



**dementia
australia™**

The new voice of Alzheimer's Australia

Royal Commission into Victoria's Mental Health System

Dementia Australia Submission

July 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 447,115 Australians living with dementia and the estimated 1.5 million Australians involved in their care.

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

Our close engagement with individuals and communities means that we are an important advocate for those impacted by dementia and we are also 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 living with all types 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 Royal Commission into Victoria's Mental Health System.

Dementia is a progressive neurodegenerative disease that impairs the cognitive and physical functions of the people living with it. There is currently no cure for dementia. The relationship between dementia and mental illness, particularly depression, is complex. Dementia is not a mental health condition. However mental illness is a risk factor for some dementias; depression and anxiety may be experienced as a consequence of dementia; and diagnosing where one condition – and treatment – ends and the other begins is a difficult exercise that has significant implications for the quality of life for Victorians living with dementia.

Effective mental health service provision consequently interfaces with dementia specific care in two ways: 1) to potentially mitigate risk factors that may lead to dementia, and 2) to act to support Victorians living with dementia where the process of cognitive decline may trigger depression and other mental health conditions.

The link between mental health, disability and aged care services inform Dementia Australia's submission. Dementia Australia is a proponent of a holistic, well integrated health care system that prioritises preventative measures for all people. This is so people living with dementia are respected and protected, and their mental and physical health needs are met.

Background

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 447,115 Australians living with dementia and without a significant medical breakthrough, there will be over one million people living with dementia in Australia by 2056.

In Victoria, there is an estimated 114,779 people living with dementia in 2019. Without a medical breakthrough, the number of people living with dementia is expected to increase to an estimated 150,653 people by 2028 and 300,867 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 (often their husband or wife)

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

from social networks, and carries significant social and economic consequences. People living with dementia constitute one of the most vulnerable groups in our society.

Dementia Australia response to questions

1. What are your suggestions to improve the Victorian community's understanding of mental illness and reduce stigma and discrimination?

Mental illness is becoming less stigmatised due to the health literacy and promotion work already being done in this space, this in turn provides a sound platform for the Victorian Government to work from.

Dementia is not a mental illness, however there are links between mental health and dementia. The symptoms and signs of mental illnesses and dementia can often overlap in the early stages of dementia, but as also symptoms typical of depressive disorders. The overlap in symptoms has led to the common misconception that dementia is a mental illness. However dementia and mental illness are separate conditions, rooted by different causes, and will often require different methods of support. This in turn can affect public understanding and access to appropriate services.

People living with dementia may experience social isolation, physical symptoms and difficulties communicating and engaging with friends and family which can contribute to the development of mental illnesses. In fact mental illness is a growing concern for many people living with dementia, experiencing high prevalence of depression and anxiety. Symptoms of dementia may also become exacerbated by pre-existing mental illness (e.g. Post-Traumatic Stress Disorder and incidences of psychosis). Thus the need for additional supports that are designed to help people with cognitive impairment and mental health issues.

Dementia Australia invites the Victorian Government to invest in early education to raise awareness and the Victorian community's understanding of mental health amongst people living with dementia and their informal carers.

2. What is already working well and what can be done better to prevent mental illness and to support people to get early treatment and support?

In the context of dementia, the Australian government funded programs like the Dementia-Friendly communities and the Dementia Friends have improved understanding and public awareness of dementia across Australia. This has helped to reduce stigma and discrimination against people living with dementia, therefore preventing further anguish and risks of developing mental illness.

Dementia Australia supports the Victorian Public Health and Wellbeing Plan 2019-2023, in promoting mental health and wellbeing as part of the key priority areas and commends previous work and attention given to mental health.

Dementia Australia also recognises programs funded by the Victorian government to support carers, and their mental health wellbeing.

3. What is already working well and what can be done better to prevent suicide?

Although there is some anecdotal evidence provided by people living with dementia, their families and carers to suggest that people with a diagnosis of dementia consider suicide, Dementia Australia does not have robust evidence to offer further comment at this stage.

4. What makes it hard for people to experience good mental health and what can be done to improve this? This may include how people find, access and experience mental health treatment and support and how services link with each other.

As described earlier, people living with dementia experience stigma, what one person diagnosed with dementia described as feeling of “*suddenly becoming invisible, a no-body*”, which adds to the sense of social isolation and loneliness.

Furthermore people with dementia will experience behavioural and psychological symptoms of dementia (BPSD) at some stage during the course of their illness.³ BPSD can include depression, anxiety, apathy, agitation, hallucinations, verbal and physical aggression, screaming, sexual disinhibition and other disinhibited behaviours.⁴ These symptoms complicate care for the individual and require sophisticated care responses.

According to Australian experts,⁴ at any one time 40% of individuals with dementia in the community may have no BPSD, 30% are estimated to have mild BPSD and 20% moderate BPSD. The care and support required for individuals with milder symptoms of BPSD differ from that required by individuals with more severe symptoms. Ten percent of individuals with dementia have severe to extreme BPSD, which equates to approximately 32,000 individuals in Australia.⁴ Both, the severity and the frequency of behaviours have an impact on care requirements. It may be difficult to provide appropriate care in mainstream services for individuals with the most severe and frequent behaviours due to their high care needs and concerns about potential disruption to other residents.⁵

The causes of BPSD are not always clear but changes in behaviour may be triggered by biological, psychological, social or environmental factors. In many cases these symptoms are an expression of emotion or unmet need that the person with dementia cannot express otherwise (for example, pain, frustration, loneliness, confusion, fear).⁶

³ Best Practice Advocacy Centre, New Zealand. (2008). Antipsychotics in Dementia: Best Practice Guide. http://www.bpac.org.nz/a4d/resources/docs/bpac_A4D_best_practice_guide.pdf

⁴ Brodaty, H, Draper, BM, Low, L. (2003). Behavioural and psychological symptoms of dementia: a seven-tiered model of service delivery. *Medical Journal of Australia*, 178, 231-234.

⁵ Alzheimer’s Australia. (2010). Supplementary submission to the Productivity Commission Inquiry: Caring for older Australians.

⁶ Algase, D., et al (1996). Need-driven dementia-compromised behaviour: AN alternative view of disruptive behaviour. *American Journal of Alzheimer’s Disease & Other Dementias*, 11(6), 10-19.

This is further compounded by difficulties in navigating the healthcare system. There is a lack of connectivity between mental health, disability and the aged care systems and lack of effective coordination of linked services administrated by the Commonwealth and States.

Better interface between health services and funding schemes, will improve access and therefore timely diagnosis and management, of dementia. Accurate and timely diagnosis improve the chances of a person living with dementia in being recognized and treated appropriately, thus reducing mental stressors and enabling better management outcomes.

Please see addendum – Witness statement of advocate [REDACTED], who was carer to her late mother.

5. What are the drivers behind some communities in Victoria experiencing poorer mental health outcomes and what needs to be done to address this?

People living with younger onset dementia may experience a *“sense of humiliation for not having the same cognitive capacity as their peers, facing economic stigma and barriers to accessing rehabilitation”*. A person living with dementia

There is a need for better health workforce training on dementia and disability support for people diagnosed with dementia, including rehabilitation, and the right to live independently, and be included in the community.

Older people living with dementia in aged care facilities experience social isolation, grief and loss. According to Professor Brodaty during hearings from the current Royal Commission into Aged Care, there is evidence that 50% of people living in an aged care facility have zero relationships within their nursing home, limited stimulating activities and social connection with staff. Aged care facilities are simply not equipped to support good mental health and wellbeing. Hence this often results in poorer mental health outcomes.

Furthermore, there is substantial evidence of overprescribed psychotropic medications for people living with dementia in aged care facilities,⁷ to manage what are often labelled as “challenging behaviours”, without really understanding the underlying needs. Pain, for instance, is a common cause of behavioural disturbances, and studies found that simply administering Panadol three times a day was effective for a number of people in reducing their agitation. Thus the need to strengthen and implement a person-centred approach to care.⁸

When asked by people about how to care for his wife [REDACTED] who is living with Dementia, [REDACTED] replied with the following: *“To walk in [REDACTED]’s shoes, to recognise that she has had a rich past, that there’s a present and that she has an evolving future.”* Encapsulating the meaning of personhood, recognising a person’s history, experience and unique identity, in order to exercise effective and quality person-centred care.

⁷ Cousins JM, Bereznicki LRE, Cooling NB, and Peterson GM (2017). Prescribing of psychotropic medication for nursing home residents with dementia: a general practitioner survey. *Clinical Intervention in Aging*; 2: 1573–1578.

⁸ Brodaty, H, Draper, BM, Low, L. (2003). Behavioural and psychological symptoms of dementia: a seven-tiered model of service delivery. *Medical Journal of Australia*, 178, 231-234.

The increasing prevalence of mental illness amongst people with dementia highlights the need for effective mental health support, tailored to people with dementia. However, at present mental health services are not routinely available to older people living with dementia in aged care, and are not within the scope of personal care or accommodation services that residential care homes provide.

A growing amount of evidence suggests there are benefits of psychological therapies in improving symptoms of anxiety and depression in people living with dementia.⁹ Whilst much of this research is within the early stages, there are positive results indicating that certain psychological therapies can be adapted to work effectively with older people with cognitive impairment.

Dementia Australia would welcome the opportunity to partner with a mental health service provider to develop a programme of support tailored for people living with dementia and a mental illness.

6. What are the needs of family members and carers and what can be done better to support them?

Carers and family members of people living with dementia need to be well supported by the mental health system.

There is evidence that although some caregivers find caring for a person with neurodegenerative disease such as dementia, to be rewarding, others find the experience to be extremely burdensome and develop significant physical and mental health problems. For example, caregivers suffer from depression at four times the rate of non-caregivers and are almost three times as likely to seek treatment for anxiety. Caregivers can become increasingly socially isolated, and the subsequent decreases in social support are closely linked to worsening caregiver mental health.¹⁰

The impact of caring tends to be greater for those who live with the person with dementia, as these carers tend to provide more hours of care on a day-to-day basis, and may experience disruption of sleep due to night time disruptions. Older carers tend to have underlying health issues themselves and so this further impacts their health. Younger carers, may experience different stressors however, with competing work, family and social demands.

“I was unable to cope with the workload which included meals, supervision, housekeeping, visits to medical facilities etc.”

“Grief at the prospect of losing [relative] to a residential care facility. Not much depression. Some anger occasionally that life should turn out this way. These emotions have not been that severe, but will probably become more so when I have to make the decision to move her in. For the moment though, I just want to enjoy the life we have together.”

⁹ Deirdre Noone, Josh Stott, Elisa Aguirre, Kelly Llanfear & Aimee Spector (2018). Meta-analysis of psychosocial interventions for people with dementia and anxiety or depression, *Aging & Mental Health*.

¹⁰ Alzheimer’s Australia. Caring for someone with Dementia: The economic, social And Health Impacts of caring, and evidence based supports for carers. Paper 42. October 2015.

“Look after yourself. Do what you need to do, to keep the stress levels down. Try to be firm with your loved one while helping them understand that you know this is very difficult for them and that you love them.”

Caring for a relative or friend with dementia can have a profound emotional impact, with carers reporting feelings of guilt, sadness, anger, lack of control and worry. Carers may also experience grief whilst caring, both for themselves in terms of loss of companionship, personal freedom and control, and for the person living with dementia in terms of loss of personhood. Anticipation and ambiguity about the future, anger, frustration and guilt have been found to be common and may occur at any stage; from diagnosis to admission to residential care and beyond.

7. What can be done to attract, retain and better support the mental health workforce, including peer support workers?

There needs to be better incentives and support in place to attract health workforce into mental health services and the appropriate funding schemes to retain them.

There also needs to be improvement in workforce skills and training, on dementia and the prevalence/interaction with mental health conditions. Staff need to be able to communicate with people with dementia, build strong social connections and identify early signs of mental illnesses.

8. What are the opportunities in the Victorian community for people living with mental illness to improve their social and economic participation, and what needs to be done to realise these opportunities?

To build a dementia-friendly community as a model of inclusive communities in which everyone’s interests and skills are recognised. A community where, people living with dementia are supported to have a high quality of life with meaning, purpose and value. In a Dementia Friendly Community:

- the public are educated to understand dementia
- people living with dementia are treated with respect and empathy
- social groups are welcoming and inclusive
- businesses provide accessible services and staff trained to help people with dementia
- employers provide support for people living with dementia to stay in the workforce
- the physical environment is easy to navigate and safe for people with dementia

9. Thinking about what Victoria’s mental health system should ideally look like, tell us what areas and reform ideas you would like the Royal Commission to prioritise for change?

As outlined in previous sections, key reform areas could include:

- Developing a robust workforce – There needs to be better understanding of dementia for those diagnosing mental health conditions and vice versa.
- Tackling stigma/discrimination and barriers to inclusion for people living with dementia.
- Improving standards of care in the aged care sector – to be better equipped in managing dementia behaviours, and mental health concerns and the combination of both.

10. What can be done now to prepare for changes to Victoria’s mental health system and support improvements to last?

Please refer to previous sections.

11. Is there anything else you would like to share with the Royal Commission?

At this stage, key observations from Dementia Australia are covered in previous sections.

Conclusion

The evidence base supporting dementia care for improved mental health (in this context) is a field in which the knowledge base has significantly evolved in recent decades, driven by the increasing prevalence of dementia within the residential aged care system, home care settings and the general community. Like all Victorians, those living with dementia will benefit from enhancements to the linked primary and acute health care systems. Dementia Australia is pleased to contribute to an improved mental health system and would welcome further involvement to contribute our expertise to support better mental health outcomes for Victorians living with dementia.

Addendum

Witness statement of advocate [REDACTED], who was the carer to her late mother.

" The experience as a carer for my mother as we navigated Victorian's health system through to diagnosis and treatment for Dementia with Lewy Bodies has left me and our family scarred and disappointed in the health system, and in particular the inability of our public mental health system to address the needs of people living with dementia.

There are a number of similarities between dementia and some mental health problems – forgetfulness, withdrawal from activities, agitation, lack of concentration can be symptoms of both depression and dementia and often dementia is misdiagnosed as a mental illness leading to people being treated within the mental health system where this may not be the most appropriate pathway. Often people exhibiting the Behavioural and Psychological Symptoms of Dementia (BPSD) are pushed into the mental health system which, in my experience, is not responsive to their individual needs. It is a complex issue and determining who and when a person should be able to access Victoria's mental health system is problematic.

Our experience was one of being shunted from facility to facility. From a general ward within a hospital, to a rehabilitation facility (connected to the hospital) back to the hospital through the Emergency Department as the rehabilitation facility found it "too hard" to get the Consultation Liaison Inpatient Psychiatry Service to visit, transferred to an aged person mental health unit as an out of area admission and finally transferred back to the mental health aged acute in-patient unit of the hospital where we first started three months earlier. Leaving aside the issue of whether being an inpatient in a mental health unit was the appropriate pathway to diagnosis and treatment, the constant moving from one section of the health system to another aggravated my mother's condition and caused delays in diagnosis and appropriate treatment.

When neuroleptics should have been stopped as they worsened hallucinations they continued. This was despite acknowledgement by treating doctors that stopping would be appropriate, that the diagnosis was most likely Dementia with Lewy Bodies and that I, after considering all options, wanted them stopped. The medication continued as it was the next treating doctor's responsibility and not theirs.

All transfers were actioned very late in the afternoon or at night without any consideration that mother was Sundowning due to dementia. Too many strangers, too many environments and changes and too much noise all contributed and exasperated my mother's agitation and triggered BPSD symptoms. All of which could have been reduced by the staff in the system having a better understanding of dementia and employing a strategy of identifying triggers and taking action, or delaying action, to reduce the stress and resulting BPSD. The system actually triggered changes in behaviour that it was trying to alleviate and treat.

Although it was difficult to access mental health treatment, if we could relive that time we would avoid the mental health system at all costs. The Mental Health Act 2014 was meant to create patient centred care that was responsive to all of the patient's medical and health needs, to provide treatment in the least restrictive way, to involve carer's in decisions, to support patients in decision making and to respect the rights, dignity and autonomy of the patient. The current system, in my experience, is not responsive to those living with dementia, often results in incorrect diagnosis, uses medication to sedate as the only response and labels people as difficult or non-compliant when the triggers of those behaviours are often the result of the actions taken in that system. The Victorian Government has provided guidelines, policies and best practices for managing Dementia in hospitals

and acute settings, however, the Mental Health System appears to ignore those guidelines and acts as a stand-alone entity. The issues that have resulted in the person entering the Mental Health System do not stand alone from that person's disabilities, age, gender, other health issues, culture and rights.

Our experience was of a lack of communication or consultation with carer's and family. Decisions were made by medical staff where they did not have the legal right to do so. It was not the practice of the health professionals to be inclusive of family and carers.

Ward environments are generally not established to deal with the requirements of a person living with dementia. Staff are not responsive to the needs of a person living with Dementia. I will never forget seeing my mother in a large, busy, extremely bright room, trapped at a table by the positioning of her wheel chair, the only woman in a group of men and the fear that was in her eyes. My mother had reduced ability to speak and she could not be heard without being extremely close to her. We had told the mental health staff her hallucinations, a symptom of Dementia with Lewy Bodies, revolved around being violently hurt by men, probably in part due to a history of abuse. Her ability to express herself was reduced by Dementia. Her ability to understand and comprehend what was happening was reduced by Dementia. She was suffering with no way to get the staff to relocate her. Staff had labelled her difficult due to previously being in the same position, trapped, she has resorted to banging twice on the table – the only way her mind would allow her to communicate her need at that time and appeared to be oblivious to the distress they were causing. Oblivious due to their lack of understanding of dementia. The Mental Health System would be greatly improved by training staff in dementia and appropriate responses – it would reduce BPSD triggers and allow staff to be responsive to the needs of a person living with dementia.

I was with my mother for hours each day that she was an in-patient. I saw her dignity was not maintained. Her stomach was exposed in general living areas to receive Clexane injections, injections that she should have been able to say "no" to on any particular day if she wanted but staff would not allow. Toilet and room doors were left open so that any passing person would see her on the toilet. Her decision that she had eaten enough was not respected as more food was spooned into her mouth. She was put in so-called princess chairs as a form of restraint. Others were trapped by trays slotted into chairs. Staff talked openly in front of others in derogatory ways about patients. One woman who was on a compulsory treatment order was told to sign documents that the staff knew she could not read because her glasses had been broken. Community visitors were steered away but the nurse unit manager from patients that were unhappy with their treatment. As her carer, I was constantly fighting for my mother's rights as Dementia had robbed her of the ability, in the main, to do so. I should not have been in this fight at such a difficult time as we grieved upon receiving the diagnosis.

People living with Dementia, due to the disease, are more reliant on family and carers to provide support than many other people that find themselves in the Mental Health System. My experience was that any history and information I provided that could assist with assessment was ignored, my rights as a holder of my mother's medical power of attorney to make treatment decisions was ignored, and I was not consulted on treatment and usually found out after the fact. I was viewed as difficult because I was determined to protect my mother's rights – rights that she did not lose because she was living with Dementia nor because she was in the Mental Health System."