



MND Australia:

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MND Australia

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**Working towards a world without motor neurone
disease**





Executive Summary

Initiative	Estimated cost
<p>Access to Care</p> <p>Funding for an aged care assistive technology supplement for people aged 65 and older as soon as they are assessed as eligible for aged care services to ensure timely access to aids and equipment to address their disability needs and to close the gap between those aged 65 and older when diagnosed with MND and younger Australians accessing the NDIS</p>	<p>\$10.5 million (over 4 years)</p>
<p>Access to information</p> <p>Development and provision of up to date and trusted information on genetic testing, counselling and support in a variety of formats from MND Associations to support decision making</p>	<p>\$100,000 (over 2 years)</p>
<p>Stop MND</p> <p>Stop MND in families with a known genetic mutation through provision of funding for IVF and pre-implantation genetic diagnosis for those who carry a genetic mutation</p>	<p>As per MacKenzie's Mission</p>

About MND Australia

MND Australia is the national voice for MND representing all Australians living with MND, their families and carers, health and community care providers and researchers.

Together with the state MND associations and our research arm, the MND Research Institute of Australia (MNDRIA) we work to advance, promote and influence MND care and research with a vision to achieving a world without MND. The [six state MND associations](#) provide direct support to people living with MND across Australia.

MND Australia is a founding member of the National Neurological Alliance of Australia which advocates for better services and increased investment in research for people affected by progressive degenerative neurological conditions in Australia.

We are committed to achieving an MND aware Australia where people living with MND, their carers and family have access to care and support to meet their individual needs to enable them live better for longer and to have hope for a future without MND.



Introduction

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

The most recent research indicates that 2,000 people are living with MND in Australia and many more carers, family and friends are directly impacted. Average time from diagnosis to death is two to three years; however a small number of people may live with MND for many years. MND affects each person differently with respect to initial symptoms, age of onset, rate and pattern of progression, and survival time.

The MND Australia Deloitte Access Economics Report¹ reveals that in Australia the per-person cost of MND in 2015 was \$1.1 million, dwarfing the cost of many other chronic health conditions. The report, commissioned by MND Australia, is the first Australian study on the economic impact of MND. The report states that the total cost of MND in Australia in 2015 was \$2.37 billion, comprising \$430.9 million in economic costs and \$1.94 billion in burden of disease costs. The enormity of the cost is akin to the brutality of MND.

There are no remissions and progression of MND is usually rapid and relentless creating high levels of disability. The social and emotional impact of MND is amplified by its complex nature, the speed of its progression and a spiralling series of losses. This results in rapidly changing, variable and complex support needs which pose a huge challenge to families, health professionals, disability services, community care, and aged care providers involved in meeting these needs.

Whilst there is currently no cure or effective treatment, there are a range of measures that will both improve the quality of life of people living with MND and reduce the cost of this condition on the community.

Timely and expert diagnosis, early and evidence-based intervention from specialist MND multidisciplinary teams, local services and MND Associations, access to aids and equipment, specialist palliative care, specialist planning and assessment and coordination of care, including a proactive framework for decision-making, play vital roles in maintaining quality of life, social engagement and independence. Early access to assistive technology and evidence-based interventions such as an expert multidisciplinary care team, non-invasive ventilation and nutritional support will improve quality and length of life.

These specialist interventions are crucial in helping people to plan ahead to prevent crisis and avoidable hospital/residential aged care admissions. They are also crucial in strengthening the informal supports available to the person, including supporting the primary carer to maintain the caring role and their own health and wellbeing.

¹ Deloitte Access Economics, 2015, [Economic Analysis of motor neurone disease in Australia](#), report for Motor Neurone Disease Australia



Recommended Funding Initiatives

Following the launch of the Deloitte Access Economics report at Parliament House, Canberra, in February 2016, MND Australia released the MND Australia Action Framework² based on the findings of the report and feedback from the MND community. This Action Framework outlined five recommendations to improve quality of life and effectiveness of service provision.

In 2018 the Action Framework was updated, in response to an increase in the discovery of MND causing genetic mutations, to include a call for access to fully funded genetic services for families with identified genetic mutations to stop MND in those families.

The six recommendations are:

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

Prior to the Federal Election in May these recommendations were distributed to all candidates seeking their support for [six steps to improve the lives of people living with MND](#) in Australia.

In the 2020/21 Budget MND Australia calls on the Government to join MND Australia in our focus to ensure access to needs-based care for all people with MND no matter their age or postcode and investment in genetic services for people with a family history of MND as the only way, at present, to stop MND.

MND Australia calls on the government to prioritise the following initiatives in the forthcoming budget:

1. Improved access to a full range of assistive technology to address the disability needs of people with a progressive, complex condition such as MND aged 65 and older to close the widening gap and increasing discrimination
2. Improved access to fully funded genetic services for families with identified genetic mutations to stop MND

² MND Australia, 2018, [National Action Framework](#)



1. Close the Gap: investment to support timely access to assistive technology to meet the disability needs of older people with MND

In the Deloitte Report¹, aids and equipment comprise one of the highest per person costs highlighting their importance. The often rapid rate of progression requires 'fast track' access to a wide range of equipment as items need to be available as soon as a need arises and may only be required for a short period of time.

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

For people living with MND, the full range of assistive technology may include aids and equipment to support comfort, independence and daily living, communication technology and non-invasive ventilation to support breathing, quality and length of life. Non-Invasive ventilation improves survival by 13 months on average³.

Under the NDIS, people living with MND who are aged 64 and younger are entitled to assistive technology to meet their needs. Where available and appropriate a person's NDIS plan will include funding for an annual payment to the MND Association to enable fast track access to a 'bundle' of assistive technology provided by that Association. In addition it will also include funding for reasonable and necessary home modifications as well as specialised and individualised assistive technology items.

Conversely the 60% of people who are aged 65 or older when diagnosed with MND join long waiting lists for aged care support. Aged care is designed to address needs related to ageing and frailty not disability and the gap between access to services for the 40% of people with MND aged under 65 compared to older Australians diagnosed with MND is ever widening as the NDIS rolls out nationally. This is leading to increasing discrimination and sadly, many older people living with MND dying before they receive a Home Care Package of any description.

MND Australia has long campaigned for those who acquire a disability aged 65 and older to have access to the NDIS. As an interim solution the [MND Australia Aged Care Position Statement](#) calls for fast track access to Level 3 or 4 Home Care Packages and additional funding for Assistive Technology.

There is insufficient funding allocated, even within a Level 4 Home Care Package (HCP), to provide the range of assistive technology a person with MND will require during the disease trajectory. In addition access to assistive technology is needed soon after diagnosis and as soon as a need arises. With no nationally consistent mechanism for provision of assistive technology, access through the various government schemes is confusing and long waiting lists are common. In its recent [submission to the Aged Care Royal Commission](#) the Assistive Technology for All

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



Alliance also recommended that the Commonwealth Government should specifically fund aids and equipment for older people with a disability as an urgent interim solution.

An annual assistive technology supplement provided as soon as a person is deemed eligible for a HCP would enable the person with MND and their family to access a 'bundle' of assistive technology from the MND Association in a similar way to those aged under 65 and receiving NDIS supports.

This supplement would not be sufficient to fund individualised, specialised assistive technology and home modifications but would enable MND Associations across Australia to provide a timely and equitable pool of generic assistive technology to people aged 65 and older as soon as a need arises. It would also ensure that HCP's, once available, fund more personal care and support to enable most people with MND to remain at home until they die. For those people in need of residential aged care the supplement would ensure access to a full range of equipment to maintain safety, comfort and communication.

MND Australia has recently reviewed the number of people registered with MND Associations currently receiving or waiting to receive assistive technology. Based on these numbers, we estimate that nationally there would be up to 450 people with MND aged 65 and older in need of an assistive technology supplement at the current price of \$7,300 to \$7,700 per annum (in line with the cost of MND Association equipment bundles funded through NDIS) at any given time.

Compared to the average equipment costs of \$31,598 per person identified by the Deloitte Access Economics Report, and a recent MND Association review of equipment provision – see Appendix - this represents a cost effective model of assistive technology provision to older people living with MND in Australia.

Access to timely needs based assistive technology would:

- Reduce or delay hospital admissions
- Reduce length of stay where an admission is necessary
- Reduce or delay entry to Residential Aged Care Facilities
- Reduce or delay the need for a Level 3/4 HCP
- Reduce carer burden
- Improve independence, quality of life, communication and community access for people living with MND
- Support paid and unpaid carer health, safety and well-being
- **Close the gap between those aged 65 and older and younger Australians with MND**

Budget over four years:

Year 1	250 people	\$1,875,000
Year 2	300 people	\$2,250,000
Year 3	400 people	\$3,000,000
Year 4	450 people	\$3,375,000
TOTAL		\$10,500,000

2. Stop MND: Improved access to genetic services, pre-conception screening, IVF and PGD

There are no therapies currently available to effectively slow down MND or stop disease progression. The past five years have seen acceleration in MND research globally, which has transformed understanding of the disease. Despite these advances, riluzole remains the only proven therapy available to people living with MND in Australia. Riluzole slows the disease process by just three months on average.

Whilst there are no therapies available to stop the disease in people living with MND today, we can help those who carry a known genetic mutation to stop the disease affecting future generations through:

- Improved access for people with a family history of MND to genetic testing under the existing arrangements for testing, including counselling
- Funding and access for those who carry a genetic mutation for pre-conception screening and access to fully funded IVF and pre implantation genetic diagnosis (PGD) services to enable them to stop MND in their family

There are around 2,000 people living with MND in Australia and about 5 to 10% of these people will have the 'familial' form of MND: that is, there is or has been more than one affected person in a family. The remaining 90 to 95% of people with MND are the only affected person in their family and are said to have 'sporadic' MND.

Although there are still some MND families in which the faulty gene has not yet been identified, the SOD1 gene, C9orf72 and other MND-related gene mutations discovered in recent years now account for about 65% of all people with familial MND. If a person with MND is found to have a MND causing genetic mutation other family members can then be tested to determine if they have the same mutation. For example, adult children or brothers and sisters of an affected person can be tested.

There are therefore approximately up to 100 to 200 people in Australia at any point in time with the familial form of MND who would have family members eligible to access genetic testing and counselling. A relatively small but significant number identified as carrying an MND gene mutation will be thinking of starting a family and may then wish to access IVF and pre implantation genetic diagnosis (PGD) to stop MND in future generations. See a recent [MND Australia blog](#) post that highlights the importance of access to these services for those carrying a known genetic mutation.

Recent research has identified the complex nature of decision making for families affected by MND regarding whether to have genetic testing or not as evidenced in this video clip from the 2018 International Symposium on ALS/MND featuring Professor Christopher Shaw talking about [MND gene testing](#)

Access to timely trusted information is therefore vital for this group of people.



MND Australia and its members the state MND Associations have been a trusted source of information to the MND community for over 35 years. Current information is sparse and dedicated funding would enable MND Australia to develop a Genetic Testing Information Campaign to include a range of information and support resources, based on world best practice and current research, and to disseminate the information effectively.

IVF and PGD is being used effectively by people to stop many other conditions. In 2018 as part of the federal budget, the Government allocated \$500 million for the Australian Genomics Health Futures mission. The first project is Mackenzie's Mission, with \$20 million being provided for pre-conception screening trial for rare and debilitating birth disorders including Spinal Muscular Atrophy, Fragile X and Cystic Fibrosis.

It is proposed that families at risk of passing MND on to future generations should also have access to fully funded pre-conception screening, IVF and pre-implantation genetic diagnosis. The number of people would be few and therefore government investment in this project would be relatively low in the short term, but would lead to a huge reduction in health, disability and aged care costs to governments in the future.

More importantly it would stop MND in these families many of whom have endured decades of loss, grief and trauma. See Associate Professor Justin Yerbury talk about the devastating impact MND has had on his family in [ABC's Australian Story](#).

Access to improved information resources in a variety of formats, preconception screening, IVF and PGD would:

- Inform decision making
- Reduce burden of disease costs to individuals
- Reduce health, aged, disability and economic costs to governments
- **Stop MND in families with a known genetic mutation now**

Budget over four years:

Information campaign

Year 1	MND Australia	\$50,000
Year 2	MND Australia	\$50,000

Preconception screening and IVF

Provide funding as MacKenzies Mission for up to 100 couples per annum

APPENDIX

Case Study 1 – Ray			
69 year old gentleman living at home with his wife who is his main carer.			
He was diagnosed with MND in 2015 at aged 66. He did not need much equipment initially, but in the last 2 years has been issued with 18 pieces of equipment.			
Equipment issued	Date issued	Date returned	Cost of AT \$
Bed stick - clamp on	12/18		110
Electric Bed + long mattress	12/18		3200
Alternating air mattress	12/18		3500
Over wheelchair table	08/18		235
Sara Stedy standing aid	08/18		1990
Toilet frame	08/18	12/18	67
Electric Hoist + slings	07/18		3420
Electric Recliner arm chair	11/08		1650
Mobile Shower chair	05/18		1170
Power tilt in space wheelchair	03/18	08/18	17500
Roho – pressure relief cushion	03/18		675
Manual tilt in space wheelchair	03/18	09/18	1300
Remote call bell	05/18		180
Shower stool	02/17	12/18	97
Shower chair	02/17	02/17	68
Bed stick	08/18		42
Walking frame	10/17	08/18	195
Crutches	03/17		40
TOTAL			35,439

Case Study 2 – Antonia

Antonia was diagnosed with MND in 2017 when she was 78 years old. She has been issued with – 17 pieces of equipment over 1 year.

Equipment issued	Date issued	Date returned	Cost of AT \$
Bed cradle	09/18		54
Electric bed + cotsides	02/18		2800
Pressure relieving mattress	02/18		400
Bedpan	04/18		40
Call bell	09/18		180
Roho cushion	05/18 (replaced 07/18)		675
Switches	09/18		180
Wheelchair mount	09/18		180
Electric hoist	06/18		3000
Sara Steady standing aid	04/18	07/18	1990
Mattress topper	07/18		600
Nebuliser	09/18		130
Sheepskin	02/18		350
Mobile shower commode + padded seat	04/18		1170
Table for wheelchair	09/18		400
Power wheelchair	05/18		17500
Manual tilt wheelchair	07/18		2800
TOTAL			32,449