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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 2025 consultation – Release 3 – Provider Obligations

Thank you for the opportunity to make a submission in response to the Consultation Draft Aged Care Rules 2025, Release 3 – Provider Obligations. 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. At the time of this submission, there are approximately 2,688 people with MND in Australia[i] and more than 55% of these are diagnosed over the age of 65.[ii]

In line with our submissions to the Department of Health and Aged Care Consultation on the new Aged Care Act (February 2024) the Aged Care Bill 2024 [Provisions] (October 2024) and the new Aged Care Rules 2024 consultation - Release 2a – Funding for Support at Home program (December 2024) we continue to advocate that people aged 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.

As mentioned in our response to Release 2a, we are encouraged by increased levels of funding within the Aged Care Rules 2024, Support at Home Program but we continue to advocate for adequate and comparable funding for people with MND aged 65 and over. Based on the rules at the time of our response, 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.

The Aged Care Act 2024 and the Aged Care Rules, while supporting people who are ageing need to provide more detail for people living with MND and other chronic diseases with complex needs. This applies to both funding models and how funding allocations are made, to meet the changing needs of a rapidly progressive disease, and how care is provided in community or a residential care home.

Without suggesting changes to the standards within the Strengthened Aged Care Quality Standards, February 2025, MND Australia recommends that the Aged Care Rules 2025 include the following amendments and additions, so that the level of care for people living with MND is clear:

<u>15-30 Standard 5 - Clinical Care (p.32)</u>

Comprehensive Care

While we acknowledge the Standard cannot be changed, we request the Rules be amended and request *evidence-based* be replaced with *evidence-informed*.

> (8) The provider must ensure that individuals receive comprehensive, safe and quality clinical care services that are **evidence-based** and person-centred and delivered by health professionals.

To read

> (8) The provider must ensure that individuals receive comprehensive, safe and quality clinical care services that are **evidence-informed** and person-centred and delivered by health professionals.

Evidence-informed takes into account both scientific evidence and clinical expertise, allowing for flexibility and adaption to individual patient needs. This is particularly important for older Australians who are aging with a complex chronic disease.

<u>15-35 Standard 6 – Food and nutrition (p.34)</u>

Provision of food and drink

We recommend, without altering the Standard that the Rules include an addition to ensure that people prescribed enteral nutrition, the prescribed method of nutritional intake for many people living with MND, is clearly included.

(3) The provider must support individuals to eat and drink

(a) food and drinks that meet their nutritional needs and are appetising and flavoursome; and

(b) variation and choice about what they eat and drink; and
(c) choice about how much they eat and drink

the following addition is recommended:

(d) any prescribed type and volumes of enteral fluids and nutrition.

Division 3 – Access by supporters etc.
156-5 Access to individuals (p. 74)

While we understand there have been changes in terminology between the Rules and published version of the strengthened Quality Standards (December 2023) including the change from '*Family and/or family and carers'* to the term '*Supporter/s'* in the new Act and Rules, we recommend:

Supporters (p. 74) can be clearer within the Rules by including 'consent for supporter interactions could also be given by a substitute decision maker'. This would be beneficial to non-verbal people living with MND.

Subdivision G – Reportable incidents
166-520 Priority 1 notice must be given within 24 hours (pp 130)

It is recommended that the text considering cognitive improvement include provisions for people who cannot communicate their wishes or the occurrence of incidents, for reasons in addition to cognitive impairment. MND, due to motor neurone damage can result in an inability to talk or move. For this reason, high-tech communication devices are used. If these devices are not set up by someone trained to ensure the device is functioning correctly, the person living with MND may be unable to communicate. For this reason, the following changes to the Rules are recommended to include in addition to cognitive impairment, physical and psychological reasons for the inability to communicate. Thus, rewording of:

(2A) **For the purposes of paragraph (2)(a), in considering whether a reportable incident has caused an individual who has any impairment that directly affects their ability to communicate, physical or psychological injury or discomfort that requires medical or psychological treatment to resolve, a registered provider:**

- **(a) must not consider the impairment, or whether the impairment affects the individual's ability to recognise or communicate the physical or psychological injury or discomfort, as:**
  - **(i) preventing the individual from being caused physical or psychological injury or discomfort; or**
  - **(ii) reducing the degree of physical or psychological injury or discomfort caused; and**
- **(b) must consider whether the individual's impairment has the result that the incident has caused the individual physical or psychological injury or discomfort (for example where the same incident has not caused injury to individuals who do not have an impairment).**

In addition to these requested amendments, we continue to welcome the opportunity being 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,

[redacted]

Clare Sullivan
Chief Executive, MND Australia

[redacted]