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Aged Care Funding Principles

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SUBMISSION

Aged Care Funding Principles

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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 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.

Aged Care Funding Principles

MS Australia welcomes the opportunity to provide a submission on the draft aged care funding principles. MS Australia welcomes the introduction of aged care funding principles to ensure that aged care funding is fair and equitable for all Australians, including those living with MS.

There are currently 33,300 people living with MS in Australia. For those aged 65 and over when the NDIS was introduced or who develop a disability and/or first access services after turning 65, they must pursue their disability needs through the aged care system. Therefore, equitable access to affordable and high-quality care is essential for older Australians living with MS.

MS Australia Recommendations

- The development of improved finance and payment materials for people navigating the aged care system including:
  - Best practice examples and case studies, including videos
  - Downloadable facts sheets and checklists
  - FAQs with clear, comprehensive answers.
- Aged care services are adequately funded to meet the needs of older people with disability and ensure they don't have to self-fund a shortfall in services.
- The introduction of a new earmarked aged care improvement levy as per *Recommendation 144* of the Royal Commission into Aged Care Quality and Safety.
- Aged care income testing takes into account the high cost of living with disability including progressive, neurological and neuromuscular conditions such as MS.
- All aged care reforms must reflect and meet the needs of older people with a disability and incorporate *Recommendation 72* of the Royal Commission into Aged Care Quality and Safety.
- An increase in funding for assistive technology with an emphasis on evidence-based and best practice supports.
- Better alignment of financing and pricing across the aged care and disability sectors.

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1. Is Australia's aged care system and how you pay for aged care easy to understand? If not, why not?

The current aged care system, including payment arrangements, is difficult to navigate for older Australians. Many people navigating the aged care system have no previous experience interacting with aged care and have a limited understanding of aged care programs, providers and associated costs. Many older people may have no carer or family support to assist them with this navigation. For people living with MS, symptoms such as brain fog, memory and fatigue make it difficult to understand and engage with complex information.

The current information available on aged care payment arrangements is brief and repetitive. It does not provide best practice examples, case studies, check lists, facts sheets or FAQs that provide clear, comprehensive answers.

MS Australia recommends the development of improved finance and payment materials for people navigating the aged care system including:

- Best practice examples and case studies, including videos
- Downloadable facts sheets and checklists
- FAQs with clear, comprehensive answers.

2. What does "fairness" in aged care funding and care services look like?

Currently, aged care services do not meet the disability specific needs of people living with MS. The funding cap on home care packages leaves many people receiving only basic services such as cleaning, personal care and meals. There is limited funding left for essential services including access to allied health and therapeutic services, supports for social and community participation and assistive technology. Residential aged care is focused on care for frail, older people and is not a suitable environment for people living with MS who are still active in their community.

Currently, older people living with MS must either self-fund the shortfall in aged care services or go without, causing a significantly increased rate of disease progression and disability leading to increased hospitalisation and greater long-term burden on the health and disability systems. A lack of appropriate supports to remain independent and living at home can lead to early and unnecessary entry to residential aged care and increase hospitalisation.

To ensure 'fairness' in aged care funding and services, aged care programs must meet the needs of older Australians living with disability. This group of care recipients should not be left to self-fund large shortfalls in services or go without.

MS Australia recommends aged care services are adequately funded to meet the needs of older people with disability and ensure they don't have to self-fund a shortfall in services.

3. Is funding for Australia's aged care system sustainable? If not, what is needed to make it sustainable?

MS Australia is concerned that funding for Australia's aged care system is not sustainable. The aged care system needs adequate long-term funding to ensure that older Australians can access all the services and supports they need.

In the final report of the Royal Commission into Aged Care Quality and Safety (Royal Commission)[1], Commissioner Briggs recommended the introduction a new aged care improvement levy:

> *By 1 July 2022, the Australian Government should introduce legislation to Parliament to establish an aged care improvement levy of a flat rate of 1% of taxable personal income. The levy imposed should be levied, and paid, for the financial year commencing on 1 July 2023 and for all subsequent financial years until the Parliament otherwise provides. The legislation introducing the levy should be based on the Medicare Levy Act 1986 (Cth).* (Recommendation 144).

To ensure long term stability of the aged care system, **MS Australia supports** the introduction of a new earmarked aged care improvement levy as per *Recommendation 144* of the Royal Commission. This will ensure sustainable and transparent funding for the aged care system now and into the future.

4. What costs do you think consumers in aged care should contribute to and to what extent? How is this different for care, compared with everyday living expenses or accommodation?

MS Australia understands the need to manage aged care costs through means testing of consumers. However, MS Australia is concerned that the current means testing arrangements do not take into account the high costs of living with disability.

People with disabilities, and their carers, are among the most socially and economically disadvantaged groups in Australia. This includes people living with progressive, neurological and neuromuscular conditions such as MS. AIHW data analysis [2] found that 38 per cent of people with disability and 51 per cent of people with severe or profound disability have a low level of personal income, compared to 27 per cent without disability. Research undertaken by UNSW and ACCOSS [3] found that people with disability face an elevated risk of poverty and it is estimated that the rate of poverty among adults with disability is 17 per cent and that people with disability make up 33 per cent of all adults in poverty. The true levels of poverty for people with disability are likely to be far higher given the report acknowledges it did not take int account the additional costs of living for people with disability.

For people living with MS and their families, the main drivers of poverty are high living and healthcare costs and reduced employment and economic opportunities[4]. Analysis of MS Australia's Australian MS Longitudinal Study (AMSLS)[5] shows that the annual cost of a person living with MS is $74,000 (up from $68,382 in 2017) with many of these being direct costs borne by the person living with MS and their carer. It also includes indirect costs from lost wages, informal care and early retirement. For those with 'severe disability', the costs are substantially higher at $123,333 compared with those living with low or no disability $32,829).

Lost wages account for 32 per cent of the economic burden of MS[6]. Many people with MS struggle to work full time hours and face poor workplace attitudes and unsupportive managers. People may have to change careers or take early retirement due to the unsuitability of their profession and/or inability to adapt their work to accommodate their disability. This reduced level of employment leads to financial stress and significantly reduced savings and superannuation. There are additional economic burdens for carers who may also have to reduce work hours, leave work or retire early to undertake their caring duties. It is estimated that over their working life primary carers in Australia will lose $392,500 in lifetime earnings and $175,000 in superannuation at age 67[7].

People living with MS face increased costs of healthcare related to their MS including specialist visits, increased GP visits, allied health services and medications. Many people living with MS have comorbidities including osteoarthritis, migraines, anxiety, depression and allergies which also attract increased healthcare costs. People living with MS also face increased living costs including home and car modifications, assistive technology, transport, energy costs (including air conditioning) and support services such as cleaning, laundry, shopping and gardening. They also face increased costs to undertake social activities and engage in their local community.

Many people living with MS struggle to access the Disability Support Pension. The current application process is difficult and lengthy, and assessment is inconsistent and not undertaken by staff with a good understanding of disability, especially progressive degenerative or 'invisible' disease such as MS.

MS Australia recommends that aged care income testing take into account the high cost of living with disability including progressive, neurological and neuromuscular conditions such as MS.

5. What does quality and appropriate care mean to you?

For people living with MS, quality and appropriate care means equitable access to supports equivalent to what would be available to them under the NDIS.

The 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 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 conditions*[8].

Despite this recommendation from the Royal Commission to date there is very little reference in the aged care reform agenda to meeting the needs of older people with disability. This includes the development of a new in-home aged care program. The A New Program for In-Home Aged Care Discussion Paper released by the Department of Health and Aged Care in October 2022 does not reference how the 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 underway across the aged care sector. 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 all aged care reforms must reflect and meet the needs the needs of older people with a disability and incorporate *Recommendation 72* of the Royal Commission.

6. What does innovation in aged care mean to you? How can funding support it?

Australia's aged care system must actively seek evidence-based and innovative ways to provide high quality care to older Australians. For people living with MS, access to innovative assistive technology is crucial to facilitating independence and participation in everyday activities. Assistive technology for people with MS can include:

- Mobility devices including wheelchairs, scooters, walkers and walking sticks
- Home modifications including ramps and grab rails
- Supports for eating, showering, dressing and toileting
- Supports for sitting, sleeping and lying down including pressure care mattresses and adjustable beds
- Communication aids including writing aids, vision and reading tools and voice recognition software
- Vehicle modifications.

There are also supports that are specific to people living with MS. Approximately 60–80% of people living with MS suffer temperature sensitivity where neurological symptoms can temporarily become exacerbated by environmental or exercise induced increases (or decreases) in body temperature causing a worsening of symptoms[9]. Access to air conditioning and cooling vests/suits can significantly reduce symptoms, however, many people need financial support to access these. Impairments in bladder and bowel function are common with MS and access to continence products and supports is crucial for maintaining good health and dignity for people living with MS.

Currently there is limited funding available under the home care packages and CHSP programs for assistive technology. For example, the average spend on assistive technology and home modifications per person per year for NDIS participants is $2,500, compared with just $51 per person per year for aged care recipients[10].

Most Australians living with MS must access assistive technology through state and territory-based aids and equipment programs. A study of assistive technology undertaken by Monash University[11] found that there are currently 87 Government funders, administering 108 assistive technology and home modifications schemes outside the NDIS. There is a distinct lack of equity and consistency across the schemes and people with similar needs receive different amounts of support depending on their age, geographic location and when and where their disability was acquired. The eligibility criteria across many of the schemes are historic in nature and are not fully aligned with assistive technology provision guidelines or good practice standards. Many schemes do not provide wraparound services to ensure appropriate customisation, training, set up and maintenance.

Access to innovative supports is not possible without adequate funding. **MS Australia** recommends an increase in funding for assistive technology with an emphasis on evidence-based and best practice supports.

7. What is the role of Government versus private investment in funding upgrades and constructing new facilities? Is the role different in rural and remote locations?

MS Australia has no feedback on this question.

8. Is there anything else you think the Taskforce members need to know about Australia's aged care system?

Aged care and disability sector reforms provide a unique opportunity to align policies, processes and regulation where applicable. There are currently a complex range of financing and pricing systems in place across these sectors. The Taskforce should take this opportunity to explore what areas of financing and pricing could be aligned across these sectors to make access easier and more equitable.

MS Australia recommends better alignment of financing and pricing across the aged care and disability sectors.

Reference

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