

## Briefing for MPs on the campaign to Make Aged Care Fair

### **What is motor neurone disease (MND)?**

MND is a devastating neurological disease that affects the brain and spinal cord. MND usually progresses rapidly and robs people of their ability to speak, move, swallow and eventually breathe, with respiratory failure being the primary cause of death. The symptoms of MND leave people with severe and complex disability needs. In most cases people living with MND remain mentally alert, becoming trapped within a failing body, although up to 60% can experience some changes in cognitive function.

There are an estimated 2000 people in Australia living with MND with a life expectancy of 2.5 years from diagnosis. There are no effective treatments that can stop progression and no yet cure. MND Australia is the national voice for people living with MND, with member MND Associations in NSW/ACT, VIC, SA, WA, QLD and Tasmania. Our vision is a world without MND and until that time we will do everything we can to advocate on behalf of those with MND to ensure they have access to the best care and support, achieve the highest quality of life and are able to die with dignity.

### **How does Aged Care affect people with MND?**

People diagnosed with MND when aged 65 or older do not have access to the NDIS and are forced to rely on Aged Care services for their care and support needs, simply because of their age.

The complex needs of people living with rapidly progressive neurological diseases, such as motor neurone disease (MND), cannot be met by existing or traditional aged care services or facilities which are designed to address needs related to ageing not disability. There are major gaps with respect to timely access, assistive technology, choice and the range, level and hours of service available.

The Government has implemented a range of aged care reforms to give older people more choice and control. These reforms also include enhanced access to four levels of home care packages covering basic home care support through to complex home care. However, the focus remains on addressing needs related to ageing and the highest Level 4 package, which aims to support people with high-level care needs, has a means tested, subsidy amount limit of \$49,500 in contrast to NDIS support which is not means tested and has no amount limit. The Australian Government has recently introduced a national prioritisation queue, but to date this does not seem to have impacted on the waiting times for access to Level 3 and 4 Home Care Packages for people with MND. As at 30 September 2017, there were 101,508 people on the national prioritisation queue with 40.2% assigned an interim package. Waiting in a queue is not tenable in the face of progressing loss of function, speech and swallowing, loss of ability to breathe and a limited life expectancy.

People with a disability over the pension age are not able to access the full range of reasonable and necessary disability supports to meet individual needs. As the NDIS rolls out nationally the gap between the services available to people with MND based on their age will continue to widen and lead to further discrimination.

**MND Australia will continue to advocate for access to the NDIS for all people with a diagnosis of MND no matter their age when diagnosed.**

**Until this is achieved we are asking the Government to:**

- 1. Make improvements to the ageing-disability interface to ensure access to reasonable and necessary supports to meet the needs of people who acquire a disability when over the pension age.**

For example:

- a. Introduce a formal 'fast track' process for automatic access to Level 4 Home Care Packages for people living with rapidly progressing and complex terminal conditions such as motor neurone disease to ensure early intervention and access to supports to meet rapidly progressing and changing needs.
  - b. If Aged Care is unable to meet the disability needs of older people, the NDIS should develop a safety net model that provides for top up funding through the NDIS to address needs not met by Aged Care.
- 2. Timely availability of assistive technology to meet needs of individual:**
- a. Provide funds for assistive technology in addition to Home Care Package funding to ensure that older people diagnosed with MND living at home 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.
  - b. Aged Care sector to ensure equitable and cost effective access to assistive technology for people in residential aged care to support their independence, comfort, communication and quality of life.
- 3. Improvements to the health/allied health/palliative and aged care interface:**
- a. Good interfaces with allied sectors, particularly health and palliative care, must be developed to ensure a coordinated inter and multidisciplinary approach to care.
- 4. The development of National Guidelines for the management of people with rapidly progressive neurological conditions:**
- a. National Guidelines for MND, based on the [UK NICE Guidelines - Motor neurone disease: assessment and management to improve care from diagnosis to end of life.](#)

Please support people living with MND in your electorate and raise these issues with Hon Ken Wyatt AM, MP.

For more information please contact us at [mndaction@mndaustralia.org.au](mailto:mndaction@mndaustralia.org.au) or call on **02 8287 4980**