

# 2025 FEDERAL ELECTION PLATFORM

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MND Australia is asking for all parties and candidates to:

- 1** Fund MND Australia to build the National MND Insights Platform. This dataset will link existing data sources and evidence to enable research and develop data driven care services for people living with MND. Costing: \$12 million over four years.
- 2** Maintain the NDIS Priority Eligibility Decision Pathway that fast tracks people with MND to gain access to the NDIS and maintain the dedicated team of planners with MND expertise.
- 3** Establish a fast-tracked pathway to access the Aged Care system, including Support at Home, for people living with MND aged 65 and over to stay in their homes longer.
- 4** Fund Aged Care supports to comparable levels to the NDIS. Costing: \$287 million a year.
- 5** Include genetic counselling under Medicare to enable access and informed decision making regarding genetic testing, thereby protecting future generations.

Over 2,600 Australians are living with motor neurone disease (MND). Every day in Australia, two people are diagnosed with MND and two people die from the 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 muscles, people with MND lose their ability to walk, speak, swallow and ultimately breathe.

MND affects each person differently. Initial symptoms, rate and pattern of progression and survival time can all vary widely.

The lifetime risk of MND is about 1 in 300 people by the age of 85. More than 55% of Australians diagnosed are aged 65 and over.

Average life expectancy for people living with MND is 27 months from diagnosis.

## 1 Fund MND Australia to build the National MND Insights Platform

Enhancing data collection and linking existing data sources and evidence will enable research and improve data driven solutions for people living with MND  
Costing: \$12 million over 4 years

- Leveraging MND data and insights will dramatically improve what we know about MND. Greater data infrastructure and analytical capacity will:
  - improve and accelerate diagnosis
  - enable greater understanding of the potential causes of MND
  - target the development of more effective personalised treatments
  - accelerate cutting-edge research and clinical trials for a cure
- This new national data platform would build on, extend, and leverage the strengths of the existing registries and databases.
- This dataset will support global collaboration and international research efforts.

## 2 Maintain the NDIS Priority Eligibility Decision Pathway

NDIS Priority Eligibility Decision Pathway that fast tracks people with MND to gain access to the NDIS and maintain the dedicated team of planners with MND expertise

- The NDIS Priority Eligibility Decision pathway enables a decision within two to five business days.
- Dedicated NDIA subject matter expert planners trained by MND State Associations are key to ensuring people living with MND gain access to appropriate NDIS funding, services and supports.
- This specialised fast-tracked access ensures people with MND are gaining access to services and supports that are key to someone living with this rapidly changing, progressive disease that creates high levels of life-limiting disabilities.

## 3 Establish a fast-tracked pathway to access the Aged Care system

Establish a fast-tracked pathway to access the Aged Care system, including Support at Home, for people living with MND aged 65 and over to stay in their homes longer

- Guarantee timely access to supports for people living with MND to ensure they receive the high-level and fast changing supports and care they need. Currently, access to the Aged Care system can take 3–15 months.
- This specialised fast-tracked access will ensure people with MND, aged 65 and over are gaining access to services and supports that are key to someone living with this rapidly changing, progressive disease that creates high levels of life-limiting disabilities.

## 4 Fund Aged Care supports to comparable levels to the NDIS

Fund Aged Care supports to comparable levels to the NDIS  
Costing: \$287 million a year

- Fund disability supports at a comparable level to the NDIS to ensure people living with MND aged 65 years and over receive the supports they need for such a complex and progressive disease.
- The Aged Care system was not built for someone with a rapidly progressing condition or disability. Funding needs to be equal to the NDIS to ensure guaranteed supports for people living with MND aged 65 and over.
- The difference between the highest-level in-home care package under the Aged Care Rules 2024 and the average NDIS package for someone living with MND (in 2024) is \$194,000 annually.

## 5 Include genetic counselling under Medicare

Include genetic counselling under Medicare to enable access and informed decision making regarding genetic testing, thereby protecting future generations

- Improving access to genetic testing for people with MND and their families will be significantly enhanced by making genetic counselling available under Medicare.
- Genetic testing is rebatable under Medicare. Making genetic counselling rebatable under Medicare will provide future opportunities for new genetic counsellors.
- This will help overcome the critical wait times for people living with MND, and their families, to gain access to genetic counselling and interpret results from genetic testing.