MND Australia Federal Election

2025 Community Talking Points

About MND and the impact of MND

- Motor Neurone Disease (MND) is the name given 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.
- People with MND lose their ability to walk, speak, swallow and ultimately breathe.
- There is no cure and we do not know what causes this disease.
- Every day in Australia, two people are diagnosed and two people die from the disease.
- Almost 2700 Australians are
- living with motor neurone disease in Australia, and the average time from diagnosis to death is just over two years.
- 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.
- There is only one medical treatment in Australia – Riluzole and it extends life by only a few months.

About MND Australia and State Associations

- MND Australia is the national peak body of state organisations that support those living with and impacted by MND.
- MND State Associations provide information, education, advice and support for people with MND, their families and carers. Each state delivers their own range of services to people living in their locality.

MND Australia seeks five key commitments in the Federal Election

1. **Fund MND Australia to build the MND Insights Platform at a cost of $12 million over four years**
   - The MND Insights Platform is a data-driven solution to identify causes of the disease, improve evidence based care, and accelerate research to find a cure.
   - There are currently a number of limitations in the collection and availability of MND data, which places significant constraints on advancements.
   - This platform will improve diagnosis, identify potential environmental, social and demographic factors contributing to the onset of disease, accelerate research and clinical trials, and optimise care and support services.
   - This dataset will lead to tangible outcomes in terms of research, consumer care, and integrated government services and ultimately better health outcomes for people living with MND and support global collaboration and international research efforts.

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.**

- In 2024 a Priority Eligibility Decision pathway was introduced to the NDIS.
- This pathway enables NDIS eligibility decisions to be assessed within two to five business days.
- The pathway includes a team of dedicated NDIA planners who have been trained by and work closely with State MND Associations.
- These subject matter experts, and this pathway, ensure people living with MND gain access to appropriate NDIS funding, services and supports quickly.
- Maintaining this pathway and team of subject matter experts ensures the large variety of aids and equipment – usually called 'assistive technology' or 'AT' needed are accessed faster. AT includes things like power wheelchairs, hoists, hospital beds, or eye-gaze technology to communicate. Many people also require home modifications such as ramps or major bathroom modifications.

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.**
   - Wait times to access the aged care system vary between 3-15 months.
   - It takes an average of 12 months to receive a diagnosis of MND and the average lifespan is merely 27 months. People require immediate support.
   - A fast-tracked pathway to access services and supports will support people living with MND aged 65 and over in the timeframe they need.

4. **Fund Aged Care supports to comparable levels to the NDIS. Costing of $287 million a year.**
   - 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.
   - The average package for a person living with MND under the NDIS in 2024 is $302,000. As of 1 July 2025, the highest-level package within the draft Aged Care Rules 2024 'Support at Home' program possible is a SAH Level 8 amount of $78,000.
   - Under the Support at Home program an additional up to $15,000 that will be made available for Assistive Technology and up to $15,000 Home Modifications
   - This is a positive step but will still not provide equity of funding for people aged over 65 when compared to a person living with MND accessing the NDIS.
   - This means that the 55% of people diagnosed with MND aged 65 years and over are not getting the complex and ever-changing disability supports they need.

5. **Include genetic counselling under Medicare to enable access and informed decision making regarding genetic testing, thereby protecting future generations.**
   - Access to genetic counselling is a vital part of the screening process for people living with MND.

- 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. Genetic Counselling is not a rebatable item. 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.
- Latest research suggests that up to 15% of MND cases involve an inherited genetic fault (familial MND). For families impacted by familial MND, genetic testing enables opportunities for future family planning to avoid passing on known MND faults.