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Royal Commission into Aged Care Quality and Safety

People with younger onset dementia in the aged care system

Dementia Australia

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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 of all ages 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 can 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 of all ages 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

There have been multiple failings in the aged care system for younger people living with dementia, their families and carers – both at the provider level and at a systemic level. The lack of a specific and consistent focus on younger onset dementia means that the needs and preferences of people living with younger onset dementia, their families and carers are currently not consistently addressed.

A redesigned aged care system must respond to the needs of the growing number of people living with younger onset dementia. Central to this is an effective interface with the National Disability Insurance Scheme (NDIS) and disability service providers to ensure appropriate and timely service options are available.

Dementia Australia urges the Royal Commission into Aged Care Quality and Safety to consider the needs of people living with younger onset dementia, their families and carers. Our submission outlines the key challenges people living with younger onset dementia face in the current aged care system and proposes recommendations to improve the situation in redesigned aged care system.

Recommendations

1. An integrated referral pathway between the disability and aged care systems is developed to ensure people with younger onset dementia receive timely access to appropriate services.
2. Mandatory education about younger onset dementia is provided to information, assessment and care planning staff across the disability and aged care settings.
3. A redesigned aged care system needs to address the accommodation needs of people with living with younger onset dementia and ensure that there are flexible models available across all programs, regardless of the age of the person.

About younger onset dementia

There are more than 459,000 Australians living with dementia in 2020, including an estimated 27,800 people with younger onset dementia. This number is expected to rise to 29,353 people by 2028 and 41,249 people by 2058.¹ Younger onset dementia describes any form of dementia diagnosed in people under the age of 65.

Although it is more common in older people, dementia is not a natural part of ageing and it affects people in their 40s, 50s and even 30s.² The misconception that dementia is a

¹ Dementia Australia, Dementia Prevalence Data 2018-2058, commissioned research undertaken by NATSEM, University of Canberra, 2018

² There are also some rare forms of childhood dementia, including Sanfilippo Syndrome, Niemann Pick Type C Disease and others.

condition of old age contributes to, and exacerbates, multiple challenges experienced by younger people with a diagnosis of dementia.

Overall, the experience for people with younger onset dementia – who often receive a diagnosis when they are in full-time employment and actively raising and financially supporting a family – is different from those diagnosed with dementia at a later stage of life. Loss of income, self-esteem and perceived future purpose can pose multiple physical and psychological challenges for people with younger onset dementia and their families.

Disability and aged care system interface

People with younger onset dementia are required to navigate their way through multiple service systems as their dementia progresses. While people living with younger onset dementia are generally eligible to access the NDIS, due to the progressive nature of their condition and need for increasing supports – which may not be available in the disability system – many people with younger onset dementia also require support from aged care services. As such, people with younger onset dementia are typically required to straddle both the aged care and disability systems – neither of which is fully equipped to respond to the needs of people with younger onset dementia.

People with younger onset dementia have long battled the challenges of straddling the disability and the aged care systems, with both systems often regarding the other as best placed to respond to the needs of younger onset dementia. Critically though, as the NDIS does not yet provide respite or permanent residential care options for people with younger onset dementia, people are required to access residential care through the aged care system.

It is clear the current aged care system is not meeting the needs of people living with younger onset dementia, their families and carers. Improving the interface between the disability and aged care systems is a crucial component in building a more effective system that appropriately responds to the care and support needs of people living with younger onset dementia.

In redesigned system, people with living with younger onset dementia should have a streamlined referral, assessment and service access process that is consistent across disability and aged care settings, and which would not require different assessment criteria and processes. In addition, it is essential that disability and aged care staff understand younger onset dementia and that services are designed to be age appropriate.

Accessing the aged care system

As most people with younger onset dementia will require access to aged care services at some stage, it is crucial for aged care information and assessment staff to understand the circumstances and support needs of people with younger onset dementia. Yet feedback provided to Dementia Australia demonstrates that this is currently not always the case.

“They just don’t get it. They hear dementia and they’re willing to help you, but when you tell them the age of your mum, they suddenly can’t do anything anymore.” Carer

In order to access services in the aged care system, individuals require an assessment, accessed through My Aged Care. My Aged Care stipulates that for people under the age of 65 years, all other support options must be considered before accessing My Aged Care. People with younger onset dementia and their carers report having to ‘convince’ My Aged Care staff why they need to be assessed for supports – often, to be turned away and told to consider other options first, despite most people attempting access to aged care supports precisely because all other options have been exhausted and supports available to them under the NDIS are no longer adequately meeting their needs.

Consequently, people with younger onset dementia may reach the point of hospitalisation before they are deemed eligible for accessing aged care supports. In 2019, the Australian Institute of Health and Welfare found that the majority of younger people received their first ACAT assessment in hospital, with two thirds having their first face-to-face meeting in an inpatient setting.³

Access to appropriate supports to prevent avoidable hospitalisations needs to be a priority for both the disability and aged care sectors. A joined up approach, whereby the disability system alerts the aged care system at the point where an individual requires aged care services, would prevent delays in accessing critical services and supports.

Recommendation 1: An integrated referral pathway between the disability and aged care systems is developed to ensure people with younger onset dementia receive timely access to appropriate services.

Understanding of younger onset dementia and of the needs of people impacted by the condition must be improved in the aged care sector. Dementia Australia advocates for mandatory dementia education in the aged care, disability and health sectors. Education about dementia must include information about younger onset dementia. Understanding the circumstances and unique needs of an individual living with younger onset dementia will ultimately help staff appreciate why access to aged care services is necessary and direct them to the appropriate supports and services. Overall, an increased awareness and education of younger onset dementia, and the typical pathway for care needs would significantly improve the experience of people with younger onset dementia and prevent unnecessary delay to accessing the support.

³ Australian Institute of Health and Welfare, *Pathways of younger people entering permanent residential aged care*. Cat. no. AGE 89. Canberra: AIHW, 2019

Recommendation 2: Mandatory education about younger onset dementia is provided to information, assessment and care planning staff.

Appropriate care options

Although most people with dementia want to remain living at home for as long as possible, there often comes a point where they may require the full time care in a residential facility. Finding suitable respite and residential accommodation is a significant challenge for people with younger onset dementia, their families and carers. Accommodation options offered under the disability system are rarely equipped to support individuals with complex neurodegenerative conditions, like dementia. While the sector is developing more suitable models to meet the needs of people with younger onset dementia, the only option for people who require full time care and accommodation is to enter residential aged care. Recent data indicates that dementia is the most common condition to trigger younger people's entry into residential aged care.⁴

Ultimately, the aged care system – where the average age of residents is 84 years – is designed to support the needs of older people. In many cases, facilities are simply not equipped to care for a younger person and there is evidence that some providers refuse to accommodate people with younger onset dementia.

“No accommodation close to us will take mum, they say it is because she is not old enough and that she is too ‘high needs’ for them.” Carer

People with younger onset dementia describe aged care facilities as isolating environments which can impact their wellbeing, feelings of self-worth and independence. Providers rarely have the capacity to provide adequate stimulation or activities that cater to the needs of younger people – who are often physically able and active, even if their cognitive abilities have changed to the point that they are unable to manage their day to day lives unsupported.

“Younger people with dementia aren't given appropriate activities (in aged care homes) and their unique needs often go unresolved.” Person living with dementia

“My partner came to be seen as a behaviour problem because he would get lost and wander into other people's rooms and because he took too long to dress. I felt that the facility blamed him rather than exploring ways to improve his experience. Some of his problems were not because he was living with younger onset dementia but were because of a general lack of care, but some issues related to the facility's lack of engagement with his particular needs.” Former carer

Incorporating more social supports and activities, targeting younger and more physically able individuals would enable a better quality of life for many already in aged care facilities. Supports that engage the individual's family members and friends would also address some of the social isolation often experienced by younger people in aged care.

⁴ Australian Institute of Health and Welfare, *Pathways of younger people entering permanent residential aged care*. Cat. no. AGE 89. Canberra: AIHW, 2019

“The decision to put someone into care is hugely emotional and stressful; having to decide on a facility which doesn't cater appropriately for people living with younger onset dementia adds to the carer's emotional load.” Former carer

Key components of providing appropriate residential care to people living with younger onset dementia include:

- Staff who are trained in dementia care and equipped to respond to the changing care needs of people living with dementia. This is particularly important when individuals enter the end of life stage, and behaviours and responses to the environment which is often the stage where people with dementia are admitted to residential aged care.
- A 'home-like' physical environment which is designed to support residents to live independently;
- A person-centred model of care which emphasises the value of each individual, their history, experiences and culture;
- Access to meaningful activities, which meet individual's needs, strengths and abilities;
- Enablement principles guide the delivery of care to maximise and maintain the individuals function and comfort.

In March 2019, the Government announced a 'Younger People in Residential Aged Care – Action Plan' to support younger people already living in aged care by finding alternative and more appropriate care arrangements, in addition to halving the number of younger people in residential care by 2025. The National Action Plan provides an opportunity to improve access to age appropriate accommodation for people with younger onset dementia. However, until more appropriate options are developed, it is imperative that the aged care sector improve its capacity to meet the needs of people living with younger onset dementia.

Recommendation 3: A redesigned aged care system needs to address the accommodation needs of people with living with younger onset dementia and ensure that there are flexible models available across all programs, regardless of the age of the person.

Conclusion

For far too long, people living with younger onset dementia, their families and carers have struggled to find appropriate services to meet their needs. Dementia Australia recommends that the Royal Commission ensures that aged care system redesign addresses the needs of people living with younger onset dementia and give careful consideration to the appropriateness of the disability and aged care sectors. Regardless of which sector people with younger onset dementia receive services, they need support and care provided by staff who understand dementia in a system that can consistently support them as their dementia progresses, irrespective of age based criteria. Dementia Australia would welcome the opportunity for further discussions with the Commissioners and Royal Commission senior counsel on this important issue.