2023–24 PRE-BUDGET SUBMISSION

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.

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.

Together we are committed to ensuring 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
- 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 neurons – the nerve cells that control the movement of voluntary muscles – progressively weaken and die. With no nerves to activate them, people with MND lose their ability to walk, to speak, to swallow and to breathe.

MND affects each person differently with respect to initial symptoms, rate and pattern of progression and survival time. Average life expectancy is just 27 months from diagnosis, with a third of people dying within one year and more than half within two years of diagnosis.

There are no known causes for MND, apart from the 10 per cent of cases which have a genetic basis. There are no effective treatments and there is no cure. 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 changing supports based on the person’s complex needs.

Our Recommendations

MND Australia seeks a Budget commitment from the Federal Government to support access and funding for the following recommendations that will improve the lives of all Australians impacted by motor neurone disease (MND).

1. Improve access and funding for needs-based person-centred in-home supports for Australians with MND who are ineligible for the NDIS.
2. Fund state MND Associations to deliver assistive technology for Australians with MND.
3. Ensure that the NDIS is sustainably funded for the future for all Australians and especially those living with MND.

Just over half of the estimated 2,100 Australians living with MND at any one time are diagnosed when aged 65 or older and unable to access supports to meet their individual needs through the National Disability Insurance Scheme (NDIS).

They 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.

1

Improve access and funding for needs-based person-centred in-home supports for Australians with MND who are ineligible for the NDIS.

For the 50-60 per cent of people who are diagnosed with MND when aged 65 or older, the current home based aged care system does not adequately address their complex and changing disability support needs. Consequently, the health and wellbeing of family and carers is negatively impacted and unnecessary or untimely admission to residential aged care often occurs.

With a third of people dying within one year and more than half within two years of diagnosis, people with MND do not have time to wait for services and supports.

Currently the maximum funding available through a Home Care Level 4 Package is $53,268[1] per annum. In contrast, a report published by the NDIS, *Participants with a neuro-degenerative condition in the NDIS*[2] (31 March 2021) reported the average annualised committed supports for the 2020-2021 financial year was $242,000 for participants with MND.

It is a fundamental human right[3,4] 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[5].

This is even more critical for people with a life limiting, rapidly progressing, degenerative and complex disability like motor neurone disease. A diagnosis of MND is devastating for the person with MND and their family no matter the person's age.

A diagnosis of MND results in progressive disability, loss of function and the consequent need to constantly adjust and plan ahead whilst facing an unknown life expectancy. Timely access to packages of care that meet assessed needs is integral to maintaining dignity and independence and supporting a person to remain at home with their family.

Senior Australians with MND have the right to access adequate services and supports through the aged care system to ensure they can choose to remain at home with their family.

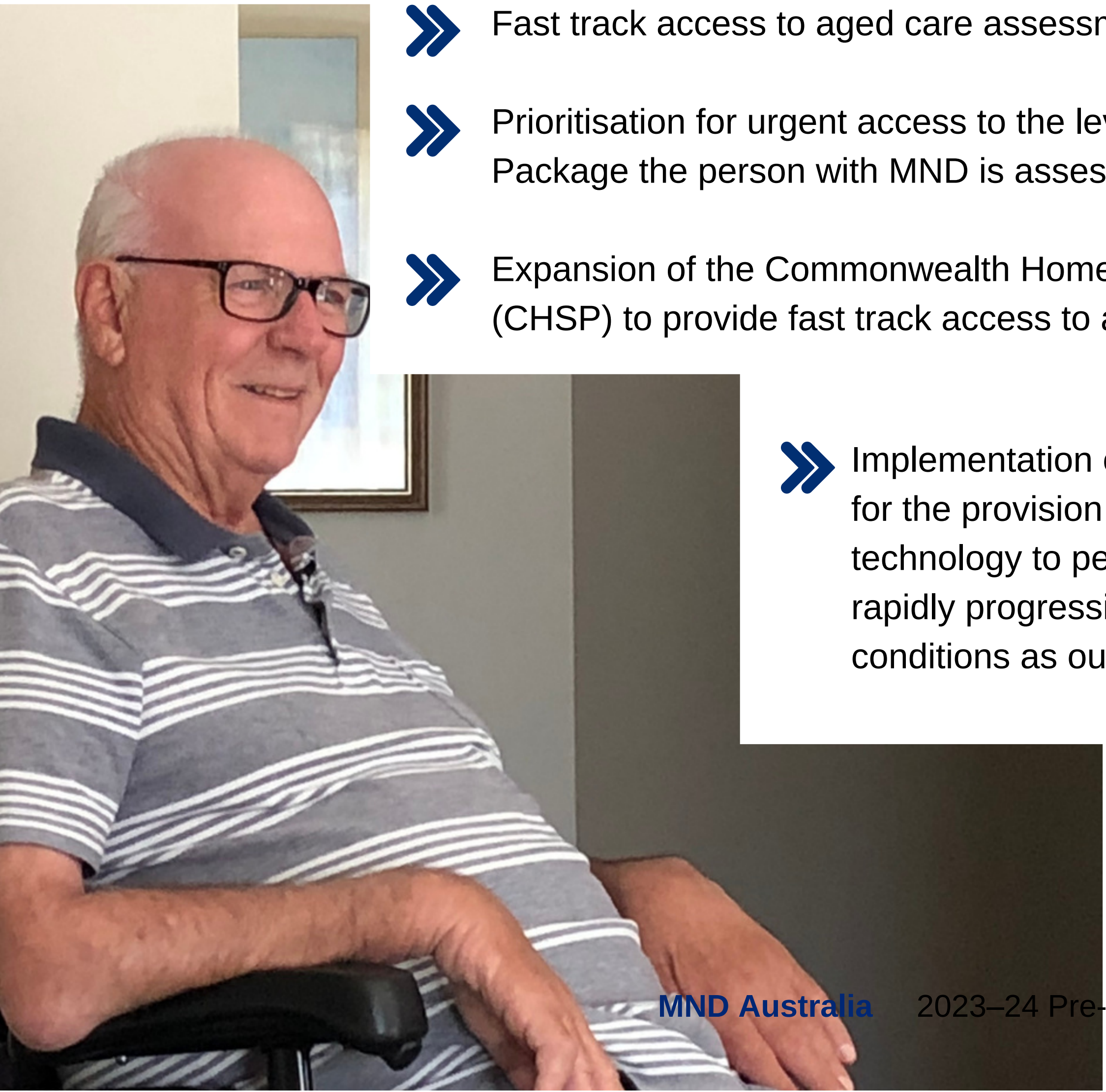
The National Strategic Action Plan for Rare Diseases [6] outlines action and policy for conditions such as MND to ensure equity of access. The Action Plan is predicated on an integrated, person-centred approach which is responsive to changing needs.

[1] My Aged Care
[2] National Disability Insurance Scheme, Participants with a neurodegenerative condition in the NDIS, 31 March 2021
[3] Convention on the Rights of Persons with Disabilities, United Nations, articles 25 and 26
[4] International Alliance of ALS/MND Associations Fundamental Rights of People Living with ALS/MND, April 2021
[5] UNCRPD 2008
[6] National Strategic Action Plan for Rare Diseases, February 2020

It is time to end discrimination in accessing supports based on age. Equity of access means ensuring timely, funded and accessible Aged Care services that are needs based and person-centred.

MND Australia calls on the Australian Government to urgently fund and implement interim measures to ensure access to in-home needs based supports for people with rapidly progressing, life limiting conditions such as MND.

These interim measures should include:



- Fast track access to aged care assessment
- Prioritisation for urgent access to the level of Home Care Package the person with MND is assessed as needing
- Expansion of the Commonwealth Home Support Program (CHSP) to provide fast track access to additional supports
- Implementation of the funding model for the provision of assistive technology to people with MND and rapidly progressing neurological conditions as outlined below

2

Fund state MND Associations to deliver assistive technology for 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, is vital.

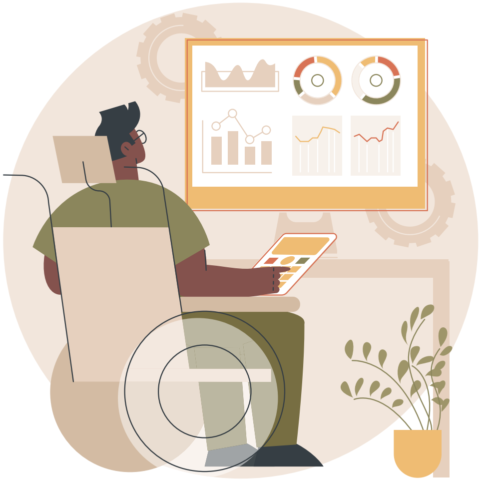
Unfortunately, funding for and access to assistive technology is not equitable and is discriminatory for people aged 65 and over not eligible for the NDIS. Older Australians have to trade off the funding for their care needs to fund assistive technology.

MND Australia seeks funding to support our state MND Associations to provide vital equipment to older Australians with MND. With funding provided in this Federal Budget the state MND Associations would be able to roll out a cost effective and proven solution for AT provision to people living with MND and other rapidly progressive neurological conditions from June 2023.

The Assistive Technology for All (ATFA) Alliance[7] 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. A national assistive technology program must be fully funded and needs based.

Federal Government funding to support MND Associations deliver assistive technology would ensure that older people living with MND are able to access vital equipment as soon as a need arises, as recommended by the Royal Commission into Aged Care Quality and Standards, from June 2023. This not-for-profit based model of AT provision would also act as a pilot project to inform the design and development of a national program with respect to older Australians living with rapidly progressing neurological conditions.

It is estimated that at any given time across Australia, approximately 450 people with MND aged 65 and older are in need of assistive technology comparable to the NDIS.



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

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
TOTAL		**$10,500,000**

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	500 people	$11,250,000
TOTAL		**$35,000,000**

3

Ensure the NDIS is sustainably funded for the future

The NDIS is essential to ensuring disability supports for all people with disability. It's a world first scheme and must be maintained and funded sustainably into the future.

The NDIS was established as a form of social insurance to ensure that people with lifelong impairments, often degenerative such as MND, would have secure access to supports and services.

MND Australia, together with our member State MND Associations, have engaged proactively and successfully with the National Disability Insurance Agency (NDIA) since the introduction of the NDIS to support a rapid response and effective planning processes and plan implementation for people living with MND that takes their progressing and complex needs into account.

The Productivity Commission in its original report (2011)[8] outlined a set of strategies to guarantee sustainable funding for the NDIS. **The original proposal was to create a specific fund, the National Disability Insurance Premium Fund**. It was also proposed that the federal government be the single funder of this entity.

The commission proposed this strategy as it had identified that funding for disability had long been contentious, fragmented, and ineffectual. However, this straightforward funding guarantee did not occur. Instead, the NDIS is part-funded federally, and **part funded by the states and territories.**

The nation's Medicare levy raised federally goes into the **Disability Care Fund** and any additional top-up funding comes out of general revenue and is reserved in the **NDIS Savings Fund Special Account.**

This disjointed funding has, as the Productivity Commission clearly pointed out, resulted in insecure long-term forecasting for the NDIS. This divided strategy, which is also not entirely transparent in nature, has led to much confusion about the long-term sustainability of the NDIS and has been the cause of much anxiety for people with disability including people with motor neurone disease.

It is imperative that the NDIS continues to be fully funded and further strengthened. MND Australia applauds the Government for commencing its independent review into the NDIS. Given the earliest the final report recommendations could be funded will be in the 2024-25 Federal Budget, MND Australia calls on the Federal Government in this Budget, to protect and enhance the NDIS and to revisit the Productivity Commissions original funding proposal to ensure that we have a strong, secure NDIS now and into the future.

[8] https://www.pc.gov.au/inquiries/completed/disability-support/report

4

Commit to funding MND Australia as a National Peak Advocacy Body

MND Australia is the representative organisation and national voice of people with MND. We provide advocacy, information, connection and research on all matters related to MND. MND Australia is committed to ensuring that people with MND have a say in all matters that affect their lives.

In its 2019 Concluding Observations, the UN CRPD committee highlighted the need for the Australian Federal Government to provide all people with disability to sustained access to independent advocacy.

Ensure that persons with disabilities are able to access continuous, sustainable and adequately resourced individual and independent advocacy programmes, particularly those not part of the National Disability Insurance Scheme.[9]

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[9] CRPD /C/AUS/CO/2-3 2019

MND Australia provides independent systemic advocacy for people with MND. This includes but is not limited to providing information and navigating tools for the NDIS, and for those not able to access the NDIS access to assistive technologies as well as access to timely and appropriate healthcare.

It is imperative that people with MND have access to MND specific advocacy, as is their right. We therefore request that the Federal government commit to providing MND Australia with annual advocacy funding to ensure MND Australia can provide optimum advocacy for people with MND.

Funding MND Australia to provide specific advocacy not only ensures that people with MND will be supported by people who are fully informed of their needs, it will ease the pressure on generalist disability advocacy services who are already stretched to capacity. In short, funding MND Australia annually as a national peak advocacy organisation is good value for the Australian public's money.

MND Australia

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