

Submission into the Voluntary Assisted Dying Bill 2021

Submission No.: 1228

Submitted by: Health Professionals Say No!

Publication: Making the submission and your name public

Position: I/We do not support the Voluntary Assisted Dying Bill

Comments in relation to: Eligibility criteria* ,The request and assessment process,Administration of the substance,Safeguards,Conscientious objection by either individuals or entities,Oversight and review,Other

Attachments: See attachment

Submitter Comments:



Health Professionals Say No!

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June 30, 2021

The Health and Environment Committee
Parliament House
George Street
BRISBANE QLD 4000

Re: Voluntary Assisted Dying Bill 2021- Legal Framework

Dear Health and Environment Committee

We represent a large network of health professionals across Australia involved in the care of those nearing their end of life or with significant health issues as well those with mental health conditions and disability. We share serious concerns around the introduction of Voluntary Assisted Dying legislation to Australia. We are particularly concerned about aspects of the proposed legislation for Queensland which we will attempt to deal with in this submission and draw reference to sections outlined below.

Health Care Worker Discussions with a Patient –

Part 1, Division 4, Sections 1, 2 & 3

(Relevant also to definitions and process for designated practitioners)

If the Health Professional were not adequately trained in the specialty of the disease, palliative care or psychiatry, they will not be able to fully assess the patient or adequately explain best clinical practice, care and options available to the patient.

It would be unrealistic and negligent to consider that all health care professionals, as simply proposed in these sections, would be adequately trained to assist with decisions around VAD or to inform patients of all their management options and outcomes. Nor would they be able to reliably assess prognosis and contributing factors leading to a request for VAD, inclusive of depression or demoralisation. This situation would require specialist doctors to ensure accurate mental health assessment, diagnostic and management options, and appropriate physical and psycho-social care has been delivered. It would also ethically wrong and sub-optimal clinical practice for a doctor involved with the care of any significantly ill individual or vulnerable

individual to be involved toward or suggest to that person that VAD could be an option for them as implied, and especially so without the person having been appropriately referred for them to experience the care usually required for their condition, whether palliative or other causes for possible demoralisation addressed.

We know from well-constructed studies and evidence that without formal assessment, that 35-45 % of those seeking assistance to end their lives are likely to have an undiagnosed depression which would not have been part of their prior history, and that 35% of people with physical as well as mental illness may lack mental capacity in making decisions about their health (1,2).

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 (3).

Of significant interest, reviewing the recently published detail of the Victorian Coroner's data analysis based on 118 active cancer patients (5), it seems that only 42% had cancers at an advanced or late stage. Interestingly, 48% reported the heavy burden of cancer treatment as an issue, rather than the illness (a potentially avoidable burden). One important implication, however, is that lack of access to high quality specialist palliative care and other supports may have resulted in many of these cancer patients being driven to suicide. This last point is especially significant considering issues with lack of access to quality medical, psycho-social and palliative care services in Queensland at present, and especially as experienced in regional areas. In these instances, legislation framed in this way would not be assessing or dealing with the cause of the person's suffering, or probable depression or demoralisation.

Further, the Royal Commission in Aged and Residential Aged Care has well demonstrated the significant rate of elder abuse and that coercive and abusive behaviours toward the vulnerable of our society often go unnoticed or not assessed. Any such request, especially from a vulnerable individual requires greater due diligence and specialist interaction. Good laws make it easier to do right and harder to do wrong – but these type of changes to the law only make coercion and abuse more likely. If enacted, without the appropriate assessments, checks, balances and oversight in place as described above, VAD legislation may initiate a gradual shift from a 'Right to die' to a 'Duty to die'.

A survey of more than 1500 medical practitioners conducted by the WA branch of the AMA has found that doctors are very concerned about the lack of safeguards in the WA euthanasia bill, and in particular, about the lack of equitable access to palliative care across the state. More than 90 per cent of doctors surveyed consider it crucial "that there should be demonstrated, equitable access to palliative care for patients at the same time as voluntary assisted dying is offered." This answer was the same whether the doctor is personally opposed to or supportive of euthanasia and assisted suicide. This concurred with a survey of 2000 WA residents that demonstrated 75% would want the Government to address palliative care service provision and regional access issues ahead of VAD.

It is also for all these reasons that TeleHealth application of VAD legislation should not be permitted. The difficulty in assessing body language, carer/family interaction with the patient and to assess the patient's environment, safety or vulnerability, or conduct a physical examination, are all impacted though remote technology and lend themselves to inaccurate assessments. Application of Telehealth arrangements should be to afford those in remote or service poor areas with medical and psychosocial support and monitoring which encourages positive physical and mental health practices, preventing isolation, loneliness or feelings of abandonment.

Another important consideration here is the power imbalance in the clinician-patient relationship. In those with serious illness and cancer the expressed desire to die often indicates a cry for help and diminishes with appropriate psycho-social support. We know from a large Australian study that even in cancer patients it is usually linked to poor family cohesion, lack of support and sense of burden or depression rather than physical suffering, and that this desire persists when the doctor approached is sympathetic to hastening death and not psychologically or palliatively trained when compared to one who is, as the causes of distress are not addressed (5). Making VAD legal, therefore, does not make it a valid "choice", when the cause of suffering is not addressed, or the person is not managed or assessed by the right specialist.

It is also for this reason that a clinician and institutions involved in the care of vulnerable and disabled individuals, those with dementia or those with terminal illness should NOT be involved in roles to end a life (6). The undue influence this would create on patient choices and their care cannot be underestimated; a point we will emphasise further in another section of this submission.

Division 4, Section 8 (a)&(b)

Impact Health Care Planning, State Coroner's Act, Person Safety & Legal implications.

N.B. This section naturally involves considerations around witnessing of the death, process of drug administration, potential loopholes for abuse and patient safety in drug administration, and needs to be considered with other aspects of the proposed legislation as mentioned around;

- i. the powers of the "Agent" and who may be a beneficiary of the patient's will
- ii. the lack of lack safeguards and inadequate selection criteria around the "Witness" who can also be dispensed the drug for collection in place of the patient
- iii. lack of due diligence and safety practices around drug administration
- iv. a 2-day lapse before reporting occurs
- v. Death Certification not recording VAD as the cause of death

We also hope to enhance your awareness of the ethical considerations and implications of the use of language and medical certification in this section.

Although Section 8 states the nature of the act is not to be likened to suicide, neither is it a medical treatment nor part of good evidence-based end of life or palliative care (7). The bill ignores that all the major medical peak body groups including the World Medical Association, the Australia and New Zealand Society of Palliative Medicine, the International Association of Hospice and Palliative Care, the American College of Physicians (to name a few) which are all clear on the reasons for definitions and the language used so, whatever named, Voluntary Assisted Dying, constitutes state sanctioned killing and does not constitute normal healthcare provision, medical treatment nor is part of palliative care. For the sake of seeking some understanding I include a brief ethical discourse to assist further clarification of terminology implications where legislation exists (8).

In relation to the Death Certification and the State Coroner's Act, a death under the proposed legislation is not a "reportable death" to the Coroner, thus eroding the power of the Coroner to investigate a potential abuse of the legislation or coercive influence. Arguably the death under the Voluntary Assisted Dying legislation may only be investigated by the Coroner where it might be reported to have contravened protocol, but given no health professional needs or reliable independent trained witness to be present at the death, this impacts on two areas: firstly, the Coroner is deprived of important knowledge about the events around the death, inclusive of coercion or violation of the deceased ingesting the drugs, or whether it was a humane or supported death.

This would be compounded by the delay from the two-day period allowed for the death to be reported to the oversight committee. The absence of medical oversight and laxity of criteria in who can be a witness deprives the necessary safety check of having a reliable trained independent or medical witness. The many permutations of who qualifies as an agent or witness and ability for estate beneficiary to be involved creates many loopholes for potential breach of safety in legislative application. The legislation facilitates the situation where both the Coroner and the oversight committee can lack the necessary information to be concerned to investigate.

Falsification of the Death Certificate not to indicate the true nature of dying also presents an inaccurate face to health epidemiology, as people may die well in advance of the illness causing complications and as many may have died from other causations before the disease itself led to dying. This has major implications to the accurate maintenance of epidemiological statistics, impacting on translational health research, health service planning and social policy agendas.

Requirements for Access to VAD

Part 2, Section 10&15

Selection Criteria & Eligibility

Our concerns here are manifold. Many factors behind VAD requests (as evidenced in the literature and in the media) are individualistic, made in the absence of evidenced best medical approaches and with subjective interpretation.

Suffering is subjective and even so, the cause of suffering is what should be addressed. It is not true that pain cannot be controlled or managed in most instances, nor is pain the usual cause of VAD requests. Defining suffering and incurable illness in legal terms is arbitrary and has inevitably resulted in extension of the law, even to children and elderly unable to speak for themselves, in jurisdictions where euthanasia and VAD practices exist. Although proponents of VAD deny this in a sloganistic manner, in our previous submission have provided evidence to the contrary with legislation been shown to extend to even to the disabled and children in Belgium, show overt abuse against the elderly in the Netherlands and offered as alternative to appropriate usual care to those with disability and chronic disease in Canada and Oregon, respectively.

Further, there is a real risk for the undermining of health initiatives toward the rising suicide agenda. Suicide rates have been actually shown to increase in overseas jurisdictions where VAD and or euthanasia legislation exists. Government priority should lie in prevention efforts for the current crisis faced in regional Australia, amongst First Nation peoples and in the young (9,10). Therefore, eligibility should not include “mental suffering” for the many aforementioned reasons in Part 1, and as the messaging given might encourage legitimisation of suicide in place of seeking help, particularly where there are inadequate areas of service provision for early detection and management, or lack of supportive care for those with co-morbidities.

As was mentioned before and as is our experience, many people have a fluctuating desire to die, which diminishes closer to death. Once given appropriate care most people change their mind. This has been supported by quality data collected by Australian Palliative Care organisations over a few decades now. It is also reflected in overseas data that many more lethal prescriptions are written than administered, with circumstances around deaths being underreported.

In the preamble to the bill, it is stated that the legislation designed would be “for the dying.” The 12-month period suggested is therefore much too long. It lends itself to an “expectation” that the person will die in this manner, irrespective of true prognosis and outcome. The accepted period should be, therefore, less than 6 months, but with greater regulation around safety, storage and administration to prevent abuse and reporting and allow for a change in decisions, desire or condition of the patient to be reassessed and responded to in line with good clinical practice. Therefore, the timings given for enactment are much too short unless the person is imminently dying and has been given the benefit of appropriate evidenced good quality end of life or palliative care.

Lastly, on the point of eligibility by geography and treatment bodies, and there needs to be strict criteria of eligibility and border restrictions and medication provision within Queensland borders only. The more variations allowed here, the greater the risk for inappropriate medication handling and with patient safety implications, inclusive of lack of oversight and reassessment of the patient.

Requesting Access to VAD and Assessment Eligibility

Part 3

The impacts of legislation on clinicians and health care settings.

Clinicians and institutions involved in the care of vulnerable and disabled individuals, those with dementia or those with terminal illness should not be involved in roles to end a life. As mentioned before, the undue influence this would create on patient choices and their care cannot be underestimated.

Doing so also creates ambiguous health systems in which many may be afraid to seek help or referral due to a blurring of boundaries and patient perceptions of what might be offered or expected. Some of us have already experienced this due to media reporting and misinformation spread about palliative care during the Victorian VAD campaign. We have seen culturally and linguistically diverse groups, elderly, homeless and first nations people express fears stemming from such campaigns, and in line with their fear or distrust of authority, subsequent to historical experiences. An example of this includes the factors that led the removal of Northern Territory legislation, as first nations people became fearful to present for medical attention. **VAD and euthanasia are not medical treatments and not of palliative care practices and should not be performed in palliative care facilities or services.** This assertion is also in line with the policies and positions statements of the Australia and New Zealand Society of Palliative Medicine, Palliative Care Nurses Australia and the International Association of Hospice and Palliative Care.

Doctors, nurses, healthcare professionals and institutions practicing best practice health care and end-of-life care should not be forced by VAD legislation to act against their ethical standards. It is not only religious conviction that drives moral and ethical thought. Many in our network are of no faith or spiritual belief, but we stand united in our ethical convictions, combined and individual experiences, through examination of evidence from jurisdictions where VAD and euthanasia exist, by knowing what can be done to ease suffering, and that health agendas should not be compromised for social ones.

A request for VAD may often be due to the assertion of one's autonomy, which on its own, cannot be considered a valid basis for a healthcare intervention. Taking a life or assisting another to do so is not a medical treatment and for us is an **infringement of our rights and ability to work in an ethical and safe work environment.** Trying to assist a person improve their sense of wellbeing or quality of life and accompany them in the different phases of their illness or aging, is not congruent with then taking their life. There are **natural ethical conflicts and tensions** which impact on the care environment, leading to moral and emotional distress in health care workers and distress, fear or suspicion in patients, carers or families.

The vast majority of doctors and nurses do not want to be involved in VAD. For many there may also be deeply held moral or faith based/spiritual beliefs. In fact, the more a health care professional is involved with those nearing their end of life or dying, the less likely they want to be involved in VAD practices. The role even when there is no cure is for dignified care and true

accompaniment of frail and ill through provision of that care. In this way healing may take place even when there is no cure. This reality also applies to many health care institutions, care homes for the aged and disabled, for community health care and personal care services, for which VAD is against their vision, charter or policies. Enforced involvement, whether it be referral or for VAD to occur within such an institution or service lends, itself to a myriad of issues. If obligation or enforcement orders exists, health care workers and carers would be made to feel complicit or to fear of disciplinary action.

If the government wishes to legislate for VAD, it is the government's responsibility to provide for it in such a way that the legislation does not violate the rights of those who have ethical, moral or institutional reasons not to be involved at any level, and who do much of the real care needed for the frail, ill and aged.

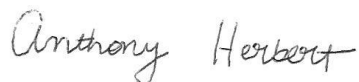
In regard to Residential Aged Care Facilities (RACFs), there are also clear accreditation standards around medication and patient safety, medication management and the delivery of palliative care. There is also legislation around medication storage and prescribing for RACFs which make it difficult for meds to be stored without an existing administration order for an indefinite period. Many of the care staff are inexperienced in the handling of dangerous drugs. The staff may well include nurses and carers many of whom would be conscientious objectors and from culturally and linguistically diverse groups. There will be many residents and families distressed if they find out residents were being killed in their care home, with moral distress and ambiguity around messaging, or around care expectation and needs being delivered in a differential manner.

Further RACF are governed from a federal level, and with many having policy or faith-based objections to allowing VAD or euthanasia within their facility. Fluctuating competence is also an issue in many aged and cognitively affected individuals who may have medication orders in place, with a requirement for even greater attention for their safety and for the other residents around them.

Thank you for this opportunity to provide our concerns and perspective on the proposed legislation. Please do not hesitate to contact us for any further clarifications or information.

Yours sincerely,

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For all signatories, please see www.healthprofessionalsayno.info

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