# intouch



**Autumn / Winter 2024** 



# From the CEO



John Blewonski | Chief Executive Officer

## Welcome to the first edition of Intouch magazine for 2024.

You may have noticed we have changed the publication schedule for the magazine. We will now have two editions a year, in March and September, instead of three.

I would like to take the opportunity, in this our Autumn / Winter edition, to acknowledge the incredible period of growth we are experiencing here at MS Plus, both with the services we offer our clients and the state-of-the-art facilities we are able to provide. The launch of our Footscray Wellbeing Centre in August last year was quickly followed by our Hobart Wellbeing Centre in December and our Blackburn Wellbeing Centre in January. To add to that, we held a 'topping out' ceremony at our future Lidcombe Wellbeing Centre site in December, marking a significant milestone for the project — on schedule for completion in October this year. In allied health service provision, we expanded our Plus Boxing service to people with MS and Parkinson's, launched Plus Hydro, Plus Balance and Plus Flex and Flow. I look forward to continuing to adapt our service offering to best meet the changing needs of our clients.

Many of our clients who access the NDIS will be aware the

long-awaited NDIS Review was completed in early December and included 26 recommendations and 139 specific actions. The report proposed a five-year transition, which includes changes to the way participants are supported to navigate services and systems, a new disability support quality and safeguarding framework and a shift to four proposed layers of supports. Types of supports include universal and mainstream services available to everyone, general foundational supports available for all people with disability under 65, targeted foundational supports for people with disability under 65 who are not eligible for the NDIS, and individual supports provided through the NDIS. We will work towards implementing these recommendations in the coming years, to ensure our clients enjoy a new and improved way to access the care they need to live well through MS Plus.

This is always a busy time of year for us, as we work towards a full schedule of events, including the Walk, Run + Roll and other World MS Day activities. I encourage everyone to get involve during May, visit our website for more information.

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## News

#### **NDIS Upskill**

## Navigating the NDIS can be a complex process.

Understanding eligibility criteria and determining the most effective way to initiate access can be challenging.

Join us for NDIS Upskill: A guide to understanding eligibility and access a free 40-minute session to guide you through the new NDIS access process and eligibility information.

Dates: 16 April, 18 June, 15 August

Time: 12:00pm AEST

To secure your spot, please contact Plus Connect to register, spaces are limited.

## Recognising World MS Day Thursday 30 May

This year for World MS Day, we are exploring the theme 'My MS Diagnosis' and the idea that 'It Takes a Village' to support someone diagnosed with a chronic condition.

At MS Plus, we understand the importance of nurturing and developing those support networks, to ensure everyone has a chance to live well with MS.

'It Takes a Village' is a celebration of the people, systems and services that support people with MS to live well.

Please come and visit us at our Walk, Run + Roll marquees in Melbourne and Sydney, with lots of fun activities and giveaways, including our traditional bear hunt! Also make sure to follow **@wearemsplus** on Facebook and Instagram as we recognise the all-important members of our village throughout May.



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

Get ready for a vibrant showcase at this year's MS Plus Art Show! We're all about capturing the essence of community support in facing MS together.

This years' Art Show theme will be 'It Takes a Village'.

We want you to show us what your 'village' looks like or what the idea of having an MS support system means to you.

The 2024 MS Plus Art Show will be open for entries from **Monday 1 April**, closing **Sunday 5 May**. Winners are announced on World MS Day **Thursday 30 May**.

We can't wait to see your entries!

Visit msplus.org.au/artshow



### Carers, Family & Friends Toolkit

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

We have created a handy printable resource 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 with MS 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 loved one. Download a copy of 'Supporting someone with an MS diagnosis' today **msplus.org.au/carers-toolkit** 



MS Plus recently launched our Carers, Family & Friends Toolkit. This online resource provides a range of information and practical tips specifically designed for people who are supporting someone with **MS. Topics include:** 



Understanding MS for carers



Understanding emotions



Parents of teens with MS



Looking after yourself



Talking about MS



Navigating support systems



Finances, legal & work



Young carers



Preparing for emergencies

### Did you know carers can access our services too?

- · Plus Connect: the gateway to information, advice, support and services
- Plus Advisor: personalised advice from an MS nurse or social worker
- · Plus Peer Support: connect with a community of other people supporting someone living with MS and their families.

Call MS Plus on **1800 042 138** to connect with our team members.

For more detail on these and other MS Plus carer resources, visit

msplus.org.au/carerstoolkit

## Pearls of wisdom from people who have kindly shared their carer's journeys with us.

#### Q: What kind of support has been helpful for you, having a child who has MS?

A: Mums words: I am fortunate that I have family and friends that support me with regular check-ins. It was difficult at the beginning when my daughter was diagnosed as my loved ones didn't know what to say or ask so they withdrew. While hard to speak up, I found having the difficult conversation upfront about how my family and friends could support me was very beneficial.

#### Q: Raising a young family with MS as part of the picture

A: a partner's insights: Since joining Peer Support as a volunteer, I've had

some really honest and vulnerable peer support conversations while supporting people going through the same thing. Some of the younger husbands I spoke with reminded me of what it was like early on, and I remember wishing that existed for me at the time. Education was helpful, but talking to someone else who gets it can't be beat.

For more information on joining peer support, visit msplus.org.au/ peersupport

#### Sharing your life journey with a partner who has MS

A: a tip from a carer: Find a good friend (in a similar situation) that you can talk to regularly and candidly.

You need a space to say things that some people (who have no real carer experience) might find a bit selfish or hard-hearted, and to someone who can listen with empathy rather than judgement.





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People living with multiple sclerosis enjoy **FREE** entry to all MS Plus events! Contact us on **1300 733 690** for your complimentary registration code.

## **Managing symptoms**

**Urinary frequency and urgency** 

Tips from Physiotherapist, **Vanessa Leung** and the MS Continence Nurse team



MS can damage the connective signals between bladder and the brain, causing a number of possible issues.

For those who do experience bladder issues, each person will experience these symptoms differently and to varying degrees.

Incontinence is perhaps the most well-known symptom and one way this can present is as urinary urgency. Urinary urgency, or urge incontinence, is when the bladder becomes overactive and you may feel a sudden and strong urge to urinate with the possibility of being

unable to make it to the toilet in time. Urinary frequency, defined as feeling the need to go to the toilet 8 or more times a day, is another bladder-related symptom.

In addition to our MS continence nurses, a physiotherapist can provide specific supports to help you better manage these tricky symptoms and improve your quality of life.

MS Plus Physiotherapist, Vanessa Leung has a few tips she provides to her clients, to help them manage their urinary urgency or frequency.

How can I manage my urinary urgency and frequency?

'It can be helpful to consider the types of fluids you are drinking e.g. coffee, tea, sugary drinks, as these are diuretics and can increase your frequency and need to urinate,' Vanessa says.

'Also, I tell my clients to try to avoid drinking 2 hours before going to bed, to reduce the urge to go in the middle of the night.'

'If you are experiencing urinary control issues, it can also be helpful to keep a bladder diary, to look at your toileting habits and speak to a pelvic health physiotherapist or continence nurse.'

'A physiotherapist can assess your pelvic floor and core muscles to address any weaknesses, while a continence nurse can empower patients with knowledge and strategies to manage their symptoms effectively, taking into account the unique challenges posed by MS,' Vanessa says.

To chat with an MS Plus physiotherapist or a continence nurse, contact Plus Connect **1800 042 138** or email **connect@msplus.org.au** 



'Finding out that I could hire a scooter made our Surfers Paradise holiday so much more fulfilling and enjoyable. I was able to move around easily and not get fatigued, allowing us to explore effortlessly,' shares Brian.

We can help you find the NDIS support you need so you don't have to miss out on a well-deserved break

Visit msplus.org.au/ndissupportcoordination



# Researchers unravel the roots of MS risk genes in Europe

Genetic factors are believed to account for approximately 30% of the total risk associated with MS, with the remaining contribution from environmental and lifestyle factors, such as smoking, obesity, and Epstein-Barr virus (EBV) infection.

The prevalence of MS exhibits geographical and ethnic variability. In Europe, the prevalence of MS is significantly higher in the north. The origins and reasons for this variation are still poorly understood. However, these differences may provide clues as to why MS has continued to rise.

It is suggested that differences in the global prevalence of MS may be partly explained by the genetic background of different populations. For example, among African American individuals with MS, there is a higher proportion of genetic traits associated with European ancestry compared to those without MS.

This European genetic influence appears to increase the risk of MS. On the other hand, Asian American individuals with MS have less of this European genetic influence. What is the reason for these variations, and where do they come from?

#### What did the researchers do?

Published in the prestigious journal, Nature, the researchers used a large ancient genome dataset (from the Mesolithic period to the Bronze Age), as well as new medieval and post-medieval genome datasets to determine present-day European ancestry relative to these ancestral populations to identify signs of lifestyle-specific evolution.

They determined whether genetic changes associated with an increased risk in MS have undergone positive selection, when this selection occurred and whether the targets of selection were specific to lifestyle. Finally, the team examined the environmental conditions that may have caused the selection of MS risk genes, including survival strategies and exposure to pathogens.

## Why are these genetic changes still around if they confer MS risk?

It is likely these genetic changes provided some survival advantage, despite their current association with MS risk. Indeed, many of the genetic changes that underwent positive selection were linked to providing protection against pathogens or infectious diseases.

## What is the significance of this research?

The late Neolithic period and Bronze Age were critical times in human history during which highly genetically and culturally divergent populations evolved and mixed. Additionally, the emergence of the herding lifestyle, which is often overlooked in comparison to the shift to farming in the Neolithic

era, may have had an equal or even greater impact on our immune responses.

This research improves our understanding of how the lifestyle and environment of our ancestors impacted our immune responses and its subsequent effect on the risk of developing MS.

Use the QR code to access the full article.

# We source all of our research focused content from MS Australia.

MS Australia is a not-forprofit organisation that empowers researchers to identify ways to treat, prevent and cure MS, seeks sustained and systemic policy change via advocacy, and acts as the champion for Australia's community of people affected by MS.

You can find out more about the latest MS research by heading to msaustralia.org.au, following MS Australia on Facebook or by signing up to their regular newsletter msaustralia. org.au/contact-us/



## **Exercise and MS**

Tips for overcoming barriers to exercise - Paralympic Bronze Medalist and person living with MS, Janine Watson

#### Managing heat intolerance

temperature results in paralysis in the get cognitive confusion and massive an experiment between me and the sports scientists at the Queensland Academy of Sport. We tried heat acclimatisation, which a lot of athletes do, it's also what the military does. We started off at 90 degrees in way through to half an hour over supervision. Your body starts to pump more blood around the body, sweat rate also increases. I wasn't sweating at all initially, which is heat acclimatisation, I could only go post, I could go 28 rounds. The effect lasts for about 3 months and with a few 'top up sessions' I was also able to perform during 40-degree

temperatures in Melbourne for the Summer Series for wheelchair tennis. Having that exposure to heat means your body can then cool down much more efficiently.

## Accepting changes to your exercise routine

When I was first diagnosed, I wanted to do what everyone else did, I didn't want to look different or seem like I was 'lazy'. Now, I have a completely different approach. Everything now is factored into recovery. Now, out of the 11 active training sessions I do in 5 days, with 22 recovery sessions inbuilt into my training sessions. For every hour I train, I have 2 hours of recovery and rest. I train when my body feels the best – which is around 9am to 12pm. It's also about the quality of training and not the quantity.

#### Tips to cool down

Before and after a game or an event, most athletes will have a slushie. I make my own, as I find regular slushies too sweet. This works better than ice water to cool you down. I also find holding slushie on the roof of my mouth, to deliberately give myself a brain freeze, will trick

my brain into thinking it's cool. Also having something with menthol, like eucalyptus or a fisherman's friend, to trick the body. Also focusing on cooling the palms of your hands, the soles of your feet and your forehead and over your sinuses will also cool you faster than an ice vest.

For more information on managing MS through exercise, visit msplus.org.au/PlusExercise



## Unlocking the power of exercise for MS: Martha's story

# For the decade after her diagnosis, Martha says she downplayed her MS — determined to carry on as normal.

'I put my head in the sand for a while, not wanting to accept it. I didn't want to read much about MS. I've never disclosed my condition to my workplace. I just didn't want people to treat me differently.

'My symptoms ebbed and flowed in that 10-year period, but they tended to recede. I would get another boost of steroids and that would keep the MS at bay. During that time, I started to realise I couldn't run anymore, I was struggling a bit.'

## Discovering the connection between MS and exercise

Around this time, Martha's husband

started a health kick and Martha decided to join him.

'I thought I'd do it with him and started going to the gym three times a week. After a while I found it strange that I could suddenly walk with greater ease and could break into a 20 metre jog again, going from dragging my leg to being without a disability with no numbness or neurological fatigue was a revelation'.

After a few stressful life events derailed her exercise regime and worsened her symptoms considerably, Martha was watching TV one night when she saw a doctor being interviewed about how much lifestyle can impact MS.

'All my pursuits were then focused

on what would serve me physically and spiritually.'

#### A balancing act

Since then, Martha has worked hard to reintegrate exercise into her schedule and with a scientific background has researched the benefits of exercise physiology: the tremendous effects that it can have on the nervous system and how it can help to repair the body.

'Exercise is a really underrated way to manage MS symptoms. Don't get me wrong, I have not resolved all my physical weaknesses yet, I am a work in progress.

'If people could bottle what exercise does for your body and brain and sell it, they'd make millions.'



## Focus on pregnancy and fertility

The question of how an MS diagnosis might impact fertility, pregnancy and the post-partum period is a common one for women with MS who may be considering starting a family — especially when most women are diagnosed between 20 and 40 years of age.

Associate Professor Vilija Jokubaitis, a renowned clinical and translational neuroscientist at Monash University, has conducted extensive research into the relationship between MS and pregnancy.

'Firstly, we advise that if you're diagnosed with MS, even if it's really early on and you've just got a very new diagnosis, all women who are of childbearing age should have pre pregnancy counselling as early as possible because there's a lot of things to consider.

'Women with MS should also advise their health care teams if they're considering a pregnancy, particularly in the next 12 months, because that's going to have implications in terms of what sort of medications you might go on,' Vilija says.

#### Does MS impact fertility?

Vilija says the good news is that MS does not seem to affect fertility. The number of children women with MS have is often impacted more by personal decisions, potentially influenced by their health condition, rather than biological capability.

'There have been several studies that have been done to try and understand fertility in the context of MS. Some of these studies have looked at a hormone called antimalarian hormone.

'The anti-malarian hormone is a hormone that is used to measure your ovarian reserve, how many eggs you've got left. Studies comparing women with MS and women without MS have shown that women with MS have roughly the same concentrations of this AMH hormone as age matched non-MS controls.'

Vilija also notes that, while fertility remains unaffected, women with

MS do tend to have fewer children.

'Once someone is diagnosed with MS, they might then start to consider things like, will I be well enough to look after a child? What happens if I can't work anymore? Will I be able to afford to support a family? And things like that. So it's not necessarily fertility so much as lifestyle considerations.'

MS is also not highly heritable. A child has an approximately 2-3.5% chance of developing MS, if one parent has it. A recent study has shown that babies born to mothers that smoked whilst pregnant had an increased risk of developing MS later in life. Therefore, if you are a smoker, we highly encourage you to quit to reduce the risk of MS in your child.

## Will my symptoms worsen during pregnancy?

Interestingly, pregnancy itself does not worsen MS, in fact, it might even have protective effects. Some studies suggest that women with MS might accumulate less disability over a 10-year period when compared to women who didn't have pregnancies.

'Every woman is different, and every woman's disease is controlled differently but it can be reassuring for most women to know that, when they're pregnant, their MS symptoms are likely to subside and their relapses likely to reduce,' Vilija says.

Vilija says it is important for women considering becoming pregnant not to defer beginning a disease modifying therapy (DMT).

'You should have a discussion with your neurologists about whether it's safe to continue your DMT or whether you should switch that therapy to something else, depending on the safety profile of that drug,' Vilija says.

'Continuing DMTs in pregnancy should be considered if you've got highly active MS. Alternatively, when you're planning a pregnancy, you can also consider the use of long-lasting DMTs that provide really effective long-term control. It is always best to speak to your neurologist about your options.'

#### What about after I give birth?

'While many women experience reduced MS symptoms during pregnancy, there can be a chance of relapse during the post-partum period.

'Particularly during the first three months after birth, we can see a rise in MS relapse rates. Thankfully, certain DMTs are safe to use within pregnancy to manage this risk.'

Most DMTs cannot be used throughout the entire pregnancy. If you stop your DMT during pregnancy, and you have active MS, we really do recommend that you

reinitiate your DMT quite quickly after you've given birth and the choice should be discussed with your healthcare team. There are some DMTs that are safe to use during breastfeeding. So if you want to breastfeed, you should be encouraged to do so,' Vilija says.

Pregnancy planning while having MS involves informed decisions backed by research. Even if there are unexpected elements in this journey, the current understanding of MS and pregnancies ensures women with MS are well-prepared to navigate the path to motherhood.

To watch the full webinar with Associate Professor Vilija Jokubaitis, visit msplus.org.au/resources

## Menopause and MS

'Women have just learned to accept and dismiss a lot of these perimenopausal symptoms and say, "well, maybe I'm ageing. Maybe this is just me now..."(but) unless we talk about these things, we're not going to come up with good strategies for how to manage them.'

#### — Dr Francesca Bridge

Francesca, a neurologist and researcher at Alfred Health and Monash University discusses the relationship between sex hormones and MS disease activity and clinical course, treatments for women experiencing menopause and empowering women to talk about their experience.

## What is the link between hormones and MS?

'We know there's significant variability in disease trajectories for people with MS. This is because of a few factors, but one of the factors we believe this is related to is hormones — particularly sex hormones,' Francesca says.

'Women are more likely to be diagnosed with MS than men, at a ratio of three to one.

'Additionally, we know that there are periods of time where there are major changes in sex hormone concentrations, the best researched example of this is pregnancy, and this can influence MS activity.

'During pregnancy there's a surge over the course of many months of oestrogen and progesterone, we see that MS becomes relatively quiescent, and people are less likely to have disease activity. But in the postpartum period, once the baby's delivered, there's a drop in oestrogen and progesterone concentrations, resulting in an increased risk of disease activity.

'So all of these things have made us think, sex hormones are having a part to play in MS, but interestingly, one of the other really important life stages where sex hormones change is that menopause period. This has been an under researched topic, and we haven't actually got a lot of data on what happens in this time.

'That means a number of our patients will go through menopause with their diagnosis [of MS] already, and we don't have enough information to be able to tell them what that looks like, or to be able to help them with that transition. For me, it seemed like an important gap in the literature.'

## How do we research menopause and MS?

'I work within a research team of clinician scientists and research scientists that all share this common interest in women's health within Monash University and at the Alfred Hospital.

'As a team we are working together to better address the gaps in the literature.

'We need to work alongside women with MS who are experiencing perimenopause and menopause to better understand what they experience during this transition and to capture how this influences their MS.'

## What treatment options are available?

'When we're speaking about menopause, we need to consider the whole person. We need to think about strategies like lifestyle, and non-pharmacological measures, and then pharmacological measures.

'In terms of general lifestyle changes, these things are beneficial from a menopause perspective, but also from an MS perspective. We know there's a lot of research coming out in the MS space about the importance of brain health, so things like exercising, keeping fit and active, is just so important for our brains. Making sure we don't smoke is incredibly important, and those things are crucial in the menopause period as well.

'When it comes to Hormone Replacement Therapy (HRT) in menopause for women with MS, again, we lack evidence. There is significant variability in reported response, with regards to whether these therapies improved MS-related symptoms.

## Feeling comfortable talking about menopause

'Unless we talk about these things, we're not going to come up with good strategies for how to manage them. So I really want to empower women and also neurologists

to really think about this phase in a woman's life. Because the other thing to say is that the MS symptoms that overlap the most with the perimenopausal symptoms tend to be the, so called, "invisible symptoms" of MS.

'We have several things we can offer women to improve their symptoms but unless we're talking about it and unless we're thinking about it, we're not going to get better about managing it. And if we don't, then women are just going to suffer in silence, I don't think that's fair.

You can listen to the full podcast with Dr Francesca Bridge, and plenty more MS Plus Podcasts on your favourite podcast player such as Apple, Spotify, Google Play, Overcast, or head straight to msplus.org.au/resources



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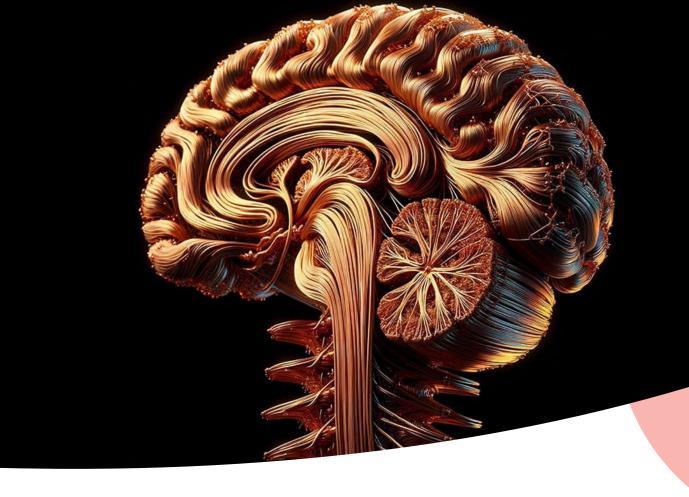
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## Researchers discover link between copper and demyelination in model of MS

In this study, published in Metallomics, researchers funded by MS Australia investigated the role of copper in the demyelination process, where the protective coating around nerves are damaged in MS.

They used cuprizone, a compound known as a chelating agent, that grabs onto copper and mimics MSlike lesions, causing demyelination in a laboratory model.

#### What did the researchers do?

The researchers thoroughly investigated copper levels during a 40-day cuprizone treatment period in the laboratory model.

Employing advanced technologies in mass spectrometry, they precisely separated copper into soluble and insoluble fractions across various brain regions, with a specific emphasis on the large white matter tract that connects the two hemispheres of the brain known as the corpus callosum.

Demyelination in the corpus callosum is a prominent feature of MS and may account for impaired performance on complex tasks.

#### What did the researchers find?

The researchers found demyelination within the corpus callosum was closely associated with a notable reduction in soluble copper, while insoluble copper remained unaffected.

To explore potential treatments, the researchers gave the model a copper compound that could get into the brain by crossing what is known as the blood-brain barrier.

This treatment increased copper levels, especially the soluble fraction, and significantly reduced the damage caused by cuprizone in the corpus callosum.

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

This study suggests that having insoluble copper in the brain and spinal cord might contribute to the damage observed in demyelinating conditions like MS. On the other hand, more soluble copper may be beneficial.

While further research is needed, this study supports the idea that delivering a copper compound directly to the brain could help preserve myelin in the brain and spinal cord in people with MS.

These findings bring hope for gaining deeper insights into how diseases like MS function, revealing new possibilities for effective treatment approaches in the future.

By understanding more about the role of copper in demyelination, we come closer to improving the health and well-being of individuals with MS. For more of the latest MS research, visit msaustralia.org.au

# How boxing helped Fatima take control of her MS



In 2015, Fatima started her health and fitness journey; beginning to eat clean and work out. After the birth of her second child, she bumped into professional boxer, Michael Zerafa at her local gym.

'Michael asked me if I needed some help in the gym, so, I explained that I had multiple sclerosis. Michael said he could help me with my training. Since then, he has been training me once a week for the last 3 or 4 months. We have been doing balance, coordination, and strength work. I've never worked so hard in my life,' Fatima says.

Research shows exercises that include big, explosive movements along with strengthening and cardio-aerobic drills (such as boxing) have been extremely beneficial to people with neurological conditions such as MS and Parkinson's. This works by training and rewiring the brain to improve impaired movements. Studies on boxing for neuro conditions have reported improvements to balance, walking speed and quality, strength, social connection and a reduction in overall falls risk.

'After my pregnancies, I felt I struggled with weakness again and Michael really helped me to address these weaknesses through training,'

Back in 2012, Fatima was a young, ambitious newlywed with big dreams. Despite feeling overwhelmed and exhausted, she was determined to build a career for herself and have it all.

'I was 21 at the time and working in retail management. I realised I was constantly dropping things and it was too painful to hold things. I eventually saw a doctor and was diagnosed with carpal tunnel,' Fatima says.

'My physiotherapist helped me with pain management. I was feeling constant pins and needles around my head, tongue, back and spine. I could also feel and hear electric buzzing running through my spine. Then one day I woke up with my spine feeling locked.

'I struggled to bend forward. So, I rolled out of bed and threw myself off the edge. I felt my spine vibrating with pain. My movements were restricted and I didn't feel right. I was eventually sent home from the hospital with the diagnosis of a pinched nerve.'

Fatima continued to experience symptoms, with no clear explanation about why this was happening. She continued to battle fatigue and at one point lost feeling in and use of one of her legs. She was told she had an infection and given antibiotics.

After a long road to diagnosis, Fatima was eventually told she had Relapsing Remitting MS in 2013.

'I was misdiagnosed one too many times and felt sick and tired of being sick and tired. But this meant it wasn't all just in my head and something wasn't right.

'After my diagnosis, I started using medication that helped me regain the use of my leg and walk properly again. I felt good and became clinically stable.'

This was the point where Fatima became motivated to take control of her health.

'Since we started working together, Michael has constantly challenged and motivated me. He has helped me feel stronger and to move easier in my everyday life. I currently train 3 times a week and can now walk, run and pick up my kids with ease. My pain levels have reduced and I feel so much happier.'

For more information on our Plus Boxing program, visit

msplus.org.au/plusboxing



# Struggling to concentrate in the office? Interruptions causing you to forget what you were doing?

These common symptoms can have a significantly greater impact on people living with MS.

But no worries! We've got your back with some pro tips to not just cope but thrive at work.

1. Use noise cancelling headphones or special earplugs to block out background noise especially when working in open plan offices.

- 2. Set aside "offline/focus time" for larger tasks to avoid interruptions and allow you to work more productively.
- 3. Take rest breaks from mentally fatiguing tasks.
- 4. Ensure you are adequately hydrated. Did you know there is a link between hydration and cognition? PwMS may restrict their fluid intake especially if they experience bladder symptoms, which you might not realise impacts your memory, ability to concentrate, recall information, find

words and learn new information.

Our Employment Support Service consultants are occupational therapists, physiotherapists and exercise physiologists specialising in neurological conditions. With decades of experience finding solutions to assist with cognition and memory symptoms at work, we can provide tailored strategies or assist with funding applications for assistive technology that you may be eligible for.

msplus.org.au/employment

'It's really hard to explain what MS is to people, not a lot of people knew the internal side of it. I am so grateful for my invaluable advocate, Diana.

She joined a meeting with my bosses and explained, "This is what MS is, this is what's going on inside."

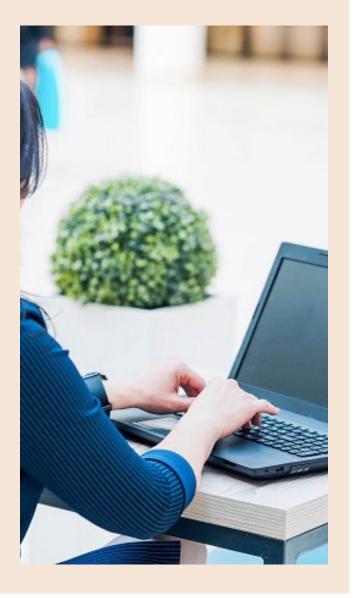
Her advocacy has made a significant impact on my workplace journey.'

**Tracey** 

# Empowering people with MS in the workplace is at the heart of our Employment Support Service (ESS).

Our dedicated ESS consultants are your advocates, bridging understanding and ensuring the best outcomes, so you can thrive at work.

Contact Plus Connect at 1800 042 138, visit msplus.org.au/employment or email connect@msplus.org.au today, to access this free service.





## What foods should I avoid with MS?

There is little evidence to show that following a restrictive diet and avoiding certain foods will prevent and slow down the progression of MS or improve MS symptoms.

Some individuals with MS may have food intolerances, in which

case we may need to restrict a food, however we would need t o replace this with alternative foods and/or supplement with the appropriate nutrients.

Everyone with MS is different and therefore there is no one size fits all when it comes to dietary advice. A tailored plan involves working with individuals to come up with a personalised eating plan together based on their goals, lifestyle, medical conditions and symptoms etc.

Further research is needed to support the safety of restrictive diets.

For more information on diet and MS, visit **msplus.org.au/plusdiet** 

## **Managing symptoms**

#### **Spasticity**

Tips from Physiotherapist, Mahenddra Raj

Spasticity is something we see a lot in our MS clinics. Spasticity can affect any muscle in the body but we tend to see it a lot in the quads and the calf.

When it does have an impact on the lower limbs, it can affect your walking, putting you at risk for falls and making it difficult for you to carry out day-to-day tasks.

If you do think you have spasticity, the first thing you want to do is speak to your neurologist or GP, to make sure they are across what is happening, as there are medications they can prescribe to help.

The second thing to do is to come and see your physiotherapist. What we can do is work out where you have your specific issue and help out with strength training, stretching or mobility tasks that can help improve some of that spasticity.

Of course with MS everyone is different, so if you were to come in we would carry out an individualised assessment to ensure the therapies we are implementing will work well for you and to make sure you are able to achieve your personal goals.

To get in touch with an MS Plus physiotherapist, phone Plus Connect **1800 042 138** 



# Processing your MS diagnosis

'For me, it's 100% about attitude. I went through most of the stages of the grief cycle, disbelief, anger, denial, etc., for a time doing things like not leaving the house unless I looked absolutely polished, because if I looked good, I couldn't possibly have MS.

'My situation is what it is, but the only thing I've never done is question 'Why me?'. That is a question that can never be answered and serves no end.

'I volunteered with Plus Peer Support for a while, about 10 years after my diagnosis. I wanted to help the newly diagnosed know that there is still plenty they can control over and above MS.'

MS Plus client Trina



## What if my goals change before I can review my NDIS plan?

If your goals or support needs change before your NDIS plan is due to be reassessed, it's important to communicate these changes as soon as possible. Your NDIS plan is designed to be flexible and responsive to your evolving needs; however, with some changes in situation, your

NDIS plan funding will no longer be adequate for your support needs. In these situations, your plan can be adjusted accordingly. There are steps you can take if your goals or needs change, including:

- **1.** Contacting your support coordinator
- 2. Requesting a plan reassessment
- **3.** Providing updated information

- 4. Attending a planning meeting
- **5.** Reviewing and revising your plan

For more detail reach out to Plus Connect 1800 042 138, email connect@msplus.org.au to connect with a support coordinator, or visit the website. msplus.org.au/ndissupportcoordination

## Ever wondered why you should consider a NDIS plan manager?

A plan manager isn't just about numbers — we can help you stay on top of your NDIS budget and manage your NDIS financial transactions on your behalf, so that you can focus on living well.

Don't tackle NDIS financial management alone. We can help.

Reach out to our Plus Connect team at **1800 042 138** or **connect@ msplus.org.au** 

Learn more: msplus.org.au/ planmanagement



#### When Alison started seeing Dr Phu Hoang, she was using a walker to get around.

Sometimes she fell. Her leg was affected by drop foot and hyperextension, and Alison could not use her left arm or hand. Even speaking was a struggle at times.

Alison can now walk an incredible 5km.

"I am living proof that MS Plus Centres are improving people's symptoms." Alison says it feels amazing to be living without visible symptoms again.

Our physios have a deep understanding of neurological conditions. They can help you improve your strength, mobility and balance – and prevent some of your symptoms from worsening over time.

Come see our physios at our wellbeing centres:

Blackburn, Vic Footscray, Vic Hobart, Tas Lidcombe, NSW

Or via telehealth if you're in ACT / regional Vic / NSW / TAS **1800 042 138** or email **connect@msplus.org.au** 

Learn more: msplus.org.au/plusphysio

## What's On

#### **Live Webinars**

Scan the QR code to register for upcoming webinars.



### **Upcoming Programs**

## MS Plus Navigate Series: Family & Friends

Over two 75-minute sessions, an MS expert will guide discussions, provide information, links to resources and answer any questions you may have.

The sessions will be facilitated by an MS Nurse and cover topics such as understanding MS, navigating the health system, where to access support and how to look after yourself while supporting someone else.

#### Dates:

Tuesday day session 7 & 14 May, 12:30pm AEST Thursday evening session 8 & 15 August, 7:00pm AEST

trybooking.com/events/landing/1092839

#### Navigate Series: Newly Diagnosed

The online 90-minute sessions run weekly over five weeks. Each session will include expert content, an opportunity to learn from others experiences and a chance to ask questions.

The sessions will be facilitated by content experts such as MS Nurses, Psychologists and Allied Health professionals.

When: Wednesday 15 May, 6:30pm-8:00pm AEST and Tuesday 6 August, 12:30pm-2:00pm AEST

#### On demand webinars

## Watch any time msplus.org.au/resource-hub

- MS progression and the impact of Progression Independent of Relapses (PIRA)
- Evidence based diet and MS: looking at the mediterranean diet
- MS brain health: what is it and how do I get it?
- Genetics and MS

#### **Podcasts**

## Listen anytime! Visit our website msplus.org.au/resource-hub

- The MS Boost: Medical gaslighting: Time to stop being the good patient with Rachel Horne
- The MS Boost: Tysabri subcut uncut
- How to build better habits with dietician Leif Lagesen
- Caregiving and ambiguous loss with Linda Rowley
- HSCT and MS
- Brain health & why it's never too late to make a change with researcher Olivia Wills

The **MS BOOST** is a new podcast series filled with concise interviews with expert guests, it's all the stuff you need to know, from the people who know it.

Make sure you're following

MS Podcasts to listen to the

MS Boosts on your preferred
player like Apple Podcasts or

Spotify to be the first to know
when new episodes are released.

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

### **Exercise Groups**

#### **NSW**

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

#### **Plus Boxing**

Fridays 9am-10:30am Studdy MS Centre, 80 Betty Cuthbert Dr, Lidcombe

#### VIC

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

#### **ACT**

To book, phone **1800 042 138** 

## Be better balanced (chair-based class)

Tuesdays 9:30am Thursdays 10am Gloria McKerrow House 117 Denison St. Deakin

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



Helping you break down barriers and achieve your goals

Emotional and practical support for every stage of your journey.









# Our services

- Accommodation
- Continence support
- Diet and nutrition
- Employment support service
- Exercise physiology

- NDIS services
- Occupational therapy
- Physiotherapy
- MS Nurse
- Information and advice



1800 042 138 connect@msplus.org.au msplus.org.au

