

**Submission
No 91**

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

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Submission to NSW Parliamentary Inquiry
Voluntary Assisted Dying Bill 2021

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I am a consultant geriatrician (a medical specialist in the care of older people). I care for older people, especially those with neurodegenerative disease (such as dementia and Parkinson's disease), stroke, frailty, fractures and falls. In over 25 years of specialist experience, I have worked in both the public and private sectors in NSW. I served on the Federal Council of the Australian and New Zealand Society for Geriatric Medicine (the peak professional body for geriatricians) from 2001 to 2021.

I write to this Parliamentary Inquiry to plead to legislators of the NSW Parliament to vote **against** the NSW VAD Bill 2021.

Voluntary Assisted Dying (VAD) is known by other names and acronyms including Voluntary Assisted Suicide (VAS), Physician Assisted Suicide (PAS), Euthanasia/Assisted Suicide (EAS), Medical Assistance in Dying (MAiD) and Euthanasia. For ease of discussion, I will refer to it as "VAD".

VAD (in all its forms and by all its other names) has been considered by medical professional groups as not being part of medical practice or palliative care. VAD has never been part of the ethos, training or expertise of medical professionals over almost 3000 years of the history of the formal practice of Medicine. In very recent times, it has been legislated in a small number of jurisdictions in the world. However (in keeping with the widespread understanding of the proper role and purpose of good medical practice), it has been rejected in most other jurisdictions in which attempts have been made to introduce it.

Setting aside the moral and ethical concerns about VAD, there are very good reasons why the NSW VAD Bill 2021 ("The Bill") should be rejected.

Specific Concerns Regarding the Bill

1. As medical professionals, we have no “requirement” for VAD legislation in order to provide high quality medical care to patients. VAD adds nothing to my ability to relieve suffering, improve care, relieve symptoms or achieve any other goal of high-quality geriatric medicine, palliative care or general symptom control. To the best of my knowledge, no hospital or residential aged care facility has expressed the opinion that they “need” access to VAD to achieve any improvement in patient outcomes. It is bewildering that the Parliament is focused on legislating VAD, with the purported aim of helping patients in NSW, whilst doing very little to provide for those aspects of medical, palliative and healthcare that we know WILL improve patient care, including access to comprehensive geriatric assessment, palliative care and the provision of minimum nursing and allied health ratios.
2. As the Bill stands, frail older people might be put in a position of considering VAD because they might feel that they are “a burden” on others (including relatives and the health care system). We have already seen this in overseas jurisdictions. Around half of people who end up undergoing VAD do so because they do not want to be a “burden” on others. Such feelings are often due to underlying depression, financial concerns, lack of availability of community services or family dynamics. There is no way that the proposed Bill can provide any safeguards to address this issue or such feelings.
3. There is no way that the Bill can prevent coercion. Whilst the Bill does not allow forcible administration of a VAD substance in an unwilling patient, most coercion is subtle and difficult to detect. Already, I find that many patients are subject to subtle coercion, for example to accept admission to residential care or to allow others to control their finances. The Bill has no protection against such subtle coercion in the realm of VAD. Witnesses to a patient’s written declaration requesting VAD are required to attest only that the patient “**appeared to freely and voluntarily sign the declaration**” (see Part 3, Division 5, Section 45, Subsection 1a), but this is a very low threshold. Whilst there is a penalty if it is later shown that witnesses acted illegally, the patient has already died and there is no requirement for the coordinating or consulting doctors to make any prior enquires attesting to the witnesses’ veracity.

4. The Bill purports to ensure that only patients who have “capacity” in relation to VAD can access the scheme. However, in Part 1, Division 3, Section 6, Subsection 2b, the Bill states that a person will be **“presumed to have decision-making capacity in relation to voluntary assisted dying unless the patient is shown not to have the capacity”**. My concern is that it is invalid to assume such capacity in an older person who may have, for example, a neurodegenerative disease (e.g. Motor Neuron Disease, Parkinson’s disease etc), or who may be on a number of medications capable of impairing capacity and who is faced with the psychological trauma of issues surrounding death and dying. This opens the door to people with impaired capacity accessing the scheme, with the concomitant danger of susceptibility to coercion. “Capacity” does not just mean ensuring that the patient has a good memory and appears free of dementia. It involves an understanding of the complex issues concerning VAD, the impact of the decision on others and the ability to weigh up the pros and cons, as well as evaluating the decision against all other options. A patient who has a neurodegenerative disease or who is suffering from challenging symptoms (pain, nausea, breathlessness) and medication-induced side-effects can rarely be expected to possess such capacity, let alone if they are lying in a hospital bed in a completely dependent (and unempowered) condition.

5. There is no requirement in the Bill for the Coordinating or Consulting doctors to have any expertise in capacity assessment. The majority of medical practitioners have no particular experience or expertise in capacity assessment. Formal training in such assessments is part of the education of geriatricians and psychiatrists, but of no other speciality or medical school training. It is a skill which takes considerable experience and training to master and not something that can be easily or quickly learnt by any brief course likely to be implemented under a VAD regime. Medical practitioners without expertise in capacity assessment will not be able to identify when or if a person lacks capacity or is being subject to subtle coercion. In any case, should the proposed legislation be enacted, there is nothing to stop amendments being made in future years which would dilute the (already inadequate) “safeguards” concerning capacity.

6. The Bill allows for a person with an illness which is **“advanced, progressive and will cause death, and will, on the balance of probabilities, cause death (A) for a disease, illness or medical condition that is neurodegenerative—within a period of 12 months, or (B) otherwise—within a period of 6 months”** (Part 2, Section 16, Subsection 1d). However, as there are no requirements for the Coordinating or Consulting Practitioners to be experts in the particular diagnosis making a person “eligible” for VAD, how can such practitioners accurately assess that person’s life expectancy? Doctors have been shown to have a very limited ability to predict an individual’s life expectancy. A doctor who is highly specialised in his or her field can say what the average life expectancy is for a particular illness, but cannot say with any confidence what an individual’s life expectancy is. Even more inaccurate would be the assessment of life expectancy by a doctor who is not an expert in that field! It is quite possible that those assessed as “eligible” for VAD under the Bill might have actually lived for many years.
7. It is very concerning that the Bill allows for neither the Coordinating nor the Consulting Doctors to be specialists in the particular illness or diagnosis with which the “eligible” patient has been diagnosed. In the Victorian VAD Board review (January to July 2021), 54% of the doctors registered on the portal were General Practitioners. Whilst GPs are experts in general practice, they are not specialists in the field of any particular terminal illness. The relative absence of specialists (and especially geriatricians and palliative care specialists) in the Victorian Portal, and the absence of such stipulation for specialists in the NSW Bill, raises grave concerns that patients will be deemed eligible for VAD without access to proper medical care or specialist input.
8. The Bill purports to allow “conscientious objection” on the part of medical practitioners to be involved with the VAD process (see Part 3, Division 2, Section 21, Subsection 2). However, the Bill goes on to impose certain obligations on the medical practitioner which constitute *de facto* involvement in the process because, as stipulated in Part 3, Division 2, Section 21, Subsection 5b, a medical practitioner who refuses the first request must **“give the patient the information approved by the Health Secretary, by Gazette notice”**. This forces an objecting medical practitioner to supply a patient with information on how to access the scheme and hence nullifies any “conscientious objection” the practitioner might have. Furthermore, Section 23 specifies that the medical practitioner who

refuses the first request, must within 5 business days, furnish a report to the VAD Board outlining the patient's identifying details and details of the request and why it was rejected. This is a burdensome requirement on medical practitioners dealing with busy clinical practices.

9. The Bill purports to prohibit the initiation of a discussion about VAD with a patient by any doctor or health care worker (Division 4, Section 10, Subsection 1). However, in Subsections 2 and 3, the Bill states that doctors and any other health care worker (which includes enrolled nurses, personal care assistants, social workers, podiatrists etc.) may initiate discussions about VAD. In the case of a medical practitioner initiating VAD discussions, the practitioner need only advise the patient about "other treatment options" and the "likely outcomes". In the case of any healthcare worker, the only requirement is that the patient also "has palliative care options available" and that the healthcare worker informs the patient that they "should discuss" the matter with their doctor. In practice, under this Bill (if enacted), any healthcare worker, no matter their skills, experience or knowledge, can suggest VAD to a patient with minimal (if any) safeguards or restrictions.

10. I have deep concerns about the implications of the Bill for residential aged care facilities. Division 3, Section 28, Subsection 1k allows that an aged care resident who undergoes VAD has no obligation to inform the residential facility that VAD is to occur. I am very concerned about the trauma this may cause to aged care staff, who often form deep and affectionate relationships with the aged care residents, if they were to be suddenly faced with the situation of a resident dying in such circumstances. I also draw your attention to other provisions of the Bill (Division 2, Subdivision 2) compelling aged care facilities to "facilitate transfer" of residents to VAD assessments and the administration of a lethal substance. Such facilitation is undefined in the Bill and it is unclear whether aged care facilities will need to actually provide transport (or cover costs) and staffing for such transfers. This is a burdensome requirement on aged care facilities, most of whom are understaffed, to say nothing about the coercion this imposes on aged care providers who have moral objections to VAD.

11. I am very concerned about the impacts of the Bill on provision of, and access to, palliative care and geriatric medical care in rural and remote areas of NSW. The Legislative Council has already undertaken two inquiries (Public Health Amendment (Registered Nurses in Nursing Homes) Bill 2020 and Portfolio Committee No. 2 – Health) that have highlighted grave deficiencies with respect to palliative and geriatric medical care in rural and remote areas of NSW. Such deficiencies included inadequate provision of palliative and geriatric care in nursing homes (e.g., no Registered Nurses on shifts resulting in the failure to provide pain and anxiety relief through appropriate medications) and in many rural and remote areas (e.g., lack of adequate General Practitioner services with experience or skills in palliative care). This results in the situation where older people in rural and remote areas and in aged care have limited or no access to medical experts with skills in end-of-life care. My concern is that under the proposed VAD legislation, an older person will be able to have a lethal VAD substance “express-couriered” to their remote location or their aged care facility to end their life, but cannot access high quality, multi-disciplinary geriatric and palliative medical care. It would be perverse and manifestly unfair if, for older people in remote locations, the State of NSW might facilitate voluntary assisted suicides in the face of terminal illness with intolerable symptoms, but would not provide adequate expert medical care and registered nurse care, which we all know would achieve the best outcomes for patients.

Likely Impacts of The Bill (if Enacted) on Medical Practice in NSW

If the Bill is enacted and becomes law in NSW, a number of deleterious impacts can be expected. The likely outcomes have already occurred in overseas jurisdictions and there is no reason to suspect that the same would not occur in NSW.

Amongst the most concerning impacts are:

1. The number of requests will progressively increase with time. This has happened everywhere VAD (in all its varied forms) has been implemented. In the Hague (Netherlands), VAD now accounts for 11% of all deaths. Numbers of patients undergoing VAD have inexorably risen in other jurisdictions. In Canada, the numbers far exceeded those expected to be “eligible” when their legislation was first introduced.

2. The patients who will undergo VAD will increasingly be people who are older, frailer and suffer from neurodegenerative diseases. As treatments for other conditions (especially cancers) improve and their mortality rate drops and the overall disease burden of neurodegenerative disease and frailty increases, more and more requests will come from older people (or their relatives/friends/carers) with Parkinson's disease, dementia, motor neuron disease general frailty. This is already evident in Victoria, where (according to the VAD Board Report of Operations, January to July 2021) 45% of all VAD deaths were in people with neurodegenerative diseases, which are age-related illnesses (i.e. occur overwhelmingly in older people) and which are known to impact cognition and capacity.
3. Doctors and healthcare facilities will start receiving requests from people other than the patient (i.e. family members, carers etc). In the Victorian VAD Board Report of Operations January to July 2021, only 36% of contacts made to care navigators were from the applicants themselves. 35% were from a family member or friend. This is disruptive to the patient-doctor relationship and increasingly raises the question of coercion.
4. The entire basis of the doctor-patient relationship will be upturned as the doctor moves from being someone who provided care, trust, symptom control and support, to one who may just be providing active deaths for patients.
5. Suicides (other than VAD) are likely to increase. This has been noted in overseas jurisdictions where VAD has already been in operation. This is unsurprising due to the mixed messages given that some suicides are approved and to be facilitated, whilst others are to be desperately prevented. This is expected to place further strain on mental health services in NSW.
6. Healthcare workers themselves may face coercion from hospital and aged care operators. Health facilities who develop policies in favour of VAD may threaten or limit the employment of doctors, nurses or other staff who conscientiously object or refuse to participate. This does not need to be explicitly stated (and in fact can be denied by the employer), but staff who consistently refuse to participate may end up being viewed negatively or as not being "team players" when it comes to interviews, opportunities for promotion or performance reviews.

In conclusion, the NSW VAD Bill 2021 has many deep flaws. It will disrupt the patient-doctor relationship. It contains no real safeguards against abuse or coercion. Any “safeguards” that are put in place can be easily overturned by future minor amendments to the legislation, which will not be subject to the scrutiny of the original Bill. VAD is not required for health and medical practitioners to provide the high-quality care they have been trained to provide. VAD is not being actively sought by either medical professionals or healthcare providers. Improvement to services and staffing are being sought, but are not being provided by this Bill. The Bill is likely to disproportionately affect older people with neurodegenerative diseases and will further entrench disadvantage and lack of access to palliative care in rural and remote areas.

For all these reasons, I urge members of both Houses of the NSW Parliament to vote against the Bill.

Yours sincerely

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