

People with progressive neurodegenerative diseases in the NDIS

Joint Position Statement

The Neurological Alliance Australia (NAA) believes that the National Disability Insurance Scheme (NDIS) will transform the lives of people living with progressive neurodegenerative diseases and has promoted and supported the Scheme since its inception. To date some NDIS participants have received plans that have had positive, life-changing impacts on their lives, however, many others have received insufficient plans that will adversely affect their quality of life and place some at risk of avoidable hospitalisation.

To ensure the best outcomes for people with progressive neurodegenerative diseases under the NDIS, the NAA recommends:

1. Improved pre-planning support for people with a progressive neurodegenerative disease;
2. NDIS planning sessions that recognise the unique needs of people with a progressive neurodegenerative disease;
3. Mandatory inclusion of Coordination of Support in all NDIS plans for people living with a progressive neurodegenerative disease; and
4. The needs of people with a progressive neurodegenerative disease be addressed in the Productivity Commission's upcoming *Review of NDIS Costs*.

Background

The Neurological Alliance Australia is an alliance of not-for-profit peak national organisations representing adults and children living with progressive neurological and neuromuscular diseases in Australia. The Alliance was established in 2010 to promote improved quality of life, coordinated services and greater research investment. The Alliance represents over 850,000 Australians living with progressive neurological or neuromuscular conditions that have no known cause and no cure. This group includes adults and children, carers, families, friends and workmates whose life has been affected by a progressive neurological condition. The impact of progressive neurological conditions on individuals and families can undermine their resilience, which is a vital element of their ability to remain purposeful and in control of their lives in addition to preventing financial and emotional burden.

Progressive neurological and neuromuscular diseases are a set of complex and disabling conditions. While this broad group contains conditions with various characteristics, different disease trajectories and life expectancy, all are degenerative and incurable. This results in significant disability and the need for expert information, care and personal assistance.

Progressive Neurodegenerative Diseases and the National Disability Insurance Scheme

The NAA has long been supportive of the National Disability Insurance Scheme's (NDIS) potential to transform the lives of people with progressive neurodegenerative diseases and our members have actively promoted the NDIS to those who meet the eligibility requirements.

When the NDIS operates as it was originally intended, and participants have the opportunity to exercise 'choice and control' by actively participating in the development of their first NDIS plan, the plan outcomes generally have been positive. However, when the progressing and complex needs of people with neurodegenerative diseases have been overlooked due to lack of understanding of these diseases or for the sake of expediency

(for example, conducting planning sessions over the phone despite communication or cognition challenges, or creating plans that do not address key support needs), the outcomes have been overwhelmingly poor.

People with a progressive neurological disease run counter to the 'traditional' trajectory of someone on the NDIS: that is, an ability to enhance independence and re-ablement through a more effective engagement of services. For someone with a neurodegenerative disease, however, care needs inevitably increase over time. NDIS plans for this cohort need to acknowledge this and balance independent goal setting with advance care planning. Individuals with neurological diseases should also have pre-planning education and support to assist them as they consider their future needs that go beyond the first year of their plan.

Consideration of their disease and anticipated progression should also be taken into consideration during planning meetings. People with cognitive or communication impairment require patience and understanding, limited distractions, clear speech, eye contact and non-verbal indicators which are difficult to achieve over the phone. Therefore, when NDIS planning sessions are conducted solely over the phone, many of which, our consumers tell us, have been conducted solely with the person's carer without the participant present (or the reverse), the plan outcomes are less than optimal and the participant (and their supporter) is deprived of choice and control.

In response to these concerns and the difficulties reported by people living with a progressive neurological disease entering the NDIS, the NAA have drafted four recommendations:

Recommendations

1. Pre-planning education/support

People with a progressive neurodegenerative disease must consider a number of elements when preparing for NDIS plans. For many, they have only recently been diagnosed and are not yet completely aware of how the disease will progress and how their needs will change. It is essential that individuals have a clear understanding of their anticipated future needs and how the progressive nature of the disease may impact them in the next 12 months (and the years afterwards) when preparing for an NDIS plan.

This is evidenced through reports of people with progressive neurodegenerative disease advising their NDIS planner of their immediate needs (e.g. social interaction) without considering their greater needs (e.g. occupational or speech therapy) despite having a clear need for them.

Case Study

Peter, the carer of a woman with younger onset dementia, felt unprepared when he and his wife attended their first NDIS planning session. Peter and his wife found it difficult and uncomfortable being asked what their needs were as he did not know how to identify or prepare for what their needs were and would be in the future. The NDIS planner had no understanding of dementia and the needs of people living with dementia and as a result the planning session focused on physical needs and solutions. As a result their first NDIS plan provided funded supports totalling \$600.

Seeking assistance to address his wife's many unmet needs in this plan, Peter spoke with one of Alzheimer's Australia's Younger Onset Dementia Key Workers who worked with Peter and his wife to better understand their immediate and future needs. The Key Worker assisted Peter in arranging an NDIS plan review and the resulting plan provided funded supports of \$32,000 (including 9 hours of home care and a week of full respite (24/7 care). This was the life-changing NDIS plan Peter and his wife had hoped for when they entered the NDIS.

Consideration of assistive technology (AT) is another important part of the pre-planning process. AT covers a range of aids and equipment to help people live more independently such as mobility equipment (walking frames and wheelchairs), specialised beds and clothing, specialised alarms and door bells, and a huge range of communication and IT equipment and devices. It is essential that AT options are considered in all NDIS plans for people with progressive neurodegenerative diseases and that follow up ensures timely access to the AT identified.

Lack of pre-planning can result in ineffective plans which require an NDIS review and/or result in negative health impacts for people with a progressive neurodegenerative disease. Therefore, funding is required either for expert organisations to provide support to people with a progressive neurodegenerative disease as they prepare for NDIS planning sessions or for targeted NDIS education for people with a progressive neurodegenerative disease. This would significantly reduce the risk of inappropriate or insufficient NDIS plans and the need for unscheduled plan reviews.

Recommendation 1

Improved pre-planning support for people with a progressive neurodegenerative disease

2. Face to face planning meetings

A face-to-face NDIS planning session with an NDIS planner who has a sound knowledge of cognitive impairment and neurodegenerative diseases, such as those in NDIS Complex Care Teams, are considered by the NAA as best practice and have produced NDIS plans that most appropriately meet the needs of people with a progressive neurodegenerative disease.

Unfortunately, this approach is not uniformly implemented.

For example, NDIS planning sessions over the phone have proved to be inappropriate for people with a neurodegenerative disease and can result in poor outcomes, often requiring an urgent NDIS plan review.

Case Studies

Leslie called Alzheimer's Australia in a state of distress as she had an NDIS planning session over the phone (with no forewarning) and could not recall who she had talked to or the details of the conversation. It took Leslie, with the help of a YOD Key Worker, over 6 hours to gather the basic information required for Leslie to apply for a review of her NDIS planning session.

Chris was asked to complete an NDIS planning session for his wife over the phone with no prior warning and not having done any supported pre-planning. On receipt of the plan, Chris contacted Alzheimer's Australia to discuss plan implementation, however, after discussing his wife's needs for the coming months and Chris's plans to return to part-time work it became clear the \$11,000 provided for 12 months were inadequate to meet his wife's complex needs. Chris is now waiting on a response from the NDIA regarding a review of his wife's plan.

Feedback from people with progressive neurodegenerative diseases has revealed that Local Area Coordinators (LACs) have also shown insufficient knowledge of their disease, the impact on their lives, most effective service interventions and the degenerative and fatal nature of their disease.

Case studies

Annie called the Parkinson's 1800 support line as she worried about an over the phone NDIS planning session that had taken place earlier that day. Annie's volume and quality of speech has been impaired due to Parkinson's and she also requires longer to respond to questions. She felt rushed and because her response is delayed she felt that the assessor didn't get a clear indication of her needs. Annie and a Parkinson's Nurse Specialist were able to take the time put information together in order to apply for a review for Annie's plan.

The first time Annie applied for disability support she was told that even with Parkinson's, a degenerative neurological condition with no cure, she was considered "not disabled enough".

A person with Multiple Sclerosis (MS) was asked by the LAC at a planning meeting, "How long will MS last?"

Another person with MS with only head movement was asked by the LAC at their planning meeting if they would require personal care or if they would be able to hang out their own washing?

To offer true choice and control in individual plans, NDIS planning sessions must take into consideration the unique needs of all participants by gaining a better understanding of the diseases impacting clients and, wherever possible, meeting with these people face to face during the NDIS planning phase.

Recommendation 2:

NDIS planning sessions that recognise the unique needs of people with a progressive neurodegenerative disease

3. Coordination of Supports for people with progressive neurodegenerative diseases

The number of NDIS participants that no longer have allocations in their NDIS plans for coordination of supports is cause for concern by NAA members. Key issues with this approach include the following:

- No allowance for a Coordinator of Supports takes away a valuable support mechanism at a time when these people need the most help (e.g. navigating a brand new disability system and often confusing technology such as the NDIS portal).
- Coordinators of Support with a good understanding of the unique needs of people with a progressive neurodegenerative disease have proved to be effective advocates who bridge the knowledge gap between the NDIS, the disease and the individual.
- Without intervention most people with progressive neurodegenerative diseases will be unable to navigate the review process and would be limited by their inadequate plan for the ensuing twelve months.

Case study

Chris is a father, an active member of the Airey's Inlet community, a keen cyclist and "pong" player, and a person living with multiple sclerosis. Chris was living in a house completely incompatible with his needs as a man with multiple sclerosis.

Finding something suitable in his hometown had proved financially impossible, and moving away from a lifetime's worth of friendships is a decision no one should be forced to make because of a disability.

Enter the NDIS, and Chris' MS Support Coordinator, Michelle.

"It was a nine-and-a-half-month journey," Chris says, "but Michelle was there right from the beginning, pushing for me to get into a new house. It's beautiful, it's warm, I've got a bedroom for each of the kids, and I don't have any steps, which is great.

"And I can say thanks to the NDIS that I have the ability to stay here in town. I believe that's the most important thing, because I've been here for so long, I've built so many relationships."

Funding in Chris' NDIS plan also covers house cleaning, assisted meal preparation, gardening and yard maintenance, transport and participation in a local exercise program.

The process of achieving these outcomes might have intimidated Chris had he tried to do so on his own.

"It's been absolutely fantastic to have Michelle supporting me through the whole journey," he says.

Coordinators of Support play a vital role in negotiating support costs with providers, making arrangements for support delivery and providing information and ongoing support to providers regarding the specific needs of people with one of these diseases.

People with progressive neurodegenerative diseases are caught between a changing disability sector and aged care sector and there are limited options available to them within the marketplace. Without the support and advocacy of a Coordinator of Supports, many people with a progressive neurodegenerative disease may fall through the cracks and be unable to access appropriate services.

Recommendation 3:

Mandatory inclusion of Coordination of Support in all NDIS plans for people living with a progressive neurodegenerative disease

4. Addressing the needs of people with a progressive neurodegenerative disease in the Productivity Commission's Review of NDIS Costs.

In the Productivity Commission's upcoming review of the National Disability Insurance Scheme's costs one of the issues the Commission has been directed to address is:

- Whether there are any issues with the scheme's design, including the application of market and insurance principles, in ensuring the best possible outcomes for people with severe and profound disability¹.

The NAA recommends the issues experienced by people with progressive neurodegenerative diseases as set out in this Position Paper are addressed in the review of the Scheme's design and that the NDIA continues to adapt and shape the NDIS to the needs of all consumers, specifically including those with progressive neurodegenerative diseases.

Recommendation 4:

The needs of people with a progressive neurodegenerative disease be addressed in the Productivity Commission's upcoming Review of NDIS Costs.

Conclusion

Implementation of these four recommendations will not only improve NDIS plan outcomes for people with progressive neurodegenerative diseases but will also directly improve outputs set out in the Productivity Commission's *Services for people with disability performance indicator framework*, ²namely:

- Access – Assistance for younger people with disability in, or at risk of, entering residential aged care;
- Appropriateness; and
- Quality – Client and carer satisfaction.

These will result in improved outcomes – in principle and in practice, including:

- Increased labour force participation of primary carers of people with disability; and
- Social participation of people with disability.

The NAA remains an advocate of the NDIS and understands the roll out of this Scheme is one of the greatest changes to healthcare since the introduction of Medicare. However, if people with a progressive neurological disease are to receive equitable and effective support within the NDIS it is imperative that the NDIA and government addresses these unmet needs. The recommendations outlined in this Position Paper will go a significant way to aligning the original intent of the NDIS with its practical application.

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¹ <http://www.pc.gov.au/inquiries/current/ndis-costs/terms-of-reference>

² <http://www.pc.gov.au/research/ongoing/report-on-government-services/2017/community-services/services-for-people-with-disability/rogs-2017-volume-f-chapter15.pdf>