

Response to Counsel Assisting's Proposed Recommendations

Royal Commission into Aged Care Quality and Safety

MND Australia

12 November 2020





ABOUT MND AUSTRALIA

MND Australia, its research arm, MND Research Australia, and members, the State MND Associations, form the only national network focused on improving the lives of all Australians living with motor neurone disease (MND) and advancing research to end MND. For over 35 years this national network has helped increase understanding of the disease and advocated for improvements in its treatment and care to ensure people living with MND have the best quality-of-life possible.

The six state MND Associations provide direct support and services to people living with MND, their carers and families and the health professionals and service providers involved in their care in all states and territories.

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ABOUT MND

MND is the name given to a group of neurological diseases in which motor neurones, the nerve cells that control the movement of voluntary muscles, progressively weaken and die.

With no nerves to activate them, the muscles of movement, speech, swallowing and breathing gradually weaken and waste, and paralysis ensues. MND affects each person differently with respect to initial symptoms, rate and pattern of progression, and survival time.

There is no known cause of MND (except in a very small number of genetic cases), no effective treatments and no cure. There are no remissions and progression of MND is usually rapid and relentless creating high levels of disability and a consequent need for a wide range of progressively changing supports.

Timely early intervention and access to expert multidisciplinary care, assistive technology (aids and equipment), specialist planning and assessment, home care services and coordination of support, including a proactive framework for decision-making, play vital roles in maintaining quality of life and independence. It also helps people to plan ahead and prevent crisis and avoidable hospital/residential aged care admissions.

Although early intervention will not slow down the disease process in MND, it will strengthen the informal supports available to the person, including supporting the primary carer to maintain the caring role and their own health and wellbeing.

PEOPLE LIVING WITH MND AND AGED CARE

Approximately 40% of the 2,100 Australians living with MND are diagnosed when under the age of 65 and 60% 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.

People under the age of 65 when diagnosed with MND, will access supports to meet their individual needs through the NDIS. People aged 65 and older must rely on the aged care system which, unlike the NDIS, is capped, means tested and designed to address ageing, not disability. With an average life expectancy of just two to three years from diagnosis most people with MND prefer to remain at home for as long as possible. However, increasing inequity and long waiting times is causing many people to be pushed into financial hardship or residential aged care earlier than they wish or need.

Increasingly older people with MND are dying before receiving the level of aged care support they have been assessed as needing. In addition the complex needs of people living 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 to support at home, choice and range of assistive technology and the level and hours of service available.

Understanding of MND within the aged care sector is limited further compounding distress for the person with MND and their family. 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.



This brief submission outlines the response of the MND Association Network to Council Assisting's final submissions that were delivered to the Commissioners on the 22nd and 23rd October 2020.

Our network strongly supports a number of the recommendations put forward which closely align with the key recommendations we outlined in our initial [submission](#) to the Royal Commission:

- 1. The NDIS should be broadened to include all people with disability, regardless of age.*
- 2. Funding to be made available for assistive technology in addition and separate to Home Care Package funding to ensure that older people diagnosed with MND who are living at home can access the assistive technology they need when they need it.*
- 3. An immediate investment in additional home care packages to address the current urgent needs of those on the national prioritisation queue.*
- 4. The introduction of a formal 'fast track' process for automatic access to Level 4 Home Care Packages (high priority) for people living with terminal, complex and progressive conditions.*

It is very pleasing that the Royal Commission has acknowledged the increasing gap in access to supports for older people with disability compared to those under 65 entitled to the NDIS.

The following table outlines the MND Australia Network response to relevant proposed recommendations.



Recommendation	MND Australia Network Response
Recommendation 9 Meeting preferences to age in place	
9.1. The Australian Government should clear the home care package waiting list, otherwise known as the National Prioritisation System, by:	
9.1. (a) immediately increasing the home care packages available and allocating a package to all people on the waiting list that do not have a package or do not have a package at the level they have been approved for (as set out in their letter from the Aged Care Assessment Team/Service). The package allocated should be at the level the person was approved for (Level 1, 2, 3 or 4). This must be completed by 31 December 2021	<p>The MND Australia Network strongly supports and welcomes this recommendation as an immediate intervention to improve the lives of older Australians and to maintain and support home based care.</p> <p>MND Australia has long been campaigning for fast track access to level three and four home care packages for people with complex, progressing and terminal conditions such as MND. Our Position Statement on Aged Care calls for immediate and sustained investment in Home Care Packages to reduce the number of people waiting on the national queue and to boost employment opportunities in the community.</p> <p>Currently 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.</p> <p>A proposed completion date of 31 December 2021 needs to be upheld in recognition of the urgent need to provide support to all people on the waiting list.</p>



<p>9.1. (b) keeping the waiting list clear by allocating a home care package at the approved level to any new entrants to the waiting list within one month of the date of their assessment. This must occur between 1 January 2022 and 1 July 2024</p>	<p>The MND Australia Network strongly supports this recommendation.</p> <p>Assuming people on the current waiting list receive a home care package during 2021 it will be vital that this recommendation is also adopted.</p>
<p>9.1. (c)publicly reporting, each quarter, the status of the waiting list, showing progress in clearing the waiting list as set out in paragraphs a. and b. above, at a national, State or Territory, and regional level. This report should include reasons for delay in clearing the waiting list and actions being taken to address the delay. This must occur every quarter from 31 March 2021 to 1 July 2024.</p>	<p>The MND Australia Network supports a transparent reporting process nationally</p>
<p>Recommendation 16 Assistive technology and home modifications category</p>	
<p>16.1. From 1 July 2022, the Australian Government (and, from 1 July 2023, the Australian Aged Care Commission) should implement an assistive technology and home modifications category within the aged care program that:</p>	
<p>16.1. (a) provides goods (including aids and appliances) and services that promote a level of independence in daily living tasks and reduces risks to living safely at home</p>	<p>The MND Australia Network strongly supports this recommendation.</p> <p>We have long advocated for timely access to assistive technology for people living with MND. In the face of progressing disability impacting on mobility, comfort, independence, communication, swallowing and breathing, timely access to assistive technology and home modifications to meet identified need is vital for people with MND.</p>

	<p>Our position statement on aged care calls for:</p> <p><i>Timely availability of assistive technology to meet the needs of the individual:</i></p> <ul style="list-style-type: none"> <i>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</i> <i>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.</i>
<p>16.1. (b) includes the assistive technology, home modifications and hoarding and squalor service types from the Commonwealth Home Support Programme</p>	
<p>16.1. (c) is grant funded.</p>	<p>The MND Australia Network provides in principle support for this recommendation.</p> <p>More details are needed but in essence a grant funded approach has potential to support and enhance the provision of assistive technology to people living with MND.</p> <p>In response to the fragmented, confusing and unreliable state and federal funded equipment loan services State MND Associations have provided assistive technology for many years, at little or no direct cost to the person with MND. This service is mostly funded through philanthropy and fundraising. This has led to an unequal approach nationally with some MND</p>



	<p>Associations able to provide a wide range of assistive technology and others only having a few items available. Aged Care grant funding for assistive technology would provide a more sustainable system which is less reliant on MND Association fundraising to continually fund their equipment loan scheme.</p> <p>A Deloitte Access Economics report¹, commissioned by MND Australia in 2015 reveals that in Australia the per person cost of MND in 2015 was \$1.1 million, dwarfing the cost of many other chronic health conditions. The report states that AT comprises one of the highest per person costs. The report also confirms the MND association equipment loan service as a cost effective model.</p> <p>More recently a cost effective MND Association assistive technology model has been developed in partnership with the NDIA to provide “equipment bundles’ or equipment rental funded by a person’s NDIS plan. People with MND under 65 have the option to include rental of individual items or bundles of equipment (@ \$8,000 p.a) from MND Associations in their NDIS plans. This ensures a cost effective solution in providing the full range of assistive technology as needs arise².</p>
<p>16.2. The assistive technology and home modifications category should continue within the new aged care program from 1 July 2024.</p>	

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://www.themandarin.com.au/123502-how-a-cost-effective-approach-to-assistive-technology-could-help-the-australian-aged-care-system-and-older-people-living-with-motor-neurone-disease/>



Recommendation 60 Equity for people with disability receiving aged care	
<p>60.1. By 1 July 2024, every aged care recipient with a disability or disabilities, regardless of when acquired, should receive through the aged care program daily living supports and outcomes (including assistive technologies, aids and equipment) equivalent to those that would be available under the National Disability Insurance Scheme to a person with the same or substantially similar conditions.</p>	<p>We strongly support this recommendation.</p> <p>Since the idea of a NDIS was first introduced over 10 years ago MND Australia has consistently advocated for access to the NDIS for all people with a disability no matter their age when they acquire the disability or are diagnosed. MND is not an age related condition, and people diagnosed after they turn 65 are significantly disadvantaged.</p> <p>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. Like the NDIS, daily living supports should be needs based, uncapped and individualised. They should include the full range of support available to NDIS participants including support coordination, personal care and individualised assistive technology.</p> <p>We believe that 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.</p> <p>We therefore call on the government to adopt this recommendation as a matter of urgency.</p>