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New Aged Care Act Rules Consultation – Release 1 – Service list

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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

Associate Professor Des Graham
President

Rohan Greenland
Chief Executive Officer

New Aged Care Rules Consultation

MS Australia welcomes the opportunity to comment on the new aged care service list set out in the new Aged Care Rules. MS Australia previously provided a [submission](#) on the development of the new Aged Care Act and emphasised the need to ensure that the new Act consider the needs of older Australians living with disability, including those living with MS. We welcome the release of the new list and the comments and recommendations outlined below focus on ensuring the list meets the needs of Older Australians with disability.

MS Australia Recommendations

- The new Aged Care Service list should be updated to better meet the needs of older Australians living with disability including:
 - ❖ Updating the list to ensure consistency of wording with the NDIS list of supports
 - ❖ Incorporating more disability supports in the list to allow older people with disability to live independently in their choice of accommodation and remain active in their community
 - ❖ Removing the focus on people moving to residential aged care if their needs increase
 - ❖ Updating the list to provide more supports for people whose disability levels have significantly worsened with age
 - ❖ Providing more supports for carers and people who provide informal supports
 - ❖ Including more detail on the supports available under the *Assistive Technology and Home Modifications List*

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 represent 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.

Convention on the Rights of Person with Disabilities

The objects of the new draft Aged Care Act give effect to Australia's obligations under the *Convention on the Rights of Persons with Disabilities* (CRPD). The CRPD aims to enable persons with disabilities to live independently and participate fully in all aspects of life. As such, the aged care system should seek to meet the rights set out in CRPD³ including:

- **Accessibility:** Equal access to the physical environment, transportation, information and communications and to other facilities and services open or provided to the public (Article 9)
- **Living independently:** The ability to live in the community, with choices equal to others, and to facilitate their full inclusion and participation in the community (Article 19)
- **Personal mobility:** Measures to ensure personal mobility with the greatest possible independence for persons with disabilities (Article 20)
- **Health:** Enjoyment of the highest attainable standard of health including access for health and rehabilitation services (Article 25)
- **Habilitation & Rehabilitation:** Support to maintain maximum independence through comprehensive habilitation and rehabilitation services (Article 26)
- **Cultural Life, Recreation, Leisure & Sport:** the right to participate on an equal basis with others in cultural, recreational, leisure and sporting activities (Article 30).

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)⁴.

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^{5,6}. The prevalence of MS and the life expectancy and average age of people living with MS have increased significantly during the last two decades^{7,8}. This has led to an increasing number of older people living with MS⁹.

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^{10,11}. There are also likely to have an increase in comorbidities including heart disease, psychiatric disorders, diabetes and cancer which can further increase levels of disability¹². 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 disability¹³.

As a result of the changes outlined above, 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 aged care system can meet the needs of older people with disability. People should have access to disability specific supports, regardless of their age and be supported to maintain their independence and remain in the accommodation of their choice. However, the proposed Aged Care List of Supports 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. Outlined below are some of the services missing from the list.

New Aged Care Service List

The proposed Aged Care Service list has gaps for people living with disability including:

- **Housing** – access to specialist disability accommodation (known as supported independent living), supports for those in a group living situation and accommodation and tenancy assistance. These supports are crucial for allowing older people to remain living in the community and in housing situations that support their needs. The focus of the proposed service list is on either staying in a person's current home or moving to residential aged care.
- **Building of skills:** Funding that supports the building of skills including taking public transport, shopping, meal preparation, managing a participant's own personal care and participating in activities. The building of these skills is essential for older people with disability to remain independent and living in the community, especially for those whose disability levels have significantly worsened with age.
- **Assistance in coordinating or managing life stages and transitions** – support for major life transitions such as transition to new living arrangements, transition out of a mental health setting and transition out of a custodial setting. These supports ensure that older people with disability can maintain their independence and not be moved to residential aged care prematurely. The focus of the proposed service list is on transitioning from hospital to home or residential aged care.
- **Assistive Technology and Home Modifications List:** The AT-HM List is ambiguous and does not appear to include the full range of assistive technology supports available under the NDIS including personal recreation equipment modification, sporting equipment modification, assistive products for safety, customised prosthetics, training in the use of assistive technology and the full range of home modifications. The NDIS has also introduced a list of replacement supports for eligible participants that includes smart watches, tablets, smart phones and apps for accessibility/communication purposes.
- **Nursing** – it is unclear if the nursing supports outlined in the proposed list are the same as the NDIS as they use different terminology and may not include specialist disability care such as tracheostomy care and training of support workers to respond to a participant's complex needs.

- **Support workers** – training support workers, family and friends to perform roles where appropriate. Training this cohort of people can expand the number of people that provide supports, fill workforce gaps and provide the person living with disability assurance that they are supported by people who are fully trained. There is no allowance in the proposed list of supports for this training.
- **Driving training and vehicle modifications** – assistive products that can be added to vehicles or modifications to help the person operate, enter, exit or ride in the vehicle, driver training and training in the use of adaptive equipment/vehicle modifications. These supports ensure that older people with disability travel independently or with family and carers. Many people over 65 can continue to use a vehicle with appropriate modifications and training.
- **Service Animals** – including assessment, matching, grooming and dietary needs and veterinary services. Service animals provide crucial support for people living with disability and there is no access to them in the proposed service list.
- **Specialist positive behaviour support** - supports provided by professionals with specialist skills in positive behaviour support including assessment, delivery of management plans, staff training and monitoring, carer training and participant capacity building. The current proposed list of supports only provides behaviour support in residential aged care settings.

In conclusion, the current list is not adequate to meet the needs of older people with disability and urgent changes must be made before the roll out of the new In-Home Support program in 2025.

MS Australia recommends that the new Aged Care Service list be updated to better meet the needs of older Australians living with disability including:

- Updating the list to ensure consistency of wording with the NDIS list of supports
- Incorporating more disability supports in the list to allow older people with disability to live independently in their choice of accommodation and remain active in their community
- Removing the focus on people moving to residential aged care if their needs increase
- Updating the list to provide more supports for people whose disability levels have significantly worsened with age
- Providing more supports for carers and people who provide informal supports
- Including more detail on the supports available under the *Assistive Technology and Home Modifications List*.

Reference

- ¹ Australian Bureau of Statistics. (2022). *Disability, Ageing and Carers, Australia: Summary of Findings*. ABS. Retrieved from: <https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/2022>
- ² 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>
- ³ United Nations. (2006). *Convention on the Rights of Persons with Disabilities*. Treaty Series, vol. 2515, 3.
- ⁴ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (August 2021). *Rapid Evidence Review: Violence, abuse, neglect and exploitation of people with disability*. Retrieved from: <https://disability.royalcommission.gov.au/publications/rapid-evidence-review-violence-abuse-neglect-and-exploitation-people-disability>
- ⁵ Kister, I., Chamot, E., Cutter, G., Bacon, T.E., Jokubaitis, V.G., Hughes, S.E., Gray, O.M., Trojano, M., Izquierdo, G., Grand'Maison, F., Duquette, P., Lugaresi, A., Grammond, P., Boz, C., Hupperts, R., Petersen, T., Giuliani, G., Oreja-Guevara, C., Iuliano, G., Lechner-Scott, J., Bergamaschi, R., Rio, M.E., Verheul, F., Fiol, M., Van Pesch, V., Slee, M., Butzkueven, H., Herbert, J. & MSBase Investigators. Increasing age at disability milestones among MS patients in the MSBase Registry. *J Neurol Sci*. 2012 Jul 15;318(1-2):94-9.
- ⁶ Beiki, O., Frumento, P., Bottai, M., Manouchehrinia, A. & Hillert, J. Changes in the Risk of Reaching Multiple Sclerosis Disability Milestones in Recent Decades: A Nationwide Population-Based Cohort Study in Sweden. *JAMA Neurol*. 2019 Jun 1;76(6):665-671.
- ⁷ 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
- ⁸ Vaughn, C.B., Jakimovski, D., Kavak, K.S., Ramanathan, M., Benedict, R.H.B., Zivadinov, R. & Weinstock-Guttman, B. Epidemiology and treatment of multiple sclerosis in elderly populations. *Nat Rev Neurol*. 2019 Jun;15(6):329-342.
- ⁹ Ostolaza, A., Corroza, J. & Ayuso, T. Multiple sclerosis and aging: comorbidity and treatment challenges. *Mult Scler Relat Disord*. 2021 May; 50:102815.
- ¹⁰ Vaughn, C.B., Jakimovski, D., Kavak, K.S., Ramanathan, M., Benedict, R.H.B., Zivadinov, R. & Weinstock-Guttman, B. Epidemiology and treatment of multiple sclerosis in elderly populations. *Nat Rev Neurol*. 2019 Jun;15(6):329-342.
- ¹¹ 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
- ¹² Ostolaza, A., Corroza, J. & Ayuso, T. Multiple sclerosis and aging: comorbidity and treatment challenges. *Mult Scler Relat Disord*. 2021 May; 50:102815.
- ¹³ Louapre, C., Papeix, C., Lubetzki, C. & Maillart, E. Multiple sclerosis and aging. *Geriatr Psychol Neuropsychiatr Vieil*. 2017 Dec 1;15(4):402-408.



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