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# From the CEO



**John Blewonski** | Chief Executive Officer

## **Congratulations to the winners of this year's MS Virtual Art Show.**

We received entries from a large number of artists again this year and it has been inspiring to see the quality of the work submitted. The competition is a special one, in the way it celebrates the creativity and expression of our MS community. Many of the submissions captured the countless different experiences of living with MS and show the important role art plays in communicating complex emotions and experiences. For more information on our award recipients, see page 7.

Another MS Plus initiative I am particularly proud of is our MS Go for Gold Scholarships. Our 2023 applications have now opened and I encourage you to put your hat in the ring for one of 25 scholarships valued up to \$2,000, to help you to realise a dream or passion. Unsuccessful applications from last year may also be resubmitted. See page 16 for more detail.

As you will see on the next page, our suite of facility upgrades are progressing well, with our Hobart clients soon to enjoy the new Murray Street location and a new Footscray Wellbeing Centre now complete. Alongside other key projects, such as our new Lidcombe

facility currently in the early stages of construction, the transformation of our old facilities into state-of-the-art wellbeing centres is at the heart of our drive to provide the very best, individualised services and supports to our clients.

Likewise, with this ethos in mind, we promised to launch many new services for our clients, that would help us on our journey to expand into other neurological conditions — and help our clients to break down barriers and achieve their goals. We have progressed steadily in the past few months, with the launch of our new Plus Hydro service for our Footscray and Lidcombe clients and our Plus Balance program, run in our Lidcombe, Blackburn and Footscray offices. This is alongside our recently launched Plus Pilates program and Boxing for Parkinson's program — which will expand to clients with other neurological conditions, including MS, in the coming months.

I am proud that we are continuing to build on our aspiration to become the home of comprehensive support for neurological conditions and I look forward to keeping you updated on our progress.

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# News



## Delivering state-of-the-art care in Victoria

### **Our new Footscray Wellbeing Centre is now complete and ready to deliver a comprehensive wellbeing service to Victorian clients.**

The Centre, located at 212 Nicholson Street, Footscray, includes a specially equipped gym, therapy and consultation rooms, as well as meeting spaces all on one level, enabling delivery of all our exciting

allied health services such as physiotherapy, exercise physiology, occupational therapy, continence nursing and dietetics.

Work on our new wellbeing centre at Lidcombe in NSW has also been underway since early April, including site preparation completed in May and structural works expected to commence in July.

The purpose-built facility will replace the current MS Studdy Centre, first opened in 1985, and deliver an advanced, tailored Wellbeing facility for people with neurological conditions and Specialist Disability accommodation in the form of 20 two-bedroom apartments. The MS Wellbeing Centre at Lidcombe is expected to be completed in July 2024.

## Tassie clients to enjoy new wellbeing centre

### **MS plus is opening a new state-of-the-art wellbeing centre at 246 Murray Street, Hobart, Tasmania**

The MS Wellbeing Centre in Hobart will provide suite of services in one place, with a focus on total wellbeing to support our MS Community, including NDIS, employment, education, information and on-site allied health services including physiotherapy and exercise

physiology, as well as remote occupational therapy, dietetics and continence support.

MS Plus is no longer operating out of the ABC Building at 1 Liverpool Street and clients are currently accessing our services remotely until the transition to the Murray Street facility is completed, expected to be July 2023. Our Tasmania-based clients have experienced no disruption to our regular services, with the MS Plus

team supporting clients virtually through telehealth during the past few months.

The Hobart team is looking forward to welcoming everyone back in person once work is complete. In the meantime, should you have any questions or need any advice or support, you can contact the Plus Connect team on **1800 042 138** or **connect@msplus.org.au**



# Parenting and MS

**Melissa, whose son Jack is 15, shares her insights into being a mum with Relapsing Remitting MS (RRMS) from pregnancy to teenage-hood.**

## **What would you say to a mum who has just been diagnosed?**

The first thing I would say is, 'don't panic, it's going to be okay!' It's going to depend on whether you have young children or older children but what I've found is that no matter what stage of MS you are at, you can always just be a mum. We tend to stress about things that just aren't important, like housework, that really don't matter. Be kind to yourself, laugh, enjoy your life and your family.

## **What has been your journey with MS?**

I was diagnosed in my early 30s. I was newly diagnosed and got pregnant within a couple of months so it was all a bit scary but it worked out, it was fine. I've done the full gamut – from baby to teenager, all while having MS.

## **What are some of the challenges you faced?**

The biggest challenge is being tired. You are tired as a mum anyway but of course with MS there's the additional challenge of fatigue. My advice is similar to the advice all mums receive, which is get lots of rest, sleep when the baby sleeps, ask for help and accept help if you need

it. Don't pressure yourself to get the house clean, just spend time with the baby. Take the time for yourself. Think about what's really important to you and your health. You can't look after a baby if you don't look after yourself.

## **What has helped you as a mum with MS?**

Always try and have some activities in mind for when you are feeling more tired versus when you have more energy, so you're still able to keep the kids entertained. When you're organised, it helps to keep your stress levels down. I've become a big list-maker these days.

You do have to accept help when you can. I used a lot of friends I made in mums' group, then kinder mums and mums at school. I still have weekly coffees with the mums I met when Jack was in prep. It is so important to reach out for support. I think a lot of mums think they have to be superheroes and do everything, which is crazy. Sometimes you just need to reach out and talk to someone. We can't do it all by ourselves, it's too hard.

## **How should you tell your children about MS?**

Every family is different, every person with MS and every child is different so you need to work out what will work for your family. I started talking to my son about it when he was quite young, as I needed to take medication and he saw me using it. You may also need to explain why you're so tired and need to have naps. Keep it low key and relaxed. With my medication I simply said that it helps to keep me well, like taking vitamins helps to keep people well. As they get older, you can build on the information you give them. You don't want to talk about it when you're stressed or upset, as that's not going to help them understand.

## **What impact has it had on Jack as a teenager?**

I think it's been quite a positive thing for both of us, which I know sounds odd, but it has taught us resilience. We realise now that things can go wrong, that things aren't perfect, but you just keep at it, you keep going. Jack has become such an empathetic and caring person because of his experiences with my health journey. He inspires me to try new things.

## Silas, whose children are 11, 9 and 4, shares his experience of being a busy dad living with MS.

### What would you say is the biggest challenge being a busy parent with MS?

When your symptoms start flaring up and you're just trying to get on with your normal day to day and your MS just isn't having it, that would be the biggest challenge for me. When I have plans to do something and my body has other plans for me that day. Maybe it's too hot, which triggers my MS, or maybe too much is stressing me out, or my ability to walk and move is impacted. Every Saturday morning is mum's break, so I'll take the kids out. My wife is amazing, very supportive, great mum, I couldn't be more blessed. On Saturday, the kids and I will go to beaches, parks, wherever and one day we were at the park and my middle child, Thomas, who is 9, he had a little styrofoam aeroplane and I threw it and as I looked up it triggered my vertigo and bang, I hit the deck! Apart from being embarrassed it was all okay. The kids were surprised but they asked if I was okay and we just carried on.

### How have you approached talking to your kids about your MS?

At a deeper level it's my own perceived concerns about what other people will say or think about my MS but in truth, people just take you as you are. Your kids especially. It's your own fear that you have to overcome. I'm pretty honest with everyone, whether it's my family, my wife and especially the kids. I've told them that this is what my MS does sometimes and they don't bat an eyelid. That's just their normal.

If you look at a family who has

gone through something, there's always a positive, the kids are more empathetic, down to earth, humble or understanding and I see that in my kids a lot. If they see someone else that has any issues, they're a bit more sensitive to it and I'm so happy to see that. Especially my eldest girl, she's a sweetheart.

### What are some of the tips you would suggest about deciding to have a family?

I'm sorry for how cheesy this is but whenever I come across someone who is pregnant, whether they have MS or not, I can't help asking, 'do you have pets? siblings? friends? You don't know what love is' and they always say, 'what are you on about?' I reply, 'you might love your partner or anyone in your life but you would die for this little kid.' There's always a reason not to and we all have our own fears, thinking we're not ready but these little things come with their own love. Of course there are many valid reasons not to have children and if it's not for you then that is absolutely valid and you should always do what works for you. Speaking just for myself, I have certainly experienced a different level of life with kids, for sure.

### Are there any modifications you have had to make as a parent?

Yes, sadly, sure. I mean, I was out building water tanks for farmers and mines before MS, so I have changed my life to work with MS. Heat affects me and working on the tools affects me, I can't be in construction. Slowly each year I've made more changes. Instead of doing something like going on a hike, on a bad day we'll


just sit and play the Nintendo Switch with the air conditioner running and the kids will have a great time! I would rather be out the back throwing balls but some days I have to take it as it comes. My main goal is to not impact the kids but as far as they know, life is great. Just working with what we've got in front of us. I'm a fun person by nature and I find ways to make them laugh and have fun and work with my strengths. It's weird to say, and maybe cheesy, but I only recently signed up to the NDIS, after 10 years with MS and it's great! The kids will say, 'hey dad, the cleaner's here' and I feel like a king all of a sudden! Come on in cleaner! I never had that luxury before.

### What are your top 3 tips for dads with MS?

Just do what you can do. If you have to think of a new way of doing something it doesn't matter, the kids are going to love spending time with you and the memories you share together.

Be open and honest, when it's the right time and place. As you're being open with others, you get a lot further. With knowledge comes understanding.

Just be present. They're great mindfulness tools, these young kids. They're always in the moment and if you can do that with your kids it's just wonderful. Sometimes if I'm getting 'zaps' — what I call that electric shock feeling from my nerves, or sometimes I get pain, my go-to would be to go on my phone or watch a show but if one of my kids wants to play lego, I find just being there with them and being present goes a long way.



## DO YOU FOLLOW MS PLUS ON SOCIALS?

Check us out on LinkedIn, Facebook and Instagram for plenty of the latest advice, stories and support for people living with MS or other neurological conditions, their family, friends and carers. Follow [@wearemsplus](#) today!



## MS, fatigue and building up your energy levels

**Fatigue is one of the most common symptoms of MS, with some studies showing up to 90 per cent of people with MS experience fatigue.**

For many, the term fatigue doesn't capture the feeling of such complete loss of energy that you are simply not able to continue with an activity and a feeling of exhaustion that's out of all proportion to any activity you may have been doing. Fatigue in MS can be both physical and mental. MS fatigue is often harder to recover from than everyday tiredness, where people can bounce back more quickly.

Usually, fatigue is the result of a combination of several factors that contribute to tiredness and lack of energy. Primary fatigue in MS is thought to be due directly to the damage occurring in the brain and spine. Although the exact cause is still unclear, research to unveil the pathophysiological relationship to

MS damage and fatigue is growing.

Secondary fatigue can occur due to external factors and it's these factors that can be in a person's control. While it can be difficult to disentangle MS related fatigue and secondary causes, focusing on what can be actioned can be helpful. While many people are aware of these secondary fatigue factors, not everyone takes the time to think about how their day to day lives may be impacting their energy levels.

Below is a quick checklist of some of the factors impacting fatigue in MS:

- medications
- sleep (or lack of it)
- MS symptoms
- depression and anxiety
- poor diet and hydration
- stress
- other medical conditions such as diabetes, anemia, menopause
- busy life schedules

Managing fatigue is based around reducing the secondary fatigue impacts where you can, taking steps to increase your energy levels and then learning how to use that energy in the most efficient way.

When trying to manage fatigue every day, it can be easy to forget to go back to basics. Often the days and months pass by, and we don't stop to check in with ourselves, reflect on our daily lifestyle patterns and review the things that are taking and giving us energy.

On the next page is a simple graphic to put on your fridge, to help recognise and remember some of the energy takers and the energy givers.

# Energy Takers

Focusing on the past  
Inconsistent sleep  
Mess and clutter  
Sedentary time  
Social media  
Overworking  
Dehydration  
Screen time  
Resentment  
Negativity  
Junk food  
The news  
Alcohol  
Stress  
Fear

Music

Nature

Resting

Sunlight

Positivity

Gratitude

Hydration

Meditation

Movement

Breathwork

Community

Decluttering

Consistent sleep

Eating whole foods

Learning something new

# Energy Givers

© @brainhealthdoctor



## Art show wraps up for another year



Barry Allen Award winner: 'The Girl I Once Knew' by Aimee Rowland.

Congratulations to our five 2023 MS Virtual Art Show award winners! The awards provide people living with neurological conditions the opportunity to express their creativity and celebrate connections through art.

This year's winners are:

### Barry Allen Award

"The Girl I Once Knew" Aimee Rowland

### Highly Commended Paintings/ Illustrations

"Happy Autumn" Jana Morgan

### Highly Commended Sculpture/Craft

"The Counsellor" Sally Waterford

### Highly Commended Digital/Photography

"Distraction" Stephen Ellis

### Highly Commended Carers Award

"Seashore" Anne Fritz

Thank you also to the 171 artists whose submissions gave us a window into your stories. We encourage everyone to take a moment to view the full gallery of winners and entries.

Visit [msplus.org.au/artshow](https://msplus.org.au/artshow)

# Exercise and MS

## Exercise Physiologists: the exercise essential **by Tasha Babet**

### What are the benefits of exercise for MS?

Research shows strong evidence for the benefits of exercise for MS symptom management, including functional benefits, such as improved strength, mobility, balance, cardiovascular fitness, psychological wellbeing, bone density and mitigating or managing secondary disease. There are also benefits for brain health, including improved neuroplasticity, neurological protection and neuro-regeneration. Exercise has also been proven to have an anti-inflammatory effect on the body, which provides a boost for the immune system. Keeping your body moving is the best thing for you!

### What role can an EP play?

An EP is an allied health

professional equipped with the knowledge and skills to evaluate, design and deliver effective exercise interventions for a wide range of medical conditions, injuries and disabilities. An EP will facilitate individualised exercise programs in a group setting, designs exercise programs (gym/home) and reviews these programs and provide a vibrant, uplifting and positive environment.

### Will my EP know if I've reached my limit?

Your exercise physiologist will come to know you and your unique limitations and will know when it is safe to exercise and how do so without or minimally exacerbating your symptoms. EPs will try and find that balance between doing too much and not doing enough.

Always make sure to communicate how you're feeling before and during your sessions so your exercise physiologist can factor in the various things that may be affecting your performance, such as how active you may have been that week, the weather etc. There is also a common misconception that you need to have a certain level of fitness to undertake EP services and that isn't true at all! You don't need to be a superfit gym junkie or even be able to walk to do EP.

To find an EP guided exercise class near you, see page 19. For more information, visit [msplus.org.au/exercise-physiology](https://msplus.org.au/exercise-physiology)

Tasha Babet is an Exercise Physiologist (EP) in the MS Plus gym in Lidcombe, NSW.







# Symptom spotlight

## Balance

Learn how MS affects balance, ways to improve it and how to prevent falls.

### How MS can affect balance

Your brain processes information gathered via your vision and other senses – but MS can disrupt the flow of information to and from your brain. Problems with balance and coordination (ataxia) are common in MS and you might experience this as unsteadiness, dizziness, tremor or shaking.

This loss of stability can cause you to feel unsteady, lose coordination or stumble. A loss of balance can happen unexpectedly – for example, you could be walking outside and lose your balance and sense of direction.

If you're experiencing this symptom, whatever you're feeling is valid. Many people with MS can feel distressed, frustrated or experience a lack of confidence as their balance is impacted, so we've detailed some ways you can work on your balance and avoid falls below.

### How to improve your balance

If you've been experiencing this symptom, your GP can help you either rule out what's causing it or make changes to improve your balance. They may refer you to a physiotherapist or occupational therapist specialising in neurological conditions to help you improve your balance and coordination and find easier ways of achieving everyday tasks.

### Staying safe and avoiding falls

If you're experiencing a lack of balance, there are some steps you can take in and outside the home to stay safe and avoid falls.

### What to do if you fall

If you fall, it's natural to feel shaken or shocked. Try your best to stay calm and not make any sudden movements.

### If you aren't hurt and feel able to get up, you can:

- Take your time, moving slowly and steadily
- Roll onto your hands and knees and look for something stable to support you, such as a bed or a chair
- Hold onto the furniture and slowly get up
- Sit down and take a moment to recover.

### If you feel hurt or unable to get up:

- Try to get someone's attention. You can use your personal alarm or mobile phone if you have one, or shout out and make a noise
- Get as comfortable and warm as you can while you wait for help
- Unless you suspect a bone fracture, change your position every half hour or so to stay comfortable and avoid pressure sores.

For more information visit [msplus.org.au/common-symptoms](https://msplus.org.au/common-symptoms)

## Our new falls and balance program, Plus Balance

### Six weeks of group classes for better balance to prevent falls

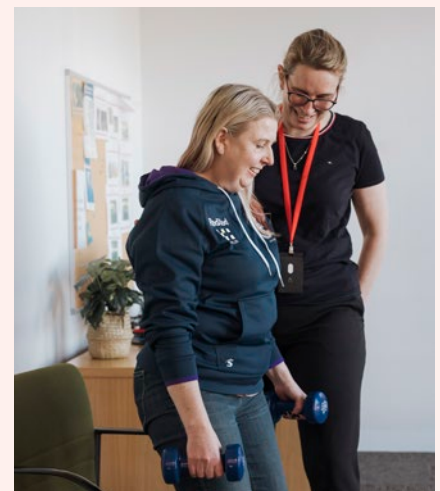
**Our Plus Balance classes are for people living with a neurological condition who have previously had a fall or are at risk of falls.**

The classes are run in our Lidcombe, NSW, Blackburn, VIC and Footscray, VIC offices by a physiotherapist or exercise physiologist, so you can feel confident and safe.

We aim to reduce the risk of falls by building on your strength, coordination and balance. Plus

Balance is also a chance to connect with other people living with a neurological condition and have some fun! You can pay for our Plus Balance class through your NDIS plan, Home Care package, or by paying privately and claiming a rebate from your private health insurer.

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



# MRIs and multiple sclerosis

**Magnetic Resonance Imaging (MRI) is a scanning tool that used for (almost) every medical condition. The machine (or the ‘tunnel’) uses large tubular magnets to take images of the relevant body part.**

An MRI can capture changes in the brain and spinal cord, so it is an important diagnostic tool for MS.

While an MRI is vital for diagnosis, the diagnosis of MS, is not usually made with just an MRI but includes other factors such as other diagnostic tools, a person’s medical story and a physical neurological examination.

MRIs are also an important part of monitoring MS activity and most people with MS have an MRI at least once a year.

## Is an MRI risky?

There are no significant medical risks associated with MRI, other than it uses a very powerful magnet so all internal and external objects must be removed from your body. Because of the risk associated with the magnet, you will be asked to complete a screening form before

every MRI. There are many things that contain metal that you may not be aware of such as ink in cosmetic tattooing (example eyebrows) and some types of hair extensions. This is why it is important to be complete the screening form before every MRI.

## Preparing for an MRI

For some people, the smaller space in an MRI and the loud banging and buzzing sound of the machine can make them feel anxious or nervous. Below is some information and advice to help make your scan a smoother experience:

### Before the MRI appointment

- Make sure you ask and know where you need to go and where to park before the scan. Having stress around travel and parking adds to the stress you may already feel.
- Make sure you have discussed with the MRI centre the costs involved with an MRI. If you need to discuss options for payment, such as bulk billing or private funding, contact your GP or the MS Nurses at MS plus talk to you

about options. There are several options you can consider that will involve reduced or no payment.

- Preparing mentally for an MRI can be helpful, practicing mindfulness and breathing techniques or preplanning a reward when you have made it through the scan.
- An MRI scan itself will take approximately 20 to 30 minutes. If you just have a brain scan. If you have a brain and spinal scan it can take about 45 mins. The whole appointment usually takes 1 to 3 hours.

### At the MRI appointment

- You will need to complete a safety check screening form.
- You will need to change into an examination gown and must remove all metal from your body (including some jewellery), as the machine uses a strong magnet. It’s better to remove the jewellery you need to before you arrive, so you don’t panic where you have put it or have issues removing it.
- You will most likely be given earphones to have on to reduce the noise.



- The radiographer doing the scan will leave you alone in the room with a buzzer and voice microphone to talk to them. They can also always see you through the window.
- It can be helpful to get a better understanding of the sounds you may hear during your scan. There are many examples on YouTube, including this short video.



**If you are anxious, claustrophobic or have other requirements**

- If you are feeling anxious or stressed about the idea of your MRI, it may be worthwhile chatting to your GP or Neurologist to obtain a mild sedative, to take before the MRI. In many Radiology

centres, you are not able to take the sedative before you arrive as you may not be competent to complete the screening form. The general practice is people arrive, complete the screening form, and take the sedative 30 minutes before the MRI. It is better to always tell the centre your plan and they can work it out with you.

- There are options for people who are claustrophobic or suffer extreme anxiety to have an MRI with complete sedation. You can discuss this option with your GP, MS team or medical imaging centre.
- Another tip may be to close your eyes when you first lie on the bed and keep them closed for the entire scan. Many people find this helpful.

- For people with assisted mobility needs, your medical imaging centre will help guide you through the options for you. You are not able to stand to have MRIs and will need to lie on the bed.

**After your MRI**

Many centres will now provide you with a copy of your MRI on a disc or a link to access the MRI via your mobile phone or online. It is very useful to have copy of your own scans to take to our neurologist or to keep with you if you are travelling long term or consider changing medical services. You can also ask for copies of reports.

Read the full article, visit [msplus.org.au/MSandMRI](https://msplus.org.au/MSandMRI)

# TRAVEL WITH PURPOSE ON AN MS ADVENTURE.

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# MS Readathon

# REGISTRATIONS ARE NOW OPEN!

EMBARK ON THE MOST  
AMAZING ADVENTURE!



Read as much as you can  
throughout August and  
help Aussies living with MS  
and their families.

Claim your FREE T-shirt  
when you register!  
(While stocks last)



[www.msreadathon.org.au](http://www.msreadathon.org.au)

# 'I had not touched sand for 16 years. My goal this year was to get back in the water'

Wayne has been working with his Support Coordinator Lisa, to get back to the beach after many years unable to reach the sand due to mobility issues. Lisa embraced Wayne's idea to get an off-road wheelchair, found the funding through the NDIS and helped to make Wayne's dream a reality.

Watch Wayne's full story:



Wayne Ruffo

## Gain access to disability-friendly facilities 24/7

The Master Locksmiths Access Key (MLAK) system allows people with disability access to dedicated public facilities, including facilities in National Parks and many Council municipalities, elevators at railway stations, the new Changing Places facilities throughout Australia, disabled toilets that are locked and even the Liberty Swing.

People with a disability can purchase a MLAK key that will open all doors, toilets, playground equipment and other facilities fitted with a lock that uses the special MLAK cylinder. Order your Master Locksmiths Access Key today [masterlocksmiths.com.au/mlak](https://masterlocksmiths.com.au/mlak)





# What's new in research?

## Detecting changes in walking early in MS could be the key to preventing progression

**MS can cause a variety of symptoms attributed to the immune system mistakenly attacking and damaging the myelin sheath in the brain and spinal cord.**

One such symptom is changed walking, or gait, which can occur even in the absence of clinical signs.

These subtle changes in gait cannot be detected using standard clinical measures (e.g., walking speed), particularly earlier in the disease course. This makes it difficult to monitor progression and make changes to current treatments to prevent further disease activity.

It has been proposed that the local divergence exponent (LDE), a sensitive measure of gait stability, better reflects the MS-related changes in walking, and may parallel changes in the brain and spinal cord detected on magnetic resonance imaging (MRI).

Research has shown that this measure is lower in people living

with MS than those without MS and is associated with falls and self-reported walking ability.

Previous studies have explored the use of LDE in clinical settings, but the data has been obtained from different body locations using various methods (e.g., treadmill walking vs overground walking). It is not clear which approach would be best to assess walking stability earlier in the disease course when treatments may be more effective in preventing progression.

### **What did the researchers do?**

Published in *Gait & Posture*, MS Australia-supported researcher Professor Mary Galea and her team recruited 49 people living with MS with an expanded disability status scale (EDSS) of  $\leq 2.5$  (no walking impairment), and 24 people living without MS to walk overground for 5 min while movement data was obtained from sensors placed on the sternum (mid chest) and lumbar (lower back) areas. The data

was used to develop models to identify gait impairment in people with MS at early disease stages.

### **What did the researchers find?**

The researchers found that the LDE measures from the sternum were more sensitive to MS-related changes, which is in line with previous studies. This suggests that this sensor location is better suited to monitor walking impairment in people living with MS earlier in the disease course.

### **What does it mean?**

By focusing on people with MS with no impairment in walking, this study highlights the sensitivity of the LDE measurements in detecting progression at the early stages of disease. While further research is required, the LDE may offer an alternative to currently insensitive tests of walking impairment in people living with MS at the early stages of disease.

**For more on the latest research, visit the MS Australia website.**

# Two in one: ageing and MS by Ruth Cotton

**'You scored only 29/30?' my GP exclaimed in mock horror. He was skimming the Mini-Mental State Assessment I'd completed. The practice nurse broke in. 'It was the season question. She thought it was summer, not spring!'**

We all laughed, knowing how much I disliked cognitive assessments. The test was part of a Medicare Health Assessment for Older Persons 75+. Clearly, it's age related but people like me with MS can experience complex cognitive and memory issues. It's a good example of the challenge of identifying what's due to MS, and what's the result of ageing. That's a double whammy.

Falls are another example. I regularly get asked by health practitioners – 'Have you had a fall since I saw you last?' It's a risk of aging, exacerbated by osteoporosis and thinning bones – and by MS. I have foot drop and leg weakness on my right side. If I fell and sustained a hip fracture, I'd be in a wheelchair immediately.

I've formed a strong attachment to my walker, but accidents will happen. A year ago, I fell out of my home elevator when it stopped just above its usual spot. It was a very narrow escape for me, with only a black eye and I've written more in my memoir *A fragile hold: Living with multiple sclerosis and other uncertainties*.

Older people are encouraged to keep physically fit and active, eat well and manage their weight. For people with MS and mobility problems, it's even harder. It's not just the logistics of exercising when you can't walk more than a block or so. As we age, our metabolism slows and there's a natural tendency to both gain weight and lose muscle strength. The odds are stacked against us.

I have a cross-trainer in my living space, with free weights and an aerobic stepper nearby. A constant reminder — have you done your exercises today?

Then, incontinence, which affects many older people. It might begin with urinary urgency, and there are medications to help. But bowel and bladder challenges intensify the daily physical and mental struggles of people with MS who are also ageing.

The good news is that we live in the digital era, when so much is within reach – not just communication, but also online exercise classes, audible books, music, movies. We are rich with resources undreamed of, to say nothing of medications, support structures and a prodigious knowledge bank about the chronic disease that shares our lives. And next time my 75+ assessment rolls around, I'll check the season first!

Ruth Cotton is an author, who writes about her experiences living with MS after being diagnosed 25 years ago at the age of 52. Visit [ruthcotton.com.au/over-coffee](http://ruthcotton.com.au/over-coffee)



Ruth Cotton



# MS and work

## How can I take control of my career?

A diagnosis of MS is a life-changing event, sometimes prompting you to rethink your priorities and career aspirations. This can be a very positive experience. It may present as an opportunity to pursue something you have always wanted to do.

Equally, despite symptom-management strategies and workplace adjustments, you may no longer want or be able to continue in your current role. This does not mean you have to stop work altogether, as there are several other options you could explore.

Consider a **different role** within the same organisation. It will

depend on the organisation you work for, but there may be an option to move to another role that allows you to better manage your symptoms.

**Have a change in direction:** this may include training or

study, seeking new employment, turning a passion into a business or becoming self-employed.

MS Plus can help you to find suitable work, visit [msplus.org.au/employment](https://msplus.org.au/employment)



# Applications **now** open

MS Go for Gold Scholarships provide one-off grants to follow a personal dream.

There are **25 scholarships** available, each valued up to **\$2000** with categories including:

- Personal Expression
- Education
- Living Your Best Life

Applications close **Wednesday 13 September 2023**

To apply, visit [msplus.org.au/GoforGold](https://msplus.org.au/GoforGold)







# Newly identified molecules could explain the protective effect of UV light in MS

**We have known for many years that exposure to UV radiation from the sun can reduce the immune response in the skin, and this can increase the risk of developing skin cancer.**

However, UV exposure can also weaken the immune response more widely throughout the body. This can be beneficial in protecting against certain autoimmune diseases like multiple sclerosis (MS).

When UV light hits the skin, immune cells in the skin travel to the nearby lymph nodes. In these “hubs” of immune activity, they “talk” with many other cells to reduce the immune response.

## **UV suppresses immunity by trapping immune cells**

In earlier work, Professor Scott Byrne and his team at the University of Sydney identified a profound effect of UV exposure: that it traps immune cells inside lymph nodes near the UV-treated skin.

Trapping the immune cells means they cannot travel to other parts of the body to cause inflammation and damage, such as to the brain and spinal cord in MS.

Interestingly, the MS medications Gilenya, Mayzent and Zeposia (fingolimod, siponimod and ozanimod) work in the same way by trapping immune cells in the lymph nodes.

The team previously showed that a fat (lipid) molecule called sphingosine-1-phosphate, was responsible for this trapping effect. This provided the first evidence that UV can suppress the immune system by altering lipids in the lymph nodes.

## **What was the aim of this study?**

In this new study, the researchers asked whether there may be other lipids induced by UV that can suppress the immune system.

## **What did the researchers do?**

Using a laboratory model, the team conducted experiments investigating lipids in lymph nodes near the skin, before and after UV exposure.

Six unique, previously unidentified lipids were increased in response to UV.

Using cutting-edge microscopic imaging technology, researchers showed that levels of these lipids increased within the lymph nodes in areas where particular immune cells, called T cells, are grouped together.

To understand the effect of these UV-induced lipids, researchers extracted them from the lymph nodes and tested them in the lab. They found that these lipids prevented T cells from multiplying.

## **UV suppresses immunity by preventing immune cell expansion**

T cells play a major role in causing inflammation and damage to the brain and spinal cord in MS.

They induce a strong immune response when they recognise a “danger signal”. The T cells then multiply rapidly to form an immune “army” against the danger.

This research has shown that UV induces lipids that suppress this rapid T cell expansion, so that the immune response is dramatically weakened.

In the case of MS, this could result in reducing the autoimmune attack on the brain and spinal cord.

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

This discovery could lead to a better understanding of how exposure to sunlight is beneficial in the context of MS.

But as Professor Byrne explains, “UV from sunlight can cause cancer. For people with MS who often struggle with heat intolerance, it can also make them uncomfortably hot.”

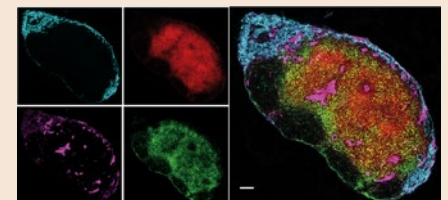
“Finding the molecules responsible for the UV effect on the immune system opens the door for development of new therapies that could mimic the immune suppressive effects of sunlight without these side effects.”

Moving from the laboratory models used in this study, Professor Byrne said, “Our next steps are to investigate whether similar UV-induced changes to these molecules occur in humans.”

This research was supported by an MS Australia Incubator grant and was published in the prestigious journal, *Frontiers in Immunology*.

Incubator grants are a type of funding that helps to develop creative and innovative ideas that may be “outside the square”. These grants aim to support the discovery of new and better ways to prevent, treat, and cure MS.

For more information on the latest MS research, visit [msaustralia.org.au](https://msaustralia.org.au)



**Shared with permission from PhD thesis: Lipids in ultraviolet-radiation induced immunomodulation, University of Sydney (2020), Benita Tse.**



# NDIS and you

## Physiotherapy and NDIS: exercise your right to move!

**What are your current NDIS goals? Has MS resulted in changes to your physical ability? Have you noticed an increase in your fatigue or changes to your walking or ability to get around?**

Physiotherapy aims to maintain or improve your level of physical functioning. An initial physiotherapy assessment will identify areas where you would benefit from assistance, including your strength, balance, endurance and flexibility. Your physiotherapist will then come up with an individualised, targeted exercise program.

**How is my physical progress tracked?**

By carrying out a set of physical outcome measures looking at your strength, balance, mobility and endurance, a physiotherapist can re-test your progress every 3-6 months, to provide you with tangible feedback on your progress.

**Do you feel you may require some form of assistance with your mobility?**

A physiotherapist can assess your suitability for mobility aids such

as four wheeled frames, crutches, wheelchairs and scooters. A physiotherapist will look to fit you for the most appropriate gait aid and can work with an occupational therapist to obtain bigger mobility aids if required, such as powered wheelchairs.

**What if I would prefer to be part of an exercise class/attend a gym?**

A physiotherapist is able to carry out 1:1 appointments in your home, in the gym or, if appropriate, assess you for your suitability to be part of a gym class with people of a similar level of physical tolerance to you. MS Plus will be opening a purpose-built gym for people with MS soon and your physiotherapist will be able to provide you with guidance and input around your attendance at a gym.

**Do you need an end of plan review, or a progress report for the NDIS?**

A physiotherapist will be able to provide written reports about your progress each year and to flag the need for further intervention earlier, if an assessment indicates this is appropriate.

**How much does a physiotherapy appointment cost?**

**NDIS initial physiotherapy assessments:**

\$193.99 per 60 minutes (incl travel time for home visits)

**Travel time for home visits:**

A maximum of 30 minutes to and from the site will be charged at \$193.99 per 60 minutes

**Private physiotherapy appointment:**

\$165 per 60 minutes

**Private physiotherapy report for access to the NDIS:**

\$165 for a report

**How do I organise a physiotherapy assessment?**

Simply phone MS Connect on 1800 042 138 and a friendly physiotherapist will give you a call to discuss how they can help you to manage your MS. A physiotherapist can provide evidence of your condition to the NDIS in the form of a targeted report. If you are on the NDIS, it may be beneficial to flag your intent for physiotherapy with your support coordinator.

## Share your thoughts with us

Have a question you'd like to ask an MS Plus expert or a story you would like to share? Email [intouch@ms.org.au](mailto:intouch@ms.org.au)

We will publish your question and answer in the next edition of Intouch magazine, as well as contacting you directly.

# 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

### JULY

#### Pain and MS

Wednesday 26 July  
12:00pm – 1:00pm AEST

### AUGUST

#### Sleep and MS

Wednesday 30 August  
5:30pm – 6:30pm AEST

### SEPTEMBER

#### Women's Health Week 4 – 8 September

#### Women's health check

Date and time TBA

#### Women's pain

Date and time TBA

## 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)

#### Pregnancy and family planning

Date and time TBA

### OCTOBER

#### Brain Health

Date and time TBA

### NOVEMBER

#### Work and Money

Date and time TBA

Please check upcoming programs on our website [msplus.org.au/upcomingwebinars](http://msplus.org.au/upcomingwebinars) 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](http://msplus.org.au/resource-hub)

- Advance car planning
- Eating to boost brain health
- What can an MS nurse do for you?
- How is MS care changing – a neurologist panel discussion
- Men, MS, sex and sexuality
- and many more!

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

#### 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 **1800 042 138**

## 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](http://msplus.org.au/resource-hub)

- “Learn from Me” series:  
Adjusting to using a wheelchair
- Tips for managing pain
- Connecting with women's health
- Menopause and MS
- Connecting with the right information
- and many more!

**Also, keep an eye out for our upcoming podcasts to be released soon!**

- “Learn from Me” series:  
Sensory issues
- Men at work
- Healthy habits
- Sleep hacks
- STIs and screening
- and more!

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

Tuesdays 1:30pm  
Thursdays 10am  
Gloria McKerrow House  
117 Denison St, Deakin

**Cost:** \$10 / session or 10 classes for \$90

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

Thursdays 11:00am  
Gloria McKerrow House  
117 Denison St, Deakin

**Cost:** \$10 / session or 10 classes for \$90



## Driven by a belief in a future cure!

Help us deliver more services, more expertise, more awareness and more research for people like Deanna, living with MS and other neuro conditions.



[msplus.org.au](https://msplus.org.au)