

## **Residential care options for people with younger onset dementia**



### **Summary**



Finding residential care that can meet the needs of someone living with younger onset dementia is a significant challenge, as eligibility for residential aged care is restricted to those 65 and over and options offered through the NDIS are limited



Government policies recommend that younger people are not forced to live in residential aged care, but for people with younger onset dementia, there are limited appropriate options in both aged care and disability support housing



People impacted by dementia report that residential aged care is typically inappropriate for younger people, which means the disability sector must become responsive to the needs of those living with younger onset dementia



A comprehensive and collaborative approach is required to ensure appropriate residential care is available for people with younger onset dementia in the disability sector while also moving towards flexible models of housing and improving dementia education among staff

## Background

Finding age-appropriate accommodation that is equipped to meet the progressive needs of people with younger onset dementia is a significant challenge. In the absence of suitable disability accommodation, the only option for many people with younger onset dementia has been to enter residential aged care. However, the Royal Commission into Aged Care Quality and Safety noted the inappropriateness of residential aged care for younger people and government policy is now to support younger people to find other forms of accommodation. An unintended consequence of this is that the lack of appropriate residential care options offered through the NDIS, combined with the strict eligibility for younger people to access residential aged care, creates significant challenges for people living with younger onset dementia, their families and carers.

**“ 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

## Issue

Suitable respite and residential care are limited for people with younger onset dementia, their families and carers. Neither the NDIS nor the aged care sector are currently set up to fully care for someone with younger onset dementia, leaving many individuals caught in between both systems with no suitable options available to them. Accommodation options offered under the disability system are rarely equipped to support individuals with complex neurodegenerative conditions like dementia as they are typically set up for people with disabilities that remain relatively stable over the course of their life. Without adequate disability accommodation, residential aged care often remains the only option for many people with younger onset dementia who require full-time care in a residential setting, despite being designed for older people.

**“ 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. ”**

The lack of appropriate service offerings extends to respite care where carers and family members are typically required to take on increasingly complex caring responsibilities, with limited opportunities for age-appropriate respite. Without access to respite that allows carers to recuperate, carers can burn out - 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

# Dementia Australia's position



Dementia Australia recognises the importance of people living with younger onset dementia accessing appropriate forms of accommodation, irrespective of the policy system through which they obtain it. Equally, Dementia Australia supports a focus on building the capacity of the disability sector to support people with younger onset dementia.



Regardless of which sector people with younger onset dementia receive services from, 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.



The core features of quality supported accommodation, as identified by people living with younger onset dementia, their families and carers 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
- 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 everyone, 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 individual's function and comfort



A collaborative approach that improves residential care options for people with younger onset dementia in the disability space, incorporates flexible models of housing and improves staff understanding of dementia and the importance of sharing knowledge across both sectors is necessary to support people living with younger onset dementia.

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