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Aged Care Quality and Safety Commission
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Cost Recovery Consultation – Aged Care Quality and Safety Commission

Thank you for the opportunity to make a submission in response to the Cost Recovery Consultation. Motor Neurone Disease (MND) Australia welcomes the opportunity to provide this submission on behalf of its members, the State MND Associations, and people living with MND.

MND Australia is the national peak body for state organisations that support those living with, and impacted by, motor neurone disease (MND). Since 1993, we have been the voice for the MND community. Our national and international networks help increase understanding of the disease and advocate for the needs of those affected. We fund world-class research for better treatments, improved care, and ultimately a cure.

Motor neurone disease (MND) is the name given to a group of neurological diseases in which motor neurons – the nerve cells that control the movement of voluntary muscles – progressively weaken and die. With no nerves to activate the voluntary muscles, they become progressively weaker to the point that the ability to walk, speak, swallow and ultimately breathe is lost. MND affects each person differently with respect to initial symptoms, rate and pattern of progression and survival time.

Average life expectancy for people living with MND is 27 months from diagnosis. A third of those die within one year and more than half within two years of diagnosis. There are no known causes for MND, apart from the up to 15% per cent of cases which have a genetic basis. There are no effective treatments and there is no cure. There are no remissions and progression of MND is usually rapid and relentless, creating high levels of life-limiting disability, regardless of the age at onset, and a consequent need for a wide range of changing supports based on the person's complex needs.

In 2024 there were approximately 2,688 people with MND in Australiaⁱ and more than 55% of these are diagnosed over the age of 65.ⁱⁱ

MND is a rare disease requiring specialised multidisciplinary team care. State Associations provide services and supports and invaluable expertise and a comprehensive understanding of MND to ensure people living with MND can be supported to navigate the health system and access supports in a timely manner.

State Associations are not securely funded and rely on philanthropy, donations, and inconsistent state and territory government funding. They play a critical role in addressing gaps by providing support to navigate funding applications, access to allied health professionals, equipment loans, and

other support services.ⁱⁱⁱ The services and supports provided assist in maintaining independence and keeping people in their homes longer.

Due to the high level of clinical related care that people living with MND may need, this can mean that some people are not accepted for a placement within an Aged Care Residential service. For this reason, supports to navigate the health system and timely access to care remains a priority to be delivered by State Associations. State Associations provide quality and safe funded supports and services supporting safety from neglect.

The cost recovery policy, in its proposed form will severely impact MND State Associations becoming registered aged care providers and maintaining aged care provider status. It will concentrate the market by risking smaller providers not being able to afford the recovery fees and limit becoming or maintaining provider status. While the need for a charging framework is understood, the amounts proposed will impose significant financial limitations on State Associations who are not for profit organisations already working in a challenging fundraising market responding to the needs of people with MND needing rapid response. This risks a flow on effect for the up to 1478^{iv} people aged 65 and over who are eligible and may likely access State Associations. Within the cost recovery policy, 3.3.2 outlines provider registration fee waivers and that the intent of provider registration fee waivers is to encourage providers to enter and operate in this market. State Associations do not meet the criteria for the Full 100% fee waiver.

MND is a rare disease with rapidly changing high support service needs. Due to the nature of the high clinical care needs of people living with MND and consequently the limited opportunities to access residential aged care, it is imperative that MND specialist organisations, such as the State Associations are not prevented from providing aged care services by registration fees.

In addition, we request that renewal applications and renewal audit costs are waived, or significantly reduced for State Associations to enable providing services and supports for people aged 65 and over living with MND. Without these waivers and exemptions, MND State Associations will be severely impacted to become or maintain a registered provider status to provide supports for people living with MND aged 65 and over.

In advance, thank you for your consideration of this request which will support delivering person centred care and services by qualified and experienced providers for people living with MND. We look forward to a response and the opportunity to discuss this request.

Kind Regards,



Clare Sullivan
Chief Executive, MND Australia



ⁱ <https://www.mndaaustralia.org.au/mnd-connect/what-is-mnd/what-is-motor-neurone-disease-mnd#:~:text=Every%20day%20in%20Australia%2C%20two%20people%20are%20diagnosed,85.%20The%20risk%20grows%20as%20people%20get%20older.>

ⁱⁱ MND Australia Submission to the Department of Health and Aged Care Consultation on the new Aged Care Act. February 2024. https://www.mndaaustralia.org.au/getattachment/f0510637-7dc7-4da3-a9ce-9a2610623a86/Aged-Care-Act-submission_27_02_24.pdf?lang=en-AU

ⁱⁱⁱ MND Australia. State MND Association services. 2024; Available from: <https://www.mndaaustralia.org.au/mnd-connect/find-services/state-mnd-associations>

^{iv} MND Australia 2024. State MND internal data analysis.