



**Advancing care, advocacy and research in support of those living  
with motor neurone disease (MND)**

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## **Submission to the Joint Standing Committee on the NDIS Inquiry into the Capability and Culture of the NDIA**

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## Executive Summary

MND Australia is pleased to provide a submission on behalf of its members – the State MND Associations – to the Joint Standing Committee on the NDIS inquiry into the Capability and Culture of the NDIA.

In summary, MND Australia recommends that:

- 1. That the National Disability Insurance Agency commits to improve and increase knowledge of motor neurone disease across the organisation and service provision.**
- 2. That the NDIA commits to improving how it communicates with participants with MND, their carers, and representative organisations by adopting clearer and more timely communications about decision-making processes, timelines and expectations.**
- 3. That the NDIA commits to establishing a Neurological/Neuromuscular voice within the agency which includes MND.**

## 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 1983, 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

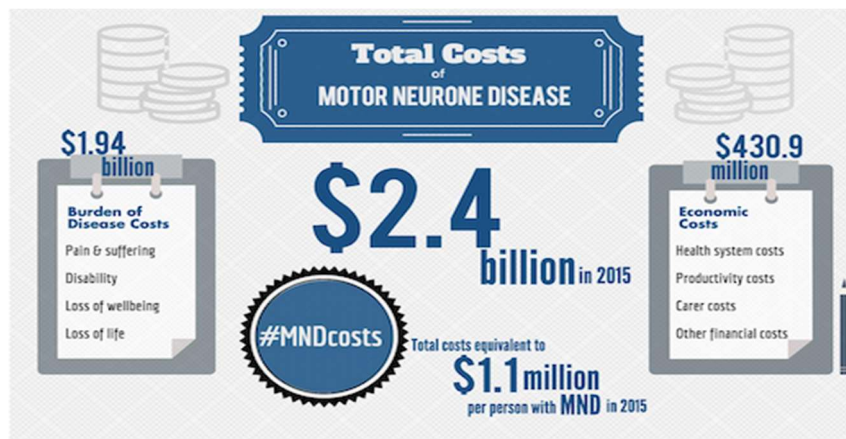
Motor neurone disease (MND) is the name given to a group of neurological diseases in which motor neurons – the nerve cells that control the movement of voluntary muscles – progressively weaken and die. With no nerves to activate them, people with MND lose their ability to walk, to speak, to swallow and 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 more than half dying 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.

The MND Australia Deloitte Access Economics Report<sup>1</sup> found that in Australia the per-person cost of MND in 2015 was \$1.1 million (\$1.22m in 2022 dollars based on RBA calculation for inflation increase 2015 to year ending 2021), 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 (\$2.63b in 2022 dollars), comprising \$430.9 million (\$477.9m) in economic costs and \$1.94 billion (\$2.11b) 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 are vital for people living with MND and that improve the quality of life of people living with MND and reduce the cost of this condition on the community. These include:

- timely and expert diagnosis
- early and evidence-based interventions from specialist MND multidisciplinary teams, local services and MND Associations
- access to person centred, needs based in-home care, assistive technology and specialist palliative care which play vital roles in maintaining quality of life, social engagement and independence
- specialist planning and assessment and coordination of care, including responding to and forecasting needs, before they become urgent.

These supports and interventions are crucial in helping people to plan ahead to prevent crisis and avoidable hospital and residential aged care admissions. They are also crucial in strengthening the informal supports available to the person, including supporting the primary carer to maintain their own health and wellbeing and their caring role.

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

Around half of the estimated 2,100 Australians living with MND at any one time are diagnosed under the age of 65 and therefore may be able to access supports to meet their individual needs through the National Disability Insurance Scheme.

MND is degenerative and incurable. This results in significant disability and the need for expert information, specialised care and personal assistance; timely and appropriate access to the NDIS is absolutely crucial for people living with these incurable and disabling conditions.

We therefore note that, the very first object of the *National Disability Insurance Scheme Act 2013 (NDIS Act 2013)* is to ‘give effect to Australia’s obligations under the Convention on the Rights of Persons with Disabilities’ CRPD). Other stated aims and purposes of the *NDIS Act 2013* also convey the values and objectives of the CRPD, that is, promoting dignity and respect for people with disability.<sup>2</sup>

One primary objective of the *NDIS Act 2013* is to ‘protect and prevent people with disability from experiencing harm arising from poor quality or unsafe supports or services provided under the National Disability Insurance Scheme’.<sup>3</sup>

The *NDIS Act 2013* therefore requires that the operation of the NDIS, including how people are assessed for eligibility, should protect, and prevent against harm and conform with Australia’s obligations under the CRPD. How a person is deemed eligible for the NDIS, therefore, is a crucial human rights issue and this is especially the case for people with incurable progressively degenerative conditions who to date have often been denied access or have had plans that are not fit for purpose due to the progressive and degenerative nature of their conditions.

Eligibility assessments can serve as a portal for persons with disabilities to access the resources needed to exercise the full range of their human rights, including rights associated with living independently and being included in the community, personal mobility, access to health, ‘habilitation and rehabilitation’, and participation in public life.<sup>4</sup> These are all crucial points for people living with neurological and neuromuscular progressive and degenerative conditions, so that they may live better longer with dignity, choice and control.

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<sup>2</sup> Gooding and Kayess, *University of Melbourne 2022*

<sup>3</sup> *NDIS Act 2013* (Cth) s 3(1)(a) (‘*NDIS Act*’).

<sup>4</sup> Gooding and Kayess, 2022

MND Australia proposes the following recommendations for the NDIA for it to better serve the needs of people with MND:

### **Improve the NDIA's Knowledge of MND and other Neurological Conditions**

In 2017 the NDIA together with MND Australia and the State MND Associations co-designed a Practice Guide which provided guidance to planning considerations for participants who enter the scheme with a diagnosis of MND. The Guide was updated in 2019. The guide is a valuable resource for NDIA staff and is a guide to the particular functional impacts of MND and, given the degenerative nature of MND. It should assist the planning required for participants with MND to take into account the current and expected needs of the participant during the life of the plan. The guide stated it is preferable that the NDIS plan contains sufficient supports to reduce the need to request plan reviews as the condition progresses and people experience greater functional loss.

Despite this Practice Guide, we note there is an increasing lack of understanding by NDIS staff of the disease and its functional impact. It appears that the Practice Guide is not being well-utilised by the Agency nor are their consistent interactions with people with MND particularly when the condition rapidly deteriorates.

We consider the Practice Guide a critical resource which must be adhered to by all NDIS staff in the management of people living with MND. In this regard, the Practice Guide should be updated, and an education and training program be undertaken with the NDIA. This will help to build greater awareness, education and understanding of MND (and also other neurological and neuromuscular conditions) within the NDIA and will ensure better support for people living with these conditions.

MND is progressive, degenerative and without a cure and people with MND have complex and unpredictable yet increasing care needs. All NDIA staff (Planners and Local Area Coordinators) and contractors need to better understand the nature of MND to reduce any inconsistent decision-making, denial of access to the NDIS or inequities in plans.

An example is an initial planning meeting for Mr N in October 2022, where with an MND NSW representative present, witnessed a planner demonstrated a lack of understanding of the complexity and progression of MND through they

- gave recommendations for specific pieces of equipment and assistive technology that would not meet Mr N's and his families ongoing needs
- stated that all initial NDIS plans are generic, and that supports is the role of the support coordinator to request a review for individual supports
- stated that ongoing mental health support would not be funded because counselling following their diagnosis had been received and there was no need for further funded supports.

### **Case study – Planners not following the Guidelines on MND**

State MND Associations keep track of NDIS Planners that understand the Practice Guide and make use of it and those that don't despite being made aware of it.

We note that some planners who do not follow the practice guidelines are more likely to set out unrealistic plans. The following are recent examples:

- No Assistive Technology funding at all included in a plan
- 12-month plans with \$3,879.80 in Core Daily Activities that must be used by the participant within three months.

Both examples ended in Reviews (not light touch) being requested early on in the plan. These are examples of how the planner did not follow or had no knowledge of the Guidelines on MND. This glaring lack of knowledge and awareness resulted in an unacceptable level of distress to the participant and onerous amounts of administrative tasks for the participant.

Those planners who do utilise the Guidelines are more likely to include the following in plans:

- Appropriate Core funding to last the length of the plan, including to take over from the informal care support which may not be sustainable.
- Appropriate levels of Core daily activities are included.
- Assistive Technology funding is included.

Planners who follow the Guidelines develop plans that best reflect the needs and supports that a person with MND may require across the duration of their plan, noting that MND is a progressively degenerative condition.

### **Recommendations**

- The National Disability Insurance Agency commits to improving the knowledge and understanding by NDIA staff and contractors of MND and the changing needs of people living with MND
- That the Practice Guide be reviewed and updated together with MND Australia and its members, and for it to be applied consistently across the NDIA and its contractors to better serve the needs of participants with MND and to minimise reassessments

### **Improve How the Agency Communicates**

Participants often feel that the supporting documentation they've obtained from neurologists and allied health professionals – often at great expense, time and effort, is neither understood nor considered by NDIA decision-makers.

This material is essential to the care and well-being of the participant, as early interventions by healthcare professionals as soon as possible after diagnosis can sometimes slow the progression of disability and thus potentially the number of services required. Put simply, people with MND need the right supports at the right time.

### Case Study – NDIS Access Declined with MND diagnosis despite credible documentation.

On 8 March 2022, an NDIS access request with documentation was submitted to the NDIS Enquiries email address for a client with MND.

Included within this documentation was a neurologist letter from a leading Brisbane neurologist specialising in MND confirming the diagnosis. This letter also referred to the Chronic Disease Clinic and MND gene panel.

Supporting documentation from the client's GP was also included stating the significant functional decline from his MND diagnosis; the need for an Occupational Therapist and Physiotherapist - bilateral leg braces to assist with mobility as well as home access and bathroom modifications due to his mobility deterioration were also stated.

The NDIS Access decision was received on the 12 April, declining access stating:

- *“Based on the available information, you do not meet the disability requirements as set out in Section 24 of the NDIS Act, specifically:*
  - o *Substantially reduced functional capacity, Section 24(1)(c)*
- *Based on the available information, you do not meet the early intervention requirements as set out in Section 25 of the NDIS Act, specifically:*
  - o *Reduces future support needs, Section 25(1)(b)”.*

A Review of the (Reviewable) decision was lodged with the Enquiries line and a request for assistance from a NDIS Director from the Robina, Logan, Toowoomba area suggested even more supporting functional decline documentation, which was sourced from the MND Clinic even though this was all noted in the previous GP documentation. A week later the client was advised that Access had been approved.

In summary, the client's Access to Plan took just over three months compared to the majority of MND Queensland clients that have had Access, Planning meetings and Plans approved within four to five weeks and with the same level of documentation presented. Given research has shown that early intervention of supports is crucial to an MND client and awareness that MND is a degenerative disease that is unpredictable and has on average a life expectancy of around two and half years post diagnosis, this was a disappointing and stressful situation for the client and their loved ones.

In some cases, over time people are unable to clearly articulate their own condition or their own needs, so the responsibility of explanation falls on family members and carers. There is an inequitable emphasis on self-advocacy; people without a support network and those with cognitive and behavioural challenges do poorly in NDIS assessment processes.<sup>5</sup>

Despite amendments to the *NDIS Participants Guarantee Bill 2021*, s 100(1B) and (1C) of the Act that allows participants to request reasons for decisions made by the NDIA, prior to any

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<sup>55</sup> <https://www.dana.org.au/ndis-works-well-but-only-if-you-can-navigate-the-system/>

internal review application; participants still do not always understand why their access has been denied or their plans cut.

The Tune Review of the NDIS (2021) stated:

*Providing people with disability with an explanation of a decision should be a routine operational process for the NDIA when making access, planning and plan review decisions. However, in the event this does not occur, the Participant Service Guarantee should empower the person with disability to require the NDIA provide this information in a manner that is accessible to them.*<sup>6</sup>

The NDIA needs to adopt clearer and more timely communications to participants about decision-making processes, timelines and expectations. This includes general information provided on the NDIA website and plain language and multilingual communications with individual applicants and participants.

### **Recommendation**

- That the NDIA commits to improving how it communicates with participants with MND, their carers, and representative organisations by adopting clearer and more timely communications about decision-making processes, timelines and expectations.

### **Establish an MND Voice within the NDIA**

The establishment of an MND voice within the advisory and consultative structure of the NDIA would ensure fair representation and better support for our community and help to address many of the issues set out in this submission in a constructive, co-operative way. However, we appreciate that the NDIA might not want to establish a disease-specific structure. Therefore, we suggest that the MND voice be included in a broader neurological/neuromuscular voice.

It is noted that in 2020 the NDIA commenced the establishment of a Neurological Community of Practice (led out of Geelong) with the goal of establishing principles to guide planners as they work with participants with these conditions. We understand this initiative was abandoned by the agency with no prior communication or consultation and no indication of any commitments moving forward.

A neurological voice can be achieved by:

- introducing a Neurological Community of Practice with inclusion of MND who can act as a point for education and referral for all NDIA staff and contractors as well as test policies, practices and processes to improve the NDIA's response
- establishing a neurological advisory group (similar to the Autism Advisory Group) to provide a strong voice on behalf of people who participate in the NDIS. The

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<sup>66</sup> [https://www.dss.gov.au/sites/default/files/documents/01\\_2020/ndis-act-review-final-accessibility-and-prepared-publishing1.pdf](https://www.dss.gov.au/sites/default/files/documents/01_2020/ndis-act-review-final-accessibility-and-prepared-publishing1.pdf)



neurological advisory group should include MND experts, service providers and people with lived experience of MND and other neurological conditions to provide advice and recommendations to the NDIA on improving the NDIS for participants living with these conditions.

### **Recommendations**

- the NDIA establish a Neurological Community of Practice with expertise in MND and other neurological disorders and progressive degenerative, neurological and neuromuscular conditions who can act as a point for referral for all NDIA staff and contractors.
- the NDIA establish a Neurological Advisory Group (similar to the Autism Advisory Group) to provide a strong voice on behalf of people who participate in the NDIS.