

**Submission
No 81**

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

Name: Clinical Professor Richard Chye

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Ms Tina Higgins
Director Committees
Standing Committee on Law and Justice
Parliament of New South Wales
Macquarie Street
SYDNEY NSW 2000

Dear Ms Higgins

NSW Voluntary Assisted Dying ('VAD') Bill 2021

I welcome the opportunity to write to you about my views on the above bill.

I am not religious or even socially conservative. I understand, respect and continually develop spirituality, and see that come through in many of my patients, even in their last days of life. However, **I cannot support the introduction of assisted dying and euthanasia.**

I am a doctor of 35 years standing in the medical profession in Australia, 34 of which have been spent in Sydney. I have been the Director of Sacred Heart Supportive and Palliative Care at St Vincent's Hospital since 1998, and spent the vast majority of my working life in palliative care.

Like many of the people who have contacted you, I was affected by the experience of the death of a loved one, my father, who experienced a painful death from cancer. His doctors (and the health system) did not know how to look after him, to look after his pain, his weakness, his fatigue, his constipation, his anguish. His doctors did not know how to talk to him about prognosis or about what would happen. He was not provided with psychological help. My family received one phone call from a social worker to see "if we were OK". It was left to me as a young medical student to explain and provide a prognosis, from what I had read. It should not been left to me to do that. Therefore, many respond by suggesting assisted dying is the quick and easy solution to the problem. But my response has been just the opposite.

After my experience, I chose to be part of a compassionate solution and become a palliative care specialist physician. I could see there was a need to support families and to educate health professionals, including doctors, about dying, and to demonstrate that the experience can be a profound and a positive one. The experience can also be one where symptom management, pain management and patient and family support play an important role in ensuring a respectful and dignified death. While this journey will always be difficult and sad, palliative care helps make this journey better.

You have heard that many surveys purport to say the majority agree that if pain is not controlled, they would agree that VAD is acceptable. This is only a normal but simple reaction. Uncontrolled pain, as the proponents of this Bill will painfully enunciate, is the main reason why they say VAD should be allowed. However many who take their lives in the face of a terminal illness, will do so not because of pain, but the many fears a difficult diagnosis and prognosis conjures. You have to ask why there are some who would have reached for deeper understanding and recognise they could not support such a notion. The real question that needs to be asked is, if well resourced palliative care is offered an opportunity to control symptoms, would VAD still be required.

Yes pain, be it physical or existential, will never always be relieved, but can be made tolerable. My chronic pain colleagues recognise and accept that chronic pain cannot be relieved, and that their focus of management is to help these patient manage, live and be active with their pain, not without pain. We would not want these people with chronic pain, who can sometimes find life intolerable, to access the provisions of this Bill.

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.

I wish to share with you several stories.

Patient A: People are afraid of dying.

I am looking after a lady with lung disease (emphysema) and lung cancer. She does not have pain, but is constantly short of breath from her disease, and is limited in her activity. Yes, she would prefer not to be breathless, but she still finds life meaningful and enjoyable; and is a strong advocate of her view of life. She is afraid of dying, afraid of suffocating when she dies, afraid of drowning in her own saliva because of other patients she had seen die from a similar illness. I had a relatively simple but lengthy conversation with her, that when she is actively dying, she will become less aware of her dying and breathlessness as she slips into a deep sleep. Palliative care will ensure that she remains unaware of her dying, and that she remains calm. I emphasised that patients do not suffocate but their breathing becomes more shallow until it peacefully fades away. I also explained that as she sleeps, she will forget to swallow her own secretions, and it sometimes come across as a noisy rattly breathing, which will not distress her as she would be unaware of it. I explained that the noise does not mean she is choking (even though to others it sounds as if it is). The noise is made when air moves across that secretion, and causes distress to those around her, which is what she herself had experienced. I commonly explain this process to families to show that dying is always comfortable when health professionals are skilled enough to provide that care, to provide that information in a calm and effective manner. This lady was much more reassured, calmer and confident that she will be looked after well, after our conversation.

Patient B: We could be missing treatment opportunities

I looked after a gentleman with advanced lung cancer who was referred to me for care. He did not want chemotherapy because of the stories that he had heard, the side effects that he thought were very severe. It is my nature to be curious about patients and their journey, and it struck me that his cancer was not fully characterised. I ask for further tests to be done, which revealed that his cancer (with an EGFR mutation) could respond to new treatments just made available. He went on tablets (not intravenous chemotherapy) with no nausea or vomiting, and his cancer responded very well for 2 years. When the tablets stopped working, he then required chemotherapy as the next treatment step. As we had developed a relationship, I was able to assure him that I would look after the side effects of the chemotherapy, which again he responded to for another 2 years, before his cancer progressed, and he passed peacefully.

Patient C: A father who was not cared for.

A son told of a story about his father, who was a very proud man, because of the accomplishments he achieved in his life. He was unfortunately struck down with a major stroke, and he could no longer speak for himself, look after himself, feed himself, toilet himself, and remained bed bound. He was in a nursing home. His son would visit occasionally, and always found him in bed, commonly in his own excrement. He was losing weight and always felt hungry because the nursing home staff did not have the time to patiently feed him. The one nurse had 50 others to look after. That son felt very helpless,

but recognised he had his own family to look after, and did not have the resources to look after his father at his own home. He was distressed by the condition of his father, and felt he would be “better off dead”. This is such a normal emotion to have. His response was not to improve that nursing home system to ensure people are cared for with dignity. His response is to support this Bill.

Too many families even today, report how poorly their loved one are being looked after, by our current health and aged care system.

Mother D: I grieved more for my son who.....

Early in my career, a grieving mother came up to me to expressed her gratitude for the work I do and a career that I had started. She told me of her loss, as her two sons had recently died. One of her young sons had died from leukaemia. The other died from a suicide. She grieved for both her sons, but especially for her son she lost to a suicide, as she felt it was life lost, rather than a life taken away from her.

Whilst we think that the commitment of suicide is of one individual’s choice. In fact it leaves many behind who will be devastated by these choices.

I fear that this Bill does not ensure good care is provided.

The 2 doctors participating in this process do NOT NEED to have the competencies to

1. Understand the patient’s disease, and the other possible treatments (current and future), leading to missed opportunities as in my Patient B.
2. Understand how to recognise depression, and possible treatments (current and future)
3. Understand how to recognise (and properly document) a patient’s poor cognition or understanding of their current illness or wishes.
4. Understand how to recognise that a patient may be under duress or pressure from family
5. Assist pain, and other symptom management.
6. Deal with existential distress

If these two doctors had incorrectly (whether out of ignorance or without regard) followed the procedure, there is no real reprimand or fines on these doctors, other than further training. In the meantime, a patient who did not wish to be euthanised has already died with no recourse or recrimination.

I recognise that many will support the proposed Bill, for it is their right (as we have seen with Covid vaccine hesitancy), to make whatever decision for themselves. But I fear it will lead to many circumstances that we can already foretell, such as

1. Many with severe illness will not seek healthcare, because they fear they will be euthanised as seen in the Northern Territory when many Aboriginal people declined to attend healthcare, when their Bill was in existence.
2. Many vulnerable will accede to family’s especially financial demands, for fear of being euthanised.

Already many patients (and their families) fear a referral to me as a palliative care physician, because they fear all I would bring to their bedside is a quick death.

My experience of more than a quarter of a century in palliative care is that about one in 20 people who are faced with a terminal illness request VAD in some shape or form. This could be as innocent as “I have lived a good life” or “I have had a good innings”. But when they do access good care, which addresses their existential distress as well as their pain, they often change their mind. It should be recognised that palliative care expertise will take more than 5 days (if not longer) to have an impact. It

is also important to recognise as well that antidepressants and psychological help can take 2 to 3 weeks before benefits arise. We cannot rush the process.

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.

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 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 VAD Bill is likely to have the unintended consequence of pushing people down the path of assisted dying. As with the experience in jurisdictions where assisted dying 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.

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. Our health professionals so often fear talking about dying, and in not doing so, prevent our communities from preparing, accessing good care, understanding and a good comfortable death.

The Bill has to be made available to all in New South Wales, be in it metropolitan Sydney, but also in the most remote town in NSW. However, access to quality care, let alone quality palliative care is not available. Your parliament's own inquiries have demonstrated poor care in our nursing home system. Your parliament's own inquiries have demonstrated poor care in regional and remote NSW, especially access to quality palliative care. Palliative Care in Australia, sadly, is dependent on the postcode.

Whilst improving palliative care services is important, however, even if specialist palliative care resources were doubled, still less than 50% of people who die in NSW will not get access to specialist palliative care.^[4] It is therefore incumbent on the rest of the health system to be skilled to:

1. talk about dying to their patients. It is much easier to talk about the next treatment (even if the likelihood of that treatment working is negligible), rather than talk about dying.
2. recognise, acknowledge and advocate for when patients do not want burdensome treatments.
3. recognise that futile treatments prolong life (and suffering) artificially without significant achieving longer (not even medium) term benefits. We already know that more than 50% of health expenditure is spent in the last year of life. We don't have systems to ensure limited healthcare resources are not wasted, but we constantly complain of constantly inadequate health resourcing. Euthanasia MUST NOT be a solution for inadequate healthcare.
4. diagnose when patients are actually dying.
5. support families when their loved one is dying.

6. provide care (and medications) to ensure that the death is calm and foremost dignified.
7. ensure everyone family member receives bereavement care, rather than the current system where one has to first recognise their difficult bereavement before seeking help. We would readily recognise that someone with a mental health issue cannot recognise their own health issue and not seek help, until sometimes it is too late.

Everyone in our health system has to be skilled in End of Life Care, and not just rely on specialist palliative care. Currently our health professionals only have to keep up to date with their areas of their own practice. They do not need know about End of Life Care. It is not mandatory that they have to learn about End of Life Care. Our learned medical, nursing, allied health professional colleges and bodies do not have to ensure their members are skilled in End of Life Care. Their programs of “continuing education” as a prerequisite for ongoing professional registration, does not need to have anything to do with End of Life Care. This could be such an easy ask and change.

Our communities celebrate a joyous birth, an achievement no matter how small. However, society constantly instills in us that death is a failure, a misadventure, a mistake, a crime, even though it is the normal progression of life. We have not explained to our communities that dying is a normal experience. We know that dying is sad, is hard, is heartbreaking because we will greatly miss someone we love, and fear how we ourselves will live when a loved one is no longer around. These are normal. These are normal feelings. These are difficult to accept.

We talk about keeping fit, about eating well, smoking less, not drinking hazardous levels of alcohol, but we do not talk about preparing for death. We well know the ideals of “preparing for the worst,” and “hoping for the best”. We should also be communicating this when people fall seriously ill. We hail the achievement of improving life span with new treatments, new technology and new ways of doing things, however we do not acknowledge that “all good things come to an end”. We do not ask our communities to prepare, because it is too hard and we fear it will lead to any earlier end. We fear it as a taboo subject.

There is a sentinel paper written by Prof Jennifer Temel in 2010 who first showed that “Among patients with metastatic non–small-cell lung cancer, early palliative care led to significant improvements in both quality of life and mood. As compared with patients receiving standard care, patients receiving early palliative care had less aggressive care at the end of life but longer survival.”^[5] This has been further confirmed by Dr Donald Sullivan who concluded that his “study suggested that palliative care was associated with increases in survival among patients with advanced lung cancer when it was received 31 to 365 days after cancer diagnosis. Palliative care was also associated with decreases in the risk of death in an acute care setting. Palliative care should be considered an integral part of comprehensive lung cancer care, with potentially meaningful patient benefits. The results of this study appear to support the timely use of palliative care among patients with advanced lung cancer.”^[6]

It led Atul Gawande (Indian-American surgeon, a New York Times best-selling author and US President Joe Biden nominee for Assistant Administrator for the US Agency for International Development (USAID)) to now teach that:

“terminally ill patients receiving palliative care improves their quality of life, including people’s sense of control and empowerment over their lives. While these positive attitudes may be expected, palliative care practices reduce unwanted medical procedures (as well as costs) and have been shown to actually increase life span - by 25 percent in one study of late-stage lung cancer patients.

If palliative doctors were a drug, the FDA would approve them.”^[7]

Palliative Care in Australia does not have to be integrated into and with Cancer Services. LifeHouse at Camperdown which has provided cancer service for almost a decade, only recently formally made Specialist Palliative Care part of their integrated service in the last 12 months. The Cancer Institute NSW does not have Palliative Care in its portfolio.

Throughout this Covid pandemic, the community has demonstrated its extraordinary capacity to meet acute need when we put our minds and resources to it. We have rightly celebrated our achievements in this regard. By contrast, the VAD Bill proposes to alleviate suffering by handing a patient a box with lethal drugs in it. This is NOT the “alternative to good care” that we as a community should be committed to advancing.

That is why I believe that before we offer people the option to die we should give them the chance to live.

I end by reflecting on Thomas More’s most famous essay more than 500 years ago, Utopia

"look after their sick, so that nothing is left undone which may contribute either to their health or ease. And as for those who are afflicted with incurable disorders, they use all possible means of cherishing them and of making their lives as comfortable as possible; they visit them often, and take great pains to make their time pass easily."

I have also expressed other views that have been collated and included in submissions from St Vincent’s Health Australia, and from Catholic Health Australia.

I would be prepared to appear at a public hearing of the NSW Parliament’s Standing Committee on Law and Justice if invited by the Committee.

Yours sincerely,

Clinical Professor Richard Chye MBBS FRACP FFPMANZCA FACHPM
Director of Sacred Heart Supportive and Palliative Care at St Vincent’s Hospital, Sydney
Adjunct Associate Professor of Medicine, University of NSW
Clinical Professor of Medicine, University of Notre Dame and University of Technology Sydney

[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. ‘Feeling like a burden to others: a systematic review focusing on the end of life’. *Palliative Medicine*. 2007;21(2), pp. 115–128, accessed at <https://journals.sagepub.com/doi/abs/10.1177/0269216307076345>.

[4] NSW Agency for Clinical Excellence, Fact of Death Report, 2013.

[5] Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non–small-cell lung cancer. *N Engl J Med* 2010;363:733-42.

- [6] Sullivan DR, Chan B, Lapidus JA, et al. Association of Early Palliative Care Use With Survival and Place of Death Among Patients With Advanced Lung Cancer Receiving Care in the Veterans Health Administration. *JAMA Oncol.* 2019;5(12):1702–1709. doi:10.1001/jamaoncol.2019.3105
- [7] Atul Gawande, Eighth The Cynthia and Alexander Tseng, Jr., MD, Memorial Lecture at the [Stanford Cancer Institute](#) and the [Stanford Center on Longevity](#), 2015
- [8] Thomas More, *Utopia* 1516