



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

Submission to the Joint Standing Committee on the NDIS – Annual Review

June 2023

MND Australia

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About MND Australia

MND Australia is the national peak body of state MND Associations 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, their muscles weaken and waste away and 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.

Executive Summary

MND Australia is pleased to provide this submission for the annual review of the NDIS to the Joint Standing Committee on the NDIS on behalf of its members – the State MND Associations. MND Australia is aware of and supportive of the current ongoing review into the NDIS and National Disability Insurance Agency (NDIA). MND Australia supports the commitment of the Federal Government to ensure the NDIS remains sustainable into the future and that it serves the needs of NDIS participants as a matter of principle.

In summary, MND Australia recommends that:

- 1. the National Disability Insurance Agency commits to improve and increase knowledge of motor neurone disease across the organisation and service provision.**
- 2. 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. the NDIA commits to establishing a neurological/neuromuscular voice within the Agency which includes MND.**

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

As noted in our previous submissions despite the development of a codesigned practice guide which was intended to provide guidance to planning considerations for participants who enter the scheme with a diagnosis of MND; there appears to be a continuing 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 has it ensured consistent interactions with people with MND particularly when the condition rapidly deteriorates.

We consider the Practice Guide is 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 on MND and its unique progressive nature be undertaken with the NDIA. This is training and education that MND Australia could facilitate.

In addition, the Practice Guide could be a useful template for the management of other neurological/neuromuscular and other conditions. This will help to build greater awareness, education and understanding of MND and other neurological and neuromuscular conditions within the NDIA. This 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. This is exacerbated by no two people with MND having the same disease journey. All NDIA staff (Planners) and contractors e.g. Local Area Coordinators need to better understand the nature of MND to reduce any inconsistent decision-making, denial of access to the NDIS or inequities in plans. It should also be noted that MND, as degenerative condition that progresses disability is in fact considered an "automatic" entry to apply to access the scheme under the NDIS Practice Guidelines Section C – however, it is clear from our participant's experiences that this specific consideration is not understood by Planners, Lacs or NDIA staff more generally.

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 developed in 2017 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**
- **Consider returning to having planners who are subject matter experts in understanding MND**
- **Increased knowledge of state based services**

Improve How the Agency Communicates

MND Australia's member associations have reported that participants with MND often feel that the requirement to supply costly supporting documentation from neurologists and allied health professionals - is neither understood nor considered by NDIA decision-makers.

Understanding this material is essential to the care and well-being of the participant, as early interventions 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 as early as possible.

In some cases, people are unable over time 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.¹

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 internal review application; participants still do not always understand why their access has been denied or their plans cut. MND Australia's members state that this remains the case despite this legislative change.

It is imperative that the NDIA adopts 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 multilingual 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, however functional impairment is what must be considered. Therefore, we propose 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 with the Neurological Community, and no indication of any commitments moving forward.

The neurological voice – hence the MND 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

¹¹ <https://www.dana.org.au/ndis-works-well-but-only-if-you-can-navigate-the-system/>

- establishing a neurological advisory group to provide a strong voice on behalf of people who participate in the NDIS. The 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 establishes 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 to provide a strong voice on behalf of people who participate in the NDIS.**