Submission No 57

INQUIRY INTO PROVISIONS OF THE VOLUNTARY ASSISTED DYING BILL 2021

Organisation: Australian and New Zealand Society for Geriatric Medicine - NSW Division

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Australian & New Zealand Society for Geriatric Medicine NSW Division

ANZSGM NSW Division Response to NSW Voluntary Assisted Dying Bill 2021

The Australian and New Zealand Society for Geriatric Medicine (ANZSGM) is the peak medical body representing specialist geriatricians. Consultant geriatricians are experts in the care of older people, especially those with neurodegenerative disease (such as dementia and Parkinson's disease), stroke, frailty and falls. We strive to provide the best possible specialist medical care, advocacy and support for older people to improve their quality of life.

We have over 1,300 members in Australia and New Zealand who work across all healthcare settings, including hospital, residential and community aged care. We have a predominant role in the management of dementia in each of these settings and our submission is made within the context of this responsibility.

The ANZSGM supports older people's rights to refuse or discontinue burdensome or futile treatment. The ANZSGM supports a dying older person's rights to a death characterised by dignity, adequate symptom control and optimal access to expert palliative care. The ANZSGM's view is that policy makers and funders of health care can best help patients nearing the end of their life by ensuring adequate provision and funding of high-quality community-care, palliative care, and specialist medical services. These services are focussed on helping people die with dignity.

There are a range of views on the ethics and morality on assisted suicide and Voluntary Assisted Dying (VAD), in the community and amongst ANZSGM members. The ANZSGM acknowledges the wide range of perspectives and ethical views amongst geriatricians in Australia and New Zealand. Some members hold differing views in good faith and views of all our members are respected. However, there are areas of common ground we urge Members of Parliament to consider. In this submission we wish to specifically address aspects of the 2021 NSW VAD Bill, proposed by Mr A Greenwich (MLA) and will confine ourselves to comments on the Bill only.

Having reviewed the 2021 NSW VAD Bill, we recommend that the Honourable Members of the NSW Legislative Assembly and the NSW Legislative Council consider the following in their deliberations on this issue.

1. We are concerned that frail older people may be put in a position of considering VAD because they feel that they are 'a burden' on others (such as family members, carers and the health care system). Such feelings are often due to underlying depression, lack of availability of community services or family dynamics. It is possible that someone may consider an older frail older person eligible on the grounds that they have a limited life expectancy.

   An older person requesting VAD should have access to comprehensive clinical assessment to address medical, psychological and social aspects of health to ensure

management options for conditions amenable to treatment have been discussed. We do not believe the proposed Bill has adequately addressed this issue.

2. The risk of potential coercion of vulnerable patients, by family members, carers or health providers is a significant concern. Coercion (a form of elder abuse) can be subtle and difficult to detect. Patients are often subject to subtle coercion, for example to accept admission to residential care or to control their finances.

   The question is whether the proposed Bill (if enacted) has sufficient protection against such 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).

3. Dementia and other cognitive disorders are more prevalent with age and thus older people who may have impaired capacity are likely to be confronted with decisions regarding VAD. It is important that a process to adequately assess capacity is in place.

   The Bill state that only patients who have "capacity" in relation to VAD can access the scheme. However, we note that (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". The issue of capacity is more challenging in the context of neurodegenerative conditions which impact cognition such as dementia. The likelihood of incapacity within this cohort of patients is significant and the risks of impaired capacity within the context of complex management options are significant.

   Patients may also be prescribed medications capable of impairing capacity. There is no requirement in the Bill for the Coordinating or Consulting practitioners to have expertise in capacity assessment. The proposed bill requires coordinating practitioners and consulting practitioners to refer to a 'psychiatrist or other registered health practitioner with appropriate skills and training' if they are unable to decide whether the person has capacity in relation to VAD. The key question is whether the coordinating practitioners and consulting practitioners will have the skills and experience to recognise when there is uncertainty about a person's capacity to make decisions on VAD.

   While we understand the assumption of capacity arguments for most medical decisions, for VAD but it important that processes are in place to ensure capacity is assessed competently. There must be some documentation that capacity has been assessed and that the person considering VAD has capacity to make VAD related decisions.

4. 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 there

are no requirements for the Coordinating or Consulting Practitioners to be experts in the particular diagnosis making a person "eligible" for VAD. The proposed bill requires coordinating practitioners and consulting practitioners to refer to a medical practitioner with appropriate skills and training if they are unable to decide whether the patient has a condition that satisfies criteria for eligibility for access to VAD

There are many scenarios common in older people such as having lots of medical conditions and and/or frailty where even doctors who are highly specialised in the care of older people cannot say with any confidence what an individual's life expectancy is.
The Bill does not properly address this scenario. Advanced age alone should not be a criterion for VAD.

5. It is critical that eligibility to act as coordinating or consulting practitioner be defined at an appropriate level, which we recommend be specialist registration. The current reference to overseas-trained specialists with limited registration or provisional registration being eligible to act as coordinating or consulting practitioner is of particular concern, noting that conditions on practice may result in these practitioners practicing within intern-level supervision arrangements in the Australian health care system.

6. The Bill purports to prohibit the initiation of a discussion about VAD with a patient by any medical practitioner 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 would include enrolled nurses, personal care assistants, social workers, podiatrists etc.) may initiate discussions about VAD under wide-ranging exemptions.

   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 recommend VAD to a patient with disproportionally negligible safeguards or restrictions.

7. Residential age facilities must be aware of VAD planning to be able to ensure that appropriate advance care planning documentation is in place, to avoid a circumstance where staff may feel under a duty of care to commence resuscitative measures if they were not aware that the resident was on a VAD management pathway.

8. We also note that other provisions of the Bill (Division 2, Subdivision 2) compel 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 provide transport (or cover costs) and staffing for such transfers. We view this as a burdensome requirement on aged care facilities, many of which may already face staffing challenges for the resident population, to say nothing of

the ability of staff themselves to conscientiously object from participating in the VAD process.

9. We are 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 many 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.

   Our concern is that under the proposed VAD legislation, an older person may still not have access high quality, multi-disciplinary geriatric and palliative care, though despite that deficiency could still have a lethal substance delivered to their location or aged care facility for the purposes of VAD. We highlight the manifest inequity that for older people in regional or remote locations, that VAD may be accessed in the context of intolerable symptoms, without those persons having access to multidisciplinary palliative care to achieve the best outcomes for patients.

CONCLUSION

The NSW Division of the ANZSGM has considered the proposed NSW VAD 2021 Bill. The Bill has weaknesses concerning capacity. For decisions as big as VAD there must be an onus on showing that the older person has capacity to make VAD related decisions and that no coercion was involved. The Bill assumes equal availability of palliative and geriatric medical services to people in rural and remote communities in comparison to their fellow citizens in metropolitan centres, which we know is not the case. We are concerned that the focus on VAD will distract from the enhancements to Geriatric Medicine, aged care and palliative care services that we know are sorely needed.