

A Roadmap to Support People with MS Living with Disability



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 improve support for people with MS 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.



On average, in 2017, the **quality of life** of people with MS in Australia is **31% less** than that of the overall Australian population.



The average age of diagnosis is only 30 and around 75% of those affected with MS in Australia are female.



Quality of life for people with MS who are living with **severe disability is 41% lower** compared to people with MS with no disability.



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.



This substantially reduced quality of life is primarily driven by the impact of MS on **pain, independent living, mental health** and **relationships**.

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.



1. Fully address NDIS issues

What needs to be done?

Address the many issues that have surfaced during the implementation phase of the NDIS.

When fully rolled out, the National Disability Insurance Scheme (NDIS) will directly benefit around 30% of the MS community (nearly 8,000 individuals). People with MS live with an unpredictable and often invisible disease, full of uncertainty. A commitment to addressing the many issues that have surfaced during the implementation phase, will reassure people with MS and their families, enabling them to maintain their independence and plan for the future.

Addressing issues during the implementation phase is crucial to ensuring that the disability needs of people with MS are met now and into the future, ensuring access to the Scheme is provided where there is need.

Implementation issues for people with MS include:

- > Difficulties with the planning process; lack of understanding of progressive neurological conditions by NDIA staff.
- > Difficulties with plan approval and plan implementation; poor communication with Support Co-ordinators and participants by Local Area Co-ordinators (LACs).
- > Errors in plans caused by the Agency not taking all the information provided by the participant into consideration. Often these are simple mistakes which could be easily avoided.
- > Difficulties with the planning review process; high volume of plans needing review; poor communication by NDIA staff regarding complaints and appeals.

In addition, it seems that those who are unable to express themselves clearly or who are unable to advocate for themselves end up with poorer funded supports in their plans.

DESTINATION

The NDIS is fully implemented in accordance with the original timetable and the most serious implementation issues are solved.



2. Improve employment options and workplace flexibility

What needs to be done?

Ensure the Disability Employment Services program maximises choice for people with MS.

People with MS are less likely to be employed than the general population. The gap in employment rates between people with MS and the general population is closing and is now within 4% of the general population, but more work needs to be done.

The Disability Employment Services (DES) program was changed from 1 July 2018 to give DES participants greater choice about the services they receive and how they receive them.

The changes aim to improve the overall performance of the DES program to help more people with disability, injury or a health condition find and maintain employment.

Whilst this reform is welcome, the rigid application of the new DES program guidelines limit what the MS specialist employment service providers are able to deliver. With the right advice and support from allied health professionals expert in MS, people with MS are able to find work and remain in their current employment longer.

The practical application of the Disability Employment Services rules contained in the DES Deed and DES Guidelines is not aligned to their overall intent nor with the goals of what the Australian Government is wanting to achieve in respect to labour force participation for people with a disability. For example, the modes of delivery permitted under the current way the guidelines are being applied, does not allow for any flexibility for people with MS working full time who may prefer regular contact through email or teleconference, rather than attending face-to-face meetings.

Also, the current Ongoing Support Guidelines do not correlate to the DES Documentary Evidence for Claims for Payments Guidelines thus restricting the provider's ability to deliver services aimed to improve the overall performance of the DES program and help more people living with MS to find and maintain employment.

DESTINATION

The implementation of the new Disability Employment Services program is adjusted to truly maximise flexibility, choice and control for people with MS.



3. Stop young people entering residential aged care

What needs to be done?

Investment in dramatically-improved accessible accommodation options, funding to provide an appropriate level of care within the NDIS, integration of the NDIS with the housing and health sectors, and investment in an appropriately trained disability support workforce.

More than 6,000 Australians aged under 65 live in aged care facilities. Of those, around 2,000 have joined the NDIS but so far only 2% of these participants receive housing support in their plans.

The recently announced Royal Commission into the aged care sector will seek to address the issue of young people living in residential aged care. MS Australia wholeheartedly supports this approach in the hope that it will prevent more young people from entering the aged care system.

New admissions of young people into residential care are not acceptable in 2018 and beyond.

Immediate adjustments are needed to:

- > Remove barriers to provide young people in RAC with NDIS packages, including Specialist Disability Accommodation allowances that enable young people to leave residential care.
- > Ensure the NDIS is integrated with the housing and health sectors so that accommodation options are available, equipment and other disability support needs are met as well as meeting health needs such as nursing and clinical supports.
- > Invest in an appropriately trained workforce to ensure young people with disabilities receive the support they need
- > Invest in specialist accessible housing and accommodation developments to dramatically increase supply
- > Commit state disability systems to deliver their full suite of services to young people who remain in aged care while they wait for the NDIS to reach them

DESTINATION

Admissions of young people into residential care is significantly reduced or stopped altogether through the implementation of an integrated care model and the provision of accessible accommodation options.





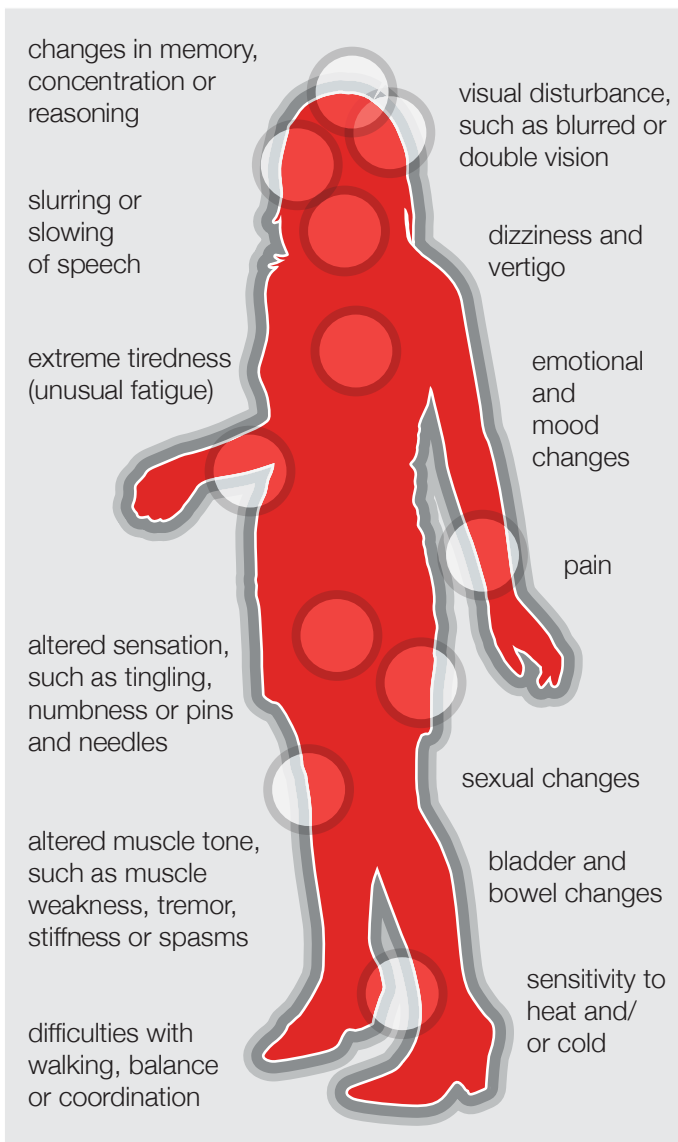
A U S T R A L I A

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:



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