

Inquiry into Aged Care Service Delivery

August 2025



What is MS?

Multiple Sclerosis (MS) is the most acquired neurological disease in younger adults around the world with over 2.8 million people affected. More than 33,300 Australians live with MS and over 7.6 million Australians know someone or have a loved one with this potentially debilitating disease.

Symptoms vary between people and can come and go; they can include severe pain, walking difficulties, debilitating fatigue, partial blindness and thinking and memory problems. For some, MS is characterised by periods of relapse and remission, while for others it has a progressive pattern of disability. MS robs people of quality of life, primarily driven by the impact of MS on pain, independent living, mental health and relationships.

MS Australia is Australia's national multiple sclerosis (MS) not-for-profit organisation that empowers researchers to identify ways to treat, prevent and cure MS, seeks sustained and systemic policy change via advocacy, and acts as the national champion for Australia's community of people affected by MS.

MS Australia represents and collaborates with its state and territory MS Member Organisations, people with MS, their carers, families and friends and various national and international bodies to:

- Fund, coordinate, educate and advocate for MS research as part of the worldwide effort to solve MS
- Provide the latest evidence-based information and resources
- Help meet the needs of people affected by MS.

George Pampacos **President**

Rohan Greenland

Chief Executive Officer

Aged Care Service Delivery

MS Australia welcomes the opportunity to make a submission to the *Senate Standing Committee* on *Community Affairs* Inquiry into Aged Care Service Delivery. MS Australia welcomes this inquiry and the opportunity to comment on the delayed implementation of the Support at Home program and provide the committee with feedback on the suitability of the aged care system for older people with disability.

This submission draws on the experiences and expertise of MS Australia's state and territory Member Organisations. These Members Organisations deliver a range of supports to older people living with MS including allied health and nursing services, in-home care services, respite and community services. Some Member Organisations also support people living with other neurological conditions including stroke, Parkinson's disease, Huntington's disease, acquired brain injury and Motor Neurone disease.

MS Australia Recommendations

- MS Australia recommends that the government immediately release an additional 20,000 home care packages to meet the demands of the current waitlist and a publicly available planned approach to the release of the remaining packages by 30 September 2025.
- Improve the aged care system to ensure equity for older people living with disability including:
 - Allow older people to access supports in both the NDIS and the aged care system as per the recommendation of the NDIS Review
 - Review the levels of funding available under the new Support at Home Program so that:
 - Funding levels are increased to match the levels of funding available under the NDIS, OR
 - Allow care recipients to top up their aged care funding with supports funded through the NDIS
 - o Ensure the new Support at Home Program service list includes disability specific supports that allow people to maintain independence, choice and control

Older people with MS

Older people living with disability make up a substantial proportion of the Australian community with 2.3 million Australians aged 65 years and over living with disability. This means 52.3% of people aged 65 and over have a disability and this represents 41% of all Australians with disability. This is a rapidly growing cohort of older Australians, with an increase from 1.9 million in 2018.

For people living with MS, improvements in MS diagnosis, access to more effective Disease Modifying Treatments (DMTs), improvements in environmental exposures and health behaviours (such as decreasing smoking rates) and improved management of health comorbidities have resulted in disability milestones being reached almost eight years later on average ^{2,3}. The prevalence of MS and the life expectancy and average age of people living with MS have increased significantly during the last two decades ^{4,5}. This has led to an increasing number of older people living with MS⁶.

People living with MS over the age of 65 are more likely to have a progressive form of MS, with 63% living with either primary progressive, secondary progressive or progressive relapsing MS. This leads to increased mobility issues, co-morbidities, psychological and cognitive problems, bowel and bladder dysfunction and limitations on undertaking activities of daily living^{7,8}. There are also likely to have an increase in comorbidities including heart disease, psychiatric disorders, diabetes and cancer which can further increase levels of disability⁹. Late onset MS (after 50 years) occurs in 5% of cases and is characterised by a more progressive course and a higher prevalence of motor disability¹⁰.

As a result of these changes in the MS disease trajectory, increasingly people living with MS are accessing supports later in life (over the aged of 65), need more complex, disability specific supports and need them for a longer period.

a) The impact of the delay on older Australians waiting for support at home, including unmet care needs and the wellbeing of seniors and their carers.

MS Australia supported the delayed introduction of the new Aged Care Act to 1 November to ensure that providers, care recipients and the Department of Health, Disability and Ageing (the Department) are appropriately prepared. However, the delay in the implementation of the Support at Home program and the roll out of 83,000 new Home Care packages from 1 July 2025 will have significant impacts for older Australians, including people living with MS.

There are currently more than 80,000 Australians waiting for a home care package at their approved level, with wait times of up to 12 months. These wait times will be further exacerbated by the delay in the release of additional packages. The longer that people wait for appropriate aged care, the higher risk of increased disability, hospitalisation and early entry into residential aged care. For people living with MS a delay in adequate service can significantly impact their levels of disability and cause irreparable damage. It also leads to a loss of independence and choice.

MS Australia recommends that the government immediately release an additional 20,000 home care packages to meet the demands of the current waitlist a publicly available planned approach to the release of the remaining packages by 30 September 2025.

b) The capacity of the Commonwealth Home Support Programme to meet increased demand for support at home prior to 1 November 2025

The current Commonwealth Home Support Programme (CHSP) primarily focuses on the delivery of lower level supports such as transport, meal and domestic assistance. Many older people living with MS require access to nursing and allied health services to maintain health and wellbeing and slow disability progression. This includes physiotherapy, occupational therapy, dietetics and exercise physiology to improve mobility, balance and strength; manage fatigue, maintain independence; improve nutrition, manage bladder and bowel issues and to prevent symptoms from worsening over time. It is therefore unlikely that the CHSP could meet the needs of older people with MS prior to 1 November 2025.

c) the impacts on aged care service providers, including on their workforce

The delay in the implementation of the Support at Home program has created uncertainty for our Member Organisations. As many of their clients do not have packages or packages at their assessed level, the Member Organisations must choose to either fund the gap in care or know that their clients are without an adequate level of care. This causes serious stress and concern for the staff interacting with clients and witnessing their decline in physical and mental wellbeing. They are also unable to take on new clients due to this uncertainty, meaning that older people living with MS cannot have access to specialist MS aged care service providers.

d) the impacts on hospitals and state and territory health systems

A delay in the implementation of the support at home program is likely to lead to an increased use of emergency systems including ambulances, hospital emergency room and hospitalisations for older people. Older people are also likely to have longer hospital stays and rely on hospital-based rehabilitation services. This will place a significant burden on already overwhelmed state and territory health systems.

e) 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

Without the immediate release of additional home care packages, the Government is unlikely to meet their target of a 3 month wait time by 1 July 2027.

f) the adequacy of the governance, assurance and accountability frameworks supporting the digital transformation projects required to deliver the aged care reforms on time

MS Australia is unable to comment on this matter.

g) the implementation of the single assessment system and its readiness to support people to access a timely assessment now and beyond 1 November 2025

MS Australia is unable to comment on this matter.

h) Any other related matters

MS Australia requests that the Committee consider the suitability of the Support at Home program for older people with disability. The Aged Care Royal Commission and the NDIS Review have both stated that the current system does not meet the needs of older people living with disability. The new Support at Home program has some improvements, however, there are still substantial gaps in funding and supports.

Aged Care Royal Commission

The Royal Commission into Aged Care Quality and Safety (Aged Care Royal Commission) found that older people with disability receiving aged care do not have access to services and supports at the

same level as those provided to people through the NDIS. The Aged Care Royal Commission recommended the new aged care system includes equity for people with disability (recommendation 72):

By 1 July 2024, every person receiving aged care who is living with disability, regardless of when acquired, should receive through the aged care program daily living supports and outcomes (including assistive technologies, aids and equipment) **equivalent to those that would be available under the National Disability Insurance Scheme** to a person under the age of 65 years with the same or substantially similar conditions¹¹.

NDIS Review

The findings of the Royal Commission were supported by the NDIS Review. Which made the following recommendation:

The Australian Government should implement legislative change to allow participants once they turn 65 to **receive supports in both the NDIS and the aged care system concurrently** and clarify when aged care supports are reasonable and necessary (Action 2.11, NDIS Review Final Report)¹².

Support at Home Program Funding

MS Australia welcomes the introduction in July 2025 of a new Support at Home Program and acknowledges that the program's new classifications levels will have significantly higher funding than the current home care packages. However, there is still a significant gap compared to the current levels of funding available to people living with MS under the NDIS.

The new Support at Home classifications will provide funding of between \$11,000 and \$78,000 per year. Even allowing for some additional funds from the new Assistive Technology and Home Modifications (AT-HM) program, there is still a significant disparity with NDIS funding. Outlined below are the average annual payments for NDIS participants with MS:

NDIS participants with MS	Average annual payments	Average annual committed payments
All participants	\$103,600	\$133,900
Participants in Supported Independent Living (SIL)	\$525,600	\$585,800
Participants not in SIL	\$85,100	\$115,300

^{*} Data as of 30 June 2025 from the NDIS Quarterly Report¹³

As outlined in the data above, there is a gap between the annual committed and annual spent budget for NDIS participants. Currently, participants face administrative and planning challenges that prevent them from spending their full budget. With significant changes to the NDIS in 2025 it is anticipated that participants will have greater opportunity to spend their full committed budget. This would make the gap between NDIS payments and the proposed aged care budgets even more significant.

The above NDIS data also shows that participants who have access to SIL have significant budgets. Access to appropriate housing is crucial to people living with MS maintaining their independence. Older people with disability need access to housing that is driven by participant choice and control and that best meets their individual needs and long and short-term goals. MS Australia provided feedback on this funding discrepancy in our submission to the Department on the New Aged Care Rules Consultation – funding for Support at Home program.

Aged Care Service List

The aged care service list for the new Support at Home Program does not include all the disability supports available under the NDIS and has a strong emphasis on people moving to residential aged care when their needs increase.

Support to live independently, build skills, transition through life stages, train support workers, travel independently and engage fully in the community are not available under this new program. Further, many supports such as specialist behaviour support, are only available in residential aged care. MS Australia provided full detail of these gaps in our submission to the Department on the New Aged Care Act Rules Service List.

A gap in suitable supports for older people with disability is likely to lead to quicker disease/disability progression, increased hospitalisation, loss of independence and choice and early entry to residential aged care.

MS Australia recommends improving the aged care system to ensure equity for older people living with disability including:

- Allow older people to access supports in both the NDIS and the aged care system as per the recommendation of the NDIS Review
- Review the levels of funding available under the new Support at Home Program so that:
 - Funding levels are increased to match the levels of funding available under the NDIS, OR
 - Allow care recipients to top up their aged care funding with supports funded through the NDIS.
- Ensure the new Support at Home Program service list includes disability specific supports that allow people to maintain independence, choice and control.

Reference

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- ⁸ Sanai, S.A., Saini, V., Benedict, R.H., Zivadinov, R., Teter, B.E., Ramanathan, M. & Weinstock-Guttman, B. Aging and multiple sclerosis. *Mult Scler*. 2016 May;22(6):717-25
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