

MND Australia 2022 Election Commitments

It is a fundamental right^{1, 2} 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 motor neurone disease (MND). The National Strategic Action Plan for Rare Diseases³ 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 funding and access to services between the National Disability Insurance Scheme (NDIS) and the Commonwealth Government-funded Aged Care system, that are needs based and person-centred, for everyone living with MND irrespective of their age.

Equity of access is about maintaining and further strengthening the NDIS to ensure that people with MND can continue to access timely needs-based and person-centred services and supports. Equity of access means ensuring that people with rare conditions such as MND have fast track access to therapies proven to slow progression and/or improve quality of life.

MND Australia seeks three key commitments during the Federal Election 2022 to ensure equity of access to improve the lives of all Australians impacted by motor neurone disease (MND):

- 1. End age discrimination in provision of services and supports for people with MND**
- 2. Ensure the NDIS is not weakened**
- 3. Fast-track access to effective novel therapies for MND**

KEY COMMITMENT 1:

END AGE DISCRIMINATION IN PROVISION OF SERVICES AND SUPPORTS FOR PEOPLE WITH MND

What is the Problem?

There is a complete lack of equity for people with MND based on their age which results in a lottery when a person is diagnosed. People diagnosed with MND aged 65 and over cannot access the NDIS for disability services and supports, and instead must rely on government-funded services through the Aged Care system.

There are clear inequities between the Commonwealth Aged Care system and the NDIS. In contrast to the NDIS, which provides needs-based and person-centred service provision, the Aged Care system has long waiting lists and inadequate funding to address the complex and changing needs of someone with MND.

With an average life expectancy post-diagnosis of just 2.5 years, people with MND do not have time to wait for services and supports as their condition rapidly progresses. We urgently need to ensure all people with MND, irrespective of age and geographic location, have equal access to appropriate in-home supports, assistive technology and home modifications to maintain their quality of life, independence, community access and participation and to support the health and wellbeing of their carer.


People aged 65 years and over and ineligible to access the NDIS must have access to the same levels of support and under the same conditions as those aged under 65. The right to access support services should not be determined by age.

¹ [Convention on the Rights of Persons with Disabilities](#), United Nations, articles 25 and 26

² International Alliance of ALS/MND Associations [Fundamental Rights of People Living with ALS/MND](#), April 2021

³ [National Strategic Action Plan for Rare Diseases](#), February 2020

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



What are the solutions?

MND Australia calls on the Commonwealth Government, other parties and independents to make a commitment to improve equity of access for older Australians with MND by:

- 1.1 funding and implementing 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**
- 1.2 establishing a central assistive technology (AT) program. As part of this, 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**

The solutions in more detail:

1.1 Funding and implementing improvements to the Aged Care system

MND Australia calls on the Commonwealth Government, other parties and independents to improve the response of Commonwealth Government-funded Aged Care services to ensure that the complex needs of people diagnosed with MND when aged 65 and over and their carers are met.

It is essential that the rapid progression of MND is wholly reflected by systems and practice within the Aged Care sector to ensure timely and effective support. The Aged Care system must provide funding through early access and supports based on assessed needs.

Concerns MND Australia have include:

- funding is inadequate even at the top level of Home Care Packages and needs to be:
 - immediately increased to comparable NDIS funded levels, and
 - addressed in the funding model of the new Support at Home Program commencing in July 2023
- people with MND are falling through the gaps with significant delays of more than 12 months in accessing any funding for home based supports, assistive technology and home modifications.

MND Australia calls on the Commonwealth Government, other parties and independents to:

- **implement Recommendation 72** of the *Royal Commission into Aged Care Quality and Safety* to improve equity of access with a focus on waiting list reduction including Home Care Packages. It is critical to introduce a formal 'fast track' process and funding for top level Home Care Packages for

people with MND who have a progressive and complex disability. MND Australia calls on Recommendation 72 to be implemented no later than 1 July 2023 for people with MND

- immediately **implement Recommendation 125** of the *Royal Commission into Aged Care Quality and Safety* so people living with MND assessed as needing social supports, assistive technologies and home modifications, or care at home should not be required to contribute to the costs of that support,
- **implement Recommendations 35 and 36** of the *Royal Commission into Aged Care Quality and Safety* to ensure entitlement to care at home based on assessed needs including palliative and end of life care and a level of allied health care appropriate to each person's needs.

MND Australia seeks an increase in funding for hours of care provided under Home Care Packages from the current one to two hours per day provided through Level 4 HCPs to funding hours of care based on need. 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*, as at March 31 2021 the average annualised committed supports for the 2020-2021 financial year was \$242,000 for participants with MND⁴ ⁵.

MND Australia also supports Palliative Care Australia's Federal Election Statement 2022, particularly its proposed national collaboration project (\$1.5m) to develop a home based palliative care model for people with complex needs under My Aged Care to enable them to remain in their own home.

These actions will reduce the burden on people with MND and their families and carers; drive nationally-consistent outcomes while streamlining access; reduce the level of administrative burden on governments; minimise downstream costs by reducing demand in other areas such as acute health and aged and community care; and align with Australia's obligations under the Convention on the Rights of Persons with Disabilities.

Implementation of Recommendation 73 of the *Royal Commission into Aged Care Quality and Safety* around annual reporting to Parliament by the Disability Discrimination Commissioner and the Age Discrimination Commissioner will provide greater transparency of Government support to people with a disability receiving aged care. It will also identify service gaps particularly around supports including assistive technologies. Given this reporting is already available under the NDIS, it must also be implemented for aged care as quickly as possible with assessment against publicly-available Key Performance Indicators.

1.2 Establishing a central assistive technology funding program

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, wellbeing and safety of carers and service providers 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.

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, it is critical that a single program provide the timely response that is required. Consistent with the Assistive Technology for All (ATFA) campaign⁶ the 90 plus existing Commonwealth and State funding streams for assistive technology should be harmonised to create a single national assistive technology program. The assistive technology

⁴ National Disability Insurance Scheme, *Participants with a neurodegenerative condition in the NDIS*, 31 March 2021

⁵ MND Australia, Pre-budget submission 2022 - 2023

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

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.

MND Australia Proposal:

Pilot a Home Based Aged Care Model with people living with MND to deliver comparable funding and support to the NDIS

MND Australia calls on the Commonwealth Government to conduct a pilot project with people with MND diagnosed 65 years and over to deliver comparable funding and support to the NDIS. The pilot will demonstrate and ensure that every person with MND aged 65 and over can receive comparable levels of funding and supports to the NDIS, appropriate to their existing and changing needs. The pilot will build an evidence base of what is required in the longer term to end age discrimination and benefit people living with MND.

MND Associations are currently providing a cost-effective national solution for people living with progressive neurological conditions such as MND under the NDIS⁷. With a relatively small and static prevalence of 2,000 people living with MND and with approximately 50% diagnosed when aged under 65 and 50% when aged 65 years or older the MND community offers the Commonwealth Government a unique opportunity to pilot a model of support. MND Australia offers to co-design the pilot with the Commonwealth Government.

KEY COMMITMENT 2:

ENSURE THE NDIS IS NOT WEAKENED

What is the Problem?

MND Australia, in partnership with our members, has engaged proactively and successfully with the NDIA since the introduction of the NDIS to support a rapid response and an effective planning process and plan implementation for people living with MND that takes their progressing and complex needs into account. Today many NDIS participants living with MND have plans that are having positive, life-changing impacts; many others, however, continue to experience a protracted planning process and struggle to receive plans.

It is imperative that the NDIS continues to be fully funded and further strengthened.

MND Australia calls on the Commonwealth Government, other parties and independents to protect and enhance the National Disability Insurance Scheme. MND Australia is concerned the *National Disability Insurance Scheme Amendment (Participant Service Guarantee and Other Measures) Bill 2021* will further erode the NDIS. These proposed changes to the *National Disability Insurance Scheme Act 2013* must not adversely impact people living with MND.

What are the Solutions?

MND Australia calls on the Commonwealth Government, other parties and independents to commit to:

2.1 ensuring the NDIS is not weakened as is likely as a consequence of the *National Disability Insurance Scheme Amendment (Participant Service Guarantee and Other Measures) Bill 2021* and that the NDIS maintains its person-centred focus including ensuring:

- **it is fit-for-purpose**
- **that participant choice and control continues**
- **rapid access for NDIS services**
- **NDIS plans take into account the rapid disease progression of MND**

⁷ 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

The solutions in more detail:

The Commonwealth Government, other parties and independents need to ensure that the legislation:

- preserves participant choice and control, particularly for people with MND. The Participant Service Guarantee is essential to make the NDIA accountable and people with MND and other rapidly progressive neurological disease need a commitment that additional flexibility will be provided to ensure needs that may change quickly and/or frequently are not impacted by delays in plan implementation or amendment
- contains eligibility thresholds and clear definitions rather than incorporating them in the Rules, to give clarity and certainty and avoid changes and inconsistencies in interpretation over time. Additional clarification around the definition of various terms such as “substantially reduced functional capacity”, “managing a condition”, and others to ensure consistency, and not multiple interpretations, from assessors
- affirms that the NDIA CEO cannot vary a Participant's Plan without consulting the participant.

Further, as part of the implementation of the legislative changes, MND Australia calls on the Commonwealth Government, other parties and independents to ensure:

- NDIS plans take into account the rapid disease progression of MND and the quick access people with MND require to NDIS funding and supports
- that planning encompass both current and prospective needs
- that NDIA staff better understand MND as a progressive, degenerative, neurological condition for which there are no effective treatments or cures
- the proposed Complex Support Needs Pathways nationally announced three years ago is implemented – linked [here](#),
- a diverse and sustainable market is created and maintained, and that in regional and rural areas participants have more choice and access to NDIS registered providers, noting that the registration process is often overly long.

KEY COMMITMENT 3:

FAST-TRACK ACCESS TO EFFECTIVE NOVEL THERAPIES FOR MND

What is the Problem?

About 1 in 300 people will develop MND over their lifetime, with their risk of developing the disease steadily increasing as they get older⁸. There is no known cause for MND (except in a very small number of genetic cases), no effective treatments and no cures. With an average life expectancy following diagnosis of just 2.5 years, there is an urgent need for access to clinical trials and fast track approval processes for therapies when proven to safe and effective⁹.

What are the Solutions?

MND Australia calls on the Commonwealth Government, other parties and independents to commit to:

3.1 Fast tracking access to effective therapies, and in doing so implementing the

⁸ 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

⁹ MND Australia Position Statement, 2017, [Development and approval of drugs to treat motor neurone disease](#)

Recommendations of the House of Representatives Standing Committee on Health, Aged Care and Sport Report *The New Frontier - Delivering better health for all Australians*, November 2021.

The solutions in more detail:

Key recommendations of the House of Representatives Standing Committee on Health, Aged Care and Sport Report *The New Frontier - Delivering better health for all Australians*, November 2021, that must be implemented and prioritised:

- **Recommendation 9** – the Australian Government establish a fund to support patients, clinicians and non-profit organisations to sponsor registration and reimbursement applications where there is no realistic prospect of a company serving as sponsor
- **Recommendation 16** – investigate further opportunities for the formation of an international Health Technology Assessment consortium similar to the Access Consortium to streamline the regulatory process for certain medicines and medical technologies
 - the Therapeutic Goods Administration work with the United States Food and Drug Administration and other overseas regulators to establish an equivalent of Project Orbis for non-cancer rare diseases, or to expand Project Orbis to include such diseases
- **Recommendation 23** – all levels of government jointly provide funding for the development of a national clinical trial register
- **Recommendation 24** – the Australian Government develop policies that encourage modernising digital technologies and practices to position Australia as the premier destination for international clinical trials.

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.

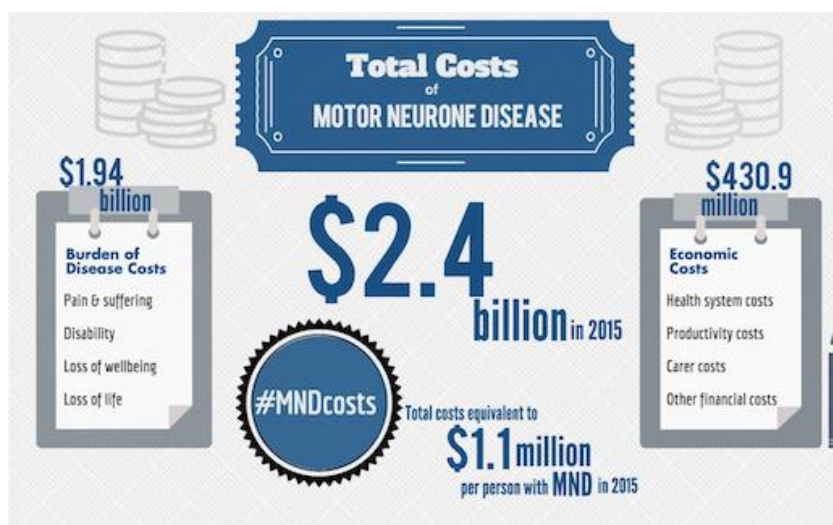
ABOUT MND

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

MND affects each person differently with respect to initial symptoms, rate and pattern of progression, and survival time. **Average life expectancy is 2.5 years from diagnosis.** There is no known cause for MND, except in 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 progressing needs.

With an estimated 2,000 people living with MND in Australia at any given time, and a prevalence rate of 1 in 11,434, MND is classified as a rare disease. Approximately 50 % of people diagnosed with MND are aged 65 or older.

Timely early diagnosis and access to expert multidisciplinary care, palliative care, assistive technology, specialist planning, assessment and support coordination and person-centred home based care play vital roles in maintaining quality of life and independence. A Deloitte Access Economics Report ¹⁰ commissioned by MND Australia, found that the total cost of MND in Australia was \$2.37 billion in 2015, comprising \$430.9 million in economic costs and \$1.94 billion in burden of disease costs.



¹⁰ Deloitte Access Economics 2015, *Economic analysis of motor neurone disease in Australia*, report for Motor Neurone Disease Australia, Deloitte Access Economics, Canberra, November