



**PLUS**  
Neuro Wellbeing

**ACT Newsletter**  
April 2024

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

**JOIN THE MAY 50K TO LEAVE MS WHERE IT BELONGS, BEHIND US...**



This May, smash your fitness goals as you help raise funds to support life-changing research into the prevention, treatment and finding a cure for multiple sclerosis.

Challenge yourself to move **50 KM (The OG)**, **100 KM (Double Up)** or **150 KM (Triple Threat)**, in your own time and at your own pace.

Take part on your own, as a team, or get your whole workplace involved!

We'll be here to support and encourage you every step of the way, as we come together to leave MS where it belongs, behind us.

**[REGISTER FOR FREE HERE](#)**

**The MS Plus Virtual Art Show is back for 2024!**



**MS Plus Art Show**

Get ready for a vibrant showcase at this year's MS Plus Art Show! The MS Plus Virtual Art Show is your chance to express your creativity and celebrate connections through art.

This year's art show theme will be 'It Takes A Village' — a celebration of the people, systems and services that support people with MS. Show us, what does the village mean to you?

The **2024 MS Plus Art Show** will be open for entries from **Monday 1 April**, closing **Sunday 5 May**. We can't wait to see your entries! Visit **[msplus.org.au/artshow](https://msplus.org.au/artshow)**

# MS WALK RUN+ROLL



Register,  
donate or  
volunteer  
today

## Sun 5 May 2024 Rond Terrace

Acton ACT 2601

Walk Run + Roll your way to  
ensure no one faces MS  
alone

[REGISTER HERE](#)



Visit [mswalk.org.au](http://mswalk.org.au) to find out more.  
E [events@ms.org.au](mailto:events@ms.org.au) T 1300 733 690

# Eternal Bonds: A Legacy of Love and Hope



It was 1976 in Cape Town, South Africa. There lived a beautiful young girl named Rosalind Lewis. Rosalind was known for her vibrant spirit and zest for life. Amitai Lapidot loved her dearly.

Tragically, Rosalind was diagnosed with multiple sclerosis (MS). This is a relentless foe. It gradually took away her ability to move freely and enjoy life's simple pleasures. Eventually, Rosalind's health declined, and she passed away. This left a terrible wound and a void in Amitai's heart. Amitai could not, at that time, step in and do much to help her fight this disease.

Now, many years later, a seed of inspiration took root within Amitai. Amidst the long-held sorrow, he was determined to honour Rosalind's memory. He wanted to do it in a way that would make a lasting impact on the lives of others grappling with MS.



Amitai is a longstanding supporter of MS Plus. He learnt about research and support. He saw how crucial they are in the fight against multiple sclerosis. Thus, Amitai decided to leave a gift in his Will. A gift in memory of Rosalind. When the time comes, it is his wish that it will be used for research into a cure.

Amitai's gift is a testament to the enduring power of friendship and love. To the ability to turn tragedy into triumph. Now it is the legacy of Amitai and Rosalind that lives on. Proving that even in the face of loss, the human spirit has the capacity to create positive changes.

Many MS Plus supporters like to include a gift in their Wills. You have supported the fight against MS before. Leaving a gift in your Will is a way to continue this support. It is about the values we share and that you hold dear in your heart.

Every time you think about the gift you will make, you will get a warm, happy feeling. Every gift, no matter what size, will make a difference. Because you'll know you will be helping a person living with MS have a better life.

At MS Plus, your charitable gift could go towards research. It would improve treatments and help fast-track a cure. A gift in your Will could also enhance the support services of people with MS. Or you could elect to fund both. It's your decision.

**Want to know more?** MS Plus has a Gift Planning Program. Call Laura or Rebecca on 1800 443 867, email [futureplanning@msplus.org.au](mailto:futureplanning@msplus.org.au), or visit [www.mymslegacy.org.au](http://www.mymslegacy.org.au).

## MS Plus Photo ID Card



The MS Photo ID Card is available at no charge for registered MS Plus clients, living in ACT, NSW, Tasmania and Victoria, who have a confirmed diagnosis of multiple sclerosis.

The card can be useful for telling others that you have multiple sclerosis. For example, it can be used at a bank to explain why a person's registered signature may have changed. Sometimes it's also useful to explain why you may have difficulty with vision, balance, coordination or slurring of speech.

To obtain an MS Photo ID Card, you need to download and complete an [application form](#) or [contact Plus Connect](#) Freecall 1800 042 138 Email [connect@msplus.org.au](mailto:connect@msplus.org.au) and ask them to post an application to you.

# what's on

Exploring the latest programs and updates from client engagement and wellbeing



## MS Genetics and Epigenetics with DR Vicki Maltby

**18 April 2024, 12.30pm – 1.30pmAEDT**

Genetics have a crucial, albeit partially understood, influence on MS. Although MS isn't directly inherited, specific genetic variations can heighten a person's risk of developing the disease. Understanding the significance of genetics and epigenetics may be a key to **unlocking further insights into MS, its progression, and the enhancement of treatments.** In our webinar, we'll feature a pre-recorded talk by Dr. Vicki Maltby, offering a comprehensive look at genetics and epigenetics in relation to MS. After the presentation a MS Nurse will be on hand to address any questions. **Register now**



### The MS BOOST

A fortnightly series filled with concise interviews with expert guests, it's all the stuff you need to know, from the people who know it.

**Brain health & why it's never too late to make a change - Listen Now!**

Olivia Wills, a brain health researcher talks about a holistic model of brain health in MS. Olivia outlines why brain health can be seen as a tangible concept that people can control by exercising, quitting smoking, managing comorbidities, eating well, and managing mental health. Olivia shares it's never too late for anyone to adopt healthier behaviours.

**The kids aren't alright – helping teens with their parents' diagnosis - Listen Now!**

In this episode of the MS Boost, we talk to Nicola Palfrey, Clinical Psychologist and Head of Clinical Leadership at Headspace, about the parenting challenge of talking to teenagers about chronic illness. Nicola shares her expert insights into approaching these difficult conversations sensitively.

We also explore the important topic of knowing the signs that your teen may need some mental health support and how to navigate access. If you are a parent with teenagers, this is an episode you will really appreciate.

## Volunteer Visitors

**Do you know an older person in aged care or who has a home care package who could use some company?**

MS Plus are proud providers of the Aged Care Volunteer Visitors Scheme where we match older people in need of company with volunteer visitors. If you know of someone who may benefit from the program, please contact our ACT program coordinator at

[ACCVSAdmin@msplus.org.au](mailto:ACCVSAdmin@msplus.org.au)

## Information for people supporting someone

The *Plus Navigate: Friends & Family* program is for people who support someone with MS.

Over two 75-minute sessions, an MS expert will guide discussions, provide information, links to resources and answer any questions. We'll cover a range of topics including:

understanding MS	navigating the health system
where to access help and support	how to take care of yourself

**Register now at <https://www.msplus.org.au/news/supporting-the-loved-ones-of-people-with-ms>**

The MS Boost will be in addition to our current series, so make sure you're following **MS Podcasts** on your preferred player like **Apple Podcasts** or **Spotify** to be the first to know when new episodes are released.



## Peer Support Groups

We have two Peer Support Groups available in ACT who welcome new members any time. If you're interested in joining a group contact Plus Connect on 1800 042 138.

### People with MS Group

**Meets:** 12.30pm, Last Friday of each month (exc Dec)

**Venue:** Gloria McKerrow House, Deakin

### ACT Weekend MS Peer Support Group

**Meets:** 10am, 3<sup>rd</sup> Saturday of each month

**Venue:** ACT Café, Canberra

## Supporting someone with a new MS diagnosis: A resource for family & friends



This booklet has been created for people who are going through the challenging and often emotional time that happens when a person they know is diagnosed with MS.

Having a diagnosis of MS can be life-changing for both the person and for those who care about them. This resource is designed to empower you with the knowledge and strategies to help support you and your person with MS.

**Download the resource here:** [Click Here](#)

### In case you missed it, MS Plus Webinars from February 2024 Progression Independent of Relapse Activity (PIRA)

In the world of MS, new terms and concepts constantly emerge, leaving many people wondering what it means for them. One such term is Progressive Independent of Relapse Activity (PIRA), which describes a specific type of MS progression, and this was discussed by neurologists Professor Helmut Butzkueven and Associate Professor Anneke Van Der Walt in the latest webinar recording which can be found [HERE](#).

Here are some key takeaways from the webinar:

- *Progression Independent of Relapse Activity (PIRA) signifies a continuous decline in neurological function without any relapse activity.*
- *Relapse Associated Worsening (RAW) is deterioration due to an MS attack or relapse.*
- *PIRA can happen to anyone with MS at any time of their diagnosis.*
- *Currently, there's no test for a PIRA event, and the need for a holistic neurological assessment that takes into account factors such as general health and mental wellbeing is important.*
- *PIRA progresses subtly and slowly; rapid symptom changes typically don't indicate a PIRA event.*

PIRA is a term that sheds light on a specific form of MS progression. It highlights the importance of early intervention, regular neurological assessments, and expert and comprehensive care for people with MS. While more research is needed to fully understand PIRA and its implications, the collective efforts of healthcare professionals, researchers, and people with MS contribute to continued progress in understanding and managing MS progression.

**You can find previously recorded webinars and podcasts on the [Resource Hub](#). If you need further information or would like to talk to our MS Nurse, please reach out to the Plus Connect team.**

## People with MS (PwMS) Taking Control Group

Our group seeks to facilitate connections, and to share information and companionship among people living with MS in the Canberra region, with a focus on living well with MS. We host regular meetings twice a month. We meet every month on the second and last Friday at 12.30pm, for around an hour or so. The meeting on the second Friday is currently via Zoom. This is a good opportunity to chat and catch up with each other without leaving our homes and for people from outside Canberra to join us. On the last Friday of the month we meet face to face at Gloria McKerrow House in Deakin.

April meetings:

- Friday 12 April , 12.30, Zoom only
- Friday 26 April, 12.30, Gloria McKerrow House, 117 Denison Street, Deakin

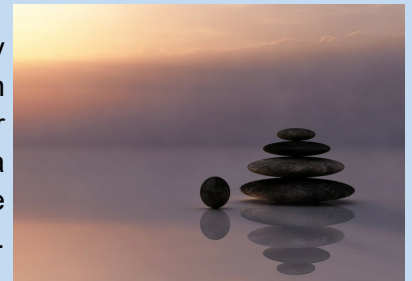


If you would like to be on the email list to: receive reminders of monthly meetings, including Zoom/Microsoft Teams links; be notified about presentations by expert speakers; and share news, information and feedback with us, please email Mary Webb and Vanessa Fanning at [pwmstcq@gmail.com](mailto:pwmstcq@gmail.com) to join our mailing list. Alternatively look for our page on Facebook: Canberra Region MSers.

We know that many people with MS do not necessarily wish to disclose their diagnosis, hence the names and email addresses of people who subscribe to our main mailing list are strictly confidential and are not

## Friday Afternoon Online Meditation

Join us online every Friday afternoon from 3:30pm for an hour of easy Mindfulness Meditation. It's an opportunity to meet other people with MS in a relaxed way. Anyone with MS or other neurological disorders or their family, friends and carers, are welcome to join us online each week for a guided meditation. Mindfulness Meditation can help us to process the events of the week, reducing stress, and helping with our wellbeing. Anyone interested, please email Helen at [woodbridgehelen@hotmail.com](mailto:woodbridgehelen@hotmail.com).



## Saturday 15 June - Canberra MS Community Day

Join us for a day of connection, information and good food.

More details to come.

## Exercise Classes at Gloria McKerrow House

### Be Better Balanced

A chair-based class for people still able to walk but struggling with balance, stamina and general movement difficulties. The classes are well rounded and paced, making it fun and accessible.

**When:** Tuesdays 9.30am — 10.30am and Thursdays 10.00am – 11.00am

### 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**