MND AUSTRALIA

2025 Federal Election Platform

Until there's a cure, there's care

ABOUT MND AUSTRALIA

MND Australia is the national peak body of State MND Associations, that support those living with, and impacted by, motor neurone disease (MND). Since 1993, we have been the voice for the MND community.

Our priorities:

- **Advocacy** – We advocate for people living with MND and our member Associations throughout Australia. We seek to improve the lives of those affected by MND through improvements to federally funded care, enhanced data infrastructure, access to new treatments and genetic testing, and investment in research.
- **Information** – We provide resources, information and service linkage for people living with MND, their carers and family, as well as the health professionals and service providers who support them to live well.
- **Funding** – We invest millions of dollars each year through our research grants program to support high-quality research to discover the causes, improve care and find treatments and ultimately a cure for MND.

KEY COMMITMENTS

MND Australia seeks commitments to implement changes that will immediately make a difference to the lives of people living with MND, their families and their carers.

1. Fund MND Australia to build the National MND Insights Platform. This dataset will link existing data sources and evidence to enable research and develop data driven care services for people living with MND. Costing: $12 million over four years.

2. Maintain the NDIS Priority Eligibility Decision Pathway that fast tracks people with MND to gain access to the NDIS and maintain the dedicated team of planners with MND expertise.

3. Establish a fast-tracked pathway to access the Aged Care system, including Support at Home, for people living with MND aged 65 and over to stay in their homes longer.

4. Fund Aged Care supports to comparable levels to the NDIS. Costing: $287 million a year.

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

MND IN AUSTRALIA

$50m

Over $50 million invested in Australian MND research since 1987 to discover causes, improve care, develop treatments and a cure

25k+

MND Australia’s total social following across Facebook, Instagram and LinkedIn. Plus over 15,000 email subscribers

2,688

Approximately 2,688 Australians are currently living with MND. This equates to around 1 in 10,000 Australians

20%

Aged Care provides approximately 20% of the funding available through the NDIS for people with MND

867

An estimated 867 Australians die from MND every year

18yrs

MND typically reduces life expectancy by an average of 18 years

6

Through the six State MND Associations, care and support is available in all states & territories

24

Nationwide, there are 24 specialist motor neurone disease clinics

2-5 days

NDIS access through the MND priority pathway is typically approved within 2-5 business days

$300k

Average annualised NDIS support package for people with MND

430

Around 430 people with MND are from a CALD background

1

There is currently only 1 medication available in Australia to slow the progression of MND

250+

State MND Associations run over 250 education sessions every year for health professionals and aged care/disability service providers

8,700

The State MND Associations’ AT libraries maintain over 8,700 pieces of equipment, at no-cost for people with MND

150+

Over 150 MND resources, publications, and website information pages are available, for both people with MND and health professionals

30+

Over 30 Australian MND researchers are funded through our grants program every year,including early career fellowships

126k

Our national website receives over 126,000 visits per year to access a wealth of content for patients, carers & health professionals

218

Every year the MND network runs over 200 information and peer support groups for people with MND, their family and their carers

ABOUT MND

Approximately 2,688 Australians are living with motor neurone disease (MND).

Every day in Australia, two people are diagnosed with MND and two people die from the 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 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[i].

More than 55% of Australians diagnosed are aged 65 and over.[ii]

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[iii].

There is no known cure for MND. Riluzole (also known as RilutekTM) 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[iv].

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[v].

1 Fund MND Australia to build the National MND Insights Platform

This dataset will link to existing data sources and evidence to enable research and develop data-driven care services for people living with MND.

Costing: $12 million over four years.

MND Australia seeks a commitment of $12 million over four years to fund the National MND Insights 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, social and demographic 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.

Our approach underpins 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 patient and 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 Maintain the NDIS Priority Eligibility Decision Pathway

This priority pathway fast tracks people with MND to gain access to the NDIS and maintain the dedicated team of planners with MND expertise.

Delays to services, supports and equipment place an unnecessary and avoidable burden on people living with MND.

The NDIS Priority Eligibility Decision pathway enables a decision within two to five business days[vi]. This specialised fast-tracked access was introduced to the NDIS in 2024.

MND is a progressive disease that creates high levels of life-limiting disabilities. Fast-tracked access is essential to access supports, services and equipment in a short timeframe due to the progression of MND resulting in rapidly changing needs.

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.

MND State Associations have provided training to and work closely with the team of dedicated NDIA subject matter expert planners to ensure people living with MND gain access to appropriate NDIS funding, services and supports quickly.

Without this fast access, people living with MND will again face delays to the essential services, care and supports they need.

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.

This dedicated group of educated planners also ensures that multiple NDIS resources are not tied up with plan disputes, complaints and signing off on inappropriate supports. They are also able to identify ways of making the whole process more efficient and saving money.

3 Establish a fast-tracked pathway to access the Aged Care system

Establish a fast-tracked pathway to access the Aged Care system, including Support at Home, for people living with MND aged 65 and over to stay in their homes longer.

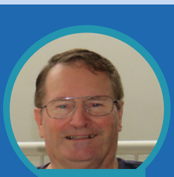
Wait times to access the aged care system vary between 3-15 months[vii]. For people living with MND, these wait times delay access to essential services and equipment that are needed as a priority.

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.

Guaranteed timely access to supports for people living with MND will ensure they receive the high-level and fast-changing supports and care they need.

A fast-tracked access pathway, similar to the NDIS Priority Eligibility Decision Pathway, will ensure people with MND, aged 65 and over are gaining access to services and supports that are key to someone living with this rapidly changing, progressive disease that creates high levels of life-limiting disabilities.

Fast-tracked services and supports will support people living with MND aged 65 and over to stay in their homes longer.

 **Graham**	 **Tony**
Age 63	Age 67
✓ Receives an NDIS plan to meet his disability needs	✗ Cannot receive an NDIS plan as he is aged 65+
✓ No waiting list for NDIS, can access approved care in his plan as he needs it	✗ Stuck on the Aged Care waiting list for over eight months
✓ Receives funding for vital equipment through NDIS	✗ No funding for vital equipment

4. Fund Aged Care supports to comparable levels to the NDIS

Fund Aged Care supports to comparable levels to the NDIS.

Costing: $287 million a 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. 55% of people diagnosed with MND aged 65 years and over are not getting the complex and ever-changing disability supports they need.

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.

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

An 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 will still not provide equity of funding for people aged over 65 when compared to a person living with MND accessing the NDIS.

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 existing funding programs and requests greater funding for Foundational Supports be prioritised.

5 Include genetic counselling under Medicare

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

Access to genetic counselling is a vital part of the screening process for people living with MND. Improving access to genetic testing for people with MND and their families will be significantly enhanced by making genetic counselling available under Medicare.

Genetic testing is rebatable under Medicare. Making genetic counselling rebatable under Medicare will provide future opportunities for new genetic counsellors. This will help overcome the critical wait times for people living with MND, and their families, to gain access to genetic counselling and interpret results from genetic testing.

Latest research suggests that up to 15% of MND cases involve an inherited genetic fault (familial MND)[ix]. 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[x].

Making genetic counselling rebatable under Medicare will increase access to genetic counsellors and provide future opportunities for new genetic counsellors.

Additionally, no cost access for those who choose to undertake in-vitro fertilisation (IVF) and preimplantation genetic testing (PGT-M) will support people by addressing the financial strain caused by these tests.

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.

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. Funding no cost access for those who choose to undertake IVF and PGT-M will alleviate this unnecessary financial strain.

Sources

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