



WHAT WE HEARD: MS, THE NDIS & LIVED EXPERIENCE

MS COMMUNITY NDIS SURVEY REPORT

MAY 2026





MS Australia is Australia's national MS not-for-profit organisation that empowers researchers to identify ways to treat, prevent and cure MS, seeks sustained and systemic policy change via advocacy, and acts as the national champion for Australia's community of people affected by MS.

MS Australia represents and collaborates with its state and territory MS Member Organisations, people with MS, their carers, families and friends and various national and international bodies to:

- Fund, coordinate, educate and advocate for MS research as part of the worldwide effort to solve MS
- Provide the latest evidence-based information and resources
- Help meet the needs of people affected by MS.

Multiple Sclerosis (MS) remains one of the most common causes of neurological disability in the young adult population (aged 18–40 years) with over 2.9 million people affected worldwide. More than 37,756 Australians live with MS and over 7.6 million Australians know someone or have a loved one with this potentially debilitating disease.

Three times as many women have MS than men. Symptoms vary between people and can come and go; they can include severe pain, walking difficulties, debilitating fatigue, partial blindness and thinking and memory problems. For some, MS is characterised by periods of relapse and remission, while for others it has a progressive pattern of disability. MS robs people of quality of life, primarily driven by the impact of MS on pain, independent living, mental health and relationships.

Acknowledgement: MS Australia acknowledges Aboriginal and Torres Strait Islander peoples as the traditional custodians of the land and sea in which we live and work, we recognise their continuing connection to land, sea and culture and pay our respects to Elders past, present and future.

Suggested citation: MS Australia. (2026). *What We Heard: MS, the NDIS and Lived Experience. MS Community NDIS Survey Report.* www.msaustralia.org.au/ndis/#surveyreport

Contents

Executive summary	5
Key findings	6
Common themes from respondents	6
Systemic issues highlighted by the survey	6
Introduction	7
A better NDIS for people living with MS	7
Overview of the survey	7
What this report covers	8
Chapter 1: Who responded	9
Survey respondents	9
Geographic diversity of survey respondents	11
Chapter 2: Access to the NDIS	13
Challenges in accessing the NDIS	13
NDIS age cut-off for people aged 65+	13
Chapter 3: Experiences with NDIS plans and reviews	14
NDIS plan review timing	14
Understanding what triggered changes to NDIS plans	15
Impact of plan reviews on supports provided	15
Types of supports changed in NDIS plans after plan reviews	16
Chapter 4: Impact of plan changes on people living with MS	18
Significant cuts across core supports	18
Physiotherapy and exercise physiology drastically reduced	18
Psychology and mental health supports removed	19
Lack of consultation and understanding	19
Emotional toll	19
How plan changes affect daily life: practical and social impacts	19
Chapter 5: Living with MS: What the NDIS often misses	20
Plans rolled over without review or consultation	20
Cuts to essential therapies	20
Psychology and mental health supports removed	20
Long delays and bureaucratic barriers	20
Lack of understanding of MS	20
Fear and anxiety around reviews	21
The system creating more barriers	21
Positive experiences with the NDIS	21

Chapter 6: Does the NDIS understand MS?	22
Perceptions of NDIS understanding of MS and neurological conditions	22
“It depends who you get”	22
Partial understanding at best	22
Lack of understanding of MS as progressive	22
No understanding of mental health impact	22
Being asked “When will you be cured?”	23
Assessors making decisions without understanding	23
<hr/>	
Chapter 7: Final reflections from the MS community	24
Why understanding MS is critical	24
Why access to therapy supports is essential	24
Why reducing stress is so important	24
Why specialist knowledge makes a difference	24
Why age equity counts	25
Why individualised support is key	25
Why listening should come first	25
Why this survey is important	25
<hr/>	
Chapter 8: Conclusion and recommendations	26
Current and emerging concerns	26
MS Australia’s recommendations	26
<hr/>	
References	26

Executive summary

In late 2025, MS Australia heard from our [Lived Experience Expert Panel](#) (LEEP), people living with MS and carers who provide advice to inform MS Australia's advocacy, that National Disability Insurance Scheme (NDIS) plans were being changed in ways that reduced or altered essential supports. MS Australia also heard similar concerns through our state and territory [Member Organisations](#), which provide frontline supports and services to people affected by MS. The *MS Australia Community NDIS Survey* was conducted to understand whether these experiences were occurring more widely across the MS community.

This report draws on the survey responses to present what people told us about accessing the NDIS, navigating planning and reviews, and the impacts of plan changes on everyday life. It aims to share lived experience clearly and accessibly so the MS community, service providers, and decision-makers can better understand where the scheme is working and where improvements are needed for people living with MS.

The findings in the report provide a detailed picture of how people living with MS are experiencing the NDIS in practice. They highlight patterns across access, planning and reviews, and the impacts of funding and support changes. Together, these insights help identify where the scheme is working well, where it is falling short, and what needs to change to ensure people with MS can live safely, independently and with dignity.

This survey takes place against a background of extensive NDIS reforms including the introduction of new functional assessments and framework planning and measures to reduce both the growth of the Scheme and the numbers of overall participants. It is crucial to understand the current issues within the NDIS and address these as part of any reform process. This survey provides a starting point for where the NDIS needs improvement and how it can better meet the needs of participants.

Informed by these findings, MS Australia recommends reforms that improve how the NDIS is planned, priced and delivered for people living with MS and other neurological conditions. Key priorities include:

- a flexible, participant-focused and sustainable pricing model that reflects real costs;
- stronger disability awareness and MS-informed capability across the NDIA and government agencies;
- evidence-based planning processes and supports that better respond to progressive and fluctuating needs;
- investment to attract, train and retain a skilled disability workforce; and
- improved housing and living supports to help people with disability maintain independence and choose the living arrangements that best meet their goals.

Key findings

Common themes from respondents

The *MS Australia Community NDIS Survey* received **939 responses**, overwhelmingly from **people living with MS or suspected MS (81%)**. The remaining 19% of respondents were those who do not live with MS themselves and bring equally important perspectives to this survey. This group includes carers (6%) who provide daily support and witness firsthand the challenges the people they care for face navigating the National Disability Insurance Scheme (NDIS). Family members and friends (7%) who offer insight into the broader impact MS has on support networks and relationships. Healthcare professionals, support coordinators, and service providers who selected "Other" contribute valuable systemic perspectives on how the NDIS serves people with MS. Together, these voices help paint a fuller picture of the MS community's experience with the NDIS – not just from those living with the disease, but from those who support, care for, and advocate alongside them. Responses came from across Australia, with strong representation from regional, rural and remote areas.

People with MS are living with a lifelong, complex neurological disease. The survey shows that when the NDIS works well, it can support independence, wellbeing, and participation. When it does not, it can add stress, fear, and harm to people's daily lives.

Common themes across respondents included:

- Access to the NDIS remains difficult for many, with delays, rejections and people being told they were "not disabled enough".
- Plan reviews are often too infrequent, and many people have to push for changes themselves.
- Reviews often lead to cuts, delays or removal of essential supports, particularly therapy and allied health supports, including mental health supports.
- Cuts to plans lead to reduced independence, worsening health, increased stress and greater reliance on carers.
- The NDIS does not understand MS well, especially its progressive, fluctuating and invisible impacts.
- The NDIS age cut-off at 65 was seen as unfair and a major barrier.

The experiences shared through this survey highlight how deeply the NDIS shapes quality of life for people with MS, particularly in the context of a progressive and often fluctuating disease. Taken together, these voices provide clear evidence of how current NDIS policy and practice affects people's real-world experiences.

Systemic issues highlighted by the survey

Survey responses point to ongoing systemic issues within the NDIS, including persistent gaps in understanding neurological conditions such as MS and what people need to live well. Many respondents described plans and supports that do not reflect the complexity, progression, or day-to-day impacts of MS. Many respondents said the NDIS does not adequately understand MS and called for MS-specific training, clearer and faster processes, and more flexible, individualised supports.

These concerns are particularly significant given proposed changes to the NDIS that place greater emphasis on assessing a person's functional capacity rather than their diagnosis. For people with progressive and fluctuating conditions like MS, where functional impact can vary from day-to-day, participants expressed limited confidence that a new assessment system will be implemented fairly and consistently. This lack of confidence is heightened by the fact that current planning and support processes are already widely experienced as difficult to navigate.

Introduction

A better NDIS for people living with MS

Over the past ten years, MS Australia has actively advocated on behalf of people living with MS for improvements to the NDIS. MS Australia's '*A better NDIS for people living with MS*' campaign continues to call for reforms to improve the NDIS for the MS community. It draws on the lived experience of people living with MS and their experience navigating the NDIS.

Overview of the survey

The *MS Australia Community NDIS Survey* was designed to gather detailed feedback and lived experience from people with MS and their carers, as well as people living with other neurological conditions, about recent interactions with the NDIS. Regarding other neurological conditions, 35 respondents reported living with, caring for, or knowing someone with another condition, including FND, MND/ALS, ataxias (e.g., spinocerebellar ataxia), NMO/NMOSD, Charcot-Marie-Tooth Disease, Stiff Person Syndrome, stroke, autism, and other rare conditions. The findings are intended to strengthen MS Australia's advocacy by bringing together real-world experiences and data on how NDIS policy and practice changes affect people with MS, and by highlighting opportunities to improve planning and supports.

The survey was open for six weeks, from 12 February to 29 March 2026, and received strong participation from people living with MS across Australia. Most respondents reported MS or suspected MS (most commonly relapsing remitting MS), and many were receiving NDIS supports at the time of the survey.

The survey included 18 questions with a mix of open-ended and free text questions, aimed to:

- identify respondents' connection to MS or another neurological condition (for example, a person living with MS, a carer, a family member, or a friend)
- capture the type of MS or neurological condition reported
- understand current or previous engagement with the NDIS, including whether the respondent (or the person they support) had an NDIS plan and any attempts to access the scheme
- explore barriers to accessing the NDIS and challenges experienced during the process
- document recent NDIS plan changes, including what prompted the change, the supports affected (for example, physiotherapy, occupational therapy, and equipment), and the impacts of any changes to budgets or hours
- gather feedback on how well the NDIS understands MS and other neurological conditions
- invite suggestions to improve NDIS planning and supports for people living with MS and other neurological conditions
- seek consent to share stories (anonymously or with attribution) to support our advocacy efforts.

Most participants consented to have their feedback shared (either anonymously or with attribution), and their words are included throughout this report.

What this report covers

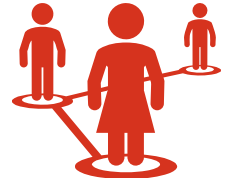
The remainder of this report steps through the key survey findings, supported by respondent comments, and draws out what they mean for improving NDIS processes and supports for people living with progressive and fluctuating neurological conditions such as MS.

The chapters are structured as follows:

- **Chapter 1** outlines the survey purpose, approach, and respondent profile.
- **Chapter 2** explores respondents' access to the NDIS, including barriers and the age cut-off.
- **Chapter 3** examines experiences with NDIS plans and reviews, including what triggers plan changes and which supports are most affected.
- **Chapter 4** describes the impacts of plan changes, including effects on safety, independence, participation, and wellbeing.
- **Chapter 5** draws together broader challenges respondents reported with plans and supports, including delays, communication issues, and gaps in MS-specific understanding.
- **Chapter 6** focuses on whether respondents feel the NDIS understands MS, and the practical consequences of inconsistent knowledge and decision-making.
- **Chapter 7** presents final reflections and additional messages from the MS community.
- **Chapter 8** summarises why these findings matter and sets out conclusions and recommendations.

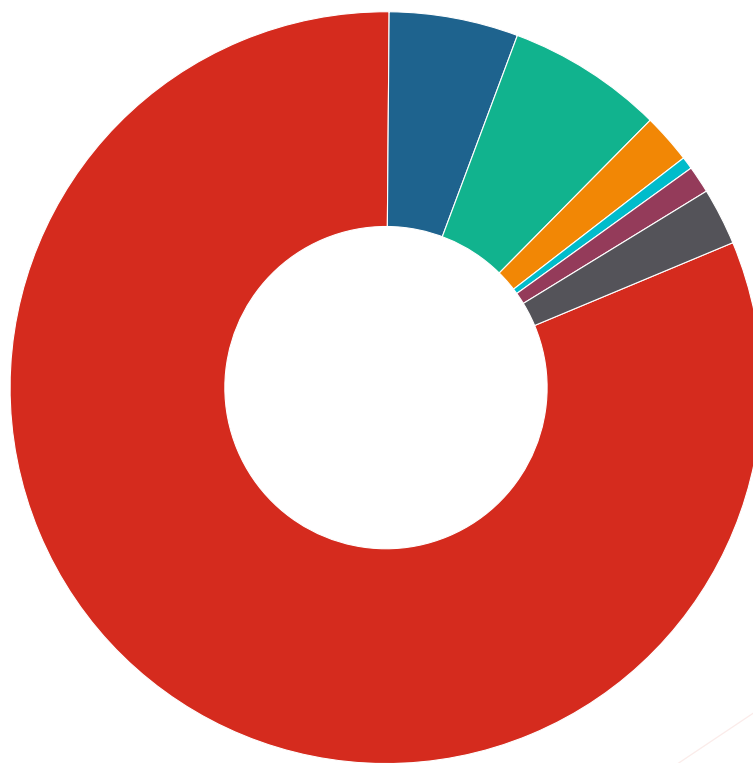
Who responded

Survey respondents



Respondents were asked to describe their connection to MS or another neurological condition. A total of 939 people participated in the survey, of which 937 completed this question. Most respondents reported living with MS or suspected MS (81%). Other respondents reported being a family member or friend of someone with MS (6.72%) or a carer for someone with MS (5.55%). Smaller proportions reported living with another neurological condition (2.13%), selected “Other” (2.45%), were carers for someone with another neurological condition (0.53%), or had a family member or friend with another neurological condition (1.17%).

What is your connection to MS or to another neurological condition?

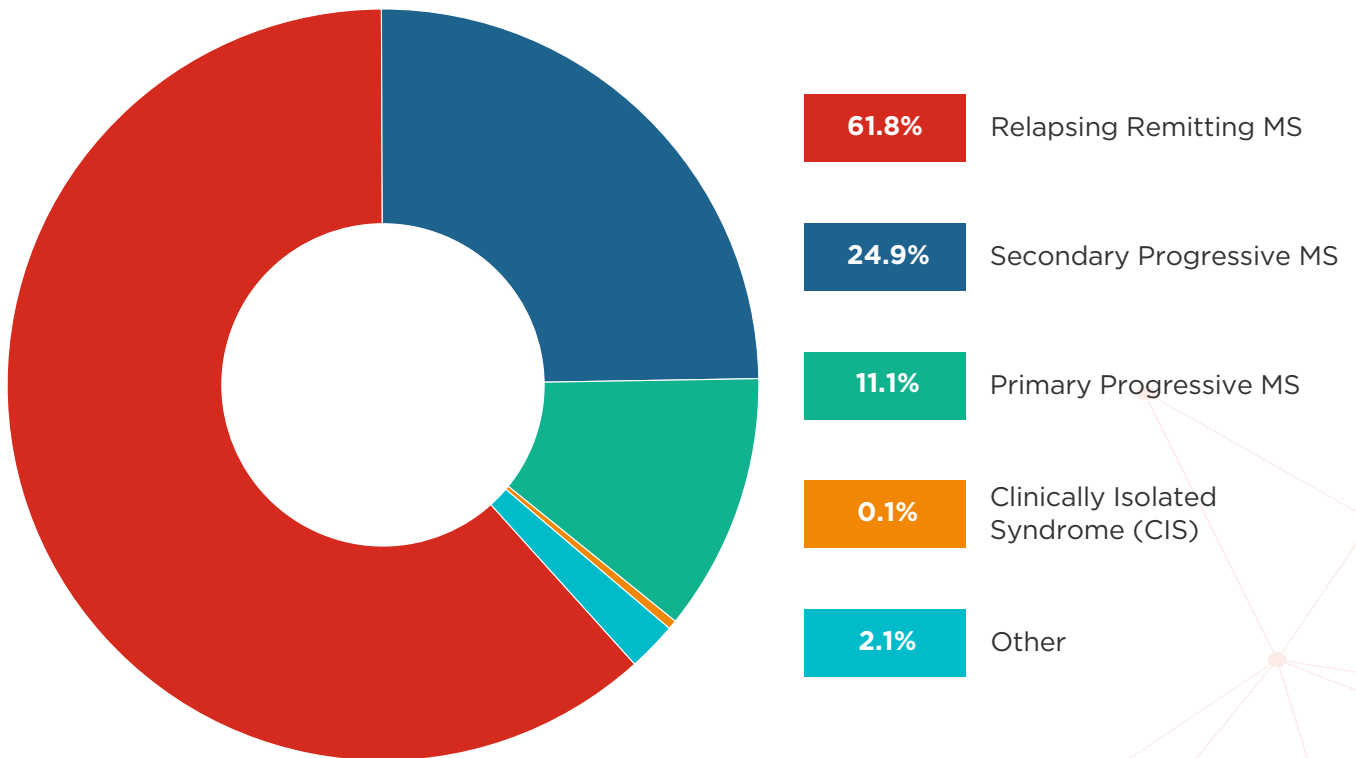


- 81.4%** I have MS (or suspected MS, e.g. clinically isolated syndrome)
- 5.5%** I have a family member or friend with MS
- 0.5%** I am a carer for someone with another neurological condition
- 6.7%** I have another neurological condition
- 1.2%** I have a family member or friend with another neurological condition
- 2.1%** I am a carer for someone with MS
- 2.5%** Other

Respondents who reported MS or suspected MS were also asked to indicate the type of MS. A total of 756 respondents answered this question.

- Relapsing Remitting MS: 62%
- Secondary Progressive MS: 25%
- Primary Progressive MS: 11%
- Clinically Isolated Syndrome (CIS): 0.13%
- Other: 2.12%

What type of MS do you have?



Relapsing remitting MS was the most commonly reported MS type, with people also reporting progressive forms of MS (secondary progressive MS and primary progressive MS). This means the survey reflects experiences of both fluctuating and progressive forms of MS.

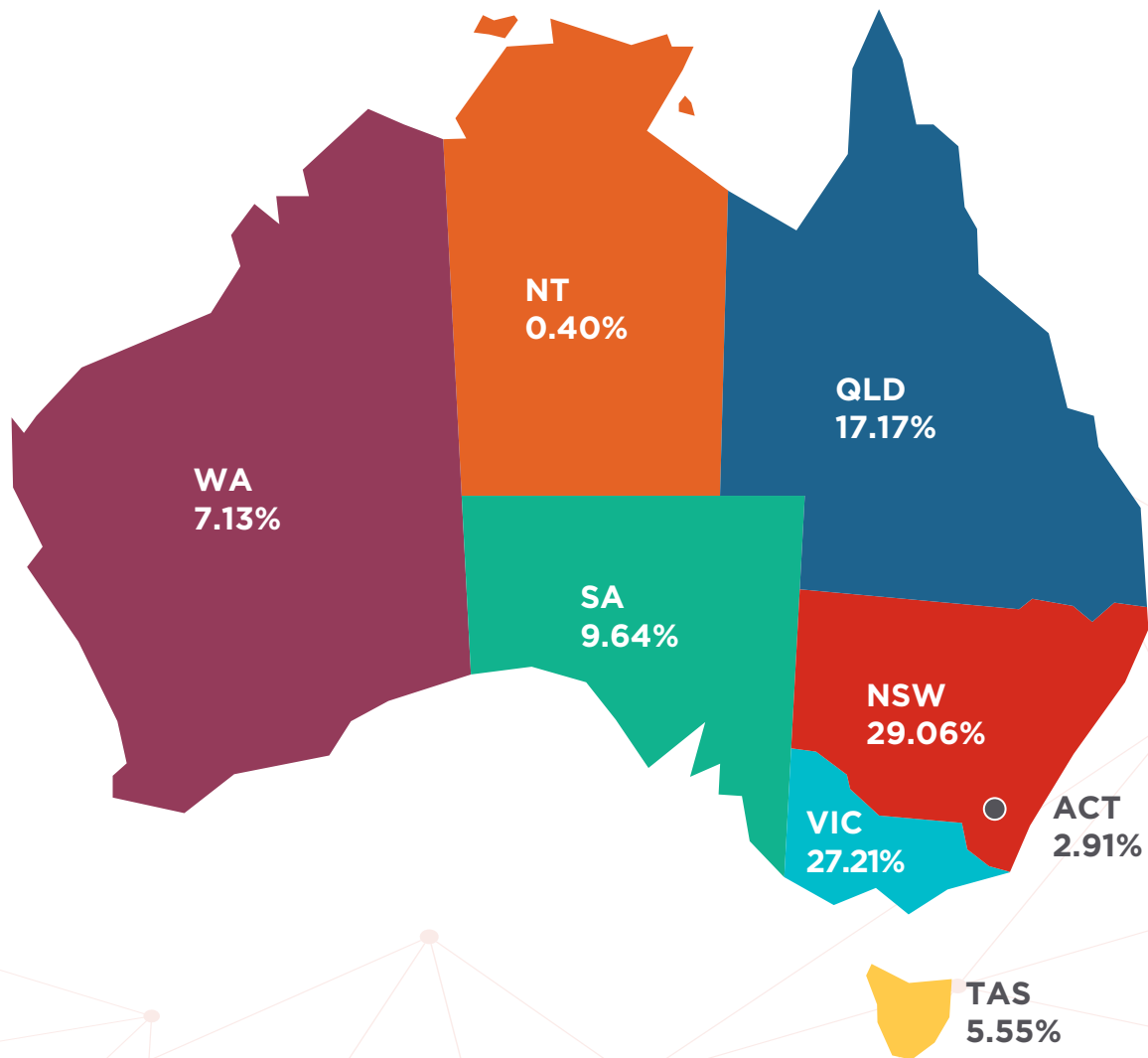
Overall, these results indicate that the survey primarily captured first-hand perspectives from people living with MS, alongside views from families, carers, and others who support people affected by MS.

Geographic diversity of survey respondents

The survey collected postcode data from 757 respondents across Australia, providing valuable insights into the geographic spread of people living with MS and their experiences with the NDIS. Respondents came from 531 unique postcodes, demonstrating remarkable geographic diversity and ensuring the survey captures experiences from communities right across the country.

Responses were received from all eight Australian states and territories.

Responses by State/Territory



The distribution broadly reflects Australia's population, with the majority of responses coming from New South Wales and Victoria, followed by Queensland and South Australia. Importantly, the survey also captured voices from smaller states and territories, including Tasmania (42 responses) and the Northern Territory (3 responses), ensuring that the unique challenges faced by people with MS in these regions are represented.

A key strength of this survey is the strong representation from regional, rural, and remote Australia. Of the 757 respondents:

- 49% (368 respondents) were from metropolitan areas (capital cities and surrounding suburbs)
- 51% (389 respondents) were from regional, rural, or remote areas

This near-equal split between metropolitan and regional respondents is significant. People living with MS in regional areas often face additional barriers to accessing services – including fewer specialist providers, longer travel distances, and limited availability of support workers. The strong regional representation ensures that these unique challenges are captured in the survey findings.

The wide geographic spread of respondents – spanning 531 unique postcodes across every state and territory, with strong representation from both metropolitan and regional areas – strengthens the validity of this survey's findings. It demonstrates that the issues identified throughout this report – including lack of understanding of MS, cuts to essential therapies, fear around reviews, and the over-65 barrier – are not isolated to particular regions but are experienced by people with MS right across Australia.

For people in regional and remote areas, these systemic issues may be compounded by limited local service options, making it even more critical that the NDIS works effectively for them.

Access to the NDIS



To understand respondents' access to the NDIS, the survey asked whether participants were currently on an NDIS plan or cared for someone who is on an NDIS plan. These responses provide important context for interpreting the findings below, including respondents' level of direct experience with the NDIS and the barriers some reported when seeking support.

Most respondents (68%) are currently on an NDIS plan, with a further 8% caring for someone who is on a plan. A smaller group (7%) reported they are currently trying, or have tried previously, to access the NDIS for themselves, while around 1% are trying to access it for someone they care for. Around 12% of respondents are not on the NDIS and have not attempted to access it.

Challenges in accessing the NDIS

While many respondents are currently on an NDIS plan, 66 respondents described difficulty accessing the scheme. Common experiences included:

- Were told they were “not disabled enough”
- Were excluded because they were over 65
- Were unsure how to apply or navigate the system
- Gave up after repeated rejections or long delays

For many, the application process was described as confusing, exhausting, and emotionally draining. Respondents who selected “Other” (3%) described a range of experiences, including being rejected, struggling to obtain required information and evidence, or deciding the process was too complex and stopping their application.

NDIS age cut-off for people aged 65+

Several respondents reported being over 65 and therefore ineligible for the NDIS despite having significant support needs. They expressed frustration at being excluded from the scheme due to age and described relying instead on aged care services that they feel are inadequate for their needs. This was often linked to the age cut-off at 65, including respondents who were diagnosed before the NDIS existed, or who were unaware of the scheme when they were eligible and now cannot access support due to their age. Some described the situation as “age discrimination”, noting that people with the same condition and level of need can receive very different supports based solely on date of birth.

Additional respondents emphasised that the aged care system is not designed for people with progressive neurological conditions. This group also included healthcare professionals and support coordinators describing barriers they observe when supporting people to access the NDIS.

“I was over 65 when the NDIS came in. As a result, I have been seriously disadvantaged compared to other people only a few years younger than me.”

SURVEY RESPONDENT

Overall, these responses indicate that most respondents currently have access to the NDIS through an active plan, while a smaller group reported difficulties accessing the scheme, including eligibility restrictions, system complexity, and limited pathways for people aged 65 and over.



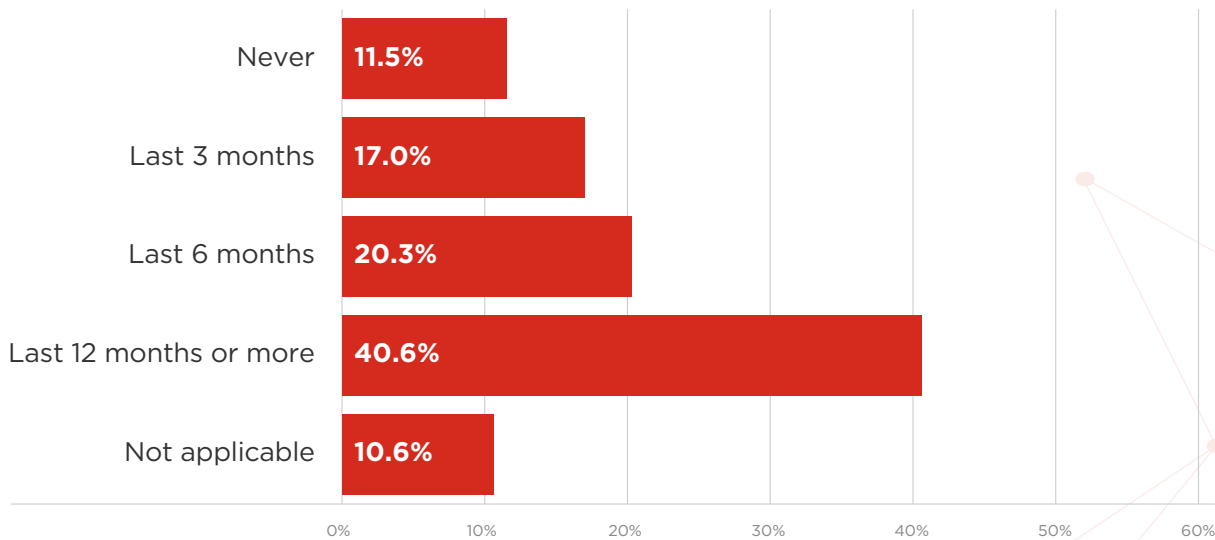
Experiences with NDIS plans and reviews

NDIS plan review timing

This section examines how recently respondents' NDIS plans were reviewed and changed. A total of 764 people responded to this question, primarily with their own NDIS plans (68.23% in Question 4), with additional responses from carers of NDIS participants.

The survey results suggest that many NDIS participants are not receiving frequent plan reviews. The largest group, over 40% of respondents (310 people), reported that their plan was last reviewed 12 months ago or more. A further 20% (155 people) reported their plan was reviewed in the last six months, and 17% (130 people) in the last three months. Nearly 12% of respondents (88 people) reported their plan has never been reviewed, while around 11% (81 people) indicated the question was not applicable to them.

When was the NDIS plan last reviewed and changed?



Considered alongside earlier findings about barriers to accessing the NDIS – including being told people were “not disabled enough”, limited understanding of MS symptoms, and an application process described as exhausting – these results raise concerns about the responsiveness of supports for people already on the scheme. For a progressive disease such as MS, where support needs may change significantly over time, infrequent plan reviews may leave participants reliant on plans that no longer reflect their current circumstances or adequately meet their support needs, potentially resulting in unmet or delayed care.

The findings below provide further context on how respondents experienced plan reviews and changes in practice, including the types of adjustments made and how these processes affected participants.

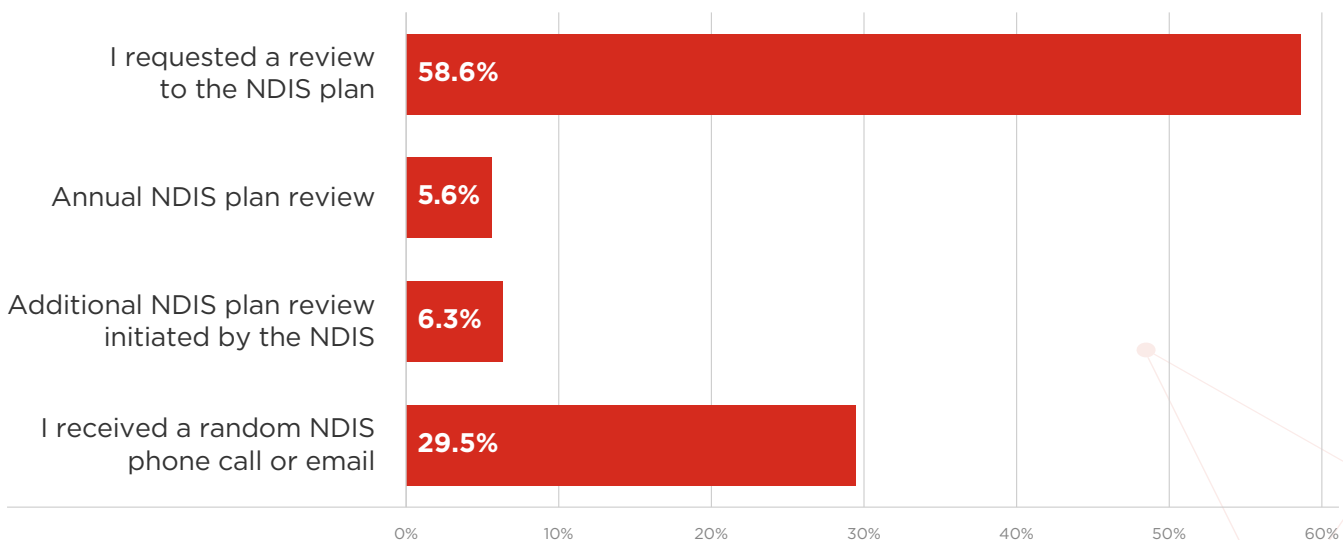
Among respondents already on the NDIS, participants described a range of experiences following plan reviews and changes, including impacts on funding, access to supports, and their sense of security within the scheme.

Understanding what triggered changes to NDIS plans

For those respondents who have experienced changes to their NDIS plan, the next question explored what prompted those changes. Of the 700 respondents currently on the NDIS (either themselves or caring for someone on a plan), 570 people answered this question about what triggered their most recent plan change.

The results show that the annual NDIS plan review is by far the most common trigger for plan changes, with nearly 59% of respondents (334 people) reporting this as the reason their plan was reviewed. This suggests that for most participants, changes to their supports only occur through the standard yearly review cycle rather than in response to their changing needs throughout the year.

What triggered the change to your NDIS plan?



Notably, almost 30% of respondents (168 people) had to initiate a review themselves by requesting one from the NDIS. This indicates that a substantial proportion of people with MS are identifying that their current plan no longer meets their needs and are actively advocating for changes, rather than waiting for the scheduled annual review.

In contrast, NDIS-initiated contact was far less common. Only 6% (32 people) reported that an additional review was initiated by the NDIS itself, and a similar proportion (6%, or 36 people) received a random phone call or email from the NDIS that led to changes.

These findings suggest that people with MS largely experience plan changes through two main pathways: (1) the routine annual cycle, or (2) through their own advocacy. The relatively low rate of proactive NDIS-initiated reviews raises questions about whether the system adequately monitors and responds to the changing needs of participants with progressive conditions like MS, where support requirements can shift significantly between annual reviews.

Impact of plan reviews on supports provided

For people living with MS who are on the NDIS, plan reviews are a critical opportunity to have their supports adjusted as their disease and needs evolve. This question asked respondents whether their most recent plan review resulted in significant changes to the supports they receive.

Of the 537 respondents who answered this question, the majority (58%) reported that their plan review did not result in significant changes to their supports. Only 42% (223 people) said their review led to meaningful changes in their plan.

These results are concerning when considered alongside earlier findings in this survey. We know that over 40% of respondents haven't had a plan review in 12 months or more, and that nearly 30% of participants had to initiate their own review because their needs had changed. Yet even when reviews do occur, most people are not seeing significant changes to their supports as a result.

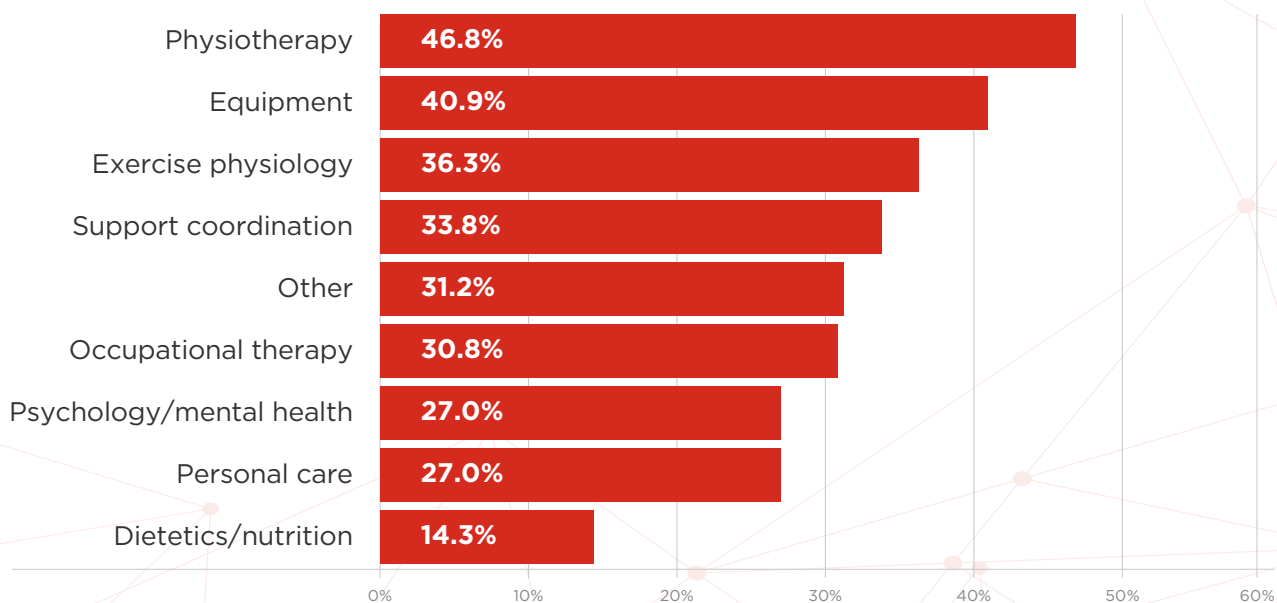
For people with a progressive disease like MS, where symptoms can fluctuate and support needs can increase over time, this suggests the review process may not be adequately capturing or responding to changing circumstances. When combined with the barriers respondents reported in accessing the NDIS in the first place, and the lack of understanding of MS among assessors, these findings paint a picture of a system that many people with MS find unresponsive to their evolving needs.

Types of supports changed in NDIS plans after plan reviews

For respondents who have experienced changes to their NDIS plan, this question explored which specific supports were affected. Of the 237 people who answered, many experienced significant changes to their plan after reviews – and not always in a positive direction.

The most commonly changed supports were therapy and health services. Physiotherapy topped the list, with nearly half of respondents (47%) reporting changes to this support. This was followed by equipment (41%), exercise physiology (36%), and support coordination (34%). Occupational therapy changes affected 31% of respondents, while personal care and psychology/mental health supports were each changed for 27% of people. Dietetics and nutrition services were the least commonly changed among the listed options, affecting 14% of respondents.

What support(s) have been changed?



A substantial 31% selected “Other” to describe additional supports that had been changed. These responses reveal a wide range of supports being affected beyond the standard categories, including:

- Daily living supports – cleaning, meal preparation, gardening, and house maintenance
- Transport – a frequently mentioned change
- Specialist therapies – podiatry, speech therapy, massage, acupuncture, myotherapy, and osteopathy
- Assistive technology – mobility aids, home modifications, and equipment maintenance
- Respite and community access – impacting social participation and carer support

Concerningly, supports such as physiotherapy, exercise physiology, psychology, and equipment were often reduced or removed rather than increased.

Respondents described having funding cut, hours reduced, or specific therapies taken away – often without consultation. One person shared that their “Daily Activities funding was cut by \$6,000 per year,” while another noted their “Assistive Technology budget radically reduced.” Several reported losing access to therapies they found beneficial, such as massage, acupuncture, and meal preparation support.

Some respondents reported that their plans were rolled over without consultation, even when their needs had changed significantly. Others described sudden cuts, long delays, or having to repeatedly re-prove their disability – a particularly distressing experience for people living with a permanent, progressive disease like MS.

A strong theme throughout the responses was fear and anxiety around reviews. Many people expressed worry that asking for help or requesting a review might actually result in losing what little support they already had. This creates a troubling situation where participants may avoid advocating for their changing needs out of fear of losing existing supports – the very opposite of what a person-centred system should encourage.

Impact of plan changes on people living with MS



Respondents who experienced changes to their NDIS plan were asked to describe how their supports were impacted. Of the 222 people who answered, the responses paint a deeply concerning picture of a system that is often reducing or removing vital supports for people living with a progressive disease.

While the majority of responses described negative impacts, some respondents did report positive changes to their supports – including increased funding for equipment, additional carer hours, or approval for home modifications and assistive technology. However, these positive experiences were significantly outweighed by those describing cuts, reductions, and the removal of essential supports.

Significant cuts across core supports

The overwhelming theme in responses was reduction or removal of supports, rather than increases to meet changing needs. Respondents described having their budgets slashed – in some cases by half or even two-thirds – often without consultation or adequate explanation. Key therapies that help people manage their MS, including physiotherapy, exercise physiology, psychology, and occupational therapy, were frequently cut or removed entirely.

One respondent described the devastating impact “I was doing really well with my physiotherapy progressing... I was building up strength and confidence and then... no funding for that anymore. Since, my strength has relapsed, and I feel a lot worse off than before. I feel the rug has been pulled from under me, I’m gutted.”

“My plan was cut down by 2/3. We had actually asked for a review 11 months prior due to change in circumstance and need for additional funding...they ended up rolling the Plan over with 2/3 less than what I’ve had the year before.”

SURVEY RESPONDENT

Physiotherapy and exercise physiology drastically reduced

Many respondents reported their physiotherapy being cut from multiple sessions per week to once a fortnight or even once a month – despite clinical evidence supporting more frequent treatment.

Another was told the cuts were “in line with best practice” when their exercise physiology was reduced from twice a week to once a fortnight – despite academic research recommending 2-4 times per week for MS.

“Physio was cut from 40hrs per year to 20hrs per year. This is the one service that has had the biggest impact on my health and wellbeing. I was still able to walk short distances at home with my 4WW [four wheel walker] but now can hardly stand to transfer from my wheelchair.”

SURVEY RESPONDENT

Psychology and mental health supports removed

A disturbing number of respondents reported having psychology completely removed from their plans. They were told that mental health support is a “mainstream” service or that “people with MS do not need psychological assistance” – despite depression and anxiety being common symptoms of living with a progressive neurological disease.¹

Lack of consultation and understanding

Many respondents reported that changes were made without consultation, with plans rolled over or cut without any direct conversation. One person received a voicemail advising their new 5-year plan was active – “no one even spoke directly to myself.” Others described assessors who “did not have time to read my reports” or ignored clinical evidence and occupational therapy recommendations entirely.

There was a recurring theme of NDIS assessors not understanding MS – particularly the link between MS and symptoms like incontinence, depression, and fatigue.² One respondent was told “there was no link with MS and continence issues” and another that “depression isn’t a symptom of MS.”

Emotional toll

Beyond the practical impacts, respondents described the significant emotional toll of these changes. Words like “stressful,” “frustrating,” “exhausting,” and “gutted,” appeared throughout responses, with many expressing distress and anxiety about the process. The uncertainty and fear around reviews – combined with the exhausting process of appealing decisions – left many feeling abandoned by a system that was supposed to support them.

How plan changes affect daily life: practical and social impacts

While the examples above show where funding reductions and removals occur, respondents also described how these changes flow through to daytoday life. People reported having to scale back routines that help them manage symptoms, rely more heavily on family and friends, and make difficult tradeoffs between supports (for example, choosing between therapy and help at home) when budgets or hours were reduced.

Across responses, impacts were commonly framed in terms of:

- Reduced independence in personal and domestic activities.
- Increased falls risk and preventable deterioration when maintenance supports were cut.
- Disrupted ability to work, study, or volunteer.
- Reduced community access and social participation.
- Increased pressure on informal carers.
- Administrative and emotional impacts, including time spent seeking reviews or appeals, uncertainty about future supports, and reluctance to request changes for fear of losing essential services.

Together, these indicate that reductions in supports can have wide-ranging effects on safety, participation, and wellbeing. These findings highlight a system that many people with MS experience as unresponsive to their needs, with vital therapies being cut despite clinical evidence, and decisions being made without adequate consultation or understanding of how MS impacts daily life.

“I had psychology completely removed from my NDIS plan altogether, because psychology is apparently a medical need that can be met mainstream and has nothing to do with my disability.”

“NDIS have stopped supporting psychology/ mental health. This has placed my daughter in serious danger of decline.”

SURVEY RESPONDENTS

“They have taken everything away from me... I can’t even cook or use a knife and fork. People with ADHD get more hours and money than us with MS.”

SURVEY RESPONDENT

Living with MS: What the NDIS often misses



The previous section focused on the experiences of respondents who had recently gone through an NDIS plan review. By contrast, this section draws on responses from the broader survey cohort, inviting participants to describe any issues or challenges they, or the person they care for, have experienced with their NDIS plan and the supports included in it. The open-ended question gave people space to describe systemic problems, communication barriers, and frustrations that extend beyond any single review event. A total of 527 people responded, providing detailed accounts of their experiences navigating the NDIS system. The responses reveal a wide range of challenges that paint a concerning picture of how the NDIS is working, or failing to work, for people with MS.

Plans rolled over without review or consultation

A recurring theme respondents shared was how their plans have been automatically rolled over year after year without any meaningful review or communication. Many respondents reported not having spoken to anyone from the NDIS for 12 months or more, with their plans simply extended without consideration of their changing needs. As one person shared: “My plan was due for renewal on December 4th, 2025, and it was just rolled over with the same funding.” While some appreciated avoiding the stress of reviews, others found their needs had changed significantly, particularly with a progressive disease like MS, and they were left without the supports they now required.

Cuts to essential therapies

Respondents frequently reported having vital therapies cut or reduced, often without consultation or explanation. Physiotherapy, exercise physiology, psychology, and dietetics were commonly affected. One respondent noted that their physiotherapy support was cut in half, from 40 hours a year to 20 hours per year, sharing “This is the one service that has had the biggest impact on my health and wellbeing. I was still able to walk short distances at home with my 4WW but now can hardly stand to transfer from my wheelchair. Only seeing my physio fortnightly for ½ hour just isn’t enough time to have an appropriate amount of treatment. I’ve definitely seen a huge decline in my functional mobility.”

Psychology and mental health supports removed

Many respondents reported having psychology removed from their plans entirely, being told it is a “mainstream” service or that “MS does not require psychological support.” This ignores the significant mental health impact of living with a progressive neurological disease. One person shared, “Psychology was cut because this could be provided through a health care plan however I cannot afford the gap of \$100 for each session.”

Long delays and bureaucratic barriers

The time taken to get equipment, home modifications, or plan changes approved was a major frustration. Respondents described waiting years for bathroom modifications, wheelchairs, or other essential equipment – often while their condition deteriorated. One person reported, “It took roughly 2 years to get the AC approved.” Another described waiting 15 months for a wheelchair replacement after their main chair failed.

Lack of understanding of MS

A strong theme throughout responses was the feeling that NDIS staff and assessors do not understand MS – particularly its progressive nature, fluctuating symptoms, and invisible impacts like fatigue, cognitive difficulties, and pain. One respondent shared they were told they would “get better” because they have relapsing-remitting MS.

“I was told there was no link with MS and continence issues... Apparently depression isn’t a symptom of MS.”

SURVEY RESPONDENT

Fear and anxiety around reviews

Many respondents expressed deep fear about upcoming reviews, worried that requesting changes or additional support might result in having their existing funding cut. As one person put it, “No Assistive Technology. Terrified of asking for a review and losing any of my funding.” Another shared, “I do not have enough money for CB [capacity building]. I will need to put in for a review since my plan has been rolled over three times now. Fear is holding me back.”

“I have an NDIS package but trying to use it has become so stressful and difficult that I avoid using NDIS as much I can...The last three years on the NDIS sped up my social isolation and disability at a faster rate than any relapse.”

SURVEY RESPONDENT

The system creating more barriers

Perhaps most concerning were responses describing how the NDIS itself has become a barrier to their wellbeing.

Positive experiences with the NDIS

While the majority of responses highlighted challenges, some respondents reported positive experiences – praising supportive coordinators, adequate funding, and the life-changing difference the NDIS has made for them. These positive stories, however, were significantly outweighed by accounts of frustration, fear, and feeling unsupported by a system that many feel does not understand or adequately respond to the needs of people living with MS.

Overall, these responses point to systemic issues in how the NDIS communicates and engages with participants, particularly when plans are rolled over or changed without meaningful review or consultation. They highlight the consequences of inconsistent understanding of MS (including fluctuating, progressive and “invisible” symptoms), and a decision-making approach that can reduce or remove essential therapies and mental health supports without clearly explaining how needs will be met elsewhere. Long delays for equipment and home modifications, combined with complex processes and administrative burden, further undermine timely, preventative support.

Taken together, the experiences in this section suggest the NDIS is not consistently responsive to the changing needs of people living with MS – while also showing that when participants do encounter knowledgeable, respectful staff and coordinators, the scheme can still be life-changing even in the context of tighter plans.

Does the NDIS understand MS?



Perceptions of NDIS understanding of MS and neurological conditions

To explore perceptions of the NDIS's understanding of MS and other neurological conditions, respondents were asked whether they felt the scheme had a good understanding of these conditions. Responses indicated low confidence overall. Among the 816 people who answered, nearly two-thirds (496 people) said the NDIS does not understand MS, while fewer than one in five (154 people) felt it does. A further 20% (166 people) selected "Other," reflecting mixed or complex views.

Most respondents who provided additional detail said that understanding often depended on "who you happen to get on the day." Some described planners or staff who listened and demonstrated a genuine understanding of MS, while others reported very different experiences. People frequently described having to explain MS from scratch, feeling that their medical or clinical evidence was ignored, and being assessed by people with little or no understanding of neurological conditions. This inconsistency meant experiences varied widely across the scheme and left many respondents feeling unheard, judged, or dismissed.

The open-ended responses provide important context to these results. Together, they highlight recurring patterns in how people experience NDIS assessments and decision-making and help explain why confidence in the scheme's understanding of MS is so low. The key themes outlined below reflect what respondents told us about where understanding breaks down in practice, and how this affects their experience of the NDIS.

"It depends who you get"

The most common theme was that understanding varies dramatically depending on which NDIS staff member, planner, or local area coordinator you are assigned. As one respondent put it, "Depends which planner you are allocated. Some have an understanding; others have no idea." Another shared, "Yes and No - it depends on who you talk to on the day that you talk to someone." This inconsistency means that people's experiences of the NDIS can be vastly different based purely on luck.

Partial understanding at best

Many respondents indicated the NDIS has some understanding, but significant gaps remain. Common responses included "somewhat," "partially," "to an extent," and "not totally." One person explained, "I think they understand functional impacts, but not the fact that it's progressive in nature and the functional impacts can fluctuate so much between person to person and day-to-day."

"The NDIS doesn't seem to understand that MS is a progressive condition as well as being incurable. They seem to think that I will require fewer support as time goes on rather than more."

SURVEY RESPONDENT

Lack of understanding of MS as progressive

A recurring concern was that the NDIS doesn't grasp that MS is a progressive, incurable disease. One respondent shared, "They think he will get better, but his primary progressive MS means he keeps getting worse. His physio is critical to keep him a bit strong and mobile, but they cut the hours." Another pointed out that their plan actually states "supports to decrease over time" - a deeply concerning approach for a degenerative disease.

No understanding of mental health impact

Several respondents highlighted that the NDIS fails to understand the mental health impacts of living with MS. One person stated, "NDIS clearly does not understand the devastating impact of MS and other conditions on the mental health of the patient and carers." Another simply noted, "It doesn't understand the importance of mental health."

Being asked “When will you be cured?”

Some respondents shared experiences of NDIS staff asking inappropriate questions that reveal a fundamental lack of understanding.

“Staff asked ‘when I will be cured?’ I gave an example, ‘Do you know anyone with Down syndrome?’ They answered ‘yes,’ so I asked, ‘when they were going to be cured?’ Of course, the person was offended. I said, ‘I was offended that they expected I would be cured and had a date for this.’”

SURVEY RESPONDENT

Assessors making decisions without understanding

A concerning theme was that people making funding decisions often don’t understand the conditions they’re assessing.

These findings highlight a critical gap in NDIS knowledge and training around MS. When over 60% of respondents say the NDIS doesn’t understand their condition – and many others say it depends entirely on which staff member they encounter – it points to a systemic issue that impacts the quality of support people with MS receive.

“Sometimes it seems that the people making decisions about people’s care of their neurological conditions do not actually understand the conditions themselves. I feel like this is a downfall of the NDIS system, as people making the decisions should understand what is going on.”

SURVEY RESPONDENT

Final reflections from the MS community



This final open-ended question gave respondents the opportunity to share anything else about the NDIS that they wanted MS Australia to know. The fact that nearly half of all survey respondents (426 people) took the time to provide additional comments speaks to the depth of feeling within the MS community about their experiences with the NDIS. These are not just statistics; they are the voices of people whose daily lives are shaped by a scheme that many feel does not understand their chronic progressive condition.

Why understanding MS is critical

Respondents repeatedly emphasised that NDIS staff and assessors do not understand how MS works. One person shared, “I have been told by people in the NDIS that MS is not real and is made up.” When assessors don’t understand the condition they’re assessing, people with MS are left fighting to justify supports that are essential to their daily lives.

“MS symptoms can fluctuate significantly, and many impacts are not visible. Fatigue, cognitive load, sensory strain and communication effort can make everyday activities far more demanding than they appear during a short phone call or meeting.”

SURVEY RESPONDENT

Why access to therapy supports is essential

Physiotherapy and exercise physiology were highlighted as critical supports that are being cut despite evidence of their effectiveness. As one respondent stated: “Physiotherapy is a life-saving support for people with MS and not just an optional extra.” When these therapies are reduced or removed, people lose the tools they need to maintain function and slow the progression of their condition.

“Most studies show daily physical activity is required to maintain function and decrease symptoms of MS. Many people with MS can’t do this themselves and require professionals and/or home exercise equipment to assist.”

SURVEY RESPONDENT

Why reducing stress is so important

The emotional toll of navigating the NDIS emerged as a powerful theme. One person described, “Being treated as a number with an initial judgement of being a list of a fake does serious damage psychologically. It brought me to my lowest point since my diagnosis.” Another shared, “You live in quiet fear of MS sneaking up on you and disabling you more. It’s not too different than the fear of NDIS changing in a negative way and you lose your support network.” For people with MS, stress is a known trigger for symptoms³ - meaning the system designed to support them may actually be contributing to their decline.

Why specialist knowledge makes a difference

Many respondents called for dedicated MS or neurological teams within the NDIS. One suggested, “NDIS applications for MS patients should only be assessed by Neuroimmunology specialist led Teams who can make educated decisions.” Another asked, “Is MS the most common neurological disease in Australia? Why can’t they have a department that can at least understand our terminology?” The current approach - where assessors may have no knowledge of MS - leads to decisions that don’t reflect the reality of living with the disease.

Why age equity counts

The over-65 barrier continues to affect many people with MS. This arbitrary cut-off means that people with the same condition and same needs receive vastly different levels of support based solely on their age.

Why individualised support is key

Respondents repeatedly emphasised that MS affects everyone differently. As one person stated, “The NDIS should be tailored to each individual who has been allowed access, this requires more flexibility and an understanding that no two people with the same disease will experience the same symptoms or difficulties.” A one-size-fits-all approach fails to meet the diverse and changing needs of people living with MS.

Why listening should come first

Perhaps the most consistent message was the need for the NDIS to listen to participants and their health professionals.

Why this survey is important

The 426 responses to this final question, combined with the hundreds of detailed comments throughout this survey, demonstrate the urgent need for meaningful change in how the NDIS serves people with MS. These are not isolated complaints; they are consistent themes that paint a picture of a system that many people experience as inaccessible, inflexible, and uninformed.

But there is also hope in these responses. When the NDIS works well – when participants have understanding planners, knowledgeable assessors, and adequate funding – it can be transformative. As one respondent shared “I’m so grateful for the NDIS, despite its difficulties. It really has been life changing and allows me to remain independent.”

The challenge now is to make these positive experiences the norm rather than the exception. The voices in this survey offer a roadmap for how to get there by training staff to understand MS, providing individualised and flexible supports, prioritising prevention and maintenance, and above all by listening to the people the system is designed to serve.

“I was over 65 years old when the NDIS started and have incurred considerable expense (\$75,000) on disability equipment which I should have been able to claim and would have been able to claim if I had been slightly younger!”

SURVEY RESPONDENT

“I guess I would like to say that nobody asks to have MS, and certainly no one wants to have Progressive MS. Rather than the NDIS helping us to live our everyday lives safely and independently, it feels to me as though we are having to fight for even the most basic of things, navigate a system that defies logic, and deal with employees who have limited knowledge about MS or disability.”

SURVEY RESPONDENT

Conclusion and recommendations



Current and emerging concerns

Currently, the NDIS often does not adequately recognise the complexity of MS and other neurological conditions. As a result, plans and supports may not match real-world needs or adapt effectively as those needs change over time.

Many respondents indicated that because the system is not working well now, they have less faith that it will work better under a new model without clear safeguards and MS-informed practice. Trust in the system is closely linked to people's willingness to engage, seek reviews, and advocate for their needs.

Moving forward with the proposed shift to a new functional assessment approach may increase uncertainty for people with fluctuating or progressive disability. Respondents raised concerns that such changes could amplify existing communication barriers and challenges in navigating the system.

Any reforms to the NDIS must be implemented using genuine co-design that include the voices of people living with disability, carers and families and disability representative organisations.

MS Australia's recommendations

MS Australia will continue to advocate for an improved NDIS through our '[A better NDIS for people living with MS](#)' campaign and our ongoing advocacy work including our [policy submissions](#). Our recommendations to improve the NDIS focus on improving the NDIA and the broader disability workforce, making Scheme more sustainable and ensuring that it meets the needs of people living with disability:

- A flexible, participant-focused and sustainable pricing model for the NDIS that reflects real costs and encourages innovation and quality service delivery.
- A sufficiently trained and skilled NDIA workforce and improved disability awareness and understanding across all government agencies
- Improved NDIS planning and supports that are evidence-based and focused on the needs of participants, including improved understanding of the needs of people living with MS.
- Increased support to attract, train, upskill and maintain a high-quality disability workforce to meet the needs of people living with disability.
- Improved housing and living supports so that people with disability can maintain their independence and choose the living arrangement that best meets their needs and long-term and short-term goals.

References

1 MS Australia (2025) *Research and Advocacy Priorities Survey Report 2025*. Retrieved from www.msaustralia.org.au/wp-content/uploads/priorities-survey-2025-report-final-1.pdf.

2 Ibid.

3 MS Australia (2025) *Living well with MS: Your guide to adapting your lifestyle*. Retrieved from https://www.msaustralia.org.au/wp-content/uploads/mlf-pwms_master.pdf



AUSTRALIA

RESEARCH
ADVOCACY
CURE

MULTIPLE SCLEROSIS AUSTRALIA
Suite 3.01, 18 Flour Mill Way, Summer Hill NSW 2130
1300 010 158
info@msaustralia.org.au
www.msaustralia.org.au