Submission
No 78

INQUIRY INTO PROVISIONS OF THE VOLUNTARY ASSISTED DYING BILL 2021

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Submission to the Inquiry into the provisions of the Voluntary Assisted Dying Bill 2021

NSW Parliament Standing Committee on Law and Justice

Thank you for the opportunity to submit to this inquiry. I provide my comments as a palliative care physician and an Associate Professor in Bioethics who has studied euthanasia and physician assisted dying for nearly 30 years. I am fully cognisant of the suffering which can be experienced towards the end of life, and indeed have an extensive research program which aims to reduce this burden. My professional experience has informed my views.

The Voluntary Assisted Dying (VAD) Bill 2021 (the Bill) should not be made law in NSW. It represents a significant danger to the sick and vulnerable members of our community and disrupts the normal provision of healthcare. It appears designed to ensure that the maximum number of citizens die from VAD without ensuring that adequate healthcare provisions, which may deflect a desire to die through VAD, are universally available. As such it does not represent a pathway to relieve suffering so much as a pathway to eliminate the sufferers. Furthermore, the content of the Bill reflects a lack of understanding of the research on requests for hastened death, and as such represents a significant risk to the welfare of the citizens of NSW.

While the process outlined in the Bill is detailed, it does not include the necessary safeguards, and even exhaustive processes cannot guarantee a just result. The proposed VAD system depends very heavily on the integrity of doctors willing to commit physician assisted suicide and euthanasia. Even though the Bill creates a VAD Board that oversees documentation, the board, however well constituted by good people, is reliant on the information they are given. As the VAD doctors are the ones who inform the patient about the process, assess their eligibility and facilitate the death, there are no independent witnesses in the whole process to protect the welfare of the patients.

Even though the 'Principles' of the Bill (clause 4) sound praiseworthy and include statements such as the need to provide the patient with high quality palliative care, support the current therapeutic relationships of the patient, and promote communication with family and carers, these principles are not in fact reflected in the Bill. This legislation promises an easy solution to suffering but this is an illusion. International experience shows that up to 25% of physician assisted suicide and euthanasia deaths are complicated and lead to delayed death and increased suffering[1].

Concerns about the debate around this Bill and its contents are listed below.

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[1] Zworth M, Saleh C, Ball I, Kalles G, Chkaroubo A, Kekewich M, et al. Provision of medical assistance in dying: a scoping review. BMJ Open. 2020;10(7):e036054.

1. **This Bill is erroneously promoted as a response to a high level of demand in the community for VAD legislation.**

However, polls showing high levels of support usually involve a single question which uses emotive words to elicit the positive response. Removal of emotive language has been statistically shown to reduce support by approximately 20%.[2] Results of the more detailed Compass Polls of September 2021[3], and just prior to this from the Sexton Marketing Group[4], indicate:

- Most Australians would prefer access and equity of appropriate healthcare ahead of consideration of VAD legislation, and

- Significant concerns about the lack of safety and consequences of aspects of legislation.

Once Australians are given contextual information to the content and implications of VAD Bills and understand more about the potential benefits of palliative care, the majority response changes to opposed. The debate is being driven by a relatively small number of proponents and a highly professional lobbying group.

2. **This Bill contains less safeguards than the NSW Voluntary Assisted Dying Bill 2017 which was rejected by parliament.**

For example, this includes: reduction of the age limit from 25 years of age to 18 years to be eligible to receive lethal drugs; no longer requiring that the patient be necessarily examined in person; no longer requiring that at least one of the doctors confirming the patient's diagnosis and prognosis needs to be a specialist in the disease concerned; no requirements for the two doctors approving a patient's death to be independent of each other; no requirement that the patient involved be examined by a qualified psychologist or psychiatrist to ensure that they are mentally competent; no requirement that the patient concerned be offered a palliative care referral; no requirement that the doctor actually act lawfully under the Bill to avoid prosecution (it is only necessary to think you are); no requirement that a medical practitioner (who is the most likely to be able to ensure eligibility requirements are met) be a member of the VAD Review Board which will oversee the legislation; and the list goes on. The removal of safeguards for the sick and vulnerable elderly in this Bill is confronting and grounds for its rejection. Once again, any amount of detail in the process does not overcome the dangers that exist. Review of the brief period when euthanasia was legal in the Northern Territory showed that guidelines

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[2] Grove GL, Hughes I, Lovell M, Best M. A Content Analysis of Euthanasia Polls in Australia and New Zealand - Words Do Matter. Intern Med J. 2021.

[3] Compass Polling. What Queenslanders really think about euthanasia and assisted suicide. September 2021. https://d3n8a8pro7vhmx.cloudfront.net/qld/pages/371/attachments/original/1631178156/Poling_Euthanasia_and_Assisted_Suicide__2021.pdf?1631178156

[4] The Sexton Marketing Group. Euthanasia & assisted suicide Western Australian polling data.

did not protect vulnerable patients from inappropriate use of the law[5]. International experience shows that in fact it is not possible to write a VAD Bill which protects the vulnerable.

3. This Bill is being debated in Parliament without examination of the topic by a comprehensive parliamentary inquiry, as has been the case in other states.

We have had the identification of abuses in aged care through the Royal Commission into Aged Care, and the National Inquiry into Disabilities. These inquiries have all confirmed fears surrounding high rates of abuse, risks of coercion, problems of accessibility to care and the current real needs amongst vulnerable social groups, First Nations people and those in rural, regional and remote settings. Our priority at this time should therefore be towards equitable delivery of accessible quality and evidenced-based care, without which there is no healthcare choice. The rapid turnaround in the current inquiry will not allow the full implications of this Bill to be examined.

4. This Bill mandates that VAD operate within the healthcare system.

Assisting someone to end their life is not a form of healthcare[6], and medical practitioners have one of the highest rates of opposition to VAD in the community.[7] The goals of medicine and healthcare involve the preservation of life where possible and comfort care when cure it not possible, while neither hastening nor deferring death. VAD terminology seeks to provide a cloak of medical legitimacy to state sanctioned killing. Reports from Victoria demonstrate increased levels of hospital staff distress, even when not directly involved in the killing[8]. It is of concern that, in the intermediate to longer term, there will be a group of doctors who see VAD as the *only* solution to suffering, and do not attempt to address the concerns of patients which may be easily resolved through measures such as high-quality palliative care. It would be a tragedy if this attitude was, as is likely will be the case, transmitted to medical students and junior medical staff.

There are precedents to the situation where healthcare workers are not involved in state-sanctioned killing, such as under the assisted suicide laws in Switzerland, and in capital punishment in USA. Killing patients or assisting them to kill themselves is in violation of medical ethics codes which have existed for millennia. If the state insists on sanctioning killing on request, it should be done outside of the healthcare system. This would avoid the situation in other jurisdictions where some groups, for example the elderly and disabled, are reluctant to access medical help due to erosion of trust in the doctor-patient relationship due to the inability to depend on the doctor to preserve life[9]. Both the Australian Medical

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[5] Kissane DW, Street A, Nitschke P. Seven deaths in Darwin: case studies under the Rights of the Terminally Ill Act, Northern Territory, Australia. The Lancet. 1998;352(9134):1097-102.

[6] Boudreau JD, Somerville MA. Euthanasia is not medical treatment. *Br Med Bull*. 2013 106:45-66.

[7] Baslev et al. 2020. Association between Danish physicians' religiosity and spirituality and their attitudes to end of life procedures. J Relig Health. 59:2654-2663.

[8] Digby R, McDougall R, Gold M, Ko D, O'Driscoll L, Bucknall T. Introducing voluntary assisted dying: staff perspectives in an acute hospital. Int J Health Policy Manag. 2020;x(x):x–x. doi:10.34172/ijhpm.2020.216

[9] Jones DA, Gastmans C, MacKellar C. Euthanasia and Assisted Suicide: Lessons from Belgium: Cambridge University Press; 2017.

Association[10] and the World Medical Association[11] are opposed to medical practitioners being involved with euthanasia and physician-assisted suicide, even where they are legal.

5. Promotion of VAD is a distraction from the real issues that need be addressed to improve the care of the terminally ill in NSW.

At present, only about half the people in NSW who would benefit from palliative care are able to access it[12]. Access to palliative care is especially difficult for those in rural, regional and remote NSW, culturally and linguistically diverse communities, aged care, private healthcare and paediatrics. Palliative Care Australia has reported that palliative care needs in Australia are expected to increase and that there is an immediate need to plan ahead to meet the increased need for person- and family-centred, accessible, flexible and responsive palliative care[13]. Research proves that the desire to die decreases when a person is supported or has experienced palliative care[14].

Currently there is much misinformation in the media regarding medical care of terminally ill patients, in particular regarding analgesia and sedative use at the end of life. There is comprehensive evidence that therapeutic use of opioids and sedatives do not shorten life[15]. There is also lack of understanding about the metabolic changes in terminal illness and reduced appetite which have been interpreted by commentators as doctors 'starving' these patients and hastening death[16]. My own experience is that when patients and family experience palliative care first-hand, they frequently comment that they would not have feared the end-of-life experience if they had known what help was available.

Requests for euthanasia and physician assisted dying are usually due to undiagnosed depression, demoralisation, loneliness, fear of being a burden or lack of support[17]. Physical pain is an uncommon reason for a request of euthanasia and uncommon at the end of life when high quality palliative care is available. Australian data suggests that at the most 2% patients experience pain at the end of life in palliative care units, and sometimes it is due to patient choice rather than lack of available analgesia[18]. Making VAD legal does not make VAD a valid "choice" to replace quality palliative care. Indeed, a lack of access to palliative

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[10] AMA Position Statement. Euthanasia and Physician Assisted Suicide. AMA 2016. file:///Users/megan_best/Downloads/AMA_Position_Statement_on_Euthanasia_and_Physician_Assisted_Suicide_2016-1.pdf

[11] WMA Declaration on Euthanasia and Physician-Assisted Suicide. 2019. https://www.wma.net/policies-post/wma-resolution-on-euthanasia/

[12] Australian Institute of Health and Welfare 2021. "Palliative care services in Australia." 26 May 2021. Canberra: AIHW.

[13] Palliative Care Australia 2018, Palliative Care 2030 – working towards the future of quality palliative care for all, PCA, Canberra.

[14] Breitbart W, Rosenfeld B, Gibson C, Pessin H, Poppito S, Nelson C, et al. Meaning-centered group psychotherapy for patients with advanced cancer: A pilot randomized controlled trial. Psychooncology. 2010;19:21-8; Mental disorders and the desire for death in patients receiving palliative care for cancer. Chochinov, H et al *BMJ Support Palliat Care,* June 2016 4:6(2).

[15] Azoulay D, Jacobs JM, Cialic R, Mor EE, Stessman J. Opioids, survival, and advanced cancer in the hospice setting. Journal of the American Medical Directors Association. 2011; 12(2):129-34.

[16] Laviano A, Meguid MM, Inui A, Muscaritoli M, Rossi-Fanelli F. Therapy insight: cancer anorexia–cachexia syndrome—when all you can eat is yourself. Nature clinical practice Oncology. 2005;2(3):158-65.

[17] Hudson PL, Kristjanson LJ, Ashby M, Kelly B, Schofield P, Hudson R, et al. Desire for hastened death in patients with advanced disease and the evidence base of clinical guidelines: a systematic review. Palliative Medicine. 2006;20(7):693-701; Oregon Death with Dignity Act: 2020 Data Summary. Public Health Division, Center for Health Statistics. February 26, 2021.

[18] Connolly A, Bird S, Allingham S et al. "Patient outcomes in palliative care in Australia. National Compendium Report January – June 2016." Palliative Care Outcomes Collaboration. Australian Health Services Research Unit, University of Wollongong, NSW Australia, website: www.pcoc.org.au ; Clark K, Connolly A, Clapham S et al. Physical symptoms at the time of dying was diagnosed: a consecutive cohort study to describe the prevalence and intensity of problems experienced by imminently dying palliative care patients by diagnosis and place of care", Journal of Palliative Medicine , 2016, 19(12): 1288–1295. doi:10.1089/jpm.2016.0219.

care removes the possibility of choice for the individual who is experiencing suffering at the end of life.

6. Experience from overseas indicates that eligibility criteria inevitably expand over time.

Once the principle of state-sanctioned killing is endorsed and entrenched in law, how can it be limited to the suffering terminally ill? If, as in NSW, euthanasia is promoted as a way for citizens to exercise autonomy, artificial limitations such as a short prognosis cannot stand. State sanctioned killing becomes a liberty issue. If I decide to end my own life, based on how I personally define quality of life and a meaningful existence, how can the state judge that decision on the basis of general values, societal norms, or consideration of objective rationality? I should not have to justify my decision, rather my decision must, in principle, be respected by the state and society as an act of self-determination. In other words, once state-sanctioned killing is permitted, death on demand will eventually follow.

This is seen in overseas jurisdictions, such as Canada, where, after legalizing 'medical aid in dying' (MAiD) in 2016 for life-limiting disease, the law was amended this year to allow MAiD for any perceived suffering, including mental illness, as well as by advance request[19]. This change of law was hailed as a victory over "discrimination against the non-terminally ill".

Key points from the Bill:

- **Access to VAD is listed as an entitlement but not access to palliative care** [s4(1)(i), see also s180(2)]

The principles of the Bill state that regional residents are entitled to the same level of access to VAD as a person living in a metropolitan region, but does not state the same entitlement with regards to palliative care. This is discriminatory and exposes the real motivation behind this Bill as being other than a desire to reduce suffering at the end of life.

- **Decision-making capacity is assumed** [s6(2)(b)]

An accurate decision-making capacity assessment would obviously be vital in assessing someone for VAD. However, in this Bill, the onus on the doctor is to prove a patient *doesn't* have decision-making capacity. Given that we are dealing with a population who have advanced disease, this is a questionable assumption at the outset. Cognitive function is known to be impacted negatively by factors such as organ failure, medical treatments, and psychological morbidity. Research shows that 35% of people with physical and mental illness may lack capacity to make decisions about their health[20]. This is a complex diagnostic area, and a high level of skill and experience is required to make this assessment[21].

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[19] Senate votes to expand Canadians' access to assisted death. The Canadian Press. Feb 10, 2021. https://www.cbc.ca/news/politics/assisted-death-amended-extended-1.5909785

[20] Breitbart, W. Depression, Hopelessness, and Desire for Hastened Death in Terminally Ill Patients with Cancer. *Journal of the American Medical Association* (Dec. 13, 2000); Lepping, P, et al. Systematic Review on the prevalence of lack of capacity in medical and psychiatric settings. *J Clin Med (Lond)* 2015; 15(4).

[21] Agrawal M. Voluntariness in clinical research at the end of life. Journal of Pain and Symptom Management. 2003;25(4):S25-S32.

The need for this specialised assessment is grossly understated and underestimated in the Bill, with no requirement for the doctor to refer to a specialist to enable an accurate assessment to be made. Cognitive impairment, including delirium and neurodegenerative disorders, are often not recognised, even by doctors. Cognitive impairment, no matter how subtle, does definitely impact decision making capacity. It is well recognised that, the more significant the decision, the more care must be taken with capacity assessment, and the more caution is required in signing off on capacity. Clearly there is no more significant decision than the decision to end your own life. Referral to a psychiatrist or psychologist at the very least should be included in the Bill to ensure the decision to access VAD is valid, as was mandated in the 2017 Bill.

- **Health care workers are allowed to suggest euthanasia and assisted suicide to a patient as long as treatment options are explained** [s10]

This is allowed in the Bill as long as information about treatment options and palliative care is also provided. This is problematic on several fronts.

Firstly, there is no attempt to ensure that the doctor giving the information has the expertise to provide accurate data. In the absence of a doctor with specialist knowledge about the patient's disease, there is no guarantee that the patient will be told of the full range of options available, and therefore the patient may not be making an informed choice. It is well known that the range of available options may vary according to the characteristics of the individual patient. However, there is no requirement that the healthcare worker discussing VAD ever contact the patient's current doctors, whether GP or specialist. No standard medical procedure would be legal in NSW with this level of information provision to the patient. Why is it allowed here?

Secondly, it is dangerous to allow the doctor to raise the subject of VAD due to the risk of coercion. Professor Brian Kelly, a psychiatrist at Newcastle University, NSW, has shown that the doctor's attitude can have a powerful influence on the patient's decision making[22]. This is compounded when the clinician has no experience or training in palliative and psychological care of patients. Even though, in the Bill, a healthcare professional can only raise the option of physician assisted suicide with a patient if they also discuss other options such as palliative care, what negative spin on the information about palliative care is a clinician without hope for the patient, or training in palliative care, and ideologically committed to physician assisted suicide, likely to communicate?

Thirdly, evidence shows that the power imbalance in the doctor-patient relationship is such that suggestions made by a doctor are often seen as directive rather than suggestive, and patients may relinquish their autonomy with the notion that 'doctor knows best'[23]. If the Parliament truly wants to avoid the risk of coercion, it should be illegal for healthcare workers to raise the topic of VAD with patients, as is the case in the state of Victoria.

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[22] Association between clinician factors and a patient's wish to hasten death: terminally ill cancer patients and their doctors. Kelly BJ, Burnett PC, and Pelusi D *Psychosomatics*. 2004 45:311–318.

[23] Goodyear-Smith F, Buetow S. Power Issues in the Doctor-Patient Relationship. Health Care Analysis. 2001;9(4):449-62.

- **VAD is not suicide** [s12]

This is clearly not true. Introduction of assisted suicide legislation turns traditional medicine on its head.

Doctors routinely assess patients for risk of suicide, the aim being to prevent this tragic outcome. The havoc and long term negative emotional legacy suffered by those left behind has been well documented[24]. No bereavement services are provided within the terms of this Bill, with families left to cope unassisted after the death.

In Australia we acknowledge that suicide is a major public health problem and therefore have a National Suicide Prevention Strategy and a National Australian and Torres Strait Islander Suicide Prevention Strategy, yet to be fully enacted[25]. We have a towards zero goal for suicide prevention. Sanctioning suicide via physician assisted suicide as an acceptable solution to one's difficulties sends the wrong message to the community, especially our young people.

Since physician assisted suicide has been legalised in the Benelux countries and Oregon, USA, unassisted suicide rates have increased in those jurisdictions, suggesting that a change in cultural attitudes in society and within healthcare, are a contributor[26]. This is hardly surprising. There has not been sufficient time in Victoria since legalisation of VAD to detect the trend due to the coroner's processes.

Suicidal thoughts often come up in the context of depression but also in other mental disorders. Psychiatrists are aware that depression is often under-diagnosed and under-treated in our community, and the high rates of depression in the terminally ill have been noted above. We also know that there are many parts of this state where there is inadequate access to mental health care. Studies show that treatment of depression in the palliative care setting is effective[27]. We know that thoughts around suicide are not static and resolve when depression is treated and that even when there are residual thoughts about wanting to die, these are not acted on when appropriate support is given[28].

This Bill risks undermining the efforts of National Suicide Prevention Strategy by promoting suicide as a legitimate solution to personal suffering. The NSW Government priority should lie in prevention efforts for the current suicide crisis faced in regional Australia, amongst First Nation peoples and in the young. This Bill should be rejected as a contradiction to these goals.

- **Adults diagnosed with a terminal illness that will cause death within six months, or 12 months in the case of a neurodegenerative condition are eligible for VAD** [s16(1)(d)]

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[24] Gazit Z. (Social) Death is not the end: resisting social exclusion due to suicide. Contemporary Social Science. 2015;10(3):310-22.

[25] https://www.health.gov.au/resources/publications/the-australian-governments-national-mental-health-and-suicide-prevention-plan

[26] Jones DA, Paton D. How does legalization of physician assisted suicide affect rates of suicide? Southern medical journal. 2015;180(10):599-604.

[27] Hart SL, Hoyt MA, Diefenbach M, Anderson DR, Kilbourn KM, Craft LL, et al. Meta-Analysis of Efficacy of Interventions for Elevated Depressive Symptoms in Adults Diagnosed with Cancer. JNCI: Journal of the National Cancer Institute. 2012;104(13):990-1004.

[28] Chochinov HM, Tataryn D, Clinch JJ, Dudgeon D. Will to live in the terminally ill. The Lancet. 1999;354(9181):816-9.

Proponents of VAD describe it in terms of hastening the death of someone who is in the process of dying. However, when someone has 6 or 12 months to live, they are not actively dying. This Bill allows living patients to be killed prematurely. Furthermore, it is well known that it is notoriously difficult to predict when death will occur[29]. This reinforces the risk of depriving NSW citizens of valuable time with their loved ones.

- **Prognosis is only on the balance of probabilities** [s16(1)(d)(ii)]

The eligibility criteria include a prognosis of 6 months, or 12 months for a neurodegenerative condition, but the standard of assessment is the balance of probabilities. There is extensive research showing that it is not possible to predict life expectancy with any accuracy[30]. We all know someone who outlived all expectations. Doctors who are highly specialised in their field can say what the average life expectancy is for a particular illness, but even they can't say with any confidence what an *individual's* life expectancy is. Even more inaccurate will be a doctor who is not an expert in that field. And yet, this Bill puts patients at the mercy of doctors who might have inadequate skills or training to determine these very issues. Patients may decide to proceed with VAD with the erroneous understanding that their lifespan is more limited than is in fact the case. This highlights the dangers of this Bill in terms of who determines eligibility criteria and the ways in which they are allowed to attempt to do so.

- **Assessment of patient's suffering is subjective** [s16(d)(iii)]

The eligibility criterion for suffering is assessed subjectively by the patient and they are not required to avail themselves of any means by which suffering may be relieved before accessing VAD if the means are not acceptable to them. Evidence shows that the wish to hasten death reduces in patients who receive good palliative care[31]. However, this effect operates only when the patient *receives* the care, not when they are just told about it. In this Bill, patients are not even required to have received a referral to palliative care, in order to find out the true extent of options available to them.

Is this Bill really attempting to reduce suffering? The rhetoric around euthanasia and physician assisted suicide tends to paint a picture of VAD as a last resort, but it is not the case if patients do not or cannot (in the case of reduced or nil access to palliative care) explore alternative solutions.

- **Mental illness does not disqualify a person from euthanasia** [s16(2)(b)]

In this Bill, as long as a person can understand the decision, mental illness (e.g., clinical depression) does not prevent a person from accessing euthanasia or assisted suicide. Suicidal thoughts often come up in the context of depression but also in other mental disorders. Psychiatrists are aware that depression is often under-diagnosed and under-treated in our community, particularly in patients who are terminally ill[32]. We also know

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[29] White N, Reid F, Harris A, Harries P, Stone P. (2016). A Systematic Review of Predictions of Survival in Palliative Care: How Accurate Are Clinicians and Who Are the Experts? PLoS ONE 11(8).

[30] White, op.cit.

[31] Breitbart W, Rosenfeld B, Gibson C, Pessin H, Poppito S, Nelson C, et al. Meaning-centered group psychotherapy for patients with advanced cancer: A pilot randomized controlled trial. Psychooncology. 2010;19:21-8.

[32] Hart, op.cit.

that there are many parts of this state where there is inadequate access to mental health care. As previously mentioned, studies show that treatment of depression in the palliative care setting is effective. We know that thoughts around suicide are not static and resolve when depression is treated. One would think that at least a trial of treatment for depression would be advisable before the patient is eligible to make the irreversible choice of accessing VAD.

- **Coordinating or consulting practitioners are not required to be specialists in the patient's illness or the patient's usual doctor** [s18]

I refer you to the abovementioned comments regarding concerns that, without specialist knowledge or first-hand information about the patient's condition, assessments of patient eligibility are likely to be flawed. While there are recommendations that the practitioner refer to other doctors if they do not have the required information, how many of us know the extent of what we don't know?

- **Consultations with coordinating practitioner, including first and final request and administration decision, can be done via telehealth** [s19(2)(c), s48(2)(b), s57(2)(b), s182]

This means that the practitioner does not even have to examine the patient in person. Doctors have had extensive experience with telehealth during the COVID-19 pandemic, and it is clear that it is difficult to accurately assess a patient through telehealth, particularly if you have not previously met that patient[33]. This is likely to be the case, as we know from the Victorian experience that in the first year of operation of the VAD Bill, the majority of VAD was administered by just four doctors[34]. The thought that a doctor would attempt to confirm the diagnosis and prognosis of a patient they have not previously met without even physically examining them would constitute medical negligence in any other setting. It is known that errors in diagnosis occurred during the time that euthanasia was legal in the Northern Territory[35].

- **A person can make euthanasia requests using "gestures", but these are not specified or recorded** [s19(3)(b), s48(3)(b), s57(3)(b)]

The obvious problem with this is that if unspecified "gestures" are enough to make a death request, it is the doctor's interpretation of the gestures that prevails. In the 2017 version of this Bill, a patient who was incapable of physically signing a request for euthanasia or who needed an interpreter was required to have their request for death filmed; a protection against a doctor or an interpreter deliberately, negligently or recklessly misreading a patient's end-of-life decision. The current Bill removes this layer of security, allowing a patient to even request death by way of non-specified 'gestures' that are not recorded anywhere. Given the seriousness of a life-ending decision, if the Parliament insists on

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[33] Butow P, Havard PE, Butt Z, Kelly B, et al. Stakeholder perspectives on the impact of COVID-19 on oncology services: A qualitative study. Presented at Clinical Oncology Society of Australia Annual Meeting 2021.

[34] Willmott L, White BP, Sellars M, Yates PM. Participating doctors' perspectives on the regulation of voluntary assisted dying in Victoria: a qualitative study. Medical Journal of Australia. 2021.

[35] Kissane, op.cit.

designating VAD to be a medical procedure, it should not be subject to any lower standard of informed consent than any other medical procedure in this state.

- **Medical practitioner must immediately accept or refuse the request** [s21(1)]

This clause suggests that the medical practitioner must immediately either accept or refuse to engage with a patient who makes a request for euthanasia. This constitutes a complete ignorance of the meaning of a wish for hastened death in the end-of-life environment. Research has shown that expression of a wish for hastened death is a sign of distress that should be addressed as a priority[36]. To refuse to engage with the patient is not good healthcare. Medical practitioners need the freedom to explore the source of the request for VAD before deciding whether to take the next step in the VAD pathway is appropriate.

A recent research study in Melbourne[37] has shown that only a minority of requests for hastened death (2 out of 41 in their study = less than 5%) proceeded to VAD.

It is well known in palliative care internationally that desire to die statements are not infrequently expressed by patients with a terminal illness, and may or may not be a request for hastened death[38], although they are often misinterpreted as such by healthcare workers. There is a distinct danger that if this Bill is passed by Parliament, end of life discussions may be misinterpreted and become triggers for VAD when in fact they are a cry for help.

- **Conscientious objection must be immediately announced to the patient** [s21(5)(a)] **and conscientious objectors still must provide "the information approved by the Health Secretary, by Gazette notice"** [s21(5)(b)]

This means that a health practitioner who might want to conscientiously object has no opportunity to consider it; it assumes that conscientious objection is always an instant decision. It might be for some, but there are others who might only come to the decision after a period of reflection, particularly if it is the first request made of them.

In the absence of human rights legislation in NSW and protection of conscience under the Anti-Discrimination Act, the conscience protections in this Bill are all there is for medical practitioners who hold to the traditional ethics of medicine. In clause 9, the Bill shields doctors from participating in the process but it is narrow; in clause 21(4) and (5), they must give the patient information that is approved by the Health Secretary – which is not yet available for scrutiny – and in clause 23(2)(h), they must report their objection and the reason for it to the VAD Board. No rationale is given for this requirement, or how this information is going to be retained, protected and used.

It also ignores the above-mentioned fact that a request for euthanasia is usually a cry for help, and that a patient mentioning VAD should not be immediately referred to the VAD pathway, but instead sensitively questioned about their fears and concerns (see above mentioned comments). The provision in the Bill risks patients missing out on the support

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[36] Johansen S, Hølen JC, Kaasa S, Kaasa S, Loge JH, Materstvedt LJ. Attitudes towards, and wishes for, euthanasia in advanced cancer patients at a palliative medicine unit. Palliative Medicine. 2005;19(6):454-60.

[37] Adams V, Katz NT, Philip JAM, Gold M. Desire to die statements in the era of voluntary assisted dying. Presented at the OPCC 2021.

[38] Johansen, op.cit.

they need at a very difficult time, if they interpret the refusal to provide VAD as a refusal to help. There is no good medical reason for this provision.

This provision requires a doctor with a conscientious objection to provide official information to the patient, presumably information that will connect them to a "VAD coordinator." This will be seen as akin to an obligation to refer by many healthcare professionals. Some medical practitioners will interpret the requirement to give information to the patient about the VAD process as being complicit in the act of VAD, so that this negates the promise of being able to conscientiously object.

- **Conscientious objectors need to advise the Board of their conscientious objection** [s23(2)(h), s34(2)(e)]

There is no justification given for this clause. It is difficult to see why this should be included in this Bill. This is a violation of privacy. It also confuses conscientious objection with professional objection to VAD for any particular patient as the latter is not addressed.

- **Expert in palliative care not involved in discussion about palliative care treatments and outcomes**

This clause demonstrates lack of understanding regarding the degree of specialisation within modern medicine. Palliative care physicians are aware of the lack of understanding regarding what palliative care can achieve amongst the larger medical community, and the patient is unlikely to get accurate information regarding possible pathways to relieve their suffering if they are not referred to specialist palliative care. It would be a tragedy if a patient were to choose VAD because they were not accurately informed regarding their palliative care options.

- **Referral to a psychiatrist or psychologist is only needed to assess capacity, pressure or duress** [s27]

Psychological referral is not required if a person is suffering from a mental illness. Please see comments above regarding the impact of mental illness on mental capacity and desire for hastened death.

This Bill anticipates problems with identifying coercion and undue influence, but underestimates them. This is of particular concern as elder abuse has been identified as a pervasive problem in NSW by the Legislative Council's report on Elder Abuse released in 2016[39]. Similar issues were identified in the Australian Law Reform Commission's report on elder abuse released in 2017[40]. While the exact prevalence of elder abuse is not established in NSW, the ALRC reported that, at the international level, estimated prevalence rates of elder abuse range from 2-14% and may be as high at 20% in older women.

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[39] Report 44 – Elder abuse in New South Wales.
https://www.parliament.nsw.gov.au/lcdocs/inquiries/2387/Report44ElderabuseinNewSouthWales.pdf

[40] Australian Law Reform Commission. Elder Abuse – A National Legal Response. ALRC 2017.
https://www.attorneygeneral.gov.au/Mediareleases/Pages/2017/SecondQuarter/Building-the-national-response-to-elder-abuse.aspx

Such coercive control is regularly observed by healthcare professionals. This is the situation where a vulnerable or elderly person is being pushed along a certain path, for example to change a will or to go into residential care, for the financial benefit, convenience or needs of the children. Coercion and undue influence can be very difficult to detect, particularly if you have not previously met the patient. As noted above, it is likely that only a small number of doctors will be willing to engage in VAD, therefore the likelihood that they have not previously met the patient is high, making it likely that there will be instances of coercion that are missed.

This often occurs in the context of the distress of family members who may wish to relieve their own suffering. Such coercion is not always conscious, but we know from Oregon, USA that fear of 'being a burden' is one of the most common reasons why patients choose physician assisted suicide[41], and older patients will be sensitive to their families' experiences of distress.

The Bill anticipates problems with capacity for decision making, which is a serious concern given the irrevocable nature of the decision to kill yourself. However, witnesses are only required to attest that the patient *appeared* to have capacity and was not coerced (see clause 44/45). That is a very low threshold, but it is understandable when you consider that witnesses are not permitted to be family members, beneficiaries under the will or someone who derives a benefit from the death. It's very possible that this person does not really know the patient very well. And whilst there is a penalty if it's later shown they were an ineligible witness, the patient is already dead and there's no requirement for the doctor to make any enquires about the witness' eligibility beforehand. This Bill does not include safeguards. It merely lists detailed processes that cannot guarantee a result and depend very heavily on the integrity of doctors willing to commit physician assisted suicide.

- **Informing treating doctor is optional** [s28(1)(j)]

A patient is encouraged to inform their treating practitioner, but the coordinating or consulting practitioners are not required to inform the treating physician. This means that a person's regular doctor might not have any say in the VAD process, despite potentially having a long-standing relationship with the patient. Apart from problems in terms of determining eligibility if the doctors who know the patient best are not involved, this is potentially a source of extreme moral distress for a healthcare practitioner who may have wished to have an opportunity to address the suffering of the patient before the VAD pathway was chosen.

- **Board is not required to be notified of the presence of a mental health condition** [s30(4)]

The list of information required to be provided to the Board does not include anything about the patient's mental health status or whether they were seen by a psychologist. This is a significant omission in terms of understanding the mental health needs of our

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[41] Oregon Health Authority, op.cit.

community, further undermining the National Suicide Prevention Strategy, and increases the opacity around the operation of this legislation and why it is accessed by patients.

- **A consulting practitioner who deems a person ineligible may still refer the patient for a second opinion** [s42]

A consulting practitioner who deems a person ineligible may refer a patient for another opinion. However, it is not clear how this would be good medical treatment if they consider a patient ineligible. This is another example of how this Bill prioritises moving patients along the VAD pathway above patient safeguards.

- **Time between first and final request can be as short as 5 days, or even shorter if the patient is expected to die or lose mental capacity within 5 days** [s49].

Research has shown that the desire for hastened death often fluctuates over time[42]. This period between first requesting VAD and receiving it does not allow sufficient time for reflection and determining whether the request for hastened death is permanent.

- **Faith-based residential aged care facilities must allow all stages of euthanasia and assisted suicide process on the premises for permanent residents** [s106ff].

Institutional conscientious objection is new in NSW. Facilities with ethos objections can advertise that fact, but in this Bill, reasonable access must be given to patients on their premises for consultations and assessments by doctors for VAD and even the carrying out of the death if the VAD doctor considers the patient should not be moved. So, preference is given to VAD over the rights of associational organisations to uphold their ethos.

This includes allowing a doctor on the premises to administer lethal injections. This means that there will be no institutions where residents can go to escape the threat of having VAD suggested to them or having to experience VAD occurring in their close vicinity, which may be interpreted as a threat. We do not know how distressing it will be to patients in faith-based organisations to be in the vicinity of patients undertaking the VAD process.

- **Faith-based hospitals are required to allow VAD navigators into the hospital to provide information** [s99)2)]

For all other parts of the process, under certain conditions, the hospital is allowed to transfer a patient out, but they are required to let a VAD navigator on site. Once again, this is a violation of institutional conscience, and means that a patient cannot select an institution where they are not at risk of having VAD suggested to them by staff, or exposed to the VAD process.

- **Supreme Court cannot review prognosis** [s109]

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[42] Chochinov, op.cit.

The only aspects of eligibility to which an application to the Supreme Court can be made are residency, capacity and absence of pressure or duress. There is no review available for prognosis or diagnosis, which are crucial aspects of eligibility for VAD.

- **Process shrouded in secrecy** [s130,131, s148]

Penalties of up to 12 months' imprisonment are available to anyone who discloses information they obtain because of their function under the Act, and information about the Supreme Court proceedings cannot be made public if it discloses personal information about a patient or any of their medical practitioners. Even the Health Minister is not allowed to access personal information. This contributes to the lack of transparency in oversight of VAD.

- **Limitation period for prosecutions** [s135]

There is a 2-year statute of limitations for prosecutions in this Bill. Given that breaches of the Act can result in death (murder has no limitation period), it is unclear why such a short period should apply here.

- **The Bill actively protects breaches** [s137]

A person is protected from both civil and criminal liability if they do something in good faith and with reasonable care and skill, believing on 'reasonable grounds' it is done in accordance with the Act. Usually, ignorance of the law is not a defence to prosecution. It is not clear why it should be in these circumstances, especially given the seriousness of the consequences.

- **Very little detail recorded by Board** [s176]

The only statistical information required to be kept by the Board is the relevant disease or illness, the age of the patient, and whether they live in regional NSW. No information about gender, education, whether they had been diagnosed with depression or another mental illness, whether they had needed to consult a psychologist, or how long they had been treated by the coordinating practitioner before their death was approved etc. is required. No information is collected regarding medications used or whether a palliative care consultation was suggested or obtained. There is also no information regarding the provider of the service. In other jurisdictions, collection of data has been seen as an important part of ensuring that the legislation is not abused, and it is difficult to understand why not even the reason why VAD is chosen is collected. This lack of transparency is even more extreme than that in Oregon, USA, where commentators have described the reporting process as designed to protect the legislators rather than the patients involved [43].

In summary, this Bill is not neutral in its attitude to VAD. It seems designed to ensure that as many people as possible die under the VAD program, with blatant disregard for the safety of

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[43] Foley K, Hendin H. The Oregon Report: don't ask, don't tell. Hastings Center Report. 1999;29(3):37-42.

vulnerable citizens who may have decided against VAD, had they been given high quality healthcare instead of a referral to a VAD navigator.

I would be happy to discuss any of the above issues with the committee if it would be of benefit.

Yours sincerely,

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