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Department of Health and Aged Care – New Aged Care Act Consultation
GPO Box 9848
CANBERRA ACT 2601

New Aged Care Rules 2024 consultation – Release 2a – Funding for Support at Home program

Thank you for the opportunity to make a submission in response to the Consultation Draft Aged Care Rules 2024, Release 2a – Funding for Support at Home Program. 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 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. At the time of this submission, there are approximately 2,688 people with MND in Australiaⁱ and more than 55% of these are diagnosed over the age of 65.ⁱⁱ

MND Australia and the State MND Associations are encouraged to see the increased levels of funding within the draft Aged Care Rules 2024, Support at Home (SAH) program, however, we have not had the opportunity to review the Rules in full and will continue to review as more draft Rules become available.

In line with our Submission to the Department of Health and Aged Care Consultation on the new Aged Care Act (February 2024) and the Aged Care Bill 2024 [Provisions] (October 2024) we continue to advocate that the new Act must 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. MND State Association internal data indicates that the average package for a person living with MND under the NDIS in 2024 is \$302,000.

MND Australia and State Associations recommend adopting the NDIS 'priority eligibility decision pathway' (priority pathway) within the Aged Care Act 2024 to ensure people with MND aged 65 and over receive fast tracked, timely access to supports and services at the highest SAH level required.

We welcome the inclusion of Assistive Technology (AT) and home modification (HM) supports and the inclusion of motor neurone disease at 211B (2).

MND Australia recommend the Aged Care Rules 2024 be clearer regarding the amounts for AT and HM. The draft Rules, in their current form, include the amount of up to \$15,000 for AT and the amount of up to \$15,000 for HM but it is not clear that a participant may receive both these amounts in full, in addition to the highest SAH level 8 funding, or other funding level.

Equally, we recommend that the Rules clearly indicate that where a participant is prescribed AT above the nominal cap of \$15,000, there is a clear process to provide additional funds for the prescribed AT and that this also apply to HM for people living with MND due to the rapid progression of MND resulting in rapidly changing support needs.

For people living with MND a forward budget is required to ensure the necessary AT and home modifications are provided at the time of need, with no financial loss to the participant as quarterly payments may not provide adequate amounts for many people living with MND.

MND Australia and State Associations also welcome the inclusion of the SAH end-of-life classification. We request the Rules clearly include that this funding is ongoing for people living with MND and they will continue to receive the SAH end-of-life amount for as long as is needed.

As mentioned, we are encouraged by increased levels of funding within the Aged Care Rules 2024, Support at Home Program. However, if a person living with MND were to receive the highest SAH Level 8 amount of \$78,000, including \$15,000 AT and \$15,000 HM, this represents a difference of \$194,000 for a person aged 65 and over, when compared to the NDIS average funding package of \$302,000. This means that the 55% of people diagnosed with MND at 65 years and over are not getting the complex and ever-changing disability supports they need.

We continue to 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



ⁱ <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.>

ⁱⁱ 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