

POSITION STATEMENT

MND Australia believes:

- People diagnosed with MND must have access to early intervention, specialised planning, ongoing expert assessment, complex support coordination, assistive technology and a range of services to meet their needs irrespective of where they live, their age or which sector funds the service
- MND associations play a vital role within the NDIS and aged care sectors to deliver specialist MND information, training and education and expert individualised and personalised support and services

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 MND Australia calls for:

- 1. 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.

Background:

MND Australia believes that people diagnosed with motor neurone disease (MND) must have access to early intervention, specialised planning, ongoing expert assessment, complex support coordination, assistive technology and a range of services to meet their needs irrespective of where they live, their age or which sector funds the service

The Deloitte Access Economics report¹, commissioned by MND Australia states that the total cost of MND in Australia was \$2.37 billion in 2015, comprising \$430.9 million in economic costs and \$1.94 billion in burden of disease costs. The enormity of these costs is akin to the brutality of MND.

Under the national disability insurance scheme (NDIS) people living with MND who are diagnosed when under the pension age are entitled and funded to access **reasonable and necessary** supports to meet their individual needs. Many people aged 64 or younger with MND are now receiving NDIS plans that are having a positive and life changing impact.

MND is not a disease related to ageing. Approximately 50% of the 2,000 Australians living with MND are diagnosed when under the age of 65 and 50% at age 65 or older. MND Australia has consistently advocated for access to the NDIS for all people with rapidly progressing neurological conditions no matter how old they are when diagnosed.

Currently people diagnosed with MND under the age of 65 and accessing the NDIS are able to continue receiving NDIS supports as they age. Those aged 65 years and over who are assessed as being ineligible for the NDIS at the time the NDIS begins rolling out in their region and who are an existing client of state-administered specialist disability services are eligible to receive ongoing disability support from the Commonwealth Continuity of Support (CoS) Programme².

Those diagnosed when aged 65 years and older who are not eligible for either CoS or the NDIS must seek disability supports funded by the aged care system.

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 Australian 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 \$49,500³ 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 package⁴. 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.

¹ Deloitte Access Economics 2015, [Economic analysis of motor neurone disease in Australia](#), report for Motor Neurone Disease Australia, Deloitte Access Economics, Canberra, November

² <https://agedcare.health.gov.au/programs/commonwealth-continuity-of-support-programme/eligibility-for-cos>

³ My Aged Care - <https://www.myagedcare.gov.au/help-home/home-care-packages/about-home-care-packages>

⁴ Home care packages program data report 1 July – 30 September 2017, Department of Health, released December 2017.

The crucial issue remains that 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.

People with rapidly progressive neurological disease have changing and complex care needs which are often not well understood by aged care staff. Anecdotal evidence indicates that the introduction of My Aged Care as the gateway to aged care services has slowed down access to specialised assessment. Needs based support hinges on timely access to specialised assessment undertaken by professionals who understand the complex and progressing nature of MND.

Under current aged care assessment processes consideration of whether a person would benefit from a specialist disability service such as complex support coordination, flexible respite, assistive technology, specialised therapy and communication aids rarely occurs.

On behalf of the MND Australia board and state MND Associations

Signed: David Ali (President)

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