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Committee Secretary
Senate Standing Committee on Community Affairs
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Review of Legislative Instruments (Aged Care) – review 1

Thank you for the invitation to make a submission to the review of the specified areas of the *Aged Care Act 2024* legislation. 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.

What is 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.

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 2025 there were approximately 2,752 people with MND in Australia and more than 63%[1] of these are diagnosed aged 65 or older.[2] Those over 65 rely on aged care funding for this degenerative, rapidly progressive condition resulting in profound disability. People who are older at time of the onset of MND also typically have shorter life expectancy.[3]

MND is a complex and rapidly degenerative disease requiring specialised multidisciplinary team care. State MND Associations provide services, supports, 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.

Response to the *Aged Care Act* (2024) review

MND Australia has particular concerns with the legislation as it currently stands, as it fails to account for the specific needs of older Australians living with a complex and degenerative disease like MND.

Our key concerns are as follows.

1. **Residential aged care does not adequately support older Australians with high-care needs like MND.**

The concern: Most people with MND prefer to stay in their home environment. However, there are times when that is not possible; for example, if they live alone, if their familial carer is no longer able to cater to their needs, or if they experience a sudden increase in care complexity. The MND state associations report that 155 people living with MND were in residential aged care facilities in 2025, representing 14% of all people aged 65+ who access support from state associations. Currently, many residential aged care providers are ill equipped to care for people with high-care needs. In consequence, many older people living with MND either are unable to secure a placement in residential care, or are not receiving the level of support they require. When declined a placement in residential aged care, it is phrased as '**clinically declined.**' Often older people then end up in hospital, taking beds from short-stay patients and placing a high financial burden on the hospital system.

KPMG's Aged Care Market Analysis 2025 reports that the aged care sector continues to consolidate, with concerns about financial viability listed as one of the top reasons for this market contraction. Further, they indicate that acquisition levels of residential care facilities remain high as "large providers [are] aiming to enhance their economies of scale by acquiring homes from providers outside the top 25 of market share."[4] This consolidation of the aged care market is likely to compromise care options for older Australians who need intensive or specialised care, as is the case for people living with MND. As MND Australia has raised in the past,[5] the changes made to the cost recovery model are likely to drive out smaller, not-for-profit, and specialised providers.

The response: Fund residential aged care to provide support for people who need high levels of clinical care. MND Australia advocates for an aged care system that caters to the wide range of caring needs older Australians face. This includes providing residential alternatives for older Australians who have complex needs and may need proactive, clinical care. We request that the Aged Care Act be amended to include specific incentives and/or requirements for high-needs care provision in residential facilities, accompanied by adequate funding for high-needs clinical care. The ABS reports that over 52% of older Australians have a disability and nearly 87% have one or more long-term health conditions;[6] this is a natural part of the ageing process and the aged care system should anticipate functional decline – including situations, as created by MND, where that decline is very rapid. While the vast majority are able to remain in the home, there is a small cohort of older Australians with complex needs who have nowhere to go other than to hospital if residential facilities are unable or unwilling to accept them.

2. **Most aged care providers do not have the expertise to support someone living with MND.**

The concern: MND is a rapidly progressing debilitating disease, particularly so for the 63% of Australians who are diagnosed at age 65 or older.[7] Life expectancy and quality of life are vastly improved by a coordinated multidisciplinary specialist team, non-invasive ventilation, specialised wheelchairs, home modifications (for example ensuring bathrooms are wheelchair accessible), and nutritional aids like a percutaneous endoscopic gastronomy (PEG) to ensure adequate nutrition and hydration.[8] Research indicates that even the simple addition of someone who can coordinate care for people living with MND can lead to a vast improvement in outcomes and reduce hospital visits. [9]

The response: Close the care gap for people with specialised needs like MND by supporting specialised service providers to become registered as aged care providers. MND Australia urges the government to make it easier for specialised community care organisations to be registered as aged care providers to fill this 'care gap' for the older Australians who most need it, by waiving fees of specialised providers and making registration and compliance less burdensome. Our MND state associations provide care state-wide (and in some cases, interstate), to ensure nation-wide coverage. They provide these services without charge to people living with MND and are often filling black spots for appropriate health care coverage, particularly for people who can not easily access a specialist MND clinic due to geographic isolation. The state associations have very little core funding, relying primarily on a mixture of state government grants (many which are time limited) and fundraising appeals. Reliable financial support of this important work, which eases the burden on the health system and the aged care system while improving outcomes for older people living with MND, would allow the work to be done to a high standard and without service interruption.

3. **The new co-pay pricing structure should reflect the clinical nature of many "Independence" expenses.**

The concern: It is appreciated that the new co-pay structure includes 100% coverage for clinical supports. We further understand why the "everyday living" category may attract a higher co-pay amount, in order to ease the burden on the aged care system. However, our concern is that the "independence" category includes services, for example assistive technology and personal care, that we consider to be clinical. It is already causing stress and concern that older people living with MND may no longer be able to afford help with basic needs, for example showering or toileting. The co-pay for these essential services can be as high at 50%. If people living with complex health conditions, such as MND, can no longer afford the co-pay for these services, it may create the tipping point where they can no longer remain in their home. It is quite possible that the comparative small savings that the co-pay represents for the Federal Government will result in a much higher occurrence of expense in other cost centres – most likely in residential aged care or hospitals.

The response: Reduce "independence" category of services co-pay amounts to reflect the clinical nature of many of those services. MND Australia is requesting that the co-pay amounts for the "independence" category of services be drastically reduced. Further, it may be advantageous to conduct economic modelling and/or request information on the specific lived experience of the co-pay matrix, particularly on older people who have complex medical conditions, to understand the implications of the high co-pay on the ability of

individuals to remain in the home and what the financial burden may be in other health-related cost centres.

4. The new co-pay pricing structure should reduce the lifetime cap.

The concern: It is appreciated that there is a lifetime cap in place for the co-pays that people reliant on the aged care system are expected to pay, as this 'safety valve' can ensure that older people are not bankrupted by accessing services. However, the very high level of the lifetime cap - $130,000 – is enough to tip an older household on a fixed income into poverty. The ABS reports that the median salary in 2022-23 (the most recent data available) was $58,216.[10] The lifetime cap therefore represents nearly 2.5 years' worth of the median Australian wage. This is a very high financial burden for any household, but particularly so for older Australians who are no longer wage earners but are on fixed incomes. It is unreasonable to expect a household to liquify its assets when remaining family members may live for decades beyond a person diagnosed with MND. It is also the case that home ownership without a mortgage can no longer be assumed for older Australians, as home ownership rates are in decline.[11] [12] For most households, MND leads to a highly intense and compressed financial burden on households. For those relying on retirement incomes, $130,000 can be an insurmountable financial burden.

The response: Reduce the lifetime cap to reflect retirement incomes. MND Australia advocates that the lifetime cap is economically modelled on the median retirement income, which the ABS reports is $24,168 for persons aged 65+.[13] We therefore suggest that the lifetime cap is substantially reduced to $25,000 or lower, to equal approximately 1 year of income for an older Australian.

MND Australia would be happy to provide any further information of case studies, or to discuss our submission with Committee Members.

We look forward to reading the report from the Review of Legislative Instruments (Aged Care).

Kind Regards,

Clare Sullivan
Chief Executive, MND Australia

mnd Australia mnd New South Wales mnd South Australia mnd Western Australia
mnd Tasmania mnd Queensland mnd Victoria

[1] MND Australia and Evohealth (2025). *Every moment matters. Addressing the human and economic toll of motor neurone disease in Australia.* Canberra. https://www.mndaustralia.org.au/getmedia/e5df789a-3318-4fb5-89c2-ed4935e3ebae/Every-Moment-Matters-report_MND-Australia.pdf

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

[3] Pfohl, S. R., Kim, R. B., Coan, G. S., and Mitchell, C. S. (2018). Unraveling the Complexity of Amyotrophic Lateral Sclerosis Survival Prediction. Frontiers in Neuroinformatics, 12:36. https://doi.org.10.1007/s12031-025-02337-4

[4] KPMG (2025). Aged Care Market Analysis 2025. p. 3.

[5] MND Australia (2025). Submission: "Consultation on the Pricing Framework, Australian Support at Home Aged Care Services 2026-27." Dated 18 July 2025.

[6] ABS (2024). "Disability, Ageing and Carers, Australia: Summary of Findings. Released 4 July 2024. Accessed on 1 December 2025 at https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release

[7] MND Australia and Evohealth report. 2025. *Every moment matters. Addressing the human and economic toll of motor neurone disease in Australia.* Canberra. https://www.mndaustralia.org.au/getmedia/e5df789a-3318-4fb5-89c2-ed4935e3ebae/Every-Moment-Matters-report_MND-Australia.pdf

[8] MND Australia and Evohealth report. 2025. *Every moment matters. Addressing the human and economic toll of motor neurone disease in Australia.* Canberra. https://www.mndaustralia.org.au/getmedia/e5df789a-3318-4fb5-89c2-ed4935e3ebae/Every-Moment-Matters-report_MND-Australia.pdf

[9] Cordesse, V., Sidorok, F., Schimmel, P., Holstein, J., and Meininger, V. (2015). Coordinated care affects hospitalization and prognosis in amyotrophic lateral sclerosis: a cohort study. BMC Health Services Research 15:1,134.

[10] ABS (2025). "Personal Income in Australia." Released 14 November 2025. Accessed on 3 December 2025 at https://www.abs.gov.au/statistics/labour/earnings-and-working-conditions/personal-income-australia/2022-23

[11] AIHW (2024). "Housing and living arrangements." Accessed on 13 January 2026 at https://www.aihw.gov.au/reports/older-people/older-australians/contents/housing-and-living-arrangements The AIHW notes, "Older Australians have traditionally had high rates of home ownership. This has often provided a key financial asset on retirement. In more recent years, the rate of home ownership among older people has decreased, consistent with decreases in home ownership seen in the broader population."

[12] AIHW (2025). "Home ownership and housing tenure." Accessed on 13 January 2026 at https://www.aihw.gov.au/reports/australias-welfare/home-ownership-and-housing-tenure AIHW notes: "Among those nearing retirement, home ownership also declined; for 50-54-year-olds, the rate decreased from 80% in 1996 to 72% in 2021."

[13] ABS (2025). "Personal Income in Australia." Released 14 November 2025. Accessed on 3 December 2025 at https://www.abs.gov.au/statistics/labour/earnings-and-working-conditions/personal-income-australia/2022-23