

NDIS Access Changes

Dementia Australia

October 2026

What needs to change?

- People living with young onset dementia face barriers accessing the NDIS which may be exacerbated by proposed changes to the access process.
- Dementia is not always understood or assessed appropriately.
- Standard assessments may not reflect everyday support needs.
- Evidence requirements can be costly and difficult to access.
- New 'treatment' requirements must not impact permanence determination. Symptom management, maintenance of function or slowing progression is not a cure.

What is Dementia Australia recommending?

- Create a dedicated access pathway for young onset dementia.
- Provide dementia-specific support for people who do not meet access requirements.
- Validate assessment tools before implementation.
- Accept evidence from health professionals, carers and support people as an important part of the assessment process.
- Strengthen dementia capability across the workforce.
- Recognise that symptom management does not change dementia's permanence.

If actioned, what impact could these recommendations have?

- Fairer and faster access to support.
- Less cost and burden for families.
- Greater transparency and confidence in decisions.
- Better support for independence and carers.

How has Dementia Australia advocated for this position?

- Consulted people living with young onset dementia, carers and professionals.
- Used lived experience and expert input to inform recommendations.
- Made a submission on National Disability Insurance Scheme access reforms.
- Called for further consultation before implementation.

NDIS Access Changes

Dementia Australia submission

2 October 2026

Introduction

Dementia Australia welcomes the opportunity to provide a submission to the Department of Health, Disability and Ageing in response to the consultation on changes to the National Disability Insurance Agency (NDIS) access process.

Dementia Australia is the peak body representing the estimated 446,500 people living with dementia of all ages and their carers across Australia.[1] 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 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 and 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 the Scheme.

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

This submission is informed by consultation with people living with young onset dementia, current and former carers and family members, clinicians, disability workers and Dementia Australia staff that work directly with people living with young onset dementia.

Young onset dementia and NDIS access reform

People with young onset dementia already face significant barriers in accessing the NDIS. Current access experiences show that dementia is not consistently understood, assessed or supported, particularly where impairment is less visible, difficult to self-report or mistaken for an ageing or mental health issue.

Dementia Australia is concerned that the new access arrangements will exacerbate these barriers. A standardised functional assessment may overlook less visible or variable impairment; the new treatment requirements may create unnecessary uncertainty about the permanence of young onset dementia which is an irreversible progressive condition with no cure; and the alternative-support provisions may increase inappropriate redirection from the NDIS to systems where appropriate services for people with young onset dementia do not exist.

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, similar to those established for people with Motor Neurone Disease, Huntington's Disease and childhood dementia, where applicants can access a fast-tracked, specialised access and planning approach.
2. Ensure that state and territory governments provide a dementia-specific targeted support package to people living with young onset dementia who are assessed as not meeting the NDIS access requirements.
3. Clarify how the guiding principles apply to progressive neurological conditions, including dementia-capable assessment, recognition of assistance currently enabling everyday functioning, proportionate evidence requirements and practical referral to other suitable services.
4. Consult on the proposed assessment tools, classifications, scoring methods and thresholds before implementation, and independently validate them for people with progressive neurological disability including dementia, including having regard to learnings from implementation of the Aged Care Integrated Assessment Tool.
5. Ensure that assessments for people with dementia consider fluctuating cognition, impaired insight, executive dysfunction and behavioural symptoms, and not rely solely on single-point or standardised assessments conducted in artificial settings.
6. Require that clinical evidence and evidence from carers and support persons be accepted as evidence of functional capacity where a short assessment is insufficient to capture a person's day-to-day functioning and support needs.
7. Provide applicants with the assessment record that clearly notes a dementia diagnosis, the evidence considered, threshold applied and reasons for proposed access decision, with an opportunity to correct factual errors and be supported to request a review of an access decision.
8. The NDIS Rules should confirm that treatment is relevant to permanence only where the treatment and all prerequisite assessment, diagnostic testing and monitoring are publicly funded, suitable and practically accessible to the applicant. Specialist evidence should determine individual suitability. Symptom management, maintenance of function, temporary stability or slower progression are not a cure. They therefore should not impact permanence determinations.
9. Implementation of the new access arrangements must recognise that dementia is a permanent, progressive and incurable neurodegenerative condition, and that symptom management, maintenance therapies or temporary functional improvement do not negate permanence.

What is needed for cognitive, degenerative, fluctuating, episodic or complex disability, including referral pathways?

Dementia Australia strongly advocates for a dedicated access and planning pathway for dementia, that operates in the same way as priority pathways for people living with Huntington's Disease and Motor Neurone Disease. There must be equity in eligibility and support for all people living with a progressive neurological disability.

Where a person living with young onset dementia does not yet meet the eligibility threshold for the NDIS, there should be a targeted support package available at the State and Territory level to provide dementia specific interventions to slow disease progression, maintain wellness for as long as possible and reduce instances of carer burnout.

Access to rehabilitation is a human rights issue. The Convention on the Rights of Persons with Disabilities recognises rehabilitation as essential to enabling people with disability to achieve maximum independence, participation and inclusion in society, while the World Health Organization identifies rehabilitation as an essential health service and a core component of universal health coverage.

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, similar to those established for people with Motor Neurone Disease, Huntington's Disease and childhood dementia, where applicants can access a fast-tracked, specialised access and planning approach.

Recommendation: Ensure that state and territory governments provide a dementia-specific targeted support package to people living with young onset dementia who are assessed as not meeting the NDIS access requirements.

Draft guiding principles

Dementia Australia supports the seven draft principles. However, the principles should more clearly explain what these commitments mean for dementia. An evidence-based and consistent process must use methods that are valid for progressive neurological conditions.

Recommendation: Clarify how the guiding principles apply to progressive neurological conditions, including dementia-capable assessment, recognition of assistance currently enabling everyday functioning, proportionate evidence requirements and practical referral to other suitable services.

What should be considered when designing a fair, consistent, transparent, disability-informed and evidence-based process?

The legislative test and future thresholds

Under section 24 of the NDIS Act, a person must have one or more permanent intellectual, cognitive, neurological, sensory or physical impairments, or impairments attributed to a psychosocial disability. Those impairments must result in substantially reduced functional capacity in at least one of six statutory activities - communication, social interaction, learning, mobility, self-care or self-management. The impairments must also affect social or economic participation and be likely to result in a lifetime need for NDIS supports.

The legislation does not define the level of reduction that will be considered "substantial". Instead, the future NDIS Rules may prescribe assessment methods, classifications and thresholds. The assessment tool, scoring rules and threshold that will determine access are therefore currently unclear.

Feedback shared with Dementia Australia indicates that current assessments can underestimate progressive neurological disability where a person remains physically capable, presents well during a short interaction, or relies on established routines and assistance from others. A standardised tool is likely to reproduce or exacerbate these problems if it is primarily designed to assess stable and/or predominantly physical disabilities.

The assessment may capture what a person can do physically, but not the level of prompting, supervision, cueing or assistance required for them to complete tasks safely.
~carer

People with young onset dementia can perk up for tests or assessment-the full impact of the decline and deterioration experienced would not be seen or appreciated. ~carer

Assessment methods and thresholds must therefore be valid for progressive, degenerative, fluctuating and less visible disabilities. Each statutory activity should be assessed as a whole, including whether the person can initiate, sequence and complete it safely, reliably, repeatedly and sustainably without prompting, supervision or assistance with decision-making. The physical ability to perform part of an activity should not be taken as evidence of functional capacity where cognitive impairment prevents the person from completing the activity without direction or support.

Concerns raised during the recent Senate Inquiry into the Support at Home program have important implications for people living with young onset dementia if similar automated assessment processes are adopted within the NDIS. **Evidence presented by Dementia Australia** to the inquiry suggests that algorithm-based assessments may not adequately capture complex cognitive needs, leading to under-assessment and support allocations that do not reflect an individual's circumstances.

For people living with young onset dementia, this risk is particularly significant given the progressive and highly individual nature of the condition. An overreliance on automated decision-making could overlook needs relating to supervision, decision-making support and future planning, resulting in inadequate support. The inquiry highlighted the importance of retaining professional judgement and person-centred assessment processes to ensure funding decisions accurately reflect an individual's needs.

A person may present well and appear not to have functional impacts, while their executive functioning is impaired and they are unable to navigate the community independently, take their medication, prepare meals or make complex decisions.
~Dementia Australia staff member

Recommendation: Consult on the proposed assessment tools, classifications, scoring methods and thresholds before implementation, and independently validate them for people with progressive neurological disability including dementia, including having regard to learnings from implementation of the Aged Care Integrated Assessment Tool.

Assessing functional capacity

The legislated definition of functional capacity asks what a person can do without assistance from other people and without assistance from another person, assistive technology,

equipment or modifications. For people with dementia, functioning may vary across environments and routines. A person may perform a familiar activity successfully or present well during a single interaction while being unable to undertake the same activity safely and reliably later the same day.

A functional capacity assessment needs to evaluate not just what a person can do, but how reliably, safely, independently and consistently they can do it across everyday life.
~ Dementia Australia staff member

Being able to do a thing is not the same as being able to do a thing safely without supervision. ~person living with young onset dementia

The Rules should distinguish personal circumstances from evidence of functional capacity. A carer's availability may be a personal circumstance, but the prompting, supervision and practical assistance they provide are evidence of what the person cannot do independently. That assistance must be identified before its effect is removed from consideration.

Dementia can also affect a person's ability to recognise and report their limitations. Assessment should not rely solely on self-report, a single interaction or the person's best performance.

My husband lacks insight into his dementia...so if he was asked questions in a functional assessment he tends to say, 'I'm fine'. He does not recognise all of the support I provide to help him in areas where he struggles. ~carer

The person should remain central to the assessment and be supported to communicate their will, preferences and experience. Evidence should also be accepted from a chosen supporter, carer, treating professional or another person familiar with the person's usual functioning. Where necessary, assessment should consider functioning across time and settings, including being conducted face to face in the person's usual environment.

Recommendation: Ensure that assessments for people with dementia consider fluctuating cognition, impaired insight, executive dysfunction and behavioural symptoms, and not rely solely on single-point or standardised assessments conducted in artificial settings.

A dementia-capable workforce

The accuracy of the future access process will depend as much on workforce capability as on the assessment method and tools. Cognitive impairment, dementia progression and increasing support needs are regularly misunderstood by NDIS staff and assessors. It is reported to Dementia Australia that current assessments are often designed for people with physical or stable disabilities and do not adequately recognise progressive neurological conditions.

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. ~ person living with young onset dementia

The consequences of limited dementia knowledge can affect whether cognitive and neurological impairments are identified, how evidence is interpreted, whether a person is

considered to meet the access threshold and whether they are inappropriately redirected to health or aged care.

The access reforms should be accompanied by significant investment in dementia capability uplift across the NDIS workforce. A standardised tool will not produce fair decisions if the people administering it do not understand dementia.

All staff involved in intake, assessment, access decisions and review should complete mandatory dementia education appropriate to their role. Assessments involving dementia should be conducted or reviewed by a practitioner with demonstrated capability.

Recommendation: Require that clinical evidence and evidence from carers and support persons be accepted as evidence of functional capacity where a short assessment is insufficient to capture a person's day-to-day functioning and support needs.

Transparency, validation and accountability

The proposed assessment approach, tools and thresholds for accessing the NDIS have not yet been specified. Before implementation, they must be independently validated for progressive neurological disability.

There are no assessment tools currently in circulation that are actually appropriate and specific enough. ~person living with young onset dementia

Reports from loved ones need to be heard as often the person living with young onset dementia will be able to mask their symptoms and importantly, deny they have any problems at all. Therefore, a functional assessment must use different assessment techniques including validated questionnaires for loved ones as well as the person living with the condition. The assessment must be a reliable and valid tool for assessing capacity in a person with young onset dementia. ~carer

Moving away from diagnosis as the basis for access should not mean diagnosis is no longer recorded. Diagnosis and impairment information will be needed to monitor NDIS access for people living with dementia and whether tools or thresholds produce different access, refusal or review outcomes for people with dementia. Further, with dementia now the leading cause of death among Australians and a major contributor to disease burden across all age groups, maintaining robust and accurate data on dementia prevalence and outcomes is essential to inform evidence-based policy, resource allocation and long-term health system planning.

Recommendation: Provide applicants with the assessment record that clearly notes a dementia diagnosis, the evidence considered, threshold applied and reasons for proposed access decision, with an opportunity to correct factual errors and be supported to request a review of an access decision.

How should the process and referral pathways reduce burden and make access easier and more equitable, including for people who are clearly eligible?

The relationship between the proposed standardised assessment and existing specialist, clinical, functional, carer and lived-experience evidence remains unclear. Existing evidence should be considered first and request further assessment only where information essential to a particular access requirement is missing.

For young onset dementia, evidence of diagnosis establishes the nature and permanence of the impairment. Further functional evidence should be limited to what is reasonably required to determine its current impact across the statutory activities. Applicants must not be required to prove that the underlying condition is progressive and irreversible.

People living with young onset dementia may face delays in accessing clinicians with relevant expertise, particularly through public services or outside major cities. Private assessments may also be unaffordable.

The testing process can be expensive and time consuming and a barrier to the provision of much needed timely support. ~carer

The out-of-pocket cost of a Functional Capacity Assessment should not be necessary to be accepted for NDIS. The prices can be excessive for people who are already struggling to make ends meet. ~Dementia Australia staff member

The burden extends beyond assessment costs. One carer described entry to the NDIS as “harrowing and needlessly confusing” and said it effectively required a family member or friend with the time and capacity to investigate the system and advocate for the applicant.

Almost everything put out needs to be in clear, non-jargonistic language. I am a native English-speaker with a PhD and a health services background. Reading through NDIS information nearly breaks me. I hate to think what others are going through. ~carer

Recommendation: Provide applicants with the assessment record that clearly notes a dementia diagnosis, the evidence considered, threshold applied and reasons for proposed access decision, with an opportunity to correct factual errors and be supported to request a review of an access decision.

What factors and evidence should determine permanence and appropriate treatment?

The amended Act will require two matters to be established before an impairment is considered permanent or likely to be permanent: the person must have undertaken all “appropriate treatment”, if any, and the impairment must be likely to persist for their lifetime.

The word ‘treatment’ is problematic in any discussion of dementia. Dementia is an incurable and progressive neurological disability. While there are interventions, both clinical and non-clinical, that may temporarily mitigate or slow the progression of symptoms in some cases, permanent remission or cure is not currently possible.

Section 25A defines “appropriate treatment” as evidence-based treatment that is publicly funded and can reliably be expected to materially improve, reverse or alleviate the impact of an impairment. This provides an important safeguard against applicants being expected to privately fund treatment and/or undergo experimental therapies in order to establish permanence.

However, the legislation allows treatment to be considered appropriate even where the person’s financial circumstances or geographical location prevent access. This creates a particular risk for people in regional, rural and remote communities. A publicly funded treatment may still be practically unavailable if the person cannot access the required specialist, treatment centre, diagnostic testing or monitoring without substantial travel, delay or personal expense.

The existence of a treatment also does not establish that it is suitable for an individual. Emerging Alzheimer’s disease modifying therapies are currently only for people in the very early stages and clinical benefit can vary significantly between individuals and generally remain modest. They also require specialist review, biomarker or genetic testing and imaging to determine eligibility and support safe treatment.

The Rules should therefore consider the whole treatment pathway, including whether the treatment and the investigations required to establish suitability are publicly funded and practically accessible. Feedback suggests that treatment may already be being used to question permanence. A situation was described where an application was declined because medication options had not been fully trialled, despite specialist evidence confirming young onset dementia:

Case example (name changed): Jane (60) was diagnosed with younger onset dementia. Jane’s application for NDIS was declined with the reasoning that medication options had not been fully trialled yet for Jane, hence, the condition was not deemed permanent. The dementia medications do not provide a cure. They may stabilise symptoms in some people, but the damage to brain cells will continue and the disease will continue to worsen overtime. ~Dementia Australia staff member

This reported experience highlights the need for clear guidance to ensure that decisions regarding treatment are made by appropriately qualified treating specialists.

Recommendation: The NDIS Rules should confirm that treatment is relevant to permanence only where the treatment and all prerequisite assessment, diagnostic testing and monitoring are publicly funded, suitable and practically accessible to the applicant. Specialist evidence should determine individual suitability. Symptom management, maintenance of function, temporary stability or slower progression are not a cure. They therefore should not impact permanence determinations.

Establishing lifelong impairment

A specialist-confirmed young onset dementia diagnosis should be sufficient to establish that associated cognitive or neurological impairment will persist for life.

Treatment may temporarily improve symptoms, maintain function or reduce the impact of an impairment without removing the impairment itself. A period of stability, temporary improvement or slower progression should therefore be distinguished from clinical evidence that the impairment will cease during the person's lifetime.

Recommendation: Implementation of the new access arrangements must recognise that dementia is a permanent, progressive and incurable neurodegenerative condition, and that symptom management, maintenance therapies or temporary functional improvement do not negate permanence.

For further consideration

The consultation paper states that current NDIS participants will be reassessed over a three-year transition period from the commencement of the access reforms. However, the detailed thresholds, evidence requirements, transition arrangements and continuity protections have not yet been settled. Further advice must explain who will be reassessed, which legal requirements will apply, what evidence will be required, and how supports will continue while a decision or review is underway.

People with young onset dementia are living with a terminal condition and require increasing level of supports as their condition progresses. Reassessment is an unnecessary burden for the individual and the system as a whole when a condition is progressive and life limiting. Dementia Australia recommends that a 'no worse off' principle be applied for existing NDIS participants.

The NDIA should monitor access, refusal, reassessment and review outcomes by impairment type, geography and priority population. This should identify whether particular tools, thresholds or evidence requirements produce systematically different outcomes for people with progressive neurological or less visible disability. Findings should inform ongoing validation, workforce development and revision of the assessment approach.

Further consultation should occur before the Rules, assessment methods and implementation arrangements are finalised.

Conclusion

As NDIS reforms continue to evolve, there is an important opportunity to strengthen the clarity, fairness and consistency of access decisions through approaches that are informed by the lived experience of people with young onset dementia. Dementia Australia remains hopeful that future reform and implementation processes will create space for genuine collaboration and co-design, ensuring the distinct characteristics and support needs associated with dementia are appropriately recognised and translated into equitable access outcomes.

We welcome the opportunity for further consultation. The Dementia Australia Policy and Advocacy team can be contacted at policy@dementia.org.au

References

1. Dementia Australia. Facts and Figures. 2026; Available from: <https://www.dementia.org.au/about-dementia/dementia-facts-and-figures>.
2. Childhood Dementia Initiative. Childhood dementia facts and statistics. 2025; Available from: <https://www.childhooddementia.org/health-professionals/understanding-childhood-dementia>.
3. Woods, B., Rai, H.K., Elliott, E., Aguirre, E., Orrell, M. & Spector, A. 2023, Cognitive stimulation to improve cognitive functioning in people with dementia, Cochrane Database of Systematic Reviews, no. 1, CD005562. <https://doi.org/10.1002/14651858.CD005562.pub3>