

MULTIPLE SCLEROSIS AUSTRALIA

Submission to the Senate inquiry into out-of-pocket costs in Australian healthcare

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About Multiple Sclerosis Australia (MSA)

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.

Our Vision

Is consistent with the Multiple Sclerosis International Foundation's vision – '**A world without MS**'

Our Mission

MSA will support our members and work towards meeting the needs of people with MS, their families and carers. We will facilitate a national comprehensive representation of the Member societies through advocacy and communication.

Our Purpose

On behalf of our members and people with MS, our purpose is to develop:

- **Research:**
Supporting ongoing research to pursue further knowledge in targeting prevention, improving treatment, enhancing quality of life and ultimately, to find a cure.
- **Advocacy and Awareness:**
Although MS impacts people differently, there are common, fundamental issues for people affected by the disease. We are steadfastly committed to giving these people a voice and remain willing and able to work with government and the Australian society to champion issues in a dynamic policy environment to bring about change to the lives of people living with this disease.
- **Communication and Information:**
Utilising traditional, contemporary and innovative channels to source information and share it with people with MS, our member societies and our key stakeholders.
- **Support for our member organisations:**
As MS specialists providing and facilitating high quality services that span the life-time needs of people affected by MS and other degenerative neurological conditions, their families and carers – from the point of early symptoms and pre-diagnosis, that addresses their changing needs.
- **International Collaboration:**
Representing the MS cause and promoting collaboration with our domestic and international partners.

Introduction

MSA is pleased to make a submission to the Community Affairs References Committee's inquiry into out-of-pocket costs in Australian healthcare.

The focus of the material and recommendations provided in this submission is on key areas of expenditure where robust research material regarding healthcare costs for people with MS is available and where national position statements have been developed and agreed within MSA.

Background

Multiple Sclerosis (MS) is a debilitating disease of the central nervous system that affects more than 23,000 people throughout Australia with a further 1,000 people diagnosed every year. It is the most common chronic neurological condition afflicting young adults. The average age of diagnosis is between 20 and 40, and 75% of people diagnosed are women.

MS varies significantly from person to person. For some people, it is a disease that comes and goes in severity with periods of unpredictable relapse and remission. For others it is a progressive decline over time. For all, it is life changing.

Symptoms can include severe pain, walking difficulties, debilitating fatigue, partial blindness or thinking and memory problems.

There is no known cause or cure.

An Economic Impact study of MS conducted by A. Palmer in 2011 stated that, "the typical course of MS is initially relapsing-remitting, with symptoms partially or completely disappearing during remissions. However, after about 10 years, the majority of people enter a secondary progressive phase and disability gradually accumulates. For a smaller group, the disease course is primary progressive, with ongoing worsening of the initial presentation. Many of these people with MS develop other chronic conditions in the course of the disease."¹

With this background in mind, it can easily be seen that out-of-pocket costs for a person diagnosed with MS will be considerable and varied over a lifetime.

At the time of preparing this submission, MSA is concerned about the negative impact of the possible introduction of further healthcare costs, foreshadowed in the recent National Audit Commission's Report such as:

- A \$15 co-payment for all Medicare services including GP visits and pathology tests
- Prescriptions costs to rise to \$41.90
- Pressure on state governments to introduce hospital emergency department charges for less urgent conditions
- A \$4,000 threshold on middle and upper income people before they can claim extended Medicare safety net payments for big out of pocket costs
- Expansion of private insurance cover to GPs
- Limits to Commonwealth funding of public hospital services
- A slowing of the roll out of the NDIS.

Any increase in costs or the imposition of new costs represents a barrier to early diagnosis and the commencement of treatment for a person with MS, in addition to the increased healthcare cost burden borne over a lifetime for a person already diagnosed with MS.

¹ Palmer A., *Economic Impact of MS in 2010 Australian MS Longitudinal Study, September 2011*, page 7.

KEY AREAS OF EXPENDITURE

Aids and equipment

The MSA position regarding aids and equipment is that people affected by MS who require the support of aids and equipment should have timely and cost effective access to enable them to maintain optimal mobility, independence and support with minimal disruption.

One in ten Australians utilise aids and equipment. Most people with severe and profound disabilities require access to aids and equipment. These can include a very wide range of items such as crutches, wheelchairs, pressure mattresses, hoists, communication aids, smart-home technology and vehicle and home modifications.

There are currently a multiplicity of different aids and equipment funding schemes across Australia resulting in duplication, fragmentation and coverage gaps. The National Disability Insurance Scheme (NDIS) will help people with severe and profound disabilities live full lives in an inclusive society because it will enable better access to vital aids and equipment.

The report of “A Needs Analysis of Australians With MS” (a detailed study to assess the needs of people with MS prepared by Deakin University in collaboration with MS Research dated November 2012) stated that “there was a wide range of equipment that participants indicated that they needed, but did not have (most particularly heating and cooling) as well as equipment that they could not afford (e.g. car modifications).”²

The following table was included in the report.

Table 22. The percentage of people who require various types of equipment that they do not currently have, and the percentage of those people who cannot afford it.³

	<i>Need but don't have</i>	<i>Can't afford</i>
<i>Mobility aids</i>	10	53
<i>Computer-related aids</i>	6	53
<i>Continence aids</i>	8	20
<i>Home modifications to assist with mobility</i>	11	48
<i>Home modifications to assist with personal care</i>	10	46
<i>Car modifications</i>	5	61
<i>Other equipment (e.g. lifting aids, special beds)</i>	5	51

The study made the following recommendation regarding aids and equipment:

“6.4 Environmental Needs (Equipment and Transport)

- a) It is recommended that people with MS receive greater financial assistance to allow them access to equipment and/or modifications that they currently need, but cannot afford. This includes the following types of equipment/modifications: Mobility aids, computer related aids, home modifications, heating and cooling, and car modifications.
- b) Larger pieces of equipment appear to be too expensive for participants.”⁴

A national aids and equipment reform agenda is needed to enable people to live full lives in an inclusive society. MSA lobbies to address the ongoing failures of existing programs to deliver an ‘end-to-end’ aids and equipment program, and to facilitate the transition to full implementation of the NDIS.

² McCabe M., *A Needs Analysis of Australians with MS*, November 2012, page 42.

³ McCabe M., *A Needs Analysis of Australians with MS*, November 2012, page 42.

⁴ McCabe M., *A Needs Analysis of Australians with MS*, November 2012, page 123.

Recommendations

MSA recommends that the key elements of a national aids and equipment agenda should include:

- 1. A national purchasing, distribution and recycling framework across all aids and equipment programs that aligns existing schemes and supports and complements the NDIS. This framework should address the provision of information, effective assessment incorporating individual requirements, choices and preferences, referral, prescription, supply and training, maintenance, replacement and recycling as well as research and development;**
- 2. A commitment to no waiting under the NDIS, especially for people under the age of 18;**
- 3. Consideration of a PBS-style aids and equipment prescription system to support and complement the NDIS;**
- 4. Development of key linkages between aids and equipment provided under NDIS and that provided through related health, rehabilitation and aged care systems, especially for young people in nursing homes and residential aged care;**
- 5. Initiation of an industry development plan for an Australian aids and equipment manufacturing industry as most equipment is imported. The plan should address the development of an effective supply chain, a skilled and available workforce, a focus on equipment standards and the credentialing of service providers;**
- 6. The capacity to bulk purchase aids and equipment and related services on a national scale would enable NDIS to achieve some efficiency.**

Energy Costs

The MSA position regarding energy costs is that people affected by MS who require high energy usage to assist in symptom management should be offered financial assistance through means tested energy rebates.

Heat intolerance is a common symptom of MS occurring in approximately 90% of people with the disease. To manage this symptom, people with MS run their air conditioners approximately 15 times more than average households resulting in high energy use with consequent economic and environmental costs. Five jurisdictions (NSW, Qld, Vic, WA and the ACT) provide means tested energy rebates where there is a medical need.

In 2010, all state governments adopted the Medical Cooling and Heating Electricity Concession Scheme. This scheme provides a concession for low income households where high energy usage is the result of a medical condition. In 2012, the introduction of the federal program, Clean Energy Future included a concession for people with a health concession card where increased energy usage is the result of a reliance on medical equipment.

The Needs Analysis study stated that “participants frequently identified heating and cooling as an important unmet need. Just under half of the participants stated that they did not have it because they couldn’t afford it.”⁵

The following table was included in the report:

⁵ McCabe M., *A Needs Analysis of Australians with MS*, November 2012, page 119.

Table 22. The percentage of people who require various types of equipment that they do not currently have, and the percentage of those people who cannot afford it.⁶

	<i>Need but don't have</i>	<i>Can't afford</i>
<i>Heating or cooling</i>	21	48

The study recommended that people with MS receive greater financial assistance to allow them access to equipment and/or modifications that they currently need, but cannot afford including heating and cooling.

Recommendations

MSA recommends the development, implementation and impact evaluation of new energy efficiency programs, and improved targeting of existing programs, for people affected by MS where the management of symptoms results in high energy usage.

Examples could include:

- **Replacement of older inefficient air conditioners with high efficiency air-conditioners to reduce running costs and minimise carbon emissions**
- **Minor home retro-fitting of energy reduction strategies such as insulation and external window coverings.**

Pharmaceutical Benefits Scheme (PBS)

The MSA position regarding the PBS is that where treatments have been approved for use by Therapeutic Goods Australia (TGA) they should be readily available and affordable through PBS subsidies.

All newly developed medical treatments are required to be reviewed and approved by TGA before they are made available for use in Australia. However, these treatments, once deemed safe and effective, may remain unavailable to people with MS due to their high cost. Further review and approval by the Pharmaceutical Benefits Advisory Council (PBAC) enables these treatments to be financially subsidised by the Federal Government through the PBS reducing the financial burden on the individual.

The Needs Analysis study made a number of findings regarding the financial burden which MS places on individuals and families that are included in this submission. The Needs Analysis also referred to an earlier study by A. Palmer in 2011 that “examined the economic impact of MS in 2010 among an Australian sample with MS and found that MS imposes a financial and economic burden, which becomes substantially greater as the condition becomes more severe.”⁷

The Economic Impact of MS study found that in a breakdown of direct costs (personal and community/government) by MS severity, 59% of the mean cost per person was attributable to the cost of pharmaceuticals.⁸ The study also found that, “the cost of pharmaceuticals was similar for mild and moderate categories but decreased when the condition becomes severe. This is likely to be due to the MS-specific immunotherapies being reimbursed for RRMS (relapsing remitting MS) only, having limited efficacy in progressive forms of MS. Hence those with more severe disease are unlikely to be prescribed these treatments.”⁹

⁶ McCabe M., *A Needs Analysis of Australians with MS*, November 2012, page 42.

⁷ McCabe M., *A Needs Analysis of Australians with MS*, November 2012, page 4.

⁸ Palmer A., *Economic Impact of MS in 2010 Australian MS Longitudinal Study*, September 2011, page 37.

⁹ Palmer A., *Economic Impact of MS in 2010 Australian MS Longitudinal Study*, September 2011, page 37.

A breakdown of the mean (annualised) direct costs per person is shown in the table below.

Table 3.11 Direct costs – by cost category and disease severity per person with MS.¹⁰

	Mild	Moderate	Severe	Not stated	Total
Prescription medication	\$9,387	\$8,725	\$5,508	\$9,057	\$8,530
Non-prescription medication	\$226	\$303	\$400	\$291	\$284
Disposable equipment	\$53	\$121	\$468	\$95	\$144
Health professional	\$617	\$1,061	\$1,071	\$950	\$858
Nursing services	\$81	\$615	\$1,501	\$127	\$487
Community and private services	\$273	\$911	\$3,056	\$312	\$929
Medical tests	\$188	\$294	\$203	\$321	\$234
Hospital stay	\$125	\$326	\$921	\$375	\$335
Alterations to car/home	\$1,157	\$2,320	\$4,839	\$1,132	\$2,125
Special equipment	\$137	\$519	\$1,455	\$432	\$492
Total	\$12,244	\$15,194	\$19,422	\$13,092	\$14,418

Recommendations

In line with the diversity of symptoms and disease progression in MS, a diversity of treatment options provides choice and improved efficacy. This diversity of options should be readily available and affordable and:

- 1. Assessment of applications for treatments to be listed on the PBS should be streamlined to facilitate timely and affordable access to treatment options. Where Cabinet approval is required, the Government's approval process should be expedited to avoid unnecessary delays in access to treatment.**
- 2. Disease related private scripts should be included in the Pharmaceutical Safety Net.**

Conclusion

This submission identifies a number of structural and operational changes that would result in positive outcomes for people living with MS, their families and carers.

MSA asks the Committee to consider adopting the recommendations detailed in the various sections of the submission and once again thanks the Committee for the opportunity to participate in this inquiry.

¹⁰ Palmer A., *Economic Impact of MS in 2010 Australian MS Longitudinal Study, September 2011*, page 38.