

A New Program for In-Home Aged Care Discussion Paper

NOVEMBER 2022

SUBMISSION



A New Program for in Home Aged Care Discussion Paper.

Associate Professor Des Graham

President

Rohan Greenland
Chief Executive Officer

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

Multiple Sclerosis (MS) is the most commonly acquired neurological disease in younger adults around the world with over 2.8 million people affected. More than 25,600 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.

A New Program for In-Home Aged Care

MS Australia welcomes the opportunity to respond to the *A New Program for In-Home Aged Care Discussion Paper* (discussion paper). MS Australia welcomes the introduction of a new program for in-home aged care to better support older Australians who wish to remain living in their homes as they age. This submission responds to the following key areas of focus for reform outlined in the discussion paper:

- Managing Services Across Multiple Providers
- Care Partners for Older Australians
- A Funding Model that Supports Provider Viability and Offers Value for Money
- Support that meets assessed needs, but is responsive to changes over time

MS Australia makes the following recommendations in relation to the discussion paper:

MS Australia Recommendations

- Future aged care reforms must reflect and meet the needs of older people with a disability
- Introduction of care partners for people receiving in-home aged care services
- Introduction of a separately funded scheme for goods, equipment, assistive technology, and home modifications
- Service providers have access to an additional pool of funds on top of an individual's budget to facilitate minor tops ups without needing a reassessment
- Older Australians can adjust the ongoing services listed in their initial support plan on a quarterly basis

Older People with a Disability

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 pursue their disability needs through the aged care system. The current aged care system does not cater to the needs of older Australians living with fluctuating or episodic disability or chronic health conditions. The Royal Commission into Aged Care Quality and Safety (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 National Disability Insurance Scheme (NDIS). The Royal Commission recommended the new aged care system include equity for people living with a 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 conditions¹.

Despite this recommendation from the Royal Commission, there is no reference in the discussion paper as to how the new in-home aged care program will meet the needs of older people with a disability. It is crucial that this Royal Commission recommendation is considered as part of the reform considerations outlined in the discussion paper. Older people with a disability must be able

to access the supports and services they need and to maintain their independence.

MS Australia recommends that future aged care reforms, including the in-home aged care program, must reflect and meet the needs the needs of older people with a disability and incorporates the recommendations of the Royal Commission.

Multiple Providers & Care Partners

MS Australia supports in-home aged care recipients having more choice and flexibility including the ability to access services from multiple providers. However, the introduction of greater flexibility must also be matched with support for older Australians and their families to coordinate their services, manage budgets and access care management.

MS Australia recommends the introduction of care partners as outlined in the discussion paper. MS Australia's experience of people living with MS receiving NDIS services is that the inclusion of Support Coordination in NDIS plans is crucial to ensuring people can navigate the disability system and access the supports they need. Participants, families and carers often lack the confidence and knowledge to navigate the system, engage with providers and advocate for themselves. Access to a trained professional who can help participants gain timely access to the services they need can lead to improved health and wellbeing outcomes, reduced stress and carer burnout and a reduced burden on the health, disability and aged care systems. Given the increased complexity of navigating the aged care system, MS Australia believes care partners can provide a similar role to that currently provided by support coordination under the NDIS.

Care partners should be available to older Australians who choose to have one and be able to provide the following supports:

- Onboarding to the aged care system and coordination of services
- Ensuring continuity of care
- Timely and flexible response to changing care needs, including crises and emergency events
- Facilitating clear communication and sharing of information across providers
- Assistance in managing budgets

Regardless of whether an older Australian chooses to have a care partner, the new in-home aged care program should ensure there are clear and enforceable guidelines in place for how providers will communicate with each other and ensure appropriate care management and continuity of care.

Funding Model & Support that meets assessed needs, but is responsive to changes over time

MS Australia supports the introduction of aged care pricing that is evidence-based and that captures the full costs of delivering care. Any funding model should ensure that older people with a disability can access the supports and services they need and that would be available under the NDIS to a person under the age of 65 years with the same or substantially similar condition

MS Australia recommends the introduction of a separately funded scheme for goods, equipment, assistive technology and home modifications with maintenance and refurbishment included, as outlined in the discussion paper. Access to these supports is crucial in ensuring that people living with MS can continue to remain in their home, maintain mobility and independence and engage in their local community. This should include access to the aids and equipment that would be available for people living with MS under the NDIS, including specialist wheelchairs, mobility aids, ramps and railings, continence aids, air conditioning and communication devices.

MS Australia recommends that service providers have access to an additional pool of funds on top of an individual's budget to facilitate minor tops ups without needing a reassessment, as outlined in the discussion paper. MS Australia supports setting this at around 25% of the total cost of a clients' budget each quarter. This flexibly in funding would provide support for people with fluctuating or episodic disability, including those living with MS, and ensure a timely response to crises, emergency events and episodic care needs. Additionally, MS Australia recommends older Australians would be able to adjust the ongoing services listed in their initial support plan as and when required within a quarterly budget, at outlined in the discussion paper. This would allow people living with MS to respond to their changing care needs, including alternating periods of relapse and remission.

MS Australia welcomes and strongly supports the ongoing work of the Department of Health and Aged Care to reform the aged care system and ensure that older Australians have access to the supports and services they need. MS Australia would be pleased to assist with any future consultations on the delivery of aged care to older Australians living with a disability, especially those living with MS.

Reference

1 Royal Commission into Aged Care Quality and Safety (2021). *Final Report: Care, Dignity and Respect (Volume 1).* Retrieved from: https://agedcare.royalcommission.gov.au/publications/final-report

