

NDIS New Planning Framework Rules

October 2026

What needs to change?

- Current NDIS planning does not always recognise the needs of participants living with young onset dementia, including progressive changes in cognition, reduced awareness of their own support needs and day-to-day fluctuations in functional capacity.
- Families and carers can provide significant unpaid support. This should not be treated as a reason to reduce funded support when the care is not freely offered, reasonable or sustainable.
- People can also miss out on support because suitable dementia-capable services, accommodation and technology are not available or easy to access.

What is Dementia Australia recommending?

- Create a prioritised planning pathway for people living with young onset dementia, similar to existing pathways for MND, Huntington's Disease and Childhood Dementia.
- Test and independently validate the new assessment-to-budget process before it is introduced.
- Ensure a dementia-capable assessment workforce with greater transparency in assessment and budget decisions.
- Make reassessment easier when dementia progresses.

If actioned, what impact could these recommendations have?

- NDIS participants living with young onset dementia would receive supports that better reflect their needs as cognition and functional capacity change over time.
- Assessments and budgets would become fairer and more transparent.
- Families and carers would be less likely to have unsustainable unpaid care treated as a substitute for funded support.

How has Dementia Australia advocated for this position?

- Raised related concerns in Dementia Australia's 2 October 2026 submission on National Disability Insurance Scheme Access Changes and referred to its August 2026 joint position paper with Carers Australia on respite
- Used lived experience expertise to inform recommendations.
- Made a submission on National Disability Insurance Scheme new planning framework rules reforms.
- Called for further consultation before implementation.

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Dementia Australia Submission October 2026

Introduction

Dementia Australia welcomes the opportunity to provide feedback on the Department of Health, Disability and Ageing's consultation on New Framework Planning Rules.

Dementia Australia is the peak body representing the estimated 446,500 people living with dementia and their carers across Australia.[1] Dementia is not a normal part of ageing and can affect people of all ages. Young onset dementia refers to any form of dementia diagnosed in individuals aged 18-64. There are also an estimated 1,500 children living with childhood dementia in Australia, arising from more than 100 rare genetic disorders.[2]

In 2026, there are an estimated 29,000 people living with young onset dementia in Australia. This figure is projected to increase to 41,000 in 2054.[1] People living with young onset dementia remain underrepresented in the NDIS, with only a minority accessing supports through the Scheme.

As the trusted source of information, education, and support services, we advocate for positive change for people living with dementia, their families, and carers, and support vital research across a range of dementia-related fields.

Dementia affects all people differently, but challenges and barriers are compounded for people living with a disability, Aboriginal and Torres Strait Islander peoples, people from culturally and linguistically diverse backgrounds, people living in rural and regional areas, and other priority populations.

Young onset dementia and NDIS planning reform

People living with young onset dementia already face significant issues within the NDIS. Current experiences show that dementia is not consistently understood, assessed or supported in the planning process, particularly where impairment is less visible or difficult to self-report. Dementia Australia is concerned that the new framework planning arrangements will exacerbate these issues; the application of a standardised functional assessment may overlook less visible or variable impairment and reduce the availability and timeliness of support for participants, families and carers.

Recommendations

1. Ensure, as a matter of equity, that people living with young onset dementia have the same access to a prioritised and dedicated planning pathway within the NDIS as those established for people with Motor Neurone Disease, Huntington's Disease and childhood dementia.

2. Publish and independently validate the complete assessment-to-budget process for progressive cognitive disability before implementation and address identified issues before rollout.
3. Require all NDIA assessors to have mandatory dementia education and training to appropriately assess people living with young onset dementia. Alternatively, assessments for people with Young Onset Dementia to be undertaken by a dedicated assessment team with specialist dementia expertise.
4. Ensure that Support Needs Assessments for people with dementia consider fluctuating cognition, impaired insight, executive dysfunction and behavioural symptoms, and do not rely solely on single-point or standardised assessments conducted in artificial settings.
5. Require the assessment report to identify and record the participant's eligible impairments, diagnosis and prognosis, evidence considered, assessment findings and resulting support categories. Participants should be able to correct errors or omissions before their budget is calculated.
6. Publish the Personal and Environmental Circumstances Questionnaire (PECQ) and informal-support offset method. Apply an offset only to assistance that is freely offered, reasonable and sustainable, and ensure unpaid care or unavailable services do not result in a person being assessed as having lower needs.
7. Ensure underspending is not considered evidence of lower need without considering service shortages, implementation delays, impaired insight and difficulty finding suitable dementia-capable support.
8. Publish the plan variation and reassessment process, including eligibility criteria, as soon as possible in 2026; prioritise disease progression and associated changes in functional cognitive and physical capacity as a reason for reassessment and ensure participants have sufficient notice and supports to meaningfully participate in the reassessment process.
9. Provide dementia-specific guidance and mandatory workforce education for plan implementation to ensure that funding can be used as intended to address communication, behavioural, physical, supervision and safety-related support needs.
10. Undertake and publish a review of age-appropriate, dementia-capable long-term accommodation for people living with young onset dementia, including regional, rural and remote gaps, and develop a plan to address availability shortfalls, with clear timelines and responsibilities across the Department and NDIA.

11. Ensure the NDIS Supports Rules allow the purchase of mainstream cognitive, communication and safety technology where it is an appropriate and cost-effective response to an assessed disability need.

Support needs assessment rules

- **Priority planning pathway**

Dementia Australia strongly advocates for a New Planning Framework for dementia that operates in the same way as priority pathways for people living with Motor Neurone Disease, Huntington's Disease and childhood dementia to ensure equity in eligibility and support for all people living with a progressive neurological disability.

Priority planning pathways recognise that standard assessment and planning processes may not adequately respond to progressive neurological conditions, where functional capacity and support needs can change substantially over relatively short periods. A dedicated pathway enables timely condition-informed and anticipatory planning, reducing the risk that supports are already inadequate by the time they are implemented. The existing NDIS priority pathway for people with Motor Neurone Disease, Huntington's and Parkinson's Disease demonstrates an established principle that planning processes should respond to the nature and trajectory of a person's disability.

Further detail is contained within Dementia Australia's October 2026 submission - *NDIS Access Changes*.

Recommendation: Ensure, as a matter of equity, that people living with young onset dementia have the same access to a prioritised and dedicated planning pathway within the NDIS as those established for people with Motor Neurone Disease, Huntington's Disease and childhood dementia.

- **Testing and validation of standardised assessment tools**

Concerns regarding the validity and equity of a standardised assessment process for people living with young onset dementia were outlined in detail in Dementia Australia's submission on *NDIS Access Changes* (2 October). The same concerns exist when those assessment findings are used to identify supports and calculate reasonable and necessary budgets under the NDIS Support Assessment Planning Rules. Limitations in the assessment process directly affect support categories and funding.

The proposed assessment tools, scoring methodology, budget-setting approach and end-to-end testing outcomes should be published and independently validated before implementation. The broader question of whether standardised assessments are appropriate for evaluating functional capacity in the NDIS is discussed in Dementia Australia's submission of 2 October, *NDIS Access Changes*.

Recommendation: Publish and independently validate the complete assessment-to-budget process for progressive cognitive disability before implementation and correct identified issues before rollout.

- **Dementia-capable assessment requires dementia-capable assessors**

As outlined in Dementia Australia's submission on NDIS access assessments (*NDIS Access Changes*, 2 October), the quality of support needs assessments depends not only on the assessment tools but also on the capability of the assessor administering and interpreting them. Standardised questions cannot compensate for a lack of understanding of progressive cognitive disability.

They did not listen to anything I said. The planner had no knowledge or understanding of young onset dementia. ~carer

Assessors require dementia-specific capability to interpret assessment results, recognise when impaired insight may affect self-reporting, evaluate conflicting evidence and determine when specialist input is required.

All NDIA assessors must therefore have mandatory dementia education and training to appropriately assess people living with young onset dementia. Alternatively, assessments for people living with Young Onset Dementia should be undertaken by a dedicated assessment team with specialist dementia expertise.

Recommendation: Require all NDIA assessors to have mandatory dementia education and training to appropriately assess people living with young onset dementia. Alternatively, assessments for people with Young Onset Dementia to be undertaken by a dedicated assessment team with specialist dementia expertise.

- **Support Needs Assessments for people with dementia must not rely solely on single-point or standardised assessments**

Dementia is characterised by progressive decline and fluctuating capacity, and individuals may present differently in structured assessment settings compared to their everyday environments. They will also have times of the day where they experience variation in cognitive ability, as well as variation on a day-to-day basis.

Cognitive impairment may also affect a participant's ability to accurately report or recognise their needs.

People with certain dementias commonly significantly overstate their capacity. And if they live alone, the person living with dementia may not have a support person with the required knowledge to help inform this. ~carer

Recommendation: Ensure support needs assessments for people living with dementia account for fluctuating cognition, impaired insight, executive dysfunction and behavioural

symptoms, and do not rely solely on single-point or standardised assessments conducted in artificial settings.

- **Assessment report template must record diagnosis and show a transparent evidence trail**

The assessment report will outline support needs and approved support categories, which will then determine the plan budget. Participants should be able to see what evidence was considered, how it was interpreted and how findings were translated into support categories.

They need to consider providing how and why the needs assessment has presented an inaccurate portrayal of the person living with dementia's need and be answerable regarding outcomes. ~carer

Participants should be able to correct incomplete or inaccurate information before it influences support categories or budget calculations.

The proposed template does not clarify whether dementia diagnoses and subtypes will remain visible alongside impairment classifications and assessment findings. If only broad impairment domains are recorded, it may be difficult to determine whether dementia-related needs have been recognised and consistently translated into equitable funding outcomes across the Scheme. 

Dementia diagnosis should continue to be recorded as a discrete data field, regardless of the methodology used to assess functional capacity or support needs. While functional information identifies what support a person requires, diagnostic data provides essential context and enables people with specific conditions to remain identifiable within NDIS data. Without it, people with young onset dementia risk becoming effectively invisible as a distinct cohort, limiting the ability to monitor access and outcomes, identify inequities, understand changing needs associated with progressive disability, and undertake effective policy, workforce, market and service planning.

Recommendation: Require the assessment report to identify and record the participant's eligible impairments, diagnosis and prognosis, evidence considered, assessment findings and resulting support categories. Participants should be able to correct errors or omissions before their budget is calculated.

Budget method rules

- **The informal-support offset must not transfer cost to families**

The proposed budget methodology includes an informal-support offset based on the frequency and durability of unpaid care. However, the consultation paper does not explain how the offset will be calculated, or what safeguards will prevent unpaid care from being treated as a substitute for funded support. Care may appear "durable" only because family members have reduced work, depleted savings or continued caring at significant personal cost.

We have gone from two incomes before my wife was diagnosed to half an income, as she can no longer work and I have huge caring responsibilities. I need to be able to work to keep a roof over our heads. ~carer

I had to leave work to care for my partner. We lost any future earnings and have been living on our super for nine years, not ideal. ~carer

These circumstances reflect unmet need, not sustainable care arrangements, which is strongly supported by the results of the September 2026 AIHW Living with Dementia Carer Survey, where 71% of women and 61% of men reported feeling overwhelmed by their caring responsibilities. 30% of carers surveyed provide more than 70 hours of care each week.

Applying an offset because support is already being provided risks increasing financial hardship, carer ill health and social and economic disadvantage.

Support needs assessments should identify a participant's full disability-related needs. Only care that unpaid carers freely choose, are reasonably able, and are likely to sustain should be considered in any offset calculation. Even then, it should be acknowledged that unpaid carers require respite from their caring role to maintain their health and wellbeing and sustain their caring role.

Given the progressive nature of dementia, the assessment and budget methods must reflect that a person's support needs will increase over time with the need for formal versus informal carer supports increasing proportionally.

A partner is a partner, not automatically a 24-hour support worker. ~carer

Recommendation: Publish the Personal and Environmental Circumstances Questionnaire (PECQ) and informal-support offset method. Apply an offset only to assistance that is freely offered, reasonable and sustainable, and ensure unpaid care or unavailable services do not result in a person being assessed as having lower needs.

- **If plan utilisation is considered, underspending must be explained**

People living with young onset dementia may be unable to use allocated funding for reasons unrelated to their level of disability support need. Dementia Australia's consultation has identified barriers to utilisation including limited availability of dementia-capable services, regional workforce shortages and people living with dementia lacking insight into the need for supports and/or being reluctant to receive or refusing services as their condition progresses.

Our first plan provided what we thought was adequate support, however, we had issues with support coordination which delayed initiation of support ... The planner highlighted our failure to utilise the plan as problematic despite our explanations for the delay and the difficulties with getting my husband to accept care workers. ~carer

Plan utilisation should not be used as an indicator of need without examining why funding was not used. Reducing future funding because a participant could not access suitable services risks reinforcing the original service gap.

Recommendation: Ensure underspending is not considered evidence of lower need without considering service shortages, implementation delays, impaired insight and difficulty finding suitable dementia-capable support.

Plan variation and reassessment rules

We have heard from people with lived experience that assessment and planning changes can result in the loss of long-standing supports, even when a person's condition has deteriorated and their support needs have increased. This is particularly concerning for people living with dementia, whose needs are progressive.

Under the new framework, an inaccurate Support Needs Assessment (SNA) may have far-reaching funding consequences for future reviews, increasing the importance of getting the initial assessment right.

A review by NDIS where they removed all my allied therapy. Exercise, physio, counselling and podiatry. ~person living with dementia

While participants may request a replacement Support Needs Assessment or seek a plan review, the consultation materials provide little detail about timeframes, interim funding arrangements or how supports will be maintained during the process. For people living with progressive conditions such as dementia, delays in reassessment or reinstating supports can lead to avoidable functional decline, while an ongoing cycle of plan variations risks creates additional uncertainty, administrative burden and emotional stress for families.

Dementia Australia advocates have reported difficulties pursuing a review due to the complexity of the process and a lack of confidence overall due to previous experiences with the NDIA.

We have also heard cases of people living with dementia being called unexpectedly to have a plan reassessment done over the phone and months before the scheduled review date. This leaves people ill-prepared for the discussion and often without necessary support people in attendance. In some cases, this has resulted in longstanding supports being removed from a participant's plan. For instance, exercise physiology support was deemed as not representing value for money and removed from the plan, as the person was not going to get better. These supports were not reinstated despite supporting clinician evidence about their importance to maintaining function and independence and direct advocacy from Dementia Australia.

Recommendation: Publish the plan variation and reassessment process, including eligibility criteria, as soon as possible in 2026; prioritise disease progression and associated changes in functional cognitive and physical capacity as a reason for reassessment and ensure participants have sufficient notice and supports to meaningfully participate in the reassessment process.

NDIS supports rules

- **Clear categories still require dementia-capable implementation**

Dementia Australia welcomes the retention of categories covering therapy, in-home and community supports, assistive technology, short-term accommodation and support coordination. Yet the availability of these supports only benefits people living with young onset dementia if assessors understand how young onset dementia creates communication, behavioural, physical, supervision and safety-related support needs.

Consultation feedback included examples of supports being refused because dementia was misunderstood as only impacting cognitive needs, not physical.

I had a phone call from the NDIS advising me that my exercise physiology had been refused despite being used fortnightly in my previous plan. The reason given was that I have Alzheimer's and that does not affect my body. ~person living with young onset dementia

Therapy can address physical, communication and functional effects arising from dementia, including where its purpose is to maintain function, slow progression or support safe participation.

It is crucial that the progressive degenerative nature of dementia is understood. This is very different from conditions that tend to be static following diagnosis. To the average untrained individual the nuanced way dementia progresses may be misunderstood. The needs of an early diagnosed individual include a range of therapies to prolong function for as long as possible because the longer the person retains function the less the burden on NDIS. ~person living with Young Onset Dementia

Recommendation: Provide dementia-specific guidance and mandatory workforce education for plan implementation to ensure that funding can be used as intended to address communication, behavioural, physical, supervision and safety-related support needs.

- **Address availability shortfalls in long-term accommodation***

Consultation feedback has identified significant problems with the availability, quality, appropriateness and affordability of long-term accommodation funded by the NDIS.

Dementia-enabled long-term accommodation should be available in individual, shared or in-home arrangements according to the participant's needs and preferences. It should provide meaningful engagement and appropriate supervision, not simply accommodation or basic personal care. Standard living arrangements, fixed staffing models and housing designed primarily around physical accessibility may not meet these needs.

The age-based cutoff for aged care entry that took effect on 1 November 2025 makes it imperative that people living with young onset dementia have fit-for-purpose, readily available long term accommodation options within the NDIS. New builds to address shortfalls must

incorporate **dementia-enabling design** to ensure spaces are cognitively accessible, safe and welcoming therapeutic care environments.

Recommendation: Undertake and publish a review of age-appropriate, dementia-capable long-term accommodation for people living with young onset dementia, including regional, rural and remote gaps, and develop a plan to address availability shortfalls, with clear timelines and responsibilities across the Department and NDIA.

* Dementia Australia refers the Department and the NDIA to its **August 2026 joint position paper with Carers Australia** for analysis of barriers to respite and short-term accommodation for priority cohorts.

- **Removal of replacement supports could narrow access to useful mainstream technology**

A replacement support is defined within the NDIS as ‘the service, item or equipment you would like to use instead of the NDIS support or supports in your plan’. The proposed approach removes the replacement-support pathway while listing some common smart devices as NDIS supports. While this may improve access to items such as tablets, smartphones, smart watches and communication apps, it may create gaps for other mainstream products that can meet cognitive, communication or safety needs more effectively or at lower cost than specialist products.

Better access to mainstream products to avoid stigma, through reimbursement - with appropriate letter of support. For instance, when we are offered GPS trackers, we look and feel like criminals, and we attract the wrong type of attention in shopping centres.
~person living with young onset dementia

Requiring extensive professional reports for low-risk, low-cost assistive technology can delay access and may impose assessment and administrative costs that exceed the value of the item itself. Experiences highlighted in the recent **Support at Home Inquiry** demonstrate the need for safeguards against unnecessary costs when publicly funded supports are purchased through regulated service systems rather than directly from the retail market. There should be a proportionate approach within the NDIS, particularly where an item is inexpensive, readily available and presents minimal risk

Recommendation: Ensure the NDIS Supports Rules allow the purchase of mainstream cognitive, communication and safety technology where it is an appropriate and cost-effective response to an assessed disability need.

Conclusion

New framework planning represents a significant shift in how participant support needs are assessed, translated into funding and responded to over time. For people living with young onset dementia, these changes must recognise the fluctuating but progressive nature of cognitive disability and be managed by an assessment and planning workforce with significantly improved dementia capability

Dementia Australia recommends that the rules and implementation arrangements be tested with people living with different types and stages of dementia before being finalised. Implementation should monitor outcomes for people living with young onset dementia and their carers so that unintended impacts can be promptly identified and addressed.

References

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