



Until there is a **cure**,
there is **care**.

Motor Neurone Disease Australia

Action Framework

mndaustralia.org.au



What is motor neurone disease (MND)?

MND is the name given to a group of neurological diseases in which motor neurones, the nerve cells that control the movement of voluntary muscles, progressively weaken and die. With no nerves to activate them, the muscles of movement, speech, swallowing and breathing gradually weaken and waste, and paralysis ensues.

Living with MND

- It is estimated that there are currently 2,000 people living with MND in Australia
- Each day two Australians will die with MND and another two people will be diagnosed
- MND affects each person differently with respect to initial symptoms, rate and pattern of progression, and survival time
- Average life expectancy is 2.5 years from diagnosis
- There is no known cause for MND (except in a very small number of genetic cases)
- There are no effective treatments and no cure
- There are no remissions and progression of MND is usually rapid and relentless creating high levels of disability and a consequent need for a wide range of progressively changing supports.

MND Fact

Around 50% of people will be under the age of 65 when diagnosed and 50% will be aged 65 or older.

What we need:

**IMPROVEMENTS TO AGED
AND DISABILITY CARE**

[Phil Brady \(pictured\) discusses the inadequacies in the aged care care system for people living with MND](#)



Cost of MND

A [Deloitte Access Economics report](#), commissioned by MND Australia states that the total cost of MND in Australia was \$2.37 billion in 2015, comprising \$430.9 million in economic costs and \$1.94 billion in burden of disease costs. The enormity of these costs is akin to the brutality of MND.

MND Fact

In Australia the total cost of MND in Australia was \$2.4 billion in 2015.

Deloitte Access Economics 2015, Economic analysis of MND in Australia

What we need:

National MND Guidelines

Until there is a cure, there is care

The social and emotional impact of MND is amplified by its complex nature, the speed of its progression and the spiralling series of losses that pose:

- huge problems of adjustment for people who have MND;
- an escalating and stressful burden on carers and families; and
- a challenge to health professionals, disability services and community and aged care providers involved in meeting the variable and complex care needs

Timely and expert diagnosis, early and evidence-based intervention from specialist MND multidisciplinary teams, local services and MND Associations, access to aids and equipment, specialist palliative care, specialist planning and assessment and coordination of care, including a proactive framework for decision-making, play vital roles in maintaining quality of life and independence. These specialist interventions are also crucial in helping people to plan ahead to prevent crisis and avoidable hospital/residential aged care admissions.

Although early intervention will not slow down the disease process in MND it will strengthen the informal supports available to the person, including supporting the primary carer to maintain the caring role and their own health and wellbeing.

People living with MND face many challenges but accessing the right care, in the right place, at the right time should not be one of them. The complex and progressing nature of MND requires an interdisciplinary approach encompassing health (GPs, neurology, respiratory, gastroenterology, neuropsychology, nursing, palliative care and allied health), disability, community, aged, respite and carer support services. Despite the complexity and rapid progression there are no guidelines available in Australia to guide professionals and to support coordinated care delivery.

People impacted by MND have two crucial needs:

- 1. CARE to meet identified needs from diagnosis through to bereavement**
- 2. RESEARCH to find effective therapies to stop MND**

MND ACTION

MND AUSTRALIA SEEKS COMMITMENT FROM ALL SIDES OF POLITICS FOR:

- 1. Improvements to aged and disability care**
- 2. Timely access to a full range of assistive technology**
- 3. Development of National MND Guidelines**
- 4. Access to fully funded genetic services for families with identified genetic mutations**
- 5. A specific commitment to fund specialist MND multidisciplinary clinic nurses**
- 6. Increased investment in research**

1. Improvements to aged and disability care

Why?

A rapid response to service provision from a range of providers with an understanding of MND, timely access to assistive technology, coordination and regular review is imperative in meeting the individual needs of a person living with MND.

MND Associations are working together to review service provision and structure to prepare for the future. The experiences with the NDIS to date have identified that NDIA staff find the complex and progressive nature of MND challenging. In addition, their understanding of the range and number of services that need to be organised and coordinated to support a person with MND and their family is limited. They struggle to work with the rapidly progressive degenerative nature of MND that means that services need to be planned and funded for future needs, as well as the present.

Following intense involvement and engagement as the NDIS has been trialled and rolled out nationally MND Associations are now reporting positive outcomes related to fast track planning, use of the *NDIA Practice Guide for MND*, assistive technology bundles and coordination of supports. Some NDIS participants living with MND have received plans that are having positive, life-changing impacts on their lives; many others, however, continue to struggle to receive plans that take their progressing and complex needs into account.

From experience we know that the needs of people living with rapidly progressive neurological diseases such as MND cannot be met by existing or traditional aged care services or facilities.

Even with the recent improvements and changes to the aged care system the focus remains on addressing needs related to ageing. Access to disability services and hours of support to meet a person's needs remain limited and major gaps with respect to the range and level of services available and waiting lists continue. These gaps are particularly apparent for people with progressive neurological diseases such as MND. These diseases are not acquired as part of the natural ageing process; however, many people do acquire these diseases in their 60s and 70s. As people age with a progressive neurological condition their needs increase, mostly because of the progression of the disease, not because of ageing.

Approximately 50% of people will be diagnosed with MND when aged 65 or older. As the NDIS rolls out nationally there will effectively be a two tiered system for people living with MND. Those aged under 65 will be able to access reasonable and necessary supports to meet their complex and changing needs. Those aged 65 or older will need to wait for a Home Care Package to become available and then have access to limited hours of support.

Desired outcomes

- MND confirmed as an early intervention group within the NDIS and aged care sectors to ensure timely planning and assessment nationally.
- Access to 'fast-tracked' care and support services to meet the complex, progressing and changing needs of all people living with MND no matter their age



2. Timely access to a full range of assistive technology

Why?

In the Deloitte report aids and equipment comprise one of the highest per person costs highlighting their importance. The often rapid rate of progression requires 'fast track' access to a wide range of assistive technology as items need to be available as soon as a need arises and may only be required for a short period of time.



MND Fact

Aids and equipment cost \$31,598 per person in 2015.

Deloitte Access Economics 2015, Economic analysis of MND in Australia

The report states that aids and equipment cost \$31,598 per person in 2015 and confirms the MND Association equipment loan service as a cost effective model in providing the full range of equipment to maintain independence and communication as needs arise.

As the NDIS rolls out nationally people living with MND and the NDIA planners are increasingly aware of the benefits of including an annual payment to the MND Associations as part of a person's plan to enable fast track access to a 'bundle' of assistive technology provided by the Association. Inclusion of funds in a person's plan for specialised and individualised assistive technology and reasonable and necessary home modifications, however, can be challenging.

For people diagnosed with MND when aged 65 or over waiting lists continue and there is insufficient funding allocated, even within a Level 4 Home Care Package, to provide the range of assistive technology a person with MND will require during the disease trajectory. For people living with MND the full range of assistive technology may include aids and equipment to support comfort, independence and daily living, communication technology and non-invasive ventilation to support breathing, quality and length of life. Non Invasive ventilation improves survival by 13 months on average¹.

Desired outcomes

- Engagement with state MND Associations to create cost-effective access to assistive technology for all people living with MND
- Funding for the full range of assistive technology as part of a person's NDIS plan
- Older people diagnosed with MND have access to the assistive technology they need to maintain their independence, quality of life, communication and community access and to support carer health and well-being
- Access to non-invasive ventilation in the management of MND to improve quality and length of life

¹ Berlowitz et al, 2016 –Identifying who will benefit from non-invasive ventilation in amyotrophic lateral sclerosis/motor neurone disease in a clinical cohort, *J Neurol Neurosurg Psychiatry*, 2016 Mar; 87(3): 280-6.

3. Development of National MND Guidelines

Why?

The Deloitte Access Report highlights that of the progressive neurological group MND is the highest cost to the NDIS. It is therefore important for governments to work strategically and collaboratively with MND Associations to minimise cost and maximise quality of life.

Despite the complexity and rapid progression there are no guidelines available in Australia to guide professionals and to support coordinated care delivery. Care provision for people with MND crosses traditional funding silos including: health, disability, equipment, respite, chronic disease, and aged and palliative care. It also involves a combination of state and federal funding. This system is a major barrier to efficient use of services, timely referrals and equitable access to quality needs-based care.

In addition, access to evidence based interventions for people with MND remains problematic. Research confirms that timely access to non-invasive ventilation (NIV), nutritional support including percutaneous endoscopic gastrostomy (PEG), multidisciplinary care, palliative care and riluzole improves quality and length of life.

In the face of changing service delivery and a new era of disability and aged care provision in Australia it is vital that new providers entering the market – the planners, assessors, health professionals and care providers – understand the complex and progressing needs of people living with MND and their families.

The National Institute of Health and Care Excellence in the UK has developed [MND guidelines](#) for health and community care professionals to support and guide them to provide timely, coordinated needs based care. We look forward to similar guidelines being available in Australia to support Australian health and community professionals to meet our desired care outcomes.

MND Fact

Of the progressive neurological group, MND is the highest cost to the NDIS.

Deloitte Access Economics 2015, Economic analysis of MND in Australia

Desired outcomes

Funding to support the development of national MND guidelines to ensure:

- Early and expert diagnosis
- Referral to the right service at the right time
- Access to timely, evidence-based care for all people living with MND
- Cross sector communication, collaboration and coordination
- Workforce support
- Optimal end of life care

4. Access to IVF and pre-implantation genetic diagnosis

Why?

The Deloitte report identified that the per person cost of MND was \$1.1 million in 2015 dwarfing the cost of many other chronic health conditions.

Between 5 and 10% of people with MND have the familial form of MND which means that the genetic mutation causing MND can be passed on to future generations. This equates to between 100 and 200 people in Australia at any point in time.

The first gene mutation (SOD1) was discovered in 1993 and accounts for around 20% of familial MND. Since 2006 more gene mutations have been discovered.

In 2011 the discovery of mutations in the C9orf72 gene was announced and has since been found in about 40% of all families with familial MND. The pace of gene mutation discovery has accelerated in recent years with advancements in technology. Known genetic mutations now account for over 60% of familial MND.

Research is moving us closer each day towards our vision of a world without MND, but the discovery and availability of an effective treatment to slow or stop MND is still likely to be many years away. Whilst there are no therapies available to stop the disease in people living with MND today, we can help those who carry a known genetic mutation to stop the disease affecting future generations through:

- Access for people with familial MND to genetic testing at no cost to them under the existing arrangements for testing, including counselling
- Funding and access for those who choose to undertake in-vitro fertilisation (IVF) and pre implantation genetic diagnosis (PGD)

PGD and IVF is being used effectively by people with many other conditions. With around 60 to 120 people with familial MND who have a known genetic mutation at any one time, government investment in this project would be relatively low in the short term, and could lead to a huge reduction in health, disability and aged care costs to governments in the future.

MND Fact

In Australia the per person cost of MND in 2015 was \$1.1 million, dwarfing the cost of many other chronic health conditions.

Deloitte Access Economics 2015, Economic analysis of MND in Australia

Desired outcomes

- Government funding to support MND families with a known genetic mutation to access genetic testing and counselling
- Those who choose to undertake IVF and PGD are able to do so at no cost to the person
- In the longer term – reduction in burden of disease costs to individuals and reduction in health and economic costs to governments
- Stop MND in families with a known genetic mutation

5. A specific commitment to fund specialist MND multidisciplinary clinic nurses

Why?

Health system costs of MND were found to be \$74.4 million in 2015.

Multidisciplinary teams should be involved from diagnosis in assessment, ongoing review and specialist symptom management to prevent crisis management and unnecessary and unwanted hospital admissions.

Evidence confirms that specialist multidisciplinary clinics can contribute to:

- longer survival;
- better quality of life; and
- greater access to evidence based therapies

Other likely contributors to increased survival for people who attend Multidisciplinary MND Clinics are:

- increased use of riluzole and non-invasive ventilation;
- attention to nutrition; and
- early referral to palliative care services

Specialist MND Multidisciplinary Clinics operate in most capital cities in Australia. The majority of these clinics do not receive specific government funding despite increasing demands on their services. The multidisciplinary clinic coordinator role is vital in supporting the team and ensuring coordinated care and timely provision of treatment for people living with MND.

Compared to those people with MND who attend general clinics, multidisciplinary care can contribute to fewer hospital admissions and shorter inpatient stays.

MND Fact

Health system costs of MND were \$74.4 million in 2015.

Deloitte Access Economics 2015, Economic analysis of MND in Australia

Desired outcomes

Specific government funding for Multidisciplinary Clinics to build capacity and ensure that these clinics can continue to provide coordinated health care, expert management and evidence based treatment for people living with MND

6. Increased investment in research

Why?

There is a cure for MND, we just haven't found it yet.

Currently there are no therapies to effectively slow down the disease or stop the progression. It is therefore imperative that research advances continue to be funded to ensure the ultimate goal of a rationally designed therapy that stops the advance of MND neurodegeneration.

The Deloitte report found that in 2015 just \$5,083 per person living with MND was invested in research and that medication costs were one of the lowest at just \$2,710 per person.

The report states that in 2015 the NHMRC estimated that they would provide \$8.07 million for MND related research in 2015. In addition the MND Research Institute of Australia invested \$2.57 million for projects commencing that year.

MND Fact

In 2015 just \$5,083 per person living with MND was invested in research.

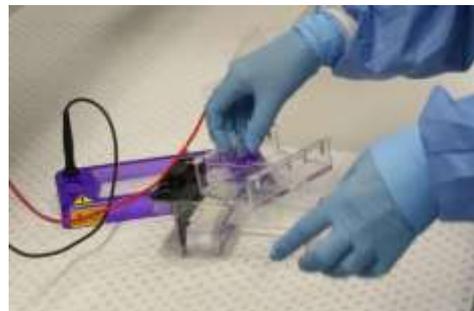
Deloitte Access Economics 2015, Economic analysis of MND in Australia

The past five years have seen acceleration in MND research globally, which has transformed understanding of the disease. During that time Australian MND researchers have been at the forefront of gene discoveries, development of biomarkers and new therapies and in understanding the causes of MND. Despite these advances Riluzole remains the only proven therapy available to people living with MND in Australia. Riluzole slows the disease process by just three months on average.

"With the transformative understanding of clinical, neuropathological and molecular genetic aspects of [MND] over the last five years, the quest for rational fundamental therapy has become a realistic hope." (Ravits et al, 2013)²

Over the last 30 years MND Associations in Australia have invested \$25 million in Australian researchers. This investment has only been possible with the continued support of committed and passionate donors, many of whom have been personally impacted by MND.

MND Australia has made a commitment to work to continue to increase funds available for research each year until we are able to stop MND – we seek the same commitment from governments.



Desired outcomes

- Government investment of at least \$20 million annually to fund Australian researchers to translate basic research findings into effective treatments to improve quality and length of life and to ultimately stop MND.
- In the longer term – reduction in burden of disease costs to individuals and reduction in health and economic costs to governments.

² Ravits et al, 2013 – Deciphering amyotrophic lateral sclerosis: What phenotype, neuropathology and genetics are telling us about pathogenesis, *Amyotrophic Lateral Sclerosis Frontotemporal Degeneration*, 2013 May; 14(01): 5–18.

About MND Australia

[MND Australia](#) is the national peak advocate for MND. Together with the [state MND Associations](#) we advance, promote and influence MND care and research with a vision to achieving a world without MND. MND Australia works to improve the lives of all Australians impacted by MND by influencing policy, providing trusted information, raising awareness, and promoting and funding the best research through our research arm, the [MND Research Institute of Australia](#) (MNDRIA).

The six state MND Associations, representing all states and territories, are members of MND Australia. The MND Association of New Zealand is an associate member of MND Australia. MND Australia is a proud and active member of the [International Alliance of ALS/MND Associations](#).

Research is the only way that we can change the future of motor neurone disease (MND). Every dollar we receive for research is directed to MNDRIA and invested in research with the best chance of understanding the causes, developing effective treatments, improving healthcare and finding a cure for MND. We believe that it is only a matter of time and hard work before we unravel MND's mystery. A cure is out there and our researchers are working hard to find it.

The key to quality and length of life for people living with MND lies in access to the best possible, evidence and needs based care including coordinated multidisciplinary care, riluzole, non-invasive ventilation, nutritional support, disability and aged care supports and services from MND Associations.

The state MND Associations support over 80% of all people diagnosed with MND in Australia.

The state Association support service staff and MND advisors aim to provide the following services:

- tailored and expert information
- active assistance to members
- home visits and ongoing support
- assistance in accessing MND clinics and local services
- equipment provision or assistance in accessing equipment from government agencies
- peer support, support groups and information programs
- carer workshops
- information and education for health, disability and aged care professionals
- local advocacy and influencing
- volunteers

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Download the report [Deloitte Economic analysis of motor neurone disease in Australia, 2015](#)