

NDIS Support Coordination and Connection Reform

Dementia Australia Submission

October 2026

What needs to change?

- Improve access to dementia-capable Support Coordination and Connection services for people living with young onset dementia.
- Strengthen workforce capability, continuity and participant choice.
- Address service gaps in regional, rural and remote areas.

What is Dementia Australia recommending?

- Guarantee access to Support Coordination and Connection services for NDIS participants living with young onset dementia.
- Ensure a dementia-informed workforce and consistency in staffing.
- Embed supported decision-making and flexible service delivery.

If actioned, what impact could these recommendations have?

- Timely access to appropriate supports and reduced stress.
- Better outcomes for participants, families and carers, including increased independence for people living with young onset dementia.
- Increased continuity of supports.

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 support coordination reforms.
- Called for further consultation before implementation.

Introduction

Dementia Australia welcomes the opportunity to provide feedback to the Department of Health, Disability and Ageing on the future design of the Support Coordination and Connection (SCC) service within the National Disability Insurance Scheme (NDIS).

Dementia Australia is the peak body representing the 29,000 people living with young onset dementia and 1500 children living with childhood dementia, cohorts within the estimated 446,500 people living with dementia and their families and 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 Australia recognises that dementia does not affect all people equally and that barriers may be compounded for people living with disabilities, 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 draws on the survey responses of people living with young onset dementia, current and former carers, sector stakeholders and staff. It is also informed by our experience delivering national information, support and advocacy services, including the National Dementia Helpline, the National Dementia Support Program and the Dementia Advocates Program.

New SCC service and implications for young onset dementia

Dementia is not a normal part of ageing and can affect people of all ages including children and young adults. Young onset dementia refers to any form of dementia diagnosed between the ages of 18 and 65. There are also an estimated 1,500 children living with childhood dementia in Australia, arising from more than 100 rare genetic disorders [1]. In 2026, there are an estimated 29,000 people living with young onset dementia in Australia [2]. This figure is projected to increase to 41,000 in 2054 [2]. People with young onset dementia are underrepresented in the NDIS with less than 20% of people living with young onset dementia estimated to be Scheme participants [3].

The misconception that dementia is a condition of old age exacerbates the challenges experienced by younger people with a diagnosis of dementia. The experiences of people with young onset dementia can be different from those diagnosed with dementia at a later stage of life. They often receive a diagnosis when they are in full-time employment and actively raising and financially supporting a family.

The additional pressures associated with dependent children and/or employment, financial commitments and societal stigma requires a flexible and agile NDIS, staffed by a dementia-informed workforce. Any new model of Support Coordination and Connection must seek to alleviate the burden of identifying, sourcing, contracting and retaining dementia-enabled supports for those living with young onset dementia and their carers.

Recommendations

1. Guarantee access to SCC services for people living with young onset dementia.
2. Ensure SCC providers employ a dementia-informed workforce with expertise in young onset dementia and its impact on families and carers.
3. Deliver continuity of support through consistent allocation of SCC personnel across Plans.
4. Embed supported decision-making principles within SCC service delivery.
5. Deliver SCC services through a person-centred approach that recognises changing individual needs and preferences.

What participants want from the new SCC service

What is working well in support coordination today that you would like to see in the new SCC service?

The current model enables participants to choose a support coordinator with demonstrated knowledge and skills in dementia and to retain that person over time, ensuring continuity and understanding of an individual's progressive needs.

Dementia-informed support coordinators understand that dementia increasingly impacts cognition and decision-making and can help plan for changing needs. They coordinate across service providers to reduce complexity and support a consistent approach to care.

Our Support Coordinator is great and I wouldn't want to not be able to choose my own.
~ carer

What would you most like to see improved in the new SCC service?

- **Guaranteed access to support coordination and connection**

A diagnosis of young onset dementia, defined as dementia occurring between the ages of 18 and 65, has profound and far-reaching consequences for individuals and their families. Unlike many older people diagnosed with dementia, those living with young onset dementia are often still working, raising children, managing mortgages and other financial commitments, and may even be caring for ageing parents. The emotional impact of receiving a diagnosis of a progressive, terminal condition is therefore compounded by concerns about family responsibilities, financial security and future care needs.

Young onset dementia is associated with significant personal, psychosocial and economic challenges. As the condition progresses and affects cognition, memory, decision-making and functional capacity, individuals and families often face considerable difficulties navigating health and disability systems.[4]

It is challenging for a person living with young onset dementia to understand and navigate a complex new service system, research available supports, negotiate provider agreements, recruit workers and manage service delivery. These responsibilities require significant

cognitive, organisational and administrative capacity at precisely the time when cognitive function is declining.

When SC funding not approved, client's partner was completely overwhelmed and unable to implement plan. Impact was YOD client was not able to use NDIS funding without SC. ~Dementia Australia staff member

Family carers are similarly affected. Many continue to participate in the workforce while also caring for children, supporting older relatives and responding to the increasing needs of a family member living with young onset dementia. Carers are often also required to assume the responsibilities of a support coordinator. This adds considerable extra burden with significant consequences that include reduced workforce participation, decreased productivity and premature withdrawal from employment, creating broader economic costs for families, employers and society. Evidence consistently demonstrates that caring responsibilities can adversely affect employment outcomes and labour-force participation.[5] [6]

Support coordination is crucial to reducing the load and strain on family members and helping to ensure the required supports are in place. ~carer

Guaranteed access to Support Coordination, proportionate to an individual's level of situational complexity, is essential for people living with young onset dementia and carers – even more so for participants without informal support - to enable timely connection to appropriate supports and reduce avoidable stress during an already overwhelming period. For participants from culturally and linguistically diverse backgrounds, and First Nations backgrounds, the systemic complexity is even more overwhelming and must be mitigated through guaranteed access to culturally appropriate support coordination.

- **Workforce capability**

NDIS participants consistently emphasise the importance of SCC workers having specialist knowledge of young onset dementia. Dementia-informed coordinators can anticipate changing needs, support decision-making and connect participants with appropriate services.

Support coordinators should be provided by someone who understands the disease completely and is able to connect the participant with the right supports. ~carer

Understanding the system is difficult for people with young onset dementia and their families. We have only recently found a support coordinator who understands our situation. ~carer

Young onset dementia often progresses more rapidly than dementia in later years [6], which means timely SCC services are critical. When needs are not understood and appropriate services are not accessed quickly, opportunities to improve outcomes and support quality of life can be permanently lost.

The time from suggestions of things which might be useful for us and getting approval and release of funds/support/items etc is very long and my concern is with the rapidity of the decline my husband is experiencing he may miss out on support in a timely fashion. ~carer

- **Continuity of support**

Participants identify continuity of the individual support coordinator, rather than continuity of the organisation, as critical to successful support coordination. Frequent changes in personnel require participants and carers to repeatedly explain their circumstances and can disrupt effective planning.

Having the same person from the beginning of our journey has been most beneficial as they get to know our needs as they change over the time. ~carer

Young onset dementia can be a rapidly evolving condition with cognition fluctuating from day to day and even within the day. A support coordinator who knows and understands the person living with dementia, their carer and the broader context of any planning decision is essential for participant and carer wellbeing, and effective plan utilisation. Where personnel changes are necessary, systems and processes must be in place to ensure information is not lost in the change of staff.

Support coordination is good, but it only works if we have someone specifically trained or experienced in younger onset dementia, who is the same person every time, with a backup person who also is familiar. Things change quickly, and having to retell your story multiple times is unhelpful. ~person living with dementia

- **Supported decision-making and autonomy**

People living with young onset dementia should be supported to participate in decisions about their lives, supports and living arrangements for as long as possible, which includes being able to exercise their legal capacity in accordance with the UN Convention on the Rights of Persons with Disabilities.

Effective implementation of supported decision-making requires staff training and capability development. SCC staff must understand the principles of supported decision-making and be equipped with practical skills to support people to make and communicate their own decisions, while respecting autonomy, rights, preferences and dignity of risk.

This is particularly relevant in dementia care, where staff often need specialised training to support communication, capacity fluctuations, and the person's will and preferences over time.

Control has remained with us while an SC who knew us well was always available for support and guidance. Now we are forced into a relationship we did not choose with people we do not know. ~carer

They need to count and to have a voice, even if that voice takes extra effort to hear. ~carer

- **Flexible service delivery: face-to-face or a virtual service?**

A person living with young onset dementia may have specific communication needs that require face-to-face interactions. For example, someone living with **Primary Progressive Aphasia** may have trouble word finding and use non-verbal cues to assist them.

Being able to meet someone face to face for the person with young onset dementia is a very important aspect. ~carer

Conversely, that same participant may have a day where their cognition has been negatively impacted by environmental factors or other health conditions, and they prefer a virtual meeting, in order to avoid any stress associated with travel, which may further impact their cognition.

To be honest, we have only met our support co-ordinator in person once (and that was to assist us with a NDIS plan conversation). The key thing is that they are responsive and available on the phone, emails and Zoom. ~carer

A person-centred approach should enable participants to choose either face-to-face or virtual SCC services, subject to their variable needs.

What else should we consider when designing the future SCC service?

Thin markets in rural and remote areas remain a significant barrier to equitable access to supports for people living with young onset dementia. Reform of SCC services alone will not improve outcomes unless participants can also access appropriate dementia-capable services within their region or through flexible cross-regional and virtual service models.

There is no point in rejigging SCC if there are no relevant services and supports in (for instance) a regional or remote setting. Deal with equity and accessibility before changing. ~carer

Service provider models and approaches:

What commissioning arrangements would best balance participant outcomes, quality, sustainability and choice and control?

What provider types would be best placed to be a lead organisation?

A dementia capable workforce is essential for any service provider, regardless of the provider model selected. Whether a lead organisation is given sole responsibility for a specific region, or multiple providers are available in each region, a workforce that understands disease trajectory, fluctuations in cognition, evolving needs and the importance of timely and responsive services is critical.

That the SCC is skilled with dementia and can act as a navigator through other funded services...There is a lack of community services for people with young onset dementia in general, so the risk is a hidden disability that is increasing in occurrence just gets hidden if the Support Coordinator service is not young onset specific. ~carer

It is also vital that the new SCC service understands and responds with empathy to the experiences of carers.

They should specialise in a particular field rather than cover all disabilities. Without my support coordinator we would not have known many of the services which we could utilize. It allowed me to continue to work a further 18mths before I needed to stop working to become a fulltime carer. ~carer

Fundamentally, the lead organisation model does not support participant choice and control, as it restricts the choice of SCC service available to the participant. Participants living with young onset dementia should have the right to SCC services with a dementia enabled workforce that has detailed knowledge of locally available services and supports.

Each region should have a dementia specific SC who understands the disease and its ramifications. ~carer

Support coordination services should have sound local knowledge of the area the person with young onset dementia resides in. They should have established contacts and understand the process for accessing a variety of supports the participant needs. ~carer

How might SCC providers manage variable need among the participants it supports? Which workforce, caseload and service capacity factors should be considered?

A multi-provider model would enable a cross-regional approach to pool resources and or combine demand where thin markets traditionally exist. This would be particularly effective if combined with increased flexibility in budget line items within participant plans, enabling participants to use funds for face to face or virtual services, subject to their varying needs on any given day due to fluctuating cognition or disease progression.

Accessibility and flexibility should be prioritised. ~carer

How should local knowledge and community connection be defined and assessed?

Where supports need to be delivered in person, local knowledge of available supports by an SCC service is essential. Beyond geographic proximity, local knowledge means a detailed understanding of a service provider's track record in the provision of timely and responsive supports that are disability specific, as well as their responsiveness to communications, administrative issues and general accessibility. It is more than just identifying a list of providers who provide support in a particular location.

They also provide information and contacts at a local level rather than sending me a spreadsheet with over 3000 service provided in the state. ~carer

Community connection means a commitment to a cohort, or region, including accountability and responsibility for poor outcomes. There is investment in the relationship from both sides. The phrase has become overused, but the implication remains: I am I am with you; I will support you.

Local, small scale, human services have enabled us to assemble a functional team of support workers without having to explain and reiterate explanation. Control has remained with us while an SC who knew us well was always available for support and guidance. ~carer

For participants living with young onset dementia, carers and family members, knowledge, understanding, and experience of the impact of dementia - combined with local knowledge - is

critical for the new SCC model. Young onset dementia is a disability with both cognitive and physical impacts, which means it is inherently complex.

If I have to have a support coordinator company who doesn't know me or anything about my specific situation, who is just on a roster like a walk-in clinic, it will be a waste of money, and very, very frustrating. ~person living with dementia

How can the SCC service best support participants in regional, rural and remote areas, or other thin markets, where support options may be limited?

The new SCC service model, whether based on a lead-organisation or multi-provider approach, will need to take an innovative approach to address the issue of thin markets in regional, rural and remote areas, as well as in terms of disability specific skills and knowledge.

Whether through a combination of market subsidisation (subsidising local services in low population areas), funding travel between regions for participants to access dementia-specific SCC support, and/or virtual delivery by dementia-enabled providers outside the region, the SCC service model will need to be flexible, responsive and agile.

so far we haven't had a good experience with SC; onto our 2nd company and they have both been lacking in different ways. our 1st sc had no experience with young onset dementia even though they were with a specialised company and also lived on the other side of Sydney with no experience or connection to our local supports and services. ~carer

Broader reform context

Dementia Australia notes that this consultation is occurring alongside broader NDIS reforms that affect planning, reassessment, support determinations and access to supports. Across these reform processes, Dementia Australia has consistently highlighted the importance of flexible, individualised and dementia-capable approaches for people living with progressive neurological conditions, including young onset dementia. These principles are equally relevant to any future commissioning model for SCC services.

Conclusion

Dementia Australia advocates for a future SCC service commissioning model that is flexible, participant-centred and responsive to the unique needs of people living with young onset dementia.

All people living with young onset dementia should have access to SCC services delivered by a dementia-informed workforce with the skills, knowledge and continuity required to support a progressive neurological condition. Future arrangements must preserve participant choice and control, embed supported decision-making, and address the challenges posed by thin markets in regional, rural and remote communities.

Above all, the future SCC model should support people living with young onset dementia to maintain autonomy, access appropriate supports and continue participating in family, work and community life for as long as possible.

For more information, please contact the Dementia Australia Policy and Advocacy team on policy@dementia.org.au.

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