



Response to the Consultation Paper: An ordinary life at home

A submission to the National Disability Insurance Agency

September 2021

This page is left blank intentionally

About Dementia Australia

No matter how you are impacted by dementia or who you are, Dementia Australia is here for you.

We exist to support and empower the estimated half a million Australians living with dementia and almost 1.6 million people involved in their care. Dementia is the second leading cause of death in Australia yet remains one of the most challenging and misunderstood conditions.

Founded by carers more than 35 years ago, today we are the national peak body for people impacted by dementia in Australia.

We involve people impacted by dementia and their experiences in our activities and decision-making, to make sure we are representative of the diverse range of dementia experiences across Australia. We amplify the voices of people impacted by dementia through advocating and sharing stories to help inform and inspire others.

Dementia Australia is the source of trusted information, education and support services. We advocate for positive change for people living with dementia, their families and carers, and support vital research.

We are here to support people impacted by dementia, and to enable them to live as well as possible.

Introduction

Dementia Australia welcomes the opportunity to provide a submission in response to the National Disability Insurance Agency (NDIA) Consultation Paper: An ordinary life at home to inform the development of a new National Disability Insurance Scheme (NDIS) Home and Living Policy.

There will likely be a point at which a person living with younger onset dementia can no longer live 'an ordinary life at home'. NDIA policy and NDIS implementation must be able to account for this transition. Currently, the NDIS tends to operate with an underlying assumption that all participants are building their capacity and gaining their independence. This creates significant challenges for people living with progressive neurocognitive disabilities, such as younger onset dementia, whose level of disability is increasing, and functional capacity and independence is declining. Limited understanding of dementia and untimely responses from the NDIA further disable people living with younger onset and limit their capacity to remain living in their own home.

When it is no longer possible to remain living at home, there are limited appropriate accommodation options for people living with younger onset dementia through the NDIS. There is a great need for innovation in the disability housing sector to develop accommodation and care options that are responsive to the needs of people living with younger onset dementia, their families, and carers.

Lastly, while we support the intent of the Younger People in Residential Aged Care Strategy, it is having unintended consequences and impacting on the care options available, in an accommodation environment in which residential aged care may in fact be the most appropriate option for some people with younger onset dementia.

Dementia in Australia

Dementia is the term used to describe the symptoms of a large group of neurocognitive diseases which cause a progressive decline in a person's functioning. Symptoms can include memory loss as well as changes in speech, reasoning, visuospatial abilities, emotional responses, social skills, and physical functioning. There are many types of dementia, including Alzheimer's disease, vascular dementia, frontotemporal dementia, and Lewy body disease.

Dementia is one of the largest health and social challenges facing Australia and the world. There are an estimated 472,000 Australians living with dementia in 2021¹ and around 1.6

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

million people² involved in their care. Without a significant medical breakthrough, there will be almost 1.1 million people living with dementia by 2058.³

Dementia is a terminal condition and there is currently no cure. It is the leading cause of death of women in Australia, and the second leading cause of death overall. It is predicted to become the leading cause of death within the next five years.⁴

It is generally not well understood that dementia is a progressive cognitive disability. Although dementia is commonly perceived to be an age-related illness, it is not a normal part of ageing. Dementia is more common in older people, but it can affect people in their 40s, 50s and even their 30s.⁵

The impact of younger onset dementia

Younger onset dementia describes any form of dementia diagnosed in people under the age of 65. In 2021, there are an estimated 28,300 people living with younger onset dementia in Australia. This number is expected to rise to 29,353 people by 2028 and 41,249 people by 2058.⁶

The misconception that dementia is a 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, their families, and carers.

Most people living with younger onset dementia will experience one or more of the following:

- problems with language and forgetting words
- losing track of time and place
- showing poor judgement
- problems with abstract thinking
- losing or misplacing things regularly
- changes in mood or behaviour

² Based on Dementia Australia's analysis of the following publications – M.Kostas et al. (2017) *National Aged Care Workforce Census and Survey – The Aged Care Workforce*, 2016, Department of Health; Dementia Australia (2018) *Dementia Prevalence Data 2018–2058*, commissioned research undertaken by NATSEM, University of Canberra; Alzheimer's Disease International and Karolinska Institute (2018), *Global estimates of informal care*, Alzheimer's Disease International; Access Economics (2010) *Caring Places: planning for aged care and dementia 2010–2050*

³ Dementia Australia (2018) *Dementia Prevalence Data 2018-2058*, commissioned research undertaken by The National Centre for Social and Economic Modelling [NATSEM], University of Canberra

⁴ Australian Bureau of Statistics (2018) *Causes of Death, Australia, 2017* (cat. no. 3303.0)

⁵ There are also some rare forms of childhood dementia, including Sanfilippo Syndrome, Niemann Pick Type C Disease and others.

⁶ Dementia Australia (2018) *Dementia Prevalence Data 2018-2058*, commissioned research undertaken by NATSEM, University of Canberra

People with younger onset dementia can also experience changes in personality, depression, anxiety, hallucinations, and aggression. The severity, type and frequency of these symptoms get progressively worse over time, requiring an increased amount of support. Significant changes in needs can occur rapidly and without warning.

The impact of dementia on younger people is quite different than the experience of older people with dementia. People living with younger onset dementia, their families and carers often face the following challenges:

- impact on employment as people are usually still in the workforce and may be the primary income earner (affecting a family's finances)
- disruptions or changes to family relationships and dynamics, especially carer 'burn out'
- isolation and a disengagement from everyday activities long before the condition requires them to
- difficulties accessing appropriate services and supports as they find themselves caught in the gaps between the disability and aged care systems

NDIS barriers to living “an ordinary life at home”

With the right support, it is possible for people living with younger onset dementia to remain living in their own home. For example, access to the right support workers, assistive technologies, and home modifications can enable a person living with younger onset dementia to maintain some independence and functional capacity.

Yet feedback provided to Dementia Australia indicates that delays or lack of access to much needed assistive technologies and home modifications mean that people living with younger onset dementia are being forced to move out of their own home and into supported independent living (SIL) options earlier than they want or need to.

In one instance reported to us, a carer paid \$9,000 for a bathroom renovation to ensure that it is safer and accessible for their partner who has younger onset dementia, and to enable them to remain living at home for longer. The NDIA did not approve their request for NDIS funding to modify the bathroom.

Another challenge people living with younger onset dementia, their families and carers face is plan reviews, which often are not timely and/or do not respond appropriately to their changing needs. Dementia Australia has also received feedback that support coordinators and participants/their representatives do not receive timely replies from the centralised NDIA email inbox. Time is of the essence for people living with younger onset dementia, whose condition can rapidly decline and consequently their support needs escalate. It is therefore essential that the NDIA has the capacity to be more responsive.

Plans need to include specialist support coordination to help look for accommodation, but it is often not included within the scope. In addition, we have received feedback that the “goal posts are constantly moving”, and support coordinators are struggling to keep up with the

changes to system, let alone participants with a progressive cognitive disability and their stressed carers.

There is also a lack of consistency in planners' knowledge of younger onset dementia, what support is needed and what accommodation is available. For example, it has been reported to Dementia Australia that some planners are giving participants the message that SIL is a last resort option so that carers feel they must cope at home to the detriment of the person living with dementia, carer and family. In one case, a carer was told by a NDIS planner that the reason the person with younger onset dementia could no longer stay at home was because they (the carer) "didn't try hard enough". Others are told that their care needs are not high enough for SIL but they are feel they cannot manage in their own home. NDIA planners must receive adequate education to ensure that they understand younger onset dementia and how it impacts on the person with a diagnosis as well as their families and carers.

These issues result in people with younger onset dementia ending up in hospital for months or being transferred between home, hospital, respite and disability accommodation while the NDIS housing exploration process occurs. The uncertainty and bouncing around from home to hospital to respite to hospital to permanent disability accommodation (only to be told they cannot be accommodated in some instances) is destabilising for people living with dementia, exacerbates their symptoms of dementia and hastens their functional decline.

Accommodation options for people living with younger onset dementia

Finding appropriate accommodation that is equipped to meet the needs of people living with younger onset dementia is a significant challenge in the current service environment. Disability accommodation options are rarely equipped to support individuals with complex neurodegenerative conditions like dementia.

Within the NDIS, SIL is the only real option housing/accommodation for people living with younger onset dementia. SIL options that are designed specifically to cater to the needs of people living with younger onset dementia are very limited.

The NDIS housing market has not yet matured enough to provide appropriate care and accommodation to all people living with younger onset dementia. People living with younger onset dementia, their families and carers require the NDIA to support innovative models of disability accommodation that is responsive to their needs.

Disability housing options require:

- 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.

People living with younger onset dementia who have dependent children have expressed concern about what will happen to their children if they can no longer live at home. Disability housing is not designed to accommodate families. They have concerns about the lack of privacy and support for people to maintain their family relationships.

Most people living with younger onset dementia have lived in their own home and have been functionally able and independent for most of their life. They are not used to disability environments and are reluctant to move into group home environments. Therefore, specialist accommodation and care for people living with younger onset dementia is preferred.

The Final Report of the Royal Commission into Aged Care Quality and Safety recommended that the Australian Government should develop, fund and implement, with State and Territory Governments, short-term, long-term and transitional accommodation and care options for younger people. It also recommended that the Australian Government should develop a Specialist Disability Accommodation National Plan that includes strategies to build a sufficient supply of Specialist Disability Accommodation or viable alternatives in the areas of need. Dementia Australia supports these recommendations.

A targeted approach is needed as a matter of priority 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 staff. It also needs to ensure developers and organisations are aiming to bridge the gap in unmet needs of people living with younger onset dementia. 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 unintended consequences of the Younger People in Residential Aged Care Strategy

While the market is developing more suitable models to meet the needs of people with younger onset dementia, the only option for some people with younger onset dementia is to enter residential aged care. Yet they are increasingly unable to access the aged care system because of the Younger People in Residential Aged Care Strategy 2020-25 (the Strategy).

Dementia Australia supports the intent of the Young People in Residential Aged Care Strategy (the Strategy) and recognises that aged care is not suitable for younger people in most instances. However, until the disability sector improves its capacity to support people living with younger onset dementia, residential aged care needs to remain an option.

Feedback we have received indicates that it is very rare for the NDIA to approve requests for people living with younger onset dementia to access an Aged Care Assessment Team (ACAT) required to enter residential aged care. This can result in people living with younger onset dementia spending months in a hospital bed while the NDIS housing exploration process occurs. Even in instances where treating health professionals and hospital social workers have supported ACAT requests and indicated that residential aged care would be the most appropriate option for an individual with younger onset dementia, the request has been denied.

We have also heard reports that people living with younger onset dementia who currently live in residential aged care are being forced to move because the aged care provider does not want to become a NDIS registered provider. Moving out of a familiar setting is unsettling and is likely to exacerbate a person's symptoms of dementia.

We are concerned that people who may need the specialised dementia care that some aged care providers offer are not able to receive this support due to a blunt interpretation of the Strategy. While we agree that aged care is not appropriate for younger people, until the disability sector can better support people living with younger onset dementia, residential aged care needs to remain a possibility. Indeed, for some people with living with younger onset dementia, aged care is the most appropriate setting as there is a dementia enabling environment and dementia educated staff who are well equipped to support their needs.

Conclusion

It is imperative that the new Home and Living Policy is designed to support the needs of people living with progressive neurocognitive disabilities, such as younger onset dementia. People living with younger onset dementia have a right to receive the support they need to enable them to live in their own home for as long as possible, and, when that is no longer possible, they require access to appropriate accommodation options in the disability sector. Dementia Australia would welcome the opportunity for further discussion with the NDIA on this critical issue.