

2026 State Election Priorities

MND Victoria is asking for all parties and candidates to:

- 1** Enable all Victorians living with MND to have equitable access to vital assistive technology, through MND Victoria's Equipment Loan Service
- 2** Improve research and care outcomes by making MND a notifiable disease
- 3** Establish a new regional multidisciplinary neuro-palliative MND clinic in North-East Victoria
- 4** Expand access to specialised genetic counselling for informed decision-making

Motor neurone disease (MND) is a progressive neurological disease that affects a person's motor neurones, which are the nerve cells that control voluntary muscle movement. Damage to and loss of these motor neurones causes progressive muscle weakness and wasting, leading to the gradual loss of the ability to move, speak, swallow, and breathe independently. The disease is ultimately fatal.

There are over 600 Victorians living with MND. Approximately 45% are eligible for the National Disability Insurance Scheme (NDIS), while 55% rely on the aged care system, which remains significantly underfunded to meet their complex needs.

Advances in gene-targeted therapies are increasing the importance of timely genetic testing and specialist genetic counselling. However, there is currently no cure for MND, and treatment focuses predominantly on symptom management and supportive care.

MND is a progressive disease, and no two journeys are the same. Every month, around 25 Victorians are diagnosed with the disease, and 25 die from it.

People living with MND need equitable access to specialist healthcare, support and services that respond to their rapidly changing needs.

**Secure MND
Victoria's
Equipment Loan
Service with
\$935,000 annual
funding**

- People living with MND require a responsive assistive technology service and specialised equipment library to meet their rapidly changing needs.
- 55% of Victorians living with MND rely on the aged care system, where delays and funding gaps restrict access to essential equipment.
- MND Victoria's existing in-house service addresses this gap by purchasing, maintaining, delivering, and retrieving equipment, but faces a funding shortfall of \$935,000.
- Victorian government funding will secure this vital service for people living with MND across Victoria.

**Make MND a
notifiable
disease in
Victoria**

- Making MND a notifiable disease and establishing a state-wide registry will address critical data gaps, enabling researchers to investigate potential contributors, risk factors and patterns of MND.
- Better data will accelerate research, support the development of new therapies and bring us closer to understanding and ultimately curing MND.

**Establish a new
multi-disciplinary
regional clinic in
North-East
Victoria**

- In MND, every month matters. Access to specialist multidisciplinary care is associated with improved outcomes and longer survival compared with non-specialist care.
- MND clinics provide best-practice care, yet Victoria's existing MND clinics are concentrated in Melbourne and Barwon, leaving many regional Victorians with limited access to specialist MND services.
- Establishing a regional MND clinic in North-East Victoria would reduce travel barriers and improve equitable access to specialist multidisciplinary care closer to home.
- Investing in regional MND care will support earlier intervention, better coordination of care and improved quality of life, while reducing pressure on acute health services.

**Invest in
specialist
genetic
counselling with
\$250,000 annual
funding**

- Around 20% of people living with MND carry a gene variant linked to the disease, including many with no known family history. Specialist genetic counselling enables people to make informed decisions about genetic testing, understand the implications of results and consider future care options—including accessing treatment and research opportunities.
- While Medicare-funded genomic testing is available for MND, access to specialist genetic counselling remains limited.
- Targeted community fundraising has temporarily enabled MND Victoria to pilot a specialist genetic counselling service. Victorian Government investment of \$250,000 annually would secure ongoing statewide access to this essential service.