

6 steps to improve the lives of people living with MND

MND Australia seeks six commitments from candidates from all sides of politics in the lead up to the 2019 Federal Election to address the urgent need to improve the lives of people living with motor neurone disease.

WHAT DO WE NEED?

1. Improvements to aged and disability care
2. Timely access to assistive technology
3. Development of MND Guidelines
4. No cost access to IVF and pre-implantation genetic diagnosis
5. Funding for specialist multidisciplinary MND clinics
6. Increased & sustained investment in research

What is motor neurone disease (MND)?

MND is the name given to a group of neurological diseases in which motor neurones, the nerve cells that control the movement of voluntary muscles, progressively weaken and die. With no nerves to activate them, the muscles of movement, speech, swallowing and breathing gradually weaken and waste, and paralysis ensues.

How many are affected?

Each day two Australians will die with MND and another two people will be diagnosed. It is estimated that 2,000 Australians are living with MND at an annual cost of \$2.37 billion to the Australian economy¹.

For more information on these 2019 Federal Election Commitments and the work of the MND Australia: Carol Birks, CEO, 02 8287 4980, carolb@mndaustralia.org.au, www.mndaustralia.org.au and read [MND Australia Action Framework](#).

To contact the MND Association in your state Freecall – 1800 777 175

To pledge your support for the MND Week Make Aged Care Fair Campaign visit [MND Action](#).

1. IMPROVEMENTS TO AGED AND DISABILITY CARE

Aged Care services are designed to support people who are frail aged and experiencing dementia, not people with progressive, complex and life limiting conditions like MND.

- Introduce a formal 'fast track' process for automatic access to Level 4 Home Care Packages for those with progressing and complex disability.
- If aged care is unable to meet the disability needs of older people the NDIS should develop a safety net model that provides top up funding to address needs not met by aged care.

Many NDIS participants living with MND have plans in place that are having positive, life-changing impacts; many others, however, are being negatively impacted by NDIS implementation problems.

- Fund specialist disability organisations to support NDIS pre-planning.
- Specialist disability organisations to undertake planning with NDIS planners as the final authority for the approval of participant plans.
- Improve training of NDIA staff.

3. DEVELOPMENT OF MND GUIDELINES

Everyone living with MND should have access to the right care in the right place at the right time. Access to evidence based care for people with MND remains problematic.

- Develop national guidelines for the management of people with rapidly progressive neurological conditions
- Support effective interfaces with allied sectors particularly health and palliative care to ensure a coordinated inter and multidisciplinary approach to care.

5. FUNDING FOR SPECIALIST MND MULTIDISCIPLINARY CLINICS

Specialist MND multidisciplinary clinics operate in most capital cities in Australia. The majority of these clinics do not receive specific government funding despite increasing demands on their services. The multidisciplinary clinic coordinator role is vital in supporting the team and ensuring coordinated care and timely provision of treatment for people living with MND.

Compared to those people with MND who attend general clinics, multidisciplinary care can contribute to fewer hospital admissions and shorter inpatient stays.

- Develop and fund multidisciplinary clinics to build capacity and ensure that these clinics can continue to provide coordinated health care, expert management and evidence based treatment for people living with MND

2. TIMELY ACCESS TO A FULL RANGE OF ASSISTIVE TECHNOLOGY

It is unclear where responsibility lies for addressing the assistive technology needs of older people with a chronic disease or disability. Funding and access is inequitable and confusing with many people sacrificing their limited income or falling through the gaps.

- Provide funds for assistive technology separately from Home Care Package funding to ensure that older people who acquire a disability can access the assistive technology they need to maintain their independence, quality of life, communication and community access and to support carer health and well-being.
- Engage with state MND Associations to create cost-effective access to assistive technology for all people living with MND.
- Provide funds to ensure access to non-invasive ventilation in the management of MND to improve quality and length of life.

4. NO COST ACCESS TO IVF AND PRE-IMPLANTATION GENETIC DIAGNOSIS

Whilst there are no therapies available to stop the disease in people living with MND today, we can help stop MND in families with a known genetic mutation.

- Improve access for people with familial MND to genetic testing at no cost to them under the existing arrangements for testing, including counselling
- Improve no cost access for those who choose to undertake in-vitro fertilisation (IVF) and pre implantation genetic diagnosis (PGD).

6. INCREASED INVESTMENT IN RESEARCH

Currently there are no therapies to effectively slow down MND or stop the progression. It is therefore imperative that research advances continue to be funded and access to clinical trials is improved to ensure the ultimate goal of a rationally designed therapy that stops the advance of MND.

Until an effective treatment becomes available access to evidence based health and supportive care to enable people with MND to live as well as possible for as long as possible is vital.

- Maintain a significant investment in medical research to treat, slow progression and ultimately cure MND.
- Invest in health and social care research to improve the quality and length of life for people with MND.