

**TALKING ABOUT ALZHEIMER'S  
ACROSS AUSTRALIA**  
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# **A GOOD DEATH IS MY RIGHT**

**PEOPLE WITH DEMENTIA AND CARERS RESPONSE  
TO THE VOLUNTARY ASSISTED DYING BILL DISCUSSION  
PAPER**

**ALZHEIMER'S AUSTRALIA VIC**

**April 2017**

“I want to die at home. I want to die in our bed, in our bedroom, with my partner with me. Others with close connections will also be welcome. I want to be able to see our beautiful garden and hear the song of the lorikeets and parrots and rosellas outside our bedroom window, I want to hear music we’ve enjoyed over our lifetime together, as well as music of my childhood and youth. I want to be surrounded by familiar things because it will have a deeply containing and comforting psychological effect.”

*Person living with dementia*

Alzheimer’s Australia Vic would like to thank the Parliamentary Committee for the opportunity to respond to the Voluntary Assisted Dying Bill discussion paper. As the peak organisation representing people living with all forms of dementia, their families and carers, we welcome the opportunity to contribute their views to the formation of this important legislation.

The following document reflects the views of consumers who have reviewed the Voluntary Assisted Dying Discussion Paper and offered their thoughts. The contributors to this response include people living with dementia, spouses and children of people who are living with dementia or who have passed away. They are from metropolitan and regional areas of Victoria, diverse backgrounds and types of dementia, including younger onset dementia.

## Executive summary

There are currently more than 104,000 people living with dementia in Victoria, with an annual national cost to the community in excess of \$14 billion (Alzheimer's Australia, 2017). Dementia is the second leading cause of death in Australia (Australian Bureau of Statistics, 2013). Despite this high prevalence, understanding of the condition, both in the community and among health professionals, remains alarmingly low.

A poll commissioned by Alzheimer's Australia in 2013, found that one in four people falsely believe that dementia is a normal part of ageing. More than half of Australians surveyed believe that dementia is not a terminal illness. Until quite recently, it was widely believed that people with dementia could not feel pain. This lack of understanding has had devastating consequences for people with dementia, particularly at end of life. We know from what our consumers tell us that people with dementia still struggle to access palliative care or receive care in a timely fashion; they are given inappropriate life-sustaining or invasive procedures; and receive inadequate pain management.

Encouraging improvements in the quality and appropriateness of care keep us hopeful; however there is still much work to be done.

At Alzheimer's Australia Vic we believe that it is possible to live well with dementia. We have witnessed many examples of people continuing to live happy, purposeful and meaningful lives long after a diagnosis. We also acknowledge that dementia can lead to profound physical and cognitive disabilities which some people may find contrary to a good quality of life. Our organisation is neither for nor against assisted dying. We do advocate, however, that all individuals should have a choice.

Similarly, it is important to note that although the consumers quoted in this response are supportive of assisted dying legislation, this should not be taken as encompassing all of the diverse views and experiences of people with dementia and carers across Victoria.

Alzheimer's Australia Vic and our consumers are concerned that some of the clauses in the proposed legislation effectively exclude people with dementia from accessing voluntary assisted dying, thereby limiting their end of life choices.

## **Recommendations**

The key recommendations in this response are:

1. That limiting eligibility to a prognosis of days or weeks remaining prohibits people with progressively deteriorating cognitive impairment from accessing voluntary assisted dying
2. That a decline in quality of life or function is a better indicator of eligibility for people with a degenerative illness
3. That psychological suffering be recognised in the legislation in addition to physical suffering
4. That the term 'mental illness' should be clearly defined as distinct from cognitive impairment
5. That people with degenerative disorders should have the right to make enduring requests for voluntary assisted dying in an advance care plan
6. That family members are included in assisted dying decision-making, with the person's consent and with proper protections for the person
7. That the person with dementia's right to be fully informed is upheld and that medical practitioners are appropriately trained in dementia care

## Final weeks or months of life

Dementia is a terminal illness with no known cure. On average, a person with dementia survives for three to ten years from the point of diagnosis (Brodaty H. S., 2012). However, as Brodaty et al found, survival prognosis is very difficult in dementia and is influenced by various factors including age, gender, type of dementia, the person's comorbidities, and the severity of the illness at the time of diagnosis.

“It is typically ten years after diagnosis that a person with Alzheimer’s dies. Because of this, I doubt that a prediction of when death is imminent can be made with any degree of accuracy. I am frequently surprised to note the apparent sudden death of residents in my wife’s nursing home.”

*Husband of a person with dementia*

Dementia, especially Alzheimer’s disease, can be broadly categorised into three phases: mild, moderate, and severe. People in severe or late stage dementia experience not only severe memory loss but physical symptoms such as being unable eat or swallow, limited or no speech, and inability to control bodily functions. People in these later stages require assistance with nearly all aspects of personal care.

People with dementia may become palliative at any stage of their journey. People with mild to moderate dementia may be in the end stage of other terminal comorbidities, such as organ failure or cancer. A person diagnosed to be in the final weeks or days of life due to dementia, as suggested in the eligibility criteria of the draft Bill, would no longer meet the legal competency requirements to contribute to medical decisions.

### **Recommendation 1: That limiting eligibility to a prognosis of days or weeks remaining prohibits people with progressively deteriorating cognitive impairment from accessing voluntary assisted dying**

People with dementia and carers feel that reducing eligibility to requests for assisted dying made only in the final days or weeks of life effectively excludes people with dementia from having choice and control over the end of their lives. They would like to see eligibility defined in a way that does not discriminate against people with incurable, degenerative illnesses.

“I support assisted death for terminally ill people who have expressed that wish at an earlier point in their illness when they are able to do so. I don’t want to creep endlessly into the night over weeks, or months, or even years.”

**Recommendation 2: That a decline in quality of life or function is a better indicator of eligibility for people with a degenerative illness**

Rather than defining eligibility by prognosis, people with dementia and carers feel that the trigger for assisted dying should be an exacerbation of symptoms or a decline in quality of life that has been laid out explicitly in advance by the person living with the illness.

“As dementia will often take away the person’s ability to speak, to communicate pain and suffering, the legislative framework should allow for identification of what the person would consider as enduring and unbearable suffering, at a point in time when they have the capacity to express themselves.”

*Daughter of a person with dementia*

## **Enduring and unbearable suffering**

People in the later stages of dementia have an increased risk of experiencing unrecognised or poorly managed pain. They are vulnerable to accidents, injuries and falls and will often experience cognitive and speech difficulties that mean that they cannot communicate their pain. The symptoms of late stage dementia – immobility, swallowing difficulties, and incontinence – make people highly susceptible to recurring chronic infections and ulcers. In the United Kingdom, two thirds of people with dementia ultimately die from pneumonia (Alzheimer's Society, 2012). We also know that people with dementia are three times more likely to receive emergency interventions and invasive procedures than people of comparable age with a different terminal illness, such as cancer (Mitchell, 2006).

In 2014, a study into the suffering of people with advanced dementia admitted to hospital showed that people who died on that admission (lived for 30 days or less) experienced high levels of suffering on the Mini-Suffering State Examination and had increased levels of malnutrition, pain, eating disorders, decubitus ulcers and agitation than those who were discharged. 100 percent of people who died in hospital received invasive action (Aminoff, 2014).

“Five days before [my mother’s] death, she lost the ability to swallow. Her death was inhumane. It was cruel. Her body took five days to shut down. She lay in her bed and recoiled each time she was touched. She moved her head from side to side as if she was seeking a means to finding relief. Her limbs appeared to spasm as she screamed in agony. This didn’t happen once, it

happened over and over again, night and day. The palliative medication did not stop the pain. Nothing alleviated the torment she was enduring. Nothing.”

*Daughter of a person with dementia*

This evidence reflects the story of many former carers. In a survey commissioned by Alzheimer’s Australia, one in four former carers were dissatisfied with the care their loved one received at the end of life (Alzheimer's Australia, 2014).

In responding to this legislation, people with dementia and carers expressed a strong desire for voluntary assisted dying legislation that will not only release people from their current suffering, but allow them to avoid future suffering and respond to a decline in quality of life that they found unacceptable.

“I witnessed that with [a family member] who spent three bed-ridden years unable to move or scratch an itch because of joint contracture due to advanced Alzheimer’s disease and vascular disease. Before that, she spent four years existing in a tub chair, unable to speak or interact with anyone. Although she was given great care in the nursing home, it took [her] eight days to die after food and fluids were withdrawn. She was 91 years old and had lived with Alzheimer’s for 22 years. Her greatest fear when she was younger was that she would end up in a nursing home like her aunt.”

*Person with dementia*

### **Recommendation 3: That psychological suffering be recognised in the legislation in addition to physical suffering**

Many people with dementia and carers held strong views on the inclusion of psychological suffering as well as physical suffering in the proposed legislation. A study in 2011 interviewed older people across six European nations on the topic of dignity. Dignity, to those people surveyed, meant open communication, privacy, self-expression and identity and not being vulnerable (Andersen et al 2011). For people with dementia and their families, the loss of dignity is a source of immense suffering that deserves recognition.

“The parliamentary discussion paper seems to be obsessively focussed on physical pain and gives very little attention or recognition to emotional pain [due to] frustration, humiliation, embarrassment, or depression. Anyone caring for a person living with dementia can tell you that even though they appear to have lost awareness of their condition, their eyes tell you that they still feel the emotional pain of having to be fed; cleaned after fouling themselves and their bedding; being totally dependent on strangers to wash them and toilet them.”

*Husband of person with dementia*

## Defining mental illness

Dementia is an umbrella term used to categorise over 100 different diseases that are characterised by a decrease in brain function due to the build-up of proteins and death of brain cells. Different types of dementia affect different areas of the brain first, resulting in distinct changes to language, motor function, visual and spatial perception, personality, mood or memory.

With appropriate support, people with mild to moderate stage dementia can meet the requirements of the Medical Treatment Planning and Decisions Act 2016.

As the Nuffield Council on Bioethics notes:

“These approaches to capacity are particularly important in connection with dementia, where capacity may fluctuate significantly, and where capacity may be retained for some decisions long after it is lost for others. It is hoped, therefore, that anecdotal evidence of professionals and care workers mistakenly assuming that incapacity is a general condition, rather than being decision specific, will become a thing of the past.” (Nuffield Council on Bioethics, 2009)

The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) lists dementia as a neurocognitive disorder, distinct from a mental illness. An assessment of capacity for a person living with dementia would require a separate process from that used to assess an individual living with a mental illness, such as depression.

“If I have incurable Alzheimer’s disease, which is affecting my behaviour and has brought on the symptom of dementia, do I have a mental illness and therefore unable to avail myself of the proposed legislation? Or am I dying of a terminal physical deposition of amyloid plaques on my brain and therefore can ask my doctor to help me die?”

*Husband of a person with dementia*

### **Recommendation 4: That the term ‘mental illness’ should be clearly defined as distinct from cognitive impairment**

People with dementia and carers urge the Parliamentary Committee to clearly define mental illness as it relates to being an exclusion criterion for voluntary assisted dying. The legislation should also recognise that cognitive impairment, both temporary and permanent, is a physical symptom of an underlying disease. People with dementia expressed their concern that the current legislation discriminated against them.



“It is not compassionate to create a legislative framework that does not allow persons with a degenerative disease that robs them of decision making capacity, to make an informed choice on assisted dying while they still have capacity to do so.”

*Daughter of a person with dementia*

“To exclude ‘suffering caused by mental illness’ on its own may be very discriminatory and cruel. My father had dementia, but the pain he was experiencing from accompanying illnesses, leukaemia and prostate cancer, was very real.”

*Daughter of person with dementia*

With this in mind, it is appropriate, then, that the legislation is amended to broaden the range of medical professionals used to assess decision-making capacity and the severity of particular illnesses. In addition to psychiatrists, the expertise of neuropsychiatrists, geriatricians and other dementia professionals could be called upon to support the assessment and decision-making process.

“It is not possible for someone with advanced dementia to seek assistance to end their life, as the bill rightly requires well-informed decision making. But I expect highly trained neuro-psychiatrists may be able to determine the capacity of a dementia patient in the early stages of dementia, suffering unbearable pain, who requests assistance to die. It is appropriate that dementia is not listed as an exclusion factor for access to assisted dying, rather the capacity to make decisions should be listed as the assessment method.”

*Wife of a person with dementia*

## **Advance care planning**

“I am a member of Dying with Dignity. I believe those diagnosed with dementia should be able to make their wishes clear regarding assisted dying in their advance care plan. A good death is my right!”

*Person with dementia*

As stated earlier, dementia stands apart from other terminal illnesses in that the later stages of the disease produce symptoms that hinder communication and cognition. Unfortunately, this means that people with dementia are at increased risk of receiving not only unwanted life-sustaining treatments, but being denied a choice in how and when they die.

A good death for people with dementia is unlikely to happen as a matter of course. A dignified death requires proper planning and support to ensure that the person's wishes are respected. An advance care plan and the nomination of a Medical Enduring Power of Attorney enable a person with dementia to ensure that their preferences are known should a medical or end of life decision be made after they have lost capacity.

“Prohibiting the request from being made in an advance care directive and requiring that a medical practitioner must deem that a person is at the end of life when the request is made, would exclude persons with dementia accessing voluntary assisted dying. Those persons who would fall outside the proposed legislative framework will be left to die an excruciatingly painful death.”

*Daughter of a person with dementia*

**Recommendation 5: That people with degenerative disorders should have the right to make enduring requests for voluntary assisted dying in an advance care plan**

The people with dementia and carers that contributed to this response felt very strongly that disallowing voluntary assisted dying instructions in advance care plans creates yet another barrier to people with dementia having genuine choice and control in end of life.

“[The legislation discriminates] particularly against those who have been courageous enough to visit a solicitor and draw up an NFR, an advance care planning document or similar for just those very reasons - that they may not have capacity later on, but wish to have a say in the matter relating to their own end of life.”

*Parents had dementia*

People with incurable, degenerative diseases should, if they wish, be able to participate in voluntary assisted dying by working with their medical team, Medical Enduring Power of Attorney and other family members to identify a quality of life or level of suffering which would be unacceptable to them and record this in their advance care plan (or other binding document). The person with dementia could then, if that is their choice, recommend that voluntary assisted dying be administered at a time when their medical team and family agree that their quality of life has declined in a way that meets their stated wishes.

“The requirement of experiencing ‘enduring and unbearable suffering’, which can be subjective, can be satisfied by the person identifying what they would consider would meet this requirement. The event of identified circumstances – for example, extreme difficulty or inability to swallow, persistent ulcers due to

the inability to move, or the inability to perform any form of self-care could be considered as the request for assisted dying.”

*Daughter of a person with dementia*

They acknowledge that suffering and quality of life is subjective and cannot be universally applied. For some people, an unbearable level of suffering meant weeks or days away from death; for others, it meant life with limited communication, joy or purpose. However, it was agreed that a measure of function, rather than time left, was a more appropriate for people with dementia.

“Writing an advance care plan commits us in a very real way to how I want my life to end, as well as the lives of others with advanced dementia, who have expressed an earlier wish to die when their quality of life has come to an end. We would both feel comforted and relieved to know we have rights under the law that would allow me to die when I am no longer experiencing any satisfaction or joy in life. I do not want to be another of the bad stories and endings of people with advanced dementia.”

*Person with dementia*

It should be noted that an assisted dying request as part of an advance care plan may not be appropriate in all instances and that the Parliamentary Committee might consider making the above recommendation applicable only in exceptional circumstances, such as for people with a terminal, degenerative condition.

“Any exemption allowing a request for voluntary assisted dying in an advance care directive could be specifically limited to conditions that fall under the umbrella of dementia.”

*Daughter of a person with dementia*

## **Involving family members**

A decline in cognitive function can make people with dementia vulnerable to financial physical and other forms of abuse and neglect. Understandably, people with dementia and carers share the concerns of many in the community that people with dementia will be pressured, directly or indirectly, to request assisted dying.

**Recommendation 6: That family members are included in assisted dying decision-making, with the person’s consent and with proper protections for the person**

People with dementia and carers believe that it is important that family members are consulted and included in the voluntary assisted dying process. They recommend that the legislation include safeguards that protect the person, as well as allow family members to participate, as long as the person has consented to this.

“The supporting team, who should be consulted in the case of dementia, should include an appropriate medical practitioner, the principal carer, another family member AND the Power of Attorney Medical/Guardian”

*Husband of a person with dementia*

## Ensuring a person’s right to be informed

Despite the high prevalence of dementia in our community, medical understanding of the condition remains low. A survey of Australian GPs showed that many did not feel confident to diagnose dementia, due to either lack of knowledge, time, or appropriate screening tools. They also felt uncertain about how to manage the condition (Brodaty H. H., 1994).

In a survey of health professionals conducted by Alzheimer’s Australia, 41 percent said they had inadequate training in identifying pain in people with dementia and 90 percent felt that they would benefit from additional palliative care training (Alzheimer’s Australia, 2014).

People with dementia and carers would like to see increased safeguards that apply to medical practitioners and better training that will ensure that the person’s right to be properly informed is met.

“I am in favour of assisted dying, but given what happened to my partner, where very clear rules were not followed by the medical profession, I am uneasy when I think about whether or not the safeguards will be followed. I have thought long and hard about why this doctor did what he did. I do not know. It does not make sense to provide medications against the rules that would lead someone to spend so long in a dementia ward. I do not understand who it benefitted.”

*Partner of a person with dementia*

Therapeutic approaches, both pharmaceutical and alternative, are poorly understood by medical practitioners and many people with dementia and their families say they receive little support or information after their diagnosis.

**Recommendation 7: That the person with dementia’s right to be fully informed is upheld and that medical practitioners are appropriately trained in dementia**

Medical professionals should have access to appropriate training and resources to support end of life choices for people with dementia. A collaborative approach, drawing on the expertise of neuropsychologists, geriatricians, palliative care professionals, and dementia experts, will ensure people have a greater understanding of their illness and available treatment options.

“Currently people with dementia have a reduced chance of receiving specialist palliative care than people with cancer. That shouldn't be. Pain is also under-recognized and under-treated in people with dementia. That is of concern me. I want to have specialist, hospice-type, palliative care provided, ideally at home. If this is not possible, our GP has advised me she would have me admitted to a local palliative care unit. This makes sense to me as, from my experience, palliative care staff deal with death and dying all the time, and they deal with it in a positive, affirming, compassionate and informed way. Dying in an acute hospital is not where I want to die.”

*Person with dementia*

## **Conclusion**

Dementia is an incurable, terminal condition. Alzheimer's Australia Vic believes that people with dementia have the right to access voluntary assisted dying if they choose with the right support, frameworks and safeguards. We ask that the Parliamentary Committee consider our recommendations on behalf of people living with dementia, their families and carers.

“Please respect my wishes and treat me as someone who has had a full and wonderful life, who has no fear of death itself and who now wants and desires a good, pain free, quick and peaceful death.”

*Person living with dementia*

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