Submission No 44

INQUIRY INTO PROVISIONS OF THE VOLUNTARY ASSISTED DYING BILL 2021

Organisation: Health Professionals Say No

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The NSW Voluntary Assisted Dying Bill (2021) Inquiry

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Heath Professionals Say No!
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1. Introduction to General Heath Care and Social Service Provision Considerations

We represent an independent secular network of over 880 health care professionals dedicated to the care of the seriously ill, aged and dying. Of the 430 represented in NSW, many have been or are in coal face or leadership positions, or with other significant associations in NSW Health and care institutions. We oppose the involvement of healthcare in euthanasia or physician assisted suicide practices and reject the misleading notion that "compassion" demands VAD legislation. This false promise of an easy solution to suffering only projects an illusion and sidelines the societal and health care actions required to compassionately ease suffering in ways we know to be effective. We seek, instead, to encourage our government toward the provision of the real care needed to achieve a high standard of end-of-life care in NSW.

We are particularly concerned by the introduction of the NSW VAD Bill into the Lower House for debate prior to the extensive inquiry required for such far-reaching legislative changes to be adequately considered. Good laws make it easier to do right, but the suggested VAD legislation has major implications requiring changes in criminal, coronial and health care regulatory acts that make mistakes, abuse and coercion more likely. The are no sufficient protections within the Bill's provisions. It is designed for the limited and minority reference group this Bill is written for. The processes described are insufficient to provide safe legal, medical and social practices, and act to erode the protection owed to our vulnerable citizens; the latter being the true duty of good government.

We are also concerned about the fundamental impact and damaging effects to Health Care the proposed legislation would have and the ambiguity and distress it would create within our healthcare and social services systems[1]. These concerns are shared by many less vocal of our society who feel intimidated or too affected to speak out within a popularist media. We share a few examples of the emails permitted for us to use for this purpose, from those who encourage our advocacy on their behalf (see **Appendix 1**.)

We also see the necessity of reminding Parliamentarians of the remarkable stresses facing NSW Health, our institutions, community services and residential aged care, whilst negotiating pandemic conditions and costs, as well as ongoing state and federal health and social agendas. The implications of the Royal Commission into Aged Care, the National Inquiry into Disabilities and the National Suicide Prevention Strategy serve to compound and heighten the negative impact of the timing of such a Bill for our state [2].

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[1] https://www.mja.com.au/system/files/issues/209_07/10.5694mja17.01217.pdf

[2] https://agedcare.royalcommission.gov.au/publications/final-report
https://disability.royalcommission.gov.au/publications/research-report-nature-and-extent-violence-abuse-neglect-and-exploitation-against-people-disability-australia
https://www.mentalhealthcommission.gov.au/monitoring-and-reporting/fifth-plan/5th-national-mental-health-and-suicide-prevention

These inquiries have all confirmed fears and our experience 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 regional settings, inclusive of the need to address rising suicide rates [3,4]. This Bill serves to jeopardise suicide prevention strategies through legitimising suicide in the law. Palliative care provision remains inadequate and shortfalls in services inclusive of Home Care Packages only increase vulnerability, as many die while awaiting care[5].

Our priority at this time should be toward the ethical and equitable delivery of accessible quality and evidenced-based care, using current frameworks for safety and quality provision of such care[6,7,8], and as guided by the recommendations from national and state inquiries, and reports into shortfalls of service provision. Without this there can be no real "choice" which, in itself, creates risks for coercion and undue influence through the introduction of this Bill into legislation.

2. *Misrepresentations inclusive of Coronial Statistics in Victoria and NSW around Suicide in the Seriously Ill and Impact of Palliative and Psychosocial Care*

i. Interpretation of Coronial Data

In the article written by Alexandra Smith titled *"Terminally ill turn to tragic and horrific methods to end their lives",* Dying with Dignity and Mr Greenwich falsely assert a misleading interpretation of coronial data on suicides in the terminally ill as a basis toward introduction of the VAD Bill. They also imply that suicide or self-harm in terminal illness would be prevented by VAD laws[9]. Both representations, unfortunately, only serve to fuel myth, without assisting the general public or NSW Parliament in understanding what can potentially be available to people with terminal illness and suicidal thoughts, through the deliberate misrepresentation of the facts for political impact alone. The article also serves to create disproportionate fears around implications of care in life-limiting diagnoses. The same strategy was used during the Victorian VAD debate.

In respect of the NCIS Report commissioned by Dying with Dignity, we would like to draw your attention to Page 5 of the document titled "LIMITATIONS" (see **Appendix 2**.) The document clearly states in this section of the report that;
- *"data contained in this report does not infer a correlation between a terminal or debilitating physical condition and the deceased's intention to engage in self-harm",*
- *"nor does it indicate that the condition was the sole or primary contributing factor to the deceased's intention to engage in self-harm. Caution is advised when interpreting this data.*

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[3] https://www.theaustralian.com.au/nation/senator-pat-dodson-rejects-assisted-dying/news-story/0e197ab55ec79ace970c78a8dd2e6a3

[4] https://www.crrmh.com.au/content/uploads/RuralSuicidePreventionPaper_2017_WEB_FINAL.pdf

[5] https://www.careabout.com.au/blog/royal-commission-summary-a-story-of-neglect

[6] https://www.cec.health.nsw.gov.au/CEC-Academy/healthcare-safety-and-quality-capability

[7] https://www.health.nsw.gov.au/mentalhealth/services/carers/Pages/support-framework.aspx

[8] https://www.health.nsw.gov.au/palliativecare/Pages/eol-pc-framework.aspx

[9] https://www.smh.com.au/politics/nsw/terminally-ill-turn-to-tragic-and-horrific-methods-to-end-their-lives-20211010-p58yqv.html

- "coronial findings in relation to non-inquest cases may not contain details about the circumstances surrounding death".

Review of published detail of the Victorian coroner's data analysis based on 118 active cancer patients[10] suggests that 34% of victims had had a history of mental illness, and only 42% of all cases had advanced cancer, meaning that the remaining 58% had cancers at an early stage. Only 14% had had contact with a Palliative Care service, despite being described as "illness probably related suicides" and having concerns about pain. Interestingly, 48% reported the heavy burden of cancer treatment as an issue, rather than the illness (a potentially avoidable burden). Those reported as "suicides likely being related to physical illness" made up only 10% of suicides in each state (one case per week). Many of these cases would not have met eligibility criteria for VAD, thus such "bad deaths" would continue despite VAD laws[11].

These results also need to be further contextualised by what we already know through evidence on good medical practice and end of life care. Namely, that 35-40% of those patients who suicided were likely to have an undiagnosed depression[12], which would not have been part of their prior history, and that 35% of them were also likely to lack capacity in making decisions about their health[13]. Strong evidence has also demonstrated that the desire to die fluctuates and diminishes closer to actual death, and significantly so when appropriate and good quality psychological and palliative care is delivered[14] . In jurisdictions overseas where euthanasia and physician assisted suicide has existed for some time, reported suicide rates in general have actually increased[15] [23].

In summary, the argument that legalisation of VAD is required to reduce the suicide rate in the terminally ill is fallacious. The coronial data represents no such claim.

ii. Implications of this data to assessments of capacity and consent

Consent is both relational and temporal as is the desire to die. It is tempered by the attitude and practices of the clinician toward the patient and can be subject to subtle coercive signals and, as aforementioned, changes again when an alternative clinical experience may be encountered. The process outlined to be mandated within this Bill to a request or exploration of desire to die creates undue influence toward assisted suicide and is contrary to the evidence on how to manage such requests and the true care needed. The fact that early evidence from Victoria demonstrated four doctors alone were responsible for over 25% of the assisted suicides under the Victorian legislation brings this likely influence into further question.

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[10] Characteristics of patients with cancer who die by suicide: Coronial case series in an Australian state. Dwyer, J et al Psycho-Oncology, August 2019

[11] Suicides, Assisted Suicides and "Mercy Killing": Would Voluntary Assisted Dying Prevent These "Bad Deaths"? Del Villar, Willmott, White, (2020) 46(2) Monash University Law Review

[12] Depression, Hopelessness, and Desire for Hastened Death in Terminally Ill Patients with Cancer. Breitbart, W Journal of the American Medical Association (Dec. 13, 2000).

[13] Systematic Review on the prevalence of lack of capacity in medical and psychiatric settings. Lepping, P, et al J Clin Med (Lond) 2015; 15(4)

[14] Mental disorders and the desire for death in patients receiving palliative care for cancer. BMJ Support Palliat Care, June 2016 4:6(2)

[15] How Does Legalization of Physician-Assisted Suicide Affect Rates of Suicide? Jones, Paton Southern Medical Assoc. 2015; 108(10)

Capacity and consent assumptions in the Bill are therefore over-simplistic and problematic. Most doctors approving VAD referrals would not have the necessary skills nor knowledge of the patient to assess capacity, evidence of abuse or coercion, or whether they feel themselves to be a burden, the latter two being common.

There is no definite evidence in the analysis that most or many of these suicides would have either met VAD
eligibility criteria, nor that VAD would prevent similar cases is future.

iii. Implications of this data for provision of palliative care and psychosocial services

One important implication, however, is that lack of access or referral to high quality specialist palliative care and other psychological and social support may have increased the likelihood of many of these cancer patients being driven to suicide. Significantly there is no evidence to suggest lack of access to VAD drove this group to suicide.

Quality and benchmarking data from the *Palliative Care Outcomes Collaborative* and *Palliative Care Australia*[16], as well as aforementioned evidence and research, not only show that desire to die diminishes significantly once palliative care is provided, but that less than 2 % of those in our care may die with any degree of pain or breathlessness. Those who do, may actually choose to forego higher doses of medication or palliative sedation offered them, for personal reasons, despite the resulting pain. These reasons include wanting to be present to relatives, to maintain a sense of control over their medication, or for spiritual reasons. Palliative care can also improve quality of life for older Australians with aged-related conditions independent of dying and should be developed in line with aged care practices and services[17].

3. Limitations of VAD Polls and Surveys versus Contextual Representative Polls & Misunderstood Demand for VAD Bills

Significant considerations regarding polls and surveys

1. It is claimed that this Bill is a response to a high level of demand in the community for VAD legislation. Polls showing high levels of support usually involve a single question using emotive language to elicit a singular positive response. Once emotive language is removed from single general questions, there is an immediate reduction in support by approximately 20%[18].

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[16] https://www.uow.edu.au/ahsri/pcoc/about/

[17] https://www.cis.org.au/publications/research-reports/life-before-death-improving-palliative-care-for-older-australians/

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

2. Sampling for push polls often involves a call via emails and social media by Pro-VAD organisations to their members. This population present a limited demographic, representative of the vocal minority reference group for which such bills are designed.

3. Results of the more detailed Compass Polls of September 2021, and just prior to this the Sexton Marketing Group, indicate:
   i. Most Australians would prefer access and equity of appropriate and accessible healthcare and palliative care AHEAD of consideration of VAD legislation.
   i. A significant majority are concerned about the lack of safety and consequences of aspects of the legislation.

When a representative cross-section of Australians is given contextual information about the content and implications of VAD bills and had aspects of bills around assisted suicide explained to them, the MAJORITY response changes to OPPOSED. Of particular significance, Australians would not want their relatives to commit suicide without their knowledge - a provision allowed for within the NSW VAD Bill and supported through falsification of medical cause of death certificates. These and more majority real and present concerns around VAD Bill contents are outlined in **Appendices 3 and 4**.

4. The NSW VAD Bill Represents an Unethical Minority World View Contrary to Good Clinical Practice

i. The NSW VAD Bill requires a significant change in legal world view and practice. Only 18 world jurisdictions have legalised euthanasia and assisted suicide practices. Five of these are in Australia. Examination of the global trend sees virtually all Bills introduced world-wide being defeated or not accepted due to concerns about the lack of safety, failure of oversight and underreporting, proven expansion of scope to vulnerable populations, proven coercion and wrongful deaths[19], ethical concerns around medical practice [20], damage to healthcare and palliative care services[21,22], and implications for rising suicide rates[23].

We include a comprehensive document examining many of these concerns with evidence, including complications and shortfalls in reporting, through objective ethical discourse. (See **Appendix 6.)** This paper was written for the International Association of Hospice and Palliative

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[19] https://dredf.org/public-policy/assisted-suicide/some-oregon-assisted-suicide-abuses-and-complications/

[20] Euthanasia and Physician Assisted Suicide are Unethical Acts. World Medical Journal Nr.1, May 2019 Vol. 65; pp 34-37

[21] https://bioedge.org/end-of-life-issues/palliative-care/euthanasia-has-had-negative-effect-on-palliative-care-in-canada-report/

[22] How does Medical Assistance in Dying affect end-of-life care planning discussions? Experiences of Canadian multidisciplinary
palliative care providers. Ho A, William L, Norman J, Joolaee S, Serota K, Twells L. Pall Care &Social Practice 2021, Vol.15: 1-14

[23] Why are suicide rates climbing after years of decline? Valko N, Linacre Q. 2017 May; 84(2): 108-110

Care by the recently deceased Professor Roger Woodruff, oncologist and palliative medicine physician, and one of our HPSN foundation members from Victoria titled, "*Euthanasia and Physician Assisted Suicide; are they clinically necessary or ethical?"* [24].

ii. The rapid uptake of VAD Bills in Australia to date is an untested local trend only. This untested trend is being imposed on health care providers and systems around Australia without consideration of the professional and patient safety objections voiced and problems that already have been created and reported on by colleagues in Victoria. Bills are said to be based on the Oregon USA model promoted by *Go Gentle* and other pro-VAD proponents.

In the United States alone there have been 88 assisted suicide bills rejected across that nation in the last 4 years due to safety concerns, with existing legislation in New York state being reversed the same year the Victorian VAD Bill was introduced on a very slim majority vote. (See **Appendix 5.**)

iii. Furthermore, the 2021 NSW VAD Bill has even less "safeguards" than its defeated 2017 counterpart. Of interest and contrary to Oregon Bill, Section 60 of the of the NSW VAD Bill is radically different to the authority given to medical practitioners to administer the lethal dose to the patient, making the NSW Bill even more contentious, ill-thought and unsafe[25]. The Oregon law contains the following provision (similarly also found within the Californian legislation[26]).

> *"Nothing in ORS 127.800 to 127.897 shall be construed to authorize a physician or any other person to end a patient's life by lethal injection, mercy killing or active euthanasia."*

iv. The presumptions in the NSW Bill ignore current standards of ethical clinical practice and patient safety considerations. It disposes of them as a matter of "conscientious objection" to be overcome or replaced by the smokescreen of bureaucratic tick-box processes which are opposite, in effect, to the principles stated in its own preamble (See Division 2, 4:(1) d, g).

Specifically, there is no "communication with family" nor expected "referral to high quality palliative care". The Bill over-rides true duty of care and brushes aside evidence-based good medical practice in favour of, and with undue influence toward, assisted suicide, as framed within this Bill and as imposed by suggested legislation within health care and aged care settings.

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[24] https://hospicecare.com/policy-and-ethics/ethical-issues/essays-and-articles-on-ethics-in-palliative-care/euthanasia-and-physician-assisted-suicide-are-they-clinically-necessary-or-desirable/

[25] *Oregon's Death with Dignity Act, Oregon Revised Statutes*, 127.800-127.995 S3.14

[26] The Californian *End of Life Option Act* 2015 Provision 443.18

The Bill's presumptions and processes ignore legitimate professional objections that euthanasia and assisted suicide practices lack evidence as "medical treatment"[27], and places patients at risk within the mandatory processes outlined. In doing so it creates harm to the doctor/nurse-patient or therapeutic relationship by undermining boundaries between end-of-life care practices that do not intend death, such as palliative care, and for those responsible for the primary care of the dying or nearing the end of their lives. It alters focus within consultations and can erode trust, lead to potential abuse within therapeutic relationships, and creates ambiguous health care environments that can lead to distress for staff, other patients, their families or carers, whilst fostering suicidal practices contrary to standards of expected good medical and psychosocial management.

NSW VAD Bill is designed by politicians and lobbyists for a niche societal agenda based on a narrow autonomy model with illusionary protections. The Bill cannot simply dismiss all position statements on ethical medical practice as irrelevant. Nor can it simply demand the creation of a medical intervention or medical agency through legislation simply to service that model. Codes of good medical conduct this Bill contravenes include those of the World Medical Association[28], the Australian Medical Association[29], the American Medical Association[30], the International Association of Hospice and Palliative Care[31], The European Association of Palliative Care, the Australia and New Zealand Society of Palliative Medicine[32] and the Australia and New Zealand Society of Geriatric Medicine[33].

5. *Legal Implications and Regulatory Consequences of the NSW VAD Bill, 2021.*

i. Principles within the proposed legislation require a significant change in world view

Coherence is a mark of good law. This Bill claims criminal law is changed to allow a class of persons to be killed confined to only terminally ill adults and only by doctors. One should ask how this Bill could make this claim when its principles are very broad. They seem to support the notion of equitable access without discrimination which suggests a foundation for future "scope creep" or expansion/relaxation of the law to others, and by others. Protections and sanctions are illusory and unenforceable and merely removable stickers from inherently unsafe legislated practices, led by arbitrary assumptions.

As a secular group of practitioners, we know one does not need to be "religious" to oppose this bill. Human life is valuable, consent is only the start of whether an action is moral, and doctors should not

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[27] Boudreau, J & Somerville, Margaret. (2013). Euthanasia is not medical treatment. British medical bulletin. 106. 10.1093/bmb/ldt010.

[28] https://www.wma.net/policies-post/wma-statement-on-physician-assisted-suicide/

[29] https://www.ama.com.au/media/euthanasia-and-physician-assisted-suicide

[30] https://www.ama-assn.org/delivering-care/ethics/physician-assisted-suicide

[31] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5177996/

[32] https://www.anzspm.org.au/c/anzspm?a=da&did=1025365

[33] https://secure.anzsgm.org/documents/FinalEuthanasiaDiscussionPointsAugust2014_final.pdf

kill their patients. This Bill is not neutral and it's not just about choice. It is weighted toward appeasing those who want the autonomy model to be elevated above other competing concerns as exemplified in the Bill's "safeguards".

We have already drawn attention in ***Section 4 iii*** of this submission that this Bill allows doctors involved in the assisted suicides to have greater powers without specific provisions toward drug administration.

ii. The practical value of safeguards

The Bill has very detailed bureaucratic processes, but at the end of the day, safeguards must eliminate the risk of death occurring otherwise by the letter of the law. In law, there is a rebuttable presumption that an adult person has capacity to make decisions which is displaced by evidence to the contrary. Assessing a person's capacity for a specific decision is a complex process. There is no one test in the law as to how to prove this. The courts consider different sorts of medical experts, evidence, and tests, as well as evidence about the patient's history, worldview, and preferences. The Bill anticipates problems with capacity and given it's such a unique and irrevocable decision to want to kill oneself, it begs to question why the Bill would not incorporate that presumption so that the doctor has to assess capacity from scratch. But this Bill incorporates the presumption (clause 6(2)) and its solution is to refer the patient to another doctor, though it's unclear how this second doctor can determine this and what information they'll have, especially if they have never met the patient before.

The Bill also anticipates problems with coercion and duress. We know about 'elder abuse', inadequate family support, mental illness, and the fear of not wanting to be a burden on others are common problems in this population. Coercion and duress can be very hard to see especially if you do not know the patient. Knowing whether a person's will has been overborne by these considerations requires a forensic analysis that befits the irreversible decision contemplated. Again, the Bill's solution is to refer the patient to a psychiatrist, other doctor, or other suitably qualified person. This second person may never have met the patient, may be reliant on information the patient gives them, and may lack the time and skills to properly investigate this concern. Moreover, these referrals to another practitioner are optional and rely on the insight of the first practitioner to be aware of the problems encountered, which cannot be assumed.

Witnesses are 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 fits when one considers that witnesses may not 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 is no requirement for the doctor to make any enquires about the witness' eligibility beforehand. The process can be completed and the patient dead within 6 days, without legal recourse.

To conclude, these are not safeguards. They are detailed tick box bureaucratic processes that cannot guarantee a safe result and depend very heavily on the integrity of doctors willing to commit physician assisted suicide. 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.

Truth, as well as accuracy, is also a casualty in the Bill's dictated processes. The Bill states that assisted suicide is not suicide (Clause 12). This is not true. It tells the doctor to record the cause of death as the underlying illness. This is also not true. If a death certificate is issued, it does not record that the person was subject to VAD. This is a problem because a death certificate has epidemiological consequences for statistics and data, for prognosis of disease processes, and the planning and provision of health services. It also embeds in the law that truth has lesser importance. When coupled to the lack of information, paucity or inaccuracy of records provided to the VAD Board and the Coroner's Court by the Bill's limited requirements, there are serious concerns toward the erosion of the Coroner's power to investigate injustice, wrongful deaths and other abuses.

The substance used to cause death is poison. Medication is not meant to intentionally kill someone. Medication that causes death would never be the subject of clinical trials for safety and efficacy or meet the TGA requirements that they are intended for diagnosis, cure, mitigation, treatment, or prevention of disease, ailment, defect, or injury[34,35]. If it is considered a medication, this would require major and changes to commonly held definitions in other legislation.

With regards to this Bill's conscience clause protection, NSW does not have human rights legislation and conscience is not a protected attribute under the Anti-Discrimination Act, so the stated conscience protections in this Bill is really all there is. In Clause 9, the Bill shields doctors from participating in the process but narrowly so; in clause 21(4) and (5), they must give the patient information that is approved by the Health Secretary – which we have not seen – and in clause 23(2)(h), they must report their objection and the reason for it to the VAD Board. There would likely be concerns about all of this, and how this information us going to be used. It overrides usual clinical practice and patient safety processes and demands complicity and altered interaction within the usual doctor's duty of care. It also can be in breach of patient confidentiality.

Doctors may have concerns about providing government information to patients about the service they object to, where they don't believe the patient is getting good and fulsome advice. In that case, they would feel like they are co-operating in the service and the only way around it would be to be permitted to supplement that government information with their own information and referrals. This behaviour might be seen as misconduct. With regards to doctors already trained in provision of evidenced based care of the seriously ill, dying, aged and those with mental health conditions, it especially creates a medical dystopia. In this case, the doctor who practices best clinical practice and tries not to create undue influence toward suicide in a patient, can be disciplined because they have done so.

Institutional conscientious objection is new in NSW (Clause 106 ff) although it is in the Queensland law. Facilities with ethos objections can advertise that fact, but reasonable access must be given to patients

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[34] Therapeutic Goods Act 1989 (Cth) s 4(1). We note the TGA ensures drugs supplied, imported, exported, manufactured or advertised for use are appropriate for health; and that drugs appropriate for health are defined as those intended for diagnosis, cure, mitigation, treatment or prevention of disease, ailment, defect, or injury.

[35] National Health and Medical Research Council, 'National Statement on Ethical Conduct in Human Research (2007)' General Guidance Section 2, see especially 2.33-2.38, 2.44, 12.

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, again preference is given to VAD over the rights of associational organisations to uphold their ethos.

We are only now learning of how distressing it is to patients, staff and carers within organisations to be in the vicinity or in charge of care of patients undertaking the VAD process. There already exists evidence for this and institutional damage in Canada and Victoria in both public and private facilities, as mentioned in ***Section 4*** of this submission. Staff and carers should be afforded safe spaces to perform their duties. Processes in this Bill are able to override usual expected best care, patient safety protocols and quality assurance expected of health care and social services.

The "protections" within this Bill are insufficient, inaccurate, cosmetic and devoid of usual safe medical and legal approaches or definitions. This renders the Bill's assumptions incorrect, as the protections are referenced only for the narrow group of individuals and doctors for whom this Bill was written.

We would be happy to answer any questions or clarify any aspects of our submission to you further. Please do not hesitate to contact us. We also respectfully thank you for your consideration of the material we present toward this Inquiry.

Yours sincerely,

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On behalf of the signatories for www.healthprofessionalssayno.info (See Appendix 7.)