MS
AUSTRALIA

Year in Review

the year to 30 June

2017

A world without Multiple Sclerosis

Contents

Vision

A world without multiple sclerosis.

Mission

Working with and representing our member organisations to meet the needs of people affected with Multiple Sclerosis (MS), their families and carers. To improve their well-being through leadership in advocacy, communication, brand and collaborative relationships and, in collaboration with, and support for, MS Research Australia, advancing research into the cause, prevention and a cure for MS.

Who we are

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.

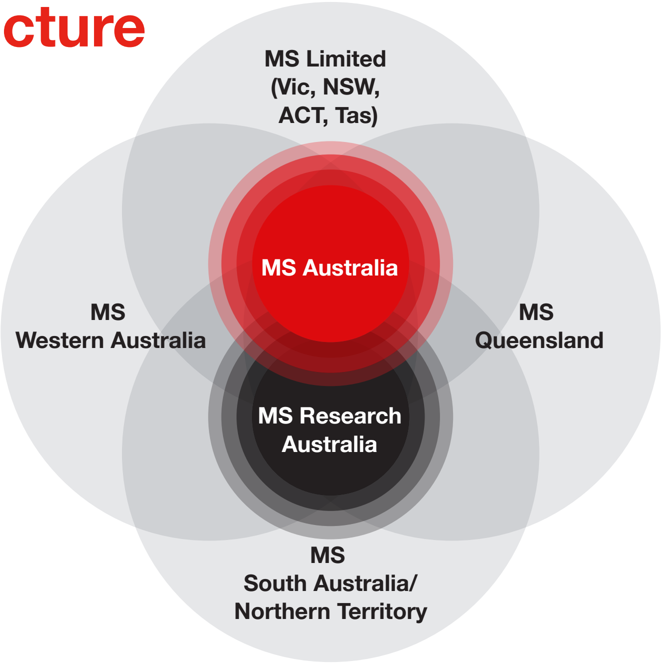
Support for our member organisations

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

MS Australia is the Australian representative member of the Multiple Sclerosis International Federation (MSIF), advancing the MS cause worldwide and promoting collaboration with our international partners.

Our MS family structure



The MS Australia Board

(for the period 1 July 2016 - 30 June 2017)

Mr Anthony Abbott AM

Mr Ron Brent (alternate for Ian Gordon)

Mr Roger Burrell

Professor William Carroll

Dr Annette Carruthers (Vice-President)

Mr William Peter Day

Ms Christina Gillies

Major General Ian Gordon AO

Assoc Prof Desmond Graham

Ms Christine Hahn

Mr William Hassell AM

Ms Sophie Langshaw

Mr Paul Murnane

Mr Ian Pennell AM (President)

Mr Alan Scott

MS Australia staff

Deidre Mackechnie
Chief Executive Officer

Bea Beswick
Project Officer

Mark Campbell
National Website and Social Media Editor

Patrick Foong
Finance Manager

Andrew Giles
National Policy Officer

Mary Michaliades
Executive Assistant

Lisa Montague
National Advocacy, Publications and Media Officer

Andrew Potter
National Advocacy Coordinator

Parliamentary Friends of Multiple Sclerosis

Purpose

The Parliamentary Friends of MS (PFMS) was established and is managed by MS Australia. It provides a non-partisan forum for MPs to meet and interact with volunteer advocates from the MS community and representatives from MS Australia, its member organisations in each state and MS Research Australia, on matters relating to raising awareness of the needs of people living with MS and opportunities to advance research into the cause, prevention and a cure for MS.

The Group is open to all Senators and MPs and has no sponsorship from external organisations. It was formally registered with the 45th Australian Parliament in April 2017 and has ten members.

The following MPs and Senators have agreed to membership of the Group:

NAME	ELECTORATE/STATE
Senator Helen Polley	Tasmania
Senator Glenn Sterle	Western Australia
Senator Claire Moore	Queensland
Senator Rachel Siewert	Western Australia
Mr Andrew Laming MP	Bowman, Queensland
Ms Justine Keay MP	Braddon, Tasmania
Ms Amanda Rishworth MP	Kingston, South Australia
Senator Louise Pratt	Western Australia
Senator David Bushby	Tasmania
Senator Deborah O'Neill	New South Wales

Co-convenors

The PFMS is co-convened by Senator Deborah O'Neill (Labor, NSW) and Senator David Bushby (Liberal, Tasmania).

Senator Deborah O'Neill
(Labor, NSW)

Senator David Bushby
(Liberal, Tasmania)

Activities

Hosted launch of Neurological Alliance Australia Joint Position Paper

The main activity for the PFMS during the year was to co-host the launch of the Neurological Alliance Australia (NAA) Joint Position Paper on the Implementation of the NDIS on Wednesday 22 March at Parliament House, Canberra, along with members of the other Parliamentary Friends groups that comprise the membership of the NAA.

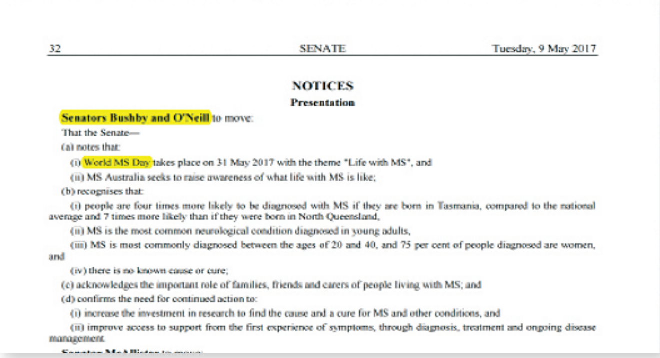
More details of this event are included in the Neurological Alliance section of this Review.

National advocates Erin Brady (left) and Lynne Smith (right) with Senator Deb O'Neill at Parliament House on Wednesday 22 March 2017.

Motion in Senate to recognise World MS Day 2017

The 45th Australian Parliament recognised World MS Day 2017 through a motion moved by our PFMS Co-chairs, Senators O'Neill and Bushby, and passed by the Senate on 10 May.

More details can be found in the World MS Day section of this Review.



32 SENATE Tuesday, 9 May 2017

NOTICES

Presentation

Senators Bushby and O'Neill to move:

That the Senate—

(a) notes that:

(i) World MS Day takes place on 31 May 2017 with the theme "Life with MS", and

(ii) MS Australia seeks to raise awareness of what life with MS is like;

(b) recognises that:

(i) people are four times more likely to be diagnosed with MS if they are born in Tasmania, compared to the national average and 7 times more likely than if they were born in North Queensland,

(ii) MS is the most common neurological condition diagnosed in young adults,

(iii) MS is most commonly diagnosed between the ages of 20 and 40, and 75 per cent of people diagnosed are women, and

(iv) there is no known cause or cure;

(c) acknowledges the important role of families, friends and carers of people living with MS; and

(d) confirms the need for continued action to:

(i) increase the investment in research to find the cause and a cure for MS and other conditions, and

(ii) improve access to support from the first experience of symptoms, through diagnosis, treatment and ongoing disease management.

Member of Multiple Sclerosis International Federation

The MS International Federation has 49 members and links to many other organisations.

The MS International Federation is the only global network of MS organisations. All of its members share a belief that the challenges in MS are worldwide, and the solutions must be too. It can be more effective and efficient by sharing its members' experiences and speaking with one voice.

MS Australia is the representative member of the Multiple Sclerosis International Federation (MSIF) for Australia.

MS Australia works actively with the MSIF leadership and other MSIF members to progress the aims of the MSIF strategy.

We are pleased to be able to contribute to MSIF's planning for World MS Day each year and to make regular contributions to MSIF publications.

More details on our work with MSIF can be found under 'International Activities'.

MSIF member organisations:

What we do and Our achievements

National Advocacy

MS Australia is the national peak body for people living with MS in Australia. We work on behalf of all state and territory based member organisations to provide a voice for people living with MS to support the development of:

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

MS Australia 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, focusing on national issues.

MS Australia is an active member of other peak bodies in Australia such as the Consumers Health Forum, the Australian Council of Social Services, National Disability Services and the Neurological Alliance Australia, working collaboratively to advance the interests of people affected by MS.

National Advocate Jenny Wallis (left) with the MS Australia National Advocacy Coordinator Andrew Potter and Justine Keay MP, Member for Braddon, Tasmania, at Parliament House, Canberra, March 2017.

National Advocates

Advocacy work is delivered through a range of activities including our National Advocates Program under the stewardship of our National Advocacy Coordinator. The Program is delivered by a network of volunteer Advocates, who advance MS Australia annual priorities and reinforce our Mission and Purpose. Photos and bios of our current team of National Advocates can be found on the MS Australia website at https://www.msaustralia.org.au/about-MSA/who-we-are/advocates

The National Advocates Program recruits and trains people with MS, and carers, to be effective Advocates and participate in public policy debates. Mentoring, support and information sharing assists the MS Australia Advocates to participate in a wide range of activities. Through this Program, MS Australia makes regular representations to Federal parliamentarians, gains media exposure and makes submissions to Australian Government enquiries.

National Advocacy Conference

At the March 2017 MS Australia Advocacy Conference in Canberra, the National Advocates learnt how to use social media as a strategy to effect change.

This social media training, presented by members of the MS Australia team, had a particular focus on the practical aspects of using the platforms used by MS Australia – Facebook and Twitter and included:

- Examples of positive impact of social media on a campaign
- Getting the message right, reputation, image, style
- How do you measure social media success?
- Connecting with the MS community, the broader community, your MPs and their staff and other ‘like’ organisations
- Setting up your account
- Dealing with ‘trolls’ and responding to negative messages

Feedback from our National Advocates indicated that this was one of our best conference/training sessions ever!

The conference was also a chance to interact with Federal politicians and their advisors at a combined Parliamentary Friends event at Parliament House in conjunction with other members of the Neurological Alliance Australia.

National Disability Insurance Scheme (NDIS)

MS Australia continues to work with our State and Territory Member organisations to closely monitor NDIS implementation, to enable early identification of issues that require advocacy.

In the year to 30 June 2017, NDIS advocacy work included two major submissions to the Australian Government, leading the work of the Neurological Alliance Australia (including a meeting between the MS Australia CEO who is also Chair of the NAA and the Minster responsible for the NDIS, the Hon Jane Prentice MP), continuing to contribute to the work of the peak body National Disability Services, and participating in various workshops, conferences and panel sessions, all regarding various aspects of issues associated with the implementation of the NDIS.

Submissions

MS Australia seeks to develop strong networks and build relationships of influence with federal parliamentarians and other government and departmental thought leaders and decision-makers to raise awareness of MS, particularly systemic issues at the national level. To this end MS Australia makes submissions to national enquiries on issues that affect our member organisations and people living with MS.

In the year to 30 June 2017, MS Australia made submissions to the:

- Senate inquiry into the delivery of outcomes under the National Disability Strategy 2010-2020
- Department of Infrastructure and Regional Development Consultation on The Whole Journey Guide (accessible public transport inquiry)
- Public Health (Medicinal Cannabis Affordability) Bill 2017 – Queensland Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee (joint submission with MS Research Australia)
- National Disability Insurance Scheme (NDIS) 2017 Price Controls Review
- Productivity Commission's review of NDIS costs (Round 1, on behalf of the Neurological Alliance Australia)
- Draft Programme Manual for the new Commonwealth Continuity of Support (CoS) Programme
- Review of Pharmacy Remuneration and Regulation
- New Disability Employment Services from 2018
- ILC Commissioning Framework
- Victorian State Disability Plan 2017-2020 (joint submission with MS Limited)
- Federal Government Pre-Budget submission to Treasury.

Pharmaceutical Benefits Advisory Committee

MS Australia is particularly passionate about the provision of affordable and accessible treatments that can improve the lives of people with MS. As with all MS medications, the efficacy, side-effect profiles and tolerability of a drug can vary greatly between individuals, and it is for this reason that a range of affordable treatment options is necessary to increase the chance of every individual finding an effective and well tolerated treatment that suits their individual circumstances.

MS Australia works with MS Research Australia and relevant pharmaceutical companies to make submissions to the Pharmaceutical Benefits Advisory Committee (PBAC) for listing of MS medications on the Pharmaceutical Benefits Scheme (PBS) to ensure they are accessible and affordable.

Two submissions were made to the PBAC during the year:

- Ocrevus® (ocrelizumab) for relapsing remitting MS
- Copaxone® (glatiramer acetate) for clinically isolated syndrome.

Neurological Alliance Australia (NAA)

The Neurological Alliance Australia is an alliance of not-for-profit peak organisations representing adults and children living with progressive neurological or muscular diseases in Australia. The Alliance was established to promote improved quality of life for people living with these conditions and funding to support research. Members of the Alliance include Alzheimer's Australia, Brain Injury Australia, Huntington's Australia, Motor Neurone Disease (MND) Australia, MJD Foundation, MS Australia, Muscular Dystrophy Australia, Muscular Dystrophy Foundation Australia, Parkinson's Australia and Spinal Muscular Atrophy Australia.

MS Australia plays a leading role in the Neurological Alliance Australia, with CEO Deidre Mackechnie chairing the NAA and National Policy Officer Andrew Giles providing secretariat support.

The NAA comprises 10 peak bodies representing neurological conditions. This year, the Alliance identified a number of shared issues relating to the implementation of the NDIS and decided that, to highlight and progress these issues, they would launch a Joint Position Statement on the NDIS at a combined Parliamentary Friends event.

The statement calls for equitable and effective support from the NDIS for people living with progressive neurological diseases, and increased investment in research. The Alliance believes the NDIS has the power to transform the lives of people living with progressive neurodegenerative diseases and this Statement sets out recommendations to ensure better NDIS outcomes.

Hosted by Senator Deborah O'Neill (Co-Chair of the Parliamentary Friends of MS) on 22 March 2017, the event was well attended by Alliance members and representatives, MPs, Senators and their advisors.

MS Australia CEO Deidre Mackechnie officially launched the Joint Position Statement, outlining the recommendations designed to ensure better outcomes for people with progressive neurodegenerative conditions.

MS Australia National Advocacy Coordinator Andrew Potter, who lives with multiple sclerosis, shared his hopes for a cure and the need to improve aspects of NDIS implementation.

The launch was aired on Channel 9 Canberra and for a time the Twitter handle #NAAaction (supported by **#NAA**) was trending number 1 in Australia. A subsequent story aired on ABCTV, online and radio nationally profiling two people and their NDIS experiences in WA and NSW.

The Alliance will continue to pursue these topics at meetings with parliamentarians and decision-makers, to both progress the recommendations and seek increased investment in research – and MS Australia will continue to ensure the needs of people living with multiple sclerosis are front and centre.

Deidre Mackechnie and Andrew Potter at the launch of the NAA Joint Position Paper, Parliament House, Canberra, March 2017

National Communications – the central source of information for MS

Publications audit

During the year to 30 June 2017, MS Australia continued its rigorous review of publications, completing the audit of all publications, and making significant progress in reviewing, re-writing and consolidating a large number of publications into a more succinct up-to-date list. Of note are the updated treatment sheets available on the MS Australia website. This includes a treatment summary sheet that provides people living with MS, their carers and families, as well as health professionals, to be able to see summary information related to each MS treatment on one page, at a glance.

Health & Wellbeing Platform

The Health and Wellbeing platform on the MS Australia website provides a range of information and advice to people with MS on issues relating to health and lifestyle. The content is delivered using a fortnightly blog format written by experts in their field.

The major themes were identified and prioritised through a survey of people with MS and the four initial focus areas: nutrition, workplace, exercise and psychological; were used as a pilot of the platform to test engagement. This has been in place for a year and the “hit rate” and feedback from people with MS has been very good so two new experts were introduced, a GP and a nurse.

The platform was re-launched on social media using the Twitter tag of **#WellbeingWednesday** with the introduction of a logo “thumb stopper”. It is performing very well on Facebook and Twitter.

#WELLBEING WEDNESDAY

Advice for living well

Uninterrupted

The **Uninterrupted** blogging site for people with MS to share their stories was reinvigorated at the beginning of this year. This led to increased engagement so we are continuing with this initiative, promoting the great work of the Uninterrupted Bloggers on social media.

UN INTERRUPTED

Personal stories about the realities of MS

John Studdy Award

The most prestigious Award of MS Australia, the annual John Studdy Award recognises *outstanding consistent and selfless provision of meritorious service to people living with MS*. This service may be at either National or State/Territory level, preferably over a period in excess of ten years or for other factors considered by the awarding committee as worthy of the award. The standard of the service is to be of such high-status that 'the nominee has made, or is making, a tangible difference' for the benefit of people living with MS and/or their families or carers.

2016 Recipient: **Therese Burke**

Therese Burke is the 2016 John Studdy Award recipient, for her many achievements and for making a tangible difference to the multiple sclerosis (MS) community.

MS Australia CEO Deidre Mackechnie thanked Therese for her outstanding commitment and passion to MS nursing. Therese is making a real difference to not only her patients, but through her research work, to all people living with MS in Australia. As Westmead MS Clinic Nurse & Clinical Trials Coordinator at Westmead Hospital & Westmead Institute for Medical Research at Sydney University, Therese is passionate about educating and empowering people with MS.

She participates in many areas of MS research, including scientific (biomarkers, genetics, pharmaceutical), clinical (fatigue, depression, quality of life, compliance, medication efficacy, pregnancy) nursing (fatigue, patient comprehension, diagnosis, nurse education) and neurol ogist initiated research, also clinical drug trials. President of the International Board for certifying MS Nurses, Therese's signature adorns the letters of certification for all newly qualified MS nurses in the member countries. She was President of Multiple Sclerosis Nurses Australasia, a member of the Australian MS Longitudinal Study (AMSLS) Steering Committee and contributes to many research publications.

Therese's contribution has been recognised internationally – she is the 2016 recipient of the June Halper Award (JHA) for Excellence in MS Nursing awarded in Washington DC by the International Organisation of MS Nurses (IOMSN). Therese was the first recipient with 'high achievement' in all eight assessment criterion. This is only the second time in its 20 years that the JHA has been awarded to an MS Nurse leader outside North America.

Therese is passionate about provision and improvement of education for MS Nurses. Her interests include new MS diagnosis and education, Clinically Isolated Syndrome (CIS) surveillance and clinical/treatment management, as well as actively supporting symptom management and improved quality of life in people with progressive forms of MS.

Therese said, "I feel fortunate to work with an amazing group of like-minded people…dedicated to improving lives. Their contributions are amazing and inspiring - the work of Professor Steve Vucic, Linda Mekhael, Graeme Stewart, David Booth, Fiona McKay and others at Westmead keeps me focused and creative. They are the unsung heroes."

Therese works as part of a multidisciplinary team and feels that this is the secret to success - collaborating with others and sharing knowledge and skills to further the fight against, and for, MS. Similarly, the support and mentorship of her many MS Nurse colleagues around Australia and globally keeps her feet firmly on the ground and constantly aiming higher.

Therese Burke accepting the 2016 John Studdy Award, from MS Australia Board President, Ian Pennell at the MS Australia Board meeting in November 2016

PREVIOUS JOHN STUDDY AWARD RECIPIENTS	
1999	Inaugural Winner – Yvonne Smith
2000	Mrs Thonad AM
2001	Elizabeth Ann Zanna Barron
2002	Ann Langley
2003	Jim Conway
2004	Graham Tribe
2005	Michael Stewart OAM
2006	David Conry
2007	Dr Leslie Sedal M.B, B.S., FRACP, M Ed
2008	Zona Tripp OAM
2009	Carol Cooke
2009	David Barnes
2010	Simon McKeon
2011	Bill Carroll
2012	Andrew White
2013	Carol and Roy Langsford
2014	Mike and Katrina Hemingway
2015	Lina Marrocco

International activities

Multiple Sclerosis International Federation (MSIF)

MSIF is a unique global network of MS organisations with 49 members from around the world, with links to many others. Protecting and advocating for the rights of people with MS is at the heart of MSIF's work.

MSIF's advocacy objectives are:

- Increased global awareness of MS amongst the public and policy makers
- Increased policy impact and opportunities for MS organisations through international epidemiological and socioeconomic comparative research and action.

MSIF's approach to advocacy has these components:

- To provide member organisations with research reports, films and other resources to advocate for changes that benefit people with MS in their country.
- To take part in advocacy initiatives as part of networks and collaborations such as the International Alliance of Patients' Organisations and the International Pediatric Multiple Sclerosis Study Group.
- To help raise awareness of MS to create an enabling environment for members' advocacy and other work.
- To support advocacy through capacity building/training in development of emerging national organisations.

Where and when appropriate, MSIF works with, or advocates to, global and international, bilateral/multilateral bodies directly.

One of MSIF's strategic priorities is to support and encourage the development of new, emerging and existing MS organisations and groups through capacity building activities.

MSIF works to build the capacity of national or local structures, which they believe – with their contextual knowledge, cultural awareness and local language – are best placed to meet the needs of people with and affected by MS living or working in the country.

MSIF's capacity building work is currently focused on the Arab region and China.

In 2017 MSIF's new five-year strategy was launched; MS Australia was pleased to be able to make a significant contribution to the development of this strategy. Within capacity building MSIF will continue to implement its existing programmes, but will also expand its regional work to include Latin America.

World MS Day - 31 May 2017

World MS Day each year is a fantastic chance to raise awareness about MS and to strengthen the network of people living with MS across the world.

A day to celebrate global solidarity and hope for the future.

This year World MS Day was officially marked on Wednesday 31 May, 2017. The theme was #LifewithMS.

The theme and campaign for World MS Day each year is led by MSIF. For World MS Day 2017, MSIF chose one of our very own MS Australia National Advocates, Mike Welsh, to feature in their international video campaign. Out of all the people nominated to take part, he was one of only three selected from around the world, and we weren't surprised. His strategy, "Any two of three," is a great tip to manage fatigue!

MS Australia National Advocate, Mike Welsh,

We were successful in securing a segment on The Project, a national nightly news program with an average viewership of one million each night. The segment profiled Mike Welsh (above) plus Tomas Kalincik, a Neurologist / Researcher and MS Australia CEO, Deidre Mackechnie. MS Australia staff members were delighted to be able to accompany Mike to the Channel 10 studios in the evening of World MS Day when the story featured, and to meet The Project panel members.

Tim Ferguson is a beloved Australian comedian, writer, director and performer who was first diagnosed when he was 19. He shared, via video, his tips for people with MS in the lead up to World MS Day. His World MS Day video was supported by Biogen.

In response to the 2017 theme, MS Australia produced videos featuring five Australian woman talking about the challenges of life with MS and sharing ideas for managing these challenges. The videos were released, one by one, in the weeks leading up to World MS Day, and received considerable social media attention.

Each of these videos can still be viewed under World MS Day 2017on the MS Australia web-site: https://www.msaustralia.org.au/get-involved/world-ms-day-2017.

MS

AUSTRALIA

About MS

Multiple Sclerosis is a chronic disease that attacks the central nervous system. There is overwhelming evidence that MS is primarily caused by an autoimmune process where the body attacks its own myelin, a fatty sheath that covers our spinal tissues and nerves, although the exact mechanism remains unclear. There is no known cause or cure.

The physical impact of MS varies as no two cases of MS are identical. The visible and hidden symptoms of MS are unpredictable and vary from person to person and from time to time in the same person. Common symptoms include:

- Extreme tiredness
- Visual disturbance, such as blurred or double vision
- Difficulties with walking, balance and coordination
- Altered muscle tone, such as muscle weakness, tremor, stiffness or spasms
- Dizziness and vertigo
- Altered sensation, such as tingling, numbness, and pins and needles
- Extreme sensitivity to temperature, usually heat
- Pain
- Bladder and bowel changes
- Emotional and mood changes
- Sexual changes
- Changes in memory, concentration and reasoning
- Slurring or slowing of speech.

The economic and personal cost of MS cannot be overestimated:

- MS is estimated to cost Australia over $1 billion per year
- Loss of productivity $494 million per year
- Australians with MS spend $78 million per year in out of pocket health care expenses
- The informal care provided by family and others to Australians with MS would cost $145M per year to replace.

Impact on employment

- 50-80% of people with MS cease to work full-time within 10 years of diagnosis
- Of the 20,400 people with MS aged 15-64, an estimated 9,800 were employed, with 5,900 being part-time
- People with MS have a 30% higher representation in part-time employment compared to the average Australian and a lower annual income
- People with MS are less likely to be in paid employment compared to those with other chronic diseases.

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.

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