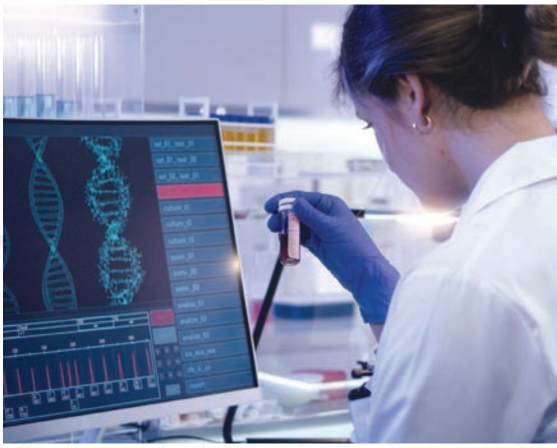
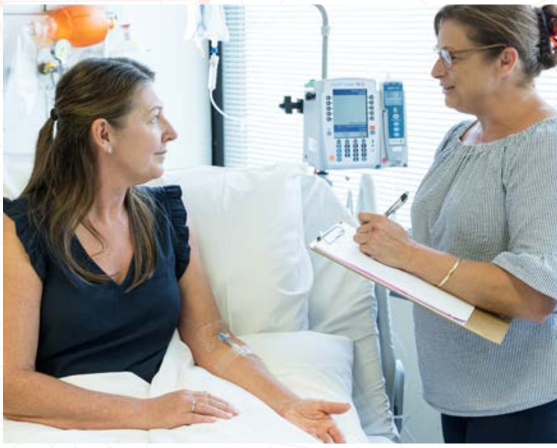
RESEARCH
ADVOCACY
CURE





2024-25 PRE-BUDGET SUBMISSION

JANUARY 2024

RESEARCH
ADVOCACY
CURE

2024-25 Pre-Budget Submission

Associate Professor Des Graham
President

Rohan Greenland
Chief Executive Officer

EXECUTIVE SUMMARY

Recommends:

RESEARCH

- **$8 million over five years** to fund a National MS Biobank to support Australian studies towards early detection and prevention of MS,
- **Funding for the establishment of a Neurological Mission** within the Medical Research Future Fund including:
    - **$250,000** to fund development of a roadmap and implementation plan.

DATA

- **$550,000** for the Australian Institute of Health and Welfare to identify the current neurological data gaps and opportunities, including:
    - **$400,000** for a scoping study leading to the development of a minimum data set for neurological and neuromuscular conditions in Australia.
    - **$150,000** for a data report on neurological conditions in Australia to report the latest available data.

MS NURSES

- **$6.5 million** to employ an additional 65 MS Nurses for the people living with MS currently without access in Australia
- **$3 million over four years** for a MS nurses pilot project in Tasmania with associated research project to assess impact.

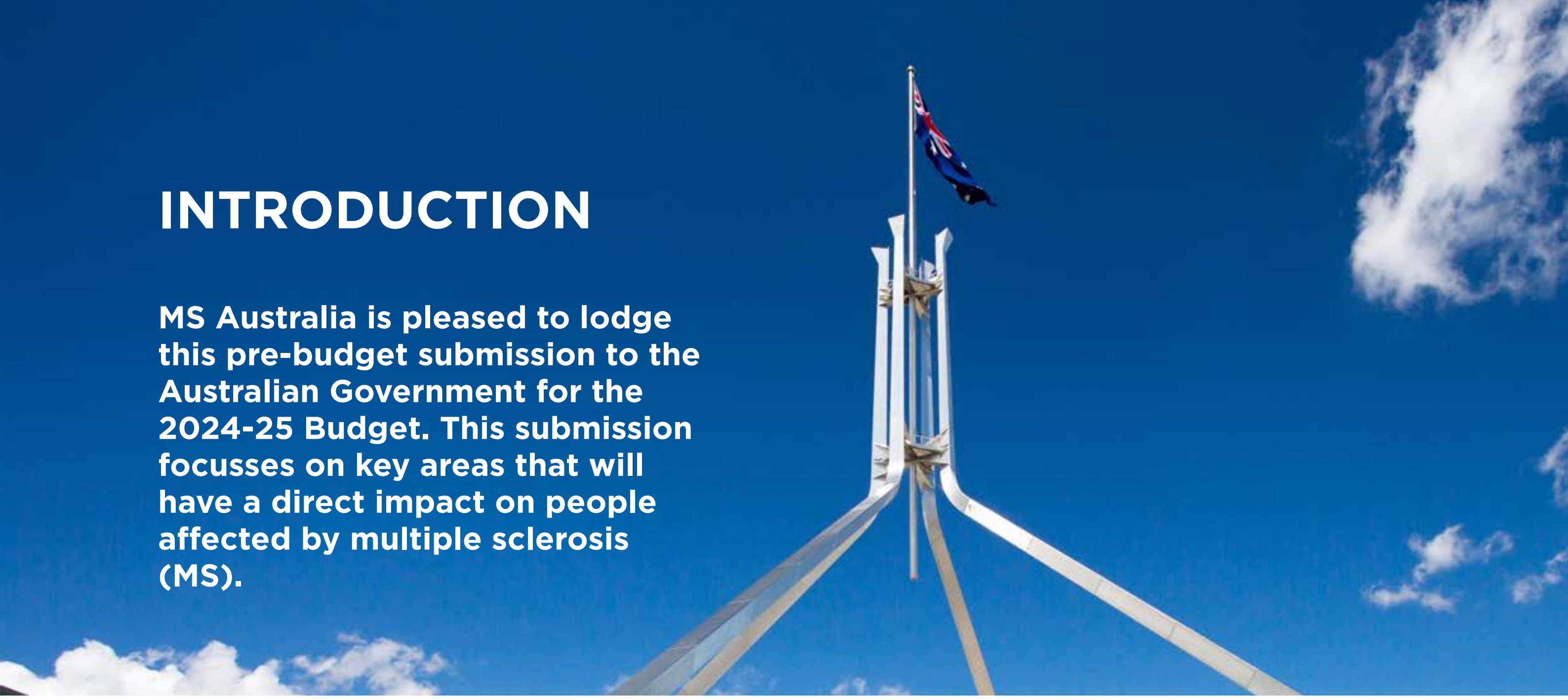
DISABILITY

- **Funding to support the implementation of the recommendations of the NDIS Review** including design, testing, consultation and development of new policies and practices
- **Funding to recruit, train and maintain a sufficient workforce** of:
    - General and specialist Navigators to assist people with disability to navigate disability systems including the NDIS
    - Assessors to undertake comprehensive, needs based assessments for NDIS participants
- **Funding for the NDIA to commission additional medical reports and assessments for NDIS applicants as required**
- **Funding to upskill the National Disability Insurance Agency** including:
    - embedding a highly skilled, person-centred, disability aware culture
    - improved disability education and training and the establishment of a resource library of disability materials
    - Increasing, recruiting and maintaining the number of NDIA staff who have lived experience of disability
    - establishing a NDIA neurological advisory group

- **Funding to develop and establish improved NDIS early intervention pathways**
- **Funding to improve living supports** including:
    - Whole-of-person housing budgets
    - Housing and Living Navigators
    - New Specialist Disability Accommodation
    - Upgrading and repurposing ageing Specialist Disability Accommodation stock
- **Funding for the design, commissioning and delivery of foundational disability supports** outside individualised NDIS packages
- **Funding a single, nationally consistent assistive technology program** to support people with disability who are not eligible for the NDIS
- **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
- **Funding to implement the recommendations of the Disability Royal Commission.**

AGED CARE

- **Funding to support the implementation of Recommendation 72 of the Royal Commission into Aged Care Quality and Safety** to ensure the aged care system meets the needs of people living with disability.



INTRODUCTION

MS Australia is pleased to lodge this pre-budget submission to the Australian Government for the 2024-25 Budget. This submission focusses on key areas that will have a direct impact on people affected by multiple sclerosis (MS).

MS Australia seeks commitments from the Australian Government through the 2024-25 Federal Budget to:

- Prevent and ultimately defeat MS in Australia through a significant investment in research funding for better treatments, prevention and ultimately, a cure for MS
- Improve access to MS Nurses
- Improve support for people with MS living with disability
- Improve support for people ageing with MS.

MS AUSTRALIA

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

MS is the most commonly 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.

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.

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. The annual costs of MS per person in Australia in 2021 were $73,457 an increase of $5,075 from 2017. Annual per person costs increase with increasing disability levels from $32,829 for people with MS with no disability to $123,333 for people with severe disability. Total costs for all people with MS in Australia have increased from $1.751 billion in 2017 to $2.449 billion in 2021.

This submission provides funding options 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:

- Research to prevent people from developing MS, improving early diagnosis and to develop effective treatments and interventions to slow or prevent disease progression
- Increasing access to MS Nurses and the associated improved health benefits
- Implementing the recommendations of the NDIS Review and the Disability Royal Commission and providing person-centred disability appropriate supports for people living with MS
- Improved access to aged care services that meet the needs of older people with disability and improve community and social participation.

MS RESEARCH

Supercharge MS research through significant investment in better treatments, prevention, information and ultimately a cure for MS

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. MS occurs because the immune system mistakenly attacks the brain and spinal cord, and MS therapies suppress the immune attack.

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. Experts believe a large proportion of MS could be preventable. Even being able to halt MS at an earlier stage has enormous potential to significantly reduce the burden of this disease.

Working with Australian researchers, MS Australia has initiatives in place to tackle the reversal of neurological damage and disability. Our urgent unmet need now is to prevent or detect MS earlier and to stop irreversible damage to the brain and spinal cord before it begins.

Using an MS Biobank to Stop MS Earlier

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.

The 'pre-MS' period

We have known for many years that the disease process in MS likely begins many years before the onset of typical clinical symptoms at around age 30-40.

But over the last decade, large studies have shown a trend of declining health in the years before MS diagnosis. A newer concept of an 'MS prodrome' has emerged, with early signs and symptoms that occur years before typical MS clinical symptoms appear[2].

Better understanding and better detection of this 'pre-MS' phase could profoundly improve our ability to recognise and diagnose MS earlier; allowing us to prevent MS or halt/delay symptoms and disability.

Finding biomarkers of ‘pre-MS’

Given the genetic susceptibility to MS, insights into the ‘pre-MS’ period have come from studies of healthy close relatives of people with MS. Brain imaging of these relatives (including many twins) showed that 14 per cent had brain abnormalities fitting MS criteria; and many of these went on to develop MS later. This suggests there are early changes in the brain before MS clinical symptoms appear[3]. However, regular brain imaging may prove impractical and too costly for screening large numbers of healthy people.

We do not have a blood test to detect early MS, however, international MS biobanks have identified promising candidates. One of these is a breakdown product of damaged nerves that can be detected in the blood. Levels of this ’neurofilament light chain’ are raised in the blood from around six years before MS onset[4] . 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

A recent study has provided the strongest evidence yet that infection with the Epstein-Barr virus (EBV, the causative agent of glandular fever) is essential for the development of MS[5] . EBV infection increased the risk of developing MS by 32-fold in a large US military cohort measured over many years. Signs of nerve damage in the blood only ever appeared after EBV infection.

We are closer than ever to preventing EBV infection, with two new-generation EBV vaccines currently in international clinical trials. In future, biobanking will be essential to monitor 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, and the effect of public health initiatives towards preventing MS.

The National MS Biobank

A national research platform is needed to develop markers to detect MS earlier, and to identify people at high risk of developing MS so we can prevent it. For this work we need very detailed insights into people’s MS, or their risk factors for MS. This will include blood and other biological sample markers and genetics. Together with clinical data and brain imaging, this rich data source will allow us to screen and group people according to risk or stage of MS.

Such a resource is essential if we are to find patterns to detect MS earlier, and ultimately a large proportion of new cases of MS could potentially be prevented.

NEUROLOGICAL MISSION

Neurological conditions should be considered a major national priority for medical research. Nearly 1.6 million Australians live with a progressive neurological or neuromuscular condition in Australia with an annual cost to the Australian economy of over $36 billion. The establishment of a MRFF Neurological Mission would bring together key researchers, health professionals, stakeholders, industry partners and patients to tackle the health challenges related to neurological conditions.

Currently, MRFF activities are based on areas of national priority identified by the Australian Medical Research Advisory Board (AMRAB) and widespread consultation. The AMRAB is required to take into account ‘the burden of disease on the Australian community’ in determining the MRFF Priorities. In 2021 the Australian National Audit Office (ANAO) undertook a review of the Department of Health’s Management of Financial Assistance under the MRFF[6]. The ANAO found that diseases with a high disability burden, such as asthma, musculoskeletal diseases and neurological and psychiatric disorders, have been overlooked or had received limited coverage with primary care meriting greater priority in funding allocations.

MS Australia calls on the Department of Health and the AMRAB to allocate funding for the establishment of a MRFF Neurological Mission.

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) National Centre for Monitoring Chronic Conditions (NCMCC) undertakes national surveillance and monitoring of chronic conditions in Australia. The AIHW NCMCC includes the measurement of risk factors, prevalence, hospitalisations, comorbidities, burden of disease, mortality and expenditure for conditions such as cardiovascular disease, diabetes, kidney disease, musculoskeletal conditions and respiratory conditions. The AIHW does undertake some monitoring of neurological conditions, including stroke, brain cancer and dementia as part of other programs of work. The AIHW also currently monitors some aspects of neurological conditions as a condition group including mortality and burden of disease. The AIHW is well-positioned to focus efforts and coordinate these data for comprehensive monitoring of all neurological conditions either individually or as a group in Australia.

The Neurological Alliance Australia (NAA), of which MS Australia is a founding member, met with the AIHW in November 2022 to discuss to discuss the current national neurological data gaps and opportunities for monitoring neurological conditions, with a view to improving health outcomes for people living with neurological conditions and inform evidence-based policy. The AIHW advised that there are two essential projects that must be undertaken to establish the current neurological data gaps and opportunities:

- A scoping study that comprises a short report reviewing and assessing Australian data sources for neurological conditions, including identifying gaps and opportunities for data improvements pertaining to the topics of interest; and
- A data report on neurological conditions in Australia that would report the latest available data.

The outcome of these projects can then help to guide the future monitoring of neurological conditions by the AIHW. The AIHW have recently undertaken a similar project with the creation of the National Centre for Monitoring Dementia (NCMD) which was established to undertake a range of data improvement activities. This included scoping data gaps and opportunities, a comprehensive data report and the implementing an ongoing monitoring and reporting program for dementia in Australia.

MS AUSTRALIA ***Recommends:***

- **$8 million over five years** to fund a National MS Biobank to support Australian studies towards early detection and prevention of MS.
- **Funding for the establishment of a Neurological Mission** within the Medical Research Future Fund including:
  - **$250,000** to fund development of a roadmap and implementation plan.
- **$550,000 for the Australian Institute of Health and Welfare to identify the current neurological data gaps and opportunities, including:**
  - **$400,000** for the for a scoping study leading to the development of a minimum data set for neurological and neuromuscular conditions in Australia
  - **$150,000** for a data report on neurological conditions in Australia would report the latest available data.

MS NURSES

Improving the healthcare of people with MS through increased access to MS Nurses

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.

The *MS Nurse Care in Australia* Report[7] 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 (equivalent to 8,000 people) do not have access to life-changing MS nurse care and have consistently worse health outcomes. MS Nurse care reduces the need for other, more costly health professionals, such as GPs and neurologists and prevents emergency department presentations and potentially, hospital admissions. It is a highly cost-effective model of care.

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.

The increasing numbers of Australians living with MS will significantly impact on the Australian health system. An immediate increase in MS Nurses is crucial if this growing need is to be met.

MS Nurses Pilot Project

The MS Nurses Pilot Project is a collaboration between MS Australia, MS Nurses Australasia (MSNA), and the University of Tasmania to co-design, implement and evaluate a best practice model of MS Nurse care in Tasmania.

Tasmania has the highest rate of people living with MS in Australia with a current MS Nurse caseload of 954 patients per FTE.

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.

- Budget for the research work undertaken by Menzies: **$1,669,656** over four years.
- Budget for an additional 2.73 FTE MS Nurse time: **$1,336,402** over four years.
- Total budget: **$3,006,058**

The project plan for pilot project has been provided as a Supplementary document to this submission.

MS AUSTRALIA

Recommends:

- **$6.5 million** to employ an additional 650 MS Nurses for the people living with MS currently without access in Australia. Based on a conservative estimate of 10% cost savings, this could reduce the cost of their overall MS care by **$77.1 million** annually
- **$3 million** over four years for a MS nurses pilot project in Tasmania with associated research project to assess impact.

DISABILITY

Improved support for people living with MS through a better, fairer NDIS

Over the past eight years, MS Australia has actively advocated on behalf of people living with MS for improvements to the National Disability Insurance Scheme (NDIS). This includes providing four submissions to the recent NDIS Review outlining the need for improved assessment, planning, early intervention and supports for people living with MS and a greater understanding of neurological conditions.

MS Australia welcomed the Final Report of the NDIS Review, Working together to deliver the NDIS Independent Review into the National Disability Insurance Scheme, (Final Report) released on 7 December 2023. The report outlines a range of important reforms for the NDIS. It is essential that the Australian Government provide support for the implementation of these recommendations including ensure appropriate resources for the design, testing, consultation and development of new policies and practices.

Navigators & Assessors

People living with MS currently struggle to navigate the complex NDIS assessment and planning systems and to access the appropriate providers to deliver the supports and services they need. NDIA staff, including planners, do not have a good understanding of disability including neurological conditions and disorders, chronic illness and progressive conditions. Local Area Coordinators do not have the appropriate skills and training to help participants understand and access the NDIS or cover too large an area to provide individual support.

Access to support coordination and plan management are crucial supports for people living with MS who may experience brain fog, memory and fatigue issues that make it difficult to manage their plan. Currently, support coordination and plan management are either not in participants plans or vastly underfunded. MS Australia's Member Organisations provide many additional hours of unfunded support coordination and plan management to help participants living with MS.

MS Australia welcomes the recommendation of the NDIS Review to introduce Navigators to support people with disability to navigate disability systems, find supports in their community and make the best use of their funding (Recommendation 4). The NDIA should have adequate funding to recruit, train and maintain this Navigation workforce, including specialist Navigators for participants who have more complex or specific needs and an appropriate number of Navigators to meet need across Australia. MS also welcomes the recommendation to introduce a new needs assessment process undertaken by a highly trained assessment workforce to undertake NDIS assessments (Action 3.4). The NDIA should have adequate funding to recruit, train and maintain this workforce and provide enough assessors so that have sufficient time when assessing people.

Currently, NDIS participants must pay for any additional medical reports and assessments required by the NDIA. MS Australia welcomes the proposed approached from the NDIS Review:

> *Where additional information is needed, the NDIA should commission and pay for professional assessments and reports. This will remove a significant inequity in the current process, which favours those who have the ability and means to collect or purchase additional information (pg. 39, Final Report)*

National Disability Insurance Agency

MS Australia is concerned that National Disability Insurance Agency (NDIA) staff are not appropriately trained and resourced to effectively engage with and support people with disability. There is a lack of understanding by NDIA staff about people living with progressive, degenerative, neurological and neuromuscular conditions such as MS. Additionally staff do not have a good understanding of disability including how to communicate with and support people with disability; understand consent, decision making and choice; and how to facilitate person-centred planning.

MS Australia welcomes the recommendation of the NDIS review to embed a highly skilled, person-centred, disability aware culture across all disability agencies and governments (Recommendation 22). This includes professional development for all staff on disability awareness, intersectionality and trauma informed practice. Further, the Final Report notes that achieving the NDIS reforms will require 'a significant investment in and uplift of capabilities in the NDIA'.

MS Australia believes this upskilling of the NDIA workforce should include disease specific training and education, such as neurological conditions, and be supported by the establishment of a resource library of disability materials for use by NDIA staff. Improved education and training will lead to improved access, planning and communication for NDIS participants. Staff understanding of disability can be further improved by increasing the number of NDIA staff with lived experience of disability across all levels of the organisation. People with lived experience of disability can bring a unique perspective to the NDIA and are better equipped to engage with people with disability and ensure they get the best outcome from the NDIS. It also increases confidence in the organisation and ensures the NDIA better reflects the cohort it represents.

Nearly 1.6 million Australians live with a progressive neurological or neuromuscular condition in Australia with an annual cost to the Australian economy of over $36 billion. The Neurological Alliance of Australia (NAA), of which MS Australia is a member, estimates that around 15 per cent of NDIS participants have a progressive neurological or neuromuscular condition. MS Australia believes that creating a neurological voice within the advisory and consultative structure of the NDIA will ensure fairer representation for those living with progressive neurological or neuromuscular conditions and improve the understanding of the NDIA in relation to these conditions. This could be achieved through funding the establishment of a NDIA Neurological Advisory Group.

Early Intervention Pathway

MS is an incurable, progressive condition and many people living with MS are on a trajectory to meet the Schemes full access criteria within their lifetime. Most people are diagnosed with MS between the ages of 20-40 and the early stages of MS are an ideal time for access to early invention supports that allow them to continue working, being an active member of their community and slow the progression of their MS. Currently, the NDIS early intervention pathway for adults is unclear and not well understood by planners and assessors. Many people do not know that they can access it, how it can support them, what supports are available and what evidence is needed to meet the criteria.

MS Australia supports the recommendation of the NDIS Review to reform the NDIS early intervention pathway to provide supports to individuals where there is good evidence the intervention is safe, cost effective and significantly improves outcomes (Action 3.7). Greater clarity around this pathway and support from a Navigator will ensure that people living with MS gets supports when they need them and slow the progression of their disability. This will allow them to continue in employment and community engagement, reduce carer burden and have long term economic benefits to the NDIS.

MS Australia also supports the recommendation of the NDIS Review to establish an early intervention pathway for the majority of new participants with psychosocial disability (Action 7.2). Many people living with MS experience depression and anxiety at much higher rates than the general population. Early access to psychosocial supports will greatly increase their mental health. Both early intervention pathways must be fully funded including funds to support the establishment of these pathways.

Accommodation

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. 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 2,067 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[8] 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 welcomes recommendations by the NDIS Review to improve living supports and ensure they are fair and consistent and support participants to exercise genuine choice and control over their living arrangements (Recommendation 8). A whole-of-person approach to budget setting, access to Housing and Living Navigators and options to trial new living arrangements will significantly improve living arrangements for NDIS participants. MS Australia also welcomes recommendations to deliver a diverse and innovative range of inclusive housing and living supports (Recommendation 9) through commissioning more Specialist Disability Accommodation and upgrading or repurposing ageing Specialist Disability Accommodation stock. These accommodation improvements need to be appropriately funded and resourced.

Recommends:

- **Funding to support the implementation of the recommendations of the NDIS Review** including design, testing, consultation and development of new policies and practices
- **Funding to recruit, train and maintain a sufficient workforce of:**
  - General and specialist Navigators to assist people with disability to navigate disability systems including the NDIS
  - Assessors to undertake comprehensive, needs based assessments for NDIS participants
- **Funding for the NDIA to commission additional medical reports and assessments for NDIS applicants as required**
- **Funding to upskill the National Disability Insurance Agency including:**
  - embedding a highly skilled, person-centred, disability aware culture
  - improved disability education and training and the establishment of a resource library of disability materials
  - Increasing, recruiting and maintaining the number of NDIA staff who have lived experience
  - establishing a NDIA neurological advisory group
- **Funding to develop and establish improved NDIS early intervention pathways**
- **Funding to improve living supports including:**
  - Whole-of-person housing budgets
  - Housing and Living Navigators
  - New Specialist Disability Accommodation
  - Upgrading and repurposing ageing Specialist Disability Accommodation stock.

IMPROVED SUPPORT FOR PEOPLE WITH A DISABILITY WHO ARE NOT ELIGIBLE FOR THE NDIS

Currently there are 33,300 people living with MS in Australia and as of 30 September 2023 there were 10,603 people living with MS who have an approved NDIS plan[9]. This means that approximately 70% of people living with MS do not receive NDIS services and are reliant on non-NDIS supports and services. Most of these non-NDIS supports are poorly funded or non-existent leaving people with disability without services or self-funding services.

MS Australia welcomes the recommendation by the NDIS Review to introduce a Commonwealth and State/Territory jointly funded set of foundational disability supports outside individualised NDIS packages (Action 1.1). These supports would provide people living with MS access to information and advice, capacity building supports, advocacy services and home and community care supports. These foundational supports will need appropriate funding for design, commissioning and delivery. These supports are crucial to the new unified ecosystem of supports for people with disability that are at the core of the NDIS Review recommendations.

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. Many of these schemes are underfunded or have reduced funding over time as the assumption is that people will receive these services under the NDIS. Many people may have to a pay large financial contributions towards the cost of items and have long wait lists and a limited number of aids and equipment from which they can choose.

As noted in the Final Report, a study of assistive technology undertaken by Monash University[10] 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. The Review recommended that:

> *The Department of Social Services, with states and territories, should develop 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 (Action 1.10, NDIS Review Final Report).*

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.

Disability Support Pension and New Start Allowance

Research undertaken by UNSW and ACCOSS[11] 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 whose reference person receives the Disability Support Pension, 43 per cent live below the poverty line.

The AIHW[12] 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[13].

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.

Disability Royal Commission

MS Australia welcomes the Final Report of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Disability Royal Commission) which made 222 recommendations that address the structural and systemic change that is needed across Australia society. The report calls for 'significant change' to end abuse and exploitation and outlines major reforms to dismantle barriers that prevent people with disability accessing inclusive education, open employment, and accessible housing. Implementing these recommendations of the Disability Royal Commission will take many years and require extensive resources to ensure the recommendations are appropriately timed, developed and implemented.

MS AUSTRALIA **Recommends:**

- **Funding for the design, commissioning and delivery of foundational disability supports** outside individualised NDIS packages
- **Funding a single, nationally consistent assistive technology program** to support people with disability who are not eligible for the NDIS
- **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
- **Funding to implement the recommendations of the Disability Royal Commission.**

AGED CARE

Funding to meet the needs of older people with disability

Currently, Australians living with MS aged 65 and over when the NDIS was introduced and those who develop a disability and/or first access services after turning 65 are ineligible for the NDIS and must pursue their disability needs through the aged care system. However, the current aged care system does not cater to the needs of older Australians living with fluctuating or episodic disability or chronic health conditions. As a result, older people living with MS must either self-fund any shortfall in aged care services or go without, causing a significantly increased rate of disease progression and disability leading to increased hospitalisation and greater long-term burden on the health and disability systems. Additionally, a lack of appropriate supports to remain independent and living at home can lead to early and unnecessary entry to residential aged care and increase hospitalisation.

MS Australia has long advocated that older people living with MS should have access to NDIS supports to meet their disability needs. As such, MS Australia welcomes the following recommendation by the NDIS Review:

> *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).*

This recommendation expands the range of supports on offer for older people living with MS. They will be able to access the supports they need from the most appropriate system including disability appropriate supports from the NDIS and ageing supports from the aged care system. Additionally, for those entering residential aged care they will still be able to access complementary NDIS supports as needed.

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 Department of Health and Aged Care ensures 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*[14]*.*

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.

MS AUSTRALIA **Recommends:**

- **Funding to support the implementation of Recommendation 72 of the Royal Commission into Aged Care Quality and Safety** to ensure the aged care system meets the needs of people living with disability.

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