



FEDERAL ELECTION STATEMENT

MND Australia seeks three key election commitments during the 2022 federal election campaign 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 disability supports and services for people with MND**
- 2. Ensure the NDIS is not weakened**
- 3. Fast-track access to effective novel therapies for MND**

Motor neurone disease (MND) is a progressive neurodegenerative condition that takes away a person's ability to walk, move, swallow, speak and breathe. Average life expectancy from diagnosis is only 2.5 years.

1. END AGE DISCRIMINATION IN PROVISION OF DISABILITY SUPPORTS AND SERVICES

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 with MND. 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. It is imperative that the recommendations of the Royal Commission into Aged Care Quality and Safety are funded and implemented to improve equity of access to in-home supports to meet the needs of older Australians.

We're calling for an end to age discrimination in disability support and a commitment to:

- 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 (*Royal Commission rec 72*)
- Establishing a central assistive technology (AT) program, with no costs and minimal waiting times for any AT that people with MND need to acquire as their disease progresses, by December 2022 (*Royal Commission rec 34*)

2. ENSURE THE NDIS IS NOT WEAKENED

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 that meet their changing needs. It is imperative that the NDIS continues to be fully funded and further strengthened. We're calling for a commitment that:

- Ensures the NDIS is not weakened as is likely as a consequence of the *National Disability Insurance Scheme Amendment*
- Maintains its person-centred focus including ensuring: it is fit for purpose, participant choice and control continues, access to funded services, and a timely planning process with plans that take into account rapid progression of MND.

3. FAST TRACK ACCESS TO EFFECTIVE NOVEL THERAPIES FOR MND

There are currently no effective treatments for MND. With an average life expectancy 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 be safe and effective. We're therefore calling for a commitment to fast track access to effective novel therapies for MND, and in doing so implement the recommendations of the report: *The New Frontier – Delivering better health for all Australians*, November 2021.

More details on our federal election commitments can be found at mndaustralia.org.au/advocacy