

# NDIA Annual Pricing Review

February 2026

## Introduction

Dementia Australia welcomes the opportunity to provide input to the 2025–26 Annual Pricing Review (APR). This submission focuses on whether pricing arrangements under the National Disability Insurance Scheme (NDIS) adequately support people living with young onset dementia.

Dementia Australia is the peak body representing people of all ages living with dementia including people living with young onset dementia and the estimated 1,500 children living with childhood dementia in Australia, as well as their carers and families.[1]

Dementia is a progressive and life limiting illness that is now the leading cause of death in Australia.[2] In 2026, it is estimated there are 446,500 people living with all forms of dementia in Australia. Without a significant intervention, this figure is projected to increase to over 1 million by 2065.[2]

Young onset dementia refers to any dementia diagnosed in adults aged 18-65. In 2026, an estimated 29,000 Australians live with young onset dementia, projected to increase to an estimated 41,000 by 2054.[3] There are an estimated 1.7 million Australians involved in the care of people with dementia.<sup>1</sup>

People with young onset dementia often receive a diagnosis during prime working, parenting and financially demanding years. The condition's progressive trajectory which is characterised by gradual loss of cognitive and physical function, means that support needs will increase over time. All people living with young onset dementia are potentially eligible for NDIS supports yet based on the latest data provided by the NDIS only a small proportion are accessing the scheme. For those who do access NDIS support, underlying scheme assumptions that prioritise capacity building, short-term interventions, or functional improvement often result in plan approvals, allocated budgets and the pricing of individual supports that do not reflect the needs of people living with dementia.

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<sup>1</sup> 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

This submission draws on Dementia Australia’s long-standing policy and advocacy work in the NDIS space, lived experience insights from people with young onset dementia and their carers to address the Annual Pricing Review Terms of Reference.

Our key recommendation is that pricing reform must recognise progressive cognitive disability, ensure choice and control through transparency, and ensure pricing accurately reflect the cost of delivering quality care for people living with young onset dementia.

## **Therapy supports**

Therapy supports are a core component of NDIS plans for people with young onset dementia, particularly occupational therapy, speech pathology, psychology and physiotherapy. These supports play a critical role in maintaining function, supporting communication, adapting environments and routines, and supporting carers as the condition progresses.

The 2025–26 APR identifies therapy supports as a priority area for pricing review and notes that current arrangements rely on flat hourly price limits that do not vary by participant complexity, service intensity or delivery context. For people with young onset dementia, therapy delivery differs from both health and aged care settings and from many other NDIS cohorts.

Therapy for progressive cognitive conditions often involves ongoing adaptation, frequent reassessment, and intensive coordination with carers and other providers and can increase costs due to the increased level of complexity and time required.

Where pricing does not recognise these factors, providers face increasing delivery costs without corresponding pricing flexibility. Over time, this risks discouraging therapy providers from working with people with young onset dementia, contributing to reduced access and undermining choice and control.

## **Recommendation**

As part of the review of therapy pricing and the planned Therapy Pilot, the NDIA should ensure that pricing evidence explicitly considers progressive cognitive conditions and outcomes focused on maintenance and adaptation.

## **Support coordination**

Support coordination is critical for people with young onset dementia because of the complexity of their support needs and the progressive impact of cognitive impairment over time.

People with young onset dementia and their carers often need help coordinating supports across disability, health, aged care, palliative care, employment and housing systems. Plans also need to be reviewed and adjusted regularly as abilities change.

The 2025–26 Annual Pricing Review identifies support coordination as a priority area for evidence gathering through the Quality Supports Program, to better understand what high-quality coordination looks like and what it costs. However, current pricing and reform settings

often treat support coordination as a short-term or stabilising support, rather than recognising situations where coordination remains ongoing and becomes more complex over time.

For people with young onset dementia, while some aspects of service navigation may stabilise in more structured living arrangements, the effort involved in supporting decision-making usually increases as the condition progresses. Coordinators often spend more time helping people understand options, communicate preferences, manage risk, adjust services, and support carers to be involved appropriately.

This type of work requires experienced coordinators with dementia knowledge and involves sustained, higher-intensity engagement. These demands are not always well reflected in current pricing assumptions.

## Recommendation

Ensure that evidence gathered through the Quality Supports Program and Support Coordination Pilot explicitly considers the needs and service profiles of people with young onset dementia and other progressive neurological conditions, and that future pricing and navigation reforms are responsive to their needs. This should include considering establishing a dementia-capable specialist navigator within the NDIS that reflects the ongoing nature of progressive neurological conditions.

## Supported Independent Living (SIL)

Supported Independent Living (SIL) represents one of the most complex and resource-intensive support types within the NDIS. The 2025–26 Annual Pricing Review explicitly draws on evidence from the SIL Quality Supports Pilot to inform future pricing reform, recognising the need to better understand the costs and features of high-quality service delivery for participants with complex needs.

Evidence from The Joint Solutions Young Onset Dementia Project highlights significant gaps in the availability of dementia-capable supported living models for people with young onset dementia. The report emphasises the need for support arrangements that can deliver escalating levels of assistance, continuity of relationships, and 24-hour responsiveness over time.[4]

The complexity associated with caring for someone with young onset dementia increases workforce intensity, governance requirements and service risk over time. If pricing evidence does not adequately reflect these factors, providers may face viability challenges in delivering SIL to this group, contributing to limited availability and inappropriate placements.

## Recommendation

As the NDIA uses evidence from the SIL Quality Supports Pilot to inform future pricing frameworks, it is important that participants with progressive neurological conditions, including young onset dementia, are adequately represented in analysis and interpretation to reflect the full complexity and cost of delivering appropriate SIL supports to this group.

## Pricing adequacy and outcomes for progressive and complex support needs

The Terms of Reference acknowledge that a single price limit may incentivise lower-cost service models that are not appropriate for participants with complex support needs. While complexity is referenced throughout the APR materials, dementia is not explicitly recognised as a driver of complexity.

For people with young onset dementia, complexity arises from factors such as fluctuating capacity, communication impairment, heightened safety and supervision needs, the importance of continuity of relationships and supports, and coordination across disability, health, aged care and palliative care systems. These factors often increase the time, skill and consistency required from workers and providers, but are not reliably reflected in existing pricing models.

The consultation also explores differentiated pricing between registered and unregistered providers, appropriately recognising the additional compliance costs faced by registered providers. However, differentiated pricing will only support genuine choice and control if participant budgets are sufficient to reflect these pricing settings. This is particularly relevant for participants who are agency-managed or who must use registered providers for certain support types, as higher prices without corresponding budget may unintentionally limit choice rather than expand it.

At the same time, registration status alone does not reliably indicate dementia capability. Lower-priced services, whether registered or unregistered, may lack the skills, experience or continuity required to safely support people with progressive cognitive impairment. Pricing models that rely solely on registration status or hourly rates risk overlooking these capability differences, leading to poorer outcomes and higher downstream costs.

The APR framework places strong emphasis on participant outcomes, but outcomes are often framed around improvement or capacity building. For people with young onset dementia, meaningful outcomes more commonly involve maintaining function, adapting supports as abilities change, and supporting carers over time. Pricing settings that assume improvement or short-term intervention do not align with these realities.

“NDIS terms and focus are based on skill/ capacity building. For those suffering from dementia this is often not appropriate as this is a degenerative disease, so skills are lost not built”. – carer

### Travel pricing and access in regional and rural areas

The APR justifies changes to travel claiming to ensure value for money. While Dementia Australia supports reducing excessive travel claims, people with young onset dementia face risks such as providers being less willing to travel to deliver in-home supports, disrupting continuity of care and limiting access to workers with dementia-specific skills.

In-home supports are often clinically necessary and a reduced willingness of providers to travel, especially in regional and rural areas, may limit access to essential supports.

Additionally, Aboriginal and Torres Strait Islander people experience substantially higher dementia prevalence and are disproportionately affected by remote service availability.[4] There is a risk that NDIS pricing and market settings may be designed and evaluated without adequate visibility of Aboriginal and Torres Strait Islander peoples' experiences.

## Recommendations

Explore the impact of cognitive impairment and progressive decline on service intensity, workforce skill requirements, continuity of care, and duration of support in the development and testing of differentiated pricing approaches.

Ensure that pricing reform and differentiated pricing design consider maintenance, adaptation, and carer capability as participant outcomes.

Monitor the impact of travel pricing changes on access to in-home supports for people with progressive neurological conditions, including young onset dementia, particularly in regional, rural and remote areas. In doing so, the NDIA should consider how pricing settings affect the viability of culturally safe, place-based service delivery models for Aboriginal and Torres Strait Islander communities.

## Choice and control: pricing transparency and informed decision-making

The consultation paper suggest that participants exercise choice and control by selecting providers and negotiating service agreements. However, for people with young onset dementia, this assumption does not reflect lived experience.

Cognitive impairment and communication difficulties significantly limit a person's ability to compare pricing and providers, or challenge decisions. In practice, carers frequently take on this role, often without adequate information or support.

Additionally, the Annual Pricing Review references benchmarking against other schemes, including health and aged care systems, to inform price limits and assess value for money. However, these comparisons are not currently presented in a way that is transparent or accessible to participants and carers.

Feedback from people living with dementia and their carers have included experiencing "Difficulties in communication with NDIA, including unclear process for accessing supports, lack of hard copies and easy read documents."

Choice and control do not exist if participants cannot understand what they are paying for, what is included, and/or why prices differ.

## Recommendations

As part of its benchmarking work, the NDIA should consider publishing clearer explanations or illustrative comparisons across NDIS, aged care and health systems for common supports including those used by people with young onset dementia. This would help clarify whether price differences reflect additional skill requirements, safeguards, service complexity, or market design features, and support informed choice and confidence in NDIS pricing.

Additionally, to support genuine choice and control develop consistent 'Easy Read' and dementia-friendly materials that explain pricing structures, service agreements, and common costs to enable participants with cognitive impairment to compare providers.

## Conclusion

Dementia Australia supports efforts to improve robustness and transparency in NDIS pricing. Recognising the progressing and complex support needs of people living with young onset dementia will improve equity in pricing reform and access to appropriate supports.

Dementia Australia welcomes the opportunity for further consultation.

## References

1. Childhood Dementia Initiative, *Childhood Dementia: the case for urgent action*. 2020: Sydney, Australia.
2. Australian Institute of Health and Welfare, *Dementia in Australia*. 2025, Australian Government.
3. Dementia Australia, *Commissioned AIHW Dementia Prevalence Data 2024-2054*. 2023, Dementia Australia.
4. Young People in Nursing Homes National Alliance, *The Joint Solutions Young Onset Dementia Project Final Report*. 2025.