

MULTIPLE SCLEROSIS AUSTRALIA

Submission to the Productivity Commission's inquiry into Superannuation: Assessing Efficiency and Competitiveness

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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:

- 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 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.

1. Introduction

MS Australia (MSA) is pleased to provide a submission to the Productivity Commission's inquiry into Superannuation: Assessing Efficiency and Competitiveness.

The focus of the comments provided in this submission are on key areas that will impact on people affected by MS. As stated above, MSA's 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.

MSA's member organisations are:

- MSWA (covering Western Australia)
- MS SA/NT (covering South Australia and the Northern Territory)
- MS QLD (covering Queensland)
- MSL (Multiple Sclerosis Limited covering Victoria, NSW, ACT and Tasmania)

Each of these state-based organisations operates independently to provide a range of services to people living with multiple sclerosis and, in some cases, to a broader group of people with other progressive neurological diseases. These services vary from state to state and include: phone information support and advice, on-line resources, MS clinics, specialist MS nursing, physiotherapy, education and information workshops, seminars and webinars, psychology, financial support, accommodation, respite, peer support co-ordination, employment services.

2. Advocacy and Support

A key component of the advocacy and support provided by MS Australia's member organisations is assisting people living with MS in employment, including as to their rights to benefits if they are unable to work.

Employment services, newly diagnosed client education programs and outreach programs have specific emphasis on employment superannuation and in particular rights to insurance benefits within superannuation.

3. The Importance of Insurance in Superannuation

MS is a condition that is usually diagnosed and can affect people during the course of their working lives (see Key Facts below). Many (although not all) experience periods of incapacity for work with some unable to work in the long-term.

Accordingly, MS is a chronic illness which can reduce a person's capacity to accrue superannuation during their working lives and to provide a sufficient retirement income. Over the last 20 years, MS Australia has arranged for legal, health and financial advice and support for more than 1000 clients with respect to insurance benefits within superannuation.

We have observed that many clients who experience broken work patterns because of their MS have received insurance benefits which have made the difference between having enough money to live off in retirement and dependency on the social welfare system.

The benefits can be life changing, providing clients with independent financial support. Generally speaking, MS is a non-compensable chronic illness which can be very debilitating and often creates major financial problems in funding day-to-day living, medication and medical supports (see Disease Burden and Economic Impact information set out below). This often leads to major loss of self-esteem and issues of depression which in turn can exacerbate the effects of MS and lead to long term welfare dependency.

It is our experience that accessing insurance benefits within superannuation can provide one of the only means to avoid this poverty trap.

Our State Members have seen many clients who do not have access to such benefits (such as the self-employed, and those whose employers do not pay superannuation) whose financial and health outcomes are invariably worse than clients who are able to access Total and Permanent Disability (TPD) or income protection insurance benefits and enjoy reasonable financial security in retirement.

It would be hard to overstate how important insurance benefits within superannuation have been in securing the retirement incomes and financial futures of people living with MS.

In our submission, it is crucial that TPD and to a lesser extent income protection insurance benefits remain accessible under the current opt out regime. Any reduction in the availability of insurance benefits and in particular automatic acceptance eligibility would have significant consequences for people with chronic illnesses whose working lives may be cut short because of disability, such as MS.

Of course, such benefits come at a cost in premiums and must be offered in an efficient and cost-effective manner. This may include product design measures such as standard default definitions including retraining and eliminating duplicate income protection insurance cover.

However, any measures which put at risk what has been a major success story in delivering life insurance to Australians should be guarded against.

KEY FACTS:

- Multiple sclerosis (MS) is a neurological condition affecting the central nervous system (brain and spinal cord) that affects more than 23,000 people throughout Australia
- It is the most common chronic neurological condition diagnosed in young adults.
- MS is most commonly diagnosed between the ages of 20 and 40
- 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 means a progressive decline over time. For all, it is life changing.
- 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.
- There is no known cause or cure.

DISEASE BURDEN AND ECONOMIC IMPACT OF MS:

- In 2010, MS was conservatively estimated to cost Australia over \$1.042 billion each year -based on a conservative prevalence estimate of 21,283 people with MS in Australia (2010 figures). This represents an average annualised cost per person with MS of approximately \$48,945 (based on the 2010 Consumer Price Index)¹, which is compared globally and found to be greater than other long-term chronic conditions such as asthma, chronic obstructive pulmonary disease and diabetes, and most other brain disorder cost estimates (mental and other neurological disorders)².
- Loss of productivity as a result of MS accounts for 48% of the overall cost of MS, suggesting that MS costs the Australian economy over \$494 million a year– the largest indirect cost associated with this disease³.
- Australians with MS spend a combined \$78 million a year in out-of-pocket expenses⁴.
- MS is the leading cause of non-traumatic disability among young and middle-aged people⁵.
- The care provided by family and other informal carers to Australians with MS would cost \$145 million a year to replace⁶.
- Of the number of people living with MS, 15,800 (66.7%) needed assistance with at least one of the 10 everyday activities considered in the 2009 Survey of Disability, Ageing and Carers (SDAC)⁷.
- Notably, 46% of people with MS needed assistance with mobility tasks (ABS 2012).
- Of the 20,400 people with MS aged 15-64 years, an estimated 9,800 were employed, with 5,900 of those people employed part-time⁸.
- People with MS have lower employment participation i.e. are less likely to be in paid employment compared to those with other chronic diseases⁹.

¹ Palmer, A. 2010, *Economic Impact of Multiple Sclerosis in 2010 Australian MS Longitudinal Study*, s.l.: Covance Pty. Ltd. & Menzies Research Institute Tasmania.

² Giovannoni G, Butzkueven, H, Dhib-Jalbut, S, Hobart, J, Kobelt, G, Pepper, G, Sormani, MP, Thalheim, C, Traboulsee, A & Vollmer, T 2017, *Brain health - Time matters in multiple sclerosis*, Oxford PharmaGenesis Ltd, Oxford.

³ Palmer 2010

⁴ Palmer 2010

⁵ Multiple Sclerosis International Federation (MSIF) 2013, *Atlas of MS 2013 - Mapping multiple sclerosis around the world*, s.l.: Multiple Sclerosis International Federation.

⁶ Palmer 2010

⁷ Australian Bureau of Statistics (ABS) 2012, *4429.0 - Profiles of disability, australia, 2009, Multiple Sclerosis*

⁸ Palmer 2010

⁹ Simmons, RD, Tribe, KL & McDonald, EA 2010, Living with multiple sclerosis: longitudinal changes in employment and the importance of symptom management, *Journal of Neurology*, 257(6), pp. 926-36