

National disability survey highlights the NDIS reform challenges ahead

22 May 2026: A new national survey shows the National Disability Insurance Scheme (NDIS) does not properly understand multiple sclerosis (MS), leading to decisions that impact access to essential care and people's ability to manage the condition and stay independent.

MS Australia says the findings underscore the urgent need to ensure that the proposed wide-ranging government NDIS reforms improve understanding of disabilities, including MS, and do not reduce access to essential supports.

A total of 939 people responded to the MS Australia survey, with nearly two in three people (61%) saying the NDIS does not understand MS, and many reporting changes to supports that have resulted in reduced therapy and funding.

Some respondents also described inconsistent experiences, with understanding often depending on who assessed their plan or reviewed their needs.

MS Australia CEO Rohan Greenland said the findings point to a concerning gap in how MS is understood within the NDIS.

"People are telling us that the realities of living with MS are not properly recognised, and decisions are made that reduce access to the therapies and supports they rely on to stay independent and manage their condition," Mr Greenland said.

"MS is often invisible and, for many people, progressive and fluctuating. When that is not properly understood or reflected in decision-making, people miss out on the support they need."

More than 40% of respondents reported significant changes following an NDIS plan review, with supports such as physiotherapy, exercise physiology and occupational therapy among the most commonly affected.

Some respondents described reduced therapy hours, removal of mental health supports, and cuts to allied health funding, even as their condition worsened, increasing the risk of injury, declining health and loss of independence.

One respondent described the devastating impact of losing access to supports:

"I was doing really well with my physiotherapy, progressing and building up strength and confidence, and then there was no funding for that anymore.

Since then, my strength has declined, and I feel a lot worse off than before. I feel the rug has been pulled from under me. I'm gutted."

Another said, "My condition is progressively worsening and I'm receiving less care."

Janine Watson, who lives with MS, said recent changes to her NDIS plan have left her frustrated with a plan that does not reflect her needs.

A Paralympic Taekwondo athlete and four-time World Champion, Janine requested increased capacity-building funding to maintain her independence. Instead, her physiotherapy support was reduced from two hours per week to 12 hours a year.

“My new NDIS plan feels generic, as if it was copied from someone else rather than made for me.

I’m frustrated because I put a lot of time and effort into preparing thorough evidence and reports for my plan review, yet it seems like none of it was considered. Now, I have an NDIS plan that doesn’t suit my needs and leaves me worse off,” Ms Watson said.

Mr Greenland said the NDIS remains essential, but improvements are needed to ensure it works consistently for people living with MS.

“It’s not perfect, but it is a critical system that must consistently deliver the support people need to live independently and manage their condition,” he said.

“What we are seeing is inconsistency. Support should not depend on who you speak to, it should be based on what people need.”

The findings follow the Australian Government’s recent announcement of changes to the NDIS in the 2026–27 Budget, including new assessment processes focused more on a person’s functional capacity rather than their diagnosis, alongside measures intended to manage plan costs.

The survey points to inconsistency in how MS is assessed and understood within the NDIS, and there is concern that this gap could widen as the Scheme shifts towards these new assessment approaches.

Mr Greenland said any reforms must improve understanding of disabilities, including MS, and not reduce access to essential supports.

“Reform must strengthen confidence that people are being assessed accurately and fairly, and must not make it harder for people with complex and progressive conditions like MS to access the support they need,” he said.

MS Australia stands ready to work with the Government on measures that improve understanding of MS within the NDIS, including:

- Improved MS-specific training for NDIS staff and assessors
- Better recognition of fatigue and other invisible symptoms
- More flexible, individualised supports that reflect the progressive nature of MS
- Faster, clearer processes for accessing and reviewing supports

“When we get this right, people with MS can participate more fully in their communities and maintain their independence for longer,” Mr Greenland said.

“This should be at the very top of the priority list for the Scheme.”

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Read the full MS community NDIS survey report here: <https://bit.ly/3Rzq9ZW>

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