NDIS Evidence Advisory Committee Consultation

November 2025

Introduction

Dementia Australia welcomes the opportunity to provide feedback to the NDIS Evidence Advisory Committee (EAC) on the current assessment of selected supports. This submission draws on feedback from people living with younger onset dementia, their carers, and Dementia Australia staff.

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.[1]

People with younger onset dementia are underrepresented in the NDIS with only a small proportion of people living with younger onset dementia accessing support through the NDIS.

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.

Dementia is the leading cause of death for all Australians.

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.

Summary of Recommendations

1. Recognise maintenance of function as a valid therapeutic outcome for progressive neurological conditions
2. Acknowledge the role of smart home technologies in supporting safety, daily living, and independence for people with cognitive disability.
3. Confirm the evidence base for exercise physiology as a safe, effective, and cost-efficient therapy for maintaining physical and cognitive health.
4. Encourage future EAC consideration of assistance animals for people with dementia.
5. Ensure that evidence assessments consider cognitive disability alongside physical and sensory disabilities.

Supports for people with younger onset dementia

People with younger onset dementia are typically active, independent, and often balancing employment, parenting, and caring roles when they are diagnosed and/or start displaying symptoms. The trajectory of dementia is one of gradual loss of cognitive function including memory, 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.

People living with younger onset dementia require access to rehabilitative, enabling, and technological supports that maintain daily functioning and prevent premature transition to aged care.

People living with younger onset dementia have reported that applications for assistive technologies or mobility supports have been refused by the NDIA on grounds of “not value for money,” based on assumptions about future aged care placement rather than functional outcomes. While these plan-level decisions sit outside the scope of the EAC, they highlight how the current assessment process is applied in ways that disadvantage people with dementia. Dementia Australia recommends that the Committee ensure its support-level assessments of value for money explicitly consider extended community participation, delayed entry to disability accommodation/residential care, and maintenance of function for supports for people with dementia.

We note that the EAC’s official criteria steer the review of supports toward outcomes that improve capacity, independence and participation. However, for progressive neurological conditions such as dementia the fundamental outcome is often the maintenance of function, slowing of decline or preservation of independence rather than measurable improvement. Dementia Australia recommends that the Committee explicitly include measures of maintenance, participation and quality of life in its evaluation criteria to ensure supports relevant to cognitive disability are not undervalued.

Exercise Physiology

Growing evidence shows exercise interventions for people with dementia improve activities of daily living (ADL), physical function (mobility, balance, strength), and mood, sleep, quality of life, with emerging evidence for cognitive domains (executive function, attention).[2]

For people with dementia, the aim is often to maintain rather than “improve” capacity, which is an outcome that is not always understood within NDIS decision-making frameworks. Dementia Australia recommends that the EAC recognise maintenance of function as a legitimate therapeutic goal and confirm exercise physiology as a suitable, evidence-based NDIS support.

Smart Home Appliances

Smart home appliances have the potential to enhance safety, independence, and quality of life for people living with dementia when used effectively. Examples include automated cooking tools, voice-activated devices, and robotic vacuums or lawnmowers.

People living with dementia have shared that they had sought access to smart home technology to assist with safe meal preparation, to maintain independence and continue community participation. These technologies may reduce reliance on paid support, promote dignity, and enable people to continue living at home longer.

Assistance Animals

The current EAC assessment focuses on assistance animals for people with autism or those with intellectual disability. Dementia Australia encourages the EAC to consider expanding future evidence assessments to include assistance animals for cognitive impairment, as emerging research suggests they support emotional wellbeing, social connection, and safety for people with dementia.[3]

Conclusion

Dementia Australia supports the EAC’s evidence-based approach to determining the suitability of NDIS supports. For people with younger onset dementia, access to evidence-informed supports such as exercise physiology and smart home technologies is critical to maintaining independence, dignity, and participation in community life.

We encourage the EAC to ensure that its recommendations encompass the needs of people with progressive cognitive disabilities, recognising that maintenance of capacity and prevention of decline are valuable and measurable outcomes in progressive conditions such as dementia.

References

1. Dementia Australia. *Facts and Figures* 2025; Available from: **https://www.dementia.org.au/about-dementia/dementia-facts-and-figures**.
2. Xiao, Y., Y. Fan, and Z. Feng, *A meta-analysis of the efficacy of physical exercise interventions on activities of daily living in patients with Alzheimer's disease.* Frontiers in Public Health, 2024. **Volume 12 - 2024**.
3. Marks, G. and K.R. McVilly, *Assistance Dogs for People with Younger (Early)-Onset Dementia: The Family Carer's Experience.* Animals (Basel), 2023. **13**(5).