PRE-BUDGET SUBMISSION 2026-27

JANUARY 2026

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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 2.8 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 can reduce quality of life, primarily driven by the impact of MS on pain, independent living, mental health and relationships.

Cover Art: Cover art by Circular Blooms (@circularblooms), an art project by Deanna, a person living with MS and a member of MS Australia's Lived Experience Expert Panel. Deanna creates digital art using MRI scans to challenge misconceptions about MS.

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 and present

EXECUTIVE SUMMARY

MS Australia is pleased to lodge this pre-budget submission to the Australian Government for the 2026-27 Budget.

Increasing number of Australia's living with MS

This pre-budget submission and its key funding asks are framed against a backdrop of an increasing rise in MS prevalence. Research released by MS Australia in December 2025[1] revealed that there has been a significant increase in the number of people living with MS in Australia over the last three years. There were 37,756 people living with MS in Australia in 2024, an increase of 4,421 people since 2021 (from 33,335 people). Since the first MS prevalence report in 2010, the number of Australians living with MS has risen by 77.4%, while prevalence has risen 45.5%, now at 139.2 per 100,000 Australians (from 95.6 per 100,000 in 2010).

Economic Impact of MS

Total costs for all people with MS in Australia increased from **$2.449 billion in 2021 to $3.004 billion in 2024**.

An increase in the number of Australians living with MS corresponds with an increase in the total costs for people with MS in Australia. Analysis of MS Australia's Australian MS Longitudinal Study (AMSLS)[2] shows that the mean annual cost of a person living with MS is $79,581, which includes direct costs borne by the person living with MS and their carer, as well as indirect costs from lost wages, informal care, and early retirement.

People living with MS now face health-related costs that are approximately seven times higher than the national average. For those with 'severe disability', the costs are more than triple at $135,780 compared with those living with no disability ($32,829).

Out-of-pocket costs for healthcare for people with MS are high, from specialist fees to medicines, imaging and allied health appointments. Additionally, there are costs for travel to appointments, parking, time away from paid work, childcare, access to exercise and dietary costs.

MS Australia's Four Key Funding Asks

MS Australia's 2026-27 Pre-Budget Submission highlights key funding priorities to improve the lives of Australians living with MS. MS Australia advocates for strategic investments in research, healthcare, disability, and aged care to address the growing personal and economic impact of MS.

Our submission has **four asks** that will improve the lives of people living with MS and reduce the economic impact of MS on the Australian health, disability, social services and aged care systems, including:

1. **MS Research and Data:** Research to prevent people from developing MS, improve early diagnosis and develop effective treatments and interventions to slow or prevent disease progression through funding a National MS Biobank, a Neurological Mission and improved neurological data.
2. **MS Nurses:** Improved access to MS Nurses across Australia for people living with MS through additional nurses, a MS Nurses Pilot Project and the development of a MS Nursing microcredential.
3. **Disability:** A better NDIS for people living with MS through improved NDIS pricing, a better NDIA workforce, improved planning and supports, a better disability sector workforce, housing and living supports and assistive technology. Improved income support, poverty measures and implementing the recommendations of the Disability Royal Commission.
4. **Aged Care:** Improved access for the 220,000 older Australians waiting for Support at Home Packages and assessments and ensuring equity of services and funding for older people living with disability.

ASK 1: MS RESEARCH & DATA

Proposal	Portfolio	Funding ask
1.1 National MS Biobank	Department of Health and Aged Care (DOHA)	**$8 million over five years** to fund a National MS Biobank to support Australian studies towards early detection and prevention of MS.
1.2 Neurological Mission	DOHA	**$300 million over ten years** for a Neurological and Neuromuscular Health Research Mission within the MRFF.
1.3 Neurological Data	DOHA	**$1.3 million over two years** for the AIHW to undertake neurological data improvement activities.

ASK 2: MS NURSES

Proposal	Portfolio	Funding ask
2.1 MS Nurses	DOHA	**$6.5 million** to employ an additional 65 MS Nurses for the people living with MS currently without access in Australia.
2.2 MS Nurses National Strategy	DOHA	**$1 million** for the development of a MS Nurses National Strategy to strengthen and expand the MS nursing workforce.
2.3 MS Nurses Pilot Project	DOHA	$3,006,058 over four years for a MS Nurses Pilot Project including: • **$1,669,656** to fund the research and evaluation work to be undertaken by the Menzies Institute for Medical Research. • **$1,336,402** to fund an additional 2.73 FTE MS Nurses time.
2.4 MS Nursing Microcredential	Department of Education	**$120,000 over five years** to develop an MS Nursing microcredential. **$90,000 over three years** to provide ten scholarships for nurses undertaking the MS nursing microcredential at a cost **of $3,000 per scholarship – waiting for confirmation from Australian College of Nursing**.

ASK 3: DISABILITY

Proposal	Portfolio	Funding ask
3.1 A Better NDIS for people living with MS	NDIA	Funding to improve the NDIS including: • Funding to create a flexible, participant-focused and sustainable pricing mode for the NDIS that reflects real costs and encourages innovation and quality service delivery. • Funding to recruit, train, upskill and maintain a sufficient NDIA workforce and improved disability awareness and improved disability awareness and understanding across all government agencies. • Funding to improve NDIS planning and supports so they are evidence-based and focused on the needs of participants, including improved understanding of the needs of people living with MS. • Funding for 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.
3.2 Housing & Living Supports	NDIA	Funding to attract, train, upskill and maintain a high-quality disability workforce to meet the needs of people living with disability.
3.3 Assistive Technology	NDIA	Funding to develop a single, nationally consistent assistive technology program to support people with a disability who are not eligible for the NDIS.
3.4 Poverty Measures	Department of Social Services & Services Australia	Funding to support an immediate increase in the rates of the Disability Support Pension, New Start Allowance and JobSeeker Payments and a more person-centred focus on the delivery of income support payments to people with disability. Funding to support the development of a new set of Australian poverty measures that include a supplementary poverty line to capture the additional costs of living with disability.
3.5 Disability Royal Commission	DOHA	Funding to support the timely and effective implementation of the recommendations of the Disability Royal Commission.

ASK 4: AGED CARE

Proposal	Portfolio	Funding ask
4.1 Home Care Packages	DOHA	Funding to meet the needs of the over 220,000 older Australians waiting for Support at Home packages and assessments including: • Funding for additional Support at Home packages, including removing rationing of packages over time. • Funding for improving, training and expanding the aged care assessment workforce. • Funding for improved and timely data on wait times for packages and assessments.
4.2 Equity for older people with disability	DOHA	Funding to ensure equity of services and funding for older people living with disability including: • Expanding the aged care service list to include supports that allow older people to maintain independence, choice and control. • Support for aged care providers to train and upskill staff and improve policies and procedures. • Increasing the levels of funding available under the Support at Home Program so that funding levels match the NDIS and/or allowing care recipients to top up their aged care funding with NDIS supports.
4.3 My Aged Care	DOHA	Funding to implement the six recommendations of the Inspector General's review of My Aged Care.

1. MS RESEARCH & DATA

1.1 NATIONAL MS BIOBANK

Improving MS diagnosis, outcomes and treatments through the establishment of a National MS Biobank

Great progress has been made in MS research over the past 25 years. In this timeframe many specific MS therapies have become available where there were none available previously.

Despite the incredible progress made, MS remains a serious burden on people's quality of life and on the economy. The great unmet need in MS is to prevent, halt and reverse neurological damage and disability.

At present, MS progression can often be significantly slowed from the time it is first diagnosed in the clinic. This is usually soon after the onset of clinical symptoms, such as vision problems, loss of feeling, pain or weakness of the limbs.

Given the powerful therapies now available, earlier detection of MS would give us the power to shut down the attack on the brain much earlier. This could help preserve precious brain tissue, halt or delay disease, and potentially reclaim many years of function for people with MS.

However, we do not yet have reliable biomarkers of pre-clinical or prodromal phases of MS that would enable this early intervention. For these discoveries, we need a harmonised national MS biobank, linked to clinical registries such as MSBase and the National Health Hub, and including asymptomatic individuals at high risk of MS.

In addition, the ultimate goal of MS research is to find therapies to stop and reverse progressive nerve damage in MS. There is no reliable biomarker for MS neurodegeneration, a major roadblock for drug development and clinical trials.

At a cost of **$8 million over five years** a National MS Biobank would:

- ✓ Improve early detection and diagnosis time
- ✓ Halt or delay disease progression
- ✓ Allow earlier access to treatments
- ✓ Improve understanding and detection of the 'pre-MS' period
- ✓ Improve monitoring of treatments and whether they are working
- ✓ Improve monitoring of environmental risk factors.

The National MS Biobank

A biobank is a collection of biological samples such as tissue, blood or serum, along with related health information, which can be used to support medical research and generate scientific knowledge.

The establishment of a National MS Biobank would not only support Australian biomarker discovery towards early detection and monitoring neurodegeneration, but advance our understanding of the disease mechanisms towards causes, better treatments and ultimately cures.

A National MS Biobank would be a national collaborative research platform bringing together the best MS researchers across Australia. It will collect blood and other biological samples such as serum, plasma and genetic material from people living with MS and their relatives.

Together with clinical data and brain imaging, this rich data source will allow us to identify ways to screen and group people according to their risk or stage of MS.

Such a resource is essential if we are to find patterns to determine if treatments are working or to detect MS earlier. Ultimately, this resource could be used to help prevent a substantial proportion of new cases of MS.

MS diagnosis

There still remain people with MS who are not diagnosed for many years. This reflects the complexity of MS, with the disease taking many years to manifest for some people. Data from the Australian MS Longitudinal Study[3] indicates that between 2017-2021, the average time from symptom onset to MS diagnosis was nearly four years. Many people diagnosed with MS continue to undergo prolonged and complex diagnostic journeys.

The 'pre-MS' period

Disease progress in MS likely begins many years before the onset of typical clinical symptoms. Studies have shown a trend of declining health in the years before MS diagnosis, known as the 'MS prodrome'[4]

Better understanding and better detection of this 'pre-MS' period could profoundly improve the ability to recognise and diagnose MS earlier.

Finding biomarkers of 'pre-MS'

People with a family history of MS have a higher risk of developing MS than the general population. Insights into the 'pre-MS' period have come from studies of healthy close relatives of people with MS.

However, regular brain imaging may prove impractical and be too costly for screening large numbers of healthy people. A biobank can provide a more cost-effective option for screening these people.

We do not have a blood test to detect early MS; however, international MS biobanks have identified promising candidates that carry the biomarkers of 'pre-MS'. Further research is needed to understand the potential of these and several other candidates as blood markers for the 'pre-MS phase. MS biobanks are critical to advancing this work.

Stopping MS before it starts

There is strong evidence[5] that infection with the Epstein-Barr virus (EBV) is necessary for the development of MS. International clinical trials are underway for two new-generation EBV vaccines.

Biobanking is essential for monitoring the rollout of EBV vaccines and assessing their impact on rates of glandular fever and MS.

A biobank would also allow us to monitor the other important environmental risk factors for MS, including:

- low vitamin D and sunlight exposure
- smoking and obesity
- the effect of public health initiatives towards preventing MS

Coordinated biobanking capability

MS Australia also supports exploring opportunities to develop a coordinated biobanking capability in Australia, as outlined in the CSIRO's *Valuation of increased coordination in Australian biobanking* report[6]. This includes conducting a comprehensive survey of biobanks and cohort studies hosted across Australia and implementing a shared national platform to search and apply for access to biospecimens and associated data. The CSIRO report estimates the direct financial benefits of a national platform for searching and accessing biospecimens and data at $39 million annually.

MS Australia notes that any national coordination of biobanking must also consider the unique needs of specialist biobanks and ensure that governance of individual biobanks remains in the control of participants and funders so that the specifics are not lost to harmonisation.

1.2 NEUROLOGICAL MISSION

Establishing a strategic, focused research model to address the profound impact of neurological conditions, both on individuals and the Australian health system.

The Neurological Alliance Australia (NAA) is a collective of not-for-profit peak and national patient organisations representing adults and children living with neurological or neuromuscular conditions in Australia. MS Australia is a founding and active member of the NAA and our CEO currently holds the Chair role.

One in four Australians live with neurological or neuro-muscular conditions.

The associated annual economic cost to the Australian economy of all neurological conditions exceeds $100 billion.

The vision of the NAA is a world where these conditions are preventable, detectable, manageable, and curable and we believe this is within reach. But to get there, we urgently need more research investment. The NAA calls for the funding of a dedicated Medical Research Future Fund (MRFF) Mission to coordinate the innovations that will make this vision a reality.

At a cost of **$300 million over ten years** a Neurological and Neuromuscular Health Research Mission within the MRFF would:

- ✓ Improve early detection and diagnosis time
- ✓ Coordinate, action, and accelerate progress in neurological and neuromuscular research
- ✓ Revolutionise the prevention, detection, treatment, and care of neurological and neuromuscular conditions
- ✓ Reduced health and disability system costs, improved quality of life for those with lived experience and a healthier, more resilient population

Neurological and Neuromuscular Health Research Mission

Current research efforts for neurological conditions are scattered across 25 uncoordinated programs and Missions within the Medical Research Future Fund (MRFF).

A Neurological and Neuromuscular Health Research Mission offers a paradigm shift, and will foster coordinated efforts across neurological, neuromuscular, and related conditions while leveraging existing investments for greater impact.

The Mission would unite and spearhead efforts across previously siloed initiatives, energising collaboration and data sharing for real, lasting change. It would build on the foundations of other MRFF-funded Missions and important neurological disease research investments.

The Mission would include rare neurological and neuromuscular conditions to drive impact by enabling cross-condition approaches that ensure underfunded areas receive the attention they deserve.

The Four Pillars of the Research Strategy

Pillar 1: Prevent	Pillar 2: Diagnose	Pillar 3: Treat	Pillar 4: Care
Reduce the incidence of neurological and neuromuscular conditions through targeted prevention strategies	Identify and diagnose neurological and neuromuscular disorders at the earliest possible stage	Innovate and refine therapeutic approaches to treat neurological and neuromuscular conditions	Enhance the quality of life for individuals with neurological and neuromuscular conditions to inform care models & drive development of evidence-based care

Research Enablers

Programs of research under each Pillar will be supported by six Enablers:

- Advanced Technology, Data, and Infrastructure
- Collaborative Partnerships
- Diverse and Inclusive People & Communities
- Public Engagement and Communication
- Harmonised Efficiency
- Robust Governance

1.3 NEUROLOGICAL DATA

High quality data on neurological and neuromuscular conditions is essential to building a strong evidence base and assisting in planning and prioritising health programs and funding, evaluating the effectiveness of intervention programs and initiatives and identifying unmet and emerging needs.

MS Australia welcomed the release of the Australian Institute of Health and Welfare (AIHW) first national estimates for the prevalence of neurological conditions. The report and suite of accompanying articles, includes statistics on the number of hospitalisations, emergency department presentations, health-system expenditure, burden of disease, aged care and mortality. The release also noted data gaps for some of the 11 neurological conditions in the report.

The AIHW have now identified potential data improvement activities to address data gaps and provide additional data insights for specific neurological conditions. Some of these activities are currently underway or planned within their existing workstream. However, they do require additional funding in 2026–28 to undertake, a second and new workstream that includes:

- Providing better understanding of the intersection between disability and specific neurological conditions, potentially revealing patterns of comorbidity.
- Producing estimates of prevalence (and potentially incidence) that are more current, and which use Australian data for specific neurological conditions.
- Exploring the possibility of creating different datasets for specific neurological conditions.
- Giving insights into the trajectory of diagnoses and health service use for specific neurological conditions, showing treatment pathways and health service use.
- Ensuring comparability across data sources, by understanding differences between mappings of specific conditions and condition groups.
- Improving understanding of the risk and preventive factors associated with specific neurological conditions, potentially revealing the trajectory of medication use with indications of how long a person diagnosed with the condition may live with that condition.

MS Australia is calling for $1.3 million over two years for the AIHW to undertake neurological data improvement activities. These funds cover staffing and other project costs including data access.

More funding for MS research and data	
There is a critical gap in funding for research to prevent people from developing MS and shorten diagnosis time.	• **$8 million over five years** to fund a National MS Biobank to support Australian studies towards early detection and prevention of MS
There is a critical gap in coordinated research and data for neurolgoical and neuromuscular conditions.	• **$300 million over ten years** for a Neurological and Neuromuscular Health Research Mission within the MRFF • **$1.3 million** over two years for the AIHW to undertake neurological data improvement activities.

2. MS NURSES

2.1 IMPROVING ACCESS TO LIFE SAVING MS NURSE CARE FOR PEOPLE LIVING WITH MS

Multiple Sclerosis (MS) Specialist Nurses or MS Nurses are an integral part of the multidisciplinary healthcare team of specialist healthcare professionals providing support, education, advice, and care for people with MS. Access to MS Nurse care brings health benefits for people with MS. These include lower disability level, slower self-reported disease progression, less severe symptoms, lower levels of depression and anxiety, and a higher quality of life.

MS Nurses are also a highly cost-effective model of care. MS Nurse care reduces the need for other, more costly health professionals, such as GPs and neurologists, and prevents unnecessary emergency department presentations and potentially, unplanned hospital admissions.

If every Australian with MS had access to MS Nurse care as part of their ongoing MS management plan, this would result in substantial cost savings for MS healthcare in Australia. It would significantly delay disease progression and contribute to an increased quality of life. There are further savings from a reduced reliance on National Disability Insurance Scheme (NDIS) supports and other health, disability and aged care programs and supports.

MS Nurse Practitioners (NP) can provide additional care including assess, plan and treat, prescribe (some) therapies, order pathology and some radiology. In November 2024 the Pharmaceutical Benefits Advisory Committee (PBAC) recommended the amendment to the PBS listings of fingolimod, ofatumumab and siponimod to allow NPs to initiate and continue treatment in consultation with a specialist physician for the treatment of MS. This change has improved access to care for people living with MS, especially those in regional, rural and remote locations where access to neurologists and other medical professionals is limited.

Many people living with MS report limited interaction with their neurologist following diagnosis, primarily because of cost, time limitations and lack of easy access for questions and concerns. As a result, the MS Nurse forms a very important part of the MS healthcare team, and they are often the main source of clinical, psychological, social, and emotional support and education for the person living with MS and their family.

MS Nurse Care in Australia Report

The *MS Nurse Care in Australia Report*[7] developed by MS Australia, in collaboration with the Menzies Institute for Medical Research and MS Nurses Australasia (MSNA), found that one-third of Australians living with MS do not have access to life-changing MS Nurse care and have consistently worse health outcomes. The report also found that the number of MS Nurses is declining.

The report made the following recommendations:

1. **Raise awareness** of the existence of MS Nurses, their value, and the supports and services they provide to people with MS and health practitioners.
2. **Assist the existing MS Nurse workforce** through mentorship and preceptorship, connecting and educating existing MS Nurses and exploring opportunities within university nursing courses to include education about MS Nursing and MS Research Nursing.
3. **Increase the number of MS Nurses** in Australia by targeted advocacy and assessing the current funding arrangements.
4. **Increase access to MS Nurses** through expanding telehealth services and advocacy to the Australian Government.

To address the recommendations of the MS Nurse care report and the urgent need for more MS nurses**, we are calling for the funding of $6.5 million for an additional 65 MS nurses across** Australia to meet the current shortfall. Based on a conservative estimate of 10% cost savings, this could reduce the cost of their overall MS care by **$77.1 million** annually.

2.2 MS NURSES NATIONAL STRATEGY

Australia has no consistent allocation of services for MS Nurses to MS patients. It appears to be driven by individual hospitals and clinics, MS neurologist implementation, funding opportunities and individual business case requests, with no underlying pattern or formula reference[8]. There is a need to establish a more consistent allocation of MS Nurses and associated ongoing funding.

There is also no agreed MS Nurse/patient ratio in Australia. However, recent work conducted in the United Kingdom recommends a caseload of 315 MS patients per MS Nurse FTE, with higher caseloads required when the case mix includes more patients with complex needs, including comorbidities or high psychosocial needs[9].

Currently, the ratio of MS Nurses across Australia far exceeds this ratio with examples of MS nurses having individual caseloads of up to 1,000 patients. Tasmania has the highest prevalence of MS in Australia, with estimates indicating that the current caseload for Tasmanian MS Nurses is approximately 954 patients per FTE.

Most employers of MS Nurses are not committed to permanent, full-time, and ongoing positions. Many MS Nursing positions are part-time and rely on repeated fixed term contracts. MS Nurses are often required to undertake extensive unpaid overtime and expected to be on-call and contactable out of hours by their patients. They provide extensive support for their clients and are often the only health professional they can contact out of hours. MS Nurses also do not receive good levels of HR support and struggle to access leave and other entitlements in an already overburdened setting.

Without immediate intervention, the MS Nursing workforce will continue to decline, placing people living with MS at even greater risk. Improved workforce planning of MS Nurses will ensure that we have an adequate nursing workforce to meet the needs of people living with MS across Australia, reduce burnout of the current workforce and allow for improved service delivery models.

The development of a MS Nurses National Strategy at a cost of **$1 million over four years** would strengthen and expand the MS Nursing workforce through:

- Establishing neurological nursing credentials in partnership with the Australian College of Nursing and recognition of the MS Nursing specialisation
- Developing a clearly defined MS Nursing career pathway
- Developing competency standards and a clear scope of practice for MS Nurses and MS Nurse Practitioners
- Establishing a mentoring and education program for new and emerging MS Nurses

- Establishing a mentoring and education program for MS Nurse Practitioners
- Removing barriers to MS Nurses and MS Nurse Practitioners to working their full scope of practice
- Developing an education campaign for undergraduate and practicing nurses on the MS Nursing specialisation
- Support for existing nurses looking to leave the profession to retrain as MS Nurses
- Support for MS Nurses to upgrade their qualifications to become MS Nurse Practitioners

Improved workforce planning will ensure that we have an adequate nursing workforce to meet the needs of the people living with MS across Australia, reduce burnout of the current workforce and allow for improved service delivery models.

2.3 MS NURSES PILOT PROJECT

The proposed MS Nurses Pilot Project is a collaboration between MS Australia, MSNA, and the Menzies Institute for Medical Research at University of Tasmania to co-design, implement and evaluate a best practice model of MS Nurse care in Tasmania.

Tasmania has the highest prevalence of people living with MS in Australia at a rate 190.1 per 100,000 (compared to 139.2 per 100,000 nationally) and a current MS Nurse caseload of 954 patients per FTE[10].

The project will assess the impact of increasing the current level of MS Nurse care provided in Tasmania to ensure a best practice caseload for nurses and MS patients. The project will include a process evaluation, so that other states and territories can apply the lessons learned during this project, and it will also include a cost-effectiveness assessment to ensure that a further roll-out will only be done when benefits outweigh the costs.

Funding is needed to support research and evaluation by the Menzies Institute for Medical Research and the required additional FTE MS Nurse time.

We estimate this pilot project would cost **$3 million over four years** including:

- **$1 million** to fund the research and evaluation work to be undertaken by the Menzies Institute for Medical Research.
- **$2 million** to fund the required additional FTE MS Nurse time.

At a cost of **$4 million over four years** a National MS Nurses Strategy and Pilot Project would:

- ✓ Increase the number of MS Nurses and MS nurse practitioners across Australia and improve the nurse/patient ratio
- ✓ Improve education and training for the MS nurse workforce
- ✓ Provide sustained employment and career opportunities for the existing MS Nurses workforce
- ✓ Sustain and support the current MS Nurse workforce to prevent loss of experienced MS Nurses due to burnout
- ✓ Determine a best practice cost-effective model of MS nurse care
- ✓ Increase access to MS Nurses across Australia, including in regional, rural and remote regions
- ✓ Improve health outcomes for people living with MS and their family and carers.

2.4 MS NURSING MICROCREDENTIAL

There is currently no formalised education or qualification for MS Nurses or well-defined career pathways, competency standards and scope of practice. There is an urgent unmet need for formal MS Nursing training for a range of nurses including:

- Nurses wanting to train as MS Nurses.
- Current MS Nurses who want to improve and extend their knowledge base.
- Neurological Nurses who want to improve and extend their knowledge of neurological conditions.
- Infusion Nurses who have patients receiving MS disease modifying therapies (DMTs) who want to improve and extend their MS knowledge.
- Nurses who work in other settings who have interactions with people living with MS who want to improve their MS knowledge.

MS Australia, in partnership with the Australian College of Nursing and MSNA, is calling for funding to develop a MS Nursing microcredential. The microcredential provides a professional qualification recognised under the Australian Qualifications Framework (AQF). These qualifications are more accessible for nurses and their employers due to the shorter timeframe and reduced costs. Over time this microcredential could be used to upskill to a graduate certificate.

The Australian College of Nursing is ideally placed to develop the microcredential in consultation with MS Australia and MSNA. They already have experience developing microcredentials, including the development of a Parkinson's Care microcredential under the Australian Government's Microcredentials Pilot in Higher Education.

We estimate the cost of developing the microcredential is **$125,000 over five years** including:

- Development and testing
- Ongoing delivery including payment of tutors
- Administration costs including online hosting
- Initial Accreditation and update after five years

To attract and support nurses wanting to undertake this qualification, we are calling for the funding of ten scholarships a year over the first three years. At a cost of $3,000 per scholarship, the full funding would be **$90,000 over three years**.

More funding for MS research and data	
The number of MS Nurses is declining and one-third of Australians living with MS do not have access to life-changing MS Nurse care and have consistently worse health outcomes.	• **$6.5 million** to employ an additional 65 MS Nurses to improve access for the people living with MS. • **$1 million over four years** for the development of a MS Nurses National Strategy to strengthen and expand the MS nursing workforce. • **$3,006,058 over four years** for the MS Nurses Pilot Project including: » **$1,669,656** for the research work undertaken by Menzies » **$1,336,402** for an additional 2.73 FTE MS Nurses time • **$120,000 over five years** to develop an MS Nursing microcredential. • **$90,000 over three years** to provide ten scholarships for nurses undertaking the MS Nursing microcredential at a cost of **$3,000 per scholarship**.

3. DISABILITY

3.1 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 called for six essential reforms to improve the NDIS for the MS community. MS Australia welcomed the final report of the NDIS Review and was pleased to see some strong alignment with our asks. However, we believe there are still outstanding issues to be addressed to ensure the NDIS meets the needs of people living with MS and other neurological conditions.

Further to these issues, the Australian Government has yet to formally respond to the NDIS Review and there is no publicly available reform roadmap or timetable. The disability sector has no warning of what NDIS reforms will take place next and the timeframe for their rollout.

NDIS Pricing

MS Australia has been calling for improved NDIS pricing arrangements including greater transparency and better evidence-based independent pricing through our The Price is Not Right campaign.

Current NDIS pricing is not consistent, does not align with the true costs of delivering services, is not indexed annually and is not evidence-based. Many prices have been frozen or reduced over consecutive NDIS Pricing Reviews and disproportionately disadvantages rural, regional and remote populations. Pricing does not adequately address the costs associated with staffing, travel, after-hours care, group supports, and the significant administrative burden associated with meeting the NDIS administrative and quality requirements.

Improving the NDIS and broader government workforce will ensure:

- ✓ NDIS Participants undergo assessments that are fit for purpose
- ✓ NDIS Participants receive a plan that meets their individual needs and makes best use of their NDIS funds
- ✓ NDIS Participants have access to the evidence-based disability supports they need
- ✓ NDIS Pricing matches the real costs of delivering high quality disability supports
- ✓ Transparent, evidence-based and participant focused decision making
- ✓ A NDIA and broader government workforce that is disability aware and treats people with disability with respect
- ✓ Disability policy and programs that are fit for purpose and better meet the needs of people with disability
- ✓ A more inclusive Australia where people with disability can be active participants in their community

Our Member Organisations are currently delivering many services at a significant financial loss and providing many unfunded hours of support, especially support coordination and plan management to NDIS participants. If these trends continue, the long-term viability of many service providers are at risk, ultimately leaving participants without adequate support. Many providers may also be forced to scale back or discontinue supports, especially those that provide condition specific support.

For people living with MS, access to allied health services and supports are essential to maintaining health and wellbeing and slowing disability progression. These supports are essential to help improve mobility, balance and strength; manage fatigue, maintain independence; improve nutrition, manage bladder and bowel issues and to prevent symptoms from worsening over time. The recent changes to NDIS pricing for therapy supports and travel will result in tighter margins for providers and limits the ability to deliver supports in rural and regional locations and into people's homes. If people living with MS cannot receive their NDIS Allied Health supports in a meaningful home and community environment, they will decline in all aspects of function and lose independent function at a faster rate. Over time this will put greater pressure on the NDIS and broader disability and health systems.

MS Australia strongly supports transferring NDIS pricing from the NDIS to the Independent Health and Aged Care Pricing Authority (IHACPA) as they have expertise in providing independent advice to government on pricing and this would ensure a coordinated approach to setting prices across the care and support sector. In 2024, the Australian Government requested that the IHACPA undertake initial work to identify opportunities for future reforms to NDIS. IHACPA have now provided advice to the Government, however, this advice has not been made public. Pricing decisions continue to be made internally by the NDIA, guided the NDIA Independent Pricing Committee who to date have not undertaken any public consultation.

MS Australia calls for **funding to create a flexible, participant-focused and sustainable pricing model for the NDIS that reflects real costs and encourages innovation and quality service delivery,** including:

- An immediate review of the current NDIS pricing for therapy supports and travel, support coordination and plan management.
- The establishment of clear independent NDIS pricing including releasing the Independent Health and Aged Care Pricing Authority's (IHACPA) review of NDIS pricing and transferring responsibility for pricing to the IHACPA.
- Introducing a tiered NDIS pricing system for therapy supports that recognises the complexity and increased costs of delivering supports to people with complex, chronic and/or neurodegenerative conditions.

National Disability Insurance Agency

The rapid changes to the NDIS over the coming years will require a highly skilled, disability aware National Disability Insurance Agency (NDIA) workforce. MS Australia has previously raised concerns regarding the NDIA workforce including the lack of disability awareness and the understanding of how to communicate with and support people with disability; consent, decision-making and choice and facilitating person-centred planning.

MS Australia welcomed the establishment in 2024 of the Neurological, Palliative care and Rare Conditions Advisory Group (NPRAG) to deliver improved experiences for people with neurodegenerative and neuromuscular disorders or rare conditions or those requiring palliative care. We look forward to continuing to work with the NDIA on improving the outcomes for people living with MS receiving NDIS services.

However, we continue to have concerns regarding the ability of NDIA staff to keep up to date with the NDIS reforms. We continue to receive feedback from people living with MS that the reforms are not being implemented consistently and in line with the updates to the *NDIS Act 2013*. Further, there are a range of new processes and roles that will be implemented in the coming years that require appropriate training and resourcing.

MS Australia calls for **funding to recruit, train, upskill and maintain a sufficient NDIA workforce and improved disability awareness and understanding across all government agencies.** This includes:

- Improved, timely and responsive training for NDIA staff on the implantation and interpretation of NDIS reforms.
- Increasing the number of NDIA staff with lived experience of disability across all levels of the organisation.
- Training and upskilling for NDIA assessors to undertake the new needs assessment process and deliver structured, reliable and valid assessments as per Action 3.4 of the NDIS Review.
- Commissioning and training of a national navigator workforce including upskilling of support coordinators as per Action 4.3 of the NDIS Review. This also includes training specialist Housing and Living navigators (Action 8.2) and Specialist Navigators for participants with more complex support needs (Action 4.2).
- Training for NDIA staff and navigators on accessible communications as per Action 5.1 of the NDIS Review.
- Training and upskilling for NDIA staff to better understand and meet the specific needs of participants with psychosocial disability as per Action 7.1 of the NDIS Review.
- Embedding a highly skilled, person-centred, disability aware culture across all disability agencies and governments as per Recommendation 22 of the NDIS Review.

NDIS Planning & Supports

Feedback received by MS Australia indicates that people living with MS are currently experiencing significant NDIS planning issues which are impacting their health and wellbeing, and the level of NDIS supports they receive. These issues have escalated since the introduction of NDIS reforms over the past twelve months including funding periods and the NDIS list of supports and the increasing focus on the economic burden of the NDIS. Issues faced by NDIS participants with MS include:

- **MS understanding:** NDIA planners do not have a good understanding of people living with progressive, degenerative, neurological and neuromuscular conditions such as MS. This leads to planners making assumptions about the supports and levels of funding needed.
- **Arbitrary decision making**: NDIA planners making decisions that are not backed by evidence or in line with legislation and guidelines. This includes the removal of previously approved supports and/or a reduction in the level of funding without adequate evidence or explanation.
- **Health Professionals reports:** NDIA planners ignoring reports from health professionals including allied health professionals, GPs and neurologists. This includes going against medical advice that removing supports could place the participant at serious risk.
- **Focus on cost-savings:** NDIA decision making focused on cost savings rather than what is best for the participant, including a focus on short-term costs over long-term savings. For example, a focus on the initial cost of a piece of equipment rather the long-term savings from the purchase of the equipment.
- **Removing therapy supports**: Many participants with MS report having therapy supports removed from their plan including exercise physiology and physiotherapy. For people living with MS, access to allied health services and supports are essential to maintaining health and wellbeing and slowing disability progression. These supports are vital to help improve mobility, balance and strength; manage fatigue, maintain independence; improve nutrition, manage bladder and bowel issues and to prevent symptoms from worsening over time. The removal of therapy supports will result in increased levels of disability for many participants with MS and may be left at serious risk, including requiring hospitalisation.
- **Disability support workers:** NDIS planners' emphasis on removing specialised supports and replacing them with inexperienced and unskilled disability support workers. For example, removing access to an exercise physiologist and replacing it with a support worker to accompany the person to a gym.

- **NDIS Managed**: NDIS planners requiring participants to have their plan managed by the NDIS without reasonable explanation, including participants who have successfully self-managed for many years. This reduces the participants independence and sense of self-worth and can reduce the choice of providers they can access.
- **Plan renewals, approvals and reviews:** Long delays in these NDIS processes result in an interruption in continuity of supports and have a significant impact on the health and wellbeing of participants with MS. Many participants can only get the plan they need after requesting an internal review and/or going to the Administrative Review Tribunal (ART).

The NDIA need to ensure that NDIA planners and decision makers are making clear, evidence-based decisions that take into consideration reports from health professionals and participants needs and preferences.

The NDIA will move NDIS participants to new framework plans over the next four years. The Department of Health, Disability and Ageing announced in December 2025 they are currently developing the rules around this new framework planning and how it works in practice. As part of this process, the Department and the NDIA need take into consideration the current issues with NDIS plans and ensure that participants do not have to wait four years for these to be implemented.

MS Australia calls for funding to improve NDIS Planning and Supports including:

- **Resource library**: Establishing a resource library of disability materials for use by NDIA staff that includes MS Australia resources. Prior to a planning meeting, staff would use the library to access materials relevant to the participant's disability. MS Australia would be very willing to engage with the NDIS on any further training or education materials required for the resource library.
- **Communication and decision making**: Improved communication around decision making and timeframes. This includes changes to plans, cutting essential supports, moving participants to NDIS managed, outstanding approvals, internal reviews and complaints.
- **Training:** Training for NDIS planners and decision makers in evidence-based and participant focused supports and the impact of removing supports. This should also include training on following appropriate processes and legislation and following the advice of health professionals.
- **Guidelines:** The development of comprehensive guidelines for NDIS planners and decision makers to accompany disability and inclusion training.
- **NDIS Review Advisory Committee:** Ongoing funding for the committee to develop a strong evidence base for NDIS supports, including regular updates that reflect the rapidly pace of change in technology and artificial intelligence.
- **Public materials:** Participants, carers, providers, health professionals and disability support workers should have access to information on the latest evidence on the benefits and risks of supports.

Housing and Living

Access to appropriate accommodation is crucial to people living with MS and maintaining their independence. People should be able to choose the living arrangement that best meets their needs and long and short-term goals. Currently, NDIS planners make assumptions about the accommodation needs of people living with MS, often with a focus on shared accommodation or living with family members. This disregards the choice of the participant, especially if they wish to remain living independently.

It is important that people with disability have access to disability appropriate accommodation. However, there are still 880 people under the age of 65 living in aged care and new people still entering each year because there is nowhere else for them to live. While there has been a substantial drop in the number of younger people entering and living in residential aged care, the latest data[11] shows that the *Younger People in Residential Aged Care Targets* are not being met and younger people are still entering residential aged care.

MS Australia calls for **funding to improve housing and living supports** including funding to:

- Implement a process for participants to try new living arrangements at key life stages, before they commit to them as per Action 8.3 of the NDIS Review.
- Commission a shared support facilitation function to empower participants sharing housing and living supports to exercise joint decision-making. as per Action 8.4 of the NDIS Review.
- Commission, in consultation with state and territory governments, Specialist Disability Accommodation where needs are not adequately met by the private sector as per Action 9.6 of the NDIS Review.
- The NDIS Quality and Safeguards Commission to strengthen Specialist Disability Accommodation regulations and ensure housing is managed in accordance with the needs of participants as per Action 9.7 of the NDIS Review.
- Develop and implement an intergovernmental strategy for upgrading or repurposing ageing Specialist Disability Accommodation stock owned by states and territories as per Action 9.8 of the NDIS Review.
- Develop and publish a targeted action plan for housing under Australia's Disability Strategy as per Action 9.11 of the NDIS Review.

3.2 DISABILITY WORKFORCE

Currently, the disability workforce is overwhelmingly made up of part-time, untrained and lowly paid support workers. There are high rates of turnover and casualisation across the sector. The 2025 NDS Workforce Census Report found that 40% of disability support workers are casual employees with a turnover rate of 26%. Permanent staff over overwhelmingly part time (79%) with a turnover rate of 16%. Over the whole year this represents a churn of over 15,300 individual employees leaving their jobs and over 15,000 new appointments, making the disability sector one of the highest turnover industries in Australia. There is no consistency in wages with 49% of workers paid under Schedule B of the Social and Community Services Employees (SCHADS) Award, 38% under an enterprise agreement, 6% covered by SCHADS Schedule E and the remainder under a range of awards and schedules[12].

As outlined in our submission to the NDIS Provider and Worker Registration Taskforce, MS Australia supports the introduction of a national disability support worker registration scheme including minimum standards, worker screening and professional development. Professionalising the disability workforce makes it an attractive career prospect and would ensure that people with disability are provided care and services by trained, motivated and experienced professionals.

To meet the growing needs of Australians living with disability, more must be done to grow and maintain the disability workforce. The Government must take a more strategic approach to attracting people to the sector, creating flexible migration pathways and identifying and responding to workforce gaps. This should be done in parallel with the work already underway to support the aged care workforce.

MS Australia calls for **funding to attract, train, upskill and maintain a high-quality disability workforce to meet the needs of people living with disability** including funding to:

- Implement a Worker Registration Scheme including a public register with a transparent and simplified registration process, requirements for professional development, a worker training and qualifications framework and requirements for providers to provide appropriate training as per Recommendation 10 of the Provider and Worker Registration Taskforce.
- Design and trial workforce attraction and retention initiatives including designing and trialling a portable training scheme and a portable sick and carer's leave scheme as per action 15.1 of the NDIS Review.
- Develop targeted and flexible migration pathways for care and support workers. as per action 15.2 of the NDIS Review.
- Develop an integrated approach to workforce development for the care and support sector including developing and overseeing a data strategy, identifying workforce gaps and implementing targeting policy responses and monitoring and evaluating actions and outcomes as per action 15.3 of the NDIS Review.

3.3 ASSISTIVE TECHNOLOGY

Assistive technology and home modifications play a critical role in the lives of people living with MS by facilitating independence and participation in everyday activities. Currently, many people living with MS struggle to get access to the assistive technology they need. Those who are not eligible for the NDIS must access assistive technology through state and territory-based aids and equipment programs.

As noted in the Final Report of the NDIS Review, 'assistive technology for people outside the NDIS is under-funded, fragmented, and complex'[13]. A study of assistive technology undertaken by Monash University[14] found there are currently 87 Government funders, administering 108 assistive technology and home modifications schemes outside the NDIS. There is a distinct lack of equity and consistency across the 108 schemes with each scheme having different eligibility criteria, long wait-times, co-payments and poor wraparound services. Action 1.10 of the Final Report recommends:

> *A nationally consistent approach for the delivery of aids and equipment outside the NDIS. This should be focused on improved planning and coordination of aids and equipment between the NDIS, health and aged care sectors and across jurisdictions[15].*

The Assistive Technology for All (ATFA) Alliance, of which MS Australia is a member, proposes the establishment of a national assistive technology program for people who are not eligible for the NDIS. Access to a national scheme would maximise the safety, independence, inclusion and participation of people with disability, reduce the burden on families and carers, drive nationally consistent outcomes, reduce administrative burden on governments and minimise downstream costs by reducing demand in other areas such as acute health, community services and aged care. MS Australia believes this is the most appropriate mechanism for implementing Action 1.10 of the Final Report.

MS calls for **funding to develop a single, nationally consistent assistive technology program** to support people with disability who are not eligible for the NDIS and to implement Action 1.10 of the NDIS Review Final Report.

3.4 INCOME SUPPORT

Research undertaken by UNSW and ACCOSS[16] found that people with disability face an elevated risk of poverty and it is estimated that the rate of poverty among adults with disability is 17 per cent (compared with 13.4 per cent across the whole population) and that people with disability make up 33 per cent of all people in poverty. In households that rely on the Disability Support Pension, 43 per cent live below the poverty line. They acknowledge that this is likely to be an under-estimate as it does not take account of the extra costs of disability.

The AIHW[17] found that 38 per cent of people with disability and 51 per cent of people with severe or profound disability have a low level of personal income, compared to 27 per cent without disability. Government pensions or allowances are the main source of income for 56 per cent of people with disability and up to 76 per cent for people with severe or profound disability. The most common payment type is the Disability Support Pension (DSP) followed by New Start Allowance. It is estimated that 60% of people who received New Start Allowance or JobSeeker Payments live below the poverty line[18].

It is clear that the rates of both the DSP and the New Start Allowance are not adequate to meet the costs of those living with disability and need to be raised immediately. Feedback received by MS Australia from people living with MS is clear that these government payments are not adequate to meet the full costs of people living with MS. It places substantial economic burden on people living with MS and their carers, and directly influences their health and wellbeing. The DSP and New Start Allowance are difficult to access and maintain and do not provide adequate support and flexibility for those seeking employment. There is a strong focus on compliance rather than supporting individuals to meet their needs.

MS calls for **funding to support an immediate increase in the rates of the Disability Support Pension, New Start Allowance and JobSeeker Payments** and a more person-centred focus on the delivery of income payments to people with disability.

MS Australia also supports the proposal from ACOSS and UNSW Sydney **to develop a new set of poverty measures** in consultation with experts, advocates and people directly affected[19,20]. This includes considering a supplementary poverty line to capture major variations in living costs among people with disability. This aligns with the recommendation of the Economic Inclusion Advisory Committee that The Government legislate official poverty measures for Australia that include a monetary and multidimensional measure, are publicly reported on annually and supported by sufficient resourcing of the ABS[21].

3.5 DISABILITY ROYAL COMMISSION

MS Australia welcomed the Australian Government response and the Joint Government Response to the Disability Royal Commission and the commitment to work in partnership with the disability community and state and territory governments to implement meaningful change for people with disability. This important and timely work seeks to meet the vision of the Disability Royal Commission:

> *'A future where people with disability live free from violence, abuse, neglect and exploitation; human rights are protected; and individuals live with dignity, equality and respect, can take risks, and develop and fulfil their potential' Final Report of the Disability Royal Commission*[22].

The Disability Royal Commission recommendations provide a clear pathway for change across a range of sectors including disability services, employment, education, housing and justice. Implementing these recommendations will take many years and require extensive resources to ensure the recommendations are appropriately timed, developed and implemented. The recent move of disability (including oversight of the response to the Disability Royal Commission) to the Department of Health, Disability and Ageing provides further opportunities to ensure that reforms can align across the disability, health and aged care sectors.

To support this reform work, MS Australia calls for **funding to support the timely and effective implementation of the recommendations of the Disability Royal Commission**.

Better supports for people living with MS with Disability	
A better NDIS for people living with MS	• Funding to create a flexible, participant-focused and sustainable pricing mode for the NDIS that reflects real costs and encourages innovation and quality service delivery. • Funding to recruit, train, upskill and maintain a sufficient NDIA workforce and improved disability awareness and improved disability awareness and understanding across all government agencies. • Funding to improve NDIS planning and supports so they are evidence-based and focused on the needs of participants, including improved understanding of the needs of people living with MS • Funding for 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.

People living with disability should be supported by a highly skilled disability workforce	• Funding to attract, train, upskill and maintain a high-quality disability workforce to meet the needs of people living with disability.
People with MS living with disability need access to appropriate assistive technology	• Funding to develop a single, nationally consistent assistive technology program to support people with a disability who are not eligible for the NDIS.
People with disability deserve to live free from violence, abuse, neglect and exploitation and to have adequate support to meet the costs of living with disability	• Funding to support an immediate increase in the rates of the Disability Support Pension, New Start Allowance and JobSeeker Payments and a more person-centred focus on the delivery of income support payments to people with disability. • Funding to support the development of a new set of Australian poverty measures that include a supplementary poverty line to capture the additional costs of living with disability. • Funding to support the timely and effective implementation of the recommendations of the Disability Royal Commission.

4. AGED CARE

4.1 OLDER PEOPLE WITH DISABILITY

Older people living with disability make up a substantial proportion of the Australian community with 2.3 million Australians aged 65 years and over living with disability. This means 52.3% of people aged 65 and over have a disability and this represents 41.7% of all Australians with disability[23]. This is a rapidly growing cohort of older Australians, with an increase from 1.9 million in 2018.

For people living with MS, improvements in MS diagnosis, access to more effective Disease Modifying Treatments (DMTs), improvements in environmental exposures and health behaviours (such as decreasing smoking rates) and improved management of health comorbidities have resulted in disability milestones being reached almost eight years later on average[24,25]. The prevalence of MS and the life expectancy and average age of people living with MS have increased significantly during the last two decades[26,27]. This has led to an increasing number of older people living with MS[28].

People living with MS over the age of 65 are more likely to have a progressive form of MS, with 63% living with either primary progressive, secondary progressive or progressive relapsing MS. This leads to increased mobility issues, co-morbidities, psychological and cognitive problems, bowel and bladder dysfunction and limitations on undertaking activities of daily living[29,30]. There are also likely to have an increase in comorbidities including heart disease, psychiatric disorders, diabetes and cancer which can further increase levels of disability[31]. Late onset MS (after 50 years) occurs in 5% of cases and is characterised by a more progressive course and a higher prevalence of motor disability[32].

Improving the aged care system to better meet the needs of older Australians living with MS would:

- ✓ Allow people to remain independent and in their homes
- ✓ Improve people's engagement with their local community
- ✓ Delay disease progression
- ✓ Reduce hospitalisations
- ✓ Reduce early entry to residential aged care
- ✓ Reduce carer burden and lost productivity due to absence from work
- ✓ Reduce the long-term burden on the health system.

As a result of these changes in the MS disease trajectory, increasingly people living with MS are accessing supports later in life (over the aged of 65), need more complex, disability specific supports and need them for a longer period.

This increasing cohort of older Australians with disability, including people living with MS, need access to disability specific supports. However, the current aged care system does not cater to their disability specific needs. Feedback received by MS Australia from many older people living with MS indicates how they have to self-fund any shortfall in aged care services or go without, causing a significantly increased rate of disease progression and disability.

4.2 HOME CARE PACKAGES

As of 31 October 2025, 107,281 people were waiting in the National Priority System for a Home Care Package (HCP) at their approved level, with wait times of up to 10 months[33]. Advice provided by the Department of Health, Disability and Ageing to the Senate Inquiry into Aged Care Service Delivery indicates there is an additional 121,595 people awaiting for an assessment[34]. This means there are over 220,000 older Australians waiting to access HCPs.

The longer that people wait for appropriate aged care, the higher risk of increased disability, hospitalisation and early entry into residential aged care. If this gap in home care packages and assessment wait times is not addressed urgently, it will continue to grow. This gap is further exacerbated by the Government's delay in releasing the 83,000 packages promised prior to the 2025 federal election, before 30 June 2026. Further, the lack of transparency around data on current wait times for both packages and assessments make it difficult to keep track of the growing gap.

As the HCP program transitions to the Support at Home program, further funding will be needed to ensure that people receiving packages at the new higher classifications are able to access them in a timely manner.

MS Australia supports the implementation of the following recommendations from the Senate Standing Committees on Community Affairs final report on Aged Care Service Delivery:

- **Recommendation 1:** The committee recommends that the Australian Government release all 83,000 packages promised prior to the 2025 federal election, before 30 June 2026.
- **Recommendation 2:** The committee recommends that the Australian Government make provision for additional Support at Home packages as a matter of urgency, to meet the needs of the over 200,000 older Australians who are either waiting for a package or waiting for an assessment for a package as identified by the Department of Health, Disability and Ageing.
- **Recommendation 3**: The committee recommends that the Australian Government work towards ending the rationing of care packages in a timeframe that is consistent with the sector's capacity to deliver the additional packages.
- **Recommendation 5:** The committee recommends the Department of Health, Disability and Ageing publish real-time information on both the waiting period for assessment and receipt of a home care service package; and review communication strategies to ensure that older people remain engaged with seeking assistance.
- **Recommendation 6:** The committee urges the Inspector-General of Aged Care to consider conducting an urgent review into the operation of the Single Assessment System.

4.3 EQUITY FOR OLDER PEOPLE WITH DISABILITY

The Royal Commission into Aged Care Quality and Safety found that older people with disability receiving aged care do not have access to services and supports at the same level as those provided to NDIS participants. The Commission recommended the new aged care system includes equity for people with disability:

> *By 1 July 2024, every person receiving aged care who is living with disability, regardless of when acquired, should receive through the aged care program daily living supports and outcomes (including assistive technologies, aids and equipment) equivalent to those that would be available under the National Disability Insurance Scheme to a person under the age of 65 years with the same or substantially similar conditions (Recommendation 72)*[35].

The findings of the Royal Commission were supported by the NDIS Review. Which made the following recommendation:

> *The Australian Government should implement legislative change to allow participants once they turn 65 to receive supports in both the NDIS and the aged care system concurrently and clarify when aged care supports are reasonable and necessary (Action 2.11, NDIS Review Final Report)*[36]*.*

This is further supported by the final report from the Senate Inquiry into Aged Care Service Delivery which states that 'insufficient provisions have been made for older Australians with a disability, or chronic or complex condition to receive appropriate at home care' and that the Australian Government cannot continue to ignore the recommendations of the Aged Care Royal Commission and the NDIS Review. The report includes the following recommendation:

> *The committee recommends that the Australian Government should consider the adequacy of daily living supports delivered through the at-home aged care system for older Australians living with a disability, in comparison with those delivered through the National Disability Insurance Scheme (Recommendation 8)*[37]*.*

Aged Care Service List

The aged care service list for the new Support at Home Program does not include all the disability supports available under the NDIS and has a strong emphasis on people moving to residential aged care when their needs increase. Support to live independently, build skills, transition through life stages, train support workers, travel independently and engage fully in the community are not available under this new program. Further, many supports such as specialist behaviour support, are only available in residential aged care.

Support at Home Program Funding

MS Australia welcomes the introduction in November 2025 of the new Support at Home Program and acknowledges that the program's new classifications levels have significantly higher funding than HCPs. However, as outlined in our submission on the new aged care funding rules and our submission to the Inquiry into Aged Care Service Delivery , there is still a significant gap compared to the current levels of funding available to people living with MS under the NDIS.

The new Support at Home classifications will provide funding of between $11,000 and $78,000 per year. Even allowing for some additional funds from the new Assistive Technology and Home Modifications (AT-HM) program, there is still a significant disparity with NDIS funding. Outlined below are the average annual payments for NDIS participants with MS:

NDIS participants with MS	Average annual payments	Average annual committed payments
All participants	$103,500	$136,900
Participants in Supported Independent Living (SIL)	$531,800	$598,100
Participants not in SIL	$85,300	$118,400

* Data as of 30 September 2025 from the NDIS Quarterly Report[38].

As outlined in the data above, there is a gap between the annual committed and annual spent budget for NDIS participants. Currently, NDIS participants face administrative and planning challenges that prevent them from spending their full budget. With significant changes to the NDIS in 2025-26 it is anticipated that participants will have greater opportunity to spend their full committed budget. This would make the gap between NDIS payments and the proposed aged care budgets even more significant.

The above NDIS data also shows that participants who have access to SIL have significant budgets. Access to appropriate housing is crucial to people living with MS maintaining their independence. Older people with disability need access to housing that is driven by participant choice and control and that best meets their individual needs and long and short-term goals.

MS Australia calls for increased **funding under the Support at Home program for older people with disability** so they can access the disability specific supports they need. Alternatively, older people with disability should be allowed to **access disability supports under the NDIS** in addition to aged care services.

The Australian Government needs to urgently address the inequity in supports and funding available for older people living with disability through both improve the aged care system and allowing access to improve the level of support available to older people living with disability in both the aged care and NDIS systems.

Reforming the aged care system to meet the needs of people living with disability needs to be met with appropriate funding to redesign services, capacity build providers, train staff and update policies and procedures.

4.4 MY AGED CARE

My Aged Care provides the single-entry point or ‘front door’ to Australia’s aged care system for older people seeking access to Australian Government–subsidised aged care services and supports. It is crucial that My Aged Care provides timely access to aged care service for all other Australians including the provision of information, registration and referral, to the point of receiving a needs-based assessment for services.

MS Australia welcomes the My Aged Care Final Review Report released the Inspector General of Aged Care. The report found that My Aged Care is currently not providing the intended ‘front door’ to the aged care system and for many older people seeking to access aged care services it is more akin to navigating a maze. The Inspector General found that My Aged Care is not equitable for older people from diverse backgrounds and those with complex needs, including older people living with disability.

> *The Inspector-General is concerned that My Aged Care is not sufficiently oriented towards supporting older people in Australia living with disability, particularly given the limited availability of accessible resources and lack of appropriate training for frontline staff. The Inspector-General notes that for people living with disability, these issues can act as substantial barriers to accessing My Aged Care*[39].

The Inspector-General made recommendations across seven thematic areas to improve My Aged Care including improving public awareness and understanding, reducing system complexity, increasing capacity and capability of the workforce, increasing navigational and face-to-face support, enabling equitable access to aged care and commitment to action.

MS Australia supports the timely implementation of the recommendations of the Inspector-General of Aged Care’s review of My Aged Care.

Increased funding and supports for older people living with MS	
Older people living with MS are overlooked in the Aged Care system which negatively affects their wellbeing and quality of life. They need timely access to supports and funding to meet their MS specific needs.	• Funding to meet the needs of the over 220,000 older Australians waiting for Support at Home packages and assessments including: » Funding for additional Support at Home packages, including removing rationing of packages over time » Funding for improving, training and expanding the aged care assessment workforce » Funding for improved and timely data on wait times for packages and assessments
	• Funding to ensure equity of services and funding for older people living with disability including: » Expanding the aged care service list to include supports that allow people to maintain independence, choice and control » Support for aged care providers to train and upskill staff and improve policies and procedures » Increasing the levels of funding available under the Support at Home Program so that funding levels match the NDIS and/or allowing care recipients to top up their aged care funding with NDIS supports • Funding to implement the six recommendations of the Inspector General's review of My Aged Care

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