Support at Home Program Inquiry

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What is MS?

Multiple Sclerosis (MS) remains one of the most common causes of neurological disability in the young adult population (aged 18–40 years) with over 2.9 million people affected worldwide. More than 37,756 Australians live with MS and over 7.6 million Australians know someone or have a loved one with this potentially debilitating disease.

Three times as many women have MS than men. 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

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Support at Home Program Inquiry

Executive Summary

MS Australia welcomes the opportunity to provide a submission to the Community Affairs References Committee inquiry into the Support at Home program. The submission highlights barriers older people living with disability, including people living with MS, face in accessing appropriate, affordable and disability-specific supports through aged care.

Key concerns include inadequate funding, limited disability-specific supports, unaffordable co-contributions, inconsistent pricing, complex hardship assistance, thin markets, and increased provider administration. These issues can reduce access to care, equipment, home modifications, respite and allied health services, increasing the risk of avoidable hospitalisation, carer burnout and premature entry into residential aged care.

MS Australia recommends reforms to ensure equitable access to supports across aged care and the NDIS, including flexible funding, fair pricing and co-contribution settings, accessible hardship assistance, stronger transition protections, targeted action on thin markets, and proper recognition of provider administration costs. These changes are essential to uphold independence, choice and control.

Lived Experience

This submission draws on the experiences and expertise of MS Australia's Lived Experience Expert Panel (LEEP) and our state and territory Member Organisations. The LEEP is a panel of people who either live with MS or are a carer for someone living with MS who provide MS Australia with expert advice to inform our advocacy work. Our Member Organisations are registered National Disability Insurance Scheme (NDIS) providers and deliver a range of supports and services to people living with MS including support coordination, plan management, allied health, accommodation, respite, social support and in-home care. 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

Equity for older people living with disability

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 Support at Home Program so that:
    - Funding levels are increased to match the levels of funding available under the NDIS, or
    - Allow aged care recipients to top up their aged care funding with supports funded through the NDIS.
- Update the Support at Home Program service list to include disability specific supports that allow older people with disability to maintain independence, choice and control.

- **Client co-payment contributions:** A review of co-payment contributions for the Support at Home program to ensure that older Australians are not facing financial distress and can afford to access the level of care that they need.

- **Support at Home Pricing:** Review the Support at Home pricing arrangements to ensure they are transparent, consistent and do not reduce the value of care available to consumers. This should include clear national guidance on reasonable pricing, travel cost allocation and provider obligations, alongside monitoring of market behaviour to prevent inflated prices for essential disability-related services and equipment.

- **Financial Hardship:** make the financial hardship assistance process simpler and more accessible for older people with disability, including by providing alternatives to face-to-face appointments, proactive support to complete applications, and clear guidance for people with complex or progressive conditions. Hardship assistance should also be reviewed to ensure it addresses the higher costs of living with disability.

- **Avoidable Hospitalisation:** Strengthening the Support at Home program to prevent avoidable hospitalisation and premature entry into residential aged care. This should include timely access to respite, interim and high intensity supports for people with complex needs, and specific measures to ensure carers can access respite before they reach crisis point.

- **Support to transition to Support at Home Program:** Providing stronger transition protections and clearer communication for people moving from the Home Care Packages Program to Support at Home. This should include plain English information, funded navigation support, transparent explanation of co-contributions and service categories, and practical guidance for providers administering the 'no worse off' principle.

- **Thin markets:** Implementing targeted measures to address thin markets in regional, rural and remote areas, including additional funding for providers delivering essential supports, streamlined requirements for associated providers such as tradespeople, and incentives to improve access to allied health, nursing, personal care, assistive technology and home modifications.

- **Administrative burden:** A review of the administrative burden for providers under the Support at Home program and ensuring that they are appropriately funded for program administration.

Older People with Disability

Older people with disability are a significant and growing cohort within Australia's ageing population. In 2022, 2.3 million Australians aged 65 years and over were living with disability, representing 52.3% of this age group and 41% of all Australians with disability[1]. The prevalence of disability, particularly profound or severe limitation, increases substantially with age.

Despite this, the current aged care system does not adequately meet the needs of older people with disability, including those with fluctuating, episodic or progressive conditions such as MS. The Royal Commission into Aged Care Quality and Safety recognised this gap and recommended that people receiving aged care who are living with disability should have access to daily living supports, including assistive technology, aids and equipment, equivalent to those available through the NDIS[2]. This is also consistent with Australia's obligations under the Convention on the Rights of Persons with Disabilities, including the rights to accessibility, independent living, personal mobility, health, rehabilitation and full participation in community life[3].

For people living with MS, ageing can bring increased disability, progressive disease, greater comorbidities and more complex support needs. The majority of people with MS who are over 65 are not eligible for the NDIS and must rely on aged care services or self-fund essential disability supports.

Feedback from our LEEP members is the Home Care Packages (HCP) program was completely unsuited to the needs of a people with progressive neurological disorders. It was designed for

people who are very frail due to ageing, not for someone who is cognitively well but requires assistance and services to stay physically well, to address severe mobility impairment, to slow progression of physical disability and to mitigate extreme fatigue.

There has been no improvement under the new Support at Home program, with people finding it confusing, inequitable and impossible to navigate. Access to supports is limited by Department of Health, Disability and Ageing's failure to comprehend the needs of a person whose care needs are not caused by age but by the symptoms of an incurable, progressively disabling neurological condition.

The below case study is from an older person living with MS and outlines the issues that people living with MS have navigating the aged care system:

Case Study – Susan

Susan* is an older person who lives with MS and is ineligible for a NDIS package. After her experiences navigating the aged care system, she relinquished her home care package.

> *My experience with My Aged Care as a person living with MS was deeply frustrating and ultimately harmful to my wellbeing. MS is a progressive condition, and it important to manage your symptoms which requires access to specialised activities, therapies and assistive supports that maintain strength, independence and daily functioning. However, My Aged Care is built for frailty and age-related decline, not progressive disability.*

Disability specific supports

The most critical therapy for Susan is an intensive neuro-exercise program delivered three times a week. It helps maintain muscle strength, mobility, hand function and significantly slows deterioration. Yet My Aged Care had no mechanism to include this evidence-based therapy in her plan.

Susan relies on remedial massage to manage spasms, pain, gait problems and muscle overuse. Although her GP referred her to an MS-specialist therapist, the system required her to use a physiotherapy-aligned massage provider with rigid session caps. This therapist had no understanding of MS and the treatment made Susan feel worse.

Supports for meal preparation were similarly ineffective. Because her fatigue, weakness and dexterity issues make cooking dangerous, she needed reliable help – yet constant changes in workers, arbitrary participation rules and lack of cooking skills made the service stressful and unhelpful.

Susan was required to make a very significant co-payment towards her package, and this was a key consideration in surrendering it. Additionally, she paid a large management fee to a provider who did nothing to manage her plan and help her access the disability specific supports she needs.

Caring role

Susan's husband is 80 years old and has had several silent strokes, vision impairment, peripheral neuropathy, fatigue and has a heart Pacemaker. Following a recent assessment, he was advised that he did not quality for any services under the Support at Home program and that if any minimal safety accommodations were required (e.g. shower and toilet rails) they could be funded from Susan's package (which she had already surrendered). The expectation of the assessor was that Susan would be her husband's carer and provide all necessary care.

Outcome

Susan is currently self-funding her care which is more cost-effective that her home care package was but is still a considerable burden on her household budget. As a result of their experiences with the aged care system and lack of support, Susan and her husband have decided to sell their home and move into an aged care facility where support is available. This is not their preferred choice as they would have like to stay living in their own home. The aged care system has not supported them to maintain independence, choice and control.

* Susan's name was changed to protect her identity

MS Australia believes that the Support at Home program must be adequately funded and designed to meet the disability-specific needs of older people. This includes access to supports that enable people to maintain independence, remain in their chosen accommodation, participate in their communities and receive equitable support regardless of whether their disability was acquired before or after the age of 65.

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 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.
- Update the Support at Home Program service list to includes disability specific supports that allow older people with disability can maintain independence, choice and control.

The impact of the co-payment contributions for independent services and everyday living services on the financial security and wellbeing of older Australians

The introduction of co-contributions for both independence and everyday living services is likely to have a significant impact on the financial security and wellbeing of older Australians. In practice, some clients are required to contribute up to 80% of the cost of services. Our Member Organisations report that this is leading to behavioural changes from clients, including:

- requesting only the bare minimum level of care, and
- reducing essential services to remain within their financial means.

These impacts may be further exacerbated as price caps and pricing changes are introduced. Our Member Organisations have specific concerns regarding the way contributions are applied to certain services. For example, pre-prepared meal services (such as Lite n' Easy) can attract multiple contributions at different points in the transaction

1. Support at Home clients typically pay an upfront contribution (e.g. 30% of the cost), regardless of financial status; and
2. A further co-contribution is calculated on the remaining cost under the 'everyday living' service category and invoiced separately.

This process is often confusing for clients and can result in minimal perceived value – for example, where a client spends $70 but receives only $10 of benefit from their package. It also reflects the increasing administrative complexity and cost burden placed on providers.

Similarly, assistive equipment falls under the 'independence' category and attracts co-contributions, which can be cost-prohibitive for many clients. This is particularly concerning for high-cost items such as wheelchairs, electric beds and commodes.

For Support at Home clients without the financial capacity to contribute, access to essential equipment may be limited. This can lead to compromised care, for example, substituting showers with bed baths, which increases clinical risk and may ultimately result in avoidable hospitalisations.

LEEP members note that the copayment contributions can have a catastrophic impact on an already tight budget, especially for those on the Disability Support Pension or Age Pension who struggle to cover their basic needs.

MS Australia recommends a review of co-payment contributions for the Support at Home program to ensure that older Australians are not facing financial distress and can afford to access the level of care that they need.

Trends and impact of pricing mechanisms on consumers

Our Member Organisations report that there is currently a significant variation in how providers are managing the move to Support at Home pricing. Some providers have paused any changes to pricing until they better understand the program while other providers have built in full cost recovery (plus margin) into their pricing. This makes it difficult for consumers to understand what they will be charged now and into the future.

Currently, providers are required to build in average travel costs into their unit pricing, regardless of whether the service incurs a travel cost or not (depending on where the client is serviced). This creates cross-subsidisation of client funds between those clients being serviced on provider premises or in community locations versus those being serviced in-home or community.

LEEP members report that pricing for aged care services and equipment have become inflated as a result of the NDIS, creating a very distorted market. When seeking any disability services or supports people are first asked if they are on a NDIS package as providers see an opportunity to charge more.

MS Australia recommends reviewing the Support at Home pricing arrangements to ensure they are transparent, consistent and do not reduce the value of care available to consumers. This should include clear national guidance on reasonable pricing, travel cost allocation and provider obligations, alongside monitoring of market behaviour to prevent inflated prices for essential disability-related services and equipment.

The adequacy of the financial hardship assistance for older Australians facing financial hardship

Although financial hardship assistance can reduce or eliminate co-contribution fees, the process to access it through Services Australia is complex and often difficult for older people with disability to navigate. It typically requires a face-to-face meeting, which creates significant barriers particularly for people living in regional and rural areas. The distance to a physical office, combined with individual health complexities, can make the process almost impossible. For people with high or complex care needs, the effort required to attend a face-to-face meeting, can have a considerable impact on their already compromised physical health, forcing them to weigh up access to financial support against their wellbeing.

As outlined above, the current aged care system does not adequately meet the needs of older Australians living with disability. Hardship assistance does not address situations where clients require a higher level of care than their current package funding allows, leaving a gap for those

with complex or increasing support needs. It also does not account for the increased costs of living with disability.

Research undertaken by UNSW and ACCOSS[4] found that people with disability face an above-average risk of poverty and it is estimated that the rate of poverty among adults with disability is 17 per cent (compared with 13.4 per cent across the whole population) and that people with disability make up 33 per cent of all people in poverty. The report notes that this research is likely to under-estimate poverty among people with disability as it does not take account of the extra costs of living with disability.

Analysis of MS Australia's Australian MS Longitudinal Study (AMSLS)[5] shows that people living with MS now face health-related costs that are approximately seven times higher than the national average. For those with 'severe disability', the costs are more than triple compared with those living with no disability. Out-of-pocket costs for healthcare for people with MS are high, from specialist fees to medicines, imaging and allied health appointments. Additionally, there are costs for travel to appointments, parking, time away from paid work, childcare, access to exercise and dietary costs.

One LEEP member and her husband are both on a government pension and they are not eligible for financial hardship assistance as they are deemed to have too high an income and too many assets. This is despite still having a mortgage on their home, a car loan for an accessibility vehicle and no superannuation. The assessment for this assistance does not take into account these additional debts, gap in superannuation and the higher cost of living with disability.

MS Australia recommends making the financial hardship assistance process simpler and more accessible for older people with disability, including by providing alternatives to face-to-face appointments, proactive support to complete applications, and clear guidance for people with complex or progressive conditions. Hardship assistance should also be reviewed to ensure it addresses the higher costs of living with disability.

The impact on the residential aged care system, and hospitals

While the intent of the program is to support older Australians to remain safely at home, and in doing so reduce demand on hospitals and residential aged care, the current realities of the system suggest this is not consistently being achieved. Our Member Organisations have clients who have remained in hospital for extended periods, in some cases up to 16 months, before transitioning to interim care while waiting for a suitable residential aged care placement.

Changes to how respite is funded and what services can be used have also reduced access for older people to desperately needed respite services. There are currently waits time for 'cottage respite' of up to six months in some regions. This delay contributes to carer burnout and increases the likelihood of hospital admissions for social reasons, further adding pressure to already stretched hospital systems, or resulting in premature entry into residential aged care.

One LEEP member was transitioned from a state-based Continuity of Support (CoS) disability program to Support at Home and as a result can no longer access specialised disability respite facilities and must go to an aged care facility to access respite. This significantly reduces choice and control and the ability to access disability specific supports.

MS Australia recommends strengthening the Support at Home program to prevent avoidable hospitalisation and premature entry into residential aged care. This should include timely access to respite, interim and high intensity supports for people with complex needs, and specific measures to ensure carers can access respite before they reach crisis point.

The impact on older Australians transitioning from the Home Care Packages Program

The transition from the HCP Program to the Support at Home Program is a significant change for older Australians. While the Government has implemented a 'no worse off' principle to protect existing HCP recipients, ensuring they do not pay more than under previous arrangements, this protection applies primarily to those approved prior to key reform dates.

The increased complexity of the Support at Home system requires older Australians to navigate new service categories, pricing structures, co-contribution requirements, and service agreements. For many, particularly those with cognitive impairment, limited digital literacy, or without strong advocacy support, this complexity can be overwhelming and may reduce their ability to make informed decisions about their care. The transition has created multiple participant cohorts with differing financial arrangements, contributing to confusion and perceived inequity among clients and their families. Additionally, the application of the 'no worse off' principle falls to providers to manage, increasing the financial & operational burden of the program.

Many older people with disability have been moved to the Support at Home program as state and territory-based CoS programs are reduced or defunded. These people are moving from a system with disability specific supports into the age care system and are met with a significant reduction in their services. One LEEP member estimates that she lost approximately $60,000 in services per year and the inability to access disability specific supports under the new program, accompanied by the additional costs of co-payments.

MS Australia recommends providing stronger transition protections and clearer communication for people moving from the Home Care Packages Program to Support at Home. This should include plain English information, funded navigation support, transparent explanation of co-contributions and service categories, and practical guidance for providers administering the 'no worse off' principle.

Thin markets including those affected by geographic remoteness and population size

Feedback from our Member Organisations indicates that there is a lack of services available in regional and rural locations, especially essential supports including personal care, nursing care, allied health and therapeutic services. Additionally, home modifications in these areas are hindered by the lack of available tradespeople and the requirement for all tradespeople completing Support at Home funded works to onboard as an 'Associated Provider.' Many businesses see this as an obstacle in these regions, thereby making it increasingly difficult to arrange home modifications. One LEEP member was told by an aged care assessor that if they wanted any home modifications done in the next six months, they would need to fund it themselves (as an out of pocket expense) due to the waiting time for tradespeople.

MS Australia recommends implementing targeted measures to address thin markets in regional, rural and remote areas, including additional funding for providers delivering essential supports, streamlined requirements for associated providers such as tradespeople, and incentives to improve access to allied health, nursing, personal care, assistive technology and home modifications.

Other related matters

Our Member Organisations report that there is a significant increase in administration since the introduction of the new Support at Home Program including assessment, billing, compliance and brokerage contract management. However, if providers were to pass this cost onto clients, it would make their packages unsustainable. There needs to be greater recognition from the government of this administrative burden and incorporate this into funding considerations.

MS Australia recommends a review of the administrative burden for providers under the Support at Home program and ensuring that they are appropriately funded for program administration.

Conclusion

The Support at Home program must deliver equitable, affordable and disability-appropriate care for older people living with MS and other disabilities. Without stronger funding, fairer co-contribution and pricing settings, accessible hardship support, clearer transition arrangements and targeted action on thin markets, older people with disability will continue to face avoidable barriers to essential care. MS Australia urges the Australian Government to strengthen the program so people can remain safely at home, maintain independence, and exercise choice and control over their lives.

Reference

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[4] Davidson, P; Bradbury, B; and Wong, M (2023), *Poverty in Australia 2023: Who is affected.* Poverty and Inequality Partnership Report no. 20. Australian Council of Social Service and UNSW Sydney

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