



PLUS
Neuro Wellbeing

ACT Region Newsletter
December 2024

Our Values - Empowerment, Community, Expertise, Creativity and Spirited



A PATHWAY BEYOND PAIN

Pain. It's something that we've all experienced in one way or another – from the sharp pain of burning your hand on a stovetop to the throbbing ache of muscle pain.

But for an estimated two-thirds of Australians living with MS, pain is an invisible but very real symptom that can have a significant impact on so many aspects of their life. And for people like 49-year-old mum, Emma, who's been living with MS for 23 years, the pain also comes without warning: ***“Nerve pain is just horrendous. It's like a really bad toothache but in a***

bigger area of the body. It just stops you in your path.”

While there are many options for treating pain, such as medications and physiotherapy, not everyone reports effective relief. We know there are different types of pain, but we don't yet fully understand the nature of MS-related pain, or how it's experienced by those living with it – because it can vary so greatly from one person to the next. Some people experience aching and burning sensations, while others experience excruciating nerve pain. It can be pain that comes and goes, or chronic pain that never leaves – in some cases, people can experience several types of MS-related pain at once. Whatever form the pain takes, you and we must continue our efforts to end it.

A couple of months ago, Emma was out walking with her husband when the pain struck without warning: ***“Out of the blue – all the way down my left leg – the nerve pain just hit me all of a sudden and I fell to the ground. I sat there for about 10 minutes because I couldn't get up. I always think what would happen to me if I'm out by myself? Or driving a car? I don't know what I'd do. I've had to withdraw myself from a lot of things I used to do... It breaks my heart because I miss being able to be a good mum for my girls and take them out to go do things.”*** The pain on its own is more than anyone should have to bear.



Dr Alice Saul is a postdoctoral research fellow at the Menzies Institute for Medical Research at the University of Tasmania. Dr Alice Saul and her team are working hard to better understand the pain people with MS experience, so more effective and targeted treatments can be found. Dr Saul's research focuses on understanding the different types of pain experienced by people with MS by using data from the Australian MS Longitudinal Study (AMSLS), which has tracked over 2,000 people with MS since 2002. Dr Saul and her team are analysing the prevalence, severity, duration, and triggers of pain and

investigating which pain management strategies are most effective overall and for specific pain types.

And for people like Emma, finding better treatments, would mean everything: ***“We need to give people living with MS hope for medicines that mean you don't have to worry or doubt your body. You don't have to cancel appointments or not be able to go out or take your children places.” Pain management would be everything. It would give me freedom and confidence.”***

It's why Dr Saul is so motivated and inspired to progress her research at the Menzies Institute for Medical Research. So, they may get a better understanding of the different ways that pain impacts the quality of life for people living with MS.

A vast majority of people living with MS will experience its unique pain – but its causes and best treatments are still little understood. Please support research with a gift this Christmas to help accelerate the development of treatments that will help people like Emma live pain free.

To donate online – <https://donate.msplus.org.au/christmas-appeal-2024>

QR Code



HOLIDAY DINNER PARTY

When: 12 December 2024

Where: Saffron Restaurant,
Franklin Street,
Kingston, ACT

Time: 5:30pm

RSVP: actmsfunding@gmail.com
by **6 December** with name, numbers
and dietary requirements

* Hosted by MS Community of Canberra

GLORIA MCKERROW PAINTING WORKS

Gloria McKerrow House will soon be having a fresh new coat of paint. The painting of the internal building will commence just prior to Christmas and be completed over the break and into the first part of the new year. This will require the artwork to be taken down and then re-hung and will be done at this time of the year to ensure minimal disruption to activities. Assistance will be provided for safe removal of artwork, moving of furniture where required, blinds removed from offices etc.

The curtains in the public areas and consultation rooms will also be replaced with roller sunshade blinds following the completion of the painting.

2024 MS GONG RIDE – THE RIDE TO FIGHT MS

The 2024 MS Gong Ride was an absolutely incredible event! With 6,531 riders registered and over \$1.3 million raised, the involvement of participants and supporters alike made a huge impact, making the day a great success. The beautiful weather and tailwind was a great bonus for the riders, helping them push through the challenge, which took them through the pristine Royal National Park and across the spectacular Sea Cliff Bridge. The Event Village with live entertainment, food vendors, and a DJ announcing the riders as they crossed the finish line created an exciting atmosphere for both the riders and their supporters as they celebrated the incredible effort and accomplishment.

Seeing the community come together for this year's The MS Gong Ride truly makes it the **Ride to Fight MS**.



In Memory of Amanda: Peter's Legacy of Love and Hope



Amanda, Peter's first wife, was diagnosed with multiple sclerosis (MS) in 1990. However, she refused to let the illness define or limit her. Known for her resilience and tenacity, Amanda approached life with a fierce determination. She wanted to remain active and positive, regardless of the challenges MS presented.

"She fought the illness and was determined not to let it define her or limit her life," Peter remembers.

Yet, there were days when the obstacles of MS weighed heavily on her, and Peter saw firsthand the toll it could take. "Sometimes, it did limit her, which caused immense frustration," he reflects. Peter noted how

deeply it impacted him to see her struggle. **For Peter, MS wasn't just an illness—it was an unfair battle that he and Amanda faced together.**

Tragically, Amanda's life was cut short over a decade ago in a car accident. The loss was unexpected. Peter's admiration for her strength and determination stayed with him. Knowing how unpredictable life can be, he was inspired to honour her memory by supporting others with MS.

Through a gift in his Will to MS Plus, Peter has found a meaningful way to keep Amanda's legacy alive. *"I see it as a dedication to Amanda,"* he says. "There are so many worthwhile causes, but I chose MS because it chose Amanda."

Peter's journey began in Nhill, Victoria. Here he spent his early years on a farm before moving to Frankston with his family. Growing up in a hard-working family, he later pursued a career in finance, dedicating 40 years to the industry. Now retired, Peter volunteers at a regional hospital. He also enjoys life on a farm with his wife, Margaret. Here they are surrounded by animals, including a beloved horse named Astro—a cherished connection to Amanda, as Astro was once her own.



Peter's decision to leave a gift in his Will to MS Plus brings him peace. He knows that Amanda's memory will continue to inspire others. "My wife Margaret is most understanding of this wish," he says. He is grateful to have her support in honouring Amanda in a way that will make a difference for those living with MS.

Could you be like Peter and want to protect future generations from MS? And pay a special tribute to a person in your life? You can do all this through a gift in your Will. This gift could help fund research, better treatments, or more services.

Become a member of the MS Callistemon League. To learn more, contact Laura at the MS Plus Future Planning Team.

Call 1800 443 867, email futureplanning@msplus.org.au or visit www.mymslegacy.org.au

MS Plus Bonbonnieres

Choose from
different
designs and
occasions



Make your next special occasion a Moment for MS and help provide vital support to people living with multiple sclerosis

what's on

The latest programs and updates from client engagement and wellbeing



DECEMBER 2024

Newly Diagnosed? Book an Allied Health Advisor appointment

Just like your MS medication, we want to help you prevent worsening symptoms. Our 30-minute Allied Health Advisor telehealth appointments (Exercise, Diet or Continence) provide you with advice and preventative strategies to keep you living well.

We recognise that after an MS diagnosis you might still feel well and be physically active, with relatively mild symptoms. However, we also know that MS can change anytime and being prepared with good lifestyle practices is key to staying well.

Allied health appointments are available to people newly diagnosed (within the first two years)

Cost: \$80 for a 30min telehealth appointment with an exercise physiologist, dietitian or continence nurse.

To book: Chat with one of our MS Nurses to learn whether an Allied Health appointment is right for you.

connect@msplus.org.au 1800 042 138

Managing fatigue at work

Fatigue is a very common symptom of MS and can significantly impact your work, but there are strategies you can learn to help.

FACETS (Fatigue: Applying Cognitive behavioural and Energy Effectiveness Techniques to LifeStyle) is an evidence-based program designed for people living with MS to help manage fatigue using 'energy effectiveness' techniques and cognitive behavioural therapy strategies.

Developed by researchers from Bournemouth University and Poole Hospital in the UK, the group program is delivered by trained professionals with no more than 12 participants. The program involves weekly 90min sessions over 6 weeks.

When: FACETS for work – Lunchtime session 5 Feb 2025 12.00 - 1.30

Learn more: msplus.org.au/FACETS

Register: <https://www.trybooking.com/CUNAE>

Cost: \$150



We can help end loneliness for an older person in your community

Do you know someone in aged care or at living at home with a home care package who is at risk of social isolation or loneliness? MS Plus proudly delivers the Aged Care Volunteer Visitors Scheme, funded by the Australian Government. We have volunteer visitors in ACT ready to visit and bring a smile and some conversation over a cup of tea to someone in your community.

If you know someone who may benefit from a visitor contact us directly at ACVVSAdmin@msplus.org.au, or submit a referral yourself to msplus.org.au/aboutACVVS



Exercise Classes at Gloria McKerrow House

Be Better Balanced

A combination of chair and circuit-based exercises designed for individuals who can still walk but have challenges with balance, stamina, and overall mobility. Classes are comprehensive and well-paced, ensuring they are enjoyable for everyone.

When: Tuesdays 9:30am — 10:00am, Thursdays 10.00am – 11.00am (online available)

Wheels in Motion

A class designed for people in wheelchairs or who are having difficulty walking. In this class the focus is on upper body mobility as well as making use of a motorised exercise bike for those it suits. This is a small group and where possible individual work is done on each person to mobilise leg movement.

When: Thursdays 11.00am – 12.00pm **Cost:** \$10.00 per class or 10 classes for \$90.00

Please call 1800 042 138 to register



Online Mindfulness Meditation

...for people with Multiple Sclerosis and other neurological conditions.

Join us every Friday afternoon, from 3:30pm - 4:30pm and experience the relaxing benefits of meditation.

Email Helen Woodbridge (woodbridgehelen@hotmail.com) and she'll send you a Zoom link for the session every Friday. Carers and family also welcome!

Peer Support

We have two Peer Support Groups available in the ACT, and new members are welcome at any time.

People with MS (PwMS) Taking Control Group

Our group meets twice a month and seeks to connect people living with MS in the Canberra region, for friendship and information sharing, with a focus on living well with MS.

Meets: 1. 12:30 to 2:00pm - 1st Friday, 6 December 2024 **Venue:** Gloria McKerrow House, Deakin
(Please note postponed from 29 November)

2. 12:30 to 2:00pm - 3rd Friday, 20 December 2024 **Venue:** Zoom only

Contact Vanessa Fanning/Mary Webb at pwmstcg@gmail.com to be added to our email list, and/or join our Facebook group 'Canberra Region MSers'. In line with privacy principles, you can unsubscribe at any time.

ACT Weekend MS Peer Support Group

Meets: 10:00am, 3rd Saturday of each month

Venue: ACT Café, Canberra

Contact Plus Connect on 1800 042 138

Tabletop Games

This is the last tabletop games afternoon for 2024! — No prior knowledge required!

When: Saturday 14 December 2024

Where: Gloria McKerrow House, 117 Denison St, Deakin ACT

Time: 1:00—4:00pm, come and go at your leisure

Please register your interest at pwmstabletop@gmail.com for updates.



*** Family, friends and carers are also welcome ***