



Year in Review

the year to 30 June

2018

A world
without
multiple
sclerosis

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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:

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.

Research

Supporting ongoing research to pursue further knowledge in targeting prevention, improving treatment, enhancing quality of life and ultimately, to find a cure.

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.

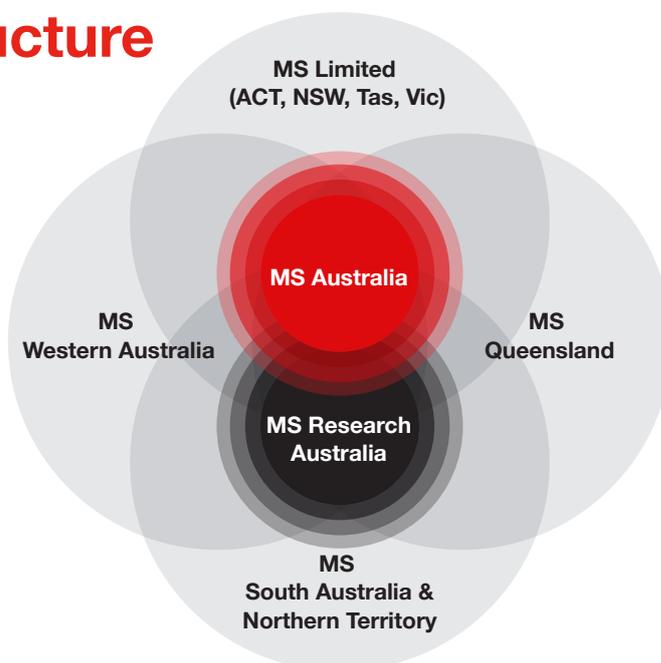
Support for our member organisations

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.

Our MS family structure



The MS Australia Board **MS Australia staff**

(for the period 1 July 2017 - 30 June 2018)

Mr Ron Brent

Mr Roger Burrell (Vice-President)

Professor William Carroll

Dr Annette Carruthers (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 George Pampacos

Mr Ian Pennell AM

Mr Alan Scott

Deidre Mackechnie

Chief Executive Officer

Bea Beswick

Project Officer

Mark Campbell

National Digital Communications Officer

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

Motion in Senate to recognise World MS Day 2018

The 45th Australian Parliament recognised World MS Day 2018 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.

Thursday, 10 May 2018

SENATE

2863

The DEPUTY PRESIDENT (11:49): Thank you. I remind senators that the question may be put on any proposal at the request of any senator.

MOTIONS

World Multiple Sclerosis Day

Senator BUSHBY (Tasmania—Chief Government Whip in the Senate) (11:50): I, and also on behalf of Senator O'Neill, move:

That the Senate—

(a) notes that:

(i) World MS Day takes place on 30 May 2018 with the theme 'Research', and

(ii) MS Research Australia seeks to raise awareness of the need for increased funding to accelerate Australian research targeting prevention, better treatments and a cure for Multiple Sclerosis (MS);

(b) recognises that:

(i) MS is the most commonly acquired neurological condition diagnosed in young adults,

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

(iii) there is no known cause or cure;

(c) acknowledges the important role of the Australian Government in funding research into MS through the National Health and Medical Research Council, the Medical Research Future Fund and in making MS medicines affordable through the Pharmaceutical Benefits Scheme; and

(d) confirms the need for continued action to:

(i) invest in research to find the cause of, and a cure for, MS,

(ii) invest in MS research in Australia to ensure leading world-class researchers remain attracted to this field of research and conduct their work here in Australia,

(iii) encourage the critical importance of early diagnosis and early treatment onto an effective therapy overseen by an expert in MS, and

(iv) encourage people with MS to adopt a brain-healthy lifestyle by taking their prescribed medicines, avoiding smoking, reducing alcohol intake, keeping active, keeping weight under control and keeping their minds active.

Question agreed to.

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 an active member of the Multiple Sclerosis International Federation (MSIF).

MS Australia is 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 Advocates

Advocacy work is delivered through a range of activities including our National Advocates Program under the stewardship of our National Advocates Program 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 Advocates at World MS Day 2018

More info about this event can be found in the 'World MS Day' section of this Review.



MS AUSTRALIA National Advocate Astrid Edwards acting as MC for the launch of 'A Roadmap to Defeat MS in Australia' at Parliament House, Canberra, May 2018.



MS AUSTRALIA National Advocacy Coordinator Andrew Potter and Catherine King MP, Shadow Minister for Health & Medicare and Federal Member for Ballarat, with Deidre MacKechnie and Andrew Giles at Parliament House, Canberra, May 2018.

Vale Betty Cuthbert

A tribute to a great Australian who lived with MS (20.4.1938 – 6.8.2017)

MS Australia mourns the passing of legendary Australian athlete, Elizabeth 'Betty' Cuthbert AM, MBE, who has died after a long battle with MS aged 79.

Betty was dubbed the 'Golden Girl', when, at just 18, she completed in the (1956) Melbourne Olympics where she won the sprint double and anchored the winning 4x100 metres relay team to a world record, making her the first Australian to win triple gold.

Born in Sydney, NSW in 1938, Betty Cuthbert's Olympic expectations were so modest that she bought herself a ticket to watch. (Source: Athletics Australia Hall of Fame).

A four-time Olympic gold medallist and world record holder, Betty Cuthbert was diagnosed with Multiple sclerosis (MS) in 1974.

MS Australia CEO Deidre Mackechnie shared:

"The world knows Betty Cuthbert as a remarkable athlete – who achieved greatness on the track. What is also known by many, and something I wish to highlight today is Betty Cuthbert's remarkable devotion to and efforts for the MS community. Betty was a passionate advocate that people living with MS should receive the best possible support and services. She also advocated for research into MS. Her lived experience with MS has helped raise invaluable awareness of the condition. Betty often stayed at the MS Studdy Centre in Lidcombe when visiting her mother who lived not far away. The staff remember her fondly when she stayed. In fact, she was staying at the MS Studdy Centre in Lidcombe on the day she held the Olympic torch, with MS staff helping her get to the event. In honour of the champion that she was, a rose was named after Betty and the road to the MS Studdy Centre in Lidcombe was renamed to Betty Cuthbert Drive. Betty Cuthbert helped to raise the profile of the disease in Australia and importantly needed funds."



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 2018, MS Australia made submissions to the:

- Regulation of mobility scooters
- Implementation of the NDIS in the ACT
- Transitional Arrangements for NDIS
- Productivity Commission NDIS Costs
- Secondary use of My Health Record Data
- Superannuation Assessing Efficiency and Competitiveness
- Victorian Disability Workforce

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.

Five submissions were made to the PBAC during the year:

- Ocrevus ®(ocrelizumab) for primary progressive MS
- MAVENCLAD® (cladribine) for relapsing remitting MS
- MAVENCLAD® (cladribine) for relapsing remitting MS re-submission
- MAVENCLAD® (cladribine) for relapsing remitting MS 2nd re-submission

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.

During this year, members of the NAA met to continue working on a number of issues relevant to the work of each member organisation, and to the communities they serve.

National Communications – the central source of information for MS

Publications audit

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 and symptom sheets available on the MS Australia web-site. 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** 

Uninterrupted

The **Uninterrupted** blogging site for people with MS to share their stories was maintained throughout the year. 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

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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.

2017 Recipient: Dr Rex Simmons

MS Australia was thrilled to announce Dr Rex Simmons as the 2017 John Studdy Award recipient, in recognition of his outstanding achievement in the development of the Australian MS Longitudinal Study for the benefit of people affected by multiple sclerosis (MS).

MS Australia CEO Deidre Mackechnie said, “Rex’s work recognised the need for research on the social and economic impacts of MS. He has worked tirelessly to provide the evidence to fill gaps in our understanding of the impact of MS and the best ways to support people with MS.”

Dr Simmons started his career in multiple sclerosis research, working on the Experimental autoimmune encephalomyelitis (EAE) animal model of MS, as a basic researcher.

In the late 1990s Dr Simmons established a voluntary national register of multi-case MS families, to assist with studies of the genetics of MS in collaboration with Australian and international genetic researchers. Whilst collecting blood samples for genetics studies, he noticed that many people with MS had quality of life issues that could potentially benefit from further research. In 2000, after organising an international workshop of experts on longitudinal data collection, Dr Simmons obtained crucial support from MS Australia to establish the Australian MS Longitudinal Study (AMSLS), which he ran at Canberra Hospital until he retired in 2014. Dr Simmons’ vision – a survey-based research study to improve the lives of Australians living with MS, was passed on in perpetuity to the Menzies Institute for Medical Research (University of Tasmania). The study’s ongoing and lasting benefits for the MS community are a testament to Dr Simmons’ foresight, passion and tireless devotion to the cause, and remains a legacy of his work.



Rex Simmons accepting the 2017 John Studdy Award, from MS AUSTRALIA Board President, Ian Pennell at the MS Australia Board meeting in November 2017.

- Dr Simmons’ research has profoundly impacted our understanding of MS, particularly in:
- Showing the benefits of early disclosure of MS in the workplace
- Understanding the reasons why people change or cease their therapy and;
- Providing the evidence to underpin advocacy for energy subsidies for people living with MS during hot weather.

These and other crucial findings, have made the AMSLS study an invaluable asset for the MS community, with tangible evidence-based outcomes for those living with the condition and their support networks.

Dr Simmons said, “MS research for a cure is vital, but we must never neglect the needs of those currently living with MS, including research on how to optimise their life outcomes.”

Dr Simmons maintains a special and ongoing relationship with the MS organisation in the ACT, who, for many years, filled envelopes with questionnaires for the AMSLS in working bees supported by cake and community.

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	Katrina and Mike Hemingway
2015	Lina Marrocco
2016	Therese Burke

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.

MSIF 50th Anniversary, September 2017

Our CEO Deidre Mackechnie, along with other leaders of MS societies around the world, gathered with more than 100 MSIF staff, volunteers, and people with and affected by MS from 39 countries in London for the Multiple Sclerosis International Federation Movement's 50th Anniversary meetings.



Our CEO, Deidre Mackechnie, with Philip Cave, grandson of Richard Cave who founded the first MS Society in UK and advocated for the establishment of MSIF. September 2017



MSIF meetings, April 2018

The MSIF meetings held in April, 2018 encompassed representatives of member organisations (MSA is the member organisation for Australia) as well as MSIF staff, volunteers, and people with and affected by MS. Deidre Mackechnie attended the meetings as CEO of the Member organisation and Matthew Miles attended in his capacity as Board Director, MSIF (nominated by MSA).

The meetings encompassed compliance with governance responsibilities: Board meeting (including open and closed sessions) plus new Board Director induction and all Board Committees (Fundraising, People with MS Advisory, Nominations) and supporting meetings (Member CEOs, Progressive MS Alliance). Additionally, the local MS research organisation Stichting MS Research hosted MSIF at a dinner celebrating the World MS Day theme of 'Bringing us closer'.

The highlight was a full day spent at Nieuw Unicum (NU) a purpose built (40 years ago) facility for people living with Progressive MS that has been recently extended and refurbished. This visit included tours of the facility and presentations showcasing the multidisciplinary approach at NU to interventions for Progressive MS (plus a visit by Queen Maxima of the Netherlands).

Navigating MS meetings, April 2018

The Navigating MS initiative is a global initiative looking at mechanisms to increase shared decision making in clinician and patient interactions with a specific focus on evaluation of risk and benefit in treatment decisions. It is driven by Multiple Sclerosis Association of America and includes clinicians, nurses and patient advocacy organisations.

The first meeting was held in 2016 and this year's follow up meeting was held in Amsterdam on 13 & 14 April 2018, with the aim of creating an action plan for enhanced shared decision making.



Representatives of MSIF member organisations and people with MS, at the celebration of the 50th anniversary of MSIF at the Houses of Parliament, London.

European Committee for Treatment & Research in Multiple Sclerosis (ECTRIMS)

National Policy Officer Andrew Giles attended ECTRIMS in October, 2017, on behalf of MS Australia. Held in Paris, with more than 10,000 delegates and 3978 abstracts, this was the largest international conference in Multiple Sclerosis so far. Over 3 days, sessions ran from 7.30 am till 7.30 pm, and 25 parallel sessions at a time, with more than 2000 posters and multiple sponsored symposia. Most major pharmaceutical companies were represented across two huge floors of stands and displays. Other meetings were held before during and after these sessions and symposia.

Andrew attended a meeting of around 20 of the MS Brain Health sponsors to hear latest developments, and there was general support and excitement about the way Australia (through MSA) is 'leading the pack' in forming a working party and developing projects to implement the Brain Health recommendations.



Andrew Giles, with (left-to-right) Dr Mikkel Anthonisen, Founder & driver of Oceans of Hope project, Peer Baneke, CEO of MSIF and Ceri Angood-Napier, Deputy CEO of MSIF, at ECTRIMS, Paris, France October 2017.

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World MS Day – 30 May 2018

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 30 May, 2018.

The theme was Research: **#BringingUsCloser**. The theme and campaign for World MS Day each year is led by MSIF.

We were delighted that the Hon Greg Hunt MP on behalf of the Government committed on World Multiple Sclerosis (MS) Day to working with both MS Australia and MS Research Australia over the next 6 months, to develop a 10-year plan to implement our 'Roadmap to Defeat Multiple Sclerosis in Australia'. We were equally delighted to receive bi-partisan support for this initiative from the Hon Catherine King MP, Shadow Minister for Health.

<https://www.msaustralia.org.au/stay-connected/world-ms-day-2018>





A U S T R A L I A

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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