mnd Australia

2024–25 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 15–20% 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 Australian Government to support access and funding for the following recommendations that will considerably 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 and is comparable in funding to the NDIS.

2. Increase research funding for genetic sequencing around MND and improve access to genetic testing and counselling for people with MND and their families.

3. Fund a Neurological Mission within the Medical Research Future Fund.

1

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

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.

The NDIS Independent Review final report (Dec 2023) addressed the very stark issue of lack of equitable supports and services for persons with disability over the age of 65 who are ineligible for NDIS packages. MND Australia supports the recommendation by the Independent Review to create a safety net to capture this cohort.

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

Currently, the maximum funding available through a Home Care Level 4 Package is $59,593.551 per annum[1]. In contrast, in a report published by the NDIS, *Participants with a neuro-degenerative condition in the NDIS* (31 March 2021)[2] 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 MND.

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.

[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

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.

MND Australia calls on the Australian Government to prioritise funding for these bridging services, to ensure access to in-home needs based supports for people with rapidly progressing, life limiting conditions such as MND are available sooner rather than later.

Further, MND Australia calls upon the Australian Government to fund organisations like MND Australia to be directly consulted and involved in co-design of the new iteration of the NDIS, including the development of the bridging supports and services for older people with disability.

Niche cohorts such as people living with MND have very particular needs when it comes to disability supports and services. It is imperative that the Australian Government understand these needs directly from people living with the degenerative and disabling condition that is MND. Given MND is widely recognised as being extremely complex, co-designed solutions developed and implemented for the MND cohort could be translatable for many less complex diseases and conditions.

MND Australia calls upon the Australian Government to wholly commit to ensuring funding for equity of access for people with MND who are ineligible for the NDIS, and that funding is committed for appropriate patient centered supports and services.

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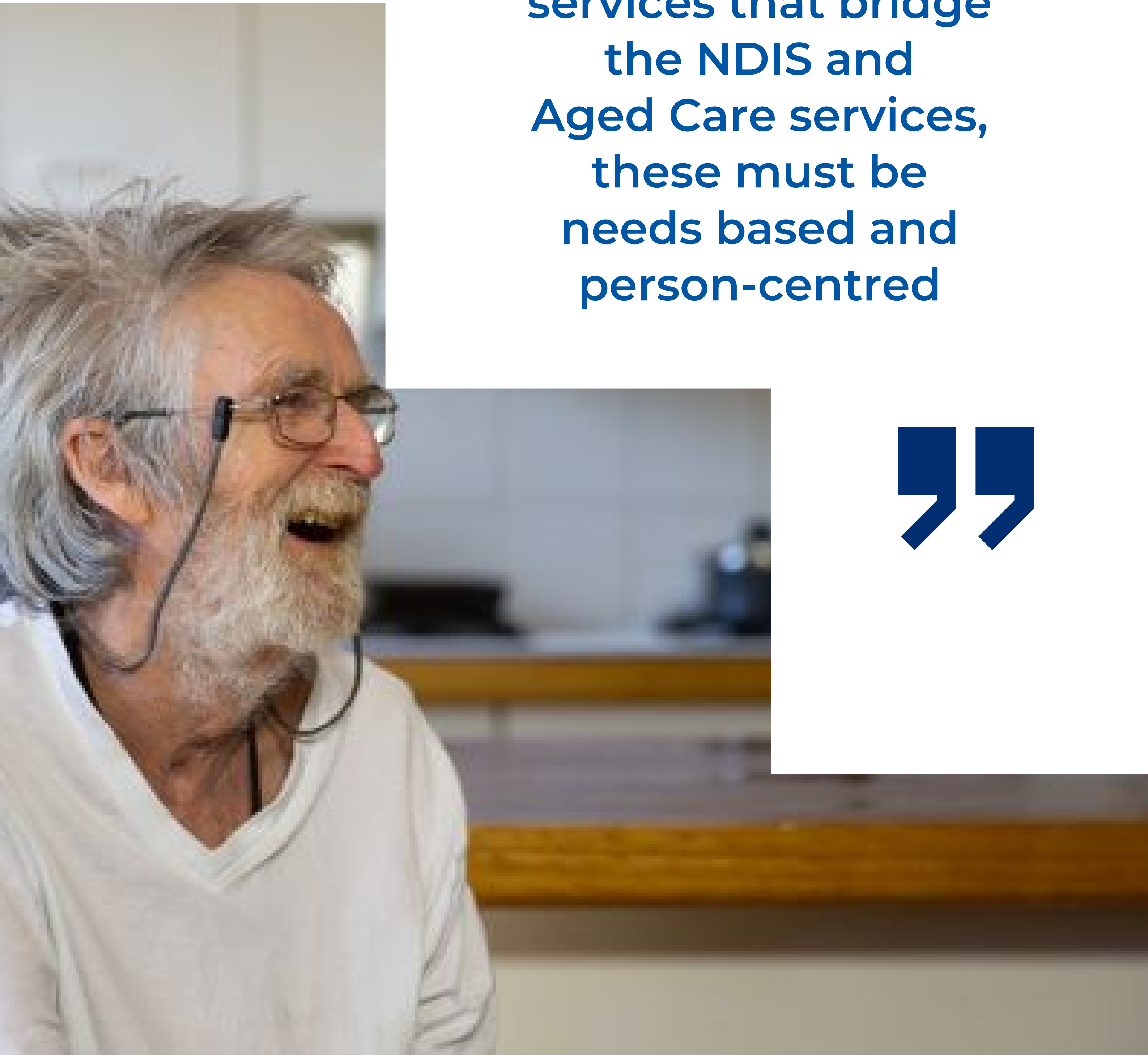
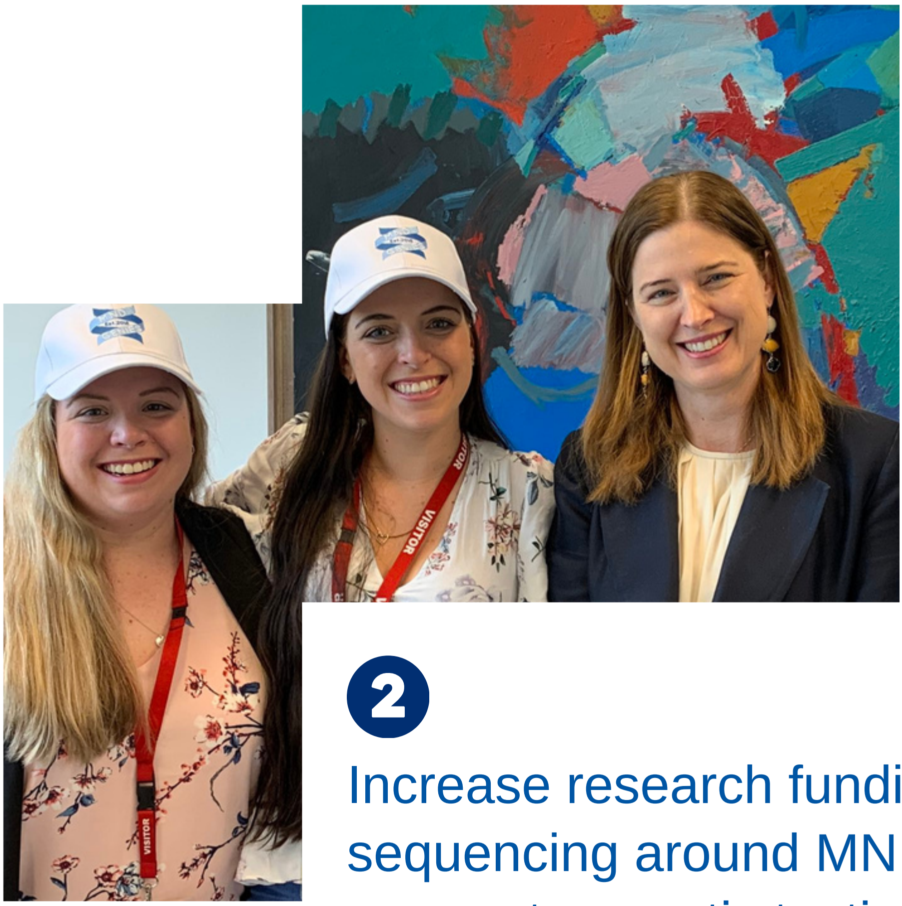
[6] National Strategic Action Plan for Rare Diseases, February 2020

> “Equity of access means ensuring timely, funded and accessible disability supports and services that bridge the NDIS and Aged Care services, these must be needs based and person-centred”





2

Increase research funding for genetic sequencing around MND and improve access to genetic testing and counselling for people with MND and their families

People with MND have told us that they need better and more timely access to genetic testing, including genetic sequencing for MND. In a recent survey[7] of people living with MND, 50% of respondents confirmed they felt there was a real need for better access to genetic screening.

Currently, approximately 15–20 of MND is ‘familial’, which means there is, or has been, more than one MND affected person in a family. Learning about the genetics of MND, genetic testing, gene mutations, clinical trials and other MND research can help to better inform people affected by familial MND.

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[7] Internal MND Australia survey of people with MND in the Lived Experience Steering Committee.

Understanding of the genetic mutations related to MND has increased over time, and is accelerating due to advances in technology and collaboration between researchers[8].

People who inherit an MND-related genetic mutation have a high, but as yet uncertain, chance of developing MND during their lifetime. However, not all people with an MND-related genetic mutation will develop MND. Other triggers may be needed for the disease to actually begin.

The age at which symptoms of MND appear in people with an MND-related genetic mutation varies greatly. It can be as early as the 20s and as late as the 80s. However, the average age of onset of familial MND is around 45 years. There is a very real and present need for access to genetic screening to be better funded and more accessible for people with the possibility of having familial MND.

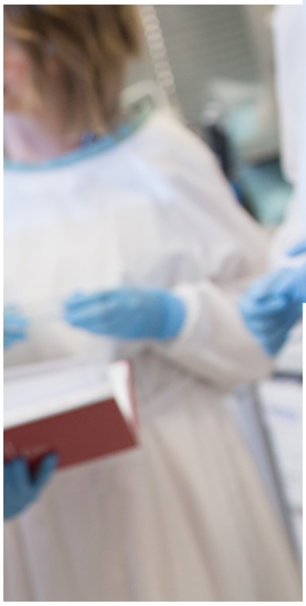
International costs for genetic screening are relatively low all things considered. In the United States patients screened for research purposes using a predetermined gene panel can cost as little as US$500. Screening the whole genome i.e. all 20,000+ genes can range from US$800-$1600 but also requires further analysis [9,10,11].

Similar costings in Australia would not stretch the health budget and would improve our understanding of the genetic types of MND, leading to better research on treatments and a possible cure.

MND Australia is concerned that there is currently a workforce shortage of genetic counsellors. This is unacceptable. Under no circumstances should any person undertake genetic screening without pre and post counselling. The shortage of, and access to, genetic counsellors needs to be urgently remedied.

MND Australia calls upon the Australian Government to commit to funding for research into genetic screening and to commit to immediately funding access to genetic screening and counselling for people with or possible genes for MND.

[8] https://www.mndaustralia.org.au/mnd-connect/information-resources/familial-mnd-and-genetic-testing
[9] https://www.vcgs.org.au/tests/frontotemporal-dementia-c9orf72/
[10] https://www.vcgs.org.au/tests/exome-sequencing/
[11] https://www.vcgs.org.au/tests/whole-genome-sequencing/



3

Fund a Neurological Mission within the Medical Research Future Fund

In 2020, the then Australian Government gave a firm commitment to funding research into neurological conditions[12]. However, MND Australia believes that there is a need to fund a specific “Neurological Mission” within the Medical Research Future Fund. A neurological mission will provide dedicated and targeted advice on research into neurological conditions, including MND.

Internationally, research into MND is uncovering evidence of potentially greater prevalence of the condition. As yet in Australia our evidence base is limited regarding prevalence. We need better data to undertake research into all the various types of MND currently impacting Australians.

MND Australia calls upon the Australian Government to commit to funding a dedicated Neurological Mission within the Medical Research Fund to provide Australians with MND and their carers and families assurance that Australia is committed to finding better treatments and a potential cure for this cruel degenerative and disabling disease.

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[12] https://www.health.gov.au/topics/chronic-conditions/what-were-doing-about-chronic-conditions/what-were-doing-about-neurological-conditions

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