NDIS Supports rules consultation

July 2025

Introduction

Dementia Australia welcomes the opportunity to provide input to the NDIS Supports rules consultation. This submission draws on feedback from people living with younger onset dementia, their carers, and Dementia Australia staff. We outline areas of concern and provide recommendations to improve understanding and application of the supports lists.

Younger onset dementia refers to any form of dementia diagnosed in individuals under the age of 65.

In 2025 there are an estimated 29,000 people living with younger onset dementia in Australia. This figure is projected to increase to an estimated 41,000 in 2054.[1] An estimated 1.7 million people in Australia are involved in the care of someone living with dementia.[2]

People with younger onset dementia are underrepresented in the NDIS with approximately only 16% of people living with younger onset dementia accessing support through the NDIS.[3]

Younger onset dementia and the NDIS

Dementia is the term used to describe the symptoms of a large group of complex neurocognitive conditions which cause progressive decline in a person's functioning.

Dementia is not just memory loss - symptoms can also include 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, Lewy body disease and younger onset dementia.

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[1] Dementia Australia (2023) Dementia Prevalence Data 2024-2054, commissioned research undertaken by the Australian Institute of Health and Welfare

[2] Based on Dementia Australia's analysis of the following publications - National Dementia Action Plan; Australian Institute of Health and Welfare (2024) 2023 Aged Care Provider Workforce Survey: Summary report, AIHW, Australian Government

[3] National Disability Insurance Agency. (2024). Disability dashboard: Younger onset dementia (as at 31 December 2024)

Dementia is the second leading cause of death for Australians and the leading cause of death of women.[4]

Although it is more common in older people, dementia is not a natural part of ageing, and it affects younger adults and children. 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 and their families.

People living with dementia, including those with younger onset dementia, live with a progressive neurological condition that results in a decline in cognitive and physical function over time. Unlike some other disabilities, the trajectory of dementia is one of gradual loss of memory as well as speech, reasoning, mobility, and the ability to complete everyday tasks. This progression means that the type and level of support needed will inevitably change over time. NDIS access requirements, reassessment schedules, and support rules focus on expectations of skill development or improvement, which are not suitable for many people living with progressive conditions like dementia. As a result, essential supports that maintain or delay decline may be removed or denied.

As part of recent NDIS reforms and changes to Section 10 on how supports are categorised and funded, some people living with younger onset dementia and their carers have experienced confusion and distress. Although the NDIA has released updated lists and guidance to improve understanding of what can and cannot be funded, people with dementia and their carers have reported that these lists are difficult to interpret, inconsistently understood and applied by NDIA staff, and often fail to acknowledge the changing support needs associated with the progressive nature of dementia. Although the supports lists are relatively new, the lack of understanding of dementia among NDIA staff is a longstanding issue that has been reported to us by people living with younger onset dementia, their families and carers.

Summary of recommendations

- Clearer, more accessible explanations of what supports are and aren't fundable
- Consistent points of contact with dementia trained specialists within NDIA for people with younger onset dementia and carers
- Dementia education for assessors, planners, support coordinators and LACs to understand dementia-related needs
- Flexibility in how allied health and alternative therapies are funded is restored

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[4] National Health and Medical Research Centre, Cognitive Decline Partnership Centre (CDPC) (2019) Supported Decision-Making in Dementia Care: Final Project Report. Sydney: NHMRC Cognitive Decline Partnership Centre, https://cdpc.sydeny.edu.au

- Funding reflects the goal of maintaining quality of life, not just functional gains
- The value and effectiveness of supports like art, music, and animal therapy for people with dementia are recognised
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- A simpler access process
- Improved communication and transparency from NDIA staff
- Faster, more flexible plan approvals that account for progressive decline

Lack of understanding of support rules

Our consultation with people living with dementia, their carers and Dementia Australia staff found that while most had heard of the NDIS Supports rules or lists, and the majority had seen or read them, very few said the lists were helpful in understanding funding eligibility and most did not feel confident in understanding what the NDIS can and cannot fund in their plan.

People living with younger onset dementia and carers consistently described the system as confusing, inconsistent, bureaucratic and unreliable. The lack of clarity around what can be funded is a concern.

> *"I feel I have absolute and total confusion on what I can do, even though it is now year 2 of my NDIS*". – Person living with dementia
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> *"They often focus on what cannot be supported but then make it difficult to understand the breadth of what is supported. It almost feels like they make the definitive NO's, but restrict the description of what is acceptable to limit what you ask for." -Current carer*
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> *"My main complaints would be:*
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> 1. *The system and understanding of what will be okay in a plan regularly change, without general newsletters or explanations, for example, the recent changes regarding NDIS 2.0. Often details and synopses are passed "word of mouth"- with lots of fear and confusion.*
> 2. *The person in the NDIA to contact regarding your plan changes regularly, so you always have to introduce yourself and explain your circumstances.*
> 3. *As a result of dealing with different people all the time, you are constantly given different perceptions of what is acceptable and what will not be included. Very hard to operate when it continually feels so "grey" (not black and white, or consistent)." – Current carer*

Many said the support lists were confusing, lacked detail on what is allowed, and how they are applied is dependent on the knowledge of NDIS staff.

> *"NDIS does not make it easy for the 'normal' person to understand!"- Person living with dementia*

> *"It makes life more stressful not knowing whether the rules will change and things will no longer be funded. I have lost trust in the NDIS as things change too frequently"- Current carer*

Dementia Australia staff who support people with younger onset dementia echoed these concerns. They noted that their clients are not aware of the transitional rules or lists and often rely heavily on their support coordinator or plan manager for interpretation. It is essential that support coordinators, local area coordinators, planners and plan managers have a good understanding of dementia as well as the supports lists.

> *"There seems to be inconsistencies of information regarding what will/won't be funded depending on who the support coordinator is". -DA Staff*

It has been reported to us that decisions about what supports are considered "reasonable and necessary" often rely heavily on individual assessor judgement, which can result in inconsistent or inappropriate outcomes when assessors lack specific knowledge of dementia as well as what supports are included. For people with progressive conditions, supports are often not about gaining independence but maintaining function, delaying decline, and ensuring quality of life. Without this understanding, necessary supports may be denied.

> *"NDIS planners often lack awareness and understanding of the specific needs associated with younger onset dementia, leading to inadequate or inappropriate support planning for clients. Clients with younger onset dementia and their carers are frequently left to independently search for support coordinators who have the necessary dementia-specific knowledge and experience, adding to their stress and burden." – DA staff*

Dementia Australia recommends:

- Clearer, more accessible explanations of what is and isn't fundable
- Consistent points of contact with NDIA for people with younger onset dementia and carers
- Dementia education for assessors, planners, support coordinators and LACs to understand dementia-related needs

> *"It would be of huge benefit if NDIS required their assessors to be engaged in ongoing training to ensure they have an adequate understanding of the disabilities. What will be funded depends on the assessors judgement of whether or not it is "necessary" to support the individual to live independently. This is incredibly frustrating". -Current carer*

Access to allied health and therapeutic supports

Concerns regarding the reduction and/or removal of allied health and therapeutic supports from NDIS plans has been reported to us as a result of the reclassification of allied health services from Core Supports to 'Capacity Building - Improved Daily Living'. These include occupational therapy, speech pathology, podiatry, physiotherapy, psychology.

> *“Decrease in support hours for: support workers, speech therapist, OT, music therapy. Planner didn’t have an understanding of the needs of someone with dementia in their early 50’s. Clearly had not read the comprehensive reports and FCA they had been sent for the plan review. Unprepared and unskilled planners in the disability sector who have limited knowledge”. – Person living with dementia*

Previously, these services could be accessed more flexibly, however, under capacity building supports, maintaining function and preventing decline doesn’t seem to be thoroughly recognised as capacity building. This creates a barrier for people with progressive conditions like dementia, where the focus of support is on delaying decline, preserving independence, and improving quality of life.

> *“What’s fair and reasonable or that gives people freedom of choice is gone” – Person living with dementia*

Allied health services are essential from early diagnosis through to advanced stages of dementia. They support individuals to manage symptoms, maintain cognitive and physical abilities, adapt to changes, and stay engaged in meaningful daily activities. Without access, there is a risk of faster decline, increased carer burden, and premature need for residential care. Access has become increasingly inconsistent, particularly for people in rural and remote areas where wait times for assessments can be months.

> *“The NDIS rules cannot be black and white as we are all individuals with our own unique disabilities. Our therapists are the [ones] who know what we need when writing our reports- the NDIS should not be making the decision whether we should be able to have it or not. Our lives are terminal, our brain is dying. . . Why can we not get the supports we need to make our limited life a little easier and safer each day. Please don’t make it such a frustrating, long-winded process" -Person living with dementia*

Dementia Australia’s position statement on allied health outlines the importance of these services and the need for an enablement-based approach. It highlights evidence showing allied health can improve outcomes and delay functional decline.

People with younger onset dementia and carers also raised concerns about alternative supports being removed from plans or inconsistently funded. Art and music therapies, though currently under review, are often misunderstood and excluded despite their value in improving engagement, wellbeing, and emotional regulation. Further, animal therapies are no longer funded. In some cases, Dementia Australia staff have reported that therapy animals may offer safer, more cost-effective outcomes than full-time assistance animals for their clients — particularly where cognitive impairment affects a person’s ability to manage responsibility for an animal.

Other supports, like assistive technology, are inconsistently applied. Common devices such as laptops or noise-cancelling headphones previously funded are now being rejected and regarded as “everyday items,” even though they provide essential cognitive and sensory support for people with dementia.

> *“No matter what AT people need, the everyday item is fine if you’re in a position to go out and make money but the way this is written we are penalised for being disabled”. - Person living with dementia*

Dementia Australia recommends:

- Flexibility in how allied health and alternative therapies are funded is restored
- Funding reflects the goal of maintaining quality of life, not just functional gains
- The value and effectiveness of supports like art, music, and animal therapy for people with dementia are recognised

Bureaucracy, delays and poor communication

For some people living with younger onset dementia and their carers, the most significant hurdle is accessing the NDIS in the first place, let alone getting the supports they need. The application process is widely described by people living with dementia and their carers as complex, bureaucratic, and inaccessible.

> *"The very act of getting onto NDIS was the biggest challenge. So bureaucratic and confusing to a layperson. Need an advocate to help you apply." – Person living with dementia*

People with dementia and especially those who live alone or lack strong support networks may struggle to navigate the paperwork, gather the required evidence, or understand what supports may be available.

> *"Individuals diagnosed with dementia face significant challenges when applying for NDIS support. The application process is often unclear, with limited information available about what supports can be accessed and what documentation—such as specialist or occupational therapy reports—is required. There is a notable lack of guidance and assistance throughout the process. These issues are especially pronounced for people with younger onset dementia who live alone and do not have a carer or support person to assist them. Due to cognitive impairment, the application process can be overwhelming and, in many cases, impossible to complete without appropriate support. Communication from NDIS is consistently poor. Clients frequently report receiving generic responses when seeking updates, with little to no detail about the progress of their application." DA staff*

DA staff report frequent issues with poor communication and unclear expectations from the NDIA. In one case, a client waited more than eight months for their application to be processed, only to be told it had been lost and would need to be resubmitted. Inquiries about progress often receive generic responses like "your enquiry has been forwarded to the relevant team," offering no real clarity or reassurance.

These delays have real consequences. For people with progressive conditions like dementia, support needs can change significantly in the time it takes for an application or plan review to be processed.

> *"A person's disease often progresses faster than the approval for appropriate funding, requiring another submission of a plan review & further delays in receiving support." -DA staff*

Recent changes have exacerbated these issues. For example, Dementia Australia staff have reported that their clients have experienced the complete removal of respite and overnight respite funding from their plans. In one case, it took over six months for this essential support to be reinstated, severely disrupting care arrangements and increasing stress for both the individual and their carer.

> *“One client experienced a major setback when their entire application was lost. After waiting over eight months, they were informed they needed to resubmit, causing distress and further delays in accessing support. Poor communication from NDIS during the application process: Clients often receive vague, non-specific responses when inquiring about the status of their application. There is no consistent or transparent communication regarding progress or expected timelines.” – DA staff*

Dementia Australia recommends:

- A simpler access process
- Improved communication and transparency from NDIA staff
- Faster, more flexible plan approvals that account for progressive decline

Conclusion

Dementia Australia thanks the Australian Government for the opportunity to provide feedback on the NDIS Support Rules. People living with younger onset dementia face challenges in accessing and navigating the NDIS. The current structure of the support rules, including changes to categorisation and funding pathways, has exacerbated confusion, distress, and, in some cases, the loss of essential supports for some.

We urge the NDIA to ensure that the design and implementation of the support rules reflects the progressive and complex nature of dementia. This includes clearer and more consistent communication, better application of “reasonable and necessary” supports, and improved understanding of dementia among NDIA staff, planners, and assessors.