Lvl 4, Woden Centre
20 Bradley Street
Philip ACT 2606

mndaustralia.org.au

The Hon Sam Rae MP
Minister for Aged Care and Seniors
Parliament of Australia

25 March 2026

SUBJECT: Open letter regarding the Integrated Assessment Tool and Aged Care access for people with MND

Dear Minister Rae,

I am writing to you on behalf of MND Australia to share our response to your recent comments on the Integrated Assessment Tool and the broader Aged Care assessment system.

We acknowledge and appreciate your commitment to improving the Aged Care system, particularly your focus on reducing wait times and ensuring fairness. These reforms are critically important.

However, as outlined in the attached statement, the experience of people living with motor neurone disease (MND) indicates that the system is not yet delivery equitable or timely outcomes for those with rapidly progressing conditions.

For people with MND, delays and inconsistencies in assessment are not administrative challenges, they have profound consequences for safety, dignity and quality of life. In many cases, they determine whether someone can remain at home at all.

We are calling for urgent, practical changes to ensure the system better reflects the clinical realities of MND, including appropriate prioritisation, transparency in decision-making, and the ability for clinical judgement to override automated outcomes where needed.

MND Australia urges the Government to act quickly to:

- Ensure transparency and accountability in the Integrated Assessment Tool
- Allow clinical judgement to override automated decisions
- Prioritise all MND diagnoses as urgent
- Address rising provider costs and co-pay barriers
- Guarantee that funding levels reflect real care needs

We would welcome the opportunity to work constructively with you and your department to address these issues and ensure the Aged Care system delivers on its intent for those who need it most.

Yours sincerely,

Clare Sullivan
Chief Executive Officer, MND Australia

MEDIA STATEMENT
MND Australia responds to Minister Rae's comments on Aged Care assessment system

MND Australia acknowledges the commitment of the Minister for Aged Care and Seniors, Sam Rae, to improving the aged care system and reducing the unacceptable wait times that previously left older Australians without support.

However, for people living with motor neurone disease (MND), the system is still falling short.

MND is a rapidly progressive and terminal neurological disease, with an average life expectancy of just 27 months from diagnosis. For many older Australians, that timeframe is even shorter. Care delays are not just inconvenient, they are life-limiting.

Recent comments from the Minister highlight that the Integrated Assessment Tool (IAT) applies consistent rules across all assessments. Yet the lived experience of people with MND tells a very different story.

Across Australia, people with the same diagnosis and similar levels of need are being assessed at vastly different funding levels — from the lowest "light touch" supports (e.g., the Commonwealth Home Support Program) through to the highest packages. This inconsistency raises serious concerns about how the system is operating in practice, and whether it is delivering the fairness it promises.

There is also a lack of transparency around how the tool works. For automated decision-making to be trusted, it must be clear what criteria are used, how decisions are made, and there must be a meaningful ability for clinical judgement to override outcomes when they are clearly inappropriate.

The case of Graham and Gaynor Crossan, recently highlighted by the ABC, reflects what MND Australia and State Associations are seeing every day. Despite advanced disease and complex care needs, Graham was denied the level of support required to safely remain at home. His wife Gaynor is now struggling to provide basic care, placing both of them at risk.

This is not an isolated case.

While we welcome efforts to speed up package allocation for people assessed as "high priority", people living with MND are typically being classified as "medium priority", facing wait times of around nine months. In many cases, individuals will have significantly deteriorated or died before support arrives.

MND Australia is calling for all people diagnosed with MND to be automatically classified as "urgent", ensuring access to appropriate care within 30 days.

We are also concerned about the real-world impact of recent pricing and funding changes. While administrative caps and pricing reforms are intended to protect consumers, providers are increasing hourly rates, reducing the purchasing power of packages. As a result, people are receiving fewer hours of care. The newly imposed co-pay system is exacerbating this problem, meaning that many are being forced to go without essential services such as assistance with showering, toileting and medication.

In some cases, people are unable to get out of bed each day due to reduced support.

This undermines dignity, safety and basic health.

Additionally, while the Minister has stated that people should not “go backwards” in their funding, MND Australia has documented multiple cases where individuals have experienced a reduction in the real value of their support following the transition to Support at Home.

The intent of reform is important but so too is its impact.

For people living with MND, the current system is too slow, too inconsistent, and not responsive to the realities of a rapidly progressing disease.

MND Australia urges the Government to act quickly to:

- Ensure transparency and accountability in the Integrated Assessment Tool
- Allow clinical judgement to override automated decisions
- Prioritise all MND diagnoses as urgent
- Address rising provider costs and co-pay barriers
- Guarantee that funding levels reflect real care needs

As the Aged Care system continues to evolve, it is critical that it does not leave behind those with the most urgent and complex needs.