

People with dementia aren't currently eligible for voluntary assisted dying. Should they be?

May 21 2024, by Ben White, Casey Haining, Lindy Willmott and Rachel Feeney



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Dementia is the [second leading cause of death](#) for Australians aged over 65. More than 421,000 Australians [currently live with dementia](#) and this figure is expected to almost double in the next 30 years.

There is ongoing public [discussion](#) about whether dementia should be a qualifying illness under Australian voluntary assisted dying laws. Voluntary assisted dying is [now lawful in all six states](#), but is not available for a person living with dementia.

The Australian Capital Territory has [begun debating](#) its voluntary assisted dying bill in parliament but the government has [ruled out](#) access for dementia. Its view is that a person should retain decision-making capacity throughout the process. But the bill includes a requirement to [revisit the issue](#) in three years.

The Northern Territory is also considering reform and [has invited views](#) on access to voluntary assisted dying for dementia.

Several public figures have also entered the debate. Most recently, former Australian Chief Scientist, Ian Chubb, [called for the law to be widened](#) to allow access.

Others [argue](#) permitting voluntary assisted dying for dementia would present unacceptable risks to this vulnerable group.

Australian laws exclude access for dementia

Current Australian voluntary assisted dying laws [exclude access](#) for people who seek to qualify because they have dementia.

In New South Wales, the [law specifically states](#) this.

In the other states, this occurs through a [combination of the eligibility criteria](#): a person whose dementia is so advanced that they are likely to die within the 12 month timeframe would be highly unlikely to retain the necessary decision-making capacity to request voluntary assisted dying.

This does not mean people who have dementia cannot access voluntary assisted dying if they also have a [terminal illness](#). For example, a person who retains decision-making capacity in the early stages of Alzheimer's disease with terminal cancer may access voluntary assisted dying.

What happens internationally?

Voluntary assisted dying laws in some other countries allow access for people living with dementia.

One mechanism, used in the Netherlands, is through [advance directives or advance requests](#). This means a person can specify in advance the conditions under which they would want to have voluntary assisted dying when they no longer have decision-making capacity. This approach depends on the person's family identifying when those conditions have been satisfied, generally in consultation with the person's doctor.

Another approach to accessing voluntary assisted dying is to allow a person with dementia to choose to access it while they still have capacity. This involves regularly assessing capacity so that just before the person is predicted to lose the ability to make a decision about voluntary assisted dying, they can seek assistance to die. In Canada, this has been referred to as the "[ten minutes to midnight](#)" approach.

But these approaches have challenges

International experience reveals these approaches have limitations. For

[advance directives](#), it can be difficult to specify the conditions for activating the advance directive accurately. It also requires a family member to initiate this with the doctor. Evidence also shows doctors are [reluctant](#) to act on advance directives.

Particularly challenging are [scenarios](#) where a person with dementia who requested voluntary assisted dying in an advance directive later appears happy and content, or no longer expresses a desire to access voluntary assisted dying.

Allowing access for people with dementia who retain decision-making capacity also has practical problems. Despite regular assessments, a person may lose capacity in between them, meaning they miss the window before midnight to choose voluntary assisted dying. These capacity assessments can also be very complex.

Also, under this approach, a person is required to make such a decision at an early stage in their illness and may lose years of otherwise enjoyable life.

Some also argue that regardless of the approach taken, allowing access to voluntary assisted dying would involve unacceptable risks to a vulnerable group.

More thought is needed before changing our laws

There is [public demand](#) to allow access to voluntary assisted dying for dementia in Australia. The mandatory reviews of voluntary assisted dying legislation [present an opportunity](#) to consider such reform. These reviews generally happen after three to five years, and in some states they will occur regularly.

The scope of these reviews can vary and sometimes governments may

not wish to consider changes to the legislation. But the Queensland review "[must include a review of the eligibility criteria](#)." And the ACT bill requires the review to [consider](#) "advanced care planning."

Both reviews would require consideration of who is able to access voluntary assisted dying, which opens the door for people living with dementia. This is particularly so for the ACT review, as advance care planning means allowing people to request voluntary assisted dying in the future when they have lost [capacity](#).

This is a complex issue, and more thinking is needed about whether this public desire for voluntary assisted dying for dementia should be implemented. And, if so, how the practice could occur safely, and in a way that is acceptable to the health professionals who will be asked to provide it.

This will require a careful review of existing international models and their practical implementation as well as what would be feasible and appropriate in Australia.

Any future law reform should be [evidence-based](#) and draw on the views of people living with [dementia](#), their family caregivers, and the health professionals who would be relied on to support these decisions.

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