MULTIPLE SCLEROSIS AUSTRALIA

Submission to the Review of Pharmacy Remuneration and Regulation

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About Multiple Sclerosis Australia

MS Australia (MSA) is the national peak body for people living with multiple sclerosis (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:

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

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

Our Vision

Is consistent with the vision of the Multiple Sclerosis International Federation – **'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 organisations 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 MS.
- **Communication and Information:**
  Utilising traditional, contemporary and innovative channels to source information and share it with people with MS, our member organisations 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

MS Australia (MSA) is pleased to provide this submission to the Review of Pharmacy Remuneration and Regulation.

The focus of the comments, suggestions and recommendations provided in this submission is on key areas that will impact on people affected by MS, with a particular emphasis on the cost of medicines and products available from the pharmacy.

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 affecting young adults. The average age of diagnosis is between 20 and 40, and 75% of people diagnosed are women.

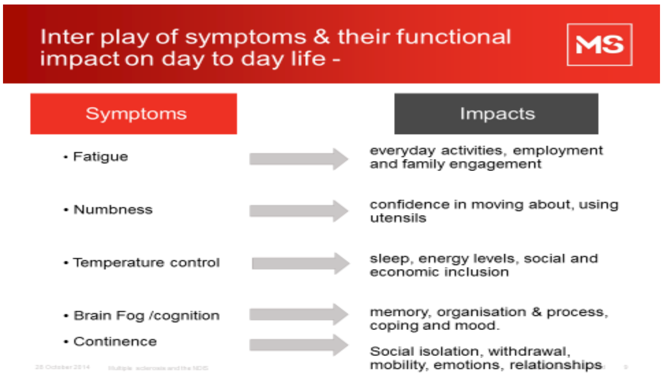
MS varies significantly from person to person. For some people, it is a disease that comes and goes in severity with periods of unpredictable relapse and remission. For others it is a progressive decline over time. For all, it is life changing.

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]

Common MS symptoms and their impacts are set out below.



Inter play of symptoms & their functional impact on day to day life -

Symptoms	Impacts
• Fatigue	everyday activities, employment and family engagement
• Numbness	confidence in moving about, using utensils
• Temperature control	sleep, energy levels, social and economic inclusion
• Brain Fog /cognition	memory, organisation & process, coping and mood.
• Continence	Social isolation, withdrawal, mobility, emotions, relationships

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

The importance of the provision of safe, effective, accessible and affordable treatments

MSA is particularly passionate about the provision of affordable and accessible treatments that can improve the lives of people with MS.

The challenges faced by people with MS can be significant and can have a devastating impact on their families and the wider community. Relapses can result in short term or long term disability, resulting in the need for physical and/ or psychological care and support, medical investigations, treatments and hospitalisation.

Being able to better manage and limit the frequency and impact of relapses can help alleviate the burden of MS on the community and the individual.

Overall, MS Australia believes each MS-specific medication provides another viable treatment option that will help to reduce the burden for many people with MS and their potential effectiveness at reducing relapse rates and severity could allow people with MS to maintain parts of their lifestyle for longer, such as employment, physical activity and exercise, as well as travel and socialising with friends.

Whilst these elements may not seem particularly significant, together they provide a person with MS purpose, focus, independence and drive which can be very useful in maintaining a high quality of life and staying on top of their symptoms. More broadly, it can ultimately mean less time in hospital, reducing the drain on valuable medical and disability resources, a lower cost for at home modifications and support, and prolonged employment, which helps to reduce the economic impact of MS on society.

Cost of MS to the individual

Out-of-pocket costs for a person diagnosed with MS will be considerable and varied over a lifetime, and MSA is opposed to the imposition of any measures that will increase these costs. We are advised that some clients of our MS service organisations are already on payment plans to pay off their pharmacy accounts by instalment.

The key concern of our submission to this Review is the cost of medications and medical products.

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.

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) 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.”[2]

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.[3] 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.”[4]

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

Table 1: Direct costs – by cost category and disease severity per person with MS.[5]

	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

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

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

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

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

The current process of providing a positive assessment of efficacy and safety from the Therapeutic Goods Administration, and ensuring accessibility and affordability through listing on the PBS makes all MS-specific medications part of the repertoire of medications available to people with MS and their neurologists. It allows for an appropriate treatment choice to be made according to the efficacy and possible side-effects in relation to an individual’s circumstances and will help to alleviate the economic cost of MS to individuals, their families and the broader community.

The timely and cost-effective dispensing of these medications is part of the process of ensuring effective management of MS.

Non-prescription medications and products

Non-prescription medications and other products for the treatment of MS symptoms such as enemas and suppositories and other products for assisting with continence issues, pain relief medications, hydrocortisone creams and ointments, and so on, all add to the cost of MS. These are not optional, luxury items, or “add ons”, but items essential to the effective management of MS.

MSA agrees with the comments set out on page 49 of the Discussion Paper regarding cost.

> *Despite the PBS Safety Net and other recent innovations, such as the potential for a $1 co-payment discount, cost can still be a barrier both to the purchasing, and quality use, of medicines. It has been put to the Panel by consumer groups that there is a need to contain out-of-pocket costs, particularly for people with chronic and complex conditions – or alternatively, spread the costs more evenly throughout the year.*
>
> *Some consumer groups have told the Review that people on low incomes who do not qualify for concession cards are particularly vulnerable to the impact of any increased costs. As a result, many delay or do not proceed with appropriate care or medication, risking an aggravation of their current condition that can potentially lead to higher costs to the overall health system in the future.*

The role of the community pharmacist

The community pharmacist plays an importance role in dispensing medications for the treatment of MS. This role is critical in providing safeguards against medication complications as set on page 45 of the Discussion Paper, although this safeguard is only effective if a person regularly uses only the one community pharmacy for all their medication needs.

Conclusion

MSA is grateful for the opportunity to provide a submission to the Review of Pharmacy Remuneration and Regulation.

As for many people affected by a chronic illness, the cost of medications and medical products for treating symptoms is the main concern for people living with MS. MSA urges the Review Panel to make recommendations that ensure medications and products are safe, effective, accessible and affordable for all.