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Consultation on the Pricing Framework, Australian Support at Home Aged Care Services 2026-27

Thank you for the opportunity to make a submission in response to the consultation paper on the Pricing Framework for the Australian Support at Home Aged Care Services 2026-27. 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%[i] of these are diagnosed over the age of 65.[ii] Those over 65 rely on aged care funding for this degenerative, rapidly progressive condition resulting in profound disability.

MND is a complex rapidly degenerating disease requiring specialised multidisciplinary team care. State MND Associations provide services and supports and invaluable expertise and a comprehensive understanding of MND to ensure people living with MND can be supported to navigate the health system and access supports in a timely manner.

1. **Do the Pricing Principles provide adequate guidance for IHACPA's development of pricing advice? If not, what changes do you recommend?**

The principles in general provide adequate guidance however the application of those principles needs careful consideration particularly in relation to ageing participants with complex health care needs and whose clinical presentation includes profound progressive physical disability and, in many cases, associated cognitive decline such as that exhibited by people with Motor Neurone Disease (MND).

For example:

Principle 1 – Access to Services

Due to the complex nature of caring for someone with MND as well as system constraints, people with MND are often dying before they even get an assessment, let alone access to services. They are then assessed by an organisation/assessor who may not understand MND and the rapid and debilitating disease trajectory. For people aged 65 years and over living with MND, this means they cannot access services.

Principle 2 - Quality care and services

Current recommended pricing does not permit the provision of evidence based, person-centred care for people with complex, progressive physical disabilities such as MND. If State MND Associations did provide all of the required services and supports that people living with MND need to keep them safe, and charged the going market rate for those services, packages would be expended far too quickly, leaving the client with no funds for carer supports quickly enough or at all and therefore without any level of adequate support for the person with MND. Without adequate funding for aged care services under SAH, people living with MND aged 65 and over will not be able to get the specialist MND support they need, let alone quality, evidence based and person-centred care.

MNDA calculate that people aged 65 and over with MND will have less than an hour a day of support under the highest possible level of SAH, Level 8 funding of $78,000. This is completely insufficient to meet the needs of a person living with this rapidly progressive, degenerative disease.

Principle 3 – Pricing equity

Pricing should be fair and equitable. Equity involves fairness and justice in the distribution of resources and opportunities, recognising that individuals have different circumstances and needs and as a result of this require different levels of support to achieve a similar outcome. Current pricing is not fair and equitable for people living with MND as they are not sufficiently funded to cover the care that is needed.[iii]

MND Australia acknowledges the increased package pricing under the 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.[iv]

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.

Principle 4 – efficiency
Pricing should optimise the value of the public investment in the aged care sector.

Ageing participants are best and most efficiently cared for by specialists in MND care. State MND Associations provide and/or coordinate safe, efficient, equitable, accessible and appropriate care, equipment and supports throughout the MND disease trajectory.

Appropriate funding for the care of ageing people with debilitating, progressive complex disorders is critical. The most efficient investment of public funds would be to provide participants with complex progressive debilitating disabilities, with additional care funds accessible only by qualified and specialist care providers, to support people staying in their homes longer. Level 3 Specialist Support Coordination in the NDIS is the precedent for this. To access this elevated funding type, providers must ensure the client meets preselected and agreed criterion and the provider must be qualified to provide the higher level of complex service.

2. **Are there specific service types, locations and population groups that IHACPA should focus on in future cost collections?**

An additional population group is required to be added, *Ageing with a complex disability*
MNDA request that IHACPA include in future cost collection work, a focus on organisations that deliver services to clients who are ageing with complex, chronic and debilitating diseases that results in profound physical disability and sometimes a comorbid neurocognitive decline such as MND. In the existing aged care pricing approaches, this highly complex population group have been overlooked.

The Australian Institute of Health and Welfare (AIHW) include that having a chronic condition becomes more common with age[v]. With improved health care and care systems in Australia, we know older people with chronic conditions are living longer and may stay in their home longer. This is also seen for people aged 65 and over living with MND.

Despite the profound complexity and disability of MND, State MND Associations indicate that ageing people living with MND prefer to remain in their own homes with their families throughout the disease trajectory until they die. MNDA recommend an additional financial loading is required to assist in the care of people living with MND and people aged 65 and over living with complex, chronic disease who exhibit concurrent profound disability and multimorbidity presentation of neurocognitive decline.

Specialist care for ageing with a complex disability in a Rural and Remote Location:
MNDA request the IHACPA focus on the delivery of rural and remote services delivered by metropolitan based specialists in care. Ageing participants have a basic human right to remain living in their chosen community with their family and friends as they age. This basic human right is no different for people and families living with MND. State MND Associations indicate that many rural practitioners do not have the knowledge and skill to care for people with this uncommon and complex disease and require specialist support. MND care is highly specialised and is invariably delivered in part or whole by specialist practitioners of the State MND Associations. Without these supports and services provided by State MND Associations, the suffering of people with MND and their families would increase exponentially.

For the safe, efficient and appropriate care of participants with MND who are living in regions classified in MMM 3 – 7 an additional funded loading consideration should be attached to essential specialist care.

3. **How can IHACPA better support providers to participate in its cost collections to continue to improve their representativeness?**

MND Australia extend a meeting invitation to IHACPA to outline the breadth and depth of the services provided to ageing participants with a complex chronic disease such as MND. Without these services, people aged 65 and over living with MND are at risk of hospitalisation and/or entering residential aged care facilities. Each of these two systems are already experiencing significant burden and residential aged care services do not have the specialised care personnel required to meet the needs of a person living with MND.

As the peak body for MND in Australia, MNDA have access to an extensive database of information collated from all states across Australia as well as access to an extensive body of evidence-based information and research relating to the care needs of people with MND. We would be pleased to share this information, research and de-identified data to contribute to a more accurate cost collection process and resulting cost profile.

4. **What factors should IHACPA take into account when considering pricing adjustments for services provided in rural and remote areas?**

Duplicate response at question two:

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For the safe, efficient and appropriate care of participants with MND who are living in regions classified in MMM 3 – 7 an additional funded loading consideration should be attached to essential specialist care.

5. **What factors should IHACPA take into account when considering pricing adjustments for services provided for people from Aboriginal and Torres Strait Islander communities, people from culturally and linguistically diverse backgrounds and other people with special needs?**

MNDA request the specific inclusion of ‘people ageing with a complex chronic disease resulting in severe disability and high care needs’ be included as a special need criterion.

In section 5.2 of the consultation paper on the pricing framework, IHACPA list 'people with special needs' as:

- people from Aboriginal and Torres Strait Islander communities
- people from culturally and linguistically diverse backgrounds
- people who are financially or socially disadvantaged
- people who are experiencing homelessness or at risk of experiencing homelessness
- lesbian, gay, bisexual, transgender and intersex people
- people requiring trauma informed care

The costs associated with funding the care that is needed for people living with MND aged 65 and over far exceed the highest level of funding available. The maximum level of support under the SAH is $108,000. This includes a base package of approximately $78,000, plus an additional $15,000 for assistive technology and $15,000 for home modifications. Despite 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.

The progression of MND requires immediate and flexible access to high-cost supports, including assistive technology, home modifications, and complex care services, that far exceed what the SAH program is designed to provide. This mismatch between capped and delayed funding and the specialised care needs of people with MND results in many individuals being unable to access the timely and comprehensive support required.[vi] Additionally, palliative symptom management and end of life care costs also far exceed those provided in the current cost profile of SAH.

MNDA continue to advocate that aged care supports are funded at comparable levels to the NDIS. As outlined earlier, the average person living with MND under the NDIS in 2024 was $302,000.

MNDA requests a pricing adjustment for people ageing with a complex chronic disease exhibiting concurrent profound disability such as MND and who need to access additional and specialist care and therapy supports to achieve a safe, equitable, efficient and acceptable health and care outcomes.

6. What provider or participant-related factors should IHACPA take into account when considering data requirements and the pricing approach for the transition of the CHSP to the Support at Home program?

People living with MND are experiencing significant delays of up to a year when transitioning from CHSP to the current HCP. 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 may pass away prior to receiving a package. 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. When CHSP ends, no earlier than 2027, access and assessment delays are likely to increase (with all of the existing CHSP cohort entering SAH). Access to services wait times will likely increase and State MND Associations, that provide CHSP support and services will have no CHSP funding to bridge the gap. This will mean people aged 65 and over living with MND, who are a population group experiencing profound disability and loss could pass away while waiting for assessments and services.

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 require a complex assessment in every case and are likely to require a Level 7 or 8 package.

Even with priority/urgent requests for assessment, people living with MND who are 65 and over, are waiting extended periods of time of up to 6 – 8 months[vii].

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.

In a December 2024, Michael Perusco, chief executive of the National Disability Services revealed to the sector providers at the recent national conference that "the number of organisations looking to leave the disability sector entirely has more than doubled in the last 12 months". [viii]

MNDA and State MND Associations remain committed to providing the care and/or advocating for access to the multidisciplinary care needed for this complex cohort and we request IHACPA consider the higher costs and care urgency for this population, particularly when CHSP ends no earlier than 2027.

7. **What future priorities should IHACPA consider when developing pricing advice for the Support at Home service list?**

An additional specialist or 'complex care loading' to participants who are ageing with a chronic health condition with concurrent profound disability such as MND and who require:

- allied health and other therapeutic services
- assistive technology and home modifications
- nutrition
- service coordination and care management
- personal care
- support and community engagement
- therapeutic services for independent living
- respite
- transport
- domestic assistance
- home maintenance and repairs
- meals

An additional specialist or 'complex care loading' for rural and remote participants who are ageing with a chronic health condition with concurrent profound disability such as MND and who require complex and specialist metropolitan based supports for:

- allied health and other therapeutic services
- service coordination and care management
- assistive technology and home modifications.

For a specialist provider such as a State MND Association, care management and coordination of services to ensure the complexity of needs of people living with MND is met, requires more detailed support compared to a person ageing without this level of complex chronic need. While not all State

MND Associations are Aged Care providers, all State MND Associations provide coordination through MND Advisors and may provide free equipment loans for assistive technology.

Thank you for your consideration of the requests provided, which will support delivering person centred care and services by qualified and experienced providers for people living with MND and ensure people have a greater chance of staying in their homes longer.

We look forward to a response and the opportunity to provide detailed pricing input in relation to the Pricing Framework for Australian Support at Home Aged Care Services 2026-27.

Kind Regards,

Clare Sullivan
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mnd Australia mnd New South Wales mnd South Australia mnd Western Australia
mnd Tasmania mnd Queensland mnd Victoria

[i] MND Australia and Evohealth report. 2025. *Every moment matters. Addressing the human and economic toll of motor neurone disease in Australia.* Canberra.
[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
[iii] MND Australia and Evohealth. 2025. *Every moment matters. Addressing the human and economic toll of motor neurone disease in Australia*. Canberra
[iv] 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.
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[vii] MND Australia and Evohealth. 2025. *Every moment matters. Addressing the human and economic toll of motor neurone disease in Australia*. Canberra
[viii] ABC Listen 2024. Disability support sector warning of mass exodus of providers. Website accessed: 15/07/2025 https://www.abc.net.au/listen/programs/radionational-drive/disability-support-sector-warning-of-mass-exodus-of-providers/104704482