

# 6

## POINT PLAN TO SUPPORT PEOPLE LIVING WITH MND

Our Six-Point Plan outlines six initiatives the Australian Government can implement to immediately make a difference to the lives of people living with MND, their families and their carers.



Over 2,300 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. With an average life expectancy of only 2 to 3 years from diagnosis, people with MND do not have time to wait for policy change.

### 1. AGED CARE



#### Fund disability supports for older people at a comparable level to the NDIS

The current difference between the highest level in-home care package and an average NDIS package for someone living with MND is over \$220,000 annually.

For the 55 per cent of people who are diagnosed with MND at 65 or older, the Aged Care system does not go anywhere near to addressing their complex and changing disability support needs.

MND Australia recommends the Government urgently:

- introduce a formal 'fast track' process for automatic access to high level in-home care packages for those with progressing and complex disability
- reduce the waiting time for in-home care packages to less than 30 days
- introduce supplementary funding for assistive technology and home modifications that meets the needs of people with MND
- fund in-home care packages for people with MND at a minimum of \$302,000

**\$200m per year**

### 2. DISABILITY



#### Improve access to the NDIS for people with MND

MND Australia recommends the Government:

- fund specialist disability organisations to undertake planning with NDIS planners as the final authority for the approval of participant plans

**\$500k per year**

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## 3. NATIONAL DATA ASSET



### Fund an MND patient registry

MND Australia, as the peak body for MND, has identified a critical need to build and manage a national data asset for MND patients in Australia. Such a resource would enable identification of potential environmental factors, optimally direct clinical and support resources and aid in recruiting patients into clinical trials. This would build on and extend the MiNDAUS Clinical Registry and the SALSA bioregistry. Further, such data will help develop targeted policy outcomes to assist people with MND to live the best lives possible for as long as possible.

A national data asset would lead to tangible outcomes in terms of research, consumer care, integrated government services and better health outcomes for people with MND. Knowledge and understanding of the disease is key to developing better care and new treatments, and the limited data we have constrains this.

Including MND as a notifiable disease would ensure the capture of all MND diagnoses and would support the development of a comprehensive data asset and a robust registry.

**\$8m over five years**

## 5. ACCESS TO MEDICINES



### Expedite access to novel treatments and clinical trials

Currently only one medicinal treatment is available to MND patients in Australia. Other treatments have recently been approved in the US and Europe and over 100 clinical trials are currently underway around the world for new MND treatments. However, none of these new treatments are available in Australia and only a fraction of the trials have Australian participation. With an average survival post-diagnosis for MND patients of only 27 months, access to trials and treatments must also be timely and efficient.

MND Australia recommends the Government enables early access to medicines and expedited access to medical trials for people with MND through:

- support for a National MND Data Asset
- improving the efficiency of the health technology review system
- prioritising MND treatments in the drug approval processes and
- establishing a MND clinical trials network

## 4. HEALTH



### Improve access to genetic testing

Around 10% of MND is caused by an inherited genetic mutation (familial MND). For families impacted by familial MND, genetic testing enables opportunities for future family planning to avoid passing on the ticking time bomb of known MND mutations.

Genetic screening for MND is now available under Medicare, however, access to genetic counselling, which is a vital part of the screening process, is extremely limited due to low numbers of genetic counsellors

MND Australia recommends the Government:

- improve access to genetic testing for people with MND and their families by making genetic counselling available under Medicare and increase funding to train genetic counsellors
- fund no cost access for those who choose to undertake in-vitro fertilisation (IVF) and pre implantation genetic diagnosis (PGD)

## 6. RESEARCH



### Fund a Neurological Mission within the Medical Research Future Fund (MRFF)

Neurological conditions affect close to 15% of the world's population, representing a huge burden on patients, families and healthcare systems. Many neurological conditions share common disruptions of biological processes presenting opportunities to share ideas and co-develop drugs.

MND Australia therefore recommends the Government establish a Neurological Mission within the MRFF.

**\$100m over five years**

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