



MND Australia:

Pre-Budget Submission 2021 - 2022

28 January 2021

MND Australia

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Working towards a world free of MND





Executive Summary

Initiative	Estimated cost
Address inequity: AT for older Australians with MND Funding for an aged care assistive technology supplement for people diagnosed with MND 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	\$10.5 million (over 4 years)
Stop MND: Improving access to clinical trials, technology and therapies Empower all Australians with MND through the development and provision of up to date and trusted information to support decision making and access to timely diagnosis, latest technologies and clinical trials. Stop MND in families with a known genetic mutation through provision of information on genomic services to support access to IVF and pre-implantation genetic diagnosis and future therapies for specific genetic mutations.	\$450,000 (over 3 years)

About MND Australia

MND Australia, its research arm, MND Research Australia, and members, the State MND Associations, form the only national network focused on improving the lives of all Australians living with motor neurone disease (MND) and advancing research to end MND. For over 35 years this national network has helped increase understanding of the disease and advocated for improvements in its treatment and care to ensure people living with MND have the best quality-of-life possible. The six state MND Associations provide direct support and services to people living with MND, their carers and families and the health professionals and service providers involved in their care in all states and territories.

MND Australia is a founding member of the 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 timely access to:

- care and support to meet their individual needs to enable them live better for longer no matter their age or postcode
- diagnosis, clinical trials, technologies and therapies



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.

There is no known cause of MND, except in a small number of genetic cases, no effective treatments and no cure. There are no remissions and progression of MND is usually rapid and relentless creating high levels of disability and a need for a wide range of progressively changing supports.

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 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.

Whilst there are currently no effective treatments, 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 assistive technology, 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. 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.

Approximately 40% of the 2,100 Australians living with MND at any one time are diagnosed when under the age of 65 and 60% at age 65 or older. People under the age of 65 when diagnosed with MND, will access supports to meet their individual needs through the NDIS. People aged 65 and older must rely on the aged care system which, unlike the NDIS, is capped, means tested and designed to address ageing, not disability. With an average life expectancy of just two to three years from diagnosis most people with MND prefer to remain at home. However, increasing inequity and long waiting times are causing many older people with MND to be pushed into financial hardship or residential aged care earlier than they wish or need.

There is a high and unmet need with respect access to treatments as well as technologies to assist diagnosis, communication, clinical care and decision making. 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. All those

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



impacted by MND are desperate for effective treatments to be discovered and available to significantly slow down or stop progression of this devastating disease. With this high and unmet need, and rapid advances in technology and research, access to up to date and trusted information is vital to improve and support access to clinical trials, latest technologies and therapies or interventions to slow or stop MND. Timely access to trusted information based on national and international research and best practice is also critical in supporting decision making and advocacy.

Recommended Funding Initiatives

In the 2021/22 Budget MND Australia calls on the government to prioritise the following initiatives:

1. Improved access to a full range of supports to address the disability needs of people with a progressive, complex condition such as MND aged 65 and older
2. Improved access to diagnosis, clinical trials, technology and therapies for people with rare diseases such as MND

1. Address Inequity: AT for older Australians with MND

Increasingly older people with MND are dying before receiving the level of aged care support they have been assessed as needing. In addition the complex needs of people living MND, cannot be met by existing or traditional aged care services or facilities which are designed to address needs related to ageing not disability. There are major gaps with respect to timely access to support at home, choice and range of assistive technology and the level and hours of service available. Understanding of MND within the aged care sector is limited further compounding distress for the person with MND and their family.

The crucial issue remains that, unlike those eligible for the NDIS, people with a disability over the pension age are not able to access the full range of reasonable and necessary disability supports to meet individual needs (see Appendix 1).

In our initial [submission](#) to the Aged Care Royal Commission we outlined 11 recommendations to improve access to supports for those who acquire a disability when aged 65 or older.

Our four key recommendations were:

1. *The NDIS should be broadened to include all people with disability, regardless of age.*
2. *Funding to be made available for assistive technology in addition and separate to Home Care Package funding to ensure that older people diagnosed with MND who are living at home can access the assistive technology they need when they need it*
3. *An immediate investment in additional home care packages to address the current urgent needs of those on the national prioritisation queue.*
4. *The introduction of a formal 'fast track' process for automatic access to Level 4 Home Care Packages (high priority) for people living with terminal, complex and progressive conditions.*



The Counsel Assisting the Royal Commission into Aged Care Quality and Safety handed down their proposed recommendations to the Commissioners on the 22nd and 23rd October 2020. The Counsel Assisting acknowledged the increasing gap in access to supports for older people with disability compared to those under 65 entitled to the NDIS. Consequently a number of the recommendations put forward closely align with our key recommendations.

The MND Australia Network strongly supports and welcomes Recommendation 9.1 as an immediate intervention to improve the lives of older Australians and to maintain and support home based care:

The Australian Government should clear the home care package waiting list, otherwise known as the National Prioritisation System by:

- (a) immediately increasing the home care packages available and allocating a package to all people on the waiting list that do not have a package or do not have a package at the level they have been approved for (as set out in their letter from the Aged Care Assessment Team/Service). The package allocated should be at the level the person was approved for (Level 1, 2, 3 or 4). This must be completed by 31 December 2021*
- (b) keeping the waiting list clear by allocating a home care package at the approved level to any new entrants to the waiting list within one month of the date of their assessment. This must occur between 1 January 2022 and 1 July 2024*

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 our [Position Statement on Aged Care](#) calls for immediate and sustained investment in Home Care Packages to reduce the number of people waiting on the national queue and additional funding for Assistive Technology. Currently with an average wait time of just over one year for half of the people on a level 4 Home Care Package, MND Associations across Australia are increasingly being told that loved ones have died before receiving the Home Care Package they had been assessed as needing. Waiting in a queue is not tenable in the face of progressing loss of function, speech and swallowing, loss of ability to breathe and a life expectancy of just 2 to 3 years from diagnosis.

MND Australia applauds the Morrison Coalition Governments' recent investment in more Home Care Packages and trusts that investment will be significantly increased when the final Aged Care commission report is handed down in early 2021. We anticipate that in addition to investing in more Home Care Packages there is also significant reform. This would not only address equity for people with disability receiving aged care but would also boost employment opportunities in the community.

Recommendation 16 focuses on assistive technology and home modifications:

The Australian Government should implement an assistive technology and home modification category within the aged care program that provides AT and services that promote a level of independence in daily tasks and reduces risk to living safely at home.



The MND Australia Network strongly supports this recommendation and urges immediate investment and action from the Australian Government. The model we are proposing offers a cost-effective solution for people living with progressive neurological conditions such as MND that could be rolled out immediately with a relatively modest investment from the Australian Government². It would also align with the recommendations of the [Assistive Technology for All Alliance](#) that recommends a national aids and equipment program for older Australians that will harmonise existing state-based AT programs and those operated by not-for-profit organisations.

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 AT as soon as a need arises. An AT item may only be required for a short period of time making purchasing items a costly exercise. 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 (see Appendix 2).

For people living with MND, the full range of assistive technology may include aids and equipment to support comfort, communication, independence and daily living 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. Alternatively funds are provided to rent individual items from the MND Associations when needed. These models work well for people with conditions like MND who have rapidly changing needs and has proven to be cost effective for the NDIA. Importantly the NDIS will also include funding for reasonable and necessary home modifications as well as purchase of specialised and individualised AT items.

An annual AT supplement provided as soon as a person is deemed eligible for a Commonwealth Home Support Programme (CHSP) or a Home Care package (HCP) would enable the person with MND and their family/carer 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 AT and home modifications but would enable MND Associations across Australia to provide a timely and equitable pool of generic AT items 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.

² Birks, O’Mara and Millington, 2020, How a cost effective approach to assistive technology could help the Australian aged care system and older people living with MND, The Mandarin, 2020, Jan

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.



MND Australia has recently reviewed the number of people registered with MND Associations 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 2) 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 clinical trials, technologies and therapies

About 1 in 300 people will develop MND over their lifetime, with their risk of developing the disease steadily increasing as they get older⁴. There continues to be a high and unmet need with respect access to clinical trials and treatments as well as technologies to assist diagnosis, communication, clinical care and decision making.

The past five years have seen acceleration in MND research globally, which has transformed understanding of the disease⁵. Despite these advances, Riluzole remains the only proven therapy available to people living with MND in Australia. Original randomized controlled trials showed that Riluzole slowed disease progression by two to three months on average. More recent real-world evidence⁶ indicates that Riluzole may extend life by more than 19 months.

The number of ALS/MND clinical trials currently underway in Australia and globally is growing. Many of these treatments are showing promising Phase 2 results and are moving into Phase 3 trials. Australia needs to be prepared to fast track the approval processes for any therapy that is proven to slow or stop progression. With two Australians dying each day from MND, waiting years for a therapy to be approved will not be acceptable to the Australian community.

Early diagnosis is key to maximizing the benefit of current treatment options and slowing disease progression. In addition timely and expert diagnosis is vital in optimizing access to clinical trials that incorporate a personalised and precision medicine approach. With no definitive test for MND, diagnosis depends on expert clinical examination and delays to diagnosis are common. Timely referral to specialist MND neurology led multidisciplinary clinics is therefore critical.

For those families carrying inheritable genetic mutations, knowledge of their status is vital in reproductive decision-making. Further, discovery of genes implicated in MND is doubling every four year and the most promising therapies under development are those targeted at patients with known genetic mutations.

It is likely that progress in precision medicine, including genetically targeted therapies, will change the natural history of MND⁴. Therefore, access to genomic screening to support early diagnosis, a precision medicine approach and guidance for exploring reproductive options is vital. Currently such access is variable and routine access to affordable genomic and reproductive technologies and genetic counselling remains elusive for many families.

Access to trials also needs to be improved for Australians with a diagnosis of MND. Currently most clinical trials are run through specialised MND Clinics located in the

⁴ Martin S, Al Khleifat A and Al-Chalabi A. [What causes amyotrophic lateral sclerosis?](#) [version 1; peer review: 3 approved]. F1000Research 2017, 6(F1000 Faculty Rev):371

⁵ Kiernan, M.C., Vucic, S., Talbot, K. et al. Improving clinical trial outcomes in amyotrophic lateral sclerosis. *Nat Rev Neurol* (2020). <https://doi.org/10.1038/s41582-020-00434-z>

⁶ Hinchcliffe and Smith, Riluzole: *Real-world evidence supports significant extension of median survival times in patients with amyotrophic lateral sclerosis*, *Degenerative Neurological and Neuromuscular Disease*, (2017), May, ; 7: 61-70 <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6053101/>



capital cities. Many regional, rural and remote patients face significant accessibility and financial obstacles to regularly attend such clinics to participate in clinical trials and are thus excluded from ground-breaking treatment opportunities. Changes to clinical trial design and the recent government extensions to telehealth rebates as a result of the COVID 19 pandemic have potential to improve access across Australia.

As well as advances in research in recent years there have been extensive and exciting advances in technologies to support communication and independence that are having significant impacts on the quality of life of people living with MND. People living with MND and the health professionals and community providers involved in their care need improved and timely access to information on the latest technologies such as voice and message banking, brain computer interfaces, environmental controls, text to speech software, communication apps and much more.

In our recent submission to the Inquiry into approval processes for new drugs and novel medical technologies in Australia⁷ we provided recommendations that aligned with the Rare Voices Australia Action Plan to improve access to clinical trials, new drugs and novel medical technologies for people with MND and other rare conditions. Information, communication and collaboration are integral to support-decision making and improve access to early diagnosis, research, clinical trials, latest technologies, personalised medicine and genomic services.

MND Australia and its members the state MND Associations have been a trusted source of information to the MND community for over 35 years. MND Australia, as the national voice for the MND community and an active member of the International Alliance of ALS/MND Associations, plays critical and key roles in advocacy, facilitating communication and collaboration nationally and in gathering, reviewing, writing and disseminating information.

The MND community is now at a pivotal phase as we face the challenge of keeping people informed in a rapidly changing environment. The pace of research is accelerating, clinical trial designs are evolving to improve access to therapies being tested, more gene mutations are being discovered making genomic testing an integral part of MND diagnosis and management and clinical registries and patient driven registries are becoming more easily accessible online. In response to this rapidly changing environment the wider ALS/MND community is seeking to create collaborations and collectives to accelerate understanding of MND, improve care and fast track the discovery and delivery of effective treatments for people living with MND across Australia.

Dedicated funding would enable MND Australia to build capacity over the next three years to develop an Information and Advocacy Campaign to include a range of information and resources, based on world best practice and current research, and to coordinate and disseminate that information effectively. This funding would also support our focus on building collaborations and communications to advance research.

⁷ Ref 64:

https://www.aph.gov.au/Parliamentary_Business/Committees/House/Health_Aged_Care_and_Sport/Newdrugs/Submissions



Access to improved advocacy and information resources in a variety of formats related to diagnosis, registries, clinical trials, latest research, new technologies, genomic testing and services such as preconception screening, IVF and pre-implantation genetic diagnosis (PGD) would:

- Improve time to diagnosis
- Empower Australians living with MND and inform decision making
- Improve and support a personalised approach to accessing clinical trials and therapies
- Strengthen connections between industry, researchers, clinicians, MND associations/foundations and people living with MND
- Support a clinical trial network and clinical research
- 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**

Budget over three years:

Information campaign

Year 1	MND Australia	\$150,000
Year 2	MND Australia	\$150,000
Year 3	MND Australia	\$150,000

APPENDIX 1

Comparative case Study: Graham and Aaron (two men living with MND)

Graham and Aaron both have rapidly progressive Motor Neuron Disease (MND). They have lived in the same regional community since childhood and played football together in the same premierships many years ago. They have maintained a close friendship over the years and still mix in the same social circles.

Graham is 66 years old. He is not eligible for the NDIS as he was unable to apply for the scheme before his 65th birthday. He has been assessed as being eligible for a level 4 home care package under the aged care system but was advised that he would need to wait 12-18 months for a suitable package to become available. He was told that he could access a lower level of support under a level 2 package in the meantime but would still need to wait 9-12 months to receive this. He wasn't sure whether he would accept this offer as he feared he would be worse off under a level 2 package. This is because he would have had to pay full fee for all of the services he had already been accessing at a subsidised rate; including home nursing, community allied health, home cleaning, personal care and in-home respite.

Graham has been forced to self-fund ramp access to his home and modifications to his bathroom in the meantime. Without these urgent modifications, he would not have been able to remain living in his own home. While he has received some support to subsidise the cost of these modifications through state funding, donations and fundraising events, his out of pocket expenses have still been significant. His need to rely on charity is also inconsistent with the principles articulated under the Convention on the Rights of Persons with Disabilities.

Things have been much more straight-forward for Aaron, who is 64 years old and is able to access support under the NDIS. His NDIS plan has enabled him to access fully funded assistive technology, including bathroom modifications and ramp access to his home. He is also able to ask for his NDIS plan to be reviewed if his circumstances change and he feels that he no longer has enough funding available to meet his needs.

APPENDIX 2

From figures collected in 2018/19

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 Steady 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