intouch

Autumn 2023

MS PLUS
Neuro Wellbeing

From the CEO

John Blewonski | Chief Executive Officer

Welcome to our first Intouch magazine for 2023.

I am pleased to launch into another year of change, growth and continuous improvement at MS Plus.

We've kicked this off by launching some really interesting new services and supports. Our upcoming Podcast series The heads-up provides expert advice on successfully navigating a new diagnosis of MS, and our Symptom hacks episodes will focus on practical tips for managing MS symptoms. We've also launched Boxing for Parkinson's program in Lidcombe, NSW and small group Pilates in Blackburn, VIC. It's great to see some fresh ideas coming to life to better service the MS Plus community.

Our events team is hard at work planning another full calendar of fundraising events to help us continue this support and to help raise greater awareness of MS among the wider community. Our popular MS Walk, Run + Roll will again run across the ACT, Victoria, NSW and Tasmania from 7 to 28 May. There is still plenty of time to get onboard, either as a participant or volunteer or even just to come and celebrate the resilience and diversity of our amazing MS community. Visit **mswalk.org.au** for more information.

Our MS Mega Challenge is an ongoing calendar of events, raising funds for our MS Go for Gold Scholarships and Finanacial Assistance Programs through team relay sports. We recently hosted the Fitzroy Mega Swim, 17–18 February and the Wollongong Mega Swim on 11–12 March, with these two events alone managing to raise $210,994

Good luck to all of those heading off on our MS Plus Ikara-Flinders Ranges Adventure from 28 May to 4 June. All of us at MS Plus are grateful for the incredible efforts of our amazing fundraisers, in whatever form that may take.

Lastly, I am pleased to announce MS Plus completed another successful NDIS triennial accreditation process in late February. Maintaining our NDIS accreditation is a means of ensuring we remain an NDIS Approved Provider [Certified] but also ensures we continue to provide the very best care to all our clients and is a common process that all healthcare providers for those living with disability must complete to continue operating. Beyond just a tick box, we really welcome this opportunity to review our internal process and quality systems to ensure we keep firing on all cylinders across the organisation.

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News

Understanding MS: Free online course now open

Understanding Multiple Sclerosis (MS) is a free online course available to people worldwide that aims to improve understanding and awareness of MS.

This dynamic course is delivered via a series of videos featuring MS experts (both academic and people with lived experience), and includes quizzes, activities, and discussions.

In doing this course you will increase your knowledge of MS-related issues and be empowered to create and contribute to personalised MS management plans.

Feedback from people who have completed Understanding MS is overwhelmingly positive, with participants finding it informative and useful. Not only do course completers improve their knowledge of MS, nearly two-thirds (63%) say they applied their learnings from the course in their everyday lives, and almost all (97%) report that they will recommend the course to someone else.

Register now via the University of Tasmania Menzies Institute for Medical Research website: **ms.mooc.utas.edu.au**

Challenge yourself with The May 50K and leave MS where it belongs, behind us!

Leave your limits behind with **The May 50K.** Run, walk or move 50 km in May and raise vital funds to leave MS exactly where it belongs, behind us! **The May 50K** is a virtual fitness and fundraising challenge to help you achieve your health and fitness goals. You can take part in your own time, at your own pace and in and around your local area. Register now **themay50k.org**

MS GoFish Raffle

Do you have your ticket?

Head to raffletix.com.au and grab some tickets for a chance to win a new 469 Outlaw Tiller Steer boat worth **$36,000,** an Elite™ Fishing System worth **$1,999** or **$500** worth of Mitchelton Wine. (VIC and NSW only)

All funds go towards helping support people living with multiple sclerosis and other neurological conditions.

Describing invisible symptoms: how to talk to family and friends about MS

Describing your MS can be particularly frustrating when you experience symptoms that are invisible to others.

Our MS Nurses spend their days supporting and talking to people about their MS symptoms, so we asked them to share their insights into how to communicate and manage these symptoms. They told us that the symptoms that tend to be hardest to describe are often the symptoms that fluctuate each day, making it even harder to capture how you are feeling on the actual day. In their experience, the top three of these symptoms are cognitive changes, fatigue and nerve pain.

The MS nurses explained four techniques they most used to help describe symptoms. These are:

The power of pictures We are all visual creatures and images are a great way of explaining tough concepts and problems like invisible symptoms. Images can make a story personal and help feel involved and connected by sparking emotional responses. Capturing an image to go with your symptoms may help you and others to understand where you are at. It may be helpful for you to begin the process by just simply drawing how you feel. You don't have to be a brilliant artist, sometimes we feel like enormous splashes of happy yellow, other times a messy mass of red and grey. Just grab the pencils and start letting it out.

Using analogies Analogies can be another good tool for helping people understand, process, and emotionally connect. How many times have we heard people say it's 'worse (or better) than childbirth', or it 'feels like I have just run a marathon'.

Using the scientific or factual definition For some people being direct and providing the scientific black and white version can be helpful to assist them in understanding.

Using other people's words Many resources have been created to help you find the right words and definitions. Google, Wikipedia and Artificial Intelligence websites like Chat GPT can potentially help. Most of us are smart enough to filter out the inaccurate information and pick and choose from the wording to help cobble together a meaningful explanation for them. It's ok to do this, just do so with your internet information filters on.

Head to **msplus.org.au/explaining-your-symptoms** for more tips.

Watch **'My bike has MS'** on YouTube, a great example of how to explain your symptoms to someone unfamiliar with MS.

WHAT IS THE HIDDEN DISABILITIES SUNFLOWER?

The Hidden Disabilities Sunflower helps people with non-visible disabilities to access the support they need. It acts as a prompt for someone to choose to let people around them know they have a non-visible disability and that they may need a helping hand, understanding, or simply more time.

Head to **hiddendisabilitiesshop.com.au** to learn more and to purchase a sunflower lanyard, card or badge.

When the impossible becomes possible thanks to Support Coordination

Katy, who was diagnosed with MS in 1995, hasn't been able to go on a holiday since 2011.

'It had been about 11 years since I had been on any kind of a holiday and to be honest, holidays were something I had ruled a line through and pretty much accepted that, because of my disability and related health issues, they were in the 'too hard basket' and weren't going to happen anymore,' Katy says.

Luckily, Katy's Plus Support Coordinator, Brianna was on the job.

'For people living with MS and who have mobility issues and other needs that must be met, many everyday tasks are more difficult and organising something like a holiday can seem impossible. Knowing what you need and how to access that help can be overwhelming and it can often seem easier to just stop doing what you love or want to do. This is where Plus Support Coordination and other MS Plus services are so important,' Brianna says.

'Support Coordinators have a bird's eye view of what help is out there and can coordinate with the NDIS to access the necessary funding. I would hate for someone to miss out on something that can give them joy, when the help is there waiting for them.'

Thanks to Brianna's efforts, Katy enjoyed an incredible holiday in Barwon Heads in October.

'Brianna was amazing, in her words, "there was no way she was not going to find a way for me to go." And she was absolutely right, at the last minute she got me there. Both me and my parents were very anxious and we just wanted to hug Brianna because she truly did go above and beyond to get me there,' Katy said.

'She looked after so many aspects, from organising a support worker, to checking with my OT about what help I would require, booking accommodation, transport, hoisting support and organising it to come out of my NDIS plan,' Katy said.

Brianna organised for Katy to stay at accommodation in Barwon Heads that caters specifically for people with accessibility needs. The accommodation provides a variety of equipment and supports, including a beach wheelchair, which Katy made good use of.

'The trip all nearly fell to pieces two days before Katy was to leave, her support worker fell sick and could not come, meaning I had to find a replacement that would be able to go for 4 days with a days' notice, and be able to support someone with high needs. By some miracle, I found someone who was able to go, literally the afternoon before leaving. Katy had the time of her life and even sent me a video of her using the beach wheelchair,' Brianna said.

'I bought a mug recently that says 'dare to dream' and with Brianna I feel like I can. It is ironic that I bought this cup just before I left for my holiday because it certainly became very prophetic,' Katy said.

'I can't tell you how good it felt, not only to be on a holiday but to be on the amazing holiday that was! The freedom and independence I felt just cannot be put into words and now I know it's possible I'm already planning my next one!'

Plus Support Coordination helps people living with MS and other neurological conditions to access the full range of supports available to them through the NDIS. For more information visit **msplus.org.au** or phone Plus Connect **1800 042 138**

I have MS...MS doesn't have me

We spoke with three people living with MS about finding joy after their diagnosis and how they are striving to live their best life every day.

SHELLY

What was the biggest challenge when you were first diagnosed?

I was diagnosed with MS in late 2021 at the age of 50 and the greatest challenge I faced was that of the unknown and uncertainty. I was incredibly fatigued and due to my symptoms I couldn't work for 6 months. I had a busy and stressful job that I loved, two tweens and a very busy life and MS put a brake on everything. I had to be very conscious not to spiral downwards with so many 'What if' questions. What if I cannot work, What if I cannot.... With lesions on the brain, brain stem and spine, it was too easy to project a future that looked very different to how I envisioned it.

To address the fear and answer my many questions I read a lot and listened to as many podcasts as I could and reached out to the MS community. To give me a sense of control, I focussed on the things I could do. I could get the best medication on offer. I could work on physio and movement, I could focus on a nourishing diet, I could accept a period of uncertainty in my life. Small steps were important. Like starting medication, starting physio, returning to work. I have been on Kesimpta for 9 months now and I am now feeling much more settled about my future.

What is something you do every day to make yourself feel good/look after yourself (outside of treatment)?

MS has taught me to live more consciously. I am more aware of how I want to live my life, what I need to bring into my life and what I need to let go of. I am my own biggest advocate and each day I make sure I take care of my energy needs. I rest when I need to, push through when I think I can but mainly, to make myself feel good, I have a rest, water the garden or cuddle our pets.

I am very conscious of staying positive and seeing the beauty in my life. It's not something that I do each day to make myself feel better as much as an attitude to make sure I appreciate the small moments.

Is there something/s you have achieved since your diagnosis you are particularly proud of?

I was project lead for an award submission for work when I first started getting symptoms. I remember sitting in a meeting saying "I'm sorry I have nothing to say. I'm not feeling well," then staying in the office meeting room and lying on the floor crying not knowing what was wrong with me. I submitted the work and walked out the door and didn't come back for 6 months. The submission went on to win a state award and we are now hoping for a national win. Having this success helps me when work days are difficult or impossible due to MS.

What advice would you give someone who is newly-diagnosed?

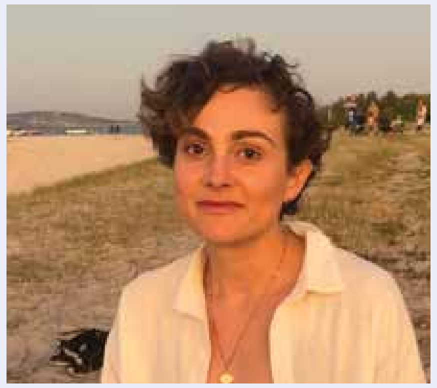
Give yourself time. I wish I knew it would take just over a year for me to feel like I could see the light at the end of the tunnel. The tunnel was very dark for a while and I had to pep talk my way through it. MS Plus was such a huge resource for me and I am so grateful for all the calls I had with the MS nurses who were so calm, patient and knowledgeable.

Connect with others in the MS community. FB groups are great for asking questions and just checking in what is and isn't normal. Local meetups are great for connecting with others who can help you uncover available support, resources and guide you in those early days.

Research and reflect. I found it important to read as much as I could and then reflect on the information to help me understand what medications would work best, what lifestyle modifications would suit me and to gauge how 'normal' my symptoms were and to cut through opinion vs science.

If you are a parent, don't over think how your kids are going to react. I did and in the end I just kept it really simple and said "You know how Mum takes medicine for her thyroid? Well, I am starting to take another medication for another autoimmune condition called Multiple Sclerosis. It's why I have been feeling really tired and have had to rest a lot." We chatted some more and I asked if they had any questions. They have been wonderful and my daughter now tells me I have 'Lucky MS' because I was awarded the MS Go for Gold scholarship and I won a google home nest in a MS raffle.

The best advice I have however is just to be really easy on yourself. MS can be tough and it does change lives, but remember, everyone's journey is uniquely their own but reach out as we are all in it together.



DIANA

What was the biggest challenge when you were first diagnosed?

The biggest challenge I had when I was first diagnosed, remains my biggest challenge now: how to translate the 'invisible' symptoms of MS. But, that is what drives my research. If this is something you find challenging too... please get in touch with me! I'll be looking to recruit people with MS for a study soon.

What is something you do every day to make yourself feel good/look after yourself (outside of treatment)?

In a nutshell, I eat good food and exercise. I swear by the 'OMS program' (please Google it!) I follow it very closely, in addition to eliminating gluten. Aside from being very deliberate about what I eat, I'm committed to two daily goals: spending time outside AND doing some sort of movement-based practice. Sometimes, that looks like a run. Other times it's a walk across the road for coffee and yoga in bed.

I meet myself where I am every day, rather than holding myself to constantly 'build on' or 'make up for' yesterday. The promise I have to myself, is to just show up to those goals each day. The way I do them might change, but I'm consistent, so I've had great results.

Is there something/s you have achieved since your diagnosis you are particularly proud of?

Two things come to mind. Firstly, working with MS Plus to establish a Queer and Gender Diverse support group for people with MS. If you identify as LGBTQIA+ and have MS, send me an email to join **queermsgroup@gmail.com.** Secondly, collaborating with other researchers from different disciplines to learn more about living well with MS.

What advice would you give someone who is newly-diagnosed?

I don't know about 'advice' because everyone's situation is so different. I have thought a lot about what I would have liked to know when I was first diagnosed. This is what I've come up with:

Take your time

- on a bad day, a positive attitude can only get you so far
- when you are not feeling well, absolutely do not feel bad about not having a zest for life
- do not feel bad about not having energy
- do not feel bad about not being productive
- a positive mindset can go a really long way... but, particularly in the beginning, I would have loved someone to say 'this is heavy and if you don't feel like trying today — I totally get it'.

Know your audience

Energy is currency and you want to start being really discerning with how you spend yours. Relationships are held together by preferences and priorities. Maybe you LOVE sport and you connect easiest watching or playing with people who 'get' the tactical skill involved in the game. People who don't understand sport, don't need to be cut out of your life... but it's a waste of your precious, finite energy to try to convince them that Port Adelaide's 119 point loss in the 2007 AFL premiership, was the greatest grand final defeat of all time (according to my dad, a Crows fan).

Not everyone has the bandwidth to understand what it's like to wake up in a body that can feel different day-to-day. That doesn't make them bad people, it just means they have different priorities, relative to their own capacities. It isn't personal. When someone (even a loved one) demonstrates to you that they don't have the capacity, don't confuse that as signalling it's your responsibility to try to make them understand your experience. The people you are closest to will generally become proximate to how curious they are about 'MS stuff'. This 'capacity to hold space for MS stuff' becomes another door you connect with people through... but don't spend your precious energetic currency trying to drag through absolutely everybody.

Avoid comparison

Let's be honest. When we ask this specific combination of questions: 'What type of MS do you have?' 'How long ago were you diagnosed?' 'What medications are you taking?' ... on some level, we are trying to plot their experience against our own, to predict our future. Tempting as it is, the course of MS is very individual. Those questions will not yield answers you can reliably apply to yourself.

Don’t resist letting this change you

Fighting to prove to everyone (including yourself) that this will not change the way you live your life, is wasted energy. More importantly though, you are denying yourself the possibility that in some ways, your life might be better.

DEANNA

What was the biggest challenge when you were first diagnosed?

I was diagnosed in 2007, which was a weird time, Myspace and Facebook were fighting over the one platform to rule them all (RIP Myspace, I still miss my glitter cursor) and Instagram hadn’t come into existence. The biggest challenge for me when first diagnosed was the poor delivery of my new illness and lack of positive representation in the MS community. The news was delivered to my Mum over the phone, she kept crying and I thought I was dying. We didn’t fully understand what MS was and I was offered very little support or education at the time. It felt like someone had attempted that tablecloth magic trick, but instead of ‘TADA’ a set table remaining it had gone horribly wrong. My dreams and hopes were shattered, fear thick and smeared, my future, defective, all that was left was a big mess. It was pretty traumatic. I ended up “Asking Jeeves”, and honestly Jeeves did me a mischief filling my head with worst case scenarios and offering not one alternative. Today, I am so grateful for the strange-beast social media has become, especially in the disability advocacy space. Newly diagnosed Deanna wishes there were positive MS representations in 2007 and having a good deep-dive stalk of an MS advocate was an option. Today, it always makes me feel better seeing other MS superstars slay their days online.

What is something you do every day to make yourself feel good/look after yourself (outside of treatment)?

My MS brought another friend to our chronic illness tea party, the big sad, also known as depression. Being a professional feeler of big feeling coupled with equally messy MS some days it is hard to feel good and look after myself. But as a fine wine I have gotten better at this with age. I see these conditions as less of my enemies now and more like my annoying little friends, that sometimes tantrum. A personal mind trick I like to play on these gremlins is ‘do the opposite’, if one is telling me to stay in bed all day, I try to do the opposite and get up. Some days I need to play this game all day, sometimes it doesn’t work and other days the gremlins are sleeping, these are usually really good days. Recently I have been making more time for my art and other things that bring me joy, like making silly TikToks or trying to dance without falling over. Spoiler alert, I do fall over and it’s pretty funny when I catch it on camera.

Is there something/s you have achieved since your diagnosis you are particularly proud of?

I have achieved so much since my diagnosis, having graduated with a double Master degree, travelling solo through many challenging countries to working on loving and accepting a forever sick body. Recently, I am particularly proud of the advocacy work I am doing in the disability space. I started an art project in which I transformed an MRI into a colourful, flowery, hope inspired art piece that won first prize in the MS Plus Art Show. You can have a look at my other work @CircularBlooms on Instagram. In 2022, I walked 10km in the MS Walk, Run, Roll and later that year curated a charity art show featuring artists with invisible illnesses with proceeds going to MS research. In October 2022, I completed the 100km Kiss Goodbye to MS Tuscany Trek in Europe, something I never dreamed would be possible for me. Last year I raised close to $8000 for MS research, vital services, and a cure. I still feel like a complete imposter when I talk about this, especially when writing it now, but it really butters my biscuit knowing despite my MS anything is possible.

What advice would you give someone who is newly-diagnosed?

My 16-year journey with MS so far hasn’t always been the most pleasant, change is scary, but I am happy to say it does get better. Medication has improved, support groups and representation has improved. MS Plus and NDIS services are a game changer. Remember you are not alone and there are so many of us, so many in fact if you say MS in the mirror three times, someone is sure to jump out and scream ‘my aunty has that’! You can probably tell by now; I mask a lot with humour.

Once upon a time I was lost in the dark seas of ‘why me’, the fear, the unknown, the unfairness of it all, the dark thoughts, the fear of never coming up for air under the crushing weight of my disability. I changed my narrative, or there wasn’t going to be anymore story to tell. I did the opposite. So, please reach out, get help, ask for support, be gentle with yourself, and on the bad days try to love yourself just that little bit harder. When life gives you waves, remember waves are made for surfing.

Symptom spotlight

Vision

How can MS impact vision?

MS can damage the nerve pathways in the brain and the optic nerve, which can cause temporary or ongoing visual changes or loss. It rarely results in total blindness.

What types of visual issues can MS cause?

- Visual loss (optic neuritis)
- Double vision (diplopia)
- Involuntary eye movement (nystagmus)

What treatments are available?

Treatment for optic neuritis
If it’s mild, it may be that it goes away on its own in four to six weeks. The most common way to treat optic neuritis is with steroids.

Treatment for double vision
You can place a patch over one eye or temporary stick-on Fresnel prism lens on your glasses to realign the two images. Your doctor may discuss other medical options, such as botulinum toxin or surgery.

Treatment for nystagmus
Wearing contact lenses or eyeglasses to improve your vision may help slow down eye movement, however it won’t fully correct nystagmus. An eye care professional can help you use null point training, suggest a magnifier to make it easier to read or changes to your posture and environment. Your doctor may also prescribe you medications or recommend a physiotherapist.

For more information visit **ms.org.au/common-symptoms**

MS Plus Virtual Art Show

Entries now open!

The MS Plus Virtual Art Show provides people living with neurological conditions the opportunity to express their creativity and celebrate connections through art.

To enter visit **msplus.org.au/artshow**
Entries close **Sunday 7 May 2023.**

Subscribe and win!

Love Intouch magazine?

Then sign up to our monthly Intouch newsletter and receive all the latest updates and advice direct to your inbox every month!

If you sign up before **Monday 1 May** to go in the draw to win a **$100 eGift voucher!**

Use the QR code below to sign up or head to **msplus.org.au/contact-us**

New types of clinical trials on the horizon for MS

The current gold standard in clinical trials is known as a "randomised clinical trial", which compares a new drug or therapy against a placebo (where the treatment given does not contain any of the active drug).

In contrast, Adaptive Clinical Trials (ACTs) are much more dynamic and flexible studies compared to traditional randomised clinical trials, because an interim analysis or evaluation of the study findings is made at pre-specified time points partway through the clinical trial.

Adaptive Clinical Trials and how they are different

Using the ACT approach, trends can be identified earlier, such as certain study arms (for example, different drugs or doses of the same drug) not being effective, worsening or improving disease outcomes.

Some ACTs can also cease ineffective study arms and replace them with a pre-specified new treatment, enabling participants to continue and contribute to a clinical trial rather than stop early and lose future study data.

The key objectives of ACTs are that participants are not exposed to inferior treatments for very long, effective treatments are identified much earlier, and multiple questions can be answered in the same clinical trial, saving not only time and money, but also improving lives for the participants.

Why ACTs are vital for MS research

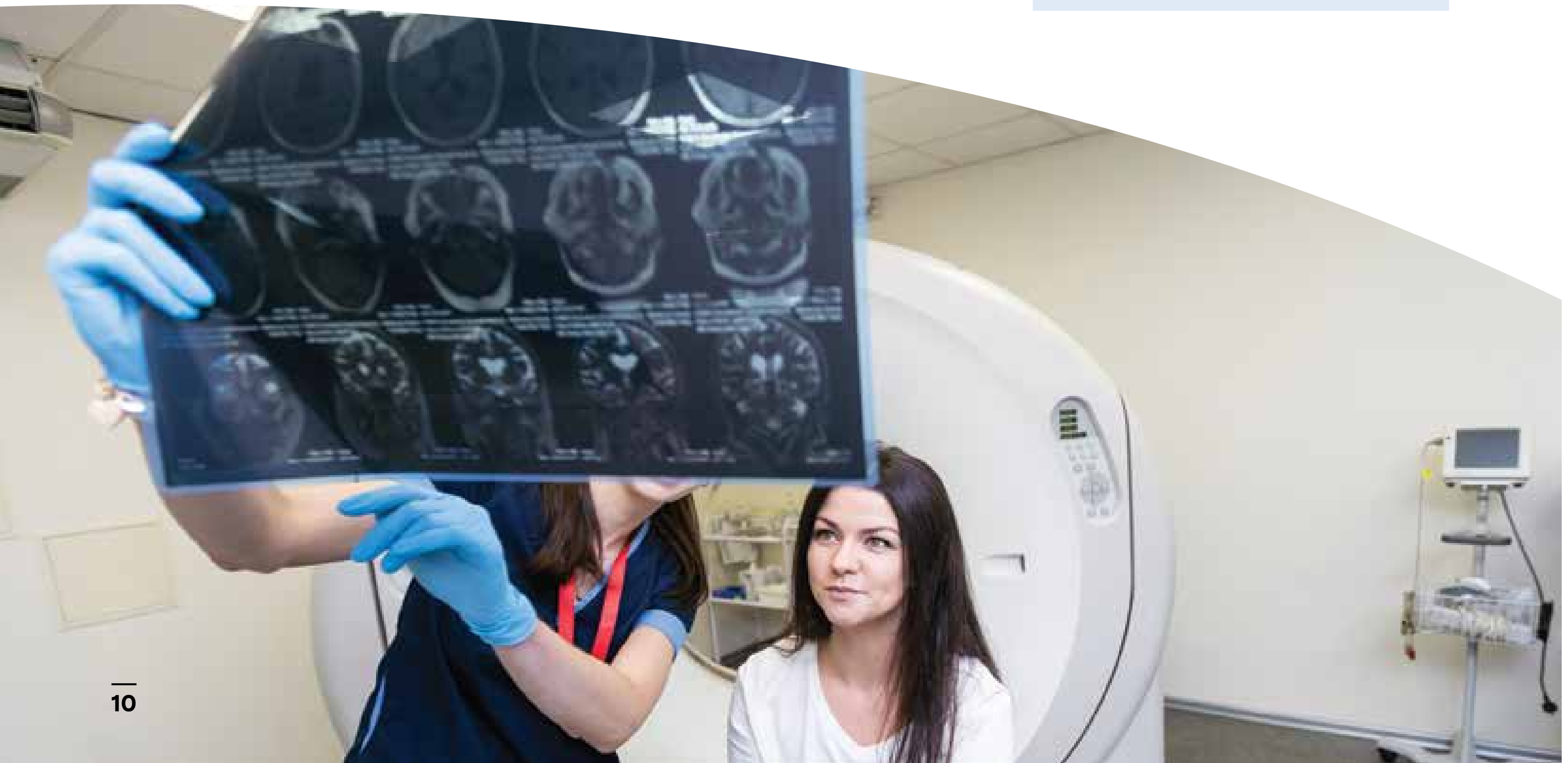
The evidence from the 'brain health in MS' initiative indicates time matters greatly in brain and spinal cord health. The sooner that MS-associated inflammation is reduced or stopped, the better the outcomes for the patient.

It is challenging to use traditional clinical trials to compare smaller groups of people with MS within a larger group, but an ACT can observe more closely specific situations to identify effective treatments under certain conditions. For example, in progressive MS, an ACT could look at what previous medications might make a new treatment more effective, or take note of sex, length of time since diagnosis, or age group, essentially any variables that may improve outcomes.

As MS is different for everyone, analysing and interpreting these subtle areas where treatments may be more effective is vital.

MS Australia developed an ACT platform to support and educate both clinical trial staff working in MS, and people living with MS, about the benefits and opportunities of ACTs and will be launching this platform in 2023. To read the full article, visit **msaustralia.org.au/news/new-types-of-clinical-trials-on-the-horizon-for-ms**

For all the latest MS research updates visit **msaustralia.org.au**



'Learning to live well with MS can be life changing'

Connecting people through our Plus Peer Support program

'I cannot emphasise enough how powerful human connection can be for both mental and physical wellbeing. Learning from people who have had to navigate a similar path to you, and are role models for living well with MS, can be the best medicine,' Senior Manager Community & Partnerships at MS Plus, Kylie Osborne says.

MS Plus' free **Plus Peer Support program** provides a unique opportunity for people affected by multiple sclerosis, their family and carers to connect and support each other.

Sally has been attending face-to-face peer support groups for 9 years, initially in the ACT and now in Tasmania.

'The group experience is welcoming and supportive. Both carers and people living with MS are automatically connected as we've all been inadvertently thrown into the 'MS club', so that means that straight away there's a bond between you.'

Peer Support Facilitators helping to create connections

Rebecca is about to start as a Peer Support Facilitator (PSF), who help to lead the sessions, for a new group she created located in Mansfield, in regional Victoria.

Rebecca Vincent

Sally Wolfhagen

'I discovered the closest in-person group was over an hour away and at an inconvenient time. I kept hearing about more and more people with MS here in my local township, a community of 10,000 plus and growing, so, I thought it was high time a support group was created.'

'MS is a silent, pervasive journey — no one can really see or fully know exactly what you're experiencing. I recently found, quite by accident, a couple of other people with MS and found such a positive and self-affirming benefit from us sharing our unique, but also somewhat aligned experiences,' Rebecca says.

Don't be afraid to reach out

'I regret waiting until I retired to join my first peer support group,' Sally says.

'Had I gone I probably would have learned about adjustments that could have been made at work so that I could have stayed longer or received assistance with transitioning to alternative work. I'll never know but I often wonder!

'Without doubt, peer support has enriched my life,' Sally says.

"Your peers can truly help you learn to live well with MS, which can be life changing"

To see if the Peer Support Program is right for you, or to apply to become a Peer Support Facilitator, email **peersupport@ms.org.au** or phone Plus Connect **1800 042 138**

Explainer

What is the difference between MS Plus and MS Australia?

As a person living with MS or another neurological condition, it may be a bit confusing, hearing about both MS Plus and MS Australia. What role does each organisation play in helping people with neurological conditions? We've created a quick explainer to help you out:

MS Plus

MS Plus works with MS Australia and other state and territory MS organisations to **manage the national fundraising** campaigns in pursuit of our mission to achieve a world free of MS. Funds raised by this campaign all go towards the comprehensive multiple sclerosis research programs coordinated by MS Australia.

MS Plus serves people affected by MS living in the ACT, Tasmania, Victoria and NSW by offering a wide range of emotional and practical supports to people living with MS, including:

- **allied health** (physiotherapy, occupational therapy, exercise physiology, diet and nutrition and continence support)
- **employment** support
- **expert advice,** wellbeing programs and peer support.
- **NDIS services** (support coordination and plan management)
- **nurse and social work advisors**

MS Plus also:

- enables access to care services for people **living with other neurological conditions** and those needing **aged care** support
- provides **respite** accommodation for people living with neurological conditions and their carers, as well as **long term accommodation.**

Education & awareness: Through education, MS Plus also empowers individuals, their families and their communities to build skills and knowledge about how to live well with MS.

MS Australia

MS Australia is the national not-for-profit organisation that, with the support of its Member Organisations and the Australian community;

- funds researchers to find ways to treat, prevent and cure MS
- vigorously advocates with and for the MS community for sustained and systemic policy change, and
- acts as the national champion for Australia's community of people affected by MS.

Research: MS Australia funds, coordinates and advocates for MS research as part of the worldwide effort to end MS.

MS Australia supports research activity in areas where Australian scientists will have the greatest impact on MS research not only here, but worldwide. MS Australia does this using two main approaches:

- supporting investigator-led research projects that are selected through a robust grant review process
- coordinating and funding major national collaborations, or research 'platforms', to address key scientific questions that no one researcher could solve in isolation.

Through this two-pronged approach, MS Australia aims to accelerate further significant breakthroughs in our knowledge of MS to work towards better treatments, prevention and a cure for MS.

Advocacy: MS Australia represents and collaborates with its Member Organisations, people with MS, their carers, families and friends and various national and international bodies to:

- Fund, coordinate, educate and advocate for MS research as part of the worldwide effort to solve MS
- Advocate for improved support, services, treatment and care to improve the quality of life for people with MS, their carers, family and friends through every stage of their MS journey.
- Provide the latest evidence-based information and resources

Education & Awareness: MS Australia is the nation's leading trusted provider of MS information. MS Australia:

- develops educational and awareness-raising programs and materials for the MS Community and general public
- works with Member Organisations, international alliances, immunological and neurological organisations to develop aligned and consistent campaigns and messaging
- consults widely with people with MS, their carers and their families to ensure education and awareness programs are representative and inclusive.

Making the most of your appointments

Appointments with doctors, nurses, physiotherapists, or other healthcare providers are an important part your health journey. Mixed messages, unclear plans and long wait times can mean these appointments don't always go as expected and when this happens you may not get what you need. As a partner in your own health care, preparing and being organised can turn around those unhelpful appointments.

Here's some top tips for getting the most from your health care professional:

Manage your time

- **Be on time,** you may need to wait but you'll likely feel less flustered.
- **Plan for possible waiting time.** Relax in the waiting room with a good book or listen to a podcast.
- Know that you may not get a lot of time with the doctor and you will need to make the most of it. To make the most of it you can:
- tell your story in order of how things happened, take notes in advance so its succinct
- pick your one or two top priorities to discuss and get them covered first.

Be clear on your expectations

- **Be clear in your mind** what you want and expect from your visit. Do you need talk about a problem, check in your progress, know the latest research and information available or just want paperwork completed?
- **Establish shared responsibilities** and who is looking after what (for example results of tests — is it your GP, nurse, neurologist, you?).
- **Know when it's not working** and when to find someone else. Be realistic, you can't have a good relationship with everyone and that's ok.

Remove some of the barriers to good communication

- Always be honest about your health
- Bring any tests results with you, ask for your test results or how you can access them (taking photos of results on your phone can be handy).
- Ask if there are other ways to find out the information you may need. For example, could a nurse, good internet site or research information be helpful?
- Confirm the plan at the end of the appointment — you could use a form you already created that has a few things to tick off like: do I need an MRI, blood test or new medication.
- Be realistic about the communication between health care professionals. Letters often take weeks, having your plan written down will ensure you are in control.

Organising your appointment admin

- Have the contact details of any health care providers you see. You could store these details in your phone or in a folder.
- If you need repeat scripts for medications have all the details ready.
- If you want a form completed, have it prepared and make sure you allow time for it to get back to you.
- Wear comfortable clothes, slip on shoes and bring your glasses.
- Bring a friend (they could take notes for you).
- Arrive hydrated — you may need a blood test.
- Clarify parking arrangements and other appointment details before the appointment.
- Be kind.

Questions for neurologists' appointments

It so easy to get distracted and go off topic in your neurologist appointments. You will get far more out of your appointment if you take even as little as ten minutes to think about what you need. Here are some areas that may help in your thinking.

My MS progress

I wondered if there are any further tests I need to confirm it is MS?

Are there other conditions it could be?

What type of MS do I have?
Or, has my MS type changed?

Am I doing, OK?

Am I due for, or do I need any other test to see if things have changed?

My MS treatments

What are the treatments options for me?

Is my treatment working?

I think I am experiencing a side effect of the treatment.

What do I do if I am worried that I am experiencing a side effect of a treatment?

Can I change treatments?

Are there any new treatments or research?

For more information visit **msplus.org.au/preparing-for-your-medical-appointment**

My MS symptoms

I have noticed recent changes in my walking, balance or ability to do things.

I have noticed my memory seems worse and my thinking has changed.

I have noticed my mood has changed lately.

I'd like to discuss my pain and if there are any alternatives to treatment.

I have noticed that my sexual function has changed.

I have noticed my bladder and bowel function has changed.

Are my new symptoms a relapse?
How do I know if I am having a relapse?

My overall health

I'm thinking about family planning, what do I need to consider?

What is the latest information on the best diet for MS?

What exercise should I do and how much?

Should I take vitamin D and how much?

Where can I get useful information about alternative treatments and options for MS?

Are there any other lifestyle changes I should make?

MS and work

Do I have to tell my employer I have MS?

Disclosing a diagnosis of MS is a very personal choice and the decision will depend on a variety of factors.

You are required to disclose your diagnosis of MS or another neurological condition if your symptoms prevent you from completing the essential tasks inherent to your work role or present an occupational health and safety risk to yourself or others. For example, a truck driver who experiences visual disturbances or takes pain medication that can cause drowsiness would be required to disclose their diagnosis of MS to the employer as the condition may impact safety while driving. If you can maintain your work role, continue to complete the tasks required, and do not present a risk to yourself, others, or the organisation, you may choose to delay disclosure or not disclose at all.

Whilst you might not have to disclose, in some instances disclosing your condition with your employer can lead to a joint action plan where your employer can better support you at work. This might be in the form of reasonable adjustments to your work role. By disclosing you may also be eligible for funding for equipment that can assist you complete your work duties through JobAccess.

If you do elect to disclose, do not feel compelled to provide information beyond what is relevant to the workplace. For example, a discussion simply about fatigue and heat sensitivity may promote a discussion to enable you to work from home or in a cooler location.

For more advice on MS and the workplace, visit: **msplus.org.au/employment**

Diet tips and tricks

Dr Yasmine Probst

Be careful of misinformation

We are overloaded with information when we are first diagnosed, including information about what we 'should and shouldn't be' eating yet there is a lot of inaccurate information out there. We need to ensure any diet recommendations we are coming across in our research is not only coming from a credible source but also will be helpful to your specific situation and under the guidance of a medical practitioner or dietitian.

How does food link with MS?

While diet cannot cure MS, there is a lot that food does to influence the MS space. This includes symptoms such depression and anxiety, high cholesterol, body weight, inflammation, fatigue, constipation and difficulty swallowing. Nutrition also goes beyond just food and drinks. What are your food literacy skills more generally for instance? Are you familiar with the kitchen and how to prepare food? Can you afford the right foods? Do your medications impact your eating? Do you have dexterity issues that make holding utensils difficult?

Why are there no dietary guidelines for people with MS?

There is no magic bullet. If we eat a certain way, a particular symptom will not disappear but rather will have an overall benefit to our lifestyle, mental and physical health more generally. This is why there are no strict guidelines for people living with MS just yet.

To watch the full webinar or to access the MS Plus dietitian service, visit **msplus.org.au/diet**

Family camps supporting and connecting MS families

Another successful MS Plus Family Camp was held in November, with the MS Readathon-funded camps running for more than two decades for people living with MS and their families. Readathon engages kids to be part of supporting people with MS, and the camps are a great example of how the readathon changes lives.

'Our camps offer the opportunity for families to connect, have fun and be supported and support others through their experiences of being a person living with MS or a family member providing care,' says Jodi Haartsen, Executive Manager, Client Engagement & Wellbeing and camp facilitator.

The camp sites offer a beautiful setting and a range of fun activities that the kids and adults can enjoy and cheer each other on as they take on a challenge. Shared mealtimes bring people together with stories and moments that create quality connections.

'I loved that there was a shared understanding which quickly created a sense of safety and community. Other parents and the MS Plus Coordinator assisted with caring for our children when needed, which allowed my husband and I some space to split across activities when required,' one participant said.

I can't really pick one defining point, that I liked most because we adored every second. I'm so grateful that our family was chosen to attend. I wish we could all go every year!'

Jodi says, 'Our family camps are an opportunity to help strengthen relationships within the family, to provide a well-deserved break for families and create wonderful memories that strengthens the whole family's sense of resilience.

Families also have an opportunity to find out more about MS. Games and activities help to create genuine understanding for kids and help put into action what can be hard to describe in words.

'After experiencing being so alone when my MS diagnosis came through at the beginning of the pandemic, I didn't know where to turn to for support. I felt medically supported, but that was it', another participant said.

'The camp on the weekend more than made up for it. I felt so supported and cared for, educated and being amongst fellow MSers, there was a real camaraderie. I've come away feeling a lot more positive and knowing that I'm not alone on this journey. The camp is so needed for all MS families, it's a lifesaver in a lot of ways.'

For more information on upcoming camp dates and locations, visit **msplus.org.au/family-camps**

NDIS and you

NDIS Plan Funds Management — what are the options and how do you decide what is right for you

There are four ways the funds in your NDIS plan can be managed:

1. NDIA (Agency) Managed
2. Plan Managed
3. Self-Managed
4. Combination of the above

During your planning meeting you will be asked how you would like the funds in your NDIS plan managed.

Option 1: NDIA Managed

The NDIA manages ALL the funds in your plan for you.

The provider delivers the service and claims the service fee directly through the NDIA via the NDIA portal. You will not be involved in the payment process, however, you will agree to the services being provided.

Option 2: Plan Management

Plan Management is a financial intermediary service. A Plan Manager manages the financial tractions on your behalf.

The provider delivers the service and sends an invoice to the Plan Manager for payment. The Plan Manager will ensure the service is in line with the plan and NDIS Pricing Arrangement. The Plan Manager will seek payment from the NDIA and pay the provider on your behalf.

Option 3: Self-Management

You are responsible for paying service providers and all the finances associated with your plan.

The provider delivers service and sends the invoice directly to you for payment. You will make payment and seek reimbursement from the NDIA via the My Place Portal.

Option 4: A Combination

You can use a combination of the previous three options.

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**

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

	Agency Managed	Plan Managed	Self-Managed
Fees for NDIS services are paid for participant	●	●	
Participant must pay invoices and seek reimbursement			●
No invoice required	●		
Invoices are required		●	●
Invoices are recorded on participant's behalf (if required)		●	
Invoices must be recorded by participant			●
Spending is tracked for you		●	
Spending is tracked by participant			●
Only registered providers can be used	●		
Registered and Non-Registered Providers can be used		●	●
Monthly statements received		●	
Service fees in line with NDIA Pricing Arrangement	●		
Service fees in line or less than the NDIA Pricing Arrangement		●	
Service fees can be charged at any rate			●
Funding must be included in a Plan to access the funding management		●	

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** for the links

APRIL

Advanced Care Planning
Tuesday 18 April
11:00am – 11:45am AEST

Eating to Boost Brain Health and Ease Symptoms
Thursday 27 April
1:00pm – 2:00pm AEST

MAY

Time to rethink MS with neurologists, Prof Jeannette Lechner-Scott and Prof Helmut Butzkueven
Date and time TBA

What can an MS nurse do for you – all your questions answered
Date and time TBA

Podcasts on Connecting to health care Connecting online and Connecting with friends and peers to be launched in May.

JUNE

Sexual problems affecting men with MS
Date and time TBA

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

On demand webinars

Watch anytime! Email **education@ms.org.au** for the links or visit our website **msplus.org.au/resource-hub**

- Exercise and MS
- Headaches in MS
- Preparing for your medical appointment
- Nutritional facts and fallacies
- How can I support someone with a recent diagnosis of MS?
- and many more!

Podcasts

Listen anytime! Email **education@ms.org.au** for the links or visit our website **msplus.org.au/resource-hub**

- "Learn from Me" series: Being a dad with MS
- Men, MS, sex and sexuality: All you need to know
- And many more!

Also, keep an eye out for our The Heads up (for newly-diagnosed) and Symptom Hacks podcasts to be released soon!

Exercise Groups

NSW

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

Lidcombe Yoga (Chair based)
Wednesdays 10:15am
Studdy MS Centre, 80 Betty Cuthbert Dr, Lidcombe

Dance for Health (independent and chair based)
Mondays 10:30am
Studdy MS Centre, 80 Betty Cuthbert Dr, Lidcombe

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

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

Marrickville Yoga (independent)
Tuesdays 9:00am
Addison Road Community Centre, 142 Addison Road, Marrickville

VIC

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

ACT

To book, phone **1800 042 138**

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

Plus Support Coordination

Plus Support Coordination can help you help you take control of your NDIS plan and connect with the services you need to live well.

How can we help?

Our experienced Support Coordinators understand the impact a neurological condition can have on you and your loved ones. We're here to ensure your funding is going towards the things that matter to you most.

We do this by:

- getting to know what you like to do – whether it's sport, painting or family time – and look at how you can use your funds to do more of what you love
- helping you understand your plan and reports, so you can take control of your own services
- matching you with providers that align with what matters to you – such as value for money, location or neuro-knowledge
- teaching you all the practical parts of managing your NDIS plan, like signing into the portal and adding your bank details to receive funds
- staying by your side throughout your plan and plan review

Depending on where you live, we can visit you in your home, see you face-to-face at one of our wellbeing centres, or via telehealth.

We have Support Coordinators across Victoria, New South Wales, ACT and Tasmania.

Support Coordination is funded by the NDIA and needs to be included in your NDIS plan. We can help you work out if it's in your plan if you're not sure.

Call us: 1800 042 138
Email us: connect@msplus.org.au