

FOUNDATIONS OF NURSING

PART 5 THE ROLE & IMPACT OF MS NURSES



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Course presenters

Dr Therese Burke, Registered Nurse - MS Specialist

Australia Adjunct Senior Research Fellow, School of Nursing, University of Notre Dame, Sydney Campus



Dr Therese Burke is an internationally dual certified in Multiple Sclerosis (MSCN) and Rare Neuroimmunological Disorders (CRND) and is currently an Adjunct Senior Research Fellow in the School of Nursing at The University of Notre Dame, Sydney, Australia where she continues to be involved with neuroimmunological research.

Therese's post-doctoral research explored the skillsets, support and education of Multiple Sclerosis (MS) Nurses and focused on defining the role in Australasia. She is also active nationally in research and education for MS Nurses Australasia (MSNA Inc) and internationally as part of the International Organisation of MS Nurses (IOMSN). Therese has extensive research experience in many aspects of MS, particularly in understanding the lived experience and identifying ways to improve the quality of life and healthcare experience for people living with MS, as well as in clinical drug trial project management and investigator initiated clinical research.

Therese was awarded a Member of the Order of Australia (AM) in the 2023 Australia Day Honours list for significant service to medicine, particularly to MS research and to nursing. Therese is the current MS Nurse International Leadership awardee, an IOMSN International Nightingale recipient for 2025 and has recently been a member of the international working group to review MS Brain Health guidelines.

Therese is a member of the MS Australia [MS Nurses Working Group](#).

Belinda Bardsley, Registered Nurse - MS Specialist

Manager, N-CRESS at Austin Health, Melbourne



Belinda works in both a clinical role as a MS nurse and in research management, overseeing MS clinical trials at a Victorian hospital. Belinda has been working with people living with MS for more than 18 years and supports them from the time of diagnosis and helps them to understand the unique complexities and challenges of MS.

Belinda manages a team of MS nurses who provide support to people living with MS and specialist MS Nurse education through preceptorship programs for new MS Nurses and by helping them develop a broader understanding of MS care and clinical trials skills by providing training by observation in their large multidisciplinary clinic.

Belinda works closely with other services, general practice, local community, national and international partners. As part of her role Belinda is actively engaged in MS research including management of the research program and oversight of clinical trials. Belinda has also been involved in research that explores the delivery and value of MS nurse care in Australia and is a co-author of the [MS Nurse Care in Australia Report](#).

Belinda was the recipient of MS Australia's [2025 MS Advocacy Award](#), recognising her more than 18 years of contribution to improving MS care through clinical leadership, education and national advocacy focused on better outcomes for people living with MS.

Belinda is the Chair of MS Australia [MS Nurses Working Group](#).

Session overview

In this session you will learn about:

- The Role and Impact of MS Nurses
- The Unique Position of MS Nurses in Patient Care
- Addressing Patient Vulnerability and Psychosocial Support
- Career Opportunities and Development for MS Nurses
- Running Effective MS Clinics and Advocacy
- Self-Care and Professional Support for MS Nurses

The role and impact of MS Nurses

Working as a MS Nurse can be a deeply rewarding experience. MS Nurses work with people who are diagnosed with MS at a time when they are actively building their lives, careers and families. They are trying to navigate a diagnosis and a disease that has an unpredictable course and no cure.

MS Nurses provide a bespoke, individualised approach and build long term relationships with their patients over many years.

Case studies – The benefits of accessing a MS Nurse

MS Nurses can be critical to changing a person's experience and outcomes. The following two case studies show how early access to an MS Nurse can significantly change outcomes for people with MS.

Case study - Clare

Clare first noticed mild foot weakness at age 28 while travelling overseas but dismissed it and continued travelling.

A year later (2008) she developed bilateral leg weakness, prompting a medical review. An MRI showed demyelination and she was diagnosed with relapsing–remitting MS by a private neurologist. Unfortunately, the neurologist was not connected with a MS Nurse.

Although Clare likely received information at diagnosis about relapses, she was overwhelmed and may not have absorbed key messages.

In the years following her diagnosis, Clare:

- Experienced multiple relapses (including episodes of leg weakness, vision loss, sensory change and periods when she could not walk and had to crawl).
- Did not understand what constituted a relapse and didn't share any details of these symptoms with her neurologist.
- Was placed on a low efficacy therapy by her neurologist.
- Disliked and avoided MRI scans.
- Did not have the support of an MS Nurse and did not receive ongoing, repeated education about monitoring and recognising relapses.

Ten years after diagnosis (2018), she attended Belinda's hospital seeking to be part of a clinical trial. At age 39 her disability had progressed substantially with an EDSS score of 5.5, she can walk only 120 metres unaided and needs a wheelchair for longer distances. She also dropped out of the workforce.

The case illustrates how the absence of MS Nurse involvement may lead to missed opportunities for early treatment, close monitoring, timely MRI surveillance, relapse education and support – key elements of a brain health approach aimed at preventing disability progression.

Learn more about EDSS Scores in Part 2: The Nuts & Bolts of MS

Case study - Steph

Steph developed early MS symptoms in April 2015 at age 22 while studying and working. She initially ignored left leg pins and needles, but over the next year her symptoms progressed, including sensory changes extending up the body.

After an MRI, Steph was diagnosed with MS by a private neurologist and commenced on a low-efficacy therapy. A key difference in Steph’s journey was that the prescribed therapy came with an MS Nurse attached to the treatment program.

In the months following diagnosis:

- The MS Nurse provided home-based injection training and continued to check in with Steph to ensure she was coping.
- The MS Nurse recognised that Steph was experiencing ongoing relapses and recommended a referral to a specialist MS nurse service at Austin Health.
- Steph’s referral was triaged by the team at Austin Health, and she was seen within a week.
- The team initiated a high-efficacy therapy while Steph was still relapsing (around five relapses in five months, including a severe cerebellar relapse with vomiting, vertigo and significant illness).
- After starting high-efficacy treatment, her disease activity was effectively switched off and she returned to feeling well, with a markedly improved trajectory.

Ten years later (October 2025), Steph is 32 with minimal disability (EDSS 1). This case highlights how MS Nurse involvement – through education, monitoring, triage and timely referral – can accelerate access to appropriate specialist care and treatment escalation, substantially improving long-term outcomes and helping prevent disability progression.

Learn more about triaging referrals in Part 2: The Nuts & Bolts of MS

Compare the pair

Both case studies outlined above involve women diagnosed in their twenties while living life to the fullest. After diagnosis they both commenced a low-efficacy interferon beta-1a therapy.

One person was given access to a MS Nurse and other was not. Ten years into their MS diagnosis their trajectories are starkly different:

CLARE	STEPH
<ul style="list-style-type: none"> • No/low-efficacy therapy for 9 years • Insufficiently educated about MS • Did not report MS relapses • Few & irregular MRIs • Continued largely unmonitored with no MS Nurse • EDSS 5.5 	<ul style="list-style-type: none"> • High efficacy therapy soon after diagnosis • Provided with support, education & information • Regular reviews and monitoring • Regular MRIs • Had MS Nurse to contact with concerns • EDSS 1

Important learnings

There are some important learnings from these two case studies that MS Nurses can take into their work:

- The MS Nurse is critical to changing a person's life trajectory. Nurses can build trust and strong relationships with patients.
- Access to education and information at time of diagnosis is crucial, especially for people with poor health literacy.
- MS Nurses have more time with patients and can provide a repetition of information at milestone moments (disease escalation, relapses, family planning) and throughout the MS trajectory.
- MS Nurses are skilled at picking up on subtle cues, understanding patients and providing an individual tailored approach.
- MS Nurses can help people understand the importance of therapies, other treatments and all the other things they will go through while living with MS.
- Neurologists are often time poor and cannot provide the education and monitoring role that MS Nurses can. Patients may also be reluctant to 'bother' the neurologist and not raise issues.
- Patients are often more comfortable disclosing sensitive and emotional information to a MS Nurse.

Clinical trials

Clinical trials help to determine if a new drug, or other interventions such as surgery, physiotherapy or psychological support, is safe and effective.

For people with MS, participating in clinical research may provide early access to new treatments and an improved quality of life. Clinical trials may offer hope when there are no other options, especially for people living with PPMS.

MS Australia Clinical Trials Network

The MS Australia Clinical Trials Network was established to facilitate the clinical trials process for MS in Australia and New Zealand and increase awareness and access to clinical trials for people with MS and other demyelinating diseases.

MS Nurses and their patients can use the network to explore current MS clinical trials identify a study that might be recruiting in their state or territory. MS Nurses can also learn of clinical trials requiring sites and access the expertise through the MS Australia Clinical Trials Network Executive Committee.

[Learn more about the MS Australia Clinical Trials Network](#)

Trial.Smart Program

The Trial.Smart program is a series of nine modules for people living with MS and their communities to raise awareness of and provide education about clinical trials in Australia. The modules are between 20 and 30 minutes long each, involve a story book and interviews with experts, and are designed to be engaging and conversational.

[Access the Trial.Smart Program](#)

Case studies – The benefits of MS Nurse relationships

MS Nurses can have a huge impact on a patient's wellbeing, even with small acts of kindness or understanding. MS Nurses build a trusting relationship with patients and are given privileged information which allow them to offer personalised care and support for each patient.

Below are some examples of the extremes where this can work:

Case study 1

The patient was a motorcyclist who had originally injured his leg in a motorcycle accident. He put his initial symptoms down to ageing and the accident. Eventually, he was diagnosed with PPMS.

He didn't want to bother his mother, and he didn't have a lot of other support systems in place. He only told the nurses at the MS clinic:

'I didn't want to worry Mum, so you guys are the only people I've ever told I have MS'

The patient attended the clinic for a clinical trial on his birthday. The MS Nurses presented him with a birthday cake and sang 'Happy Birthday'. The patient was overwhelmed and burst into tears.

These small acts of kindness from the MS Nurses were a crucial support for a patient who was very isolated and lonely.

Case study 2

The patient had a suspicious radiological fracture, and her neurologist spoke to her about it. The neurologist spoke to the patient to get a better understanding of how the fracture came about because it didn't match the kind of slip she said she'd had.

When the MS Nurse spoke to the patient she opened up and admitted the fracture occurred in an act of family violence:

'If I tell you what really happened, will you promise not to tell my father?'

In this case, because of the trust and rapport built with the MS Nurse, the patient felt safe to disclose.

MS Nurses should be aware of the potential red flags and cues that patients may display and what to do if they are disclosed.



IOMSN has reviewed this project that was developed by Therese Burke as a resource for MS Nurses. IOMSN has concluded that this project is fair balanced and accurate and is valid for educational purposes.

What to love about being an MS Nurse

There is a lot to love about being a MS Nurse and it can be a rewarding and empowering career, including:

- **Privileged role:** Access to privileged information means nurses can make a difference in people's lives.
- **The wins:** MS Nurses will see wins in clinic all the time!
- **Happy times:** Nurses are there for the happy times in patients' lives including blossoming relationships, weddings and babies.
- **Constant evolution of treatments:** Ongoing research continues to transform MS care and improve outcomes.
- **Continual learning**
- **Unique and autonomous role:** MS nurses have a unique capacity to influence care and outcomes.
- **Streamline & escalate:** MS Nurses streamline care and escalate concerns when required, making a significant difference for people with MS.
- **Avoid the need for unnecessary medical intervention:** Early support and monitoring can prevent avoidable complications and presentations.
- **Empowerment:** MS Nurses empower patients to live well with MS.

Most importantly, the role of the MS Nurses changes the trajectory of the disease for their patients.

[Learn more about empowering your patients in Part 4: Embedding Empowerment](#)

Career opportunities and development for MS Nurses

There are a range of diverse career pathways for MS Nurses, including:

- **Management:** a role managing a team of MS Nurses that can still include patient contact.
- **MS Nurse led clinics:** working in a clinic led by MS Nurses based at hospitals, community services and/or a travelling clinic that visits rural and remote areas.
- **MS Nurse Practitioners:** MS Nurse Practitioners can provide additional care including assess, plan and treat, prescribe (some) therapies, order pathology and some radiology.
- **Clinical Trials:** MS Nurses can play a critical role in the delivery of clinical trials and advancement of MS research.
- **Nurse led research:** Nurses can do research in a range of areas from a quality improvement activity to projects with nurses across the country and globally.
- **Disability service:** MS Nurses can support people with MS in navigating progressive disability, service access and long-term support needs.
- **Area of interest:** Some nurses specialise in a particular symptom or area of MS (e.g. continence, sexual health).
- **Other settings:** This includes infusion centres, home care and private neurology clinic nurses.
- **Travelling:** MS Nurses can visit other areas/centres and see how other MS nurses work including undertaking preceptorship programs.
- **Get involved:** Join MS Nurses Australasia (MSNA) including being a state representative or joining the Executive Committee. You can also get involved with the International Organization of Multiple Sclerosis Nurses (IOMSN).

[Learn more about the work of MSNA and how to become a member](#)

[Learn more about the work of IOMSN and how to become a member](#)

Running a quality clinic

Here are some tips for setting and running a quality MS Nurse clinic:

- **Think laterally:** The most effective solution may be more administrative support, such as help with phone calls and clinic bookings.
- **Be clear and assertive about your role:** Ensure your organisation understands the scope, value, and impact of the MS Nurse role, and actively supports and champions it.
- **Advocate for resourcing:** Lobby for appropriate workplace conditions, including adequate FTE and secure positions. The MS Nurses Working Group continues to advocate more broadly with governments and funders.
- **Use the evidence:** The [MS Nurse Care in Australia](#) report outlines how MS Nurses improve health outcomes and provide economic benefits – use this to support local advocacy.
- **Build a business case:** MS Nurse Business Case templates can help support proposals for additional roles or service expansion. If you need assistance, reach out to the MS Nurses Working Group.
- **Learn from others:** Visit other centres for ideas and inspiration, including through preceptorship opportunities.
- **Plan for sustainability:** Explore long-term, viable service models and reach out to other MS Nurses to share approaches and lessons learned.
- **Clinical research:** Explore whether involvement in clinical research is feasible within your service.
- **Nurse-led clinics:** Consider establishing a nurse-led clinic to support sustainable funding models and streamline care.

[Access the MS Nurses Business Case](#)

MS Nurse Care in Australia Report

The *MS Nurse Care in Australia Report* by MS Australia, in collaboration with the Menzies Institute for Medical Research and MSNA, explores the patterns of access to MS Nurses in Australia and the impact on health outcomes for people living with MS.

The report found that the number of MS Nurses is declining, and one-third of Australians living with MS (equivalent to 8,000 people) do not have access to life-changing MS Nurse care and have consistently worse health outcomes. Access is even worse for those living in outer regional, remote, or very remote areas, with almost half having no access to MS Nurse care (48.8%).

MS Nurses are a highly cost-effective model of care. MS Nurse care reduces the need for other, more costly health professionals, such as GPs and neurologists and prevents unnecessary emergency department presentations and potentially, unplanned hospital admissions. It is a highly cost-effective model of care.

If every Australian with MS had access to MS Nurse care as part of their ongoing MS management plan, this would result in substantial cost savings for MS healthcare in Australia. It would significantly delay disease progression and contribute to an increased quality of life. There are further savings from a reduced reliance on disability, aged care and community supports.

The report made the following recommendations:



Raise awareness of the existence of MS Nurses, their value, and the supports and services they provide to people with MS and health practitioners



Assist the existing MS Nurse workforce through mentorship and preceptorship, connecting and educating existing MS Nurses and exploring opportunities within university nursing courses to include education about MS Nursing and MS Research Nursing



Increase the number of MS Nurses in Australia by targeted advocacy and assessing the current funding arrangements



Increase access to MS Nurses through expanding telehealth services and advocacy to the Australian Government

MS Nurses working group

In September 2022, MS Australia established the MS Nurses Working Group to implement the MS Nurse Care in Australia Report recommendations and improve access to MS Nurse care.

You will see Working Group members Belinda, Therese, Tim and Sharon as presenters through the course.

[Read the full MS Nurse Care in Australia Report](#)

[Find out more about the MS Nurses Working Group](#)

Self-care for MS Nurses

People with MS will reach out to the people that are there to help them, but it can sometimes be a real burden. It is important for MS Nurses to look after themselves and practice the following:

- Set boundaries and focus on the things you can do and remember that you cannot fix everything.
- Don't be a martyr to the role.
- Don't undervalue your intellectual property.
- You are not alone, even if you're working independently. Reach out to other MS Nurses.
- Don't reinvent the wheel - there are many MS Nurses around Australasia that have created many useful tools, tips and templates that can be used and they are happy to share. Reach out to MSNA for some support in your area.
- When you're ready, give back, for example, through volunteering with MSNA.
- Practice what you preach e.g. brain health.

Conclusion

MS Nurses are central to MS care – providing timely education, continuity, monitoring and psychosocial support that can meaningfully change a person’s disease pathway. The case studies in this session show that early access to an MS Nurse helps people recognise and report relapses, engage in regular review and MRI surveillance, and move quickly to appropriate therapy, with the potential to prevent avoidable disability progression.

Beyond clinical management, MS Nurses build trusted relationships that enable people to disclose sensitive concerns, reduce isolation, and feel safe and supported across life milestones. MS Nurses also strengthen services by improving triage and coordination, supporting access to clinical trials and emerging therapies, and advocating for sustainable clinic models and resourcing.

There are many career opportunities and development for MS Nurses across their careers and a lot to love about the unique and reward careers that MS Nursing offers. Finally, it is important for MS Nurses to set boundaries, seek peer support and supervision, and practise the same self-care and brain health principles they promote to patients.



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