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New Aged Care Rules Consultation –
Release 2a Funding for Support at
Home Program

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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

New Aged Care Rules Consultation

MS Australia welcomes the opportunity to comment on the *new Aged Care Rules – Release 2a Funding for Support at Home Program*. MS Australia previously provided submissions on the development of the [new Aged Care Act](#) and the [new Aged Care Service List](#) and emphasised the need to ensure that the new Act and Rules consider the needs of older Australians living with disability, including those living with MS. We welcome the release of the new Rules, and the comments and recommendations outlined below focus on ensuring the list meets the needs of Older Australians with disability.

MS Australia Recommendations

- Review the levels of funding available for older people with disability under the new Home Supports Program so that:
 - ❖ Funding levels are increased to match the levels of funding available under the NDIS.
 - OR
 - ❖ Allowing care recipients to top up their aged care fundings with supports funded through the NDIS
- The Department of Health and Aged Care provide more detailed information and advice on the new AT-HM program including eligibility and available supports. This should also include a consultation on the details of the program.

Older People with Disability

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 disability¹. This is a rapidly growing cohort of older Australians, with an increase from 1.9 million in 2018. Additionally, the rate of disability, especially profound disability, rapidly increases with age:

Profound or severe disability prevalence by age and sex, 2022

Age Group (years)	Males with disability (%)	Females with disability (%)	Males with profound or severe limitation (%)	Females with profound or severe limitation (%)
65–69	41.5	39.5	10.6	13.7
70–74	46.5	43.8	14.9	13.1
75–79	55.4	51.4	19.5	22.2
80–84	66.6	68.5	28.7	31.8
85–89	76.8	77.6	39.6	50.6
90 and over	86.3	82.2	64.7	68.8

Source: Australian Bureau of Statistics, Disability, Ageing and Carers, Australia: Summary of Findings 2022

Older Australians with disability are now making up the majority of the aged population and their needs are profound and complex. They require access to disability specific supports to meet these needs.

Aged Care Royal Commission

The current aged care system does not cater to the needs of older Australians living with disability, especially those with fluctuating or episodic disability or health conditions. 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 conditions².

NDIS Review

MS Australia has long advocated that older people living with MS should have access to NDIS supports to meet their disability needs. As such, MS Australia welcomed the following recommendation by the NDIS Review:

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)³.

The Final Report also notes that 'People aged over 65 will likely benefit from foundational supports, but should receive most of their supports from the aged care system'. They should be able to access the supports they need from the most appropriate system including disability appropriate supports from the NDIS and ageing supports from the aged care system.

Older people living with MS

Australians living with MS aged 65 and over when the NDIS was introduced and those who develop a disability and/or first access services after turning 65 are ineligible for the NDIS and must either self-fund their care or pursue their disability needs through the aged care system.

Improvements in MS diagnosis, access to more effective Disease Modifying Treatments (DMTs), improvements in environmental exposures and health behaviors (such as decreasing smoking rates) and improved management of health comorbidities have resulted in disability milestones for people living with MS being reached almost eight years later on average^{4,5}. The prevalence of MS and the life expectancy and average age of people living with MS have increased significantly during the last two decades^{6,7}. This has led to an increasing number of older people living with MS⁸.

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^{9,10}. There are also likely to have an increase in comorbidities including heart disease, psychiatric disorders, diabetes and cancer which can further increase levels of disability¹¹. 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 disability¹².

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.

Taking into consideration all the matters outlined above, it is critical that the new Support at Home program is sufficiently funded to meet the needs of older people with disability. The Support at Home program should provide adequate funds to allow older people to access disability specific supports, regardless of their age and supports to maintain their independence and remain in the accommodation of their choice.

New Aged Care Rules

Support at Home Funding

MS Australia acknowledges that the new Support at Home classification levels will have significantly higher funding levels 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	\$102,300	\$132,000
Participants in Supported Independent Living (SIL)	\$523,100	\$562,000
Participants not in SIL	\$83,700	\$112,800

* Data as at 30 September 2024 from the *NDIS Quarterly Report*¹³

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 the coming year 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. As outlined in our submission on the new [Aged Care Service list](#), the new list of supports is missing a range of housing supports including access to specialist disability accommodation.

These proposed funding levels need to be urgently addressed to ensure that older people with disability are not at a disadvantage if they get their supports from the aged care system. The new Support at Home program needs to better align with the recommendations of the Aged Care Royal Commission and the NDIS Review.

MS Australia recommends reviewing the levels of funding available for older people with disability under the new Home Supports Program so that:

- Funding levels are increased to match the levels of funding available under the NDIS, OR
- Allowing care recipients to top up their aged care fundings with supports funded through the NDIS.

Assistive Technology

MS Australia welcomes the introduction of an AT-HM program to provide a range of assistive technology and home modifications. However, it is unclear why the program has short-term and ongoing categories and what the difference is between supports available under each. We note that the list of eligible conditions for the short-term category includes multiple sclerosis. While we strongly support this inclusion, we would not welcome a system whereby access to assistive technology for older people is limited by a prescribed list of conditions. These supports should be available for all older people who need them. Alternatively, we would not welcome a system where people living with MS can only access short term supports and no longer term/ongoing supports.

The supports that will be available under the AT-HM program are essential for many older people and to date the list of supports has not been publicly released. The Department of Health and Aged Care needs to provide more comprehensive information on how the program will operate and undertake consultation before finalising the details.

MS Australia recommends the Department of Health and Aged Care provide more detailed information and advice on the new AT-HM program including eligibility and available supports. This should also include a consultation on the details of the program.

Reference

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