



**dementia  
australia™**

**Royal Commission into Aged Care  
Quality and Safety**

**Support for Carers of People  
Living with Dementia**

**Dementia Australia**

**June 2020**

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## 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 459,000 Australians living with dementia and the estimated 1.6 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

For most people living with dementia, informal carers are an integral part of their lives, their care and their ability to remain safe and supported in their own home or in residential aged care. Carers of people with dementia are often a spouse or child and typically they provide wide-ranging supports, including assisting with activities of daily living, personal care, and responding to changed or responsive behaviours, as well as making decisions about treatment options, use of services, finances, and care arrangements.

The critical role that informal carers play in supporting people living with dementia must not be underestimated. Carers of people living with dementia face their own challenges in the current aged care system, including difficulties in navigating two systems (My Aged Care and the Carer Gateway) and a lack of support services, especially respite. To enable people with dementia to live at home for as long as possible, it is critical that the needs of carers are understood and well supported. It is therefore imperative that a new or redesigned aged care system does not overlook the significance of informal carers and that the Royal Commission into Aged Care Quality and Safety includes recommendations specific to this cohort.

In this submission, we focus on three critical areas that need to be addressed to ensure carers of people living with dementia receive the support they need to maintain their caring role:

- system accessibility
- multicomponent, early intervention support
- flexible respite

Support for carers of people living with dementia will ultimately minimise unnecessary hospitalisations, delay premature entry into residential care and ensure that people living with dementia live well.

Dementia Australia makes the following recommendations for a redesigned aged care system.

## Recommendations

1. Design a service access gateway and a holistic assessment process that recognises the importance of carer supports alongside services for people with dementia.
2. Provide a multi-component early intervention support program for carers of people living with dementia that combines education and training opportunities to equip carers to fulfil caring duties - with access to psychosocial interventions and supports that help to maintain the carer's mental health and wellbeing.
3. Prioritise flexible dementia specific and/or inclusive respite funding to enable the delivery of innovative respite services where and when they are needed.
4. Ensure that mandatory dementia education requirements apply to all respite providers, with providers demonstrating dementia capacity as a requirement of their funding.

## The impact of caring for people living with dementia

In 2020 there are an estimated 459,000 Australians living with dementia and it is predicated that this will increase to 1,076,000 by 2058.<sup>1</sup> As the number of people living with dementia continues to increase, so too does the number of people providing informal or unpaid care to people with dementia. It is estimated that over 300,000 Australians are currently providing informal/unpaid care to people living with dementia.<sup>2</sup>

Many people with dementia rely on informal carers to supplement any formal care they receive in their home (if they receive any formal support at all). Even people receiving the highest level home care package usually rely on additional supports from an informal carer, as services alone are rarely sufficient to enable someone with dementia to remain at home or to live well. Carers therefore reduce pressure on aged care services, either by supplementing a formal support package or, in some cases, completely replacing formal support.

Carers report that caring for a person living with dementia can be a demanding role. Carers are faced with supporting someone with a terminal, degenerative condition, who is likely to experience a wide range of symptoms, all of which represent a progressive cognitive decline and ultimately a diminishing of their ability to live independently. Caring for a person with dementia therefore differs from caring for people with other health issues. The duration of the disease, progressive nature of the disability, and the lack of cure can create a uniquely challenging caring situation for the carer.

*“Carers are the forgotten ones that don’t get the help and support needed, they also need to go on an unknown journey, and are often more frightened than the person with dementia.” Carer*

Although many carers report a willingness to care and gain a sense of pride from their caring role, they also describe the associated challenges, including reduced psychological wellbeing, physical health concerns and significant financial strain. For older carers, especially, they may be experiencing their own health concerns as well as psychological and physical changes as a result of the ageing process. The impact of caring tends to be greater for those who live with the person who has dementia, as these carers typically provide more complex care, deliver more hours of care on a day-to-day basis, and may experience disruption of sleep due to night-time disturbances.<sup>3</sup> The demands of caring for someone with dementia also place carers at increased risk of social isolation, as they sacrifice their own personal interests and relationships to fulfil their caring duties.

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<sup>1</sup> Dementia Australia, *Dementia Prevalence Data 2018-2058*, commissioned research undertaken by NATSEM, University of Canberra, 2018.

<sup>2</sup> Dementia Australia analysis of Alzheimer’s Disease International and Karolinska Institute, *Global Estimates of Informal Care*, 2018 available at <https://www.alz.co.uk/adi/pdf/global-estimates-of-informal-care.pdf> and Dementia Australia, *Dementia Prevalence Data 2018-2058*, commissioned research undertaken by NATSEM, University of Canberra, 2018.

<sup>3</sup> J Schneider, J Murray, S Banerjee and A Mann, A cross-national study of co-resident spouse carers for people with Alzheimer’s disease: factors associated with carer burden, *International Journal of Geriatric Psychiatry*, 14(8), 1999, pp 651-61.

*“Carers need to be recognised as people living under a lot of stress. It is Important to include reference to carers when referring to people living with dementia. The carer stress affects the person with dementia and they can’t understand why. This is problematic. He would think the stress was his fault. I can’t fulfil my role of caring because situations put us under so much pressure.” Carer*

Almost half of carers of people living with dementia are of working age.<sup>4</sup> Over time, many carers will need to reduce their working hours, or to stop working entirely, so they can provide increasing levels of care. For carers of people living with younger onset dementia, and for younger carers, this can be particularly challenging.

*“The long wait time for supports significantly impacted my family. I had to give up work to care full-time for my mother, I then became ill when the burden and worry became too much and then had to put my mother (who was only 78 at the time) into full-time care. I am now in a position of having to start looking for work after being out of the market for over 18 months.” Carer*

The social distancing measures and restrictions put in place during the COVID-19 pandemic have magnified the need for effective carer supports, as the situation has exacerbated caring responsibilities and highlighted just how isolated carers can be. The mental health consequences for carers are substantial - their care responsibilities have increased as regular activities and respite opportunities have been disrupted, and Dementia Australia staff are observing an increase in reports of carer stress and burnout. For people living with dementia, their families and carers, the extent and impact of social distancing and other COVID-19 measures is likely to be significant and potentially long lasting.

## System accessibility

Access to carer supports is often dependent on an individual’s level of knowledge about the different systems as well as their proximity to available services. Carers of people living with dementia often report to Dementia Australia that they are confused about where to go for support or what support is available to them – which delays their access to important services.

*“Face to face is so important. When you call people, you don’t know who you’ll get - it’s a lottery. A case manager would be useful. So many different institutions aren’t joined up at all and in the end no one knew how to help me and I’d get passed on to someone else.” Carer*

Although the introduction of the Carer Gateway creates an avenue for accessing supports which are dedicated to carers, engagement with, and understanding of, the Gateway is limited. Many carers of people living with dementia report that having to access two separate access points for services – My Aged Care and the Carers Gateway – is confusing and adds to the complexity of navigating service systems.

A robust body of evidence suggests carers need access to a range of supports to help maintain their physical and mental health, in addition to psycho-educational supports to assist them in their caring role. The existing Carer Gateway aims to provide carers access to

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<sup>4</sup> Australian Institute of Health and Welfare, *Dementia in Australia*, AIHW, Canberra, 2012.

these supports; however carers may lack awareness of the Gateway and the services available to them. Linking the Carer Gateway with the aged care system more overtly would enable all those impacted by a diagnosis of dementia to receive the supports they need, when they need them.

While we await the Government response to the Royal Commission, My Aged Care and the Carers Gateway should work together to provide a holistic support package that meets the needs of the individual with dementia and their family and carers. A joint system approach, where individuals who access My Aged Care system will automatically access the Carers Gateway, would potentially reduce confusion about operating two support systems and increase engagement from carers.

*“There should be only one “easy to access and navigate” aged care system. The Carers Gateway and My Aged Care means the care must learn to navigate two systems. Access to aged care services is complex.” Former carer*

In considering a redesigned aged care system, the Royal Commission needs to recognise the pivotal role of carers in supporting people living with dementia. This means that access to carer supports should be considered in the development of an aged care access and care finding system. In a redesigned aged care system, we need an integrated approach to carer supports rather than separate gateways and care planning that takes into account the needs of for person with dementia and carer.

**Recommendation 1:** Design a service access gateway and a holistic assessment process that recognises the importance of carer supports alongside services for people with dementia.

## Multi-component early intervention support

Without any formal training or education, carers of people living with dementia undertake a range of complex caring tasks, including administering medications, providing personal care, managing changed behaviours/recognising the needs of person with dementia, as well as making difficult decisions about treatment options, finances, and care arrangements.

*“Carers lives completely change when they begin caring fulltime for people with dementia. Your life is just put on hold and you have to be available 24/7. Speedy access to supports is critical to carers wellbeing – carers are grieving as well as caring.” Former carer*

It is critical that all carers have access to carer support programs and services, from the point of a dementia diagnosis. The core features of effective carer supports include:

- Practical learning resources about dementia and caring for someone living with dementia;
- Skills training to help build resilience and manage stress;
- Psychosocial interventions such as counselling and social/peer support; and
- Flexible respite options.

*“As my mother declined, she became more challenging to care for and I had to learn how to care for her, on my own. In my mother's case I took a proactive role in her care, however, in most cases the person's partner may have problems of their own and may find navigating the services difficult. If someone could help them navigate supports, that would be of great service in addition to those provided by the Commonwealth Home Support Program.” Carer*

From the point of diagnosis, carers should be encouraged to engage in early intervention supports tailored to build resilience and manage stress in a productive and sustainable way. These supports are critical to proactively maintaining the mental and physical health of carers in order to sustain their caring role.

Access to supports which address the psychological, social and physical impacts of dementia and target both the individual with dementia and their family and carers are most effective at delaying entry to residential aged care.<sup>5</sup> Multi-component carer support combines individual interventions, such as skills training, education and psychosocial supports, into a structured program that is led by a qualified professional. Compared to individual interventions, multi-component support programs delivered to carers on a regular basis, demonstrate the most promise in delivering effective and long-term outcomes for carers – for example, improvements to carer's wellbeing and self-efficacy, as well as reduced depressive symptoms.<sup>6</sup> Access to a structured multi-component support program, from the point of dementia diagnosis, would ensure more carers receive the right supports and training they need to carry out their role, and potentially reduce risk of carers reaching burnout.

**Recommendation 2:** Provide a multi-component early intervention support program for carers of people living with dementia that combines education and training opportunities to equip carers to fulfil caring duties - with access to psychosocial interventions and supports that help to maintain the carer's mental health and wellbeing.

## Flexible respite

In 2012, the Australian Institute of Health and Welfare found that 39% of primary co-resident carers of people with dementia had used respite services. The key reasons for accessing respite were: emotional stress and strain (49%); increasing needs of the care recipient (22%); carer employment issues (9%); and carer's need for time to maintain regular activities (7%). Over half of co-resident primary carers of people with dementia (52%) also reported needing additional support and 48% stated respite care was the main area in which they needed more help.<sup>7</sup>

Respite may be used to give carers a break from their caring responsibilities, for mental or physical relief, to allow carers to engage in social or recreational activities, or in response to a crisis, and enable the person with dementia to continue to remain living at home for as long as is appropriate. Respite improves carer emotional wellbeing and physical health,

<sup>5</sup> J.A Luker, A Worley, M. Stanley et al., The evidence for services to avoid or delay residential aged care admission: a systematic review, *BMC Geriatrics* 19, 2019 pp.217

<sup>6</sup> D. Parker D, S. Mills, J. Abbey, Effectiveness of interventions that assist caregivers to support people with dementia living in the community: a systematic review, *International Journal of Evidence-based Healthcare*, 6(2) 2008, pp.137-72

<sup>7</sup> Australian Institute of Health and Welfare, *Dementia in Australia*, AIHW, Canberra, 2012

provide time for carers to look after themselves, and enhance autonomy and independence.<sup>8</sup> Respite is essential for carers to sustain their caring duties.

However, access to respite is limited in the current system, where a lack of local services and, in many cases, a lack of sufficient resources to meet the needs of people living with dementia prevents access to respite.

*“I would take husband to my daughter’s home for a few weeks to access respite in Mudgee. There was nothing available here.” Carer*

Difficulties in accessing respite are particularly pronounced for individuals with additional special needs, for example those from culturally and linguistically diverse backgrounds, and Aboriginal and Torres Strait Islander people – who have additional requirements for respite care and even fewer local services to provide the care required. Similarly, individuals living in regional, rural or remote locations struggle to access appropriate respite within a reasonable distance.

*“I had to drive hundreds of kilometers to access services and supports...I just want to take them somewhere I know they will be cared for.” Carer*

Over recent years, we have seen the move to individualised support packages underpinned by the concept of consumer directed care (CDC), with the funding of supports specifically tied to the goals/needs of people living with dementia. Within this reform, the focus is on individualised supports for the ‘care recipient’ rather than the dyad as a whole, which means that the immediate needs of people with dementia are prioritised over those of their carer.

Cottage based respite along with residential respite are particularly valued service types for carers, yet carers of people living with dementia, especially those with high or complex care needs, experience poor availability despite a clear market demand. Indeed, we often hear reports of these types of services not accepting people living with dementia who experience significant behavioural symptoms, or when they do admit them, the carer is called within a day or two (sometimes within a matter of hours) and asked to take the person they care for home. Respite options for carers who so desperately need a break from their caring responsibilities are therefore almost non-existent. This arguably leads to premature entry to residential aged care; yet had the carer been able to receive respite, they may have sustained their caring role for longer.

The increased supply of such services, as well as the capacity of services to support people living with dementia, must be a core component of a new aged care system. A more flexible range of service options is also vital. For example, carers may need a break from the physical demands of caring but they may not want to be separated from the person they care for. In a new aged care system, support for couples to access in-home or residential respite at the same time should be commonly available to allow them to spend quality time together while the carer receives a break from the physical care tasks. This type of respite is currently difficult to access.

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<sup>8</sup> M Hamilton, G Giuntoli, K Johnson and K Fisher, *Transitioning Australian Respite*, Social Policy Research Centre, University of New South Wales, 2016



In 2016, a literature review examined the features of high quality flexible respite.<sup>9</sup> The key components of flexibility in the provision of respite identified were:

- Who: Respite care needs to consider how it is going to benefit the individual with dementia and the carer.
- What: Respite should include a range of activities, tailored to the needs of the individual.
- Where: The setting of respite care should be chosen in response to the consumer's needs and preference, and not constrained by it. Settings include in-home respite, host home respite, day centres, outings and residential care.
- When: Respite needs to be responsive to the situation of the individual. This requires consideration to the time, frequency and duration of respite services.

The review also highlighted the need for government and providers to consider how policies and programs can support the uptake and delivery of flexible respite services.

There are very few dementia-specific or dementia-inclusive respite options available in the current system. Dementia Australia recommends that flexible dementia specific and/or inclusive respite funding is prioritised in a new aged care system to enable the delivery of respite where and when it is needed. Raising the foundational level of dementia skills across the aged care workforce will go some way to address this issue, but the sector also needs to be incentivised to develop flexible and responsive respite options for people living with dementia, their families and carers, rather than excluding them from accessing services on the basis of their diagnosis.

**Recommendation 3:** Prioritise flexible dementia specific and/or inclusive respite funding to enable the delivery of innovative respite services where and when they are needed.

**Recommendation 4:** Ensure that mandatory dementia education requirements apply to all respite providers, with providers demonstrating dementia capacity as a requirement of their funding.

## Conclusion

Carers play an integral role in supporting people living with dementia and in alleviating pressure on the aged care system. As the population of people living with dementia in Australia continues to grow, the reliance on carers will increase. Dementia Australia therefore advocates for stronger recognition of the significant role of carers of people living with dementia, for improved carer supports tailored to meeting their mental health needs and for an aged care system that holistic considers the entire family unit.

Dementia Australia strongly recommends that the Royal Commission include the recommendations outlined in this submission in its final report. We would welcome the opportunity to discuss this submission with the Commissioners and Senior Counsel.

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<sup>9</sup> L Phillipson, E Cridland and K Cappetta, *Understanding the factors that contribute to 'flexibility' in the provision of respite for people with dementia and their carers: A Literature Review*, Dementia Australia, 2016