



**dementia
australia™**

The new voice of Alzheimer's Australia

**Health, Communities, disability
Service and Domestic Family
Violence Prevention Committee:**

**Inquiry into aged care, end-of-life and palliative
care and voluntary assisted dying**

A response from Dementia Australia

April 2019

About Dementia Australia

Dementia Australia (formerly known as Alzheimer's Australia) is the peak, non-profit organisation for people with dementia and their families and carers. We represent the more than 447,000 Australians living with dementia and the estimated 1.4 million Australians involved in their care.

Dementia Australia works with people living with dementia, families, carers, all governments, and other key stakeholders to ensure that people impacted by dementia are appropriately supported – at work, at home (including residential aged care) or in their local community.

Our close engagement with people impacted by dementia means that we are well placed to provide input on policy matters, identify service gaps and draw on our expertise to collaborate with a wide range of stakeholders, including researchers, technology experts and providers.

In addition to advocating for the needs of people of all ages living with all forms of dementia, and for their families and carers, Dementia Australia provides support services, education and information aimed at addressing the gaps in mainstream services.

Dementia Australia is a member of Alzheimer's Disease International, the umbrella organisation of dementia associations around the world.



Introduction

Dementia Australia welcomes the opportunity to provide a submission to the Health Committees' inquiry into aged care, end-of-life and palliative care and voluntary assisted dying in Queensland.

The recent Royal Commission hearings into Aged Care have shone a light on a number of challenges across aged care services, which impact the lives of people living with dementia, their families and carers. These challenges arise from the point of diagnosis, where access to support, and navigating the aged care system proves difficult for many individuals. Variability in the quality and safety of services across Australia is also of peak importance, where too many people living with dementia have been subject to cases of abuse or neglect. An underpinning concern however, is workforce capability and capacity. Dementia Australia believes mandatory dementia education should be embedded into training for all medical, health, allied health and care staff – a view often supported by many aged care staff themselves.

A stronger focus on palliative and end of life care is another key priority Dementia Australia advocates for across Australia. We firmly believe that comprehensive palliative care should be available for people living with dementia across all settings. Whether an individual's wish is to remain at home or in a residential aged care facility, access to the right palliative care is critical to ensuring people with dementia die well.

Dementia Australia is neither for nor against voluntary assisted dying. We support the right of people with dementia to have choice in their end of life care including their right to access voluntary assisted dying measures where they are available.

Background Information

Dementia is the term used to describe the symptoms of a large group of illnesses which cause a progressive decline in a person's functioning including loss of memory, intellect, rationality, social skills and physical functioning. There are many types of dementia including Alzheimer's disease, vascular dementia, and frontotemporal dementia. Dementia is a progressive neurological disability and is the leading cause of disability burden for people over the age of 65 years in Australia.¹

Dementia is one of the largest health and social challenges facing Australia and the world. Dementia is not a natural part of ageing. It is a terminal condition and there is currently no cure. It is the leading cause of death of women in Australia, the second leading cause of death in this country, and is predicted to become the leading cause of death within the next five years.²

There are 447,000 Australians living with dementia and without a significant medical breakthrough, there will be over one million people living with dementia in Australia by 2056.

¹ Australian Institute of Health and Welfare (2012) *Dementia in Australia*

² Australian Bureau of Statistics (2016) *Dementia: Australia's leading cause of death?* Accessed online

In Queensland alone, there is an estimated 84,940 people living with dementia in 2019. Without a medical breakthrough, the number of people living with dementia is expected to increase to an estimated 116,195 people by 2028 and 207,124 people by 2058. Dementia affects people's abilities and memories and has a profound impact on the individual and their loved ones. It is cloaked in stigma and misunderstanding, isolates people with dementia and their carers from social networks, and carries significant social and economic consequences. People living with dementia constitute one of the most vulnerable groups in our society.

Recommendations

The key recommendations made in this response are;

Aged Care

Recommendation 1: Queensland Health should have suitable dementia specific guidance on how to access services. This information should be easily accessible from the moment of diagnosis. Adopting effective system navigators – which are user friendly for people living with dementia – will also assist people with dementia to access the services they need.

Recommendation 2: A concerted focus on workforce skills and sustainability is a vital component of the aged care system as a whole, and a focus on mandatory dementia education should be a key consideration for the future of aged care in Queensland

Palliative Care

Recommendation 3: More options for appropriate palliative care, especially for those in rural communities, should be made available, including community or home based care, residential care, hospice care and acute care settings. Incorporating the views and wishes of people living with dementia will be integral to the development of appropriate palliative care options.

Recommendation 4: Advanced care planning conversations should be encouraged early on, following a diagnosis of dementia, to allow individuals to exercise choice in their palliative care.

Recommendation 5: Queensland Health should make a concerted effort to expand awareness and education on palliative care and dementia, across medical, health and community settings. This will improve accessibility to appropriate palliative care for people living with dementia.

Voluntary Assisted Dying

Recommendation 6: That psychological pain be recognised in addition to physical pain

Recommendation 7: That family members are included in assisted dying decision making with the person's consent and with the proper protections for the person

Recommendation 8: That the right of a person with dementia to be fully informed is upheld and that medical practitioners are appropriately trained in dementia care

Recommendation 9: That people with degenerative disorders have the ability to make enduring requests for voluntary assisted dying in an advanced care plan

Response to Inquiry

Section 1: Aged Care

From the point of diagnosis people living with dementia, their families and carers can encounter various challenges, including an inability to receive a timely diagnosis, difficulty in navigating the aged care system and insufficient support options that appropriately respond to the progressive nature of the condition. Following a diagnosis, people with dementia frequently report feeling unsure about where to turn for support.

Dementia Australia's Strategic Direction: *Designing a new future 2018-2023*³ sets out what we believe to be the priorities in aged care, to ensure people with dementia receive the care and support they need throughout their journey with dementia. Our recent appearance at the Royal Commission into Aged Care also provided the opportunity to highlight a number of significant systemic challenges the aged care system faces in meeting the current and future needs of people impacted by dementia. These issues are seen across all states and territories, and can broadly be categorised into three areas; inequitable access to aged care services, inconsistent quality and safety of services and the underpinning issue of dementia education.

Recommendation 1: Queensland Health should have suitable dementia specific guidance on how to access services. This information should be easily accessible from the moment of diagnosis. Adopting effective system navigators – which are user friendly for people living with dementia – will also assist people with dementia to access the services they need

Current estimates state that 70% of people living with dementia, live in the community.⁴ The majority of these individuals will require increasing amounts of support throughout the progression of the disease.

Current Department of Health waitlists reveal that over 100,000 people are waiting for home care packages and that many have been waiting for more than twelve months. 18.7% of the individuals on the waitlist are from Queensland, which equates to 19,585 people in need of home care support. Like most states, the majority of packages needed are at the highest level – level 4.⁵

In addition to the wait time, people with dementia are also challenged by the lack of other more targeted supports (e.g. restorative approaches, reablement, respite, specialised services, services that address psychological need, or services to meet the needs of marginalised communities such as those from a culturally and linguistically diverse background) that they need in order to maintain an independent and fulfilling lifestyle.

³ <https://www.dementia.org.au/national/about-us/our-organisation/strategic-direction>

⁴ Australian Institute of Health and Welfare. Dementia in Australia. Canberra: AIHW, 2012 Cat. no. AGE 70.

⁵ www.gen-agedcaredata.gov.au

Equally, many people newly diagnosed with dementia are not connected to information, advice, counselling or services that focus on maintaining/supporting autonomy and independence. A more consistent access to early interventions has been shown through the National Dementia Service Program⁶ to enhance the ability of people living with dementia, their families and carers to synthesise information about a dementia diagnosis, plan ahead and have key discussions about informed consent, medical and other powers of attorney, advance care planning and service preferences.

Although the proportion of those waiting that have dementia is difficult to quantify (because of lack of data), it is clear from individuals and families in contact with Dementia Australia that the shortage in appropriate-level packages and targeted supports, is having a significant impact on the ability of people with dementia, their families and carers to remain at home, and potentially increasing the number of acute health interventions required.

Even once an aged care package has become available, people with dementia are no more confident in navigating the system to ensure they receive the right support at any given time – and given the progressive nature of dementia, support needs can often change.

Navigational support that is approachable for people living with dementia (e.g face-to-face support, or a helpline service where staff are knowledgeable on the topic of dementia) should be a priority and would enable people with dementia, their families and carers to receive support that encourages reablement and suits the unique needs of someone living with dementia.

Quality and safety

As highlighted in the Royal Commission hearings, quality and safety mechanisms in dementia-specific care are neither consistent nor effective across the aged care system. There is a spectrum of issues around quality in aged care that ranges from poor quality to criminal negligence and abuse.

Essential drivers of quality improvement will include improved regulation and publicly reported quality indicators – which will help encourage transparency amongst providers on the services they offer. Ultimately, people with dementia, their families and carers want to have clear information about the quality of services being offered and the impact of those services on quality of life. Encouraging transparency from providers will not only allow consumers to make better informed decisions when it comes to their care, but should also have a positive impact on the provision of high quality care amongst providers.

Recommendation 2: A concerted focus on workforce skills and sustainability is a vital component of the aged care system as a whole, and a focus on mandatory dementia education should be a key consideration for the future of aged care in Queensland

The key enabler to a successful aged care system is its workforce. Yet Dementia Australia's experience, together with feedback from consumers and providers, suggests that, not only is the sustainability of the aged care workforce an issue but the general capacity of the workforce to meet the needs of people with dementia is hampered by a lack of consistent education and training.⁷

⁶ Dementia Australia, *Redesign of Dementia Consumer Supports*, 2017

⁷ Dementia Australia, *The Future of Work and Workers*, 2018

Personal care attendants (PCAs) and community care workers make up the majority of the aged care workforce (according to Department of Health statistics, PCAs make up 70 percent in residential care while community care workers accounts for 84 percent of community care workers, respectively) and the majority of these workers hold a Certificate III in Aged Care (individualised support). However, because of the way the current qualifications are structured, dementia-specific education is at best offered as an elective and there is no mandatory component within their training.

Given the rapidly increasing prevalence of dementia, embedding dementia specific education into training should be made mandatory requirement. Understanding the symptomology and challenges people with dementia face, in addition to the appropriate care that is needed to support someone living with dementia are necessary skills, without which, we cannot expect health and care professionals to deliver the standard of care that people with dementia need and deserve.

Section 2: Palliative Care

Palliative care supports people to live their life as fully and as comfortably as possible when living with a life-limiting or terminal illness. Support also extends to family members and carers, to help them cope during the illness and in their bereavement. Early engagement with palliative care, enables people with a terminal illness to receive support when the individual needs it, to ease pain, as well as supporting them with physical, psychosocial and spiritual concerns.

On average, people with dementia survive for three to ten years from the point of diagnosis.⁸ However, 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. Throughout the progression of dementia, individuals are likely to experience advancing symptoms of dementia. People in the later stage dementia often experience worsened symptoms; including severe memory loss and physical symptoms such as being unable eat or swallow, limited or no speech, and inability to control bodily functions. Often due to limited speech and difficulties communicating, people in the later stages of dementia are often at a heightened risk of poorly managed pain.

However, whilst this may be the typical progression for some, many people with dementia may become palliative at any stage of their journey. For example, people with mild to moderate dementia may be in the end stage of other terminal comorbidities, such as organ failure or cancer – thus evidencing the pressing need for palliative support to be available to people with dementia from the initial diagnosis.

Recommendation 3: More options for appropriate palliative care should be made available where and when it is needed, including community or home based care, residential care, hospice care and acute care settings. Incorporating the views and

⁸ Brodaty, H.S. (2012) Dementia time to death: A systematic literature review on survival time and years of lost life in people with dementia *international psychogeriatrics* 1034-1045

wishes of people living with dementia will be integral to the development of appropriate palliative care options.

People with dementia being cared for at home or in a residential aged care facility may receive specialist community palliative care services. However, in comparison to patients with cancer, the proportion of people with a diagnosis of dementia using specialist palliative care services is low (75.4% versus 2.4%),⁹ with many people with dementia dying in hospitals and receive palliation there.

We know from what our consumers tell us that people with dementia struggle to access palliative care or receive care in a timely fashion; they are given inappropriate life-sustaining or invasive procedures; and they receive inadequate pain management. Access can be especially difficult for people from diverse backgrounds and those with behavioural symptoms of dementia

Dementia Australia emphasise that comprehensive palliative care for people living with dementia should be available when and where it is needed, including community or home based care, residential aged care, hospice care, and acute care settings. There is a need to improve the provision of palliative care services for people living with dementia in each of these settings, and to increase the ability of health professionals, staff, families and the community to meet the specific palliative care needs of people living with dementia.

Currently in Queensland there are only a handful of options for people to receive palliative care outside a hospital setting. However, for the most part people will receive palliative care in a clinical, rather than a care setting – where their palliative options are more limited and may not reflect their wishes.

'In my experience there are not sufficient options for palliative care and end-of-life care that suit the needs of people living with dementia, in Queensland. While Brisbane has karuna palliative care, people in regional areas are not very well covered. There is also a lack of staff training; I visited one of my Italian clients while he was in palatine care in his nursing home, and they had Italian music on for him but forgot to give him his hearing aids and when I pointed this out they said oh he can't hear any longer. Most of all, for people on home care packages, arrangements should be made to receive this care at home.'

Carer of a person living with dementia

Recommendation 4: Advanced care planning conversations should be encouraged early on, following a diagnosis of dementia, to allow individuals to exercise choice in their palliative care.

Advance care planning provides an opportunity for people with dementia, their families and carers to consider their options for palliative care, and exercise choice over the treatment they wish to receive, while they are still able to. Engaging with advance care planning conversations at the time of diagnosis helps to enable coordination of resources and

⁹ Palliative care outcomes collaboration (2017) Patient outcomes in palliative care: national results for July-December 2016 Detailed report.

services, further ensuring that the individual's wishes for palliative care can be acted upon when needed. Even if a person lacks capacity, it is important they are given support to enable them to participate in advance care planning conversations. A person living with dementia must also be provided with the opportunity to choose and prepare a substitute decision-maker, who may be required to make decisions when the person is no longer able to communicate their own preferences.

Recommendation 5: Queensland Health should make a concerted effort to expand awareness and education on palliative care and dementia, across medical, health and community settings. This will improve accessibility to appropriate palliative care for people living with dementia.

Understanding and awareness of the unique palliative care needs for people living with dementia is essential to the delivery of high quality care. Much like we see in other parts of aged care, dementia awareness and understanding is generally not widespread - despite the prevalence of dementia, making it the second leading cause of death in Australia.

Dementia specific training amongst health and care staff, on the palliative care options that might suit the needs of people living with dementia, would help foster informed conversations between individuals, their families and carers, on their palliative care options.

'Not only are (people living with dementia, their carers and families) people not aware of local carers organisations, or how to get assessed in order to get home care assistance, but even less informed about palliative care options'

Carer of a person living with dementia

'Not only Queensland, but the whole country needs to raise awareness about dementia, the need to learn about the illness in order to live better with it as well as be a better carer, but of course also about later stages and the need to plan for palliative care and end of life, possibility of donating brain to research and similar.'

Carer of a person living with dementia

Section 3: Voluntary Assisted Dying

Dementia Australia have consulted with consumers across states and territories, who have mixed views towards voluntary assisted dying. Some are strongly in favour of it in being legislated, while others are opposed. Similarly, it is important to note that although this response suggests support towards assisted dying legislation, this should not be taken as encompassing all of the diverse views and experiences of all people with dementia and carers.

Overall, Dementia Australia is neither for nor against assisted dying. We do advocate, however, that all individuals should have a choice and that any potential legislation regarding voluntary assisted dying does not exclude people living with dementia – who we believe should be entitled to the same end of life options as others.

Unlike other terminal conditions, the later stages of dementia often hinder communication and cognition. This means that people with dementia are more likely to be given unwanted

life-sustaining treatments, and are often denied the choice in how and when they die. A 2014 survey highlighted that one in four former carers were dissatisfied with the care their loved one received at the end of life.¹⁰

A dignified death requires planning and support, especially for people with terminal and progressive diagnoses like dementia. Without choice and informed options, people with dementia are forced to die in uncomfortable and unwanted conditions – not only does this impact the person living with dementia, but their family and carers.

‘As much as I believe in life being a gift of god to be cherished and respected, I believe no human being should be allowed to suffer in pain and total lack of dignity as I have witnessed my loved ones that I have cared for.’

Carer of a person living with dementia

Consultation with people living with dementia, their families and carers have informed the following recommendations for the implementation of voluntary assisted dying legislation:

Recommendation 6: That psychological pain be recognised in addition to physical pain

As dementia progresses, the need for support with every day activities increases, often to the point where people require support for almost all aspects of their personal care. This gradual loss of independent living often bares a strong psychological impact of people living with dementia. Feelings of frustration, loss of dignity, embarrassment and depression are often experienced by people living with dementia, especially those in the later stages.

For these reasons, the emotional pain and psychological pain associated with terminal diagnoses should be considered within the qualification for voluntary assisted dying.

Recommendation 7: That family members are included in assisted dying decision making with the person’s consent and with the proper protections for the person

Whilst we stress the need for inclusion for people with dementia in to access voluntary assisted dying, it is also imperative that there are strong safeguards to ensure people living with dementia are not directly or indirectly pressured into a decision. The gradual decline in cognitive function can make people with dementia vulnerable to abuse and neglect. This can be a concern for the person with dementia, their families and carers.

Providing there is consent from the individual for others to be involved, we believe that it is important for family members and carers be included in the voluntary assisted dying process and be given equal access to support and information throughout the process.

Recommendation 8: That the right of a person with dementia to be fully informed is upheld and that medical practitioners are appropriately trained in dementia care

Despite its prevalence, understanding and awareness of dementia still remains low. A lack of dementia specific knowledge is well documented across a number of groups, including aged

¹⁰ Alzheimer’s Australia (2014) *End of life care for people with Dementia Survey report*

care workers, community groups and even medical practitioners – who have reported on their lack of confidence in diagnosing dementia.¹¹

In order to appropriately support an individual's end of life decision, medical professional must have the appropriate skills and training. Dementia Australia supports a collaborative approach, whereby medical professionals in addition to receiving dementia training, utilise the expertise of neuropsychologists, geriatricians, palliative care professionals and dementia experts to ensure the best possible advice is being given to the people with dementia.

Recommendation 9: That people with degenerative disorders have the ability to make enduring requests for voluntary assisted dying in an advanced care plan

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. 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 pain 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.

Allowing people with dementia to provide instruction on voluntary assisted dying in an advance care directive would need to override any legislation that stipulates a prognosis of days or weeks remaining is required. Legislation in Victoria prohibits people with progressively deteriorating cognitive impairment from accessing voluntary assisted dying.

“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

Conclusion

Dementia is a terminal and incurable condition – which is currently affecting 477,000 people across Australia and 84,940 in Queensland. Dementia Australia believes that people with dementia should have the same rights as others when it comes to end of life choices, both with regards to palliative care and voluntary assisted dying. We ask the Committee to consider our recommendations made on behalf of those living with dementia, their families and carers.

¹¹ Brodaty, H. H (1994) General practice and dementia: a national survey of Australian GP's. Medical journal of Australia, 10-14