

A Roadmap to Support People Ageing with MS



Objective

People with MS have two fundamental needs:

1. Better treatments, prevention and, ultimately, a cure for the disease
2. Improved support for the management and care of MS

This Roadmap sets out what is needed **within the next 10 years** to ensure that we can continue to support people ageing with MS, especially those aged over 65 living with a disability. We want to make sure that everyone with MS has effective and appropriate management, interventions and support.

Why is this important?



MS is the most commonly acquired neurological disease in young adults around the world with over 2.3 million people affected.

25,600 Australians live with MS and over 7.6 million Australians know or have a loved one with this potentially debilitating disease.

25,600



Just over **half of Australians aged over 65 live with a disability**, with almost 20% of older Australians living with a profound or severe disability.



More than **100,000 people** across Australia are now waiting in the queue for a home-care package.

MS causes **significant and chronic disability** to people in the prime of their lives and therefore has a substantive health burden and economic cost to the Australian health system.



Costs to the Australian community now exceed **\$1.9 billion** every year. 50% is due to the **lost productivity** of Australians living with MS and their carers.



It is estimated that approximately **28%** of all MS organisation clients across Australia are aged **over 65**.



Therefore there are at least **7,200** people with MS aged over 65 who are, or may be, **accessing services and support as their condition progresses**.

1. Maintain the momentum of aged care reforms

What needs to be done?

The recommendations of recent aged care sector reviews need to be implemented and the current reform process needs to be progressed as a matter of urgency whilst the work of the Royal Commission into the aged care sector is undertaken.

The need to maintain reform momentum

On 16 September 2018, the Prime Minister announced a Royal Commission into the aged care sector. The Department of Health's website says:

"The Royal Commission will primarily look at the quality of care provided in residential and home aged care to senior Australians. It will also include young Australians with disabilities living in residential aged care settings."

In recent years there have been many reviews of the aged care sector and major reforms have commenced. For example, in 2017, the Government embarked on the More Choices for a Longer Life budget measure and in 2018 announced the Single Quality Framework and a new Aged Care Quality and Safety Commission.

MS Australia is keen to see the momentum of reform maintained whilst the work of the Royal Commission continues, and then to see the recommendations of the Royal Commission addressed and implemented as a matter of urgency.

DESTINATION

The aged care sector reform agenda is maintained and improvements to the sector are made whilst awaiting the recommendations of the Royal Commission.

2. Help people to stay at home as long as possible

What needs to be done?

People are adequately supported to stay at home for as long as possible through accurate assessment of functional impairments, making appropriate recommendations for their care and support and investing in additional, new home care packages.

Support to stay at home for as long as possible

We are keen to ensure that people are adequately supported to stay at home for as long as possible and only be recommended for residential care when every other possible avenue of care and support has been exhausted. This will, for example, require an intervention in Aged Care Assessment Team processes to ensure a person's functional impairment is accurately assessed and appropriate recommendations can be made for their care and support. We do not want people with MS to run the risk of being admitted to residential or aged care facilities earlier than is absolutely necessary.

This also necessitates investment in additional home care packages to alleviate long waiting lists. MS Australia supports the Council for The Ageing (COTA) recommendation for 30,000 additional packages to ensure older Australians never have to wait longer than three months.

What to consider when making an assessment

Eligibility for home care packages is assessed by Aged Care Assessment Teams; there is a need to mandate the appropriate, adequate and expert assessment of a person's disability

needs, including the application of an understanding of progressive neurological conditions such as MS, and other special needs that a person with MS may have; here are some examples:

- > Aids and equipment
- > Flexible respite options (for the person with MS and their carer(s))
- > Appropriate therapy/health service supports with a level of hours of support adequate to ensure a person can remain at home
- > Medical cooling (90% of people with MS are heat intolerant and run their air conditioners 15 times more than average households)

There is also a need to ensure an integrated approach to assessing the needs of the individual including the impact and implications for family. Often when ongoing support through, for example, an MS clinic, can be provided, the burden of care can be minimised and the family feel more able to sustain the home environment. Support for the primary carer and family to return to their own personal pursuits and roles is also critical.

DESTINATION

People with MS aged over 65 are adequately supported to stay at home for as long as possible through accurate assessment of any functional impairments, implementation of appropriate plans for their ongoing care and support, and an immediate investment of an additional 30,000 home care packages.

3. Equal access to assistive technology

What needs to be done?

State and Federal Governments must come together to develop a sustainable solution to the equitable provision of assistive technology to all Australians.

The current system

The National Disability Insurance Scheme (NDIS) provides support for people with disabilities, their families and carers. Rollout of the scheme commenced in 2013. In the aged care sector, My Aged Care is the main entry pathway to the aged care system, providing a central access point to aged care funding. Home care funding for older people living independently in their own home has been consolidated into two main programs: the Commonwealth Home Support Programme (CHSP) and Home Care Packages (HCP) Programme. Under this new funding structure, it is unclear where responsibility lies for addressing the assistive technology needs of older people with a disability, people acquiring a disability because of the ageing process and/or people experiencing frailty.

Funding and access to assistive technology for people over 65 in Australia is inequitable and confusing. Programs for people over 65 are spread across multiple departments at both the Commonwealth and State level. There is limited coverage under some private health insurance and condition-specific not-for-profits. Despite the spread of funding streams, many people are sacrificing their limited income to self-purchase or are simply falling through the gaps. The lack of clarity about what will happen to the Commonwealth Government's Continuity of Support Program after July 1st 2019 makes access to assistive technology all the more precarious.

Short term solutions

Federal and State Disability Ministers to:

1. Confirm funding arrangements after 1 January 2019 and provide clear information to the sector about where older Australians with a disability will go to receive their assistive technology services.
2. Confirm that they will honour their legislative obligations to provide support and services to all Australians living with a disability, by confirming they will continue to subsidise the purchase or hiring of assistive technology through state-funded assistive technology programs (such as SWEP in Victoria), until such time as an equitable program is developed for older Australians with a disability.
3. Ensure sufficient funding for assistive technology requirements is available to older Australians.

DESTINATION

A nationally consistent, adequately funded, assistive technology program is established, that provides equitable access to assistive technology such as would be available to people with disability aged under 65 years through either state programs or the NDIS.



A U S T R A L I A

About MS

Multiple Sclerosis (MS) is a chronic disease that attacks the central nervous system (the brain, spinal cord and optic nerves). The progress, severity and specific symptoms of MS cannot be predicted. MS is a lifelong disease for which a cure is yet to be found; however, doctors and scientists are making discoveries about the treatment and management of MS every day.

Common symptoms of MS

The symptoms of MS can be both visible and invisible to others, are unpredictable and vary from person to person and from time to time in the same person. They include:

changes in memory, concentration or reasoning

slurring or slowing of speech

extreme tiredness (unusual fatigue)

altered sensation, such as tingling, numbness or pins and needles

altered muscle tone, such as muscle weakness, tremor, stiffness or spasms

difficulties with walking, balance or coordination

visual disturbance, such as blurred or double vision

dizziness and vertigo

emotional and mood changes

pain

sexual changes

bladder and bowel changes

sensitivity to heat and/or cold

About MS Australia

MS Australia (MSA) is the national peak body for people living with MS in Australia. Our role is to work on behalf of all state and territory based member organisations to provide a voice for people living with multiple sclerosis across the country to support the development of:

- Research
- Advocacy and awareness
- Communication and information
- Services provided by our member organisations
- International collaboration.

MSA advocates across all stakeholders, governments and communities, on behalf of our members, to represent people who are diagnosed with the disease, their carers and the broader MS community.

MSA works closely with partner organisation, MS Research Australia – the largest not-for-profit funder and coordinator of MS research in Australia.

For information about Multiple Sclerosis and MS Australia: www.msaustralia.org.au