VADSA Position Statement: Providing an end of life choice of assisted dying for people with dementia

By way of background, one of the contributors wrote of his father:

> *My father was a retired professor of electrical engineering, but without a plan for dying. He would have wanted an assisted death had he realised the nature of his Alzheimer disease diagnosis. While conducting a consult round with the registrar and medical students, I observed my father, normally a private person, defaecate in the ward corridor we were passing through. I expect my father, when still intellectually sound, would have been horrified by this prospect.*

Very few people would be philosophical about such an occurrence in their own futures. There has to be a solution for the conflict between a person's predictable wishes when well *versus* outcomes when severely demented.

It would generally be agreed that people with dementing illnesses should have choice in their end of life care, including voluntary assisted dying (VAD). The natural history of most dementias, however, means people will survive longer than 12 months after they have lost capacity[1]. Under current Australian laws, this would exclude them accessing VAD, which is unjust because some will experience suffering as a result.

The VAD legislation in every Australian state includes a 12 month prognosis to death for those with a neurological condition, as well as the requirement to have capacity at every stage of the process, including when the VAD substance is delivered by the pharmacists. The 12 month prognosis, combined with the requirement for capacity, in effect precludes most people with dementia from accessing VAD. The NSW VAD Act goes further by specifically excluding dementia as an eligible condition.

Dementia is the leading cause of death for women in Australia, second for men. The evidence shows that the incidence of dementia is increasing.

There will likely be two classes of people with dementia who will be denied the choice of VAD under current legislation: one characterised by severely impaired individuals with an acknowledged wish and plan for assisted dying made prior to loss of capacity (AD-p) but unable to effect it; and one characterised by no plan for dying (AD-np). So, the challenging question arises: "Can families or carers follow an ethical path to enable assisted dying in these groups?"

For those people who have an acknowledged wish for assisted dying and have made an assisted dying plan, the AD-p group, it would be ethical for a person's plan to be acted upon as closely as practicable by their caring community. This might be termed "Planned Assisted Dying". The issue here, however, is that to have gained approval for VAD for neurological degenerative diseases requires the prediction of death in under 12 months, a restriction that will result in very few approvals. The preferred option would be to remove the time limit to death, thus allowing a person to be assessed as eligible for VAD and, therefore, Planned Voluntary AD. A second, but less preferred, option would be the inclusion of an additional criteria of “an expectation of loss of capacity within 12 months”. Such a criteria would allow a person diagnosed with dementia to request VAD, and be assessed as eligible, while they still have capacity.

For AD-np, it is already the case that family members and nursing and medical carers reach agreement on appropriate management. We propose that legislation include provision for ‘Community Granted AD’,

[1] ‘capacity’ is defined in each state VAD Act as the person having decision making capacity in relation to voluntary assisted dying; each VAD Act further states that ‘capacity’ is presumed unless there is evidence to the contrary. The South Australian VAD Act, for example, defines decision making capacity in S4, a Section containing over 350 words.

to allow family and carers to include assisted dying as an option in the end of life treatment plan. This process would be safe, ethical and compassionate.

We therefore seek the following legislative changes to enable people with dementia to access assisted dying.

1) **People who request VAD while they have capacity**
   a. **Removal of the time limit:** removal of the criteria for a neurological condition of "expected to cause death within 12 months" in current VAD legislation would enable people to make a valid VAD end of life choice request well in advance of cognitive decline. Current legislation which includes a time limit to death discriminates against those people who will suffer with an illness which will cause loss of capacity well ahead of the 'expected 12 months to death'. The 'time limit to death' will deny most people with such an illness any possibility of a request for VAD.
   b. **Criteria of loss of capacity within 12 months:** An alternative, but less desirable amendment, would be to include an additional provision in relation to the 12 month prognosis for a neurological condition, such as "death or loss of capacity in relation to voluntary assisted dying" (S26(4) in the South Australian VAD Act). This would enable a person to request VAD if they were expected to lose capacity within a year, but not necessarily die.
   c. **Loss of capacity after being assessed as eligible for VAD:** once assessed as eligible for VAD, it is expected that most people will choose to end their life while they still have capacity[2]. For some people, their disease may progress more rapidly and they may lose capacity before their chosen date. Provision would need to be made to allow people with a neurological condition, who have been assessed as eligible for VAD, to still proceed with an assisted death.
2) **People who did not request VAD, or were assessed as eligible for VAD, but have lost capacity**
   Community Granted AD: The concept of the Community Granted AD option needs legislative infrastructure. This could include amendment of the Advance Care Directive process to allow a person to describe the circumstances in which they would request assisted dying. Discussions with hospital colleagues suggest Community Granted AD would be an acceptable pathway if it had legislative approval. This would provide resolution for the carers and families of individuals who no longer have the capacity to decide for themselves.

   There could be many reasons why a person did not document a request for VAD while they had capacity, even if there is evidence that they may have discussed it. These reasons could include being isolated by a disability, lack of information about how to request VAD, lack of awareness about VAD, carers who had a conscientious objection to VAD, the complex process to request VAD as well as managing a tiring and stressful illness, lack of support from family or community, and their doctor not providing information because the VAD Act prohibits them from so doing. None of these reasons is sufficient to deny the person an end to their intolerable suffering.

In summary, to enhance the end of life choice of people diagnosed with dementia, separate legislative amendments are proposed to support people who were assessed as eligible for VAD while they had capacity, and those who did not make an end of life plan while they still had capacity.

Frances Coombe, President VADSA

Anne Bunning, Vice President VADSA

Stephen Kenny, LLB

Robyn Layton, AO, KC, LLD

Carolyn Lawlor-Smith, BMBS

John Willoughby, MBBS, PhD, FRACP

[2] Experience from Canada, where dementia has always been an eligible condition for Medical Assistance in Dying (the Canadian equivalent of VAD), is that patients proceed while they still have capacity (pers comm, June 2023).