



Lvl 4, Woden Centre  
20 Bradley Street  
Philip ACT 2606

[mndaustralia.org.au](http://mndaustralia.org.au)

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

**via email:** [community.affairs.sen@aph.gov.au](mailto:community.affairs.sen@aph.gov.au)

### **Implications of the Delay to the Support at Home Program and lack of Additional Home Care Packages**

Thank you for the opportunity to make a submission to the inquiry regarding implications of the delayed commencement of the new Support at Home Program to 1 November 2025 and withholding of the release of any additional Home Care Packages. 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.

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%<sup>i</sup> of these are diagnosed over the age of 65.<sup>ii</sup> Those over 65 rely on aged care funding for this degenerative, rapidly progressive condition resulting in profound disability.

## **1. Impact of the delay on older Australians waiting for Support at Home, including unmet care needs and the wellbeing of seniors and their carers**

The delay of the Support at Home Program, from 1 July 2025 to 1 November 2025 further impacts on people living with MND aged 65 and over, who already experience inequity in funding when compared to the funding available under the National Disability Insurance Scheme (NDIS).

MND Australia acknowledges that the delay by the Australian Government was intended to ensure that systems are in place and was the result of sector feedback highlighting the rushed timeframe.<sup>iii</sup>

The delay in releasing further Home Care Packages has resulted in more than 80,000<sup>iv</sup> people aged 65 and over without the care and supports they need. For a person living with MND and others with complex, chronic and progressive conditions<sup>v</sup>, this may mean a person will pass away prior to receiving a package and not receive essential supports and services in the time that is needed.

Members of the MND Australia Lived Experience Network (LEN) and State MND Association feedback includes that people over the age of 65 are experiencing uncertainty and are unclear about the new Support at Home Package and what is included. This uncertainty is further impacted by the delay.

This is essential to ensure their wellbeing, and the wellbeing of their carers who also face uncertainty.

While MND Australia welcome increases in funding levels in the Support at Home Program, funding still remains below the needs to support a complex condition such as MND. The difference between the highest level Home Care Package and the average NDIS package for someone living with MND in 2025 is \$194,000 annually. The average package for a person living with MND under the NDIS in 2024 was \$302,000.

These delays not only impact people waiting to be assessed and assigned a package but further extend a lower payment package in an ongoing broader inequitable funding environment, based on the age of a person at the time of diagnosis of MND.

Currently, the highest level Home Care Package, Level 4 funding is \$63,440.65 a year.<sup>vi</sup> The highest level of funding under the new Support at Home Program will be \$108,000, this includes a base package – at the highest level – of approximately \$78,000, plus an additional \$15,000 for Assistive Technology and \$15,000 for Home Modifications.

Despite the inequity in funding, an increase in funding, beyond the new Support at Home package is urgently needed for people living with MND. Delayed access to increased levels of funding, under the Support at Home package impacts on people living with MND and their carers, delaying essential supports and services. This includes a delay in access to the End-of-Life Pathway.

The End-of-Life pathway payment of \$25,000 for people with an anticipated life expectancy of three months or less, is welcomed by MND Australia and supports people to stay in their homes longer.

Participation time limits of the End-of-Life pathway need to be removed to enable people receiving this essential care and support, for as long as is required. This will ensure that a person receives funding to their need, rather than returning to a lower package and risk of reduced supports, until they die.

For a person living with MND, they may not have certainty, or be able to receive an end of life diagnosis, guaranteed to three months.

## **2. The capacity of the Commonwealth Home Support Programme to meet increased demand for support at home prior to 1 November 2025**

The Commonwealth Home Support Programme is unlikely to meet increased demand for support at home prior to 1 November 2025. People living with MND experience wait times of up to 15 months<sup>vii</sup> to receive a package for aged care services in Australia and there are significant delays of up to a year when transitioning from CHSP to the current HCP.

The CHSP provides entry-level services, dependant on a person's needs. In general, CHSP services are not for people with intensive, multiple or complex needs<sup>viii</sup> however many people living with MND are assigned these packages due to inaccurate assessments or based on their need at the time of assessment when they may be newly diagnosed.

Delays in obtaining an accurate assessment, being allocated a package and then further delays to receiving services, result in many people aged 65 and over living with MND dying prior to receiving a package.

The wait times result in people waiting months for services such as but not limited to, assistance with transport, shopping, domestic help such as cleaning and washing clothes and personal care such as help showering or dressing. For a person living with MND these supports and services may be urgently required due to early symptoms such as muscle weakness and fatigue and the rapid progressive decline in muscle function that may be experienced.<sup>ix</sup>

In addition to this, most CHSP clients are considered to be 'lower care' and will presumably enter Levels 1 – 4 of the SAH program. MND clients typically have multiple high needs and are likely to require a Level 7 or 8 package.

## **3. The impacts on aged care service providers, including on their workforce**

Delays to the commencement of the Support at Home program and to the release of the Aged Care Rules 2025 is resulting in huge uncertainty and confusion in the sector.

In addition to the impact of delays to the Support at Home Program, consideration and planning to alleviate future delays is urgent. CHSP has been critical for some of the State MND Associations to be able to provide some funded care to support MND clients aged 65 and over to remain safely at home and out of hospital.

The MND State Associations leverage fundraising and philanthropy to fund this service gap - coordinating services and providing subsidised or free services and equipment. This position is fast becoming unsustainable with the cost of living and cost of doing business increasing exponentially. Providers of care to participants with complex disabilities need fair and sustainable pricing to continue to care for this priority ageing population with complex chronic disease and concurrent profound disability.

## **4. The impacts on hospitals and state and territory health systems**

As a result of the delay, there may have been hospitalisations that would have been prevented with earlier supports and services and access to the End-of-Life pathway. In contrast to this, in the absence of the End-of-Life pathway commencing 1 July 2025, people that may otherwise have been

provided the dignified option to receive palliative care in their home – between 1 July 2025 and 1 November 2025, have potentially not been enabled this choice and pathway.

#### **5. The feasibility of achieving the Government's target to reduce waiting times for Home Care Packages to 3 months by 1 July 2027, in light of the delay**

Based on current wait times and delay in assessment, it is unclear how this target will be met.

For people living with MND reducing wait times for aged care funding would be significantly reduced by the establishment of a fast-tracked pathway to access the Aged Care system. This will support people to stay in their homes longer. This fast-tracked pathway for people living with MND is urgent. Increased funding for a person living with MND, will provide supports and services urgently needed. The delay from 1 July 2025 to 1 November 2025 further disadvantages people aged 65 and over living with this progressive complex condition.

The NDIS Priority Eligibility Decision Pathway fast tracks people with MND to gain access to the NDIS and through a dedicated team of planners with MND expertise. State MND Associations have provided training to and work closely with the team of dedicated NDIA subject matter expert planners to ensure people living with MND gain access to appropriate NDIS funding, services and supports quickly. The Priority Eligibility Decision Pathway enables a decision within 3-5 business days.

It takes an average of twelve months to receive a MND diagnosis and based on the average lifespan being merely 27 months, this means that people living with MND will often have significant disability at the point of diagnosis and require immediate support.

Guaranteed timely access to supports for people living with MND will ensure they receive the high-level and fast-changing supports and care they need. Any delay to increased funding, coupled with extended wait times is detrimental to people living with MND aged 65 and over receiving the care they need.

#### **6. The adequacy of the governance, assurance and accountability frameworks supporting the digital transformation projects required to deliver the aged care reforms on time**

MND Australia is interested if there was any co-design process regarding the digital transformation projects.

#### **7. The implementation of the single assessment system and its readiness to support people to access a timely assessment now and beyond 1 November 2025**

While the establishment of a Single Assessment System for aged care<sup>x</sup> streamlines processes, an assessment system needs to meet the needs of ageing participants with a complex illness.

There remains a risk of assessments not being comprehensive/fit for purpose due to a one-size-fits all assessment process and yes/no answer fields.

While a single assessment tool may remove duplication, it is essential the assessment tool takes into account people living with complex and progressive diseases and conditions.

State MND Associations indicate the following issues in relation to assessments and the assignment of packages:

- Inaccurate assessments have led to delays in the assignment of a package at the required level and do not take into account the rapid progression many people living with MND experience. An assessor with an understanding of MND, like an MND specialist worker undertaking assessments will reduce the risk of an inaccurate assessment to ensure services and supports are received sooner.
- Assessment appointments initially booked face to face are sometimes changed to a telephone assessment, with little notice. A telephone assessment may not be suitable for people living with MND, due to difficulties in relation to speech. This may also be at a time when they have received a recent terminal illness diagnosis and are navigating a complex and changing aged care system. These changes may result in State MND Association coordination staff not being able to attend to ensure an accurate assessment, reflective of current and future needs is received.

The implementation of the single assessment system and its readiness to support people living with MND to access a timely assessment now and beyond 1 November 2025 is not clear unless the system addresses the one size fits all nature of assessments, that causes people to slip through the cracks and receive an assessment that is not appropriate to their need.

## **8. Any other related matters**

### **End-of-Life Pathway – impacts of delay**

MND Australia are interested to learn if the delay in the roll out of the Support at Home Program has included investment in time for training and stakeholder group specifically to the End-of-Life Pathway and **recommend** that time limits in relation to the End-of-Life pathway be removed.

### **Inequity of funding between the NDIS and Aged Care Funding pathways be addressed**

MND Australia acknowledges the increased package pricing under the Support at Home Program (SAH) however funding remains inequitable for a person living with MND aged 65 and over. The average package for a person living with MND under the NDIS in 2024 was \$302,000.

There are no co-payment requirements under the NDIS. Co-payment requirements are included within the SAH program. Under the SAH, the highest-level package possible at Level 8 is \$78,000 and the maximum level of support under the SAH is \$108,000. This maximum level of support includes the base package, highest Level (Level 8) of approximately \$78,000, plus an additional \$15,000 for assistive technology and \$15,000 for home modifications.

Despite the potential to access complex assistive technology beyond the \$15,000 maximum, if there is a prescription from a suitably qualified health professional and supporting evidence of the item's cost, this does not meet the financial cost of care required<sup>xi</sup> by a person living with MND.

MND Australia **recommends** a measured and sustainable loading based on the severity of physical disability, support needs and formalised functional assessments needs to be included for true equity.

## Increase in Home Care Packages

MND Australia recommends an immediate increase in Home Care Packages and a reduction in wait times to ensure people aged 65 and over have access to supports and services.

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> MND Australia and Evohealth report. 2025. *Every moment matters. Addressing the human and economic toll of motor neurone disease in Australia*. Canberra.

<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)

<sup>iii</sup> ABC 2025. *Aged care reforms delayed after sector raised survival issues*.

<https://www.abc.net.au/news/2025-06-04/aged-care-reforms-delayed-until-november/105374798>

<sup>iv</sup> The Guardian. 'A huge human cost': Labor criticised over delays to aged care reforms as waitlist grows. Article: <https://www.theguardian.com/australia-news/2025/jul/28/labor-faces-backlash-aged-care-reforms-delays>. Accessed 19 August 2025.

<sup>v</sup> MND Australia 2025. Submission to IHACPA, Consultation on the Pricing Framework, Australian Support at Home Aged Care Services 2026-27. [https://www.mndaustralia.org.au/getmedia/ac138745-f095-4a47-9ec9-5522b8779f80/IHACPA-Pricing-Framework-for-Australian-Support-at-Home-Aged-Care\\_MNDA-Submission.pdf](https://www.mndaustralia.org.au/getmedia/ac138745-f095-4a47-9ec9-5522b8779f80/IHACPA-Pricing-Framework-for-Australian-Support-at-Home-Aged-Care_MNDA-Submission.pdf)

<sup>vi</sup> Australian Government myagedcare 2025. Website: <https://www.myagedcare.gov.au/help-at-home/home-care-packages>. Accessed 19 August 2025.

<sup>vii</sup> MND Australia and Evohealth. 2025 *Every Moment Matters: Addressing the human and economic toll of MND in Australia*, Canberra.

<sup>viii</sup> Department of Health, Disability and Ageing 2025. Website: <https://www.health.gov.au/our-work/chsp/delivering-services>. Accessed 19 August 2025

<sup>ix</sup> MND Australia and Evohealth. 2025 *Every Moment Matters: Addressing the human and economic toll of MND in Australia*, Canberra.

<sup>x</sup> Department of Health, Disability and Ageing 2025. Website <https://www.health.gov.au/our-work/single-assessment-system>. Accessed 14/08/2025

<sup>xi</sup> MND Australia. 2024. Submission to the New Aged Care Rules 2024 Consultation – Release 2a – Funding for Support at Home program. <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.>