



# MS NURSES HELP LIGHT THE WAY THIS CHRISTMAS

A diagnosis of multiple sclerosis (MS) often brings a mix of questions and uncertainty. At this pivotal moment, MS nurses are often the first to provide expert guidance and compassionate support, helping people understand their condition and plan the next steps.

Yet despite their critical role, nearly one in three Australians living with MS don't have access to an MS nurse. This gap in care represents thousands of people navigating the complexity of their MS without the support they need to live well.

MS nurses don't just provide clinical advice. They are trusted companions who walk beside people from the moment of

diagnosis, offering reassurance, validation, and a sense of connection. This kind of support can be life-changing, especially during times of transition and uncertainty.

### **Connie's Story: From uncertainty to understanding**

Connie was just twelve when her body began sending signals she didn't understand - blurry vision, exhaustion, and pain. For years, her symptoms were misunderstood and dismissed, leaving her feeling isolated and confused. By her twenties, the uncertainty had taken a toll on her mental health and self-esteem.

During a particularly long and agonising wait to see a specialist, Connie sought

support from an MS nurse. She wasn't expecting much. But what she found was transformative.

"They listened, validated my symptoms and gave me practical ways to cope," Connie recalls. "More than that, they helped me believe in myself again."



Connie and her partner in Greece

# FROM THE CEO

## ROHAN GREENLAND



As we approach the end of another big year, it's appropriate to reflect on some of the milestones that are helping propel us faster and further down the pathways to cures.

All these have been made possible with the amazing support of the MS community, including our hard-working Member Organisations, donors, supporters and partners.

In 2025, we:

- Announced \$5.7m of funding for a record number of MS research grants.
- Saw the first participants enrol in PLATYPUS, the Australian extension of the UK's cutting-edge OCTOPUS clinical trial, designed to find effective treatments for progressive MS, supported by MSWA.
- Worked with MS Canada to establish the new multi-million-dollar global MS prevention and early detection initiative.
- Released the Living Well with MS Guide at Government House in Canberra.
- Launched InforMS, a platform enabling participants with MS to track health data, share insights with care teams and contribute anonymous data to research.
- Helped drive change with six major submissions to the Federal Parliament and Government Departments and agencies, frequently referenced and influencing policy across aged care, disability and the PBS.
- Released a major new report, commissioned from the Menzies Institute for Medical Research, giving new MS prevalence and economic impact data for Australia.
- Played a significant role in the development the Neurological Alliance's new Blueprint for a national neurological action plan for Australia, launched at Parliament House in September.

- Ran, walked and rolled our way to another successful May50K, helping to raise much-needed funding to support world-class MS research.
- Commenced a major review of our highly-regarded research program to ensure that every dollar we allocate gets the best bang for your buck when it comes to achieving real and lasting progress in MS research.

As we approach stumps to another busy year, I want to pay tribute to members of our Lived Experience Expert Panel (LEEP).

Now numbering almost 60 people living with MS, the LEEP helps ensure that the lived experience voice is embedded in all we do, from research, to policy development, communications and advocacy.

A big thank you, too, to our hard-working Board Chair, George Pampacos, and all our Board directors. Individually, they are outstanding in their contribution to the MS cause. Collectively, they are stellar.

Finally, a heartfelt thank you to all in the MS community, including our wonderful MS Member Organisations, that do so much to support our research and advocacy missions.

You are engaged, committed, passionate and dedicated. Your feedback and support is greatly valued.

Best wishes for Christmas and the New Year.

We looked forward to working hard to make 2026 another big year as we collectively commit to a world without MS.

**Rohan Greenland**  
CEO, MS Australia

That single conversation marked a turning point. For the first time in years, Connie felt heard, understood and less afraid.

Today, Connie is thriving. She's studying for a PhD focused on improving the diagnostic experience for others, determined to make sure no one else endures the same uncertainty she did. But she hasn't forgotten the compassion that helped her find her footing at the scariest time of her life.

Her story is powerful—but it's not unique.

### Why MS nurses matter

The *MS Nurse Care in Australia Report* clearly shows that access to an MS nurse leads to better health outcomes, improved emotional wellbeing, and greater confidence in managing the condition. People with regular nurse contact report feeling calmer, more in control, and better equipped to live well with MS.

In fact, the report highlights just how transformative this support can be, with 78% of those who accessed MS nurse care saying it was helpful, and those with

regular contact experiencing the greatest benefits.

People with access to MS nurse care also reported slower disease progression, lower disability levels, and better quality of life.

Despite this, access to MS nurses remains uneven across Australia. For some, services aren't available nearby. For others, they simply don't know this kind of help exists. Without it, many are left to manage their MS alone.

### Investing in ms nurse care: a smart and compassionate choice

The strength of the MS nurse workforce lies not only in their clinical expertise but in their compassion. They are often the first point of contact for someone newly diagnosed, and they remain a consistent source of support throughout the journey.

For donors, investing in MS nurse care is one of the most impactful ways to improve lives today. Every dollar invested in MS nurses can save around \$13 in broader healthcare costs by helping people with MS stay well through reduced hospitalisations,

emergency visits, and reliance on higher-cost providers like neurologists and GPs. Funding an MS nurse workforce expansion isn't just compassionate, it's smart.

As MS prevalence accelerates, the role of MS nurses becomes increasingly important, not just as care providers, but as educators, advocates, and stabilising forces in a complex disease landscape. The *MS Nurse Care in Australia Report* offers compelling evidence that expanding access to MS nurse care is both clinically beneficial and economically sound.

### Help more people connect with the guiding light of an MS specialist nurse.

As we approach the festive season, it's important to remember that while many are preparing to celebrate, others are simply hoping for a calmer, easier day. For people with MS, the holidays can be a time of heightened uncertainty. The support of an MS nurse at this time can help bring comfort, clarity and connection when it is needed most.

Help light the way for Australians with MS this Christmas. Donate to the MSA Christmas appeal where your gift will help create the change needed for a future where no Australian has to face MS alone.

[www.fundmsresearch.org.au/christmas-appeal-2025](http://www.fundmsresearch.org.au/christmas-appeal-2025)



# NEW MS DIAGNOSIS GUIDELINES AIM TO DELIVER TREATMENT EARLIER AND IMPROVE CARE

The McDonald Diagnostic Criteria are guidelines to help clinicians provide an accurate diagnosis of MS. They were first developed in 2001, have been updated several times to account for new information about the disease, and were last updated in 2017.

A committee made up of 56 international experts from 16 countries, with expertise in clinical management, radiology, methodology, epidemiology and patient perspectives, came together to review and update the 2017 McDonald Diagnostic Criteria. The committee is co-sponsored by the European Committee for Treatment and Research in MS (ECTRIMS) and the National MS Society (US).

The latest update was published online in *Lancet Neurology* and two supporting papers were published in the same issue – one on imaging guidelines and another on eye tests, which help clinicians spot signs of MS in the visual system more easily.

## What has changed?

The 2025 updates include several improvements that make diagnosis faster, easier, and more accurate.

## Recognising MS earlier through MRI findings

- Radiologically Isolated Syndrome (RIS) – MS-like damage seen on MRI scans, even without symptoms, can now be diagnosed as MS if other tests support it.

## Easier diagnosis

- Clinicians no longer need to see signs of MS damage occurring over different dates (called dissemination in time).
- A single episode of symptoms may be enough for an MS diagnosis if other signs are present.
- The optic nerve is now included as a key area to check for MS-related damage.
- Optical Coherence Tomography (OCT), which is a simple eye scan, can help detect damage to the optic nerve.
- A new unified framework helps clinicians diagnose all types of MS, including primary progressive MS.
- A newer test that looks for certain proteins in spinal fluid (called kappa free light chains or kLFCs) can help confirm an MS diagnosis, sometimes without needing the older test for oligoclonal bands. This makes it easier and faster for some people to get diagnosed.

## More accurate diagnosis

- MRI scans remain the most important tool.
- New signs seen on MRI scans, like a small vein in the centre of a lesion (called central vein sign or CVS), or a dark rim around it (known as paramagnetic rim lesions or PRLs), can help clinicians feel more confident that what they're seeing is MS and not something else.
- For people over 50 with other health risks (like vascular risk factors or headache disorders), extra checks like spinal cord scans and fluid tests are recommended to confirm a diagnosis.
- Additional laboratory tests should be used for confirming diagnosis in children and adolescents.



### Why does this update matter?

Getting diagnosed with MS earlier means people can start treatment sooner, and that can make a big difference in long-term health and quality of life. The updated McDonald Diagnostic Criteria gives clinicians more tools and flexibility to confirm a diagnosis, even when symptoms are mild or unclear. This helps reduce delays and uncertainty, which can be stressful for individuals and families.

The changes also make it easier to diagnose MS in children and older adults, who may show different signs of the disease. By improving accuracy and reducing the chance of misdiagnosis, the new criteria support better care and more personalised treatment plans from the very beginning of someone's MS journey.

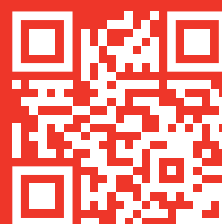
### What's next?

Clinicians can begin using the updated McDonald Diagnostic Criteria right away, as they have now been peer-reviewed and published. To support this transition, the National MS Society andECTRIMS are developing a range of educational resources. These resources are designed to help clinicians understand and apply the new criteria confidently and consistently, ensuring people with MS receive timely and accurate diagnoses.



## THE RAW NERVE

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[www.msaustralia.org.au/podcast](http://www.msaustralia.org.au/podcast)

# MENOPAUSE DOES NOT WORSEN DISABILITY IN MS



In Australian women, the average age of menopause is 51 years. With MS onset between 20 and 40 years of age, most women with MS will experience menopause while living with MS.

Smaller studies in the past have given conflicting results on how menopause affects MS. MS disability may worsen after menopause, but it has been challenging for researchers to separate the effects of menopause from the effects of ageing. Also, common menopausal symptoms such as hot flashes can be mistaken for worsening MS symptoms.

## What did the researchers do?

In a large study led by Australian researchers, 987 Australian women answered questions about their menopause status and age at menopause. Women with “relapse-onset MS” (either relapsing-remitting or secondary progressive MS) were included, and clinical data from the MSBase

registry were used to monitor disability for an average of 7 years. Researchers analysed whether menopause reduced the time to confirmed disability progression (defined as sustained increases in Expanded Disability Status Scores (EDSS) for at least 6 months), as well as the time to progress to secondary progressive MS.

## What did the researchers find?

The researchers found that menopause did not speed up disability progression, nor did it speed up the transition to secondary progressive MS.

Instead, faster disability progression was linked to being older at the onset of MS, as well as having MS for longer or a higher level of disability at baseline (“baseline” being when the first EDSS measurement was recorded). On the other hand, exposure to high-efficacy disease modifying therapies protected against disability progression.

Having more disability and having MS for longer at baseline were both associated with faster transition to secondary progressive MS, while exposure to high-efficacy disease modifying therapies was protective.

There was no difference between pre- and postmenopausal women in the speed of disability progression.

Time since menopause did not change the speed of disability progression.

## What does this mean for women living with MS?

Menopause can be challenging for many women with MS. This study reassures women that menopause does not speed up the progression of disability or hasten the transition to secondary progressive MS. These findings will help women and their healthcare providers make informed decisions about managing their health as they navigate this stage of their lives.



Kate experienced the symptoms that led to her MS diagnosis in July 2005 while travelling with her family in the UK.

In February 2006, she was diagnosed with MS and received steroid treatment in the hospital. Newly diagnosed and a year and a half into her university degree, Kate struggled to manage her MS symptoms.

“I couldn’t sit through a whole lecture because I was so dizzy, I couldn’t drive, I couldn’t work, I couldn’t walk for long periods, let alone play sports...I still lived at home with my parents, and there was no prospect of moving out with my symptoms as they were.”

Despite her difficulties navigating her MS early on, Kate sought support from her university to manage her symptoms and continue her studies. She engaged with specialists and worked towards managing her symptoms, adjusting to her new normal.

### Daily life and living with MS

Since graduating from university, Kate started her career in IT. Her position as an IT consultant is fully work from home, a change that she describes as a ‘revolution’ for her fatigue management.

To remain active, Kate has been doing yoga for 10 years and says exercise is a great way to manage her fatigue, especially when she’s experiencing an exacerbation of her MS symptoms.

“It can be incredibly hard to push myself to do exercise when I’m feeling very fatigued, but I know that once I’ve done a couple of sessions, I can start to break out of that cycle.”

### Women in STEM

A self-described ‘nerd’, Kate was drawn to work in computing from a young age.

Working and studying in a male-dominated industry, she is passionate about increasing the representation of women in STEM through mentorship and networking.

“It can be incredibly intimidating being the only woman in the room at the start of your career, and the imposter syndrome IS real, but over my 15-plus years in the industry, I’ve learnt to better trust my skills and instincts, established great working relationships with many colleagues and found support from women-focused IT community groups.”

### Being part of the LEEP

Kate joined the Lived Experience Expert Panel (LEEP) when it was first established and is an active and engaged member, bringing a range of lived experience to the panel. This includes offering insights into being diagnosed and living with MS from a young age, accessing care in a regional area and balancing professional responsibilities with disease management.

“Seeing how closely MS Australia is involving the LEEP in many aspects of design, strategy, and research makes me very optimistic for the future care and empowerment of people living with MS in Australia.”

### Support and U-turns

Kate’s hope for the future is that young people will see there is an exciting and fulfilling life to be had beyond their MS diagnosis.

“As much as it may not feel like it when you start your MS journey, there are so many things that you can do and be and create. This is not the end of your story, it’s a diversion, maybe a couple of U-turns, but your interests and passions are still the same. With a few adjustments, the things you dreamed of are still within your reach, even if it takes a little longer or the outcome looks a little different to what you’d expected.”

## MEET THE RESEARCHER

### DR DAVID STACEY

UNIVERSITY OF SOUTH AUSTRALIA



#### TELL US ABOUT YOUR RESEARCH PROJECT - HOW MACROPHAGE-DERIVED EXTRACELLULAR VESICLES HELP REPAIR MYELIN

The current project will lay the foundation for us to apply a novel human research design called 'recall by genotype' where we will look for biological differences between participants with either a 'high' or a 'low' genetic risk of MS. Whereas most MS studies in humans compare people with and without disease (often referred to as case-control studies), none of the participants in this study will have MS. This means that any differences we find between the genetic risk groups are more likely to reflect causal biology rather than biological consequences of already having MS. We will also explore potential ethical issues concerning the use of RbG in MS research and determine how best to communicate personal genetic information directly to participants.

#### WHY IS THIS RESEARCH IMPORTANT AND HOW WILL IT INFLUENCE THE UNDERSTANDING AND TREATMENT OF MS?

The RbG design is an innovative approach that, to our knowledge, has not yet been utilised in Australian research or the MS field internationally. Consequently, we expect to generate findings that will complement those from other approaches (e.g., animal, human cell culture) already being applied in the MS field.

Moreover, human studies leveraging genetic data have been extremely useful in disentangling causal from other (e.g., correlated, consequential) disease mechanisms, so the findings from this and subsequent studies have the potential to inform MS treatment and/or prevention. Since we will compare the levels of >1,000 proteins between the two MS genetic risk groups, this project may also highlight novel early MS biomarker candidates.

#### WHAT DO YOU ENJOY MOST ABOUT WORKING IN THE LAB AND WHAT ARE SOME OF THE CHALLENGES YOU FACE?

I most enjoy the problem-solving aspects of research, particularly the process of uncovering the biology underlying genetic discoveries. This is a huge challenge because genetic discoveries only tell us which regions of the genome are associated with human diseases and traits, not 'how' they are associated. The 'how' is crucial if we hope to translate genetic discoveries into clinically useful biomarkers, treatments, or preventive measures.



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