

POSITION STATEMENT

MND Australia believes:

- People diagnosed with MND must have access to a range of services to meet their disability needs irrespective of where they live, their age or which sector funds the service
- Access to reasonable and necessary government funded disability supports based on the age of a person when they acquire, or are diagnosed with, a disability is discriminatory and contravenes article 19 of the United Nations Convention on the Rights of Persons with Disabilities
- Investment in Home Care Packages to reduce waiting list for higher level care at home, as recommended in the Royal Commission into Aged Care Quality and Safety Interim Report¹, will improve the lives of thousands of older people, reduce the need for residential aged care and boost home care sector employment opportunities during a time of rising unemployment

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. Immediate and sustained investment in additional Home Care Packages to reduce the number of people waiting on the national queue and to boost employment opportunities in the community
 - b. 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 changing needs
 - c. 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 the needs of the individual:**
 - a. Provide an assistive technology supplement in addition to Home Care Package or Commonwealth Home Support Program (CHSP) 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.

¹ <https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf>

Background:

MND Australia and its members, the State MND Associations, form the only national network focused on improving the lives of all Australians living with motor neurone disease (MND). We believe 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 report², 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.

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 are entitled and funded to access **reasonable and necessary** NDIS supports to meet their individual needs and are able to continue receiving NDIS supports as they age. Those diagnosed when aged 65 years and older 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. In addition, Home Care packages are means tested and subsidy amount limited (varying from \$8,785.55 for a Level 1 to \$50,990.50 for a Level 4 per annum)³ in contrast to NDIS support which is not means tested and has no amount limit.

The interim report of the Royal Commission into Aged Care Quality and Safety published October 2019⁴ confirms the shocking tale of neglect of people in the Aged Care system in Australia. The report highlights the long waiting times for Home Care Packages with many people dying whilst on this waiting list. With an average wait time of just over one year for half of the people on a level 4 package MND Associations across Australia are increasingly being told that loved ones have died before receiving the Home Care Package they had been assessed as needing. 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 life expectancy of just 2 to 3 years from diagnosis.

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 has rolled out nationally the gap between the services available to people with MND based on their age has widened. This is leading to increasing discrimination and contraventions of article 19 of the United Nations Convention on the Rights of Persons with Disabilities, of which the Australian Government is a signatory.

In addition people with rapidly progressive neurological disease have changing and complex care needs which are often not well understood by aged care staff. The Royal Commission interim report confirms that the assessment process via My Aged Care is confusing, confronting and access to

² Deloitte Access Economics 2015, [Economic analysis of motor neurone disease in Australia](#), report for Motor Neurone Disease Australia, Deloitte Access Economics, Canberra, November

³ Department of Health, Aged Care Subsidies and Supplements: New Rates of Daily Payments from 1 July 2019, 2019, https://agedcare.health.gov.au/sites/default/files/documents/06_2019/aged_care_subsidies_and_supplements_new_rates_of_daily_payments_from_1_july_2019.pdf, viewed 26 September 2019.

⁴ <https://agedcare.royalcommission.gov.au/publications/Documents/interim-report/interim-report-volume-1.pdf>

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specialised assessment problematic. 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 Lamperd (President) Dated: 30 July 2020