

Accommodation for people with younger onset dementia

Although people with younger onset dementia typically want to reside in the community for as long as possible, there often comes a point for many where living in their own home is no longer an option and appropriate supported accommodation services are required.

Finding age-appropriate accommodation that is equipped to meet the needs of people with younger onset dementia is a significant challenge in the current service environment. In the absence of suitable disability accommodation, the only option for most people with younger onset dementia is to enter residential aged care.

The disability sector, with support from the Australian Government, requires a multifaceted approach to acknowledge and respond to the pressing need for appropriate accommodation. This could be achieved through: building dementia friendly accommodation; working with the aged care sector; and tailoring existing accommodation to meet the needs of and support people living with younger onset dementia.

Issue

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 existing disability system are rarely equipped to support individuals with complex neurodegenerative conditions like dementia. While the market is developing more suitable models to meet the needs of people with younger onset dementia, the only option for most younger people with dementia is to enter residential aged care.

Ultimately, the aged care system is designed to support the needs of older people - where the average age of residents is 84 years. In many cases, facilities are simply not equipped to care for a younger person and there is evidence that some 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 mental health, wellbeing, feelings of self-worth and independence. Facilities rarely have the capacity to provide adequate stimulation or meaningful activities that cater to the needs of younger people, who are often physically able and active in the earlier stages of the disease, 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

The lack of appropriate service offerings extends to respite care. Carers and family members are typically required to take on increasingly complex caring responsibilities, knowing that opportunities for age-appropriate respite are limited. Without access to respite that allows carers to recuperate, carers can quickly become overworked - impacting their own health, financial security and quality of life.

“Carers need to be able to take a break when necessary, otherwise they burn out.... The lack of respite care meant that I was exhausted.” Carer

In March 2019, the Government announced its National Action Plan to reduce the number of younger people living in aged care and to improve access to age appropriate accommodation. The National Action Plan provides an opportunity to improve access to crucial supports for people with younger onset dementia.

Dementia Australia’s position

Currently, people living with dementia under the age of 65 have limited or no physical access to appropriate residential care under the NDIS (acknowledging that there is funding support for admission into residential aged care). With support from the Australian Government, a targeted approach is needed as a matter of priority, within the National Action Plan, that addresses issues with both short and long-term accommodation for younger people with complex disabilities like younger onset dementia. This involves looking at all-encompassing design standards for the built environment, and specialised training for care staff and administrators. It also needs to ensure developers and organisations are aiming to bridge the gap in unmet needs of people living with younger onset dementia.

The disability system has a responsibility to provide supports for people living with dementia who are under the age of 65. As such, it is imperative that the NDIS plays a leading role in driving design standards, providing funding to deliver a targeted approach to improving access to accommodation, and ensuring staff have the training and resources needed to support people with younger onset dementia. Without appropriate supports, people are left to attempt to access aged care because there is no other choice.

The design of future disability accommodation should be underpinned by best-practice models with a clear focus on a human rights based approach to care, which demonstrably supports

the needs and preferences of the individual at the forefront of the care model. The core features of quality supported accommodation, as identified by people living with younger onset dementia, their families and carers include:

- Staff and administrators who are trained in dementia care and are empowered and equipped to respond to the changing care needs of people living with dementia. This is particularly important when a person's social interaction and responses to the environment deteriorate, or when they enter the end-of-life stage. This can sometimes present a challenge to ongoing caregivers who do not have sufficient training and support to understand and manage what is happening with their loved one at which point they are often 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 the individual's needs, strengths and abilities;
- Reablement principles should guide the delivery of care, where the focus of care is not to 'treat' individuals but to work with the individual and their family to maximise and maintain the individual's function and comfort.

Improving access to residential care in rural, remote and regional locations must receive specific attention in the National Action Plan. The existing supply of aged care and disability accommodation in remote locations is too limited, meaning that most people have to travel long distances to receive any form of residential care. The disability sector needs to consider more innovative ways to deliver respite care to individuals in remote communities through working with providers and Aboriginal Health Services. For example, the NDIS could allow for respite care to be delivered in a hotel or local accommodation with support from a paid carer or support worker. Increasing access to culturally safe, flexible respite options would ease pressure on existing providers, who lack the capacity to provide short-term respite in rural and remote communities, as well as supporting informal carers to maintain their caring role.

“As aged care isn't appropriate, there aren't many residential care facilities that can be accessed for those with younger onset. They are often too far away and in a lot of country areas they are non-existent.” Person living with dementia