Submission No 32

INQUIRY INTO PROVISIONS OF THE VOLUNTARY ASSISTED DYING BILL 2021

Organisation: Live and Die Well

Date Received: 22 November 2021

1. Introduction

This review of the Voluntary Assisted Dying Bill 2021 has concentrated on the first 6 parts of the Bill.

The Bill has a number of similar elements to the End of Life Choices (Voluntary Assisted Dying) Act 2021 that was passed by the Tasmanian Parliament in March 2021. This Bill is more streamlined being 78 pages long instead of the 180-page length of the Tasmanian Act.

This Bill is being promoted as being about maximizing patient autonomy while providing extensive safeguards to protect the vulnerable. Despite the window dressing of safeguards, the analysis provided below seeks to demonstrate that there are significant risks for vulnerable people associated with this Bill as they may unwillingly and/or unwittingly access assisted suicide or euthanasia.

2. Eligibility Criteria

2.1. Eligible Medical Condition

The eligibility criteria in the Bill are detailed in Clause 16(1). Clause 16(1)(d) covers the qualifying medical condition of the patient. The way this subclause is drafted, it provides two paths for the criteria to be satisfied. 16(1)(d)(i) requires that the person has a disease, illness or medical condition that is advanced, progressive and will cause death. The patient then needs to satisfy a prognosis condition in 16(1) d)(ii) or an intolerable suffering condition in 16(1)(d)(iii). Consequently, the person's unrelieved suffering is put on an equal footing with their prognosis in terms of the eligibility criteria. This situation could allow people who do not have a terminal illness qualifying for access to assisted suicide or euthanasia even though they could have many years to live. Could this clause structure allow for someone requiring dialysis, people with advanced diabetes or another serious but treatable health condition to qualify for assisted suicide or euthanasia?

2.1.1. Diagnostic inaccuracy

The diagnosis of the medical condition, illness or disease that is required in Clause 16 (1) (d) is subject to the problem of diagnostic inaccuracy. The following points need to be considered in relation to diagnostic inaccuracy:

- 1 in 7 medical diagnoses in Australia are incorrect.[1] This figure has been found in other studies.
- Getting a second opinion by a specialist can significantly change the original diagnosis.[2] There is no requirement for a specialist in the Bill.
- Lack of physical examination can increase the risk of misdiagnosis. The Bill doesn't require a physical examination[3] by the assessing medical practitioners. They could perform their role by audio-visual link.

[1] https://www.uq.edu.au/news/article/2020/09/one-seven-medical-diagnosis-incorrect
[2] https://pubmed.ncbi.nlm.nih.gov/28374457/
[3] https://pubmed.ncbi.nlm.nih.gov/26144103/

2.1.2. Prognosis predictions are difficult to make accurately.

The prognosis requirements of the Bill that are covered in Clause 16 (1) (d)(ii) need to be considered in the context of standard medical practice. The following points need to be considered in judging whether prognosis should be used as part of the eligibility criteria:

- "*The median isn't the message*"[4]: prognosis is a statistical construct and a person's prognosis is usually expressed as a median based on historical statistical data for the underlying condition. It is essentially a time period in which 50% of the people who have a condition tend to die in.
- In Washington State, USA, that has legalised assisted suicide for people with a prognosis of 6 months or less, a total of 167 people since 2009 have died outside the 6 months period from their first request and that constitutes 11.5% of the total amount of people who have committed assisted suicide.
- The Australia Commission on Safety and Quality in Health Care *National Consensus Statement: "Predicting prognosis and the timing of dying can be difficult. ... it may be difficult to distinguish clinical deterioration that is reversible from deterioration that is irreversible and part of the normal dying process."*[5]

2.2. Decision Making Capacity (DMC)

The patient needs to satisfy that they have decision making capacity during the assessment process as part of the eligibility criteria contained in Clause 16 (1) (e). The decision-making capacity of a patient is defined in the Bill in Clause 6 (1) as being based on a number of factors. Clause 6 (2) then states that decision making capacity of the patient can be presumed unless there is evidence to the contrary. Furthermore clauses 27(1)(a), 38(1)(a), 52 (f)(c) and 62 (2)(b)(c) allow for the coordinating, consulting or administering practitioner to refer the patient if they are unsure about their DMC. Clause 6(1) and Clause 6(2) seem to be contradictory in that subsection (1) requires a certain standard of decision-making capacity by the patient whereas subsection (2) assumes the patient has decision making capacity.

The assessment of decision-making capacity is far from a trivial exercise as indicated by the following points:

- Accurately assessing a person's decision-making capacity is critical to assessing whether they are choosing assisted suicide or euthanasia in a fully rational manner.
- According to Dr Chris Nickson an Intensivist and ECMO specialist at the Alfred ICU, the more serious the decision to be made, the greater the care needed to ensure that capacity can be assumed.[6]
- A range of studies have shown that patients who lack decision-making capacity can often go undetected by their GPs in a primary health setting or by health care professionals in a hospital or hospice setting. These studies have discovered:
    - 28% of hospital inpatients lacked the necessary capacity for medical treatment.[7]

[4] https://journalofethics.ama-assn.org/article/median-isnt-message/2013-01
[5] https://www.safetyandquality.gov.au/sites/default/files/migrated/National-Consensus-Statement-Essential-Elements-forsafe-high-quality-end-of-life-care.pdf, page 17.
[6] https://litfl.com/capacity-and-competence/
[7] http://imj.ie/mental-incapacity-for-treatment-decisions-where-do-doctors-stand/

  - Up to 60% of people with mild to moderate cognitive impairment (MCI) are undiagnosed.[89]
  - Patients with MCI demonstrate significant impairments in relation to capacity to consent.[10]
  - 54% of a group of people who were receiving palliative care had significant cognitive impairment that was previously undetected.[11]
  - 85% of terminally ill cancer patients had impaired capacity based on a standard test while only 33% were rated by physicians as being impaired.[12] Hence 52% of patients with impaired capacity where missed by physicians.
  - An Australian study found that there is a lack of a uniform approach to determining capacity and this is a significant challenge in a rural hospital setting. To effectively safeguard people's rights, robust, valid and reliable objective measures to decision-making capacity assessment are required.[13]

- In the context of MCI, one study[14] has found that 77% of hospital patients over the age of 60 were detected to be cognitively impaired using one of two cognitive screening tests whereas staff physicians only detected 57% of this impaired cohort and staff nurses detected 83% of this impaired cohort. This study highlights that assuming decision-making capacity based standard interactions between healthcare professionals and their patients is problematic and is prone to error.
- These findings indicate that the approach proposed in the Bill to decision-making capacity assessment is completely inadequate to reliably detect whether people who are experiencing varying degrees of cognitive impairment.
- A more robust method of assessing decision-making capacity is required. Telehealth is not going to help this.

2.3. Voluntariness

The eligibility criteria of the Bill require that the person requesting assisted suicide and euthanasia is doing so on a voluntary basis and is not subject to pressure or duress as specified in Clause 16 (1) (f). Detecting whether someone is being coerced by a third party into requesting assisted suicide or euthanasia is not a simple matter. Furthermore, external factors are not the only things that can influence a person's voluntariness. Voluntariness can be impacted by internal factors identified by Dr Laura Roberts[15]:

- **Developmental factors**: this was implied in the previous NSW VAD Bill defeated in 2017 that had a minimum age of 25,

[8] https://litfl.com/capacity-and-competence/ ,
[9] https://bmcgeriatr.biomedcentral.com/articles/10.1186/1471-2318-12-47
[10] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2676965/
[11] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3309124/
[12] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6345171/
[13] https://onlinelibrary.wiley.com/doi/abs/10.1111/ajr.12592
[14] https://bmcgeriatr.biomedcentral.com/articles/10.1186/1471-2318-12-47
[15] https://ajp.psychiatryonline.org/doi/pdf/10.1176/appi.ajp.159.5.705

- **illness-related considerations**: some medical conditions/treatments/associated pain can give rise to apathy and avolition that can impair a patient's judgements quite separate to their decision making capacity. Previous or current substance abuse addictions also have any effect. The degree of physical dependence can also be a factor in diminished voluntarism,
- **psychological issues and cultural and religious values**: Psychological issues and cultural and spiritual values influence the decisions people make.

Approaches for screening for voluntariness are not well developed in the medical community and are only now becoming more accepted.[16]

3. Assessment Process Issues

3.1. GPs lack knowledge about palliative care and treatment options

- The Bill assumes that the *coordinating practitioner* has appropriate expertise to present to the patient the relevant information about their relevant medical condition, potential treatments and options for palliative care as outlined in Clause 28 (1) (b) & (c) of the Bill. The relevant information in relation to palliative care is an important factor for the person in determining how their physical and mental pain could be alleviated. However, a 2017 national survey found that 75% of Australian GPs do not have a strong understanding of palliative care.[17] Hence it is unlikely that an important parameter of choice for people considering assisted suicide or euthanasia will not be provided by a doctor with the appropriate expertise.
- In most jurisdictions that have legalized assisted suicide or euthanasia, the majority of people that access the law are diagnosed with some form of cancer. Hence, a *coordinating practitioner* who is not an oncologist is at a significant disadvantage in being able to give people the most up to date version of the relevant information to help them make an informed decision. This disadvantage would be remedied if the Bill required that the *coordinating practitioner* be a **specialist** in a college that was most relevant to the relevant medical condition that the person was experiencing.

3.2. Impact of mental health on DMC and Voluntariness

- Depression and demoralisation can impact a patient's decision-making capacity, the freedom of their choices and also contribute to suicidal ideation.[18][19][20] Consequently, the mental health of patients making requests for death needs to be taken seriously.

- Studies have found that GPs do not detect depression in around 50% of cases[21]. Furthermore, depression diagnosis is particularly low for older adults.[22] Demoralisation is even harder to detect than depression as the symptoms are different and less commonly

[16] https://www.coreimpodcast.com/2020/07/22/capacity-2-0-and-voluntarism/
[17] *Research into awareness, attitudes and provision of best practice advance care planning, palliative care and end of life care within general practice,* Department of Health https://www.health.gov.au/sites/default/files/gp-best-practice-research-project.docx
[18] https://link.springer.com/article/10.1186/1472-6939-14-54
[19] https://bmcmedethics.biomedcentral.com/articles/10.1186/1472-6939-14-54
[20] https://www.jstor.org/stable/3528690?origin=crossref&seq=1
[21] https://ps.psychiatryonline.org/doi/full/10.1176/appi.ps.201600096
[22] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6541426/

encountered. Psycho-oncological professionals are more skilled in the diagnosis and treatment of demoralisation.[23]

- In 2008, Professor Ganzini from the Department of Psychiatry at the Oregon Health and Science University published a study[24] that showed that 3 of the 18 (or 17%) in the study cohort that died by consuming a lethal dose were depressed. None of those three received any assessment from a mental health professional despite their being an option for this in the Oregon Act. The study suggests that in some cases depression is missed or overlooked by the assessing doctors.

- A Lancet study[25], co-authored by Dr Philip Nietschke, looked into 7 people who either died under or where attempting to access the Northern Territory's Rights of the Terminally Ill Act 1995. Four out of the 7 has symptoms of depression. study cited another study that found that only 6% of psychiatrists in Oregon, USA thought that they could make a competent assessment of whether a person was depressed from one consultation.[26]

3.3. Person withholding of information from doctors

- A 2019 study found that clinicians do not receive information from at least 40% of patients facing potentially life-threatening situations (depression, suicidality, abuse, or sexual assault).[27] Of these four categories of imminent threats, three are highly relevant to the assessment of the eligibility criteria.
- The Lancet study of the Northern Territory legislation referred to above also highlighted evidence of nondisclosure of previous mental health issues.
- In the context of elder abuse, it is not uncommon for instances of abuse to be unreported.[28]
- There is a need for the person's GP and family to be consulted.

3.4. Information gaps that arise from the potential exclusion of family, carers, GPs and other health care professionals

While there are circumstances in which family/carers and GPs/other healthcare professional will be involved in the dialogue occurring between the coordinating practitioner/consulting practitioner and the patient, these interactions are not guaranteed by the structure of the legal framework in this Bill.

There is no requirement in the Bill that the coordinating or consulting practitioner to consult the patient's GP. Clause 25 (3) does not prevent the coordinating practitioner from using relevant information provided by other registered health professionals to make their first assessment. An identical provision is included in clause in 36(3) in respect to the assessment of the consulting practitioner.

Despite these provisions there is no requirement for either practitioner to do proper due diligence in terms of obtaining the person's full medical history. This potential information gap may have an impact on determining a correct diagnosis, prognosis, and the adequate assessment of decision-making capacity and voluntariness.

[23] https://www.mja.com.au/journal/2013/199/6/depression-and-cancer
[24] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2562435/
[25] https://pubmed.ncbi.nlm.nih.gov/9798585/
[26] https://pubmed.ncbi.nlm.nih.gov/8890683/
[27] https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2747759?resultClick=1
[28] https://link.springer.com/article/10.1007/s10896-019-00084-w

Clause 28 (1) (j) encourages the coordinating practitioner to inform the patient that they should inform any medical practitioner that they are currently receiving treatment from about their request for assisted suicide or euthanasia. However, this advice is left up to the patient.

There is no clause in the Bill that requires the family or a carer to be informed that the person is seeking to end their life by assisted suicide or euthanasia.

Clause 28 (4) includes a provision for the patient to nominate another person to be briefed by the coordinating practitioner in relation to the patient's medical condition/treatment options/palliative care options and their request for assisted suicide or euthanasia. However, this provision is only operative if the patient gives consent.

Family members are excluded from the assessment and poison administration process in the following manner:

- They can't be either the coordinating or consulting practitioner (this is a good clause): Clause 18(d),
- They can't be a psychiatrist, registered health practitioner or other person who receive a referral from either the coordinating or consulting practitioner to review a patient's decision-making capacity or voluntariness: Clauses 27(4)(a 38(4)(a),
- They are an ineligible witness for the patient's written declaration: Clause 44 (2)(b),
- They can't be the administering practitioner: Clause 55 (d),
- They can't be the witness when the administering practitioner administers the lethal does to the patient: Clause 63(2)(a).

While these exclusions can prevent self-interested family members from having conflicts of interest, there is also a chance that the family members may be uninformed about what is going on with their relative.

The fact that these two groups of people can be excluded from the process outlined in this Bill have an impact on how well the Board and the Tribunal can play their role in providing protection for the vulnerable.

4. Limited oversight by the Board and the Tribunal

The Board, in the context of approving a prescription of a poison substance, is primarily concerned with the documented dialogue between the coordinating and consulting practitioner and the patient concerned. There is currently no provision within the Bill to confirm that what gets presented to the Board in this documented dialogue is the full picture of the person's physical and mental health, decision making capacity or voluntariness as there are no objective witnesses. There is no requirement for the patient's GP/healthcare professionals or family to be consulted as outlined in the previous section. This incomplete picture in turn limits the ability of the Board to fully perform its role:

- to refuse, approve or disapprove authorisations for VAD Substance prescriptions as covered in Clause 71-72: in Clause 72 (1) (b) the Board must refuse to issue an authorisation in the case when "*the Board suspects that the requirements of this Act have not been met in relation to the patient*." For the Board to have this suspicion they would need to either receive information from a family member/carer/GP or other healthcare professional who knows the patient who might have information that presents the case in a different light.

When these people can be excluded from the process it reduces the ability of the Board to refuse authorisation when something illegal is occurring,

The Tribunal role is also compromised if key stakeholders can effectively be left out of the assessment process:

- there is a question about whether family members, carers or GPs would have standing to make an application to the Tribunal. Clause 108 (c) does allow for the Tribunal to grant permission to be an eligible applicant who has a special interest in the medical care and treatment of the patient. It is unclear who would have a special interest.
- If the family members, carers or GP of the patient are kept ignorant of the patient's wishes to access assisted suicide or euthanasia then they are unlikely to make a complaint.
- A complaint can only be made about the patient's residential eligibility, their decision-making capacity or their voluntariness. The patient's diagnosis or prognosis are not considered by the Tribunal despite 1 in 7 diagnosis in Australia being incorrect.

5. Other Concerns about the NSW VAD Bill 2021

5.1. Situational Crime Factors associating with Self Administration

There are situational crime factors surrounding the contact person that is required by clause 66 for patients who select the self-administration option. The contact person will have knowledge of where the VAD substance will be stored in the patient's residence. They are also allowed to possess the lethal poison. So, they will have a potential method to bring about the patient's death without their consent.

There is no requirement in the Bill that excludes someone from being a contact person if they will directly or indirectly benefit from the patient's death. Hence, they will potentially have a motive to commit a criminal act.

The lack of any compulsory screening of potential contact person's through the Working with Vulnerable Person's system or for a criminal history also exposes the patient to risk.

In summary, the Bill does not protect the patient from choosing a contact person who might have a prior history of abusive and or criminal behavior, a motive to hasten the patient's death and a relatively easily accessible method located within the patient's home to end their life that will most probably not be investigated by police or a coroner.

Another issue is that the Bill does not require that the mental health of the contact person be reviewed. They will have access to a poison that can cause a rapid death. The suicide rate of veterinarian is the highest for any profession as they have ready access to pentobarbital.[29] This access will undermine suicide prevention strategies.

5.2. Clause 10

Clause 10 deals with a restriction in the ability of health professionals to initiate discussions with a person in relation to assisted suicide or euthanasia. Subsection (2) allows medical practitioners and registered nurses an exemption from this provision if they inform the person about their treatment and palliative care options. However, given the complex nature of potential treatments for cancer or neurodegenerative conditions and the options for palliative care it is unlikely that most registered

[29] https://news.vin.com/default.aspx?pid=210&Id=9717454

health practitioners would have enough expertise in this area. Hence, they should not be encouraged to initiate conversations on this topic.

5.3. Slow deaths or complications with assisted suicide/euthanasia

The Bill in clause 55 allows for a nurse practitioner or a registered nurse with at least 5 years' experience to administer lethal doses to patients. What will these nurses do if the patient is dying slower than expected? This is not uncommon given the experience of slow deaths in jurisdictions such as Oregon and Washington State in the USA.

Do these nurses have the training and or authority to administer other poisons that will hasten the process? A recent study by Zworth et al details how administering practitioners in other jurisdictions deal with deaths that are taking too long.[30] The main strategy used is for neuromuscular blockers (NMBs) to be used to accelerate the person's death. NMBs are used commonly in anaesthetics. Their administration is normally guided by medical devices that can help monitor the patient to guide dosage levels. The knowledge of their use is quite specialised. Do administering practitioners have adequate training in this area?

There are no provisions in the Bill that require the administering practitioner to preserve the life of the person in the event that there are complications. One of the main complications that arise from the ingestion of barbiturates that would be part of the self-administration process is pulmonary edema[3132]. Pulmonary edema is a serious health condition that will require high level of first aid skills and require rapid hospitalisation and intensive care attention. The likelihood that a nurse practitioner or a registered nurse could deal with this situation at a person's home is questionable.

5.4. Use of Audio-visual communication links

Apart from issues surrounding the negative impact that audio-visual communication links will have on the assessment of the eligibility criteria as mentioned above there also remains an issue about the legality of this practice.

The Victorian Voluntary Assisted Dying Review Board released its Report of Operations for January – June 2020 on 1/9/20. The report drew considerable attention to the issue of the legality of using telehealth to provide access to assisted suicide. The report highlighted that "due to sections 474.29A and 474.29B of the *Commonwealth Criminal Code 1995* as amended by the *Criminal Code Amendment (Suicide Related Material Offences) Act 2005*, it is an offence to use a carriage service (such as telephone or telehealth) for suicide-related material, which may include voluntary assisted dying. This places medical practitioners at risk of prosecution."

Federal Attorney General, Christian Porter, in comments to The Age[33] on Tuesday said that "*Advice to the Commonwealth officials at the time indicated that it was a requirement of the Victorian legislation that consultations occur in person and so there seems no conflict with Commonwealth offences relating to inciting or instructing suicide online*,". This Bill explicitly promotes the option for

[30] Zworth M, Saleh C, Ball I, et al. Provision of medical assistance in dying: a scoping review. BMJ Open 2020;10:e036054. doi:10.1136/ bmjopen-2019-036054

[31] https://journals.sagepub.com/doi/pdf/10.1177/000331976401501005

[32] https://www.npr.org/2020/09/21/793177589/gasping-for-air-autopsies-reveal-troubling-effects-of-lethal-injection

[33] https://www.theage.com.au/national/victoria/euthanasia-laws-used-by-124-terminally-ill-victorians-to-end-their-lives-20200901-p55rav.html

doctors to use an audio-visual link for consultations in clauses 23(2)(d), 51(2)(e) and 183. Consequently the proposed new NSW laws would place medical practitioners at risk of prosecution.

6. Institutional Conscientious Objection

Part 5 is completely unacceptable. A hospital or aged care facility can make provisions for patient transfer if they wish to seek assessment for or access to assisted suicide or euthanasia at another institution or location. These facilities should be under no obligation to provide a patient with access to any part of the process on their grounds or be required to assist in the eligibility assessment or the administration of assisted suicide or euthanasia.