support.

In addition, we operate St Joseph's Hospital, Auburn. St Joseph's has a proud tradition of more than 100 years of providing quality health care in a compassionate and highly personalised atmosphere. The hospital provides inpatient, outpatient and community service, and is a centre of excellence in rehabilitation, mental health for older people, Huntington Disease and palliative care.

1.2 Executive Summary

SVHA is well placed with our extensive experience in delivering high quality hospital, health and aged care to provide feedback to the NSW Parliament's Standing Committee on Law and Justice's inquiry into the provisions of the Voluntary Assisted Dying Bill 2021 (hereafter referred to as the Bill). We understand these provisions in the context of the Objects of the Bill, which are to:

> (a) enable eligible persons with a terminal illness to access voluntary assisted dying, and
> (b) establish a procedure for, and regulate access to, voluntary assisted dying, and
> (c) establish the Voluntary Assisted Dying Board and provide for the appointment of members and functions of the Board

SVHA does not support the introduction of Voluntary Assisted Dying (VAD) in NSW. Our position is that the provisions in the Bill are:

- unneccessary, if access to comprehensive high-quality palliative care is available, including for the poorest and most vulnerable members of our community;
- unsafe, as the NSW VAD Bill includes several dangerous provisions; and
- unethical, as legislating for VAD undermines the fundamental commitments of healthcare professionals.

Instead, we are strong advocates for better planning, investment and access to palliative care and end of life services across the State. Such care can respond to concerns around suffering at the end of life in a way that is safe and does not breach the ethical commitments on which medicine is founded.

SVHA recognises and acknowledges that there is a small number of people who experience distress at death that no current drug can fully address. Only if allowed and available can palliative care reduce that distress.

The following submission has been informed by representatives, including our leading palliative and end-of-life care specialists, other clinical and non-clinical leaders, from our public and private hospitals and aged care facilities. It is also based on our experience of operating our services in the context of VAD legislation in Victoria.

1.3 SVHA Submission on Voluntary Assisted Dying Bill 2021

Voluntary Assisted Dying is Unnecessary

SVHA does not support the introduction of Voluntary Assisted Dying (VAD) in NSW. Our position is that the provisions in the Bill are unneccessary if access to comprehensive high-quality palliative care is available, including for the poorest and most vulnerable members of our community.

Across New South Wales, some geographical areas and population groups have poor access to universally agreed upon end of life care interventions, which are recognised as human rights by the United Nations.[1]

Such care incorporates access to a full range of palliative care services, including adequate pain relief, psychosocial and spiritual care, advance care directives, and support of the right to withdraw or withhold burdensome treatments.

There is inadequate access to palliative care for vulnerable groups, such as Aboriginal and Torres Strait Islander people, culturally and linguistically diverse communities, and others living in poverty and on the margins of society, but inequity of access and care is also obvious geographically in a large and diverse state such as New South Wales.

SVHA supports the Palliative Care New South Wales 2021/2022 NSW State Budget Submission, which argued for significant increases in funding for palliative care services, including:

- Increase Palliative Care in community-based settings by $24m per annum
- Increase Palliative Care funding in hospitals by $16m per annum.
- Invest in clinical psychologists in each Local Health District specialising in palliative care/grief and bereavement
- Improve access by carers and families to education, information and support
- Invest in palliative care training in Residential Aged Care facilities.[2]

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[1] THE RIGHT TO END-OF-LIFE PALLIATIVE CARE AND A DIGNIFIED DEATH, CONTRIBUTION FROM UN-ECLAC FOR THE EXPERT GROUP MEETING ON “CARE AND OLDER PERSONS: LINKS TO DECENT WORK, MIGRATION AND GENDER”, 2017. https://www.un.org/development/desa/ageing/wp-content/uploads/sites/24/2017/11/ECLAC-contribution.pdf

[2] Palliative Care NSW NSW Budget Submission 2021/2022

Accordingly, the State should invest further in strengthening the reach and improving the access of all people in NSW to palliative care and end of life planning first.

Our experience of working with patients across our hospitals, and in particular our palliative care units is, that when there is absence of adequate end of life care, VAD has been seen as the only viable option. Patients facing end of life choices should never be put in a position where they think the only option available to them is VAD.

> "As someone who cares for terminally ill patients each day, I don't support the introduction of euthanasia. As the director of Sacred Heart Supportive and Palliative Care at St Vincent's Hospital, Sydney, I have seen the discipline of palliative care grow from a small cottage industry for terminally ill patients to a modern specialty offering specialist palliative care and supportive care to people in need, and help them live well before they die.
>
> People who may otherwise have enjoyed more time with their loved ones may see assisted dying 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 assisted dying instead of requesting and obtaining support to alleviate distress during their final days or months."
>
> **Clinical Professor Richard Chye** MBBS FRACP FFPMANZCA FAChPM
> Director of Sacred Heart Supportive and Palliative Care at St Vincent's Hospital

Our experience from participating in discussions about the VAD legislative framework in Victoria is any form of 'safeguard' which purports to protect patients from potentially only considering VAD by informing patients about palliative care is meaningless if there are no adequate palliative care options available.

> "If there are gaps in people's end of life care, they should be addressed through improving their access to high quality care, which is consistent with the community's expectations of a care system committed to healing and the provision of comfort, and never killing.
>
> If there are gaps in existing care interventions, they should be addressed by the same means that we use to address gaps in any other area of health practice: through funding for community and social education, research and innovation."
>
> **Clinical Professor Richard Chye** MBBS FRACP FFPMANZCA FAChPM
> Director of Sacred Heart Supportive and Palliative Care at St Vincent's Hospital

SVHA recognises that even the doubling of specialist palliative care services across NSW, will not be sufficient to support all people in NSW who are dying.[3] As such, SVHA argues that end of

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[3] NSW Agency for Clinical Innovation, 2013. Fact of Death Analysis Palliative and End of Life Care: Analysis of Admitted Patients in the NSW Public Hospital System

life care should be treated as “everyone’s business” and that mandatory training for every health professional includes the skills to:

1. systematically seek to recognise and understand a patient’s (and their caregivers) burdens (symptoms, distress) whilst they undergo difficult or burdensome treatments;
2. recognise people who are dying;
3. communicate in a effective but compassionate way to patients and their families;
4. implement care to ensure patient die comfortably to ensure families are not traumatised by a poorly managed death;
5. implement care to ensure patient die comfortably without fear of retribution;
6. ensure families are contacted and provided with bereavement support after the death of a loved one.

Voluntary Assisted Dying is Unsafe

SVHA does not support the introduction of Voluntary Assisted Dying (VAD) in NSW. Our position is that the provisions in the Bill are unsafe, as the NSW VAD Bill includes several dangerous provisions, including:

- The Bill enables doctors and other health practitioners to initiate discussions about and even suggest VAD as an option, providing that they also mention standard treatment options and their likely outcomes.[4] Given the powerful influence that health practitioners have in their patients’ decision-making, this creates a dangerous situation in which patients who might not otherwise have chosen VAD are led in that direction. Patients should be assured that their doctors and health practitioners will not suggest or recommend VAD as a solution to their health concerns;
- The Bill’s safeguards against coercion leave it up to assessing VAD doctors to detect coercion.[5] However, coercion is subtle and notoriously difficult to detect, especially if a person has been made to feel like a burden by their community, family, or the medical profession;
- The Bill sets a dangerously low threshold for decision-making capacity in relation to VAD[6], much lower than required to develop their wills;
- The Bill does not safeguard people who may change their minds, especially when their decision-making capacity has changed since they were approved;
- The Bill’s Voluntary Assisted Dying Board does not have sufficient powers to review the appropriate use of VAD because the documentation only requires steps to be undertaken, but does not ensure the validity of those steps.
- The Bill does not require any of the doctors involved in VAD to have specialist knowledge in relation to the disease or condition their patient is suffering from, and yet requires these same doctors to make a judgment about how long the person has to live in order to consider

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[4] Voluntary Assisted Dying Bill 2021 (NSW), Part 1, Division 4, no. 10.

[5] Voluntary Assisted Dying Bill 2021 (NSW), Part 2, no. 16.

[6] Voluntary Assisted Dying Bill 2021 (NSW), Part 1, no. 6.

their eligibility. Nor does it require that these doctors have the right experience or specialist knowledge to explain possible new effective treatments for their underlying illness, understand how new (or existing) treatments are availbale to overcome depression; or understand how specialist palliative care can be implemented to improve distress and allay fears of dying.[7]

- The Bill does not require that doctors assessing a person for VAD inform that person's regular care provider (whether GP, hospital, or aged care service) of their intention to pursue VAD. This compromises the ability of regular carergivers to be able to adapt their care to meet their circumstances, and to prepare to respond to any complexities that the VAD process gives rise to.

❖ VAD regimes are inherently unsafe

Even if the problems with the current NSW Bill were addressed, such legislation is inherently unsafe:

- This is true at the most basic level. The legislation involves dispensing lethal drugs that are designed for the purpose of ending human life. Once dispensed into the community, no safeguard can protect against the misuse of such drugs, nor their use by people other than those they were intended for;
- Evidence from other jurisdictions reveals that one of the most common reasons a person seeks after VAD is "fear of being a burden".[8] People regularly experience such feelings when they are ill, and our community rightly works hard to assure that they are valued and that support is available to them. A VAD regime which sees this as a reason for a person to end their life contradicts these efforts, and makes life more unsafe for people already in a precarious position;
- As noted in the previous section, coercion is notoriously difficult to detect. There is every likelihood that people will be coerced into receiving VAD – explicitly or implicitly – without the assessing doctors detecting this;
- The legislation will inevitably broaden its focus. Evidence accrued from overseas jurisdictions demonstrates that the scope of eligibility for VAD expands over time, both through formally amending legislation and through the failure to prosecute lack of compliance.
- Such broadening includes the provision of VAD to persons who cannot or do not consent. For example:
    - Newborns can now be euthanased in the Netherlands in certain circumstances[9];

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[7] Voluntary Assisted Dying Bill 2021 (NSW), Part 3, no. 18.

[8] That such factors are common reasons for individuals undertaking VAD is evidenced through 23 years of data captured in Oregon: https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Pages/index.aspx

[9] A. A. E. Verhagen, P. J. J. Sauer; End-of-Life Decisions in Newborns: An Approach From the Netherlands. *Pediatrics* September 2005; 116 (3): 736–739. 10.1542/peds.2005-0014;

    - Children can now be euthanased in Belgium in certain circumstances[10];
    - Non-voluntary euthanasia especially for the most vulnerable who are unable to express their wishes (whether previous or current wishes) has been a regular feature in the Netherlands and Belgium[11];
- Judgments of what constitutes suffering are largely subjective, and are inevitably expanded to include non-terminal conditions such as chronic depression or dementia[12];
- Although touted as an "easy death", there are known complications with the administration of VAD[13];

❖ Combat suicide rate

SVHA argues the contradiction of society's efforts to address the problem of suicide on one hand while potentially introducing legislation that affords, and even praises, individuals who choose to take their lives in certain circumstances.

Some parts of Australia have the highest suicide rates in the world, and our society laments when we see people, old and young, who see no hope in their current life situation and for whom suicide appears as the only option. In such cases, our society rightly avoids blame towards the victim, and seeks instead to address the various tragic circumstances, which led to this to prevent others from doing the same. Often this involves addressing lack of adequate support networks, socio-cultural factors, and any health conditions, which include a high risk of suicide.

In such a context, establishing a group of select people for whom deliberately ending their life is not only tolerated but valued, and indeed praised (as recent media coverage surrounding those who have ended their lives by VAD reveals) sends a deeply confusing and contradictory message to those who we are trying to help, and undermines our society's attempts to say that suicide is never an answer.

SVHA argues that addressing the problems which give rise to a desire for VAD can be achieved through the means our society already commits to responding to the tragedy of suicide by addressing lack of adequate support networks, socio-cultural factors and health needs and concerns of individuals.

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[10] AM Siegel, DA Sisti and AL Caplan 'Pediatric euthanasia in Belgium: disturbing developments.' JAMA 311.19 (2014): 1963-1964.

[11] UN Human Rights Committee (HRC), UN Human Rights Committee: Concluding Observations: Netherlands, 27 August 2001; Cohen-Almagor, Raphael. 'First do no harm: intentionally shortening lives of patients without their explicit request in Belgium.' Journal of Medical Ethics (2015): medethics-2014

[12] Kouwenhoven, Pauline SC, et al. 'Opinions of health care professionals and the public after eight years of euthanasia legislation in the Netherlands: A mixed methods approach.' Palliative medicine 27.3 (2013): 273-280

[13] Groenewoud, J. H., van der Heide, A., Onwuteaka-Philipsen, B. D., Willems, D. L., van der Maas, P. J., & van der Wal, G. (2000). 'Clinical problems with the performance of euthanasia and physician-assisted suicide in the Netherlands'. New England Journal of Medicine, 342(8), 551-556

❖ Impact on health professionals

Legislation such as VAD gives rise to unprecedented ethical issues and potential distress for caregiving staff and families. Cases in other jurisdictions bring this to the fore.

These are examples from facilities in Canada which has a Medical Assistance in Dying (MAiD) regime in place, which illustrate some of the ethical issues and distress such legislation can give rise to for health professionals

(1)

- A resident from an aged care facility accesses MAiD, but instructs caregiving staff not to inform his family nor other residents;
- The staff farewell the resident from their facility, knowing that he is leaving to be euthanized, but cannot disclose this to family or other residents;
- When the man is deceased, the staff need to explain this both to family and to other residents, creating a situation not unlike other suicides or unexpected deaths, but with the added emotional complexity of 'knowing all along';

(2)

- A long term in-patient at a sub-acute palliative care service has been through the process and has been approved for MAiD;
- The patient has selected a day on which the MAiD procedure will be completed;
- Their condition is such that they require aggressive medical treatment to live until their preferred MAiD day. If the patient chose not to undertake such treatment, they would die naturally and with adequate pain management before this time;
- The patient requests such treatment from medical staff, who provide it whilst knowing that its purpose is to prolong life until euthanasia can be enacted;

(3)

- A patient was admitted into an inpatient palliative care unit with severe pain and expressed that she would "rather die than endure that pain".
- This led her health professionals to immediately start the MAiD process.
- When her pain was better controlled, she said that her words were misinterpreted as a "figurative speech" and she never wanted MAiD.

Even setting aside these somewhat extreme cases, issues surrounding how staff deal with cases in which someone dies in a way that would once have been tragic (i.e. suicide) and is now normalised (through a VAD regime) gives rise to distress and grief which are not solved through legislative instruments.[14]

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[14] See for example Mathews, Jean Jacob, David Hausner, Jonathan Avery, Breffni Hannon, Camilla Zimmermann, and Ahmed al-Awamer. "Impact of Medical Assistance in Dying on Palliative Care: A Qualitative Study." Palliative Medicine 35, no. 2 (February 2021): 447–54. https://doi.org/10.1177/0269216320968517.

In addition, including VAD as a “treatment” option for health professionals undermines the inherent requirement for a health practitioner to address a patient’s actual distress. Once VAD is available, it is inevitable that some practitioners will prefer their patients take this path rather than other more time-consuming care pathways, and some unscrupulous practitioners will likely lead their patients towards VAD.

- **Impact on families and the community**

Death is always difficult for families and the community. However, there is evidence that witnessing or being proximite to a death by VAD leads to more significant trauma.[15] St Vincent’s has witnessed first hand the deep and often fractious effect VAD has on the people who are left behind when a person takes their life through VAD. This has prolonged families’ grief leading to a longer and more complicated bereavement that is unnecessary, and adds further burdens on our stretched health system.

Voluntary Assisted Dying is Unethical

SVHA does not support the introduction of Voluntary Assisted Dying (VAD) in NSW. Our position is that the provisions in the Bill are unethical, as legislating for VAD undermines the fundamental commitments of healthcare professionals, which are upheld in the Hippocratic tradition of medicine.

These include commitments to cure where possible, to care always and never intentionally to inflict death. In addition, this tradition of care trains clinicians to provide effective pain management and to respect patients’ decisions (or, if they are not competent, their substitute decision-maker’s decisions) to forgo treatments that are too burdensome or do not achieve significant benefits: in doing so, it ensures that clinicians act in accordance with the needs and preferences of their patients.

This tradition of care – which is the foundation of modern medicine and underpins our healthcare system in NSW – never accepts that intentionally inflicting death on patients nor assisting them to take their own lives are part of healthcare. [16] It is these latter interventions that would be made legal if the VAD legislation passes.

Patients should be able to access healthcare without fear that those providing care to them would *ever* consider that ending their life, or giving them the means by which they end it themselves, is a “treatment”.

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[15] Wagner, Birgit, J. Müller, and A. Maercker. ‘Death by request in Switzerland: Posttraumatic stress disorder and complicated grief after witnessing assisted suicide.’ European Psychiatry 27.7 (2012): 542-546.

[16] This position is is consistent with the World Health Organisation and the Australian Medical Association’s positions on VAD. https://www.wma.net/policies-post/wma-resolution-on-euthanasia/ https://ama.com.au/position-statement/euthanasia-and-physician-assisted-suicide-2016

Faced with the problem of suffering at the end of life, NSW should choose to respond in a way which is *consistent* with long-held ethical commitments, through quality end of life care, rather than by breaching those commitments.

- **St Vincent's Health Australia and VAD**

In the interests of full transparency, we wish to bring to the Committee's attention that, in relation to VAD, we hold the same position as the Australian Medical Association, the World Medical Association and other Catholic providers. That is, according to our Code of Ethical Standards, assisting someone to end their life is not part of medical practice. As such, none of our facilities in New South Wales will provide or facilitate VAD.

Our focus will remain on providing excellent palliative care. In Victoria, where VAD is legal, we have developed processes to respond to concerns or questions about VAD in a compassionate and respectful way. If a patient wants to access it, we do not obstruct them; we provide release from care as well as a transfer to another provider if a patient wants to seek out that option.

If VAD passes into law in New South Wales we would look to implement the same approach. Accordingly, we seek to ensure that the proposed VAD Bill allows Catholic facilities – and indeed any other institutions, faith-based or otherwise – to genuinely opt out of a voluntary assisted dying (VAD) scheme on the grounds of conscientious objection.

Public Hearings of the NSW Parliament's Standing Committee on Law and Justice

St Vincent's Health Australia is prepared to appear at a public hearing of the NSW Parliament's Standing Committee on Law and Justice if invited by the Committee.