

# MND Australia:

## Pre-Budget Submission 2022 - 2023

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### MND Australia

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**Working towards a world free of MND**



## Executive Summary

### Initiative

#### Improve equity of access to needs-based person centered in-home supports for older Australians with MND

Fund and implement improvements to the Aged Care system to provide comparable funding and support for people with MND to that available under the NDIS.

#### Improve equity of access to assistive technology for older Australians with MND

Establish a central assistive technology (AT) program to ensure there are no costs and minimal waiting times for any AT that people with MND need to acquire as their disease progresses.

### 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.

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 to live better, for longer, no matter their age or postcode
- Timely diagnosis, clinical trials, technologies and therapies

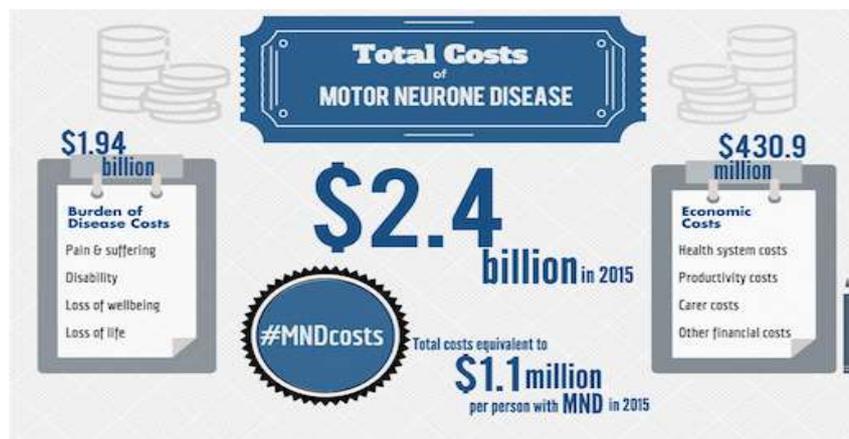
### About MND

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.

MND affects each person differently with respect to initial symptoms, rate and pattern of progression and survival time. Average life expectancy is 27 months from diagnosis. There are no known causes for MND, apart from the 10% of familial cases, no effective treatments and no cures. There are no remissions and

progression of MND is usually rapid and relentless creating high levels of disability and a consequent need for a wide range of supports based on the person’s changing and complex needs.

The MND Australia Deloitte Access Economics Report<sup>1</sup> 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 interventions from specialist MND multidisciplinary teams, local services and MND Associations and access to person centred home based care, assistive technology and specialist palliative care play vital roles in maintaining quality of life, social engagement and independence. Specialist planning and assessment and coordination of care, including a proactive framework for decision-making are also vital for people living with MND.

These 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 50% of the estimated 2,000 Australians living with MND are diagnosed when under the age of 65 and 50% at age 65 or older. A vast majority of 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. Increasing inequity, inadequate funding for services to meet assessed needs 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. *(NB Tony in the case study below now lives in an aged care facility,*

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

separate from his wife who is still living in the community. This was born of necessity as he couldn't get adequate help at home).

## **Recommended Funding Initiatives**

In our 2022/23 Budget submission MND Australia calls on the government to prioritise the following initiatives:

1. Funding and implementation of improvements to the Aged Care system to provide comparable funding and supports for people with MND to that available under the NDIS by July 2023.
2. Establishment of a central assistive technology (AT) program to ensure there are no costs and minimal waiting times for any AT that people with MND aged 65 or older need to acquire as their disease progresses from December 2022.



Graham	Tony
<ul style="list-style-type: none"><li>• Lives with MND</li><li>• Age 63</li></ul>	<ul style="list-style-type: none"><li>• Lives with MND</li><li>• Age 67</li></ul>
<ul style="list-style-type: none"><li>✓ Receives an NDIS plan to meet his disability needs</li></ul>	<ul style="list-style-type: none"><li>✗ Cannot receive an NDIS plan as he is aged 65+</li></ul>
<ul style="list-style-type: none"><li>✓ No waiting list for NDIS, can access approved care in his plan as he needs it</li></ul>	<ul style="list-style-type: none"><li>✗ Stuck on the Aged Care waiting list for over eight months</li></ul>
<ul style="list-style-type: none"><li>✓ Receives funding for vital equipment through NDIS</li></ul>	<ul style="list-style-type: none"><li>✗ No funding for vital equipment</li></ul>

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## 1. Improve equity of access: in-home supports comparable to the NDIS for older Australians with MND

Equity of access is about ending discrimination based on age. There is a complete lack of equity for people with motor neurone disease (MND) and other rapidly progressive neurological disease based on their age at diagnosis. This drives an urgent need to improve equity of access to services and support for older Australians with MND irrespective of age and geographic location.

With an average life expectancy post-diagnosis of just 27 months, people with MND do not have time to wait for services and supports as their condition rapidly progresses. The current levels of funding provided by the Aged Care system to people who are diagnosed with MND and other rapidly progressive neurological disease when aged 65 or older do not adequately address their complex and changing needs or the needs of carers.

The maximum funds available through a Home Care Level 4 Package is just \$50,990.50 per annum. In contrast, a report published by the NDIS, *Participants with a neuro-degenerative condition in the NDIS*<sup>2</sup>, as at March 31 2021 the average annualised committed supports for the 2020-2021 financial year was \$242,000 for participants with MND.

It is a fundamental right<sup>3, 4</sup> that every person with a disability must have equity of access to services and support to facilitate quality of life, independence, safety and community participation. This is even more critical for people with a rapidly progressing, degenerative and complex disability like MND.

The National Strategic Action Plan for Rare Diseases<sup>5</sup> outlines action and policy for rare diseases such as MND to ensure equity of access. The Action Plan is predicated on an integrated, person-centred approach which is responsive to changing needs.

**Equity of access is about ending discrimination based on age. Equity of access means ensuring comparable funded and accessible services between the National Disability Insurance Scheme (NDIS) and the Commonwealth Government-funded Aged Care system that are needs based and person centred irrespective of their age.**

MND Australia calls on the Commonwealth Government to provide funding in the 2022/23 budget to fund and implement the recommendations of the *Royal Commission into Aged Care Quality and Safety* to improve equity of access to home based supports based on the needs and wishes of older Australians.

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<sup>2</sup> National Disability Insurance Scheme, *Participants with a neurodegenerative condition in the NDIS*, 31 March 2021

<sup>3</sup> [Convention on the Rights of Persons with Disabilities](#), United Nations, articles 25 and 26

<sup>4</sup> International Alliance of ALS/MND Associations [Fundamental Rights of People Living with ALS/MND](#), April 2021

<sup>5</sup> [National Strategic Action Plan for Rare Diseases](#), February 2020



Specifically MND Australia calls on the Commonwealth Government to fund and implement:

**Improvements to the Aged Care system to provide comparable funding and supports for people with MND to that available under the NDIS by July 202**

## **2. Improve equity of access: AT for older Australians with MND**

Given the needs of people with MND are complex and can change rapidly, timely access to a range of assistive technologies to support independence, comfort, communication and breathing, as well as the health and wellbeing of their carer and service provider safety is vital. Unfortunately, funding for and access to, assistive technology is not equitable and is discriminatory for people aged 65 and over compared with the NDIS. Older Australians have to trade off the funding for their care needs to fund assistive technology.

MND Australia calls on the Commonwealth Government, other parties and independents to establish within the Aged Care system a separate funding stream for assistive technology. To achieve this, MND Australia requests **implementation of Recommendation 34** of the *Royal Commission into Aged Care Quality and Safety* to establish an assistive technology and home modifications category within the aged care program from Dec 2022.

Specifically, MND Australia calls on the Commonwealth Government to fund and implement:

**Establishment of a central assistive technology (AT) program to ensure there are no costs and minimal waiting times for any AT that people with MND need to acquire as their disease progresses from December 2022**

It should establish a harmonised and nationally consistent assistive technology program to support people with disability who are excluded from the NDIS. In particular, for people with MND and other rapidly progressive neurological disease it is critical that a single program provides the timely response that is required.

The Assistive Technology for All (ATFA) Alliance<sup>6</sup> recommends a national aids and equipment program for older Australians that will harmonise existing state and commonwealth based AT programs and those operated by not-for-profit organisations. The assistive technology program must be fully funded and equal to the NDIS, needs based, and with no requirement for people with MND to contribute to the cost of purchase or maintenance of AT.

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 and time consuming exercise, leading to higher

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<sup>6</sup> Assistive Technology for All, Briefing Paper, [Improving access to assistive technology for people with disability who are excluded from the NDIS](#), 2021



waste disposal and poor or no referral systems when the equipment is either scrapped or on-sold.

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 average<sup>7</sup>.

MND Associations are currently providing a cost-effective national solution for people living with progressive neurological conditions such as MND under the NDIS that could be rolled out immediately with a relatively modest investment from the Australian Government<sup>8</sup>. Where available and appropriate, a person's NDIS plan will include funding for an annual payment, currently \$7,300 to \$7,700 per annum, to enable fast track access to a 'bundle' of assistive technology from the MND association. Alternatively, funds are provided to rent individual items from the MND associations when needed. These models work well for people with progressing neurological conditions like MND who have rapidly changing needs and have also proven to be cost effective for the NDIA.

**Importantly the NDIS provides additional funding for reasonable and necessary home modifications as well as the purchase of specialised and individualised AT items.** In the NDIS report<sup>9</sup> as at 31 March 2021 capital costs, typically AT and home modifications, comprise 12% of annualised committed supports for people with MND. This equates to approximately \$25k annually for each person with MND to cover the cost of AT rental or bundles as outlined above, purchase of specialised and individualised AT and home modifications.

Compared to the average equipment costs of \$31,598 per person identified by the 2015 Deloitte Access Economics Report<sup>1</sup> (NB based on costs pre full roll out of the NDIS) 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 carer burden
- Improve independence, quality of life, communication and community access for people living with MND
- Support carer and service provider health, safety and well-being
- **Improve equity of access between those aged 65 and older and younger Australians with MND**

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<sup>7</sup> 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.

<sup>8</sup> 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

<sup>9</sup> National Disability Insurance Scheme, Participants with a neurodegenerative condition in the NDIS, 31 March 2021



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 assistive technology comparable to the NDIS at any given time.

**Budget to cover MND Association AT bundles or rental 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
<b>TOTAL</b>		<b>\$10,500,000</b>

**Budget to cover AT and home modifications comparable to the NDIS (including AT bundles or rental) over four years @\$25k per person:**

Year 1	250 people	\$6,250,000
Year 2	300 people	\$7,500,000
Year 3	400 people	\$10,000,000
Year 4	450 people	\$11,250,000
<b>TOTAL</b>		<b>\$35,000,000</b>