

MULTIPLE SCLEROSIS AUSTRALIA

Pre-budget submission for the 2022-23 Federal Budget

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Introduction

Multiple Sclerosis Australia (MS Australia) is pleased to lodge this pre-budget submission to the Australian Government for the 2022-2023 Budget. This submission focusses on three key areas that will impact people affected by multiple sclerosis (MS).

MS is the most commonly acquired neurological disease in younger adults around the world with over 2.8 million people affected. More than 25,600 Australians live with MS with 8400 of them currently being supported by the National Disability Insurance Scheme at a cost of around \$700 million per year. Over 7.6 million Australians know someone or have a loved one with this potentially debilitating disease.

MS is the result of damage to myelin – a protective sheath surrounding nerve fibres of the central nervous system. When myelin is damaged, this interferes with messages between the brain and other parts of the body. 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, measured at 31% below the norm for people with MS. The economic costs of MS to the Australian community are increasing rapidly and now exceed \$1.75 billion every year. The cost of MS management is \$114,000 per year for a person with severe disability.

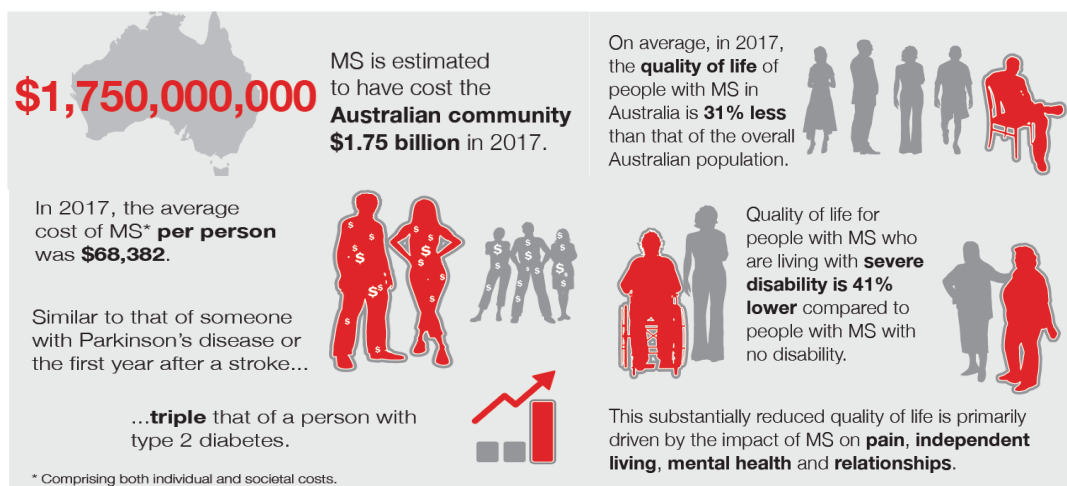


Figure 1. The economic and personal cost of MS – some facts and figures¹

The urgent unmet needs for MS in Australia are:

- Better treatments, prevention and ultimately, a cure for the disease - there is no known cause or single cure, but a cure could well be within reach.
- Improved support for the management and care of MS - through systemic improvements to the health care, disability care and aged care sectors.

MS Australia seeks commitments from the Australian Government through the 2022-23 Federal Budget to:

1. Supercharge MS research through significant investment in better treatments, prevention, information and ultimately a cure for MS.
2. Improve support for people with MS living with disability through a better, fairer NDIS and equitable support for those over 65 years in the aged care sector

¹ The Health Economic Impact of Multiple Sclerosis in Australia 2017 report, commissioned by MS Research Australia and prepared by the Menzies Institute for Medical Research, University of Tasmania, August 2018

3. Improve the healthcare of people with MS through increased access to MS Nurses

Summary of MS Australia recommendations

In this submission we outline the urgent unmet needs in MS research and MS support, and our associated recommendations, towards these three major commitments:

1. Supercharging MS research

1. Fund a National MS Biobank to support Australian studies towards early detection and prevention of MS, at a cost of \$8 million over 5 years.
2. Develop a matching national data infrastructure towards a deeply characterised national MS cohort.
3. AIHW be funded to work with the Neurological Alliance Australia (NAA) to produce a data set and accompanying reports for as many of the neurological/neuromuscular conditions represented by the NAA as possible, similar to those produced for other chronic condition groups.

2. A better, fairer NDIS

4. Include a representative of the Neurological Alliance Australia (NAA) on the existing NDIA Industry Chief Executives Forum.
5. Establish a Neurological Advisory Group via the NDIA, similar to the Autism Advisory Group.
6. Improve the understanding of NDIA staff and their contractors of the needs of people living with progressive, degenerative, neurological and neuromuscular conditions such as MS, with a particular focus on recognising and addressing invisible symptoms, such as neuropathic pain, fatigue and cognitive issues.
7. Promulgate the MS Snapshot and associated video provided by MS Australia in 2019 throughout the NDIA and its contractors
8. Introduce within the NDIA a substantial core group of staff (a Neurological Community of Practice) with expertise in progressive degenerative, neurological and neuromuscular conditions that can act as a point for referral for all NDIA staff and contractors.
9. Identify and recommend additional funding to address current and future knowledge gaps (recommendations 5, 6, 7) in the upcoming review of the NDIS.
10. Abolish age discrimination in NDIS eligibility by amending the Age Discrimination Act and the NDIS Act to remove this inequity.
11. Implement recommendation 72 of the Aged Care Royal Commission, "Equity for people with disability receiving aged care 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".
12. Fund and resource the NDIS accordingly in the upcoming review of the NDIS.

3. Additional MS Nurses

13. Invest \$5 million to employ an additional 50 MS Nurses for the 8,000 people with MS currently without access in Australia. This could reduce the cost of their overall MS care by \$64.3 million annually, assuming cost savings of 10%.

1. Supercharging MS research

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 the neurological damage and disability. Rates of MS are high in Australia compared to other countries and rising rapidly, but 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 - to stop irreversible damage** to the brain and spinal cord before it begins.

1.1 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.

1.1.1 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 appear².

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.

1.1.2 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% 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 appear³.

² Makhani N, Tremlett H. The multiple sclerosis prodrome. *Nat Rev Neurol*. 2021 Aug;17(8):515-521.

³ M. Mortazavi et al. Multiple sclerosis and subclinical neuropathology in healthy individuals with familial risk: A scoping review of MRI studies. *Neuroimage Clin*. 2021;31:102734.

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 - yet. But 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 6 years before MS onset⁴. Further work is required to understand the potential of this, and several other candidates, as blood markers for the “pre-MS” phase. MS biobanks will be critical to this work.

1.2 Stopping MS Before It Starts

One of the ultimate research goals is prevention of MS: stopping MS before the disease process starts.

Here, biobanks have been critical to our understanding of disease initiation.

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 MS⁵. EBV infection increased the risk of developing MS by 36-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.

1.3 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.

1.4 You can’t improve what you don’t measure

Currently, the Australian Institute of Health and Welfare (AIHW) commonly reports on 10 major chronic condition groups: [arthritis](#), [asthma](#), [back pain](#), [cancer](#), [cardiovascular disease](#), [chronic obstructive pulmonary disease](#), [diabetes](#), [chronic kidney disease](#), [mental health conditions](#) and [osteoporosis](#).

It does not collect nor publish reports on neurological or neuromuscular conditions with the notable exception of epilepsy.⁶

⁴ K. Bjornevik et al. Serum Neurofilament Light Chain Levels in Patients With Presymptomatic Multiple Sclerosis. *JAMA Neurol.* 2020 Jan 1;77(1):58-64.

⁵ K. Bjornevik et al. Longitudinal analysis reveals high prevalence of Epstein-Barr virus associated with multiple sclerosis, *Science* 375, 296 (2022)

⁶ <https://www.aihw.gov.au/reports/chronic-disease/epilepsy-in-australia/contents/about>

Some of the peak bodies in Australia that represent communities of people living with conditions such as multiple sclerosis and motor neurone disease have, in the past, allocated scarce resources to the commissioning of consultants to provide basic demographic and economic impact data. This data is a key foundation for building a platform for planning and prioritising health policies and evaluating the effectiveness of intervention programs and initiatives. Many smaller peak bodies representing fewer patients and with less resources have to manage as best they can without accurate up-to-date data sets and reports.

Minimal data sets might include basic demographic information such as condition prevalence, incidence, hospitalisations, accidents and emergency presentations, contribution to deaths, burden of disease and economic impact. The AIHW is best placed to collect and report this information as it does for the other chronic conditions listed above.

MS Australia recommendations:

- 1.** Fund a National MS Biobank to support Australian studies towards early detection and prevention of MS, at a cost of \$8 million over 5 years.
- 2.** Develop a matching national data infrastructure towards a deeply characterised national MS cohort.
- 3.** AIHW be funded to work with the Neurological Alliance Australia (NAA) to produce a data set and accompanying reports for as many of the neurological/neuromuscular conditions represented by the NAA as possible, similar to those produced for other chronic condition groups.

2. A better, fairer NDIS

The NDIS is Australia's first publicly funded national disability insurance scheme. Legislated in 2013, and in full operation since 2020, the scheme has provided life-changing benefits to many Australians.

However, the NDIS is not without fault or its critics.

Over the last decade and across 28 policy submissions, MS Australia has actively advocated on behalf of people living with MS for improvements to the NDIS. For every positive story of an Australian helped by the Scheme, there are countless others who have been left behind. MS Australia stands ready to support the new Labor Government's intent for significant reform.

To improve the NDIS for the MS community, there are three essential areas for reform:

- Better representation of people with MS and other progressive neurological conditions within the National Disability Insurance Agency (NDIA).
- A better understanding of MS and the needs of people with MS.
- Provision of disability supports and services regardless of age.

2.1. Better representation of people with MS and other progressive neurological conditions within the National Disability Insurance Agency (NDIA)

1.6 million Australians live with progressive, degenerative neurological or neuromuscular conditions. MS Australia is calling for the neurological voice to be incorporated into the advisory and consultative structure of the NDIS/NDIA, to ensure fair representation and better support for our community.

MS Australia recommendations:

4. Include a representative of the Neurological Alliance Australia (NAA) on the existing NDIA Industry Chief Executives Forum.
5. Establish a Neurological Advisory Group via the NDIA, similar to the Autism Advisory Group.

2.2. A better understanding of MS and the needs of people with MS

Greater awareness, education and understanding of MS within the NDIA will ensure better support for people living with MS.

MS Australia recommendations:

6. Improve the understanding of NDIA staff and their contractors of the needs of people living with progressive, degenerative, neurological and neuromuscular conditions such as MS, with a particular focus on recognising and addressing invisible symptoms, such as neuropathic pain, fatigue and cognitive issues.
7. Promulgate the MS Snapshot and associated video provided by MS Australia in 2019 throughout the NDIA and its contractors
8. Introduce within the NDIA a substantial core group of staff (a Neurological Community of Practice) with expertise in progressive degenerative, neurological and neuromuscular conditions that can act as a point for referral for all NDIA staff and contractors.

9. Identify and recommend additional funding to address current and future knowledge gaps (recommendations 5, 6, 7) in the upcoming review of the NDIS.

2.3. Provision of disability supports and services regardless of age

All Australians with MS should be entitled to support from the NDIS regardless of their age.

Those aged 65 and over when the NDIS was introduced and those who develop a disability after turning 65 are ineligible for the NDIS and must pursue their disability needs through the aged care system. This is a concern because the aged care system is designed to address frailty and dementia rather than the disability needs of people with MS, especially those whose progression of disability has been slowed or delayed through disease-modifying treatments. This age cut-off has created a grossly inequitable two-tier system of support.

People outside the boundaries and eligibility of the NDIS, especially those living with fluctuating or episodic disability or chronic health conditions not deemed as permanent disability, are missing out. Those living with neurological conditions or those living with mental health issues are experiencing gaps in service delivery, access and continuity of care. Supports are available only if self-funded or through the aged care sector, which is capped and means tested. This discrimination based on age is unacceptable and unfair.

The inequities between the aged care sector and the NDIS must be addressed.

People with MS aged 65 and over need adequate support to stay at home, engage in the community, stay at work with appropriate support and flexibility. This would ensure financial security is maintained to cater for such things as housing, aids and equipment and a quality social life. In general, aged care support has a much greater focus on personal care and in-home support rather than community participation – an important, often vital aspect of life for a person affected by a chronic condition such as MS.

MS Australia recommendations:

10. Abolish age discrimination in NDIS eligibility by amending the Age Discrimination Act and the NDIS Act to remove this inequity.
11. Implement recommendation 72 of the Aged Care Royal Commission, “Equity for people with disability receiving aged care 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”.
12. Fund and resource the NDIS accordingly in the upcoming review of the NDIS.

3. Additional MS Nurses

3.1. Australian 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. However, changes in traditional funding models have reduced the number of MS Nurses in Australia, particularly in rural and regional areas, and overall access.

The findings from the *MS Nurse Care in Australia Report*⁷ indicate that people with MS who are unable to access MS Nurse care are adversely affected in terms of health outcomes.

3.2. Analysis of MS Nurse patterns of access, care, and health outcomes

A survey of 1,417 people with MS in Australia identified the patterns of both access to MS Nurse care and receiving MS Nurse care. We examined whether factors such as personal or clinical characteristics, lifestyle behaviours, or use of disease modifying therapies, influenced whether people with MS received MS Nurse care, or had access.

3.3. Access to Nurse care

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. 31.5% of people with MS in Australia do not have access to MS Nurse care and have consistently worse health outcomes. Among those living in outer regional, remote, or very remote areas, almost half reported having no access to MS Nurse care (48.8%). However, even among those living in major cities, a substantial percentage (28.4%) indicated that they did not have access.

3.4. Value of MS Nurses

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. \$5 million would cover the cost of an additional 50 MS Nurses for the 8,000 people currently without access in Australia. This could reduce the cost of their overall MS care by \$64.3 million annually, assuming cost savings of 10%. MS Nurses provide tailored care.

The potential cost savings far outweigh the MS Nurse salary costs by between six and 26 times, depending on whether we assume 5% or 20% of costs would be avoided.

The survey showed that people with MS were very satisfied with the frequency and type of support provided. This included help with management of MS symptoms, treatments, and side effects. Access to MS Nurses improved self-management and self-care, mostly reflected in better medication management.

3.5. Benefits of MS Nurse care

MS Nurse care directly benefits people with MS and provides better health outcomes. *The Brain Health: Time Matters in MS*⁸ initiative reported that improved access to specialist care in MS reduces disability progression. Other international studies have also demonstrated improved health outcomes and significant cost savings with specialist nursing services for chronic diseases, both within and beyond MS care.

⁷ <https://www.msaustralia.org.au/about-us/reports-and-financials/>

⁸ <https://www.msbrainhealth.org/recommendations/brain-health-report/>

There is a strong case to be made that every Australian with MS should have access to MS Nurse care as part of their ongoing MS management plan. This would result in significant cost savings for MS healthcare in Australia. The results support the need for policies and practices, and access to funding, that will improve access to MS Nurse care.

MS Australia recommendation:

- 13.** Invest \$5 million to employ an additional 50 MS Nurses for the 8,000 people with MS currently without access in Australia. This could reduce the cost of their overall MS care by \$64.3 million annually, assuming cost savings of 10%.

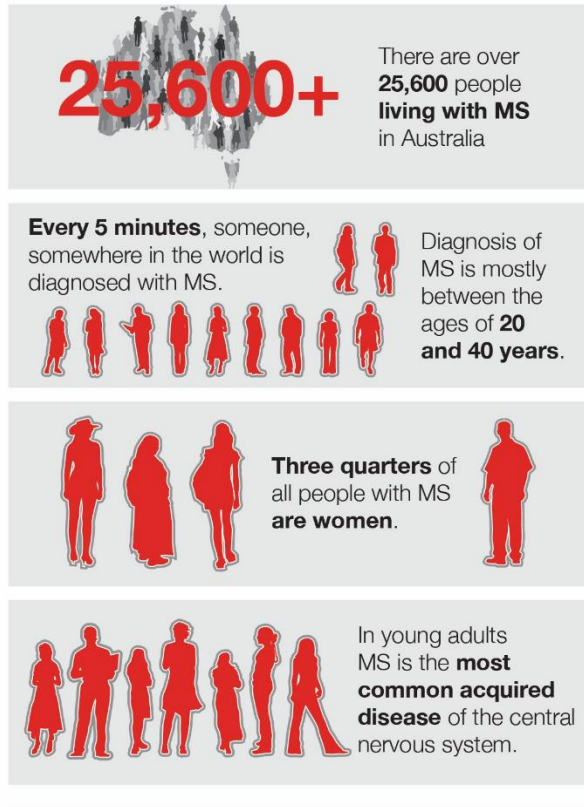
Key facts about MS

Multiple Sclerosis (MS) is a chronic disease that attacks the central nervous system (the brain, spinal cord and optic nerves).

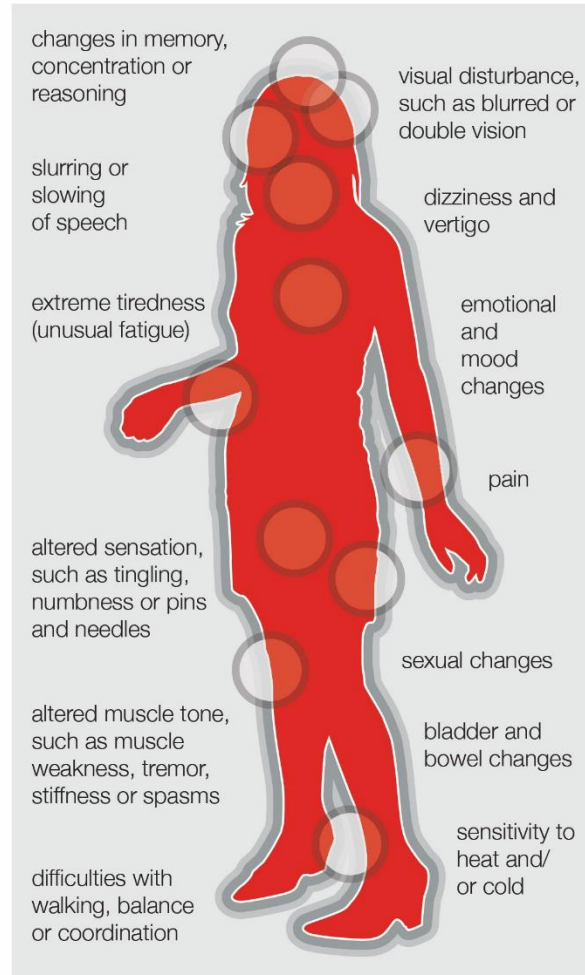
There is no known cause or cure.

MS varies significantly from person to person. For some people, it is a disease that comes and goes in severity with periods of unpredictable relapse and remission. For others it means a progressive decline over time.

For all, it is life changing.



The symptoms of MS can be both visible and invisible to others, are unpredictable and vary from person to person and from time to time in the same person. They include:



About MS Australia

MS Australia is the national peak body for people living with MS in Australia. Working on behalf of all state and territory-based member organisations to provide a voice for people living with MS across the country to support the development of:

- Research
- Advocacy and awareness
- Communication and information
- Services provided by our member organisations
- International collaboration.

MS Australia advocates across all stakeholders, governments and communities, on behalf of the members, to represent people who are diagnosed with the disease, their carers and the broader MS community.