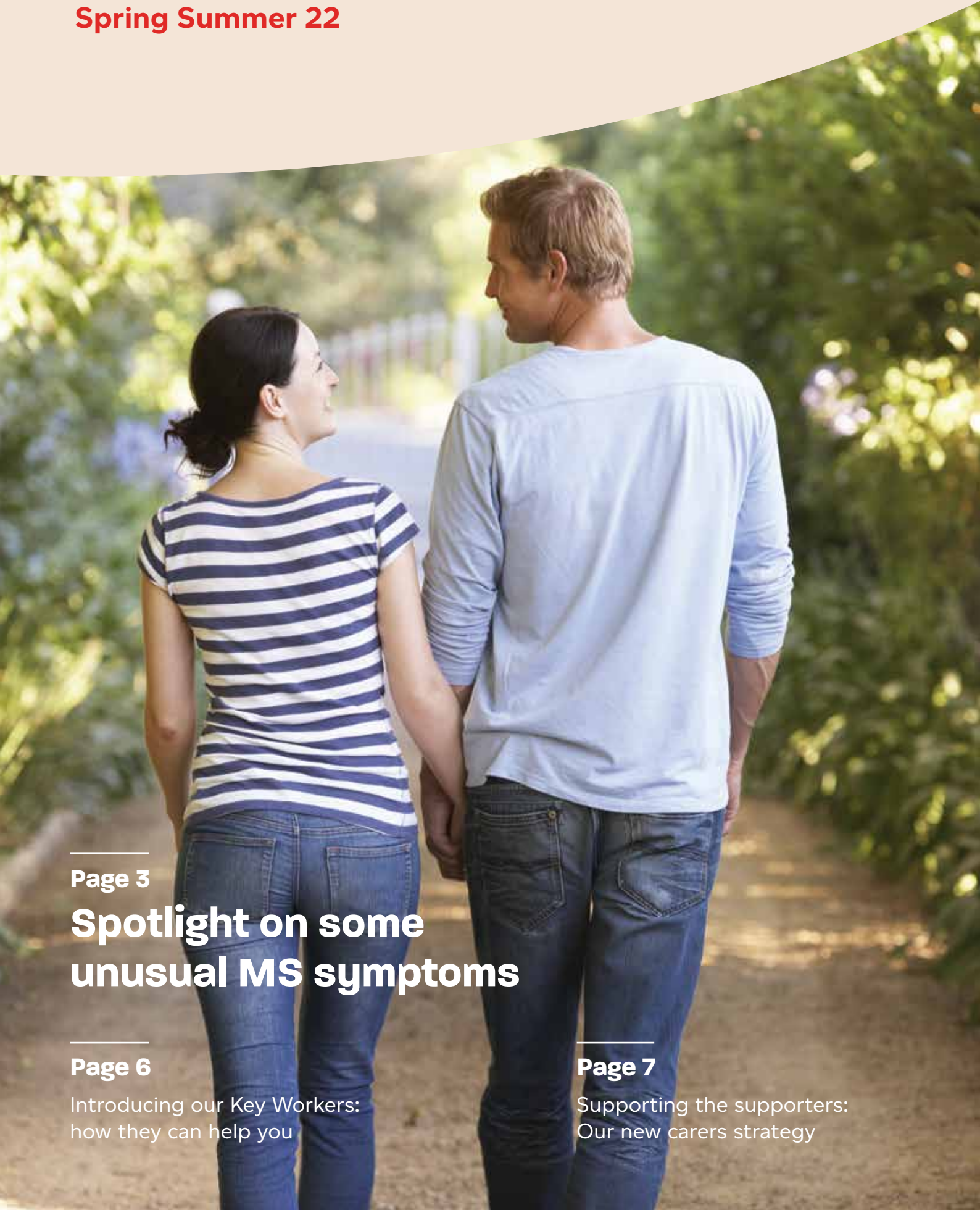


Spring Summer 22



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## Spotlight on some unusual MS symptoms

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Introducing our Key Workers:  
how they can help you

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Page 7

Supporting the supporters:  
Our new carers strategy



# From the CEO



John Blewonski | Chief Executive Officer

**It has been another busy year for the team at MS Plus. We have progressed many projects and initiatives that form part of the MS Plus Strategic Directions 2020–2025, which is about meeting the evolving needs of people living with multiple sclerosis and other neurological conditions, now and into the future.**

Some of our key achievements under the Strategic Directions include:

- rebranding to MS Plus, and the development of the MS Plus website
- expansion of our existing Allied Health, NDIS and Employment Program to support people living with neurological conditions other than MS
- expansion of service delivery to people over 65 years through the acquisition of Nursing Port Stephens
- delivery of a new Diversity and Inclusion Strategy to better support our clients, staff and volunteers
- reimagining of our Plus Connect service to include our new 'Key Worker' roles (see page 6)
- development of the MS Plus Carers Strategy (see page 7)

**Disclaimer:** Information and articles contained in Intouch are intended to provide useful and accurate information of a general nature for the reader but are not intended to be a substitute for legal or medical advice. MS Plus is not recommending medical or legal advice and readers must seek their own as may be appropriate.

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We have also made significant headway in our plans to expand and develop our facilities, including breaking ground on the Wellbeing Centre at Lidcombe, NSW.

We again opened our MS Go for Gold Scholarships and held our popular Virtual Art Show competition and I would like to congratulate all our successful applicants.

This year MS Plus marked 30 years as a Community Visitors Scheme participant, with volunteers providing companionship for isolated older members of our community. We also released our 2021–2022 Annual Report at the Annual General Meeting held on 2 November, I encourage you to take a moment to review this great snapshot of our work during the last financial year, available on our website.

It's been wonderful to see our much-loved events back in the community. I was excited to see our signature MS Gong Ride event go ahead, with picture perfect weather, after 3 consecutive cancellations. Well done to everyone who participated, fundraised and volunteers, as well as to our event organisers.

Wishing everyone a safe and happy holiday period. I look forward to sharing another incredible year with you in 2023.

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## News



### The Gong returns for its 40th anniversary

**Our signature event the MS Gong Ride returned for the first time in two years on Sunday 6 November. We celebrated the Gong's 40th anniversary with 10,000 riders managing to raise in more than \$2.5 million.**

Riders undertake either a 52km or 79km cycling course from Sydney to Wollongong to help raise funds to support people living with MS. A big congratulations to our top three fundraising teams for 2022: Team MICH Fulton Hogan in third place with \$56,968, MS Avengers in second place with \$65,333 and in first place Soft Cogs Inc, who raised an impressive \$96,167.

'On behalf of our dedicated events team here at MS Plus, I would like to thank everyone for their patience with the delays and changes to this much-loved event over the past few years,' says MS Plus CEO, John Blewonski.

'However, our participants have shown their adaptability by enthusiastically joining our online MS Gong Ride last year and with a show of force this year. We quickly reached participant capacity once entries opened and your fundraising efforts mean the world to the MS community.' Visit [msgongride.org](https://msgongride.org)

## Research

### Changes in gut bacteria linked to MS

Changes to the gut microbiome have been linked to several inflammatory diseases, and is emerging as a potential environmental contributor to MS. The International Multiple Sclerosis Microbiome Study (iMSMS) has brought together a team of experts to perform a large-scale and detailed study of how the gut microbiome affects MS disease susceptibility and progression. The iMSMS study found gut microbiome composition and function were substantially different between disease subtypes and were modestly associated with diet. The gut microbiome was also affected by Disease Modifying Therapies (DMTs) — suggesting DMTs have considerable effects on the gut, which may be part of their therapeutic action. To read more, visit [msaustralia.org.au/news](https://msaustralia.org.au/news)

### Christmas lights for MS

Spread joy and hope this Christmas by lighting up your home to raise funds and awareness for MS. Embrace the festive cheer with a few solar lights, some tinsel in your window, or a full-blown display. Sign up in November, so you have plenty of time to prepare before you flick the lights on when December starts. Taking part is easy. Simply set up your normal Christmas lights, print out your QR code poster and share your fundraising link. Regardless of the size of your display, Christmas spirit is bound to be abundant.

Visit [doitforms.org.au/event/christmas-lights-for-ms](https://doitforms.org.au/event/christmas-lights-for-ms)







# What are some of the rare and usual symptoms of MS?



**Jodi Haartsen, Executive Manager, Client Engagement & Wellbeing**

**As an MS Nurse Practitioner, I heard many stories of unusual symptoms people experienced. Some were related to MS, but this wasn't always the case. MS affects many different parts of the body and it becomes tempting to just blame every weird or odd thing you feel on MS. However sometimes unusual symptoms can be a sign of another health-related problem, so it's important to discuss what you are experiencing with your medical team.**

When the unusual symptoms were related to MS, it often came as a relief for people to have that confirmed. Even if there isn't an easy and quick treatment, knowing it was MS was a useful starting point. Here's a few of the numerous unusual symptoms that can be troublesome, but are less common in MS.

## UNCONTROLLABLE OR INAPPROPRIATE CRYING AND LAUGHING - PSEUDO BULBAR AFFECT (PSA)

A person with PSA laughs in outbursts when they don't think something is funny, or really sob cries when they don't necessarily feel sad. It occurs when the circuits in the brain between an actual emotion like sadness and the outward expression of the emotion, like crying, are disconnected. This symptom can be incredibly frustrating and debilitating, leading to social isolation and depression. While needing a holistic approach to management, there are some medications that may help with this symptom. Loss of humour can also be a rare symptom in MS, it's not related to PSA but can occur independently.

## ITCHINESS (OR PRURITIS)

Itch associated with MS can be debilitating, difficult to treat and dramatically impacts quality of life. MS itch is a sensory disturbance, like sensory pain. In clinical practice, people with MS often needed lifestyle changes to cope with the itch. MS itch can occur in unusual places. Some people described to me feeling like their itch was inside their skull and came on in tiny bursts, while for others it was constant and resulted in substantial skin damage. Itchiness is one of a group of MS symptoms that are called **paroxysmal symptoms**. These are symptoms that can occur as motor (muscle and movement) symptoms, sensory or pain, visual symptoms among others.

## INTRACTABLE HICCUPS

Intractable hiccups is another paroxysmal symptom of MS. Intractable hiccups don't go away for weeks to months on end. Hiccups unrelated to MS can also occur and are more common in another condition closely related to MS called Neuromyelitis Optica. Intractable hiccups are extremely uncomfortable, can be painful and may require hospitalisation for treatment.

## INTRACTABLE VOMITING

Can also be a rare paroxysmal symptom of MS that can be associated with hiccups or occur on its own.

## CROCODILE TEARS

The term crocodile tears apparently comes from the ancient belief that crocodiles weep after killing their victims. I'm not so sure about that, but I do recall meeting two people with MS having what is called the "crocodile tears" symptom. Also known as Bogorad syndrome, this is the shedding of tears while eating or drinking in patients recovering from Bell's Palsy (a facial weakness), which can occur in MS. It is also referred to as gustatory lacrimation. This symptom can resolve over time, physiotherapy can be of benefit and there are various treatments available such as Botox.

## SEIZURES

Seizures (epileptic seizures) occur in about 2-5% of people with MS. Seizures are the result of abnormal electrical discharges in an injured or scarred area of the brain (usually specific locations).

While seizures may occur as part of MS, they may also be the result of an infection, fever or abrupt cessation of certain medications. It is vitally important to speak to your medical team if you are experiencing symptoms that could be seizures.

Seizure symptoms depend on the type of seizure you're having, but in general, could include: loss of consciousness or awareness

- confusion, behaviour changes
- falls with no recalls or warning
- strange sensations and emotions
- uncontrollable jerking movements of arms and legs
- staring
- aura.

**"This can be a very distressing time for people, as uncertainty and anxiety add to what can already be a debilitating symptom.**

**Navigating unusual symptoms can also often require communication amongst multiple doctors, nurses and specialists, which can be frustrating."**

## PSEUDOATHETOSIS

Pseudoathetosis is abnormal writhing movements, often of the fingers, caused by damage to pathways of the brain. These pathways transmit and processes information about where your body is in space, called proprioception. Reports of Pseudoathetosis in MS are extremely rare, so I was surprised when a young man in his early twenties came to our clinic with this symptom. His description over the phone of his 'fingers just randomly moving all over the place' made not very much sense to me. After excluding other causes, it was clear that his symptom was part of his MS relapse, and once his relapse was treated and a more effective MS treatment started, the symptom fortunately resolved.

## HEARING LOSS

Intractable Impaired hearing happens in less than 6% of people with MS. Deafness, in one or both ears, is even more unusual. That's why when a lovely 17-year-old girl came to clinic and told me she was deaf in one ear, I was concerned. There were multiple other investigations undertaken to rule out other causes. We also gave IV steroids, as we knew there was a chance this was a relapse, albeit unlikely. A new lesion on MRI confirmed it was an MS relapse and with treatment, the hearing loss resolved. Over my years in MS nursing, I saw only three other people experience MS-related hearing loss.

**"It is not uncommon for these symptoms to take longer to investigate, as often other causes need to be excluded. They can also be challenging to describe."**

These are not the only rare and unusual MS symptoms. If you are a person living with MS or a concerned family or friend, it's very important to discuss any changes, no matter how unusual, with your health team. MS specialist neurologists and MS nurses who have many years of experience in MS are more likely to have heard these symptoms before and can be a useful resource.

If you are concerned, please reach out to our experienced MS Nurses at MS Plus on **1800 042 138**



# Our new Key Workers

## Working in partnership with you

**Our Plus Connect team wants to hear your unique story and help you overcome any barriers. Whether you know exactly what you want or you're not sure where to start, we're here.**

That's why we're changing the way we operate so we can better partner with you! When you contact MS Plus, we'll partner you with a dedicated Key Worker who will be with you from day one. Your Key Worker will be a committed partner you can trust who knows a little bit about you — so you won't have to start from the beginning every time you call.

Our Key Workers understand the impact neurological conditions can have on you and your loved ones. They'll help you access the services you need, when you need them, so you can focus on living well and stay in touch to ensure you're getting what you need.

We'll also gradually transition our existing clients over to having a dedicated Key Worker too.

New MS Plus Key Worker, Georgia said, 'I'm very pleased to have the opportunity to take on the role of key worker, and know that clients will receive a more individualised service to assist them in their journey living with MS.'

'I'm looking forward to seeing how the key worker roles continue to provide ongoing support to clients now and in the future, with the opportunity to build strong client relationships that provide optimal support for people living with MS,' Georgia says.

We'll be in touch with more information about your new Key Worker in the coming months as we transition to a new way of supporting you!

In the meantime, visit [msplus.org.au/plusconnect](https://msplus.org.au/plusconnect)



**Natalie Bryant, Senior Manager Intake & Engagement Services talks about launching the new Key Worker roles:**

### What is great about the new Key Worker roles?

The Key Worker roles enable us to provide a much more personal experience on Plus Connect, the Key Workers will partner with our clients and continue to support them along their journey.

### What will this mean for our clients?

Our clients will have a "go-to" person within MS Plus to support them with navigation of services. The Key Worker will partner with them through any bumps in the road, providing ongoing check-ins to determine if there is any further support that they need and to keep clients up to date with services that are available to them, within MS Plus and beyond.

We're excited to commence the transition to this new way to support our clients, with our goal to provide support for every stage of a client's journey.



# Supporting the supporters: A new MS Plus Carers Strategy

**We understand that many people living with MS have a wonderful support crew helping them on their journey. This can be a family member, friend, neighbour, partner, child or another significant person. Some people think of themselves as carers, others don't identify with that term.**

Providing this care and support can be incredibly meaningful and rewarding. However, it can also be challenging at times and impact on a carer's ability to achieve their own goals and live well. At MS Plus, we wanted to partner with the people who do this day in and day out to understand how we can help. We have developed a carers strategy to help us deliver a program based on what people told us they need, with insights from 250 research participants.

We found the most common barriers to living well for carers identified in the research included (in order of prevalence):

- lack of time for themselves
- less time and energy to maintain a social life
- the impact on their mental wellbeing (e.g., feeling isolated or burnt out)
- view caring as their duty/role
- the physical nature of the caring role and their own physical wellbeing
- the changed relationship with the person they care for
- lack of support to allow them to maintain their own career and interests
- lack of finances.

Based on this feedback, MS Plus has identified 6 key focus areas for support. Focus areas include

- information on support services and MS specific education

- an understanding person to talk to
- respite, outings and retreats
- financial assistance and employment support
- advocacy and support for navigating the service system
- access to programs that support mental health and wellbeing.

Several key projects and initiatives have been created under each of these key focus areas, to assist us in delivering the strategy in the coming months and years. The carers strategy was launched in time for National Carers Week, Sunday 16 October to Saturday 22 October — an opportunity to recognise, celebrate, and raise community awareness about the diversity of Australia's 2.65 million carers and their caring roles. To read the full MS Plus Carers Strategy, visit [msplus.org.au/carers-program](https://msplus.org.au/carers-program)





# Trekking for MS



Sue with daughter Maddie and son Michael.

**Sue, a Support Coordinator at MS Plus, is living with multiple sclerosis. She's also mum to Maddie who is taking on the MS Plus Ikara-Flinders Ranges Adventure next year. Maddie will fundraise to fight MS as they take on the life-changing trek through a beautifully rugged and colourful landscape.**

'The ultimate thing about raising money for MS is finding a cure. That would be the wish list thing in my lifetime, not only to help people with MS but to find a cure. I appreciate Maddie's efforts and everybody's efforts in raising money,' Sue said.

Maddie, a paramedic, is taking on the Flinders trek in May 2023 and aims to raise \$6,000 for MS Plus.

Sue's personal experience living with multiple sclerosis also means the cause is even closer to her heart.

'I do love my job. The important thing is I have that lived experience. I know what it's like. People are a little bit vulnerable — it's a scary thing to have MS. I don't generally tell my clients that I have MS. They say: "You really get it."

Sue was diagnosed with MS in 2000 and has had 5 relapses in the past 22 years, all mostly affecting her left side. She lives with numbness in her hand, foot drop, fatigue, memory problems and experiences regular falls. Her falls have resulted in numerous fractures and, at times, a fear of leaving the house.

Sue manages her fatigue with exercise and recently dropped an incredible 25kg in the lead up to her 60th birthday. For the numbness in her hand, Sue used the Plus Employment Support Service, to get voice recognition software on her computer to help her complete her work. For her short-term memory problems, Sue uses strategies she learned during her time working in Plus Connect that she shared with others living with MS.

'I manage my shortcomings with brain fog and memory with strategies like diaries and notes.'

Reflecting further on her time with Plus Connect, Sue remembers the impact fundraising like Maddie's can have on individual lives.

'I remember a man needed a replacement battery for his wheelchair. We were able to apply for funding [through the Plus Financial Assistance Program] raised through the MS Mega Swim. We were able to fund that for him and it meant he was mobile. I've seen so many success stories. It makes you really proud.'

Sue's excited to see Maddie take on the Ikara-Flinders Ranges Adventure next year. She's proud of her daughter for committing to fundraise for vital MS services and research into better treatments and ultimately the search for a cure.

'The Flinders Ranges are beautiful. The outback and countryside are just magical, why wouldn't you want to be a part of that? The fundraising is a bonus.'

To support Maddie on her MS Plus Ikara-Flinders Ranges adventure, head to [doitforms.org.au/fundraisers/madeleinecaoduro/flinders-ranges](https://doitforms.org.au/fundraisers/madeleinecaoduro/flinders-ranges)

For more information on how to join the MS Plus Ikara-Flinders Ranges Adventure in 2023, see page 12.

# MS Go for Gold Scholarship — Congratulations!

**Well done to the 25 recipients of our 2022 MS Go for Gold Scholarships! We once again had an overwhelming response to the program, receiving 165 applications this year, all for a variety of inspiring goals.**

The judges found it extremely difficult to award only 25 scholarships, as there were so many deserving candidates. The scholarships provide up to \$2,000 for people living with MS to fulfill a dream or goal they would otherwise be unable to pursue.

We would like to say a special thank you to all our MS Mega Challenge fundraisers, whose hard work provides the funding for our Go for Gold scholarships each year, as well as other critical MS supports and services.

We encourage anyone unsuccessful in the current round to please apply again in 2023. If you need additional help to live well with MS — we are here for you. Contact our Plus Connect team on **1800 042 138** to find out how we can help you or your loved ones.

**Below are just a few of our successful applicants' stories.**

## EMILY

**Category: Personal Expression**

Ever since she was little, Emily has dreamed of becoming an artist. After losing her father, who was her biggest supporter and following her MS diagnosis, Emily lost her passion for art.

After a while, Emily realised that others could benefit from her experiences and she became a Plus Peer Support leader, providing one on one phone support and organising a group of local peers to get together and share their MS journeys. Emily is now in a place where she feels ready to begin creating art again and her wish is to attend art classes and purchase art supplies, with the hope of one day helping others through art.

'I have a dream of one day leading and guiding others with MS to

heal themselves and their lives through art and encouraging them to rediscover their joy, something that can be lost amid MS-related busy-ness.

Emily will use her new skills to teach other people living with MS within her Peer Support Group.

'Art can alleviate depressive feelings by giving a person something else to focus their thoughts on. Some people find the practice of making art calming, almost meditative.'



## PAULA

**Category: Education**

After her MS diagnosis, Paula began seeing a psychologist — where she met a therapy dog on his very first day on the job. After adding a labradoodle puppy Buddy to her family almost a year ago, Paula now dreams of training Buddy to become a therapy dog, who can come to work with her once she completes her Graduate Diploma of Psychology in February next year.

'I currently work as a Support Worker for a company that provides day programs for adults with disabilities and I love it. Working as a canine therapy team, Buddy and I would love to continue this work on a part-time basis with participant group procedures tailored for us.

'I also plan to register to work independently as a support worker and offer services including Animal-Assisted Therapy with Buddy. This may be out in the community, in a client's home, or in a multi-disciplinary office space.

'Buddy is already an emotional support dog for me and a special presence in our family. To be able to spend more time with him and share his love with others would bring me even more joy,' Paula says





## CHRISTINE

**Category: Personal Expression**

In 2006, Christine wrote a silly story for one of her best friends, Stacey, after Stacey's best furfriend passed away. Due to life getting busy, Christine was never able to show the story to her friend. Stacey, a type 1 diabetic who passed away in 2011.

Over the next decade, Christine toyed around with the idea of creating a children's book from this silly story. It wasn't until late 2011 that she decided to face her fears and try to self-publish.

Stacey and Toby: The Very Odd Day tells the story of an incredible little girl named Stacey, who has a wild imagination and a four-legged best friend named Toby. The book is about the adventures of a bright, tough girl who just happens to have an invisible disability – type 1 diabetes.

'Since being diagnosed with my own invisible disease and connecting with the community, I've come to realise just how many of us there are, but so little representation in children's books,' Christine says.

Christine will use her scholarship funds to illustrate and market the second book in her series. 'To create more empathy in the world, in support of people with disabilities, would be amazing.'



## BEN

**Category: Personal Expression**

When Ben started losing mobility about 5 years ago he decided to learn to draw and paint, as a way of staying connected with his young daughters and as therapy to help to manage his chronic pain. As his children have grown, Ben's dream has evolved to wanting to take art classes and use professional materials to paint their portraits.

'My dream is to be able to paint my daughters at different ages and by doing that stay close and connected to them as they are getting older and going to high school, they spend more time out of home as I seem to spend more time at home.'

Ben will now be able to attend an online art class, to allow him to manage his fatigue and participate at times of the day when he has the most energy.

'The ultimate dream is that, by learning painting and art techniques, it will allow me to continue to connect with my daughters plus act as a form of therapy for my pain and fatigue. One day I may be able to sell paintings and contribute even more to my family.'

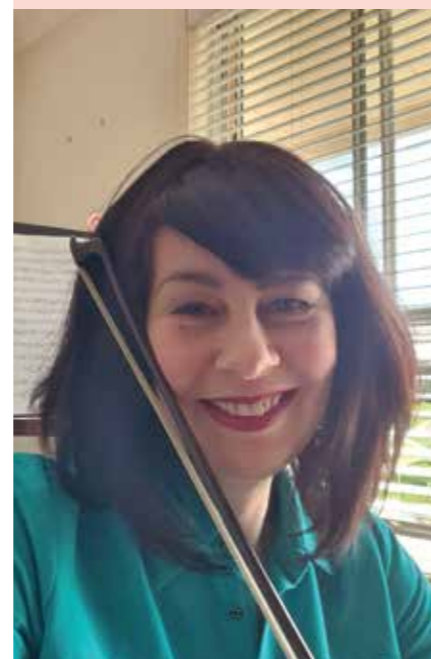
## ZIENNA

**Category: Personal Expression**

I have always wanted to learn the cello. It is something that I consider a dream and a luxury. I play the violin, I would also love to play the cello to not only experience the joy and accomplishment of learning a new instrument but to receive the benefit of creating new neural pathways by learning a new instrument.'

Zienna's MS has impacted her ability to work and to participate in her life the way she would like to. Her Go for Gold Scholarship will mean a return to something she loves.

'The scholarship will be used to buy an adult cello, including case and bow. This was not something I could afford to do with the resources I have and it was relegated to a dream and a luxury.'



## What's new in research?

# Sleep in MS: more important than we thought

**New Australian research has shown that sleep difficulties are far more common among people with MS than in the general community.**

Some of the risk factors for poor sleep include a greater level of disability and specific MS symptoms, including fatigue, depression, anxiety and cognitive difficulties.

However, it has been unclear whether poor sleep itself is associated with reduced quality of life in people with MS, or whether this is due only to the effects poor sleep has on other symptoms of MS. This is important because it has implications on whether treating poor sleep is likely to make a clinically meaningful difference to the health of people with MS.

A new study from the University of Tasmania's Menzies Institute for Medical Research has examined this question through the Australian MS Longitudinal Study (AMSLS). The AMSLS is one of MS Australia's collaborative research platforms and is a survey-based research study running since 2001. Approximately 2,500 people complete the research surveys each year.

### What did the researchers do?

To examine whether poor sleep is associated with reduced quality of life in people with MS independent of their other symptoms, researchers surveyed 1,717 people with MS within the AMSLS.



### What did the researchers find?

More than two-thirds of people with MS (68%) experienced poor sleep. This is up to twice the rate of sleep problems in the general community (33%-45%). Poorer sleep was associated with being younger, overweight or obese, having a recent MS relapse, higher disability levels and three groups of MS symptoms ('pain and sensory', 'feelings of anxiety and depression' and 'fatigue and cognition').

The effect of sleep and MS symptoms on quality of life were also measured. Study author Dr Laura Laslett says, 'Interestingly, sleep dysfunction stood out as being strongly associated with health-related quality of life, independent of other symptoms of MS.'

She added, 'I think the most important take-home message from this research is that both sleep and MS symptoms are independently related to quality of life, and that effects of sleep on quality of life are not just secondary to MS symptoms.'

### What does this mean for people with MS?

We don't yet fully understand what drives poor sleep in MS. Changes in the brain in MS are present in people with MS who have sleep disorders and likely also impact sleep. The study also showed that specific MS symptoms, including anxiety, fatigue, depression and cognitive issues, were associated with poorer sleep. These could be impacting sleep, and vice versa. Further research is needed to find the most effective ways to address sleep problems in MS. If you are experiencing sleep problems, please consult your MS healthcare team.

Head of Research at MS Australia, Dr Julia Morahan, says, 'This is such an important study because it gives us another potential lever to improve health in MS. We are so grateful to the AMSLS participants who generously give their time and information to help others with MS.'

To participate in life-changing research visit [msaustralia.org.au/amsls](https://msaustralia.org.au/amsls)

You can read all our recipient stories on the MS Plus website: [msplus.org.au/goforgold](https://msplus.org.au/goforgold)



# THE MS PLUS IKARA-FLINDERS RANGES ADVENTURE

28 MAY 2023 - 2 JUNE 2023

## BE PART OF SOMETHING LIFE-CHANGING

Join us on The MS Plus Ikara-Flinders Ranges Adventure and discover a beautifully rugged and colourful landscape in a timeless land of history and wonder, while raising funds for a future free from the effects of MS.

[doitforms.org.au/event/flinders-ranges](http://doitforms.org.au/event/flinders-ranges)



## Exercise and MS

**MS Exercise Physiologist, Caitlin Ireland discusses exercise strategies for people with multiple sclerosis.**

### How much exercise should I be doing each week?

The Canadian Physical Activity Guidelines for Adults with MS recommends the minimum for people with MS is 2 x 30-minute aerobic sessions at a moderate intensity and 2 x 30-minute strength or resistance training sessions. They can be done on alternate days or combined in a single session. I do recommend that if someone has quite a low cardiorespiratory fitness, to start with a shorter duration. Start with 10 to 15 minutes and work up to 30 minutes.

### What do you mean by 'moderate intensity'?

Moderate intensity is classified as working at about 60-70% of our maximum predicted heart rate. Although a lot of people with MS also have autonomic dysfunction — meaning the heart rate is blunted and doesn't necessarily increase with increased workload, so it's not always an accurate way to measure intensity. Here at the MS Plus Gym at Lidcombe we use the Rate of Perceived Exertion (RPE) at a scale of zero to 10. A moderate workout will aim for about 3-5. We can also use the 'talk test'; you should be able to answer a question but not sing — so starting to get breathless. For resistance training, moderate intensity means if you were to do 3 lots of 10 of an exercise, on the 9th and 10th repetitions you should only be able to do another 2-4 repetitions at most.


### Is High Intensity Interval Training (HIIT) safe?

There is a lot of evidence to show HIIT is a very safe and effective aerobic workout for people with MS and is in fact recommended for those who experience heat intolerance. Back to the RPE scale — we should be working at between a 7 or an 8 followed by a longer period of rest e.g., for a 15 second sprint, at least 15-45 seconds rest in between.

**Remember, be kind to yourself. Not every session will be better than the last. Just do what you feel up to that day.**

### Caitlin's top tips to get moving


1. Make it enjoyable
2. Schedule it into your day like an appointment



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# Our MS Heroes

In 1986, Vic Bilbrough met Kathy Adamson at the Department of Veterans' Affairs in Melbourne. Kathy and Vic married in 1991. However, while working in Germany and later in Melbourne, Kathy experienced vision problems and became unsteady on her feet. Two years into the marriage, her health declined. Kathy learned she had multiple sclerosis.

After Kathy's diagnosis, Kathy and Vic spent several months travelling around Europe and the UK. They visited Germany, where Kathy had many friends.

Kathy passed away in 1998 and Vic passed away in 2020. At Vic's memorial service, people remembered Vic and Kathy for their many accomplishments.

'Kathy was an all-rounder, excelling at violin, piano and singing, softball and netball. She won many awards at Glen Waverley Secondary College,' recalled sister Lynne Adamson.

Kathy studied arts and German at Monash University and spent a year perfecting her German in Cologne.

She became a teacher and taught German in private schools in Melbourne and Hamburg.

Lynne remembers Vic as 'clever, witty and talented.'

'He was also wonderful at woodwork. One time, he made the most beautiful wooden guitar,' she said.

Brother David remembers Vic as sporty and musical. 'He could sing and play guitar. At 12, he won a local talent competition. He also formed a band with his best friend Steve and brother Stan,' he said. Unfortunately Vic didn't leave a will, but David, his executor, had an inkling of his last wishes.

'Vic mentioned a few times he and Kathy wanted to leave a generous gift to MS Plus as a thank you for the support staff had given them. The family liked the idea of supporting the MS cause,' said David.

'By leaving this gift in their names, we hope others will be supported with their MS challenges when they need help,' added David.

For more information on leaving a gift in your Will contact us on **1800 443 867** or visit [myslegacy.org.au](http://myslegacy.org.au)

## MS and heat intolerance



To maintain core temperature in a healthy range, we first vasodilate and then we sweat. When myelin is damaged, nerve impulses find it much harder to travel the length of the nerve. When things get too warm, these damaged nerves find it even harder to get message through.

### What symptoms can be triggered due to heat intolerance?

- decreased cognitive function
- numbness in the extremities
- fatigue
- blurred vision
- tremor
- weakness

### Triggers

- hot weather
- exercise
- running a temperature
- hot drinks
- hot shower
- diurnal rhythms

### Managing heat intolerance

There are many products on the market designed for rapid cooling:

- cooling vests
- cooling neckties
- bed pads
- cool hats
- cooling towels
- pillows

For more information visit [msplus.org.au/heatsensitivity](http://msplus.org.au/heatsensitivity)

# Physiotherapy vs. exercise physiology: what's the difference?

At MS Plus, we have highly skilled Physiotherapists (physios) and Exercise Physiologists (EPs) – both of which have a deep understanding of MS and other neurological conditions. We're here to demystify one of the common questions – what's the difference between a physio and an EP? And which health professional is right for you?

## What does a Physio do?

MS Plus **Physios** carry out targeted assessments to diagnose and treat neurological conditions through exercise-based rehabilitation and education. They can help you manage symptoms such as fatigue, weakness and heat sensitivity, reduce pain and stiffness, increase mobility, and prevent progression of your condition.

### Our physios can

- assess if manual therapy or stretches would be beneficial in providing symptom relief
- carry out a neurological assessment aimed at identifying your main impairments, and design a targeted exercise program to address them
- provide education to help you understand your condition and use this knowledge to maintain function and capacity

### Treatment could include

- soft tissue work aimed at providing pain relief or improving function
- prescribing stretches to improve your joint mobility and health
- prescribing exercises to improve or maintain your strength/functioning. This could be in the form of gym-based exercises, gait-re-education, or body-weight/bed-based program
- rehabilitation aimed at relearning or maintaining functional skills such as sit to stands

## What does an EP do?

MS Plus **EPs** are equipped with the knowledge and skills to design safe and effective exercise and movement programs for people with MS or other neurological conditions. Our MS Plus EPs can help you manage symptoms, reduce pain, and improve mobility, strength, balance and mental health.

### Our EPs can

- formulate specialised exercise-based programs tailored to your desired goals (1:1 or in a group setting)
- work with you to identify achievable, realistic, and measurable goals
- use exercise to manage symptoms, such as fatigue, muscular weakness, spasticity, balance, pain, cognitive declines, anxiety and depression and incontinence.

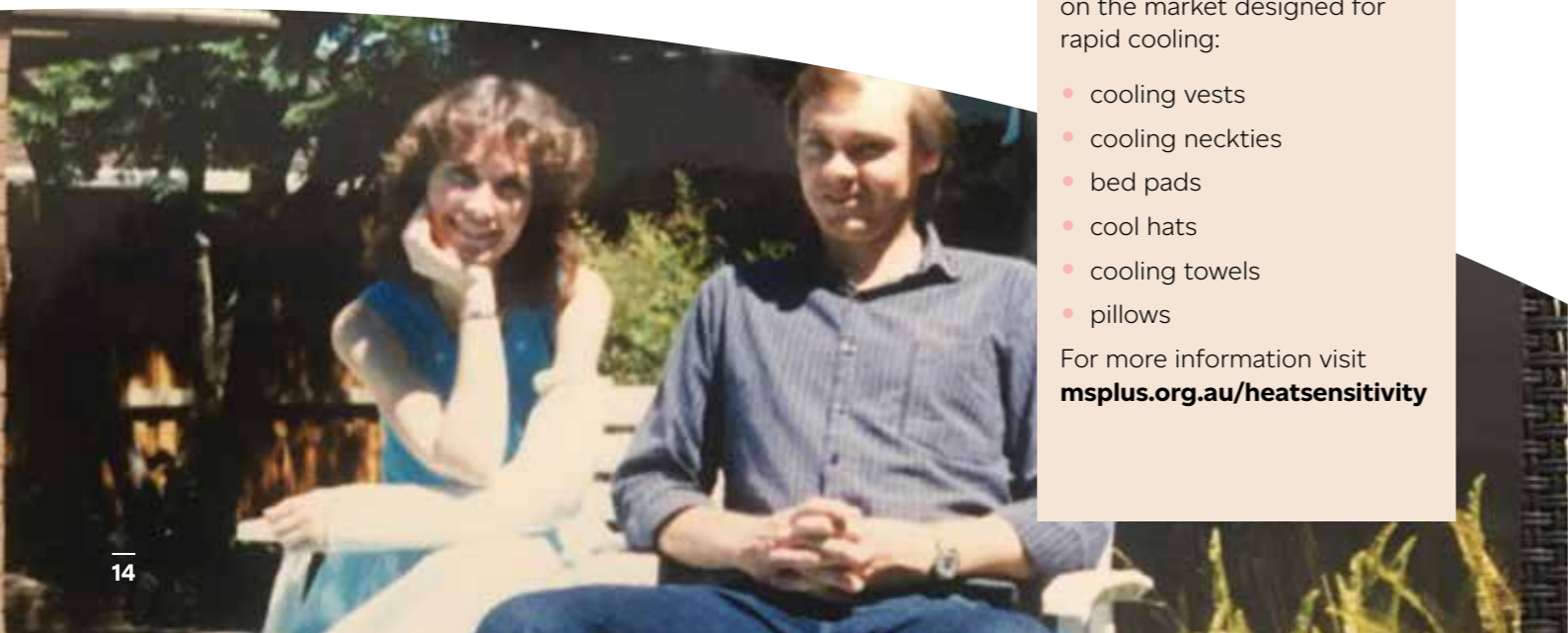
### Recommendations could include

- home-exercise programs that use the equipment available within your home to achieve your goals
- specific neuromuscular balance exercises to re-train gait (walking) and improve balance and in turn, prevent falls.
- education on motivation techniques to help achieve your exercise goals

Seeing a physio and EP from the same organisation means we can combine our expertise to help you achieve your goals, manage your symptoms and live life to the fullest.

'Working together with Mahendra (MS Plus Physiotherapist) allows us to make sure we're targeting the right areas for the individual with two sets of eyes and professional experience,' said Caitlin, MS Plus Exercise Physiologist. 'We're always coming up with ideas on how best to support our clients and discuss what program adjustments or treatments are needed get them closer to their goals.'

We understand your limits and can help you renew your confidence and push your boundaries safely. Call us on **1800 042 138** or email [connect@msplus.org.au](mailto:connect@msplus.org.au) to book an appointment.







## Diet tips and tricks

### With the holiday season approaching, what are some tips on healthy meals while eating out?

- try to select meals which looks like the plate model. This includes half a plate of vegetables/salad, a quarter of a plate of lean meat/meat alternative and a quarter of a plate of wholegrains
- try to pick venues which offer healthy choices on their menu
- consider sharing meals or choosing entrée sizes if enjoying multiple courses
- order vegetables or salad as a side in place of chips or bread
- choose grilled options instead of fried or crumbed options
- choose clear sauces rather than creamy sauces and request this on the side to control the amount you are having
- choose water, sparkling water, or diet soft drinks instead of alcohol and sugar sweetened drinks.

- Drinking water can reduce the amount we eat by increasing the feeling of fullness.

### What are some quick and easy snack ideas?

- vegetable sticks (e.g. cucumber, carrot, celery, tomatoes) and dip (e.g. Tzatziki, hommus, beetroot, avocado)
- nuts and seeds
- tinned legumes (e.g. Edgell Snack Time chickpeas, black beans, kidney beans)
- fruit (e.g. fresh, frozen, dried, tinned/canned)
- yoghurt (low fat/no fat, reduced sugar/no added sugar)
- dairy drinks
- crackers (e.g. Vitaweets, Ryvita biscuits) and low fat cheese or tinned fish.

### How can I select healthy choices at the supermarket?

#### Choose:

- fresh or frozen vegetables or fruit

- high fibre, wholegrain and low GI breads, pasta, noodles, rice and cereals
- low fat and calcium containing dairy drinks
- choose low fat and reduced sugar yoghurts
- choose low fat and reduced salt cheese
- choose lean meats with fat and skin removed
- use the free FoodSwitch app or Healthy Picks app for Aldi products.

### How can I improve my bowel health?

- gradually incorporating 25-30g of fibre each day
- fibre can be found in vegetables, fruit and wholegrains
- aim for 6-8 cups of water each day
- a fibre supplement such as Metamucil may be beneficial.



## NDIS and you

### Assistive Technologies

Assistive technologies (AT) are physical supports that help you to do something more easily or safely and to do something you otherwise cannot do.

### What are common pieces of AT funded through NDIS plans?

- non-slip mats, that assist you to move around your home safely
- special forks, that assist you to eat
- higher risk AT items, such as wheelchairs and adjustable beds.

### What is the difference between low, mid, high cost AT?

#### Low cost:

- \$1,500 or under
- purchased out of the Core Consumables budget in your plan
- items can be bought off the shelf/are easily accessible

- assessed to require very minimal support when setting up or using this item. Most of these items will require a letter of support from your AT Assessor.
- examples: continence products, grab rails, threshold ramps, cooling AT, simple mobility devices such as walking sticks, basic shower chairs and communication devices.

#### Mid cost

- \$1,500–\$15,000
- purchased out of the Capital Supports budget in your plan
- items that may require more input from your occupational therapist, such as trialing items and then providing either a support letter or NDIS application to get approval
- examples: standing hoist, a customized shower chair, a non-scripted mobility scooter and pressure care mattresses.

#### High cost

- above \$15,000

- purchased out of the Capital Supports budget in your plan. If funds are not present in Capital budget, a NDIS application will be required to be submitted for approval
- are complex in need and need specialised assessment/knowledge to ensure it is the right solution
- will need a quotation
- examples: scripted power wheelchair, ceiling hoists, power adjustable beds and complex car modifications.

### How can an occupational therapist (OT) assessment assist with AT recommendations?

It is important to have an assessment with a qualified allied health professional, such as an OT, to ensure the any equipment is the best fit for you.

For more information, visit [msplus.org.au/NDISservices](https://msplus.org.au/NDISservices) or phone Plus Connect **1800 042 138**







# Your wellbeing

## Keeping up your hobbies

Hobbies provide an important outlet from daily stressors — preventing us from getting burned out in our busy lives. Hobbies can fill the day when we are no longer working. Studies have shown hobbies provide numerous health benefits from lower blood pressure to better physical function, higher positive psychological states and less memory loss.

For a person living with MS, symptoms such as fatigue and issues with dexterity, balance and strength can impact on your ability to start or continue a favourite past time. However, there are lots of ways you can keep doing what you enjoy, by changing the way you complete your hobbies or even starting new ones.

**Most hobbies can be adapted using a physical aid, adapted tools or equipment or even certain apps, for instance:**

- tables with adjustable heights, including those with built in pottery wheels
- paint brushes with thicker handles
- GoPro, tripods or remote controls for cameras
- card holders and automatic card shufflers
- large print braille scrabble or large font bingo cards
- knitting aids, hoop holders, needle threaders, portable stitching frames for sewing and knitting
- fishing rod holders or harnesses and hook threaders. Electric fishing rods
- writing aids to help secure pencils or pens to your hand.

To view the full webinar with Andrea Salmon and Peter Simpson from Assistive Technology Australia, visit: [msplus.org.au/resource-hub](https://msplus.org.au/resource-hub)



## Who can help you adapt your hobby to suit your needs?

**Occupational therapists** — can help improve hand function and modifications

**Physiotherapists** — can help with a balance assessment and retraining and strength training

**Assistive Technology Mentors**

**Others with MS**

**Social media**

**Online forums**



**Peer support is the act of connecting with others who are in a similar situation. By drawing on your own experience, you can share stories and feelings with people who 'just get it', providing each other with friendship and understanding.**

'The experience [of joining an MS peer support group] was life-changing for me. Not only did I receive great and relevant information and education about MS, but I was also no longer isolated and alone.' Nichole, Peer Support Participant

Our trained peer support volunteers are people with experience of living with multiple sclerosis or caring for someone who is.

We offer plenty of options to access peer support, including:

- **Face-to-face**
- **One-on-one over the phone**
- **Groups over the phone**
- **Telelinks** (short-term programs)

For more information, visit: [msplus.org.au/peersupport](https://msplus.org.au/peersupport)

# What's On

**Our MS education and wellbeing events cover a wide range of topics and can be accessed from the comfort of your own home.**

## Live webinars

To register, email [education@ms.org.au](mailto:education@ms.org.au) for the links

## NOVEMBER

### Chair Yoga by Webinar (6-weeks)

Tuesdays from 8 November, 10:00am – 10:45am AEDT

**Cost:** \$60 (assistance available)

It's not too late to join, as weekly recordings are available to all who register!

## DECEMBER

### Coping at holiday time

Wednesday 7 December, 5:30pm – 6:30pm AEDT

### 2022 in Review: Research Update

Monday 12 December, 5.30pm – 6.30pm AEDT

## FEBRUARY

### Gut health and MS

Date and time TBC

### Pilates by webinar

Date and time TBC

And more to come! Please check the website for dates and times closer the date.

## On demand webinars

Watch anytime! Email [education@ms.org.au](mailto:education@ms.org.au) for the links or visit our website [msplus.org.au/resource-hub](https://msplus.org.au/resource-hub)

- nutrition facts and fallacies for someone living with MS
- breaking down barriers to exercise with Paralympic Bronze Medalist, Janine Watson
- sleep well with multiple sclerosis
- live well with multiple sclerosis
- coping with the heat
- improving your mental health
- managing a relapse in multiple sclerosis
- and many more!

## Podcasts

Listen anytime! Email [education@ms.org.au](mailto:education@ms.org.au) for the links or visit our website [msplus.org.au/resource-hub](https://msplus.org.au/resource-hub)

- "Learn from Me" series: Being diagnosed with MS as a teen
- "Learn from Me" series: Adjusting and managing SPMS
- "Learn from Me" series: Juggling work and MS
- and many more!

## Exercise Groups

### NSW

To book, phone Plus Connect **1800 042 138**

### Lidcombe Yoga (Chair based)

Wednesdays 10:15am  
Studdy MS Centre, 80 Betty Cuthbert Dr, Lidcombe

### Dance for Health (independent and chair based)

Mondays 10:30am  
Studdy MS Centre, 80 Betty Cuthbert Dr, Lidcombe

### East Gosford Exercise Group (independent)

Wednesdays 10:30am (school term only)  
East Gosford Lions Hall

### West Chatswood

**Community Learning Facility**  
565 Mowbray Road, Chatswood  
To book, phone Plus Connect **1800 042 138**

### Marrickville Yoga (independent)

Tuesdays 9:00am  
Addison Road Community Centre, 142 Addison Road, Marrickville

### VIC

For queries relating to exercise groups in Blackburn, please call Plus Connect **1800 042 138**

### ACT

To book, phone **(02) 6234 7000**

### Be better balanced (chair-based class)

Tuesdays 1:30pm  
Thursdays 10am  
Gloria McKerrow House  
117 Denison St, Deakin  
**Cost:** \$10 / session

### Wheels in motion (chair-based class)

Thursdays 11:00am  
Gloria McKerrow House  
117 Denison St, Deakin  
**Cost:** \$10 / session





# You can help fast-track research for MS this Christmas.

Please give a gift to MS research and fast-track new treatments for people living with MS like Bronwyn.



To donate to vital MS research this Christmas,  
call **1800 287 367**  
visit [www.msplusdonate.org.au/bronwyn](http://www.msplusdonate.org.au/bronwyn)  
or scan the QR code.

