PRE-BUDGET SUBMISSION 2025-26

JANUARY 2025

MS AUSTRALIA

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RESEARCH
ADVOCACY
CURE

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) is the most acquired neurological disease in younger adults around the world with over 2.8 million people affected. More than 33,300 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.

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.

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EXECUTIVE SUMMARY

MS Australia is pleased to lodge this Pre-Budget submission to the Australian Government for the 2025-26 Budget.

MS Increase

Research released by MS Australia in February 2023[1] revealed that there has been a significant increase in the number of people living with MS in Australia over the last four years. There were 33,335 people living with MS in Australia in 2021, an increase of 7,728 people (from 25,607 people) since 2017. Notably, this increase is accelerating (more than doubled) from MS Australia's previous estimate from 2010 to 2017 where there was an increase of 4,324.

Taking the 2021 Australian Census population estimates into account (and noting slowed population growth from the previous reporting period due to COVID-19 and the halt in overseas migration to Australia), there were 131.12 people living with MS per 100,000 people in Australia in 2021. This is an increase from 103.7 per 100,000 people in 2017 and aligns with the increase in prevalence in local areas of Australia and globally.

Economic Impact of MS

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 annual cost of a person living with MS is $73,457. This figure is a $5,075 increase in costs from 2017, with many of these being direct costs borne by the person living with MS and their carer. It also includes indirect costs from lost wages, informal care, and early retirement.

For those with 'severe disability,' the costs are more than triple at $123,333 compared with those living with low or no disability ($32,829).

Out-of-pocket costs for health care 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.

Total costs for all people with MS in Australia increased from **$1.751 billion in 2017 to $2.449 billion in 2021**.

Four Key Funding Asks

MS Australia's 2025-26 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 national MS Nurses national strategy, a MS Nurses pilot and the development of a MS nursing microcredential
3. **Disability:** Improved support for people with MS living with disability through improved NDIS pricing, a better NDIA workforce, a better disability sector workforce, housing and living supports, assistive technology, improved income support and implementing the recommendations of the Disability Royal Commission
4. **Aged Care:** Improve older people living with MS through increased funding under the Support at Home Program.

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	The Australian Institute of Health and Welfare were previously funded to identify the current neurological data gaps and opportunities. Building on that scoping study we are now calling for **$550,000 over four years** to take the project forward.

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 million over four years** for a MS Nurses pilot project 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
2.4 MS Nursing Microcredential	Department of Education	**$30,000** to develop a MS Nursing microcredential **$90,000 over three years** to provide scholarships for nurses undertaking the microcredential (10 scholarships a year)

ASK 3: DISABILITY

Proposal	Portfolio	Funding ask
3.1 NDIS Pricing	Independent Health and Aged Care Pricing Authority	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
3.2 NDIA	NDIA	Funding to recruit, train, upskill and maintain a sufficient NDIA workforce and improvement disability awareness and understanding across all government agencies
3.3 Disability Workforce	NDIA	Funding to attract, train, upskill and maintain a high-quality disability workforce to meet the needs of people living with disability
3.4 Housing and Living	NDIA	Funding to improve housing and living supports
3.5 Assistive Technology	NDIA	Funding to develop a single, nationally consistent assistive technology program
3.6 Income Support	Services Australia	Funding to support an immediate increase in the rates of the Disability Support Pension, New Start Allowance and JobSeeker Payments
3.7 Disability Royal Commission	DSS	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 Older People with disability	DOHA	Increased funding under the Support at Home program for older people with disability

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 over the past 25 years. In this timeframe we have delivered many specific MS therapies 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 can often be delayed or significantly halted from the time it is first seen 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.

Earlier detection of MS requires the development of reliable markers of early disease, an effort that is reliant upon MS biobanks to collect blood and other biological samples to enable medical research and generate scientific knowledge. A nationally collaborative approach to MS biobanks would significantly improve the impact of biobanking on MS research.

MS Australia is calling for the establishment of a National MS Biobank to support MS Australian studies towards early detection and prevention of MS.

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.

MS Diagnosis

Data from the Australian MS Longitudinal Study[3] indicates that in 2017-2021 the average time to diagnosis was three years and almost 11 months. However, there remain people who are not diagnosed as having MS for many years. This reflects the complexity of MS, with some people taking many years to manifest.

Many people diagnosed with MS continue to undergo prolonged and intricate diagnostic processes.

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 our ability to recognise and diagnose MS earlier.

Finding biomarkers of 'pre-MS'

People with a family history of MS are at more risk 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 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. Further work is required to understand the potential of this, and several other candidates, as blood markers for the 'pre-MS phase. MS biobanks are critical to this work.

Stopping MS Before It Starts

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

Biobanking is essential to monitoring any rollout of EBV vaccines, and 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.

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 enable medical research and generate scientific knowledge.

A National MS Biobank would be 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.

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 or national patient organisations representing adults and children living with a neurological or neuromuscular conditions or neurological disorders 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 neuromuscular conditions, or neurological disorders.

The associated annual economic cost to the Australian economy 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.

Neurological and Neuromuscular Health Research Mission

Current efforts for neurological disorders are scattered across 25 uncoordinated programs and Missions.

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

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.

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 diseases 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.

Currently, the Australian Institute of Health and Welfare (AIHW) undertakes some limited monitoring of neurological conditions, including stroke, brain cancer and dementia. However, there is no national neurological dataset that incorporates comprehensive national surveillance and monitoring of neurological conditions. The AIHW is well-positioned to develop and coordinate this dataset as they currently undertaken similar work for chronic health conditions.

MS Australia and the NAA welcomed the funding and establishment of the AIHW's *Neuro Conditions Expert Advisory Group* in 2024 to undertake initial scoping for a neurological data set. MS Australia and the NAA are calling for further funding of **$550,000** over four years for the AIHW to build on the work undertaken in the initial scoping study.

The outcome of these projects will help to guide the future monitoring of neurological conditions by the AIHW. The AIHW undertook a similar scoping study and data report during the creation of the National Centre for Monitoring Dementia which undertakes a range of dementia data improvement activities.

2. MS NURSES

2.1 MS NURSES

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) symptomatic therapies, order pathology and some radiology. At their November 2024 meeting the Pharmaceutical Benefits Advisory Committee (PBAC) recommended that MS NPs be allowed to prescribe certain MS treatments under the PBS. This change will improve 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.

MS Nurse Care in Australia Report

The *MS Nurse Care in Australia Report*[6] developed by MS Australia, in collaboration with the Menzies Institute for Medical Research and MS Nurses Australasia 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.

Movement Disorder Nurse Specialist Pilot

In 2020 the Department of Health and Aged Care funded the Movement Disorder Nurse Specialist (MDNS) pilot to increase the capacity of nurses to care for people living with neurological conditions. Funding went to four PHNs to deliver care to people living with Parkinsons disease, with each PHN implementing a different model to meet the unique needs of their community. Evaluation of the pilot[7] found that all models delivered positive benefits to patients and carers, the nurses involved in the pilot, and the health system overall, including:

- Patients maintained their quality of life over the period of the evaluation despite the progressive and degenerative nature of neurological conditions
- Patients and carers experienced increased access to specialist care; increased access to supportive care (such as the NDIS); greater understanding of neurological conditions; greater ability to self-manage and provide care at home; and greater coordination of care.
- It built the overall capacity of the health workforce, supported greater collaboration at the system level, and delivered system efficiencies.
- The specialist nurses relieved pressure on other specialist neurological services and patient usage of other health services including fewer presentations to the Emergency Department, fewer planned and unplanned hospitalisations, and overall fewer days in hospital if they were hospitalised.
- The pilot was cost effective when compared to some other interventions for patients with Parkinson's disease.

The evaluation also found that a sustainable neurological nursing workforce requires support from employers, adequate time to see patients, funding for training (including travel and backfill), mentorship and peer support.

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.

We are also calling for the development and implementation of a National MS Nurses Strategy with an accompanying pilot project to co-design, implement and evaluate a best practice model of MS nurse care, as outlined below.

2.2 MS NURSES NATIONAL STRATEGY

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.

2.3 MS NURSES PILOT PROJECT

MS Australia in partnership with Menzies Institute for Medical Research and MS Nurses Australasia is calling for funding for the development of a MS nursing pilot including:

- Co-design, implement and evaluate a best practice model of MS Nurse care in a location to be determined
- Assess the impact of increasing the current level of MS Nurse care to ensure a best practice caseload for nurses and MS patients
- Evaluate the outcomes, so that other states and territories can apply the lessons learned during this project
- A cost-effectiveness assessment.

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 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 MS Nurses Australasia is calling for funding to develop a MS nursing micro-credential. The microcredential provides a professional qualification recognised under the Australian Qualifications Framework (AQF). Theses 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 MS Nurses Australasia. They already have experience developing microcredentials including the development of a Parkinsons Care microcredential under the Australian Governments Microcredentials Pilot in Higher Education.

The MDNS pilot evaluation[8] found that in rural and remote areas a generalist nurse with some additional specialist training could be beneficial to communities with a small number of nurses that need to support people with a variety of conditions. These nurses could also form part of a 'hub-and-spoke' model with a specialist MS nurse located in a larger regional or urban centre. A MS nursing microcredential would be the ideal training option for these nurses and could also be paired with the Parkinsons Care microcredential.

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**.

3. DISABILITY

3.1 NDIS PRICING

MS Australia calls for improved NDIS pricing arrangements including greater transparency and better evidence based independent pricing. Feedback from our state and territory Member Organisations is that the current NDIS pricing arrangements are not consistent, do not align with the true costs of delivering services, are not indexed annually and are not evidence-based. 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.

As has been widely reported and acknowledged, service providers across the disability sector are providing unfunded hours of support, especially support coordination and plan management.

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. MS Australia welcomed funding in the 2024-25 budget for the IHACPA to work with the Department of Social Services and the NDIA to undertake initial work to reform NDIS pricing arrangements, including reviewing existing pricing approaches and developing a pricing data strategy. MS Australia provided a submission to the IHACPA on NDIS pricing reform and made recommendations to support the creation of a flexible, participant-focused, and sustainable pricing model for the NDIS, ensuring that both participants and providers benefit from a system that reflects real costs while encouraging innovation and quality service delivery.

MS Australia calls for **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.** This includes funding to:

- Transfer NDIS pricing to the IHACPA
- Implement changes to NDIS Pricing arrangements as recommended by the IHACPA
- Develop and implement a NDIS pricing data strategy based on advice from the IHACPA.

3.2 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. We have also raised concerns regarding the inconsistency of decision-making, poor assessment and planning processes and inconsistency with legislation and guidelines.

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 who 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 improvement disability awareness and understanding across all government agencies.** This includes:

Improved, timely and responsive training for NDIA staff on the implementation 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
- Resourcing for the NDIS Quality and Safeguards Commission to establish a quality function to drive quality improvement across the disability sector as per Action 12.1 of the NDIS Review

Improving the NDIA and broader government workforce will ensure:

- ✓ NDIS participants only have to tell their stories once and are not exposed to ongoing trauma
- ✓ Participants undergo assessments that are fit for purpose
- ✓ Participants receive a plan that meets their individual needs and makes best use of their NDIS funds
- ✓ Costs savings from reduced administration due to fewer inquiries, internal reviews and Administrative Appeals Tribunal cases
- ✓ Disability policy and programs are fit for purpose and better meet the needs of people with disability
- ✓ A government workforce that is disability aware and treats people with disability with respect
- ✓ A more inclusive Australia where people with disability can be active participants in their community.

- Targeted training and capability building for government organisations and staff, professionals and providers who deliver government services as per Action 2.2 of the NDIS Review
- Embedding a highly skilled, person-centred, disability aware culture across all disability agencies and governments as per Recommendation of the NDIS Review.

3.3 DISABILITY WORKFORCE

Currently, the disability workforce is made up overwhelmingly of part-time, untrained and lowly paid support workers. There are high rates of turnover and casualisation across the sector. 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 grown 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.

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.

3.4 HOUSING AND LIVING

Access to appropriate accommodation is crucial to people living with MS 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 1,271 people under the age of 65 living in aged care 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[9] 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
- Strengthen the NDIS Quality and Safeguards Commission's 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.

3.5 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'[10]. A study of assistive technology undertaken by Monash University[11] 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.*[12]

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.

3.6 INCOME SUPPORT

Research undertaken by UNSW and ACCOSS[13] 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% (compared with 13.4% across the whole population) and that people with disability make up 33% of all people in poverty. In households whose reference person receives the Disability Support Pension, 43% live below the poverty line.

The AIHW[14] found that 38% of people with disability and 51% of people with severe or profound disability have a low level of personal income, compared to 27% without disability. Government pensions or allowances are the main source of income for 56% of people with disability and up to 76% 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[15].

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 and the rate their disease progresses at. They are also 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 Australia 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.

3.7 DISABILITY ROYAL COMMISSION

MS Australia welcomes the Australian 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[16]

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. To support this work, MS Australia calls for **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% of all Australians with disability[17] 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[18,19]. The prevalence of MS and the life expectancy and average age of people living with MS have increased significantly during the last two decades[20,21]. This has led to an increasing number of older people living with MS[22].

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[23,24]. 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[25]. Late onset MS (after 50 years) occurs in 5 per cent of cases and is characterised by a more progressive course and a higher prevalence of motor disability[26].

Improving the aged care funding for 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 people living with MS indicates that many older people living with MS have to self-fund any shortfall in aged care services or go without, causing a significantly increased rate of disease progression and disability.

NDIS Review

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)[27].

The Final Report does note that 'People aged over 65 will likely benefit from foundational supports… but should receive most of their supports from the aged care system'. In light of this, it is critical that the aged care system meets the needs of people living with disability and that they fully implement Recommendation 72 from the Royal Commission into Aged Care Quality and Safety (Royal Commission):

> *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[28].*

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.

Support at Home Program Funding

MS Australia welcomes the introduction in July 2025 of a new Support at Home Program and acknowledges that the program's new classifications levels will have significantly higher funding than the current home care packages. However, as outlined in our submission to on the new aged care funding rules, 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	$102,300	$132,000
Participants in Supported Independent Living (SIL)	$523,100	$562,000
Participants not in SIL	$83,700	$112,800

*Data as at 30 September 2024 from the NDIS Quarterly Report[29]

As outlined in the data above, there is a gap between the annual committed and annual spent budget for NDIS participants. Currently, participants face administrative and planning challenges that prevent them from spending their full budget. With significant changes to the NDIS in 2025 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 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.

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