dementia australia™

The new voice of Alzheimer's Australia

Aged Care Financing Authority (ACFA)

Respite Care Consultation

Submission from Dementia Australia

April 2018

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 425,000 Australians living with dementia and the estimated 1.2 million Australians involved in their care.

Dementia Australia works with individuals and families, all levels of government, and other key stakeholders to ensure that people with 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 consumers 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.

dementia
australia™

Background

Dementia Australia welcomes the opportunity to contribute to the Aged Care Financing Authority (ACFA) Respite Care Consultation.

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. It is a broad term used to describe a loss of memory, intellect, rationality, social skills and physical functioning. There are many types of dementia including Alzheimer's disease, vascular dementia, frontotemporal dementia and Lewy body disease. Dementia can happen to anybody, but it is more common after the age of 65.

Dementia is not a natural part of ageing. It is a terminal condition and there is currently no cure. Dementia is one of the largest health and social challenges facing Australia and the world. It is the leading cause of death of women in Australia, the second leading cause of death in this country and it is predicted to become the leading cause of death within the next five years.[1]

Dementia affects people's functional abilities and memories and has a profound impact on the individual and those around them.[2] The disease is cloaked in stigma and misunderstanding,[3] isolates people with dementia and their carers from social networks,[4] and carries significant social and economic consequences.[5] People living with dementia constitute one of the most vulnerable groups in our society.

There are more than 425,000 Australians living with dementia in 2018 (including 25,000 people under the age of 65 years with younger onset dementia) and, without a significant medical breakthrough, there will be over one million people living with dementia in Australia by 2056.[6] It is estimated that there are approximately 1.2 million Australians involved in the care of people living with dementia.[7]

The cost of dementia to the Australian economy is significant and growing rapidly. In 2018, dementia is estimated to cost Australia more than $15 billion. By 2025, the total cost of dementia is predicted to increase to more than $18.7 billion in today's dollars, and by 2056, to more than $36.8 billion.[8]

---

[1] Australian Bureau of Statistics (2016) *Australia's leading causes of death* Available online at http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/3303.0~2016~Main%20Features~Australia's%20leading%20causes%20of%20death,%202016~3

[2] Mitchell, S. et al. (2009) The clinical course of advanced dementia, *The New England Journal of Medicine*, 361: 1529-38

[3] George, D. (2010) Overcoming the 'Social Death' of dementia through language, *The Lancet*, 376: 586-87

[4] Blay, S. & Peluso, E. (2010) Public stigma: The community's tolerance of Alzheimer's disease. *American Journal of Geriatric Psychiatry*, 18(2): 163-7

[5] Access Economics (2003) *The Dementia Epidemic: Economic Impact and Positive Solutions for Australia*. Report for Alzheimer's Australia, Available online at: www.fightdementia.org.au/research-publications/access-economics-reports.aspx

[6] The National Centre for Social and Economic Modelling NATSEM for Alzheimer's Australia (2016) *Economic Cost of Dementia in Australia 2016-2056*

[7] Alzheimer's Australia (2011) *Pfizer Health Report Issue #45 – Dementia*, Pfizer Australia

[8] The National Centre for Social and Economic Modelling NATSEM for Alzheimer's Australia (2016) *Economic Cost of Dementia in Australia 2016-2056*

The Need for Dementia-Specific Respite Care

> *"Respite has given Mum and I a new lease on life and a much more positive and confident way to deal with the stages of ageing and dementia without a feeling of isolation. We now look forward to a more positive future with growth, friendship and love." Carer of a person living with dementia*

Respite services are critical in providing a break for carers and for promoting social engagement for people with dementia, as well as helping people with dementia to live at home for longer. High-quality respite should provide the opportunity for people with dementia of all ages to participate in activities that are enjoyable and meaningful. This may include activities that provide them with companionship, stimulation, and engagement in the community, as well as meeting the needs of carers. Respite can be beneficial for both people with dementia and carers when it:

- Supports the social participation of people with dementia and their ability to pursue activities of interest;
- Gives carers time to look after themselves and their own work, health and social needs;
- Helps keep carers well and improve the quality of care they provide;
- Sustains carers so they can continue their caring role and the person with dementia can stay living in their own home.[9]

However, it is clear that, based on feedback from people impacted by dementia, there is a national shortage of dementia-specific respite care that meets the needs of carers and people living with dementia.

Over half of primary carers of people with dementia have indicated they need more support, and the greatest single unmet area of demand is for respite care[10]. Carers repeatedly identify good respite care as an important support for a sustainable caring relationship. In a recent Dementia Australia consumer survey, respite care was ranked second only to peer support amongst programs identified by carers as having been most useful to them. In the same consumer survey, limited respite care was identified as the top area of support that consumers felt needed to be addressed.

As care needs increase, people with dementia are often turned away from respite services. Many respite services have explained to families and carers that they are not staffed to provide care to people who have complex behavioural symptoms of dementia, who are incontinent or have other high care needs.

A recent Carers Australia report highlighted that many residential respite providers are unable to provide secure settings and/or enough trained staff to support individuals with dementia or other high care needs. The report recommended a focus on dementia-specific respite and improved training in dementia care for the workforce. When specifically asked

---

[9] Alzheimer's Australia (2016) *Flexible respite services for people with dementia and their carers - information for consumers*, Available online at https://www.dementia.org.au/files/NATIONAL/documents/Flexible-Respite%20Brochure-Consumers.pdf

[10] Alzheimer's Australia (2013) Respite Review Policy Paper, Available online at https://www.dementia.org.au/files/NATIONAL/documents/Alzheimers-Australia-Numbered-Publication-33.pdf

about accessing respite for people with high care needs, including dementia, 64 percent of respondents to Carers Australia felt it was much harder to access than if you had less complex needs:

> *"A few local residential aged care facilities accept people with dementia behaviours really quickly, but have no dementia expertise or resources and just want the business. They then complain to families about the behaviours. I have had several carers very distressed about this, and it makes them reluctant to book residential respite in the future."*[11]

Data also suggests that flexible aged care respite options are very limited in Australia, with only 67 out of the 1405 national providers offering flexible respite services.[12] Further, current residential respite options continue to be very limited, and not assisted by the fact that people seeking and waiting for permanent care are often using respite places.

Greater investment in flexible respite options, including day respite and cottage-based overnight respite, is needed. A Dementia Australia review of respite care undertaken for the Australian Government made a number of recommendations for respite care policy, including the need for:

- A dementia supplement for all forms of respite care, in recognition of the higher costs of caring for a person with dementia.
- Greater flexibility in the provision of respite care to make it more responsive to consumer needs and preferences, including better funding to meet the high demand for centre-based day respite and in-home day respite.
- A reduction in direct and indirect cost barriers to accessing respite care.
- A more co-ordinated approach that links respite with timely access for carers to counselling and support services.[13]

A dementia supplement for respite providers, similar to the supplement which is provided within home based care, is required - though the effectiveness and quantum of such a supplement must be modelled. A dementia supplement would acknowledge the additional costs associated with providing dementia-specific respite and create an incentive for providers to develop these services. It should only be available to services that can demonstrate they have the capacity to care for people with dementia.

Dementia Australia also strongly supports the intent of the proposed Integrated Carer Support Service (ICSS) to improve access to respite care. The ability to 'cash out' or access informal respite through friends and neighbours is important, particularly for rural and regional carers (for example, when a carer needs to arrange someone to be at home with the person with dementia while they attend an appointment in a metropolitan area).

Dementia Australia has resources to support consumers and respite care service providers. Two booklets were published as part of the *Making Flexible Respite Care a Practical Reality*

---

[11] Carers Australia (2018) *Improving access to aged residential respite care*, February 2018

[12] Department of Health (2017) *Stocktake of Australian Government Subsidised Aged Care Places as at 30 June 2017*, Available online at https://www.gen-agedcaredata.gov.au/Resources/Access-data/2017/October/Stocktake_data_30_June_2017

[13] Alzheimer's Australia (2013) *Respite Review Policy Paper* Available at https://www.dementia.org.au/files/NATIONAL/documents/Alzheimers-Australia-Numbered-Publication-33.pdf

project, supported by the Australian Government through the *Aged Care Service Improvement and Healthy Ageing Grants Fund*. The project was conducted by Dementia Australia, in partnership with the University of Wollongong and Carers Australia. The booklets were developed in consultation with consumers including people living with dementia and carers, as well as an expert service provider reference group. The resources are available online:

- Flexible respite services for people with dementia and their carers - information for consumers https://www.dementia.org.au/files/NATIONAL/documents/Flexible-Respite%20Brochure-Consumers.pdf
- Flexible respite services for people with dementia and their carers - information for service providers https://www.dementia.org.au/files/NATIONAL/documents/Flexible-Respite%20Brochure-Service-Providors.pdf

Response to Specific Consultation Items

1. The process for applying for and seeking access to respite care

> *"It's all well and good to be given 63 days, but it is getting the 63 days that is the issue. You have to be an acrobat, jump through hoops." Carer of person living with dementia*

People impacted by dementia tell Dementia Australia that the process of applying for and securing respite care is typically a challenging one. A number of elements play a role in this:

- Navigating My Aged Care can be complex and time consuming;
- Conversations about respite typically occur at time when carers are very stressed or under pressure;
- The pathways to services are unclear, even when accessed via My Aged Care;
- Eligibility for respite does not necessarily translate into access to respite, let alone access to quality dementia-specific respite.

> *"It is OK for the likes of us dealing with the system but if you are not used to dealing in such a way it is difficult. I would go as far as to say that the health system is bedevilled by this problem. I found it very difficult to handle the "system"…and I had real problems coping." Carer of a person living with dementia*

The process of accessing and implementing respite care needs to be simplified and made more user-friendly. My Aged Care has complicated access to services for consumers and has made matters confusing, with the referral processes for the most basic of services to support families becoming complex and frustrating for families and service providers. In order to address some of these challenges, Dementia Australia recommends more comprehensive support to navigate the respite system and the identification and implementation of quality indicators to facilitate more informed decision making. In addition, clear and consistent fees and pricing for all forms of respite is required.

2. Bottlenecks or delays in accessing either residential or non-residential respite care

> *"Bottlenecks, delays, road blocks…..call it what you like; the delays are caused by the My Aged Care gateway refusing to process ACAT applications. I do not believe that ACAT is at fault as they rely on referrals coming to them via My Aged Care." Dementia care worker*

Dementia Australia consumers and staff report significant delays in accessing residential and non-residential respite care services. There are several reasons for this including:

- A lack of appropriate respite services to refer to;
- Not enough respite places available in preferred settings (i.e. in-home or cottage respite rather than residential aged care);
- The availability of respite is hampered by shortcomings in other parts of the aged care system e.g. lack of higher level home care packages that can more easily accommodate respite needs within the package structure;
- Respite flexibility is limited, especially in instances where emergency respite is required;
- Referral pathways are not clear or functional.

> *"Bottlenecks are definitely increasing when it comes to applying for long term respite and it's a matter for support workers to inform carers to plan and book respite in advance to avoid missing out. Carers usually want and need respite ASAP, not wait for 2 months." Dementia care worker*

Dementia Australia recommends that the referral and access pathways for respite are reviewed. Further, the incorporation of respite into mainstream home care and residential care should be reviewed for effectiveness, consistency and equity of access.

3. Whether current provider funding structures for the provision of residential respite care are appropriate

4. Whether the current system for allocating respite bed days to residential care providers impacts the availability and provision of respite care

Data shows that the number of people accessing respite care is rising, but it is not clear what is driving this change, or indeed, whether there is sufficient respite available.Providers of residential respite care do not have a separate allocation of residential respite places. Rather, a portion of each permanent allocation of residential care places may be used for the provision of respite care and it is up to the provider to decide what mix of permanent care and residential respite care they provide.

Feedback provided to Dementia Australia by people living with dementia, their families and carers suggests that this funding and operational model is not satisfactory. We have anecdotal evidence that providers are not offering respite beds, especially for people with dementia with high care needs, as there is no funding incentive to do so. This places increasing pressure on the carers who need the support of respite the most.

> *“I have tried again recently (to access respite) and have found it more difficult and was told many providers are finding demand for very high care is soaring and the Government pay more for those people than for respite so they are using beds they used to use for respite. This is leading to difficulties for the people in respite – they now find themselves in places with the majority of other residents being very high care which is not what they want.” Carer of a person living with dementia*

It is clear that residential respite places are frequently being used by clients awaiting a permanent residential aged care place. As the ACFA notes in Attachment A to the Consultation Paper, the number of residents entering permanent care within a week of a respite care stay has been increasing since 2010. The increase has been noticeably more significant since 1 July 2014. This may indicate that care recipients who intend to enter permanent care are first accessing respite care while they arrange their financial affairs or await the completion of aged care means testing.

To overcome this issue, there should be a distinct funding envelope for residential respite care places. A dementia supplement covering all forms of respite care would also recognise the higher costs of caring for a person with dementia and help incentivise providers to offer more services. Dementia Australia recommends that this supplement should only be available to services who can show they have put in place strategies and training for caring for people with dementia. It would also acknowledge the additional costs associated with providing respite to this group and would create an incentive for providers to develop dementia-specific services which include social engagement opportunities where possible. A respite supplement would be in line with the Government’s focus on increasing choice through implementation of consumer directed care.

There also needs to be more opportunity for overnight and/or shorter-term respite as well as more consistent and accessible respite in the home. Families and carers have told Dementia Australia that some providers are putting a two-week minimum on respite bookings in residential care, while availability of respite in community settings is incredibly limited.

Finally, the recommendations in the Aged Care Legislative Review should be considered. The allocation of residential aged care places, for example, may be improved by discontinuing the Aged Care Approvals Round (ACAR),

5. Costs to consumers and/or carers seeking to access respite care

Ascertaining the costs to consumers and/or carers to access any element of the aged care system, including respite, is incredibly difficult for people impacted by dementia to determine. The range of experiences families have suggests that the role of Centrelink in assessing financial capacity and the implications on the process for receiving respite are unclear at best and variable at worst, and that these complex conversations are occurring at a time of peak stress for the person with dementia as well as their families and carers.

It is also clear from the experiences of service users that the comparable costs of respite across care settings are inconsistent. As such, Dementia Australia recommends the ACFA undertakes detailed modelling to better understand the cost of services across the respite spectrum.

6. Impact of the current arrangements on equity of access for respite care recipients, including access in an emergency, or to residential respite for periods of less than one week

Anecdotal evidence from our consumer networks indicates that there is still significant unmet demand for appropriate, high quality respite services for people with dementia, particularly those living in rural and remote areas, those with significant behavioural and psychological symptoms of dementia, and those with a need for culturally specific services, such as older people with dementia from Culturally and Linguistically Diverse (CALD) backgrounds or from Aboriginal and Torres Strait Islander communities. This goes for shorter term as well as longer term forms of respite.

However, robust data on the accessibility of respite services for people impacted by dementia – or the appropriateness of these services in delivering quality dementia care – is lacking and requires further investigation.

7. Any unintended impacts or consequences of the current arrangements supporting access to residential respite care

Constrained market and high demand for respite means there are unregulated respite care providers who operate outside of the aged care regulatory framework. Anecdotal evidence from Western Australia in particularly suggests that staff qualifications and care standards in these settings are variable and that people entering these services are not supported by robust regulatory frameworks.

For carers of people living with dementia, the limited availability of quality dementia respite means that their own wellbeing and that of their carers is adversely affected as they are not able to access support interventions when they would be most effective, i.e. before a crisis point. Additionally, because access to emergency respite is limited, people with dementia end up being inappropriately admitted to emergency hospital settings. Hospital environments are inappropriate for people with cognitive impairments and can exacerbate symptoms of dementia. People living with dementia who are hospitalised experience worse clinical outcomes and longer lengths of stay as well as a higher likelihood of readmission compared to people without dementia. Not only is this detrimental to the person with dementia but it also results in a high cost to the health care system.

8. Use of Commonwealth Home Support Programme respite care services and the interaction with other programs that deliver respite services, including residential respite care

While waiting to access overnight respite services the role of Commonwealth Home Support Programme (CHSP) funded services are vital as they can give the carer and person living with dementia in-home support. CHSP services offer short term in-home respite while arrangements are being made for short-term and long-term residential respite. People impacted by dementia tell us they are a valuable and necessary support to families living with dementia.

However, it is not possible to ascertain the consistency and accessibility of these services, or their connectedness to other programs. Feedback provided to Dementia Australia suggests it is variable and dependent on:

- The provider
- The level/acuity of care needs
- The location in which respite is required.

9. Any other matters relevant to respite care

a) Staffing – skills, training and qualifications

Dementia Australia advocates for improvements to the quality of the aged care workforce across the board, including in respite services. At a time when the number of people needing access to aged care services is increasing, and the acuity of care required is also increasing, ratios of direct care staff to residents in aged care services are often decreasing, and the number and proportion of qualified nursing staff positions in aged care, particularly residential care, has fallen dramatically. Dementia Australia is concerned that these trends are already impacting on the quality of care offered to some of the most frail and vulnerable people in our community, and that the situation has the potential to worsen in the future as demand pressures increase.

Dementia Australia looks forward to the comprehensive aged care workforce strategy that is currently under development, and hopes there will be opportunities to focus on clear education standards and career pathways for the workforce. Further, a cohesive, structured and integrated national approach to dementia education and training is needed, including minimum standards for education and training for those working with people with dementia. Staff working in respite services should also be educated in therapeutic and lifestyle interventions as well as effective communication.

b) Respite care for families living with younger onset dementia

> *“Applying for an ACAT assessment in order to seek respite care is very frustrating for our clients. Applications have to go through My Aged Care. As soon as the intake person is told the applicant is under 65 they refuse to proceed with the application. This is so unfair.” Dementia care worker*

Younger onset dementia develops before the age of 65, even as young as 35 years of age, and currently, there is an estimated 25,938 people with younger onset dementia in Australia, a number which is expected to rise to 29,375 people by 2025 and 42,252 people by 2056.[14] For many years people with younger onset dementia have fallen through the cracks of the disability and aged care systems.

Dementia Australia has long believed that the National Disability Insurance Scheme (NDIS) will transform the lives of people living with progressive neurodegenerative diseases and has promoted and supported the Scheme since its inception. To date some NDIS participants living with dementia have received plans that have had positive, life-changing impacts on

---

[14] The National Centre for Social and Economic Modelling NATSEM for Alzheimer’s Australia (2016) *Economic Cost of Dementia in Australia 2016-2056*

their lives. However, many others have faced barriers in accessing a plan or have received insufficient plans that adversely affect their quality of life.

Unfortunately people with dementia and their families still face the difficult issue of a lack of appropriate services to cater for the needs of younger onset dementia, both within the community and in residential care. Often aged care facilities are unwilling or unable to take on clients who may have significant behavioural symptoms and are still very mobile. Access to appropriate supports in the community, including respite, is thus essential to delaying premature entry into residential care for people living with younger onset dementia.

However, the current arrangements for accessing respite care, particularly residential respite, are challenging for people with younger onset dementia who are under the age of 65. Their inability to access an Aged Care Assessment Team (ACAT) assessment limits their options for respite in the aged care system and makes a stressful period even more so.

Conclusion

The respite care experience is generally not well understood or mapped in terms of data, costs or quality of services. Issues around equity of access are compounded when complex care needs like dementia are present and families and carers report the emotional, physical and financial impact this has on them. Dementia Australia welcomes this review by the ACFA and looks forward to working with the Authority and Government to ensure quality respite care for people impacted by dementia is timely and equitable.