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Committee Secretary  
Senate Standing Committee on Community Affairs  
PO Box 6100  
Parliament House ACT 2600

#### Aged Care Bill 2024 [Provisions]

Thank you for the opportunity to make a submission in response to the Aged Care Bill 2024 [Provisions]. 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 them, people with MND lose their ability to walk, speak, swallow and ultimately breathe. MND affects each person differently with respect to initial symptoms, rate and pattern of progression and survival time.

Average life expectancy is just 27 months from diagnosis, with a third of people dying within one year and more than half within two years of diagnosis. There are no known causes for MND, apart from the 15–20% 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. At the time of this submission, there are approximately 2,300 people with MND in Australia<sup>i</sup> and more than 55% of these are diagnosed over the age of 65.<sup>ii</sup>

MND Australia and the State MND Associations support the Government's and the opposition's ongoing commitment to aged care reform and the rights-based, person-centred approach in the new Aged Care Bill 2024, however we are concerned about the limited level of detail in the Bill and the consultation and submission timeline to provide feedback on the Bill.

Many inclusions in the Support at Home package are very much welcomed by the MND community, specifically the increase to the highest level of funding, Assistive Technology and home modifications support and the End-of-Life Pathway, as a start. In line with our Submission to the Department of Health and Aged Care Consultation on the new Aged Care Act in February 2024, the new Act must also clearly state that people 65 and over will receive supports and services equitable to those available through the NDIS under the aged care system and that these supports and services must be timely. We look forward to working with the government in achieving that equity in the near future.

MND Australia feel it necessary to be involved providing implementation advice on a financial model regarding Support at Home, Assistive Technology funding, drawing on established models with the State Associations. This includes fast-tracked access, such as adopting the NDIS priority pathway model as time is of the essence due to the rapid progression of MND. The State Associations can provide consistent evidence of unmet needs and poor outcomes for those living with MND over the age of 65 years.

We would also welcome the opportunity to be involved in discussions regarding the reallocation of the Commonwealth Home Support Package (CHSP) service type recategorisations (Specialist Support Services) prior to 2027 as these services are particularly important to, and provided to, people living with MND.

MND Australia welcomes the opportunity to provide further information in addition to the information contained in this submission if required.

Kind Regards,



**Clare Sullivan**  
Chief Executive, MND Australia



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<sup>i</sup> <https://www.mndaustralia.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.>

<sup>ii</sup> 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](https://www.mndaustralia.org.au/getattachment/f0510637-7dc7-4da3-a9ce-9a2610623a86/Aged-Care-Act-submission_27_02_24.pdf?lang=en-AU)