



2025–26 PRE-BUDGET SUBMISSION



About MND Australia

MND Australia is the national peak body of state organisations that support those living with, and impacted by, motor neurone disease (MND). Since 1993, we have been the voice for the MND community. Our national and international networks help increase understanding of the disease and advocate for the needs of those affected. We fund world-class research for better treatments, improved care, and ultimately a cure.

About MND

Motor neurone disease (MND) is the name given to a group of neurological diseases in which motor neurons – the nerve cells that control the movement of voluntary muscles – progressively weaken and die. With no nerves to activate muscles, people with MND can lose their ability to walk, speak, swallow and ultimately breathe. MND affects each person differently. Initial symptoms, rate and pattern of progression and survival time can all vary widely.

The lifetime risk of MND is about 1 in 300 people by the age of 85. At the time of this submission, there are approximately 2,688 people living with MND in Australia[i] and more than 55% of these are diagnosed aged 65 and over[ii]. Evidence indicates that average time from the onset of symptoms to confirmation of diagnosis is 10 to 18 months[iii].

Average life expectancy for people living with MND is 27 months from diagnosis. A third of those die within one year and more than half die within two years of diagnosis. In 2022, 793 people with MND died in Australia[iv].

There is no known cure for MND. Riluzole (also known as Rilutek™) is the only medical treatment for MND currently available through the Pharmaceutical Benefits Scheme (PBS). In general, Riluzole extends life by only a few months[v].

Up to 15% of MND cases have a known genetic basis through a well-established family history. However, as we continue to better understand the complex genetic nature of MND, it is becoming clear that genetic changes are a factor in a much higher percentage of cases.

In the majority of cases, the progression of disease is rapid and relentless, creating high levels of life-limiting disability. People living with MND have complex, constantly changing needs, which require a wide range of supports. Due to the nature of disease progression, the last 12 months of life can be tumultuous for people living with MND and their loved ones. Loss in function and independence is rapid and significant, prompting the need for regular contact with the health system, and leading to high levels of carer stress[vi].

Each day in Australia two people are diagnosed with MND and each day two people with MND die.

There is no known cure.

Disease progression is often rapid and relentless, creating a wide range of changing needs and supports.

People living with MND can experience a variety of changes in the early stages, such as stumbling or falling, changes in dexterity that can affect dressing and using cutlery, slurred speech, trouble swallowing, muscle twitching, or cognitive and behavioural changes. As MND is a degenerative condition, these symptoms will worsen over time. The support and equipment needs of someone living with MND will therefore change, often rapidly.

People living with MND benefit greatly from coordinated, multidisciplinary care, as well as assistive technology. This care team may include a neurologist, care coordinator, occupational therapist, physiotherapist, orthotist, respiratory specialist, speech pathologist, dietitian, nurse, social worker, psychologist or counsellor, palliative care expertise, MND Association Advisor, NDIS Support Coordinator, and community service providers.

A large variety of aids and equipment, usually referred to as 'assistive technology' (AT) are needed. Common forms of AT include power wheelchairs, hoists, hospital beds, or eye-gaze technology to communicate. Many people also require home modifications, such as ramps or major bathroom modifications.

It takes an average of twelve months to receive an MND diagnosis and based on the average lifespan being merely 27 months, this means that people living with MND will often have significant disability at the point of diagnosis and require immediate support.

Our Recommendations

MND Australia seeks a Budget commitment from the Australian Government to implement the following four initiatives to immediately make a difference to the lives of people living with MND, their families and carers.

- 1** Funding to build a National MND Dataset (*MND Insights Platform*) to link existing data sources and evidence to enable research and to develop data-driven solutions to care services for people living with MND. *Australian Government investment of \$12 million over four years.*
- 2** Include genetic counselling under Medicare to enable access and informed decision making regarding genetic testing, thereby protecting future generations.
- 3** Improve access to the NDIS for people with MND to support and ensure planning that meets the individual needs of each person. *Australian Government investment of \$500,000 per year.*
- 4** Fund disability supports for older people in the Aged Care system at a comparable level to the NDIS, to ensure people living with MND aged 65 years and over receive the supports they need for such a complex and progressive disease. *Australian Government investment of \$287 million per year.*



1

Fund the MND Insights Platform to build a National MND Dataset, to link existing data sources and evidence to enable research and to develop data-driven solutions to care services for people living with MND. *Australian Government investment of \$12 million over four years.*

MND Australia seeks a commitment of \$12 million over four years to fund a National MND data Platform. This is a data-driven solution to improve the diagnoses, treatment, and research of motor neurone disease in Australia.

Increased knowledge and understanding of MND is key to advancing better care and new treatments. However, there are currently a number of limitations in the collection and availability of MND data, which places significant constraints on advancements. MND Australia has identified a critical need to build and manage a new MND Insights Platform for people living with MND in Australia as a solution to address the current limitations in knowledge and treatments.

This platform would improve diagnosis, identify potential environmental factors contributing to the onset of disease, accelerate research and clinical trials, and optimise care and support services. Further, it would aid more efficient recruitment for clinical trials, support precision medicine and influence public health policy. This data-asset advocates for global collaboration and data sharing to foster international research efforts and policy development.

There is currently limited information exchange across existing MND databases. This new national data platform would build on, extend, and leverage the strengths of the existing clinical registry, bio registry and other MND databases. This data platform would lead to tangible outcomes in terms of research, consumer care, and integrated government services and ultimately better health outcomes for people living with MND. Knowledge and understanding of the disease is key to developing better care and new treatments, and the limited data we have constrains this.



2

Include genetic counselling under Medicare to enable access and informed decision making regarding genetic testing, thereby protecting future generations.

MND Australia recommends and calls on the Australian Government to:

- Improve access to genetic testing for people with MND and their families by making genetic counselling available under Medicare
- Fund no cost access for those who choose to undertake in-vitro fertilisation (IVF) and preimplantation genetic testing (PGT-M)

Latest research suggests that up to 15% of MND cases involve an inherited genetic fault (familial MND) [vii]. For families impacted by familial MND, genetic testing enables opportunities for future family planning to avoid passing on known MND faults.

Genetic screening for MND is now available under Medicare. However, access to genetic counselling, which is a vital part of the screening process, is extremely limited due to low numbers of genetic counsellors.

People living with MND have told us they need better and more timely access to genetic counselling and genetic testing. Accessing both counselling and testing can be very difficult and varies in states and territories across Australia[viii]. Making genetic counselling rebatable under Medicare will increase access to genetic counsellors and provide future opportunities for new genetic counsellors.

MND Clinics provide multidisciplinary treatment and support for people living with MND across Australia and the health professionals involved in these clinics and services are experienced in MND.

Incorporating genetic counsellors into multidisciplinary MND clinics would provide better support for people to identify if they have familial MND.

For people who know which genetic fault is causing MND in their family, it may be possible to undergo pre-implantation genetic testing for monogenic disorders (PGT-M). PGT-M is a special type of in vitro fertilisation (IVF). In PGT-M, embryos are created outside the body and tested for the presence/absence of the MND gene fault. Only unaffected embryos are considered suitable to be placed into the womb [ix]. This option reduces the chances of passing on an MND related faulty gene and has the potential to stop MND in future generations [x].

MND Australia welcomed this testing becoming available within the Medicare Benefits Schedule as a rebatable item in November 2021. However, IVF PGT-M carries significant financial costs with Medicare rebates. MND Australia recommends the Australian Government fund no cost access for those who choose to undertake IVF and PGT-M.



3

Improve access to the NDIS for people with MND to support and ensure planning that meets the individual needs of each person. *Australian Government investment of \$500,000 per year.*

MND Australia recommends the Australian Government allocate \$500,000 annually to fund MND State Associations to provide crucial pre-NDIS support, helping people living with MND understand the purpose, scope and limitations of the NDIS.

Navigating the NDIS can be challenging for some people living with MND due to the complexity of the system and the progressive nature of the disease. MND State Associations play a vital role in bridging this gap, acting as an independent, trusted voice that supports individuals with MND and provides guidance to NDIS planners.

People with MND often face frustration and confusion when navigating the NDIS, as their rapidly changing needs and expectations are not always well understood. MND State Associations are uniquely positioned to bridge the gap between participants and planners, acting as a knowledgeable and impartial resource. This funding will ensure that these services are sustainable, enabling better outcomes for participants and the NDIS alike.

It will ensure that MND State Associations can:

- Educate individuals with MND about their entitlements under the NDIS, the intent of the funding, and its legislative framework
- Help individuals understand the purpose and limitations of NDIS funding to better align expectations with what the scheme can provide
- Assist participants in preparing for planning meetings, ensuring their needs are clearly articulated and align with the NDIS framework
- Provide insights to NDIS planners about the unique and evolving needs of people living with MND, reducing misunderstandings and promoting more effective and collaborative planning.

The key benefits of this funding include:

- 1. Increased understanding and reduced conflict.** Many people with MND perceive NDIS planners as gatekeepers who decide "what they can have and what they can't." This can lead to conflict and dissatisfaction. By improving participants' understanding of the NDIS's purpose and limitations, MND State Associations can help align expectations, reduce misunderstandings, and foster a more collaborative relationship between participants and planners.
- 2. Improved communication and outcomes.** With specialist support, individuals with MND can approach the NDIS planning process more informed and better prepared, ensuring their needs are clearly communicated and their plans are more aligned with their expectations and the NDIS's intent.
- 3. Better support for planners.** Planners often lack the specific knowledge required to understand the progressive nature of MND and its implications for participant needs. By serving as an independent and informed voice, MND State Associations can enhance planners' understanding of MND, ensuring that plans reflect both participant needs and the NDIS framework.
- 4. Efficient use of NDIS funding.** By fostering understanding and collaboration, this approach can reduce funding misalignment and prevent the need for extensive plan reviews or disputes, ultimately ensuring more efficient use of NDIS resources.

An annual allocation of \$500,000 to fund MND State Associations to provide pre-NDIS support services reflects the collective costs incurred by MND State Associations delivering services that are currently unfunded but critical for improving NDIS access and outcomes for people living with MND. MND State Associations will also provide support to 'support coordinators' for registration requirements that come into effect as of 1 July 2025. State Associations are covering a major gap in this support and the consequences of not being able to meet the demand is critical.

This funding support will reduce conflict between participants and planners, ultimately improving satisfaction regarding the NDIS experience. It will provide greater clarity for people with MND about their entitlements and the NDIS's purpose, ensuring plans are realistic and aligned with their needs.

The benefits of this funding will provide an improved understanding among NDIS planners of the unique challenges faced by people with MND, resulting in more appropriate and effective plans. It will provide enhanced equity in access to NDIS funding for people with MND, ensuring their needs are met in a timely and appropriate manner.



4.

Fund disability supports for older people in the Aged Care system at a comparable level to the NDIS, to ensure people living with MND aged 65 years and over receive the supports they need for such a complex and progressive disease. *Australian Government investment of \$287 million per year.*

MND Australia calls on the Australian Government to invest \$287 million per year to ensure people with MND aged 65 and over receive supports and services equitable to those available through the NDIS. Access to these supports must be timely.

Despite the increased funding levels within the new Aged Care Rules 2024, more is needed to address the inconsistency of funding between the NDIS and aged care support. The difference between the highest level in-home care package under the Aged Care Rules 2024 and the average NDIS package for someone living with MND in 2024 is \$194,000 annually.

The aged care system was not built for someone with a disability aged 65 and over and while the proposed reforms within the Aged Care Rules 2024 are a good start, the inequity of funding levels remain if the new Aged Care Rules 2024 are implemented at the proposed funding levels.

MND Australia requests that equal access to funding, regardless of age is prioritised and that this access is timely. MND Australia also recommend a formal 'fast-track' process for people living with MND to automatically receive the highest level in-home care package.

The Hon Minister Bill Shorten, Minister for the National Disability Insurance Scheme announced that from 1 July 2024, MND will be included under the 'priority eligibility decision pathway' within the NDIS [xi]. The timeline for a priority eligibility decision pathway within the NDIS is two to five business days [xii]. MND Australia recommends and requests that the Australian Government match this pathway for people living with MND aged 65 and over.

The average package for a person living with MND under the NDIS in 2024 is \$302,000 [xiii]. As of 1 July 2025, the highest-level package within the draft Aged Care Rules 2024 'Support at Home' program is a SAH Level 8 amount of \$78,000.

While we welcome the additional up to \$15,000 that will be made available within the top tier Assistive Technology and the up to \$15,000 Home Modifications Scheme of the 'Support at Home' program. Additional and ongoing funding that is not time limited, for assistive technology and home modifications continues to be urgently needed to meet the specific, high-level needs of people living with MND.

In addition, MND Australia recognises the importance of Foundational Supports outside of the NDIS and requests greater funding for Foundational Supports be prioritised as part of the negotiations between Commonwealth and state governments.

The difference between the highest level of funding within the Aged Care Rules 2024, if a person living with MND were to receive the SAH Level 8 amount of \$78,000 and \$15,000 Assistive Technology and \$15,000 Home modifications, is a difference of \$194,000 for a person aged 65 and over, when compared to the NDIS average funding package of \$302,000.

The funding inequity between the NDIS and Aged Care system means that the 55% of people diagnosed with MND aged 65 years and over are not getting the complex and ever-changing disability supports they need.

Further Information

MND Australia welcomes the opportunity to provide further information in addition to the information contained in this submission. Please contact Clare Sullivan, CEO of MND Australia, on clare.sullivan@mndaustralia.org.au or 0415 265 262.

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