EVERY MOMENT MATTERS

Addressing the human and economic toll of motor neurone disease in Australia

30 MAY 2025

mnd Australia | evohealth report

OUR MISSION

To improve the lives of everyone impacted by MND through advancing high quality care, advocacy and research.

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.

MND Australia acknowledges that we work on the lands of Aboriginal and Torres Strait Islander people and we pay respect to Elders, past present and emerging.

We commit to working in collaboration with Aboriginal and Torres Strait Islander communities and peoples to improve health, emotional and social well-being outcomes in the spirit of partnership.

CONTENTS

ABOUT THIS **REPORT**

Background

Every moment matters: Addressing the human and economic toll of motor neurone disease in Australia is an evidence-based analysis of the human and economic impact of motor neurone disease (MND) in Australia. Independently written by Evohealth, a specialist health advisory firm, the report was developed in collaboration with an expert Advisory Committee comprising of MND clinicians, leading researchers, and people with lived experience of MND.

The report aims to guide policy decisions that enhance care, support, and quality of life for people living with this progressive, terminal condition and those individuals that care for them. It provides a comprehensive analysis of MND's impact and delivers five recommendations to address these challenges and improve outcomes.

Approach

The report has been informed by:

- A comprehensive review of published academic and grey literature.
- Interviews with Australian clinicians, researchers and advocacy groups representing people with lived experience.
- A cohort-based economic model and analysis to quantify the direct and indirect costs of MND, along with its impact on quality of life in Australia, now and into the future (methodology detailed in Appendix A).
- Contributions of our expert Advisory Committee members.

Funding for this report was contributed by Biogen and Neurizon. To ensure independence and objectivity, Biogen and Neurizon were not involved in the report's development. All conclusions and recommendations are based solely on Evohealth's independent research and analysis.

Unless otherwise specified, all financial data is presented in Australian dollars.

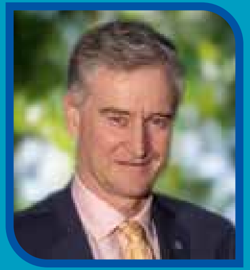
ACKNOWLEDGEMENTS

Evohealth extends its sincere gratitude to the individuals and organisations whose invaluable contributions supported the development of this report.

We particularly acknowledge the Advisory Committee for their critical oversight and insightful contributions during the report's development.

The committee included the following members:

Dr. Thanuja Dharmadasa
Neurologist & Clinical
Neurophysiologist
Royal Melbourne Hospital



Associate Professor
Robert Henderson
Neurologist
Royal Brisbane & Women's
Hospital

Todd Johnson
Person living with MND
Board Member MND Victoria

Associate Professor
Allan McRae
System Genomics - Institute for
Molecular Bioscience
University of Queensland

Graham Opie
CEO
MND NSW

Clare Sullivan
CEO
MND Australia

EXECUTIVE **SUMMARY**

Every day in Australia, two people are diagnosed with Motor Neurone Disease (MND), and two lives are lost to the disease. [1]

MND is a rare, progressive neurodegenerative condition that affects motor neurons, which are nerve cells responsible for transmitting signals from the brain and spinal cord to the muscles. These signals enable essential movements such as walking, talking, swallowing, and breathing. Over time, degeneration of these motor neurons through MND causes the muscles to weaken, leading to a gradual loss of voluntary control over these movements. MND may also cause cognitive changes that affect how a person thinks, behaves, regulates their impulses and inhibitions, as well as their ability to reason, make decisions and communicate effectively. [2] Together, physiological changes from this degeneration result in diminished independence and ultimately death. [1, 3, 4] In 2025, Evohealth modelling estimated that 2,752 Australians are living with MND, equivalent to approximately 1 in every 10,030 people. [5] The cost of this devasting disease in Australia is estimated at $5.02 billion annually, a figure projected to rise to $7.51 billion by 2050 without any new significant interventions. [5]

> *This is a devastating disease that robs individuals of everything – their autonomy, their livelihoods, and eventually their lives.*
>
> A/Professor Robert Henderson, Neurologist

A complex and progressive disease

MND affects people differently. Not all symptoms occur in the same order, progress at the same rate or affect everyone. There are several forms of MND which are differentiated based on the specific pattern of nerve involvement, and where the symptoms begin. [6] These include:

- Amyotrophic Lateral Sclerosis (ALS), the most common form.
- Progressive Bulbar Palsy (PBP).
- Lower Motor Neuron (LMN) predominant ALS [known historically as Progressive Muscular Atrophy (PMA)].
- Primary Lateral Sclerosis (PLS).
- MND with Frontotemporal Dementia (MND-FTD). [7]

All forms lead to a progressive decline in muscle function. While most individuals face rapid progression of the disease, some will experience a slower deterioration. Early symptoms such as muscle weakness and fatigue are often subtle and can be mistaken for other conditions, contributing to a lengthy average time to diagnosis of 13 months. [8, 9] Adding to its complexity, in most cases the cause of MND remains unknown, and no direct diagnostic test exists. [4] Its rarity means many primary healthcare professionals (HCPs), such as General Practitioners (GPs), may encounter only one or two cases in their entire careers, or none at all. [6] This limited clinical exposure often results in delayed referrals to a neurologist specialising in MND, which, in turn, delays commencement of appropriate treatment and care. [10]

Once diagnosed, the rapid progression of MND necessitates frequent adjustments to care coordination and planning. Timely access to support and funding is crucial to manage these evolving needs. However, Australia's health, disability and aged care systems are failing to provide equitable access to funding and support for people living with MND, leaving many waiting to access essential care during the limited time they have left. [11] This failure must be addressed.

Treatments and care

Currently, there is no cure for MND. [1] Existing therapies focus on managing symptoms, slowing disease progression, and enhancing quality of life. Care needs to be delivered via a network of providers encompassing multidisciplinary team (MDT) clinics, State MND Associations and experienced HCPs and palliative care providers. [12]

Common treatments, interventions and support for people living with MND are outlined below:

Multidisciplinary Team (MDT) care, involving HCPs both within and outside of MND clinics, has been shown to improve both quality of life and survival, potentially extending life up to 7-24 months. [13, 14]

Non-invasive ventilation (NIV) helps people with MND breathe more easily without surgery or invasive procedures. It can increase survival by up to 13 months, alleviate breathlessness and fatigue, and improve sleep quality, thereby enhancing overall quality of life. [15]

Pharmacological treatments, including riluzole (Rilutek® and Teglutik®), prolong survival times by 6-19 months for those who commence treatment early. [16] For individuals who carry the SOD1 gene, tofersen (Qalsody®) is showing significant benefits. [17] Edaravone (Radicava®), administered via intravenous (IV) infusion, became available on the Pharmaceutical Benefits Scheme (PBS) on 1 May 2025 and is now available by prescription for people with ALS – the most common form of MND. Edaravone must be first prescribed within two years of symptom onset. [57, 58]

State MND Associations provide a suite of support services, including advice, equipment loans, specialist allied health services and referrals, carer support and respite, as well as assistance with navigating government funding submissions. [24]

Augmentative and Alternative Communication (AAC) devices reduce isolation, improve social participation, and enable independence. [18, 19]

Specialised equipment and home adaptations help support independence, improve safety, and prevent falls and subsequent hospital admissions, helping people with MND live comfortably and safely at home. [20]

Nutritional aids are crucial for managing dysphagia in people with MND. Early enteral feeding via Percutaneous Endoscopic Gastrostomy (PEG) or Radiologically Inserted Gastrostomy (RIG) helps maintain nutrition, hydration, and energy, supporting overall health and quality of life. [21, 22]

Palliative care provides essential support for people living with MND, their families and carers. It focuses on improving quality of life from diagnosis through to end-of-life care. [23]

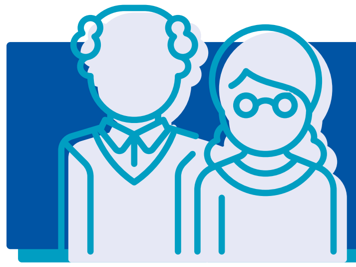
Despite clear benefits, including improved quality of life and increased survival times, accessing and coordinating these interventions remains challenging for people living with MND.

Challenges exist but their impact is not the same for all

Funding inequities

A significant barrier to accessing care and interventions for people living with MND in Australia is the vast disparity in funding support, which is determined solely by the individual's age at the time of their application.

Those diagnosed under 65 years of age are eligible to apply for and access funding support from the National Disability Insurance Scheme (NDIS), which offers comprehensive and flexible funding for care needs in the home. [25] In contrast, individuals diagnosed at age 65 and over receive funding through the Support at Home program, which is designed to support ageing individuals rather than those with complex disabilities. [26] (a) The maximum level of funding under the Support at Home program is approximately 36 per cent of the average funding accessible through the NDIS. Table 1 outlines the differences between the two funding pathways, highlighting the inequities in the time to access support and the level of care provided.



Age matters: The average NDIS funding package for people with MND is approximately three times higher than the maximum Level 8 Support at Home program funding.

Note (a): *the Support at Home package is still being developed by the Australian Government at the time of printing, 30 May 2025. This report focuses on the Support at Home program as the primary funded aged care pathway for people aged 65 and over living with MND. To ensure clarity and consistency, all future references to aged care funding throughout the report will use the term "Support at Home program" to refer to this package, unless otherwise specified.*

Table 1. Comparison of NDIS and Support at Home program for people living with MND.

	NDIS	Support at Home program
Eligibility	Under 65 years old	Aged 65 and over
Access time	Fast-tracked, typically within 2-5 days for people with MND. [26, 27]	Time to access is unknown. Previous packages have wait times of up to 15 months. [73]
Services	Comprehensive support including personal care, therapies, assistive technology, home modifications, and support coordination.	Basic care services including personal care, limited therapy, and basic equipment.
Funding	Not means-tested, no cap, with an average of $302,000 per year per person in 2025. [34]	Means-tested, with the maximum available care package set at $108,000 per person per year in 2025.
Proportion of people	37% of people with MND (1,018 individuals in 2025). [5]	63% of people with MND (1,734 individuals in 2025). [5]
Total cost	$305.68 million annually. [5]	$187.45 million annually. [5]

Source: Evohealth developed from multiple sources [5, 26, 27, 34, 73]

Evohealth modelling estimates that in 2025, 63 per cent of people living with MND are aged 65 and over at the time of diagnosis and are therefore eligible for the Support at Home program. This represents 1,734 people, at a cost of $187.45 million to the Federal Government. Conversely, 1,018 people, or 37 per cent, are eligible for NDIS funding, at a cost of $305.68 million to the Federal Government. [5] This discrepancy in funding based on age contributes to the inequity in access to care and support for people living with MND, ultimately impacting their quality of life and the resources available to meet their needs.

Access to appropriate care and informed care providers

Following a diagnosis of MND, individuals and their families typically face an overwhelming and complex healthcare journey, often with limited initial guidance. While online resources are available, they can be difficult to interpret during such an emotionally charged time, leading to confusion about care priorities and delays in accessing essential services.

Specialist MND clinics, which offer MDT care, play a crucial role in improving quality of life and survival outcomes, and in reducing hospital admissions and functional deterioration. [28, 29] However, these clinics are primarily located in metropolitan areas, requiring those in regional and remote Australia to travel long distances to access care.

Additionally, there are significant variations in the services and support offered across MND clinics in Australia, including inconsistencies in review processes, costs, access to specialists and allied health professionals, and interventions such as NIV.

When access to specialist MND clinics is limited, individuals with MND often rely on community-based HCPs. However, due to the complex nature of the disease, many of these professionals lack the specific knowledge and experience needed to deliver specialised MND care. As a result, people with MND and their carers often face the overwhelming task of seeking out specialists with MND experience and coordinating the necessary care independently, which can be time consuming, frustrating and difficult. Additionally, some essential services, such as remedial massage, may not be covered under funding packages, leaving individuals without this necessary care, or having to cover the costs themselves.

National standardised clinical guidelines for MND are currently under development. This is a critical step, as the absence of clear, evidence-based recommendations for diagnosis, treatment, and ongoing care has contributed to wide variability in clinical practices across providers, regions, and states. This inconsistency directly impacts the accessibility, timeliness, and quality of care available to Australians living with MND.

State MND Associations play a critical role in addressing these gaps by providing support to navigate funding applications, access to allied health professionals, equipment loans, and other support services. [24] However, these associations are not securely funded, relying instead on philanthropy and inconsistent, or non-existent, state and territory government funding. This exacerbates inequities in care and support services.

The burden and impact of MND is immense

With no cure on the horizon and inequitable access to care and treatments, the burden on people living with MND, their carers, and society is immense.

People living with MND

Living with MND is a journey of continuous loss, marked by rapid physical decline that affects independence, autonomy, and emotional well-being. The inability to engage in once-enjoyed activities, perform daily tasks such as eating or brushing teeth, or communicate effectively, compounds feelings of frustration, grief, and loss of identity. The mental health toll is profound, and individuals frequently experience anxiety, depression, and a persistent sense of uncertainty for their future. [30, 31]

The financial impact is equally challenging, with substantial costs incurred for care, medical equipment, and home modifications. Not all of these costs are covered by the available funding packages, often resulting in out-of-pocket costs. Whilst many insurance policies and superannuation funds include provisions for individuals facing terminal illnesses such as MND, eligibility requirements to access these benefits are inconsistent, and many individuals simply remain unaware that these benefits exist, so do not seek them out. The economic impact of MND is far-reaching, with an estimated $155.72 million lost in productivity due to reduced or lost income. [5] Collectively, these issues contribute to significant household financial strain, requiring difficult decisions about care priorities and resource allocation.

Carers

Carers, often immediate family members, shoulder immense responsibilities, dedicating 5.37 million hours of unpaid care annually, valued at $212.02 million. [5] As the disease progresses, the carer role becomes all-encompassing and will typically include physical assistance, advocating for needs, medical team coordination, and emotional support. [32] Many carers are often forced to reduce their employment, leading to lost income, superannuation, and stalled career progression, contributing to a significant financial burden that is difficult to overcome.

Caregiving takes a significant toll on carers' physical and mental health. The unpredictable progression of MND requires caregivers to maintain constant vigilance. They must respond to rapidly evolving symptoms and needs, including changes in mobility, communication, and breathing. Adapting to these shifts demands ongoing learning and quick adjustments, as well as acceptance of changing roles in established relationships, often leaving caregivers emotionally and physically exhausted. [33]

> It [MND] was a cruel, cruel punishment for both of us.
>
> Former carer of a person who passed away from MND

Many carers find that their experience doesn't end with the death of their loved one. Instead, they may face prolonged grief and the considerable challenge of rebuilding their lives after years of intense caregiving. Despite their critical contributions, carers often lack access to dedicated support services and resources leaving them to navigate these challenges largely on their own. [31]

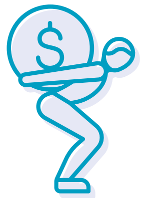
5.37 million hours of unpaid care were provided in 2025, equivalent to **$212.02 million** in lost carer wages. [5]

Society

Evohealth modelling estimates the combined economic and burden of disease cost of MND in Australia to be **$5.02 billion in 2025**. [5] This includes economic costs from lost productivity, unpaid carer burden, direct healthcare system costs, and the burden of disease cost, which estimates the value of lost years of healthy life. If no changes are made to the management of MND and support for those living with the disease and their carers, its burden in Australia is projected to reach **$7.51 billion by 2050**. [5]

$982.44 million – Total economic cost of MND in 2025, includes healthcare system costs, financial supports, research funding, and productivity losses. [5]

+



$4.04 billion – Estimated annual total burden of disease cost, including years of life lost or lived with disability. [5]

$5.02 billion – Total costs of MND in Australia in 2025 [5]

$7.51 billion – Projected annual cost of MND in Australia by 2050. [5]

Making every moment matter – recommendations to support improved quality of life for people impacted by MND

Time is of the essence for people living with MND, and access to timely, appropriate care is critical. We must provide equitable support for all Australians living with MND, irrespective of their age.

Our expert Advisory Committee has developed five key recommendations with the potential to significantly improve the quality of life for those impacted by this devastating disease:

1. The Australian Government to establish a nationally consistent funding pathway to fund care and support for people living with MND, irrespective of age.
2. The Australian Government to fund an integrated MND data strategy and registry, that supports research and care in Australia.
3. MND Australia to develop a national directory of healthcare professionals with MND experience, with funding provided by the government.
4. The Australian Government to fund MND Australia to develop a National MND Support Program targeted at people living with MND and their carers.
5. MND Australia to work with regulators to develop and implement consistent definitions and practices for terminal illness in superannuation and life insurance policies.

Time is crucial in the battle with MND, every moment matters.

There is an urgent need to implement these recommendations to improve the quality of life of people impacted by MND and ensure equitable access to appropriate services and support for all.

PREVALENCE OF MND IN AUSTRALIA

Prevalence of MND now, and by 2050 [5]

2025: 2,752 ▶ **2050:** 4,304

Deaths due to MND [5]

2025: 896 ▶ **2050:** 1,462

CAREGIVER AND FAMILY IMPACT

5.37 million unpaid care hours provided by informal carers in 2025 [5]

Equivalent to **$212.02 million** in unpaid care provided by informal carers [5]

ECONOMIC COSTS ASSOCIATED WITH MND

Total health system costs **$27.11 million** [5]

Total financial support **$493.14 million** [5]

Total productivity losses **$457.36 million** [5]

Research funding **$4.83 million** [5]

BURDEN OF DISEASE COSTS ASSOCIATED WITH MND

Years of life lost (YLL)

15,760 years of life lost due to premature mortality in 2025 [5]

Life expectancy for people living with MND is **18 years less** than the Australian average [5]

Equivalent to **$3.70 billion** in costs [5]

Years Lived with Disability (YLD)

1,420 years of healthy life lost due to disability in 2025 [5]

Equivalent to **$0.33 billion** in costs [5]

Disability adjusted life years (DALY)

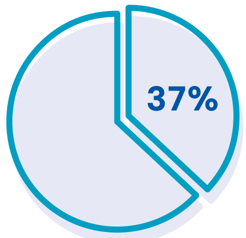
17,180 disability adjusted life years lost due to MND [5]

Total economic costs **$982.44 million** ✚ Equivalent to **$4.04 billion** in costs

Total cost of MND estimated at $5.02* billion in 2025 [5]

DISCREPANCY BETWEEN THE NDIS AND SUPPORT AT HOME PROGRAM FUNDING MODELS

37 per cent eligible for NDIS in 2025 [5]

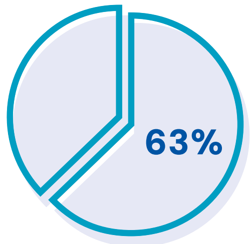


Equivalent to **1,018 people** living with MND eligible

At a cost to the Federal Government of **$305.68 million**

Average NDIS funding package of **$302,000 per person** [34]

63 per cent eligible for Support at Home program in 2025 [5]



Equivalent to **1,734 people** living with MND eligible

At a cost to the Federal Government of **$187.45 million**

Maximum funding package of **$108,000 per person** in 2025. [26]

By 2050, as the population ages, the proportion of people eligible for NDIS is projected to decline to 33 per cent, whilst simultaneously, the proportion of people accessing the Support at Home program will increase to 67 per cent. [5] This shift will have a flow-on effect to the State MND Associations, requiring them to manage a greater demand for their services to ensure people with MND continue to receive the necessary support.

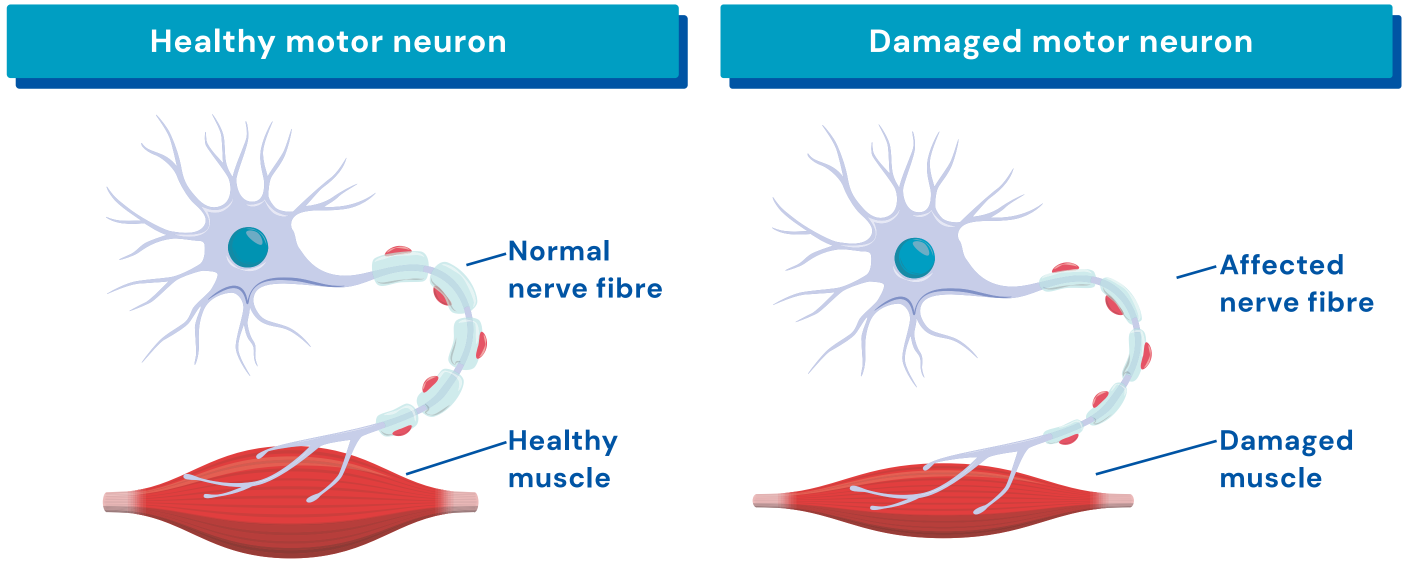
**Totals may not add up precisely due to rounding*

WHAT IS MOTOR NEURONE DISEASE?

Motor Neurone Disease (MND) is a complex neurodegenerative condition that disrupts the critical communication between the brain, spinal cord, and muscles, leading to a gradual loss of muscle control. [1] As MND progresses, simple actions such as walking, talking, swallowing and even breathing become difficult. The deterioration of motor neurons, as illustrated in Figure 1, leads to increasing disability and ultimately results in death, often within two to three years of diagnosis. [1, 3, 4]

The average life expectancy for a person diagnosed with MND is just 2 to 3 years. [1]

Figure 1. Function of a healthy neuron compared to a neuron affected by MND.



A healthy **neuron sends messages smoothly** between the brain, spinal cord, and muscles.

These messages **control movement, reflexes, and other essential functions,** enabling daily activities such as speaking, swallowing, and moving to be performed with ease.

In MND, **neurons become damaged** and die, breaking the connection between the brain, spinal cord, and muscles.

This damage prevents messages from reaching the muscles, causing them to weaken and lose function over time. This leads to difficulties with movement, speaking, swallowing, and breathing.

Source: Adapted from multiple sources [1, 7, 35]

MND affects slightly more men than women, and predominantly occurs in adults aged 50 to 70 years of age, although it can occur across a wider age range. [4]

The prevalence of MND in Australia is increasing, primarily due to our growing and ageing population.

In 2025, an estimated 2,752 people are living with MND, this number is expected to rise to 4,304 by 2050. Similarly, deaths from MND are expected to increase, with 896 deaths estimated in 2025 and 1,462 projected in 2050. These numbers, though stark, only hint at the human toll of the disease. [5]

2025

2,752 people living with MND
1 in 10,030 Australians

896 deaths

2050

4,304 people living with MND
1 in 8,772 Australians

1,462 deaths

MND is a heterogeneous condition, with each individual's presentation shaped by a unique interplay of genetic, biological, and environmental factors. [36] Early signs such as subtle muscle weakness, twitching, or difficulty with speech can be easily mistaken for other conditions, often leading to delays in diagnosis. The disease's progression is equally unpredictable. While many individuals face a rapid decline, some experience a slower, more protracted journey. [1]

Despite extensive and ongoing research efforts, there is currently no cure for MND. [1] Treatment and care is focused on improving quality of life. The progressive loss of independence, growing reliance on assistance for basic functions, and the mental and emotional toll weigh heavily on the person living with MND, as well as their carers and families. The journey with MND is marked by the typically rapid progression of the disease, its continuous changes and uncertainties, and ultimately its devastating and inevitable prognosis of death. [37]

Forms of MND and their progression

There are several forms of MND, each affecting motor neurons in different patterns and resulting in different symptoms and rates of progression. [4, 7, 8] These forms are summarised in Table 2.

ALS is the most common form of the disease, and in some parts of the world, MND is referred to as ALS. It accounts for approximately 70 per cent of all cases of the disease.

Table 2. Overview of MND types, symptoms, and progression

Type of MND	Affected motor neurons	Initial symptoms	Progression
Amyotrophic Lateral Sclerosis (ALS)	Upper and lower motor neurons.	Muscle weakness (usually starts in a limb).	Gradually spreads to other muscles affecting speech, swallowing, and breathing.
Progressive Bulbar Palsy (PBP)	Upper and lower motor neurons.	Slurred speech, changes in voice and difficulty swallowing.	Restricted to speech and swallowing muscles for a protracted period (>6 months), then spreads to limbs.
Progressive Muscular Atrophy (PMA)	Predominantly lower motor neurons.	Muscle wasting, weakness and weight loss.	Slower progression than ALS, may later generalise into classical ALS.
Primary Lateral Sclerosis (PLS)	Upper motor neurons only.	Muscle stiffness, spasticity, balance issues and slow movement.	Very slow progression, affecting speech and movement.
MND with Frontotemporal Dementia (MND-FTD)	Upper and lower motor neurons.	Motor difficulties, personality and behaviour changes and cognitive decline.	Motor symptoms follow or develop alongside Frontotemporal Dementia (FTD), typically more rapid progression.

Source: Evohealth developed from multiple sources [4, 7, 8]

The complex nature of MND

MND is not only devastating in its outcomes, but also profoundly complex in its presentation, diagnosis and progression.

A rare disease

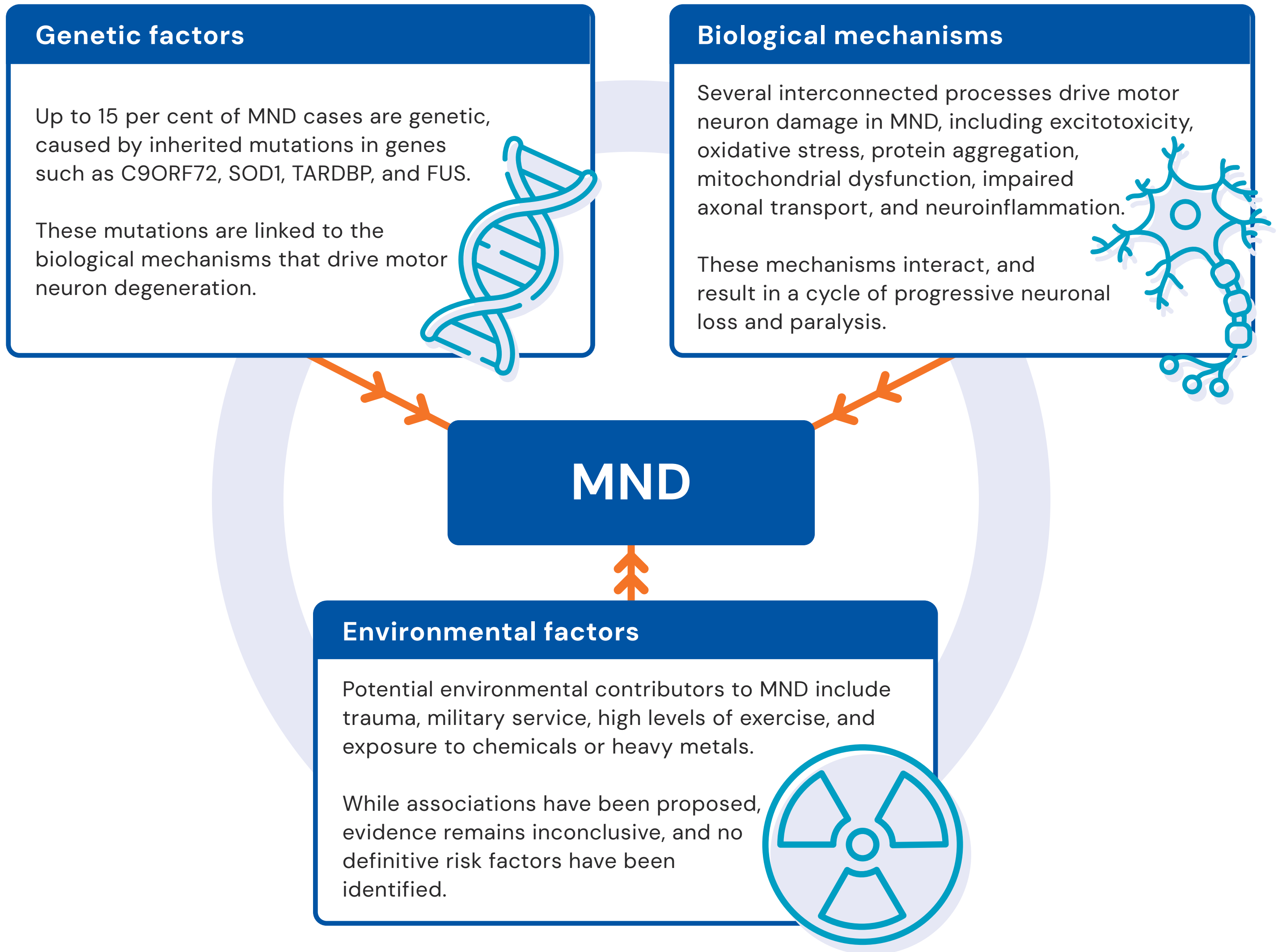
With an estimated prevalence in Australia of just 1 in every 10,030 people, MND is considered a rare disease and many primary healthcare professionals (HCPs), such as General Practitioners (GPs), may encounter only one or two cases in their entire careers, if any at all. [5, 6] As result, the possibility of MND typically is not front of mind for HCPs.

Early symptoms, such as muscle weakness, cramps, or fatigue, are subtle and often mistaken for other conditions. [4] Even after diagnosis, the limited experience with this disease among HCPs can hinder the delivery of effective and appropriate care.

An unknown cause

Adding to this challenge is the lack of a clear understanding of what causes the disease. While research is uncovering biological, genetic, and environmental influences, a definitive causal factor remains elusive. [36, 38, 39]

Figure 2. Biological, genetic, and environmental factors driving MND



Genetic factors

Up to 15 per cent of MND cases are genetic, caused by inherited mutations in genes such as C9ORF72, SOD1, TARDBP, and FUS.

These mutations are linked to the biological mechanisms that drive motor neuron degeneration.

Biological mechanisms

Several interconnected processes drive motor neuron damage in MND, including excitotoxicity, oxidative stress, protein aggregation, mitochondrial dysfunction, impaired axonal transport, and neuroinflammation.

These mechanisms interact, and result in a cycle of progressive neuronal loss and paralysis.

Environmental factors

Potential environmental contributors to MND include trauma, military service, high levels of exercise, and exposure to chemicals or heavy metals.

While associations have been proposed, evidence remains inconclusive, and no definitive risk factors have been identified.

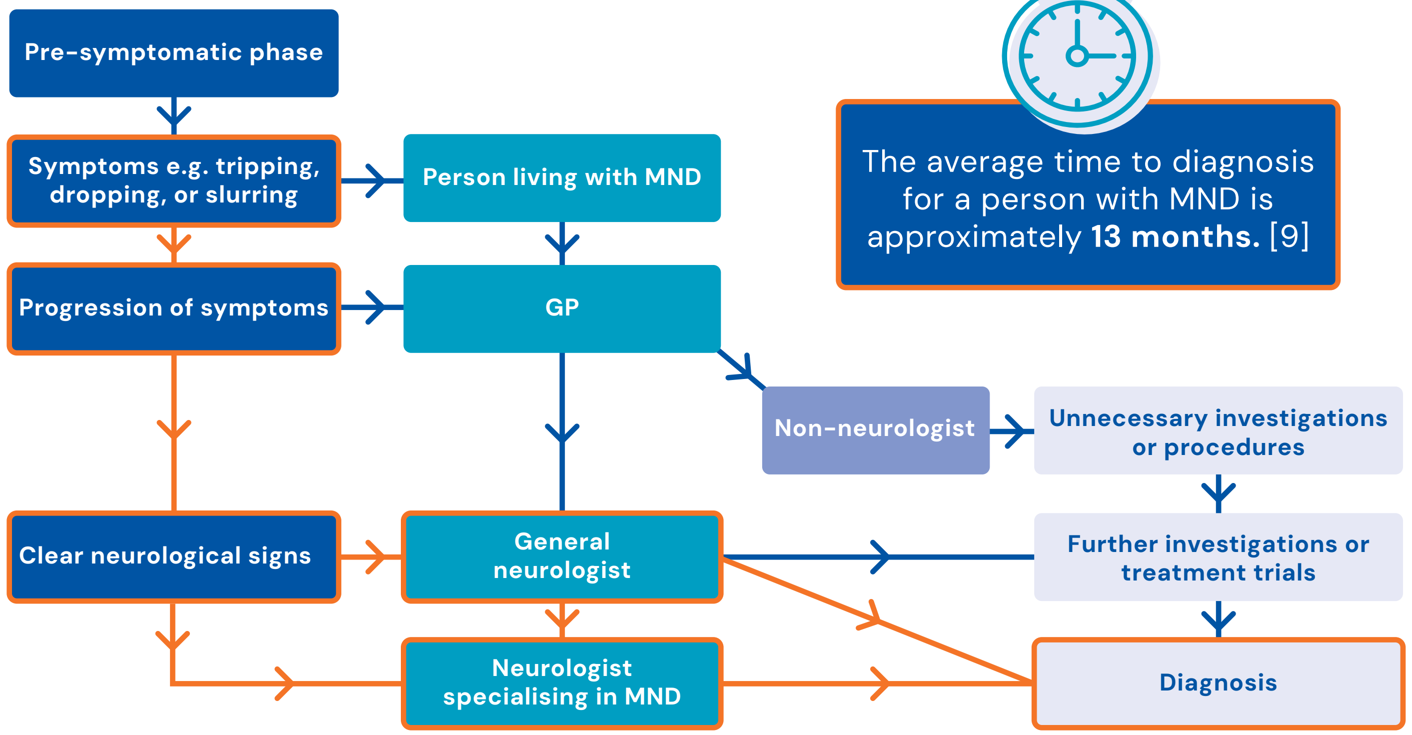
Source: Evohealth developed from multiple sources [36, 38, 39]

Diagnostic delays

Variability in initial symptoms and insufficient knowledge about the disease, from both the clinician and community perspectives, can contribute to significant delays in receiving a diagnosis, with a lengthy wait of 13 months on average in Australia. [9]

The diagnostic pathway for people living with MND is illustrated in Figure 3. Most will initially present to their GP with symptoms which may be subtle and mimic other conditions. This can result in referrals to several (non-neurologist) specialists, further lengthening diagnostic delays through unnecessary testing, procedures, and in some cases, surgeries. If a neurological issue is suspected, the GP or other specialist will refer the person to a neurologist, a specialist doctor which is qualified to diagnose MND. While the diagnosis is made on the basis of clinical features, the neurologist may also conduct a series of tests to rule out other conditions. These tests may include nerve conduction studies (NCS), electromyography (EMG), magnetic resonance imaging (MRI) scans, and a lumbar puncture. [4, 40]

Figure 3. Diagnostic pathway for MND



The average time to diagnosis for a person with MND is approximately **13 months.** [9]

Source: Adapted from Mimics and chameleons in motor neurone disease [41]

The complex nature of MND means not all specialists are experienced in the disease, resulting in a lengthy diagnostic process or unnecessary procedures, which can be costly, prolong uncertainty and delay access to essential and time-sensitive interventions. [9] Compounding this is the challenge of accessing neurologists in Australia, with wait times often exceeding 12 months, particularly outside of metropolitan centres. [9]

A communication challenge

A diagnosis of MND is life-altering, bringing shock, devastation, and fear for the individual and their family. The emotional impact of a terminal prognosis is profound, which may be compounded by how the diagnosis is communicated. [42] Poor communication, whether due to a lack of empathy, discomfort, insufficient information, or an unwillingness to deliver such a diagnosis, risks exacerbating the emotional toll of diagnosis on individuals. People with MND and their families will often feel isolated as a result, as they are left to process this devastating news without the clinical guidance and support critical for this time. [43]

> *I am absolutely shocked that people could be given a diagnosis of a life-limiting illness when they are alone, with no support in the room.*
>
> Carer of a person with MND, whose diagnosis was given without a support person present.

The pace of progression

The typically rapid progression and relentless deterioration associated with MND leads to challenges in care. Needs evolve quickly, requiring care plans and palliative care to be frequently reassessed and adjusted. [11] For carers, this demands constant vigilance, ongoing education, and adaptability, often under considerable emotional and physical strain.

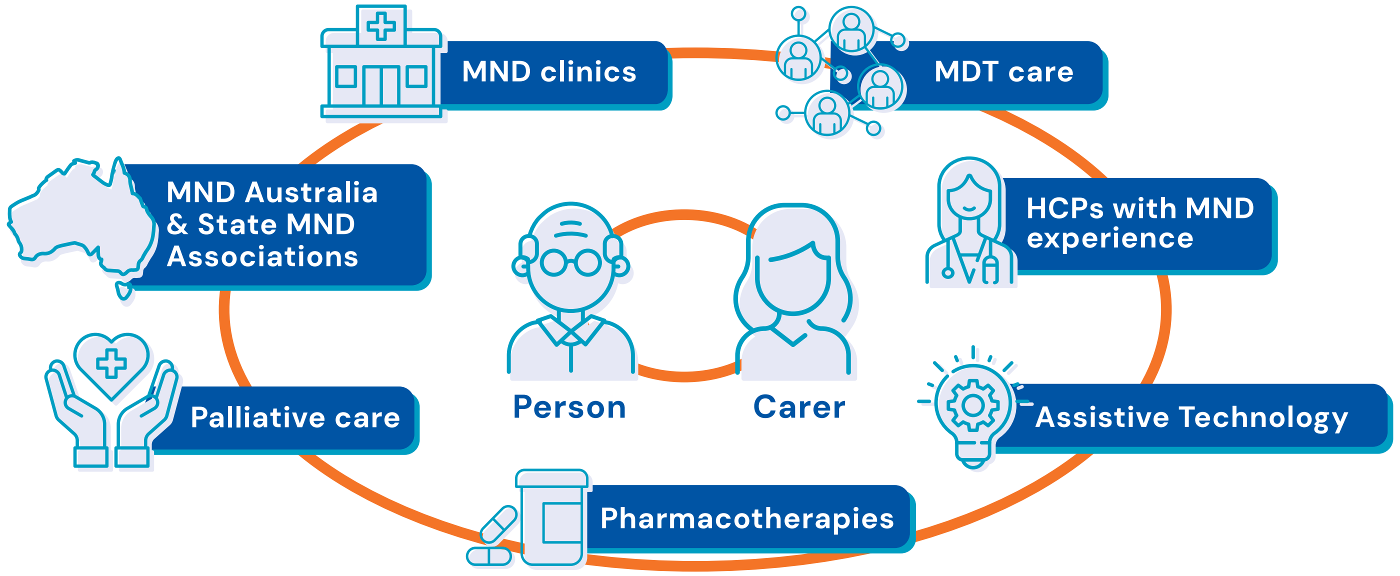
MND is immensely complex.

With its uncertain causes, diagnostic delays and rapid progression, MND creates many challenges for people living with the disease, their carers, and the entire healthcare system.

MULTIDISCIPLINARY CARE AND **TREATMENT APPROACHES IN MND**

Currently, there is no cure for MND. Existing therapies focus on managing symptoms, slowing disease progression, and enhancing quality of life. [1] These approaches are multifaceted, forming a network of care a person living with MND can utilise throughout their disease journey. They include MND clinics, multidisciplinary team (MDT) care, State MND Associations, HCPs with MND experience, assistive technologies, pharmacotherapies and palliative care. This treatment and care network is critical to optimising quality of life and typically falls to the carer to manage and coordinate, particularly as the disease progresses. [12]

Figure 4. MND treatment and care network



Source: Evohealth

The role of the carer

The role of the carer typically falls to a spouse or family member, who accept a wide range of responsibilities that evolve as the disease progresses. [44] These include:

- Assisting with daily activities such as feeding, bathing, dressing, toileting and other related tasks.
- Providing support for movement and transfers.
- Monitoring breathing problems and assisting with ventilation equipment.
- Ensuring medications are taken as prescribed. [44, 45]

In addition to physical care, carers frequently take on other essential roles, including:

- Searching for information about MND and available resources.
- Coordinating care and liaising with HCPs.
- Offering psychological reassurance and maintaining a sense of normalcy.
- Adopting additional family responsibilities.
- Advocating for the needs and preferences of the person living with MND. [44]

Multidisciplinary team care

MDT care involves a team of HCPs working collaboratively to provide comprehensive support from diagnosis, and has been shown to improve both survival and quality of life for people living with MND. [8] Key members of the MDT may include neurologists, clinical nurse consultants, dietitians, occupational therapists, physiotherapists, speech pathologists, social workers, psychologists, MND advisors, and support coordinators. [28]

Benefits of MDT care for people living with MND

- Extended survival.
- Enhanced quality of life.
- Reduced hospitalisations.
- Shortened hospital stays
- Improved access to specialist resources.
- Continuity of care.
- Timely discussions on critical issues.
- Holistic service range.

MDT care has been shown to improve both quality of life and survival, potentially up to 7-24 months.

Source: Adapted from multiple sources [13, 14, 46–48]

MND clinics

Across Australia, MND clinics provide MDT care for people living with MND. These clinics involve HCPs experienced in MND who conduct regular assessments and develop tailored treatment and care plans. Often HCPs in these clinics are also involved in research, providing opportunities for people with MND to participate in clinical trials and access innovative treatment options. The composition of HCPs in these clinics varies, and not all clinics have the range of HCPs needed by people with MND. Some clinics offer a broad selection of services, while others may lack essential specialists and allied health professionals. [28] MND clinics are typically associated with major hospitals in metropolitan areas, compounding access barriers for those in regional or remote locations.

MND Australia and State MND Associations

As the national MND peak body, MND Australia focuses on advancing high quality MND care and support, providing evidence-based information on disease management, advocating to government, and funding research to improve treatments and quality of life outcomes. [49]

State MND Associations advocate in their relevant jurisdictions, as well as providing a range of vital services and supports. This may include education and training, development of informative resources, assistive technology loan pools, support groups, healthcare navigation, and regional telephone MND Information Lines. [24] Some State Associations also employ HCPs with extensive MND experience, ensuring access to specialised and informed care. In addition, MND Advisors employed by State Associations assist people living with MND in accessing healthcare and support services, planning for future needs, and navigating both the NDIS and Support at Home program. [24]

HCPs with MND experience

A range of HCPs support people living with MND, both within MND clinics and in the broader community. [28] These professionals play a crucial role in delivering a range of services to improve quality of life, and support people living with MND throughout progression of the disease. While people with MND will ultimately be under the care of HCPs with MND experience, early in the disease journey, they may encounter a range of providers who have limited or no experience with the condition. Accessing HCPs without specific MND experience can delay access to appropriate care and treatment.

Assistive Technology

As MND progresses and muscle function and mobility declines, assistive technologies (ATs) become essential to managing daily activities and maintaining independence. These tools support mobility, communication, and basic needs, enabling people with MND to adapt to their rapidly changing abilities. [50]

Key types of AT include:

Non-invasive ventilation (NIV)

NIV plays an important role in managing respiratory muscle weakness, a common and progressive symptom of MND. This weakness can cause breathlessness (dyspnoea), and nocturnal hypoventilation, leading to complications such as morning headaches, poor sleep, fatigue, and daytime drowsiness, all of which affect quality of life. [51–53]

NIV improves gas exchange and provides respiratory support to weakened muscles, slowing the decline in lung function. [51–53] This improves energy levels and sleep quality, supporting greater participation in daily activities. While NIV cannot stop MND progression, it is a vital intervention, extending survival and enhancing quality of life. [15] Research has shown that using NIV can increase survival time by up to 13 months [15]

Specialised equipment and home modifications

Specialised equipment helps people with MND manage muscle weakness and maintain independence and safety. [20] Early-stage tools such as crutches and walking frames assist with balance, while power wheelchairs and hoists become essential as mobility declines. These aids prevent falls, improve posture, and reduce complications like pressure sores. [20, 54] Home modifications, including ramps, wider doors, and adapted bathrooms further enhance safety and accessibility, enabling individuals to remain at home comfortably. [20]

Augmentative and Alternative Communication (AAC)

Over 80 per cent of people with MND experience communication difficulties affecting their ability to express thoughts, emotions, and needs. [18] AAC aids, such as eye-tracking devices and speech-generating systems, help maintain effective communication and reduce feelings of isolation. [50]

These tools foster social connection, enable control over the environment, and support participation in decision making. By enhancing independence and reducing emotional strain, AAC devices play a vital role in improving quality of life for people living with MND. [18, 19]

Nutritional aids

Nutritional aids help manage difficulties with swallowing (dysphagia), a common issue for people with MND that can lead to weight loss and accelerated disease progression. [21] Enteral feeding, via Percutaneous Endoscopic Gastrostomy (PEG) or Radiologically Inserted Gastrostomy (RIG), ensures adequate nutrition and hydration by bypassing the swallowing mechanism. When necessary, early implementation of PEG or RIG feeding reduces procedural risks and helps maintain energy levels, supporting overall quality of life for people with MND. [21, 22]

Pharmacotherapies

Currently, there is no cure for MND, and treatments that can stop or reverse progression for people living with all types of the disease remain a distant prospect. [55] Available treatments primarily aim to slow disease progression, delay functional decline, and extend survival times. Treatments currently available in Australia are outlined in Table 3.

Table 3. MND pharmacotherapies

Name	Use and action	Reimbursement status
Riluzole Rilutek® Teglutik®	The precise mechanism of riluzole is not fully understood, however it appears to interfere or reduce excessive glutamate release from neurones, protecting them from excitotoxicity. [56] It has been shown to extend survival time by 6-19 months for those who commence treatment early. [16] Riluzole is available as a tablet (Rilutek®) or in liquid form (Teglutik®) for people with MND who have trouble swallowing.	PBS listed
Edaravone Radicava®	Edaravone is a free radical scavenger that removes molecules causing oxidative stress in cells, including motor neurons. By doing so, it diminishes motor neuron damage and slows the progression of MND. Edaravone must be prescribed within two years of symptom onset. [57, 58] It is administered via an IV infusion.	PBS listed
Tofersen Qalsody®	About 2 per cent of people with MND have an inherited superoxide dismutase 1 (SOD1) gene mutation which causes the body to produce a toxic form of the SOD1 protein, leading to neuron cell death. Tofersen is designed to reduce the toxic SOD1 protein in the body. [59] Tofersen is currently available for people with MND that have a SOD1 mutation under the manufacturer's compassionate access program in Australia, and is under consideration by the Therapeutics Good Administration (TGA) for registration. [60] It is administered intrathecally.	Under consideration for registration with the TGA.

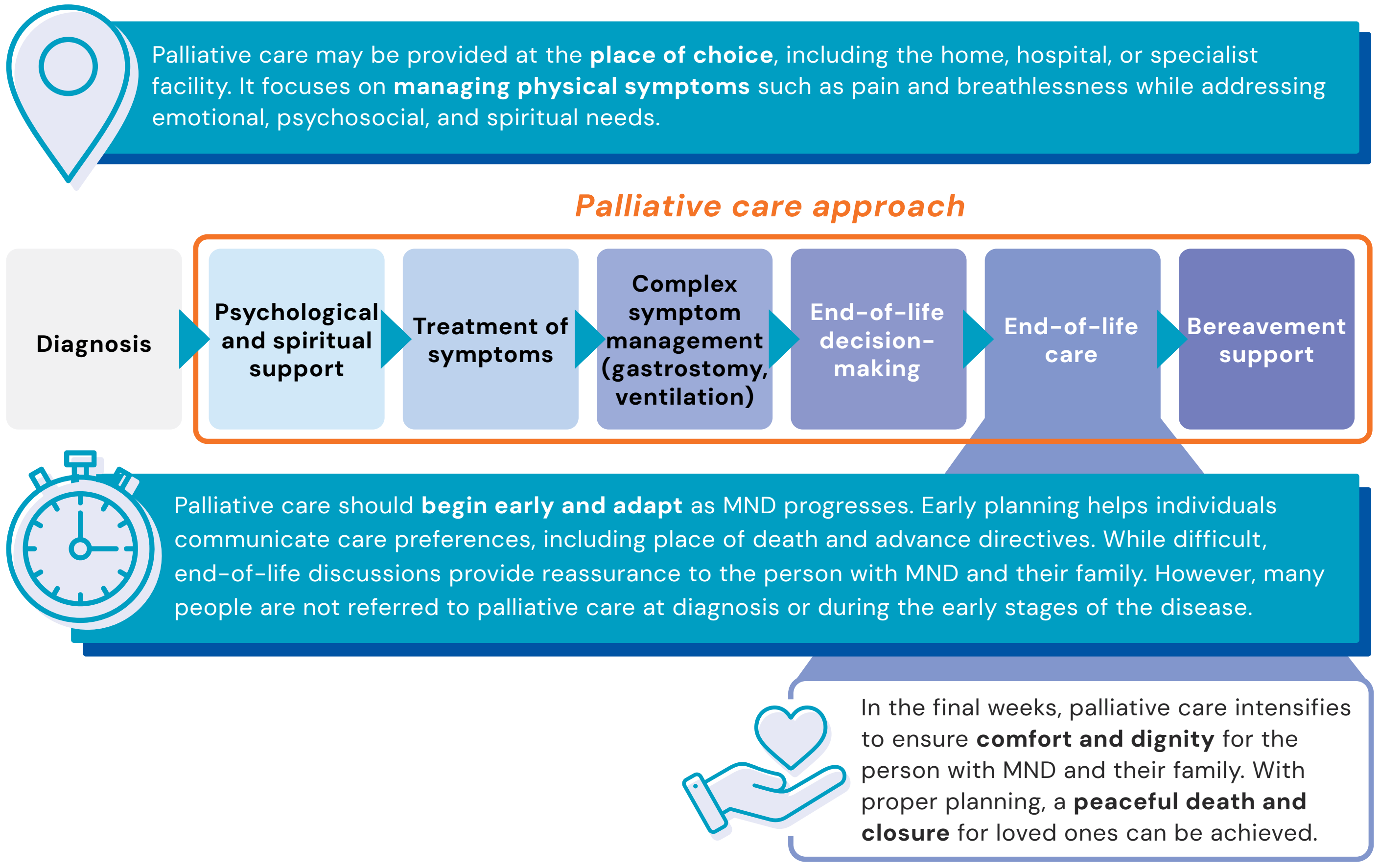
In addition to the MND therapies described above, other medications may provide relief for symptoms, such as excess saliva production, muscle cramps, breathing difficulties, and constipation. [8] However, not all are subsidised under the PBS, and therefore contribute to out-of-pocket costs for individuals.

While pharmacological treatments play an important role in disease management, MDT care and assistive technologies have a more significant impact on improving quality of life for people living with the disease. [21]

Palliative care

Palliative care is a family-centred approach providing essential support for people living with MND, their families and carers. As described in Figure 5, palliative care focuses on improving quality of life from diagnosis through to end-of-life care. [23] While access to palliative care benefits all people living with MND, services are limited across Australia, particularly in rural and remote areas. These gaps create disparities in support leaving many without the comprehensive care they need. [61]

Figure 5. Palliative care journey



Palliative care may be provided at the **place of choice**, including the home, hospital, or specialist facility. It focuses on **managing physical symptoms** such as pain and breathlessness while addressing emotional, psychosocial, and spiritual needs.

Palliative care approach

Diagnosis → **Psychological and spiritual support** → **Treatment of symptoms** → **Complex symptom management (gastrostomy, ventilation)** → **End-of-life decision-making** → **End-of-life care** → **Bereavement support**

Palliative care should **begin early and adapt** as MND progresses. Early planning helps individuals communicate care preferences, including place of death and advance directives. While difficult, end-of-life discussions provide reassurance to the person with MND and their family. However, many people are not referred to palliative care at diagnosis or during the early stages of the disease.

In the final weeks, palliative care intensifies to ensure **comfort and dignity** for the person with MND and their family. With proper planning, a **peaceful death and closure** for loved ones can be achieved.

Source: Adapted from Amyotrophic lateral sclerosis: improving care with a multidisciplinary approach [62]

WHAT HAS CHANGED IN **MND CARE OVER THE LAST DECADE?**

In the last 10 years, significant increases in public awareness and research into MND have occurred, alongside changes to policy and legislation in Australia.

The evolution of the NDIS

The NDIS, introduced on 1 July 2013 and fully operational by 1 July 2020, has been transformative for many Australians living with MND. [63] It provides individualised funding for essential supports, accessible to those who submit applications while under the age of 65. NDIS funding is typically processed within one working week via a Priority Eligibility Decision Pathway for people living with MND. Once approved, individuals continue to receive NDIS support for life, including after they turn 65. [64] However, despite these benefits, the system remains complex and bureaucratic to navigate.

Increased public awareness and funding

Public awareness of MND has grown significantly, driven by the combined efforts of MND Australia, State MND Associations, and Fight MND. These advocacy initiatives have raised funds, increased visibility, and fostered greater understanding and support for people living with MND and their families. The collective efforts of these organisations have transformed Australia's MND research landscape, advancing knowledge, treatment, care and service provision. However, improving national coordination of these research initiatives remains an ongoing priority.

Advances in genomics and personalised therapies

Advances in genomics and personalised therapies have significantly enhanced our understanding of MND. Up to 30 genes and genetic mutations are linked to MND, and the ability to precisely and successfully target a genetic variant has been realised with the development of gene-based therapies, including Tofersen. [65] Stem cell therapies, which may deliver neuroprotective proteins, are also being explored. The shift towards precision medicine, where treatments are tailored to an individual's genome, is becoming increasingly realistic with faster, more affordable genome mapping. [66]

While these advances are promising, they come with challenges. As genetic testing becomes more accessible, the demand for genetic counselling is increasing, yet resources in Australia are struggling to keep pace. Genetic counsellors play a crucial role in helping individuals navigate complex hereditary information and risk factors, a process requiring careful communication of sensitive information that may cause family stress or conflict. However, access to this specialised support remains limited due to workforce shortages, and the lack of available Medicare rebates imposes additional financial barriers for those who need it. [67]

Evolving clinical pipeline

The last decade has seen several advances in the understanding and treatment of MND. Increased clinical research has explored gene therapies targeting specific mutations, stem cell therapies aimed at slowing disease progression, reversing the disease, or even achieving a cure, and neuroprotective therapies, including antioxidants, which protect cells from free radical damage and oxidative stress – a hallmark of neuronal death. [68, 69]

Voluntary Assisted Dying (VAD) legislation

VAD is the assistance provided by a HCP to a person with a terminal illness or disease to end their life, using specific drugs that can be self-administered or given by a registered practitioner. [70] The person receiving VAD must act voluntarily, without coercion, and have full decision-making capacity. Safeguards are in place to ensure VAD is used appropriately. [70] In Australia, VAD legislation is now in place in all states and territories except the Northern Territory. While the laws vary slightly by jurisdiction, they are broadly similar. These laws mark a significant shift in options for people living with MND, offering greater autonomy and choice for many in managing the end stages of a disease without a cure. [70]

Evolving data infrastructure

Efforts to enhance MND data collection and develop comprehensive MND datasets have gained momentum over the last decade. Australian databases, including MiNDAUS and SALSA, consolidate clinical and demographic information to improve disease understanding and inform care strategies. State MND Associations, universities, and research institutes also maintain their own MND datasets. However, these datasets remain fragmented and incomplete, highlighting the need for a single, unified national data registry to drive evidence-based decision-making and support research initiatives.

DISPARITIES IN ACCESS TO MND TREATMENT AND CARE

The complex nature of MND, combined with the typically rapid progression of the disease, creates significant and dynamic challenges for those affected by it. Currently the health, disability and aged care systems do not equitably meet the unique needs of people living with this disease.

Funding support payments are inequitable

In Australia, funding to support people living with MND is provided through two distinct pathways: the NDIS and the Support at Home program. [25] (a)

Access to these pathways is determined by the age at which an individual is diagnosed with MND and applies for funding support. For access to the NDIS, an individual must be diagnosed and submit their application for funding before the age of 65. The NDIS pathway offers comprehensive and flexible support for high-cost care needs throughout the individual's lifetime. [25] In contrast, individuals diagnosed at age 65 and over are funded under the Support at Home program, where, in 2025, the maximum level of funding available is approximately 36 per cent of the average funding provided by the NDIS. [26] This inequity stems from the primary purpose of the Support at Home program being to support older Australians with general care needs, rather than those managing a complex, progressive neurodegenerative disease.

The differences in access, funding amounts, and administration between these two pathways create significant inequitable disparities in the care and support available to individuals, resulting in very different challenges and outcomes, as outlined in the Table 4. [25]

Note (a): *This report focuses on the Support at Home program, which commences on 1 July 2025, as the primary funded aged care pathway for people aged 65 and over living with MND. To ensure clarity and consistency, all future references to aged care funding throughout the report will use the term "Support at Home program" to refer to this package, unless otherwise specified.*

Table 4. Access, services and funding model of NDIS and Support at Home program

	NDIS	Support at Home program
Access	People who are diagnosed with MND and apply for NDIS funding prior to turning 65 years of age are eligible for this pathway. Assessment decisions and funding access is fast-tracked, typically within 2–5 business days of application. [27]	The Support at Home program supports people diagnosed with MND at age 65 and over. Eligibility requires an assessment by an Aged Care Assessment Team (ACAT), and there can be a delay in accessing funding. The length of delay under the new program is unknown at this time; however, previous funding pathways experienced waits of between 6–15 months. [73] These delays significantly impact individuals with MND, as the disease typically progresses rapidly and care needs evolve daily, creating critical gaps in support during the waiting period. Consultation with former carers of people living with MND included examples where individuals died from MND before their funding was approved.
Service	The NDIS provides comprehensive and flexible support, including: • Personal care, therapy, and respite services. • ATs (e.g., mobility aids, communication devices). • Home modifications to accommodate increasing care needs. • Support coordination to help individuals manage their plans effectively. Regular plan reviews enable adjustments to funding and services. However, these reviews can be challenging as they can delay access to funding at a time when the disease is rapidly progressing and needs of the person with MND are changing.	The Support at Home program provides general care services such as: • Personal care and household assistance. • Limited access to allied health services. • Basic equipment and support coordination. However, it lacks adequate provisions for complex care needs, leaving significant gaps in support for people living with MND, and as a result, many rely on services provided by State MND Associations.
Funding model	NDIS funding is not means-tested or capped, with MND participants receiving an average annualised support package of $302,000. [34] This funding is tailored to each person's unique needs, goals, and disability requirements. It is allocated to specific support categories at the start of each plan period, allowing participants to access approved supports and services as needed. If funds are exhausted, a request can be made for a new plan or additional funding to maintain necessary support. However, funding cannot be used for all cost-of-living expenses, meaning additional costs remain (e.g., mortgage repayments, non-PBS medicines, and specific therapies).	The maximum level of support under this program is $108,000. This includes a base package of approximately $78,000, plus an additional $15,000 for assistive technology and $15,000 for home modifications[1]. Complex assistive technology may be accessed beyond the $15,000 maximum, provided there is a prescription from a suitably qualified health professional and supporting evidence of the item's cost. The progression of MND requires immediate and flexible access to high-cost supports, including assistive technology, home modifications, and complex care services, that far exceed what the Support at Home program is designed to provide. This mismatch between capped and delayed funding and the specialised care needs of people with MND results in many individuals being unable to access the timely and comprehensive support required to maintain their dignity, safety, and quality of life.
Proportion of people	37% of people with MND (1,018 individuals) access NDIS. [5]	63% of people with MND (1,734 individuals) access Support at Home program. [5]
Total cost to Government	$305.68 million annually. [5]	$187.45 million annually. [5]

[1] *Participants receiving services under the Restorative Care Pathway are not eligible to receive high-tier funding for home modifications. [77]*

IN THEIR OWN WORDS – **LIVED EXPERIENCE STORIES**

Ron's story: Living with MND and accessing NDIS

Ron Hobden, with wife Annie and children Lizzie and Henry.

My name is Ronald Hobden, and in June 2023, at the age of 35, I was diagnosed with MND. This diagnosis has profoundly impacted my life as a husband to Annie and a father to our beautiful young children, Lizzie (5) and Henry (2). Before MND, I lived a vibrant, active life, full of energy, adventure, and plans for the future. I was just a week away from running a marathon, a testament to my love for pushing myself physically and mentally. Since my diagnosis, my world has changed in ways I never could have imagined. Tasks that were once second nature have become major challenges. However, with the support of the NDIS, I've been able to maintain my role as a father, husband, and active participant in family life. This support has been life changing.

While the NDIS is an incredible system, the greatest challenge is the time it takes to access necessary resources. The 'change of circumstances' reviews is lengthy and slow, and for someone living with MND, time is not a luxury we have. The disease progresses rapidly, and the system doesn't reflect that pace. For example, it took months for my wheelchair and eye gaze communication device to be approved. During that waiting period, leaving the house became increasingly dangerous and difficult. The world outside felt further and further away, and my ability to communicate with my loved ones was slipping away. It was one of the most isolating and frustrating experiences of my life.

Without a doubt, the NDIS funding and services have been essential. They have allowed me to continue being a present and engaged father and husband. I can still be "dad" to Lizzie and Henry, not just someone they watch from a distance. This is invaluable.

Before receiving support, my wife, Annie, was bearing the full weight of caregiving. While Annie is extraordinary (and still my main care giver) it was unsustainable for her to shoulder that burden alone. The NDIS has provided us with the support we desperately needed, relieving some of that pressure from Annie and allowing her to simply be "a wife and mum" again, not just a carer. For our children, having two present, loving parents is everything. For me, it is the difference between existing and truly living.

What aspects of NDIS funding have helped the most?

The assistive technology, particularly my eye gaze communication device, has been transformative. With it, I can still communicate with my children and Annie. I can say "I love you," I can read bedtime stories, and I can express my thoughts in a way that feels authentically me. Equally important is the support I receive for community access. The ability to be present as Lizzie and Henry experience the world, to watch them at swimming lessons, cheer them on at sports, or simply join them on a family outing is profoundly meaningful. This support allows me to create memories with them, and they will carry those memories with them for the rest of their lives.

What's needed from NDIS that is currently unavailable?

A simple improvement for the NDIS would be the creation of a pre-approved checklist of essential items for people with MND. We know the equipment and support that will be required as the disease progresses. A standard checklist could eliminate the need for repeat occupational therapist reports and long approval waits. For example, people with MND will almost certainly need a powered wheelchair, a communication device, and home modifications. Rather than making each of these requests an individual battle with multiple assessments, the system could pre-emptively grant access to these supports as soon as an MND diagnosis is confirmed.

This proactive approach would relieve families of the emotional strain of "proving" they need help while navigating the shock and grief of an MND diagnosis. It would also reduce the workload on NDIS planners.

While I've outlined the challenges, I also want to acknowledge the incredible improvements I've seen in the system. The faster timeframes under the new system have made a real difference. The introduction of direct contacts who can provide support has been a game-changer. Having a person to reach out to, someone who knows my case, understands the urgency, and works with us brings comfort and reassurance. It reminds us that we are not alone in this.

For me, MND is not just a disease that affects the body, it affects the heart, the mind, and my whole family. NDIS has given me the opportunity to remain present for Annie, Lizzie, and Henry. Every day that I get to say "I love you" to my family is a day that I feel like I'm still winning.

> ***We are so lucky to live in a country with a system such as NDIS. There is absolutely no way most families could wear the financial burden of MND without this support.***

Jean's story: Navigating life with MND through a funded aged care pathway

Jean Leitch

Attempting to access funding from My Aged Care is definitely a challenge. The first of the challenges is the embarrassment of having the need to access the funds. My initial experience of being interviewed was demeaning. The 'interview' was by telephone. There was no personal contact. Therefore, it was not possible for my needs to be assessed with clarity. The questionnaire appeared to be a general 'tick-a box' with no inclusion of a question regarding an individual's specific health issues and needs. The questioner made comments such as, "Can't your family help you with this?". The questions left me flustered. I was subsequently re-interviewed and offered a Level 3 package, which I have only very recently accessed after an 11 month wait.

The funding, at the moment, is allowing me one hour of domestic assistance per week. It also includes payment of my hydrotherapy and podiatry, various well-being activities and general gardening. I should be able to receive personal care as my condition continues to deteriorate. The aged care company that I have chosen appears to withdraw more money in weekly fees than the amount required to pay for my services.

The whole My Aged Care process is complex and incurs a lengthy wait, during which time the health of a person with MND deteriorates rapidly. The financial impact has been significant. During the wait for funding, we purchased most of the equipment required to keep me safe and independent. This included a mobility scooter and a portable electric wheelchair for indoor use, as my mobility, balance and ability to care for myself have markedly declined. We were also required to partially fund indoor handrails and a platform for a ramp. Further to this, we took out a reverse mortgage to fund an accessible main bathroom and a kitchen, which are important for my safety, independence and well-being.

The impact on the health and well-being of my husband, now carer, is obvious. He struggles to care for me and my needs, contend with the household chores and most of the cooking, and take me to the many medical appointments I need.

Private funding

For people living with MND who are ineligible for the NDIS, such as non-Australian citizens, or for those with insufficient Support at Home program funding, private payments are often required to cover essential services and support. While some private health insurance plans may partially cover costs, out-of-pocket expenses can place significant financial strain on individuals and families, often forcing them to deplete savings or incur debt to afford necessary care.

Accessing superannuation and insurance benefits

Many insurance policies and superannuation funds include provisions for individuals facing terminal illnesses such as MND. Insurance policies typically have terminal illness clauses that allow policyholders to access their benefits early upon receiving a diagnosis. Similarly, some superannuation funds permit individuals to withdraw their super benefits early if they are diagnosed with a terminal illness. [74] These benefits provide essential financial and cost-of-living support to people living with MND as their disease progresses, expenses increase, and household income declines.

However, the definitions of terminal illness and eligibility requirements for accessing benefits vary across superannuation funds and insurance policy providers, creating inconsistencies in access. Additionally, many individuals diagnosed with a terminal illness are unaware that these benefits exist, and as a result, do not realise they have access to this financial support.

Challenges in accessing and coordinating care

Beyond the financial challenges of MND, individuals and their families face significant difficulties in accessing timely and coordinated care. Navigating the complex healthcare system can be overwhelming, from the initial confusion and lack of guidance following diagnosis to ongoing struggles in obtaining consistent, specialised care. State MND Associations play a vital role in addressing these barriers, yet these organisations face ongoing challenges in securing government funding to sustain their services, further complicating the care journey.

From diagnosis to 'now what?'

Receiving a diagnosis of MND is life-altering, often marking the start of a complex and overwhelming journey. For many, the immediate challenge is navigating the question, "What do I do now?"

At a time of immense stress and shock, people living with MND and their families are left searching for guidance. While there is a wealth of information about MND available online, accessing and understanding it can be daunting in the face of a grim prognosis.

This initial information gap and lack of support for navigating what to do following a diagnosis often delays access to critical care and services. Direct referral to State MND Associations at the point of diagnosis plays a crucial role in closing this gap. These organisations provide timely access to information, emotional support, and assistance navigating the healthcare systems. Their early involvement ensures that people newly diagnosed with MND can connect with appropriate services and support networks quickly, helping to reduce distress and improve care outcomes during this critical time.

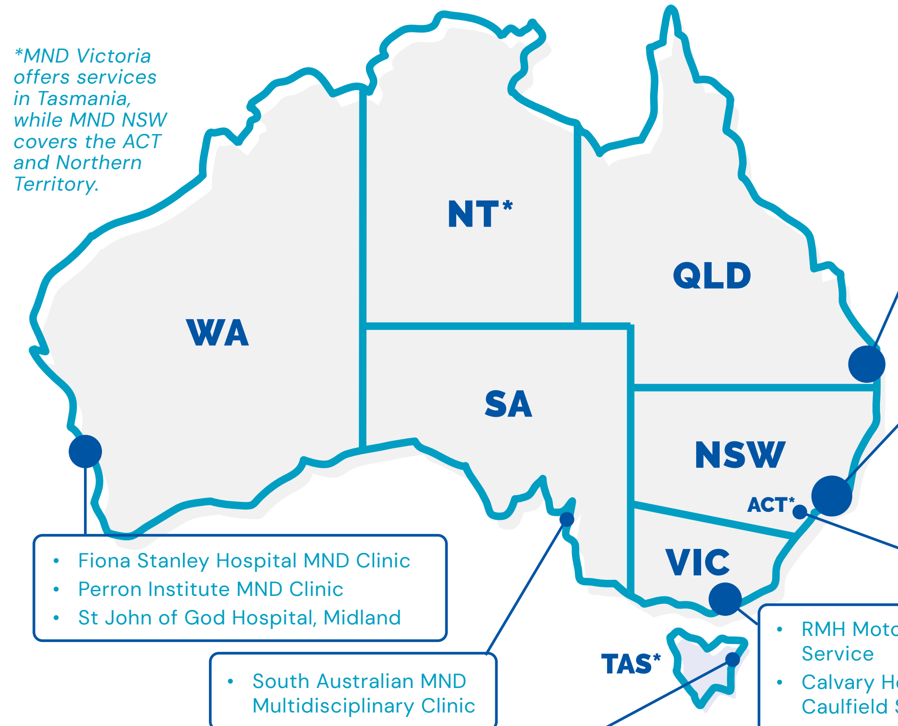
Limited access to, and inconsistent services available from MND clinics

MND clinics across Australia (see Figure 6) deliver MDT care tailored to the needs of people living with MND, integrating expertise across neurology, allied health, palliative care and other specialist services (such as respiratory and gastroenterology). [28] These clinics focus on proactive care interventions and provide access to clinical trials for new and innovative therapies. It is well established that MDT care improves the quality of life for people living with MND by providing a comprehensive approach to managing the disease and its symptoms. [13, 14, 46–48]

MND clinics operate in both public and private healthcare settings, resulting in some services within these clinics being covered by Medicare, while others may incur out-of-pocket costs depending on the specific services provided and the healthcare provider's fees. [28] Most clinics are located in or near metropolitan areas and have long wait times for appointments and delays in accessing specialist MND services. For people with MND living in regional, rural, and remote parts of Australia, accessing these clinics can be extremely difficult or even impossible, particularly given mobility challenges and care needs. This places financial, physical, and emotional strain on people with MND and their families, and in some cases, leads individuals to forgo accessing these essential services altogether.

For those who can access a MND clinic, the services offered vary between facilities and states. For example, some clinics provide direct access to non-invasive ventilation, a critical and potentially life-extending treatment, while others require individuals to seek access through separate services. The availability of allied health professionals, such as physiotherapists, occupational therapists, and speech pathologists, also differs significantly across clinics. These inconsistencies create disparities in the care people with MND receive – while some benefit from comprehensive, multidisciplinary support, others are left with critical gaps in their care and must organise these services independently.

Figure 6. Locations of MND clinics across Australia



**MND Victoria offers services in Tasmania, while MND NSW covers the ACT and Northern Territory.*

- Princess Alexandra Hospital MND Clinic
- Prince Charles Hospital Specialist Outpatient Clinics
- Royal Brisbane and Women's Hospital
- The Sunshine Coast University Hospital MND Clinic
- Gold Coast University Hospital

- Murwillumbah MND Clinic
- Calvary Health Care MND Service
- Liverpool Hospital MND Clinic
- Macquarie Neurology Clinic
- Clinica Neurology
- Concord ALS/MND Multidisciplinary Clinic
- Auburn Hospital MND Clinic
- Hunter New England MND Multidisciplinary Clinic
- Illawarra Multidisciplinary MND Service

- ACT Multidisciplinary MND Clinic

- RMH Motor Neuron Disease (MND) Clinical & Research Service
- Calvary Health Care Bethlehem Statewide PND Clinic, Caulfield South
- MND Clinical & Research Service, Royal Melbourne Hospital
- Northern Health Progressive Neurological Disease Clinic, Bundoora

- Fiona Stanley Hospital MND Clinic
- Perron Institute MND Clinic
- St John of God Hospital, Midland

- South Australian MND Multidisciplinary Clinic

- Launceston General Hospital MND Clinic

Source: Evohealth [28]

Lack of HCPs with MND experience

State MND Associations and their MND Advisors are a key source of support for people living with MND. With deep expertise in the disease, its management, and education, they help bridge the gap created by the shortage of HCPs familiar with the disease. These associations also play an important role in educating healthcare providers, equipping them with the knowledge needed to better understand and manage MND.

Many people with MND rely on local primary HCPs to coordinate their care. However, most community HCPs have limited exposure to MND and may not know who in their networks does. This creates a "luck of the draw" scenario, where finding an HCP who understands the complexities of MND can feel like a matter of chance. As a result, the responsibility for identifying and coordinating appropriate care often falls to the person with MND or their carer, placing considerable strain on their time, energy, and financial resources.

> *A person with MND can often see numerous different allied health professionals before finding one with specialist MND experience. It often comes down to luck. State MND Associations can make navigating this space better and a national directory of healthcare professionals with MND experience will address this.*

Lack of Australian MND Clinical Guidelines

National standard clinical guidelines for MND are currently under development. This is a critical step toward improving care, as the absence of nationally endorsed guidelines has contributed to significant variation in how MND is diagnosed, treated, and managed across Australia. Clear, evidence-based recommendations are essential to support healthcare professionals in symptom management, multidisciplinary care coordination, and the integration of assistive technologies.

Until these guidelines are finalised and implemented, care practices continue to vary widely between providers, regions, and states, resulting in fragmented and inconsistent care experiences for people living with MND. This variability not only affects the quality and equity of care but also contributes to delays in accessing essential treatments and services. It also perpetuates gaps in MND-specific knowledge and expertise among HCPs.

Inadequate funding for State MND Associations

The support provided by State MND Associations is invaluable, yet government funding for these organisations is insufficient, inconsistent year on year, or in some states, simply absent. Table 5 shows a snapshot of funding for State MND Associations in FY 2024. This forces State MND Associations to rely heavily on philanthropy, restricting their ability to plan, resource, and provide services sustainably.

Table 5. Amount of government funding received by State MND Associations.

	Government funding FY 2024	Government funding as a proportion of total income (%)
New South Wales[2]	$787,125 per annum (Comprised of two and three year agreements)	14%
Queensland	$200,000 one-off donation and $71,003 non-recurrent grant (2024-2025 financial year)	7.85%
South Australia	$600,000 per annum For four years to June 2026	17.9%
Tasmania[3]	$70,000 Per year for 4 years	26%
Victoria	$932,718 (Comprised of two, three and four year agreements)	19.9%
Western Australia	$474,774.39 (per annum)	17%

State MND Associations tirelessly advocate for, and secure resources to support people living with MND, often filling critical gaps where public funding falls short. To enhance support options, all State MND Associations have taken on the additional expense and regulatory burden of becoming registered NDIS providers, operating under the NDIS Quality and Safeguards Commission, and Aged Care providers, operating under the Aged Care Quality and Safety Commission. Despite these challenges, they remain dedicated to ensuring people with MND receive essential care and support. Without their services, few alternatives exist, and many would be left without the assistance they need. However, without consistent government funding, the sustainability of these vital services remains at risk.

> *Without MND Queensland, I don't know where we would be today.*
>
> Carer of a person living with MND

---

[2] *NSW provides services to the Northern Territory and the ACT, neither Territory receive standalone funding.*
[3] *Services for Tasmania are offered by MND Victoria*

THE BURDEN OF **MND ON INDIVIDUALS, CARERS AND SOCIETY**

MND has a devastating impact on people living with the disease, as well as their carers, families and our broader society. Evohealth modelling estimates the total cost of MND in Australia was $5.02 billion in 2025, with this cost projected to rise to $7.51 billion in 2050 if no significant breakthroughs in treatments occur. [5] The disease's progressive nature intensifies its impact over time, tightening its grip not only on individuals, but also on their economic and social stability.

$5.02 billion – Estimated total cost of MND in Australia in 2025. [5]

A journey of loss for people living with MND

Living with MND is a journey marked by continuous loss, as individuals face an often rapid progressive decline in physical abilities impacting their sense of self and emotional well-being. [30]

> *MND is honestly the stuff nightmares are made of.*
>
> Person living with MND

Physical and emotional decline

The loss of physical abilities from MND is extremely distressing. [30] As physical abilities decline, people living with MND often experience a loss of autonomy and control over their lives. The inability to engage in activities once enjoyed, along with the loss of independence in everyday tasks such as eating, bathing, toileting and walking, leads to feelings of anger, frustration, and grief. For many losing their voice is a particularly devastating symptom as is it such a crucial part of their personal identity. [30]

People living with MND feel deprived of a future. As they learn more about the disease, anxiety and distress increase as the reality of what lies ahead becomes more apparent. [30] The overall emotional toll of this disease often leads to depression, social withdrawal, and a pervasive low mood. [31]

The rapid progression of MND means individuals are constantly adapting to changing symptoms, which in turn necessitates major changes in every aspect of life, including home modifications, changes to work patterns and social and leisure activities. [30] Collectively these changes are physically, emotionally and financially taxing. [31]

The financial toll on individuals with MND

The financial burden of MND is significant, compounding the physical and emotional challenges of the disease. It includes loss of income, productivity, healthcare costs and premature mortality.

Evohealth modelling estimates that people with MND collectively lose an estimated $155.72 million annually because of their reduced productivity and ability to work. [5] This loss represents a significant portion of income for many households, forcing individuals to face financial insecurity alongside the rapid progression of their disease.

For those under 65, particularly younger individuals under the age of 50, the impact is especially devastating, as many have yet to accumulate financial security, pay off mortgages, or build substantial savings. While the NDIS provides essential funding for supports and services, it does not offer direct financial assistance. People with MND must still cover everyday living expenses, mortgage repayments, and increasing out-of-pocket healthcare costs.

In addition to lost income, people with MND bear considerable direct healthcare costs. Among hospital care, pharmaceuticals, and specialist consultations, healthcare costs totalled $27.11 million in 2025 for this group. [5] Costs rise commensurate with the rapid progression of disease, further straining personal finances.

Premature mortality adds another layer of financial impact. Productivity losses due to early deaths were valued at $89.63 million in 2025, reflecting the significant economic contributions lost as individuals succumb to the disease. [5]

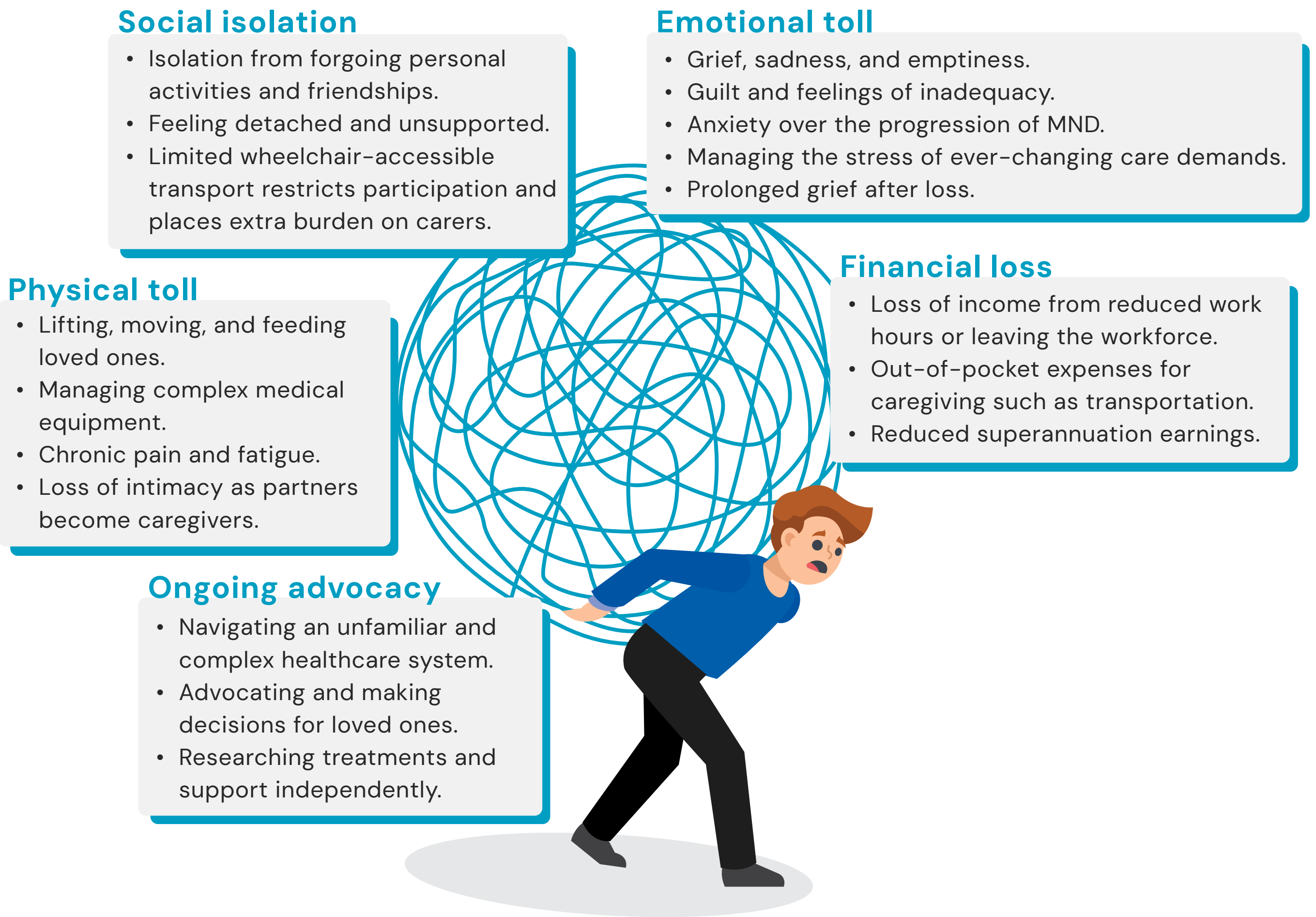
These combined financial challenges underscore the burden MND places on individuals, who must navigate the dual impact of losing income and incurring rising medical expenses, while coping with disease progression.

The burden of care

Carers, often spouses or immediate family members, play a vital role in supporting individuals living with MND. They take on an overwhelming array of responsibilities, from providing physical assistance to coordinating care, often without respite. [31] On average, informal carers dedicate around 37.5 hours per week to caregiving, the equivalent of a full-time job. [31] This places a significant and sustained burden on carers, as illustrated in Figure 7.

> *It is not just about the person living with the disease, it is important to recognise the impact on the individual and their caregiver.*
>
> Person living with MND

Figure 7. The multifaceted burden of caring for people living with MND



Social isolation
- Isolation from forgoing personal activities and friendships.
- Feeling detached and unsupported.
- Limited wheelchair-accessible transport restricts participation and places extra burden on carers.

Emotional toll
- Grief, sadness, and emptiness.
- Guilt and feelings of inadequacy.
- Anxiety over the progression of MND.
- Managing the stress of ever-changing care demands.
- Prolonged grief after loss.

Physical toll
- Lifting, moving, and feeding loved ones.
- Managing complex medical equipment.
- Chronic pain and fatigue.
- Loss of intimacy as partners become caregivers.

Financial loss
- Loss of income from reduced work hours or leaving the workforce.
- Out-of-pocket expenses for caregiving such as transportation.
- Reduced superannuation earnings.

Ongoing advocacy
- Navigating an unfamiliar and complex healthcare system.
- Advocating and making decisions for loved ones.
- Researching treatments and support independently.

Source: Evohealth adapted from multiple sources [5, 31, 32, 75]

As part of their role, carers often undertake strenuous tasks such as lifting, moving, and feeding their loved ones, as well as managing complex medical equipment. [31] Over time, these demands lead to chronic pain, fatigue, and other health issues, resulting in direct medical costs for carers, lost productivity, and a diminished quality of life. [32] The constant demands of caregiving leave little time to access essential services such as physiotherapy or mental health support, causing their own health and well-being to be neglected.

The emotional and social toll of caring

Caring for someone living with MND imposes a harsh emotional toll. Many carers experience feelings of sadness, inadequacy, and even guilt as they struggle to alleviate their loved one's suffering and adjust to a new and unfamiliar interpersonal dynamic. Watching the progression of MND and facing an inevitable bleak future adds layers of grief and anxiety. [32]

Social isolation is a major consequence of the caring role. Many carers forgo personal activities and friendships, leaving them feeling detached and unsupported. This isolation is compounded by insufficient targeted support for carers, including from healthcare providers, whose primary focus remains on the person living with MND. [33]

The emotional toll does not end with the loss of their loved one. Bereavement leaves carers grappling with sadness, emptiness, and the challenge of rebuilding their lives after years of intense caregiving. For some, this transition is marked by prolonged grief continuing long after their loss, making it difficult to redefine their daily routines. [31]

Despite the immense sacrifices carers make, there is limited research into the total burden of their role or how best to support them. Addressing this gap is critical to ensuring carers receive the recognition, resources, and respite they so desperately need. [75]

> *If we don't do it, no one else will… but what about us? Who looks after us?*
>
> Former carer of a person who passed away from MND

Navigating a complex system

Given the immediate lack of information and guidance following diagnosis, carers quickly become responsible for navigating an unfamiliar and complex healthcare system during a time of profound shock. Many carers describe feeling lost as they struggle to understand the implications of the disease, available support and treatments, and how, where and when to access them. [31] The situation is worse for those with poor health literacy or from health priority groups, such as Aboriginal and Torres Strait Islanders, or those from culturally and linguistically diverse backgrounds.

> *On diagnosis, it was a big shock and a mad scramble. We had to do all the research ourselves; we were not provided with any information.*
>
> Former carer of a person who passed away from MND

In addition to coordinating and managing care, the carer also becomes an advocate for the person they are supporting, often needing to make crucial decisions on their behalf. Caring for someone with a complex disease requires carers to learn as they go, both in regard to the disease and the complexities of health care.

Financial toll on carers and households when bills rise and income falls

Evohealth modelling estimates that unpaid carers provided 5.37 million hours of care in 2025, valued at $212.02 million. [5] This figure highlights the substantial economic value provided by carers, often at the expense of their own financial stability. As the disease progresses, carers frequently need to reduce their work hours or leave the workforce entirely, resulting in lost income (including superannuation) and diminished career progression.

The financial impact of caregiving is further exacerbated by the lack of formal support services and resources. Limited access to financial assistance and advice leads to carers shouldering these costs, diminishing long-term financial security over time.

Carers provided **5.37 million** hours of unpaid caring support for people living with MND in 2025, equivalent to **$212.02 million.** [5]

MND imposes significant financial strain on households. For those of working age, the disease often results in the loss of one or both incomes. Older Australians who are already retired may experience a rapid depletion of their savings due to the costs associated with managing the disease. Evohealth modelling estimates that productivity losses for carers and people living with MND total $367.74 million, comprising $212.02 million in lost carer wages and $155.72 million in lost productivity for those living with MND. This equates to an average of $133,626 per household. [5] This highlights the significant economic impact of reduced workforce participation and the caregiving demands associated with the disease.

Over time, as severity of symptoms increases and household income decreases, out-of-pocket expenses for medical equipment, pharmaceuticals, home modifications, and care services begin to climb. For those aged 65 and over, reliance on the Support at Home program may further limit the resources available to meet the extensive care requirements of the disease.

This combination of reduced income and escalating costs places considerable financial pressures on many families, requiring difficult decisions about how to balance care and family needs with available resources. These figures underscore the importance of systemic reform to ensure all individuals and families affected by MND receive equitable and adequate support.

Productivity losses for people living with MND and their carers average **$133,626** per household, totalling **$367.74 million** annually in Australia. [5]

IN THEIR OWN WORDS – **LIVED EXPERIENCE STORIES**

Jane Simpson's story: Caring for a person living with MND.

Jane Simpson: wife and carer of Robert Simpson who lived with MND for 10 months after his diagnosis. Jane is now an MND Australia Ambassador and Chair of the MND Lived Experience Research Advisory Panel, she also hosts a MND podcast – *"Let's talk MND"*

When you are thrust into being a carer for a person with MND, the challenges are many.

Initially, you are faced with the cold, hard fact that your person, the person you love, is going to die. You enter a new world of neurologists, MND Clinics (if you are lucky), doctors and allied health and you learn very quickly that you must advocate for your person. You also have family and friends to "comfort" and deal with their emotions.

Typically, when the word carer is used, the things that come to mind are the 'doing' things; feeding, bathroom assistance, moving, and assisting with all forms of care. What I wish people would better understand is that the carer is often a partner, and a big shift occurs from the original partner relationship to that of carer. This is complex change when you're in that relationship and it is confusing. You are suddenly living within the confines of MND, and the life and the relationship you had is now so different. You still need moments of time where you can be who you once were, pre MND.

Psychological, emotional, and grief support are all important for MND carers. The ability to share all the thoughts that they don't want to upset anyone else with.

It is so important for the carer to have "time out", even if that means walking around the block or sitting in the car in the driveway. This sounds bleak, but when you have no income and no access to external carers, often this is what is available. If the Government can't assist, we need the community to rally behind us. The MND world is one where you need to learn very quickly to be an advocate in the medical system for your person. You need to become a researcher for all the bits and pieces that make the life of the person living with MND easier or more comfortable. You also need to consider and face the issues of end-of-life care, Wills, Powers of Attorney, Medical Powers of Attorney and voluntary assisted dying. This is all incredibly daunting.

A devastating disease, a profound cost

Along with the costs already outlined, MND has a significant impact on the Australian economy. Evohealth conducted a cost of illness analysis to develop an MND economic model, which was used to calculate total costs of the disease in Australia in 2025 and project these costs through to 2050.

This model considers direct costs (including therapeutics, research, government expenditure, outpatient services, emergency department visits, support services), indirect costs (including mortality costs, and productivity losses from reduced employment and informal care) and societal costs which were estimated using Disability-Adjusted Life Years (DALYs) – combining Years Lived with Disability (YLD) and Years of Life Lost (YLL). The detailed modelling methodology used, including limitations and assumptions of the model, is included in Appendix A of this report, with a summary of the modelling outputs provided in Appendix B.

The total cost of MND in 2025 is estimated at $5.02 billion, comprising $982.44 million in economic costs and $4.04 billion attributed to the burden of disease. [5]

$5.02 billion – The total cost of MND in Australia in 2025. [5]

Quality of life for a person living with MND, pictured in their home environment.

Direct costs

Direct costs include all healthcare expenditure directly linked to MND, such as costs of hospitalisations, pharmaceuticals, specialist and allied health services, support funding (NDIS and Support at Home program) and diagnostics. These costs are outlined in Table 6:

Table 6. MND direct costs 2025

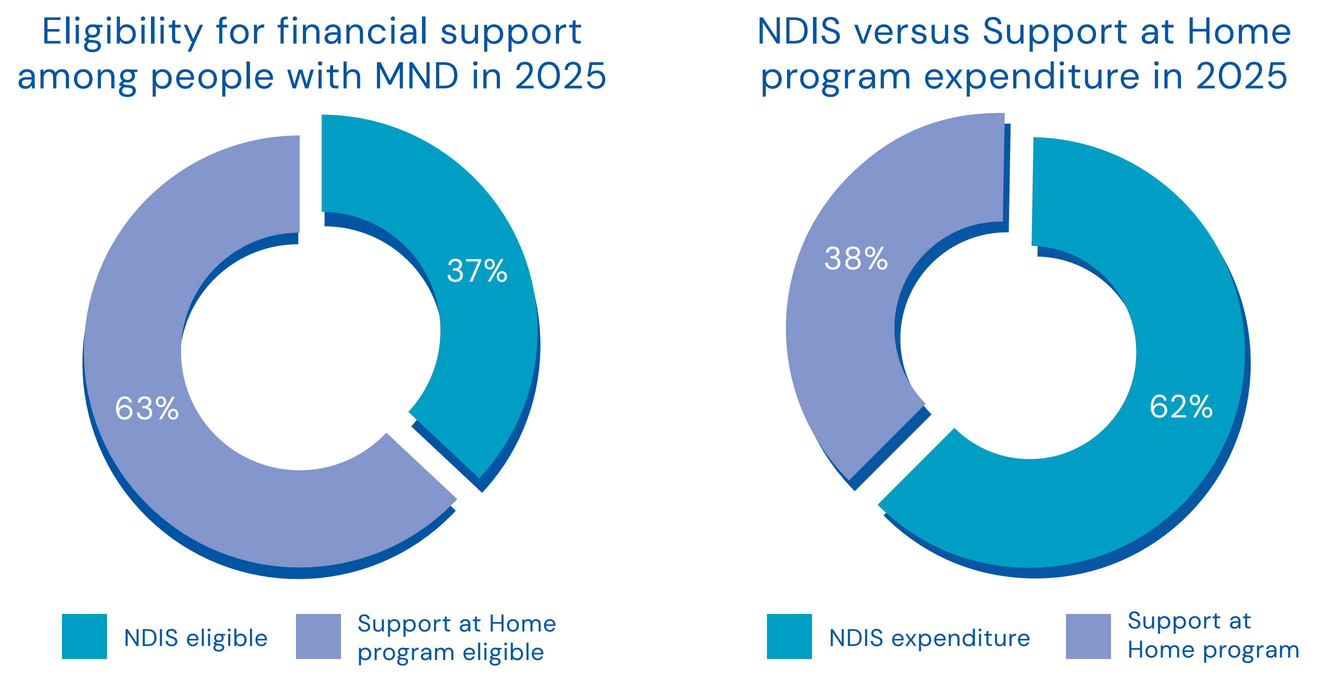
Component	2025 costs
NDIS expenditure	$305.68 million
Support at Home program	$187.45 million
Public hospital admitted patient	$16.18 million
National Health and Medical Research Council (NHMRC) funding	$4.83 million
Public hospital outpatient	$3.08 million
Private hospital services	$2.54 million
Pharmaceuticals	$2.35 million
General practitioner services	$0.82 million
Medical imaging	$0.79 million
Specialist services	$0.70 million
Allied health and other services	$0.42 million
Pathology	$0.21 million
Emergency department	$0.02 million
Total direct costs	**$525.08 million**

Hospital-related costs remain relatively low because the majority of MND care is managed within the community, with acute care services accessed only as needed. This highlights the vital role that community-based care, including MND clinics, State MND Associations, HCPs, and access to essential equipment plays in helping prevent costly hospital admissions and supporting people with MND to remain at home for as long as possible.

Financial supports

The disparity in funding between the NDIS and the Support at Home program highlights a significant inequity for those diagnosed at age 65 and over. 63 per cent of people living with MND are eligible for the Support at Home program with the remaining 37 per cent eligible for NDIS. Yet NDIS contributes 62 per cent ($305.68 million) of funding supports for people with MND compared with the Support at Home program contribution of 38 per cent ($187.45 million). [5] This highlights a very significant disparity in support, based purely on the age at which a person is diagnosed and applies for funding support, rather than their care needs.

Figure 8. Eligibility for NDIS and Support at Home program compared with expenditure for each.



Eligibility for financial support among people with MND in 2025

NDIS versus Support at Home program expenditure in 2025

Source: *Evohealth modelling [5]*

Indirect costs

Indirect costs capture the economic losses associated with reduced productivity of individuals living with MND, and their carers. These costs include the financial impact of premature mortality, the lost wage burden of informal carers, and the productivity losses of those living with MND.

Evohealth modelling estimates total indirect costs at $457.36 million annually. Of this, $155.72 million is attributed to productivity losses from individuals living with MND, $212.02 million reflects lost wages for informal carers, and $89.63 million is due to premature mortality, as summarised in Table 7. [5]

Table 7. MND indirect costs 2025

Component	2025 costs
Premature mortality cost	$89.63 million
Informal carer lost wages	$212.02 million
Individual with MND productivity loss	$155.72 million
Total indirect costs	**$457.36 million**

With direct costs estimated at $525.08 million and indirect costs at $457.36 million, the total economic cost of MND in Australia for 2025 is projected to be $982.44 million.

$982.44 million – The total economic cost of MND in Australia in 2025. [5]

Societal costs

Societal costs are summarised in Table 8. These are derived from years lived with disability (YLD), which is derived from prevalence rates and disability for severe motor impairments, and years of life lost (YLL) based on premature mortality estimates compared to a life expectancy of 83 years. [5]

Table 8. MND societal costs 2025

Component	2025 Costs
Years Lived with Disability (YLD)	$0.33 billion
Years of Life Lost (YLL)	$3.70 billion
Total Burden of disease costs	**$4.04 billion**

In 2025, 15,760 years of life are projected to be lost to MND due to premature mortality and people living with MND lost an average of 18 years of their life expectancy. [5] Similarly, in 2025, 1,420 years of healthy life are projected to be lost to disability due to MND. The combined impact of YLL and YLD sees 17,180 DALYs lost to MND in 2025, which translates to a burden of disease cost of $4.04 billion. This figure reflects the immense burden on individuals, families, and society.

$4.04 billion – Total burden of disease costs in Australia in 2025. [5]

Future projections

The total costs of MND are anticipated to increase by 50 per cent to $7.51 billion in 2050. This projection is based on current disease prevalence rates, and growth in general and ageing population figures. It also assumes that per the current therapeutic development pipeline, a cure for MND will remain undiscovered by this date.

By 2050, the costs of MND in Australia will **increase by 50% to $7.51 billion.** [5]

A CALL FOR EQUITABLE CARE FOR **ALL PEOPLE LIVING WITH MND**

MND is brutal, disabling and ultimately fatal. Highly effective disease-modifying or curative treatments applicable for all persons with MND remain elusive. The impact of the disease is severe and reflected in the burden it places on individuals, carers and the Australian economy.

People living with MND need fast access to consistent, high-quality support and care to optimise their quality of life. Yet, this is not accessible to all. In Australia, the age at which someone is diagnosed with MND and applies funding support determines the level of care and support available to them, and consequently, the quality of life they can lead.

This is simply unjust.

While age is a significant factor in MND, it is not solely a disease of ageing, yet it is often treated as such. Funding through the Support at Home program is grossly inadequate and bureaucratically slow, preventing many individuals from accessing the critical support they urgently need.

For people living with MND, every moment matters.

All people living with MND, regardless of age should have access to the services, support and care they need to optimise their quality of life throughout their disease journey. There is an immediate need to address the inequities in access to funding, care, and support for those living with this brutal disease in Australia.

KEY RECOMMENDATIONS TO IMPROVE QUALITY OF LIFE FOR PEOPLE IMPACTED BY MND

We have developed five recommendations that address critical gaps and inequities in funding, care, and support services for people living with MND, their carers and families. By implementing these targeted initiatives, healthcare providers, policymakers, and the broader MND community can work together to improve quality of life, access to care, and outcomes for people impacted by this disease. These recommendations recognise the need for systemic change and identify interim steps to address inequities and gaps that exist today.

Recommendation 1

The Australian Government to establish a nationally consistent funding pathway to fund care and support for people living with MND, irrespective of age.

The inequity in funding support between the NDIS and the Support at Home program has been consistently highlighted throughout this report. The maximum funding available through the Support at Home program, approximately $108,000[4], is significantly lower than the average NDIS package of $302,000. [34] This amount is insufficient to meet the complex and progressive needs of people living with MND.

Additionally, the Support at Home program involves a slower administrative process, with funding approvals often taking considerably longer than those processed under the NDIS Priority Eligibility Decision pathway, where approvals are typically completed within 2 to 5 business days. [64]

To address this disparity, it is recommended that:

- Funding for people diagnosed with MND at age 65 and over be brought into alignment with the average NDIS funding available to MND recipients.
- A fast-track approval process for the Support at Home program be established, mirroring the NDIS Priority Eligibility Decision pathway, to ensure people with MND can access critical support quickly.

---

[4] *Under the Support at Home Program, the maximum funding package is estimated at $108,000 per person in 2025. This includes a base package of around $78,000, plus an additional $15,000 for assistive technology and $15,000 for home modifications.*

Immediate solutions

While it is recognised that implementing this recommendation will require significant time and effort, we propose an immediate solution: the Government should provide predictable and sustainable funding to MND Australia to support State MND Associations in bridging the substantial gaps between the maximum level of support available through the Support at Home program and the average support provided under the NDIS. This funding would also enable the development of nationally consistent support programs and services tailored to the unique needs of people living with MND and their carers, as outlined in Recommendation 4.

Recommendation 2

The Australian Government to fund an integrated MND data strategy and registry, that supports research and care in Australia.

Currently, there is no consolidated MND data registry in Australia. Data is fragmented across multiple sources, making it difficult for researchers, healthcare professionals, and other stakeholders to access critical information. This fragmentation impedes research, delays clinical trial recruitment, and limits the ability to plan services and effectively advocate for funding.

To address these challenges, it is recommended that:

- A detailed data needs analysis, strategy, and robust implementation plan be developed in collaboration with the MND community to ensure the MND data registry meets stakeholder requirements and integrates with existing data systems.
- An integrated MND data registry be developed to consolidate data for research, care, and advocacy purposes.
- Government funding be secured to support the development, implementation, and ongoing maintenance of the registry, ensuring it is interoperable and accessible for research and clinical care purposes.

An integrated MND data registry will be crucial in transforming how MND care and research is conducted in Australia. It will enable stakeholders to make informed decisions, accelerate clinical trials, and ensure people living with MND receive the best possible care.

Recommendation 3

MND Australia to develop a national directory of healthcare professionals with MND experience, with funding provided by the government.

The complex nature of MND means that the number of HCPs with expertise in the disease is limited. Currently, no single directory exists to help individuals locate HCPs with relevant experience, resulting in delays, frustration, and additional costs as people make appointments with HCPs, then realise they do not have the necessary experience. This lack of a central resource also creates inefficiencies for HCPs trying to refer people with MND to experienced professionals.

To address these challenges it is recommended that a national directory of HCPs with MND experience be developed with funding provided from government. This work could be facilitated by MND Australia in collaboration with State MND Associations, and would aim to:

- Enable people living with MND and their carers to more efficiently contact HCPs who have the necessary experience to provide high quality care.
- Support HCPs by offering a resource for referring people with MND to the right care providers.
- Improve access to timely, effective care by reducing delays in treatment, streamlining the referral process, and ensuring that people living with MND can access the appropriate expertise without unnecessary barriers.
- Provide a centralised resource that is regularly updated and maintained to reflect the evolving landscape of MND care and expertise across Australia.

Recommendation 4

The Australian Government to fund MND Australia to develop a National MND Support Program targeted at people living with MND and their carers.

This report outlines the unique challenges and support needs of people living with MND and their carers. Whilst funding from the NDIS and the Support at Home program plays an important role in addressing some of these needs, the characteristics of MND, combined with the inconsistency in funding access, means many people affected by MND need to seek additional support and guidance from MND Australia and the State MND Associations. However, the services and support offered by these organisations differ widely across Australia and are currently underpinned by the sporadic nature of government funding received, and their fundraising initiatives.

To address this gap, it is recommended that:

- Sustainable government funding be provided to MND Australia to support the development and coordination of a National MND Support Program ('the Program') which would include services, interventions, and resources that address the unique needs of people living with MND and their carers.
- MND Australia work with the State MND Associations to implement the Program, thereby ensuring consistent access to specialised services and support for all people affected by MND across Australia.

This funding will support appropriate resourcing, service planning, and access to services nationally. It will also allow MND Australia and the State MND Associations to maintain their focus on providing much needed support to people impacted by MND, rather than expend effort and resources on fundraising initiatives.

Recommendation 5

MND Australia to work with regulators to develop and implement consistent definitions and practices for terminal illness in superannuation and life insurance policies.

Many insurance policies and superannuation funds include provisions for individuals facing terminal illnesses such as MND to access their benefits early. [74] However, the definitions of terminal illness and eligibility requirements for accessing benefits vary across superannuation funds and insurance policy providers, creating inconsistencies in access. Additionally, many individuals diagnosed with a terminal illness are unaware that these benefits exist, and as a result, do not realise they have access to this financial support.

It is recommended that Government support the standardisations of these definitions and eligibility criteria to simplify access to policy benefits and superannuation funds for all people living with a terminal illness. Once defined, government should formally announce these changes to drive awareness of these policy benefits in the community and ensure consistent adoption across the superannuation and insurance sectors.

The journey of people living with MND, their families and carers is filled with many challenges as they battle a relentlessly progressive and unforgiving disease.

Every moment matters for those impacted by MND. Whether it's accessing the right level of funding to support the best quality care, seamlessly accessing timely care from experienced MND providers or accessing support to navigate the challenges of the disease, every moment should be focused on living the best quality life.

> *For me, MND is not just a disease that affects the body, it affects the heart, the mind, and my family. Every day that I get to say, "I love you" to my family is a day that I feel like I'm still winning.*
>
> Ronald Hobden – Dad and husband living with MND

ABBREVIATIONS

ACAT	Aged Care Assessment Team
AAC	Augmentative and Alternative Communication
AIHW	Australian Institute of Health and Welfare
ALS	Amyotrophic Lateral Sclerosis
AT	Assistive Technology
DALY	Disability Adjusted Life Years
EMG	Electromyography
GRIM	General Record of Incidence of Mortality
HCP	Healthcare Professional
HESRI	Health Evidence, Synthesis, Recommendations, and Impact
IV	Intravenous
MND	Motor Neurone Disease
MND-FTD	MND with Frontotemporal Dementia
MDT	Multidisciplinary Team
MRI	Magnetic Resonance Imaging
NCS	Nerve Conduction Studies
NDIS	National Disability Insurance Scheme
NHMRC	National Health and Medical Research Council
NIV	Non-invasive Ventilation
PBP	Progressive Bulbar Palsy
PEG	Percutaneous Endoscopic Gastrostomy
PBS	Pharmaceutical Benefits Scheme
PMA	Progressive Muscular Atrophy
PLS	Primary Lateral Sclerosis
RIG	Radiologically Inserted Gastrostomy
STRC	Short-Term Restorative Care
VAD	Voluntary Assisted Dying
YLD	Years Lived with Disability
YLL	Years of Life Lost

APPENDIX A – ECONOMIC MODELLING METHODOLOGY

Cost of Illness approach

A Cost of Illness (COI) approach was used to measure the economic burden of MND in Australia. This method was chosen because it provides a comprehensive estimate of the total financial and societal costs associated with MND, capturing both direct expenditures and the broader economic impacts. Given the high healthcare costs, significant informal caregiving burden, and substantial productivity losses associated with MND, a COI approach allows for a more holistic assessment compared to other economic evaluation methods. In quantifying the total economic burden, this approach highlights the scale of the disease's impact on individuals with MND, their families, and the healthcare system, supporting informed policy and funding decisions.

- Direct costs included medical and non-medical healthcare expenditures such as hospital services, pharmaceuticals, and disability support programs.
- Indirect costs captured broader economic losses from reduced productivity, caregiving burdens, and premature mortality.
- Societal costs were estimated using Disability-Adjusted Life Years (DALYs), combining Years Lived with Disability (YLD) and Years of Life Lost (YLL).

Prevalence-based modelling

A prevalence-based approach was employed to estimate the number of individuals living with MND and the associated disease burden. This approach was chosen over an incidence-based method, which tracks disease progression and costs over time, because prevalence better captures the total burden of MND at a given point in time. Given the rapid disease progression and high mortality associated with MND, incidence-based modelling may underestimate the total number of individuals affected and fail to reflect the ongoing care needs of those living with the condition. By focusing on prevalence, this method provides a more robust estimate of the total disease burden, ensuring that both direct and indirect costs are adequately represented.

1. **Prevalence estimation:**
    - ◇ Data sources:
        - Prevalence data were provided by State MND Associations, which included both the number of cases (people living with MND) and deaths due to MND recorded by these organisations.
        - National-level MND mortality data were sourced from the General Record of Incidence of Mortality (GRIM) dataset provided by the Australian Institute of Health and Welfare (AIHW).

- Scaling using the death ratio method:
  - To adjust for underreporting in the state data (estimated to capture around 85% of cases), a death ratio method was applied.
  - This method compared the total deaths recorded by the state organisations to the total deaths reported in the GRIM dataset.
  - The ratio of state-recorded deaths to GRIM deaths was calculated. This ratio was then used to scale up the prevalence numbers provided by the states, under the assumption that the level of underreporting for deaths also applied to the living cases.
  - This approach ensures the prevalence estimates account for individuals missed by state organisations, providing a more accurate picture of the total number of people living with MND.

2. **Validation:**
   - Prevalence estimates were validated against international benchmarks and national mortality trends to ensure consistency with observed patterns in MND prevalence and mortality.

Economic analysis of MND

1. **Direct costs:** These included all healthcare expenditures directly linked to MND, encompassing medical and non-medical expenses associated with managing the disease. These costs reflect the substantial financial burden placed on individuals, families, and the healthcare system.
   - Hospital care: Costs for public and private hospital services, including admitted patient care, outpatient services, and emergency visits.
   - Pharmaceuticals: Drug costs were sourced from PBS data, reflecting treatments for MND.
   - Specialist and Allied Health Services: Included consultations with neurologists, physiotherapists, occupational therapists, and speech pathologists.
   - Support services: NDIS expenditure, aged care costs, and Support at Home program.
   - Diagnostics: Expenses for medical imaging, pathology, and genetic testing.
2. **Indirect costs:** These captured economic losses resulting from reduced productivity and caregiving demands, reflecting the broader financial impact of MND on individuals and society.
   - Productivity losses: Estimated based on reduced employment capacity of people with MND, adjusted for return-to-work rates.
   - Caregiving burdens: Valued unpaid care using ABS income data.
   - Premature mortality: Quantified economic losses from early deaths based on average annual incomes and a life expectancy of 83.
3. **Societal costs:** These were calculated to measure the broader impact of MND on health and well-being beyond direct financial losses:
   - Years Lived with Disability (YLD): Derived directly from AIHW burden of disease estimates, capturing the years of healthy life lost due to disability caused by MND.

   - Years of Life Lost (YLL): Estimated directly from AIHW burden of disease data on premature mortality, reflecting the total years of life lost due to MND.
   - Monetised DALYs: DALYs were monetised using a societal willingness-to-pay threshold, providing a holistic measure of the disease burden.

Data sources

The analysis relied on the following data sources:

1. Prevalence data: Sourced from State MND Associations and scaled using GRIM mortality data (AIHW).
2. Mortality data: MND-related deaths were obtained from the GRIM dataset (AIHW).
3. Pharmaceutical costs: Data from PBS covered MND-specific medications.
4. Burden of disease metrics: YLD, YLL, and DALYs were obtained from AIHW.
5. Economic data: ABS income and employment data were used to estimate productivity and caregiving losses.
6. Healthcare costs were sourced from AIHW's Health System Spending on Disease and Injury in Australia dataset and include public hospital admitted patient services, public hospital outpatient services, private hospital services, emergency department services, general practitioner services, medical imaging, specialist services, allied health and other services, and pathology services.
7. Healthcare inflation adjustment: All healthcare costs were adjusted for inflation using Consumer Price Index (CPI) data for healthcare services provided by the ABS.

Assumptions

1. **Prevalence estimation**
   a. Prevalence data was sourced from MND State Associations for New South Wales, Australian Capital Territory, Northern Territory, Queensland, Western Australia, South Australia and Victoria.
   b. To obtain a comprehensive national estimate of MND prevalence, the death-ratio method was applied using GRIM mortality data (AIHW). This was used to:
      i. Adjust prevalence estimates for states that provided data, ensuring consistency.
      ii. Account for limitations in the capture rate of MND cases by State MND Associations, acknowledging not all individuals with MND are registered with these organisations.
      iii. Estimate prevalence in states and territories where data was not available.
2. **Mortality estimation**
   i. Mortality rates were based on GRIM AIHW datasets and applied by age group.
   ii. The mean mortality rate per age group was used to smooth fluctuations in the data.

3. **Population forecasting**
   1. LGA-level population projections were generated using ARIMA models, forecasting out to 2050.
   2. Population age distributions were adjusted using ABS projections, ensuring consistency over time.
4. **Direct cost**
   1. NDIS
      - i. People with MND who apply for funding before the age of 65 are eligible for the NDIS.
      - ii. The estimated annual cost of an NDIS package for individuals living with MND was determined to be $302,000 per eligible person. This estimate was initially referenced by MND Victoria, based on their direct experience supporting individuals with MND. [34] To ensure robustness, this figure was subsequently validated against additional stakeholder insights and with the advisory committee. After evaluation, it was confirmed to be the most realistic and representative estimate of average NDIS package. However, given the complexity and lack of comprehensive data surrounding NDIS packages for individuals living with MND, this figure is likely a conservative estimate, with the average package potentially exceeding this amount.
      - iii. Given the complexity of the NDIS system and the variability in service use, not all allocated funding may be fully spent in a given year. As a result, the actual cost to the government for NDIS support may be lower than the estimated aggregate package cost, depending on individual service usage and unspent funds within the system.
   2. Support at Home program
      - i. All individuals aged 65 and over are assumed to receive the maximum level of support under the Support at Home Program, valued at approximately $108,000 per year. This includes a base package of around $78,000, plus an additional $15,000 for assistive technology[5] and $15,000 for home modifications[6]. This assumption was discussed with stakeholders and validated by the advisory committee, which confirmed that the majority of individuals living with MND would likely require the highest level of support due to the progressive nature of the disease and the associated high care needs. As no data was available on the distribution of support levels within the program, this assumption was necessary to ensure a realistic and representative cost estimation.
   3. Hospital costs
      - i. Hospital expenditure was sourced from AIHW health system spending on disease and injury data set.
   4. Pharmaceutical costs
      - i. Pharmaceutical costs were underrepresented in AIHW hospital expenditure data, so PBS data was used instead to provide a more accurate estimate.

---

[5] Complex assistive technology may be accessed beyond the $15,000 maximum, provided there is a prescription from a suitably qualified health professional and supporting evidence of the item's cost.

[6] Participants receiving services under the Restorative Care Pathway are not eligible to receive high-tier funding for home modifications. [77]

      - ii. Government subsidy and patient co-payments were included in the total cost.
      - iii. The model does not account for future drug innovations or newly approved treatments beyond riluzole.

5. **Indirect costs**
   1. Productivity losses
      - i. The economic impact of lost productivity was based on the median Australian wage.
      - ii. Employment rates were sourced from ABS unemployment data and applied by age group.
      - iii. People with MND are assumed to exit the workforce immediately upon diagnosis and remain unable to work.
   2. Informal carer burden
      - i. Carers were assumed to spend on average 37.5 hours per week a week caring for the person living with MND. This was determined by literature reviews, stakeholder consultations, and advisory committee input.

Limitations

- Potential misclassification in mortality data: The GRIM dataset (AIHW) used for scaling prevalence numbers relies on accurate classification of MND as the cause of death. However, MND-related deaths might be misclassified under other conditions (e.g., respiratory failure or cardiac arrest), leading to potential underestimation of prevalence when scaling state-reported data.
- Future advancements in MND treatments or changes in disease progression may not be fully reflected in this model.
- Informal caregiving costs, which include unpaid care provided by family members and friends, represent a significant economic and social burden. These costs are challenging to quantify due to the variability in caregiving responsibilities, unreported caregiving hours, and the lack of comprehensive data on informal care networks. Furthermore, the emotional and physical toll on caregivers, which may lead to reduced workforce participation or additional healthcare needs for the caregivers themselves, is often excluded from economic analyses. Consequently, the informal caregiving costs reported in this study are likely underestimated, as they do not fully capture the extensive and multifaceted impacts of unpaid caregiving for individuals with MND.

APPENDIX B – ECONOMIC MODELLING OUTPUTS

Category	Subcategory	Details	2025 Costs
Economic costs associated with MND	**Health system**	Public hospital admitted patient	$16.18 million
		Public hospital outpatient	$3.08 million
		Private hospital services	$2.54 million
		Pharmaceuticals	$2.35 million
		General practitioners	$0.82 million
		Medical imaging	$0.79 million
		Specialist services	$0.70 million
		Allied health and other services	$0.42 million
		Pathology	$0.21 million
		Emergency department	$0.02 million
	Total health system costs		$27.11 million*
	Financial support		$493.14 million
	Research funding	Federal Government MND research investment	$4.83 million
	Total direct costs		$525.08 million*
	Productivity losses	Informal care replacement cost	$212.02 million
		Patient productivity loss	$155.72 million
		Productivity lost from mortality	$89.63 million
	Total indirect costs		$457.36 million*
	Total economic costs		$982.44 million*
Burden of disease costs associated with MND	**Years of Life Lost (YLL)**	15,760 years of life lost due to premature mortality in 2025	Equivalent to $3.70 billion
	Years Lived with Disability (YLD)	1,420 years of healthy life lost due to disability in 2025	Equivalent to $0.33 billion
	Disability Adjusted Life Years	17,180 disability adjusted life years lost	Equivalent to $4.04 billion*
Total cost of MND		**Economic Costs + Burden of Disease Costs**	**$5.02 billion***

**Totals may not sum exactly due to rounding.*

REFERENCES

1. MND Australia. What is motor neurone disease? 2024; Available from: https://www.mndaustralia.org.au/mnd-connect/what-is-mnd/what-is-motor-neurone-disease-mnd?gad_source=1&gclid=EAIaIQobChMIouWG9un9iAMVG2APAh3QqAOPEAAYASAAEgI56PD_BwE.
2. MND Australia. Cognitive and behaviour change in MND. 2024; Available from: https://www.mndaustralia.org.au/mnd-connect/information-resources/cognitive-and-behaviour-change-in-mnd.
3. NHS UK. Motor neurone disease. 2021; Available from: https://www.nhs.uk/conditions/motor-neurone-disease/.
4. National Institute of Neurological Disorders and Stroke. Motor Neuron Diseases. 2024; Available from: https://www.ninds.nih.gov/health-information/disorders/motor-neuron-diseases.
5. Evohealth, MND economic model. 2024.
6. MND Australia. Overview of MND. 2021; Available from: https://www.mndaustralia.org.au/mnd-connect/for-health-professionals-service-providers/overview-of-mnd-for-health-professionals#:~:text=The%20trunk%20muscles%20and%20respiration,legs%20(flail%20leg%20type).
7. MND Australia. Types of MND. 2024; Available from: https://www.mndaustralia.org.au/mnd-connect/what-is-mnd/types-of-mnd.
8. Dharmadasa, T., et al., Motor neurone disease: progress and challenges. Med J Aust, 2017. 206(8): p. 357-362.
9. Sharrad, D.F. and D.W. Schultz, Factors contributing to delays in the diagnosis of motor neuron disease – A South Australian study. J Neurol Sci, 2019. 407: p. 116540.
10. Zoing, M. and M. Kiernan, Motor neurone disease – caring for the patient in general practice. Aust Fam Physician, 2011. 40(12): p. 962-6.
11. Brennan, F.P., M.D. Gardiner, and M. Narasimhan, Motor neuron disease: The last 12 months. Aust J Gen Pract, 2022. 51(5): p. 329-336.
12. Lau, F., F. Brennan, and M. Gardiner, Multidisciplinary management of motor neurone disease. Australian Journal for General Practitioners, 2018. 47: p. 593-597.
13. Rooney, J., et al., A multidisciplinary clinic approach improves survival in ALS: a comparative study of ALS in Ireland and Northern Ireland. J Neurol Neurosurg Psychiatry, 2015. 86(5): p. 496-501.
14. Traynor, B.J., et al., Effect of a multidisciplinary amyotrophic lateral sclerosis (ALS) clinic on ALS survival: a population based study, 1996-2000. J Neurol Neurosurg Psychiatry, 2003. 74(9): p. 1258-61.
15. Walsh, L.J. and D.M. Murphy, The Benefit of Non-invasive Ventilation in Motor Neuron Disease. Open Respir Med J, 2020. 14: p. 53-61.
16. Andrews, J.A., et al., Real-world evidence of riluzole effectiveness in treating amyotrophic lateral sclerosis. Amyotroph Lateral Scler Frontotemporal Degener, 2020. 21(7-8): p. 509-518.
17. ALS Association. Tofersen. 2023; Available from: https://www.als.org/navigating-als/living-with-als/fda-approved-drugs/tofersen#:~:text=Tofersen%20was%20shown%20to%20reduce,and%20neurodegeneration%2C%20by%2050%25.
18. MND Australia. Dysarthria & Communication 2021; Available from: https://www.mndaustralia.org.au/mnd-connect/for-health-professionals-service-providers/managing-symptoms/communication-in-mnd.
19. Paynter, C., et al., The impact of communication on healthcare involvement for people living with motor neurone disease and their carers: A longitudinal qualitative study. Int J Lang Commun Disord, 2022. 57(6): p. 1318-1333.
20. MND Australia. Equipment, assistive technology & home modifications. 2024; Available from: https://www.mndaustralia.org.au/mnd-connect/living-with-mnd/equipment-assistive-technology-home-modifications.
21. Simon, N.G., et al., Motor neuron disease: current management and future prospects. Intern Med J, 2015. 45(10): p. 1005-13.
22. MND Australia. Dysphagia & nutrition. 2021; Available from: https://www.mndaustralia.org.au/mnd-connect/for-health-professionals-service-providers/managing-symptoms/swallowing-nutrition-management.
23. MND Australia. End of life care: A guide for people living with MND. 2021; Available from: https://www.mndaustralia.org.au/getmedia/eeaabc08-8c23-41ca-bae9-1e4927a757f3/MNDAus_EndofLifeGuide_digital-version.pdf.
24. MND Australia. State MND Association services. 2024; Available from: https://www.mndaustralia.org.au/mnd-connect/find-services/state-mnd-associations.
25. MND Australia. Government support & benefits. 2024; Available from: https://www.mndaustralia.org.au/mnd-connect/find-services/government-support-benefits.
26. Australian Government Department of Health and Aged Care. Support at Home program handbook. 2024; Available from: https://www.health.gov.au/our-work/support-at-home/about

27. NDIS. When do we make priority eligibility decisions? 2024; Available from: https://ourguidelines.ndis.gov.au/home/becoming-participant/applying-ndis/when-do-we-make-priority-eligibility-decisions.
28. MND Australia. MND clinics. 2024; Available from: https://www.mndaustralia.org.au/mnd-connect/find-services/mnd-clinics.
29. Cordesse, V., et al., Coordinated care affects hospitalization and prognosis in amyotrophic lateral sclerosis: a cohort study. BMC Health Services Research, 2015. 15(1): p. 134.
30. Pinto, C., et al., Emotional distress and well-being among people with motor neurone disease (MND) and their family caregivers: a qualitative interview study. BMJ Open, 2021. 11(8): p. e044724.
31. Australian Psychological Society. Psychological wellbeing and care for people living with Motor Neurone Disease (MND) and their carers. 2024; Available from: https://psychology.org.au/getmedia/f97c28ca-8f2d-4dfb-ae9d-f7689ddf69c2/aps_mnd-community-resource-guide-carers.pdf.
32. Gluyas, C., et al., Factors to consider for motor neurone disease carer intervention research: A narrative literature review. Palliat Support Care, 2017. 15(5): p. 600-608.
33. Ewing, G., et al., Suitability and acceptability of the Carer Support Needs Assessment Tool (CSNAT) for the assessment of carers of people with MND: a qualitative study. BMJ Open, 2020. 10(12): p. e039031.
34. MND Australia. 2025-26 Pre-budget submission. 2024; Available from: https://www.mndaustralia.org.au/getmedia/666e2a5c-5b52-4217-a3cf-842bc37f70e0/2025-to-2026-PreBudget-Submission-MND-Australia.pdf.
35. MND Malaysia. What is MND? 2023; Available from: https://mndmalaysia.org/en_gb/what-is-mnd/.
36. Turner, M.R., et al., Controversies and priorities in amyotrophic lateral sclerosis. Lancet Neurol, 2013. 12(3): p. 310-22.
37. MND New Zealand. Progression of MND. 2024; Available from: https://mnd.org.nz/about-mnd/what-is-mnd/progression-of-mnd/.
38. MND Association. Inherited MND. 2024; Available from: https://www.mndassociation.org/about-mnd/mnd-explained/inherited-mnd.
39. MND Association. What causes MND? 2023; Available from: https://www.mndassociation.org/about-mnd/mnd-explained/what-causes-mnd.
40. MND Australia. More About MND: A guide for people living with MND, their family and friends. 2024; Available from: https://www.mndaustralia.org.au/getattachment/12ebc8d0-fbe8-4f99-84d5-e6b952b65086/MoreAboutMND_guide_MNDAustralia_web_2024.pdf?lang=en-AU.
41. Turner, M.R. and K. Talbot, Mimics and chameleons in motor neurone disease. Practical Neurology, 2013. 13(3): p. 153.
42. Aoun, S.M., et al., Breaking the news of a diagnosis of motor neurone disease: A national survey of neurologists' perspectives. J Neurol Sci, 2016. 367: p. 368-74.
43. Aoun, S.M., et al., Receiving the news of a diagnosis of motor neuron disease: What does it take to make it better? Amyotroph Lateral Scler Frontotemporal Degener, 2016. 17(3-4): p. 168-78.
44. MND Australia. Caring for a loved one with MND. 2024; Available from: https://www.mndaustralia.org.au/mnd-connect/support-for-carers-family-friends/caring-for-a-loved-one-with-mnd.
45. MND Association. Information for care workers. 2023; Available from: https://www.mndassociation.org/professionals/management-of-mnd/management-by-specific-professions/information-for-care-workers.
46. Van den Berg, J.P., et al., Multidisciplinary ALS care improves quality of life in patients with ALS. Neurology, 2005. 65(8): p. 1264-7.
47. Chiò, A., et al., Positive effects of tertiary centres for amyotrophic lateral sclerosis on outcome and use of hospital facilities. J Neurol Neurosurg Psychiatry, 2006. 77(8): p. 948-50.
48. O'Brien, M., B. Jack, and J. Mitchell, Multidisciplinary team working in motor neurone disease: patient and family carer views. British Journal of Neuroscience Nursing, 2011. 7: p. 580-585.
49. MND Australia. About us. 2024; Available from: https://www.mndaustralia.org.au/about-us.
50. MND Australia. Role of assistive technology in MND. 2021; Available from: https://www.mndaustralia.org.au/mnd-connect/for-health-professionals-service-providers/wellbeing-and-support/assistive-technology.
51. Bourke, S.C., et al., Effects of non-invasive ventilation on survival and quality of life in patients with amyotrophic lateral sclerosis: a randomised controlled trial. Lancet Neurol, 2006. 5(2): p. 140-7.
52. Piepers, S., et al., Effect of non-invasive ventilation on survival, quality of life, respiratory function and cognition: a review of the literature. Amyotroph Lateral Scler, 2006. 7(4): p. 195-200.
53. Walsh, L.J., et al., Use of non-invasive ventilation in motor neuron disease - a retrospective cohort analysis. Chron Respir Dis, 2021. 18: p. 14799731211063886.
54. MND Association. Mobility and movement. 2024; Available from: https://www.mndassociation.org/support-and-information/living-with-mnd/mobility-and-movement.

55. MND Australia. Medication for MND. 2024; Available from: https://www.mndaustralia.org.au/mnd-connect/living-with-mnd/medication-for-mnd#:~:text=Medications%20for%20MND%20may%20assist,(e.g.%20pain%2C%20drooling).
56. MND Australia. Riluzole. 2022; Available from: https://www.mndaustralia.org.au/mnd-connect/information-resources/riluzole.
57. MND Australia. Pharmaceutical Benefits Advisory Committee (PBAC) consultation on Edaravone. 2023; Available from: https://www.mndaustralia.org.au/getattachment/58f0d5ab-c45b-454f-8624-c63b4cc32a06/Edaravone-PBAC-Consultation-overview-and-draft-submission-resubmission-January-2024.pdf?lang=en-AU.
58. Australian Government Department of Health and Aged Care. Recommendations made by the PBAC – March 2024. 2024; Available from: https://www.pbs.gov.au/info/industry/listing/elements/pbac-meetings/pbac-outcomes/recommendations-made-by-the-pbac-march-2024.
59. John L. Cerillo, M.P. Tofersen. 2023; Available from: https://www.ncbi.nlm.nih.gov/books/NBK594270/.
60. Australian Government Department of Health and Aged Care. Notice for tofersen (Biogen Australia Pty Ltd). 2024; Available from: https://www.tga.gov.au/resources/designations-determinations/notice-tofersen-biogen-australia-pty-ltd.
61. Velaga, V.C., et al., Palliative and End-of-Life Care for People Living with Motor Neurone Disease: Ongoing Challenges and Necessity for Shifting Directions. Brain Sci, 2023. 13(6).
62. Hogden, A., et al., Amyotrophic lateral sclerosis: improving care with a multidisciplinary approach. J Multidiscip Healthc, 2017. 10: p. 205-215.
63. Luke Buckmaster, S.C. The National Disability Insurance Scheme: a chronology. 2018; Available from: https://www.aph.gov.au/About_Parliament/Parliamentary_departments/Parliamentary_Library/Research/Chronologies/2018-19/NDIS.
64. MND Australia. MND to receive specialist pathway in the NDIS. 2024; Available from: https://www.mndaustralia.org.au/articles/mnd-to-receive-specialist-pathway-in-the-ndis.
65. Macquarie University. A decade of impactful research. 2024; Available from: https://www.mq.edu.au/research/research-centres-groups-and-facilities/centres/motor-neuron-disease/our-research.
66. Genomics Education Programme. Motor neurone disease: Could gene therapies be the answer? 2022; Available from: https://www.genomicseducation.hee.nhs.uk/blog/motor-neurone-disease-could-gene-therapies-be-the-answer/.
67. Institute of Medicine Committee on Assessing Genetic, R., The National Academies Collection: Reports funded by National Institutes of Health, in Assessing Genetic Risks: Implications for Health and Social Policy, L.B. Andrews, et al., Editors. 1994, National Academies Press (US) Copyright 1994 by the National Academy of Sciences. All rights reserved.: Washington (DC).
68. Lu, L., Y. Deng, and R. Xu, Current potential therapeutics of amyotrophic lateral sclerosis. Front Neurol, 2024. 15: p. 1402962.
69. Tomlin, C. Regenerative Medicine: A New Path for ALS Treatment. 2023; Available from: https://www.cedars-sinai.org/discoveries/a-new-path-for-als-treatment.html.
70. ELDAC. Overview of Voluntary Assisted Dying. 2024; Available from: https://www.eldac.com.au/Our-Toolkits/End-of-Life-Law/Voluntary-Assisted-Dying/Overview#:~:text=Voluntary%20assisted%20dying%20(VAD)%20is%20the%20assistance%20provided%20by%20a,the%20VAD%20medication%20themselves%2C%20and.
71. MND Australia. Submission to the Department of Health and Aged Care Consultation on the new Aged Care Act. 2024; Available from: https://consultations.health.gov.au/ageing-and-aged-care/new-aged-care-act-exposure-draft-consultation/results/107-organisationsubmission-mndaustralia.pdf.
72. Australian Government Department of Health and Aged Care. Features of the new Support at Home program. 2024; Available from: https://www.health.gov.au/our-work/support-at-home/features.
73. Australian Government My Aged Care. Home Care Packages. 2024; Available from: https://www.myagedcare.gov.au/help-at-home/home-care-packages.
74. Australian Government Australian Taxation Office. Access due to a terminal medical condition. 2024; Available from: https://www.ato.gov.au/individuals-and-families/super-for-individuals-and-families/super/withdrawing-and-using-your-super/early-access-to-super/access-due-to-a-terminal-medical-condition.
75. Galvin, M., et al., Individual quality of life in spousal ALS patient-caregiver dyads. Health and Quality of Life Outcomes, 2020. 18(1): p. 371.
76. Fight MND. 2024 cure & care investment. 2024; Available from: https://fightmnd.org.au/wp-content/uploads/2024/11/FightMND-Grant-announcement-2024-investment-booklet.pdf.
77. Leora Health. Support at home: Aged care at home is changing in July 2025. 2025; Available from: https://leorahealth.com.au/support-at-home-aged-care-at-home-is-changing-in-july-2025/.

DISCLAIMER

This Report has been prepared by Evohealth Pty Ltd (**Evohealth**) on behalf of Motor Neurone Disease Australia (**MNDA**).

MNDA has commissioned Evohealth to develop an independent report and economic model examining the human and economic impact of motor neurone disease (MND) in Australia.

This Report is not intended to be, and should not be used by any other person or entity other than a Recipient and Evohealth accepts no duty of care whatsoever to any such other person or entity.

While reasonable efforts have been made to ensure that the contents of this Report are factually correct, this Report is provided by Evohealth on a general basis only. Neither Evohealth or any of its directors, officers, employees, advisers, consultants, contractors and agents make any representation or warranty, express or implied, as to the currency, accuracy, reliability or completeness of the information referred to or contained in this Report and none of those persons or entities accepts any responsibility or liability (except a liability that cannot lawfully be excluded) for any reliance placed on the contents of this Report by any person. This Report does not purport to be comprehensive or to contain all the information a Recipient may desire or require in respect of its subject matter. The Recipient should make its own enquiries and obtain its own independent advice in relation to the information contained within this Report before making any decision or taking any action based on its contents.

To the maximum extent permitted by law, Evohealth and its directors, officers, employees, advisers, consultants, contractors and agents disclaim and exclude all liability for any loss, claim, demand, damages, costs and expenses of whatsoever nature (whether or not foreseeable): suffered or incurred by any person relying or acting on any information provided in, or omitted from, this Report or any other written or oral opinions, advice or information provided by any of them; or arising as a result of or in connection with information in this Report being inaccurate or incomplete in any way or by reason of any reliance thereon by any person; and whether caused by reason of any negligence, accident, default or however otherwise caused.

Each recipient of this report acknowledges and accepts each of the matters and conditions contained in this Disclaimer.

Date of preparation: 30 May 2025

Authors: Renae Beardmore, Maggie Bawer, Theresa Doueihi and James Taylor

Economic model: James Taylor

Report design: Adam Sorgini

Suggested citation: MND Australia and Evohealth. 2025. *Every moment matters: Addressing the human and economic toll of MND in Australia,* Canberra.

30 MAY 2025

www.**mndaustralia**.org.au

Level 4, Woden Centre
20 Bradley Street Philip
ACT 2606 AUSTRALIA