# FOUNDATIONS OF MS NURSING

## PART 3
## THE RESCUE MISSON

MS AUSTRALIA

MS Nurses Australasia Inc

IOMSN
International Organization of Multiple Sclerosis Nurses

# Contents

# Course presenters

## Karina Dodd, Registered Nurse – MS Specialist

*MS Nurse, Central West Neurology and Neurosurgery in Orange, NSW*

Karina Dodd is a MS Nurse based at Central West Neurology and Neurosurgery in Orange, NSW. She has a background in midwifery and holds a Master of Nursing and a Master of International Public Health. She has worked as an MS Nurse since 2021.

In her role, she supports people living with MS across the Central West, a large rural and remote region where many face significant barriers to accessing healthcare. She is currently coordinating a study called REACH-MS, which aims to improve access for regional and rural people with MS through digital resources and education.

Karina is passionate about supporting people to make informed decisions about their healthcare and is committed to improving equity in access to MS care. She is proud to be part of MSNA, a network of nurses dedicated to enhancing the lives of people living with MS through expert care, education, and advocacy

## Tim O'Maley, Nurse Practitioner – MS Specialist

*Nurse Practitioner, Queensland Health & Administrative Secretary MSNA*

Tim was one of the first MS Specialist Nurses and the first MS Nurse Practitioner in Australia. He works as a MS Nurse Practitioner across two Queensland hospitals with his MS nurse-led and patient-focused clinics.

Tim provides nursing services to patients from the time of diagnosis and across their life span and has worked with some patients for over 20 years. He works with a range of other clinicians including Neurologists, GPs, nurses and allied health.

As a nurse practitioner Tim provides patients with a wide range of services including assessing, planning and treating MS symptoms, prescribing (some) symptomatic therapies and ordering pathology and some radiology.

Tim further contributes to the work of MS nurses through support, mentoring and education for other MS nurses and pioneering the development of web-based education for people living with MS.

Tim is a member of the MS Australia MS Nurses Working Group.

**Introduction to Part 3 is provided by Dr Therese Burke**, Registered Nurse MS Nurse Specialist & Adjunct Senior Research Fellow, School of Nursing, University of Notre Dame, Sydney Campus

## Session overview

In this session you will learn about:

- Disease modifying drugs (DMDs)
- Autologous haematopoietic stem cell transplant (AHSCT)
- Complementary therapies
- Shared decision making

## Diversity of people living with MS

All people with MS are different. Each person has their own symptoms, background, values and lifestyle. These differences matter when talking about DMDs.

MS Nurses may meet people at many stages, such as before diagnosis, soon after, or years later. People respond to MS in different ways. Some feel angry, some deny it, some search for lots of information, and others accept it or become strong advocates.

The emotions and behaviours of people living with MS can change over time. The key role of the MS Nurse is to build a trusting relationship, understand the person, and guide DMD discussions in a supportive and flexible way.

We do note / acknowledge that many publications and resources will refer to these medications as DMT's (disease modifying therapies or treatments). We have chosen to refer to them as DMDs to separate medication from other therapies / treatments which include anything from complementary therapies and supplements to diet choices, exercise and allied health interventions.

## Disease modifying drugs

**Disease modifying drugs (DMDs)** are also known as immunotherapies. They modify immune system activity to reduce the frequency and severity of attacks on the brain and spinal cord. These medications are most commonly prescribed for relapsing remitting MS, where they have been shown to have the greatest impact.

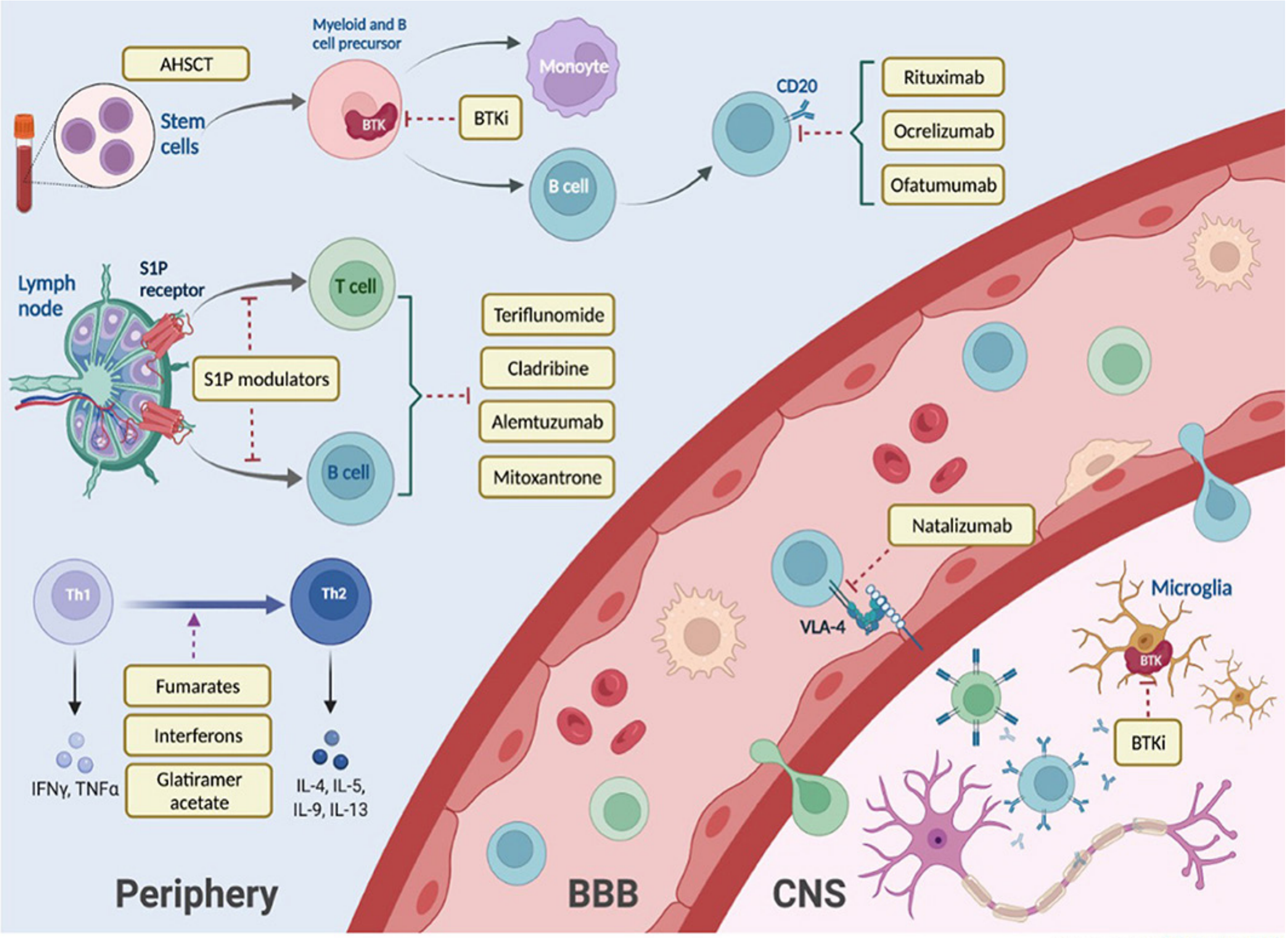
### History of DMDs

In the last 30 years, treatment for MS has improved considerably. In the past, steroids were often the first option and care mainly focused on managing symptoms. Today, people living with MS have many more choices, including DMDs that can help control MS and make it less unpredictable.

The first DMD was listed on the PBS in Australia in 1996 and in New Zealand, Pharmac approved the first MS treatments in 2000.

Even now, no treatment is perfect. Nothing can stop relapses 100% of the time, and treatments cannot reverse disability that has already happened. Because every person with MS is different, the best plan is one that fits the person's health needs, lifestyle, and preferences.

## Immunotherapy for MS through the years



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## MS disease modifying drugs

Each MS Nurse works in a different environment including hospitals, community settings and in urban vs regional or rural locations. MS Nurses should determine the best course for a patient in consultation with each individual patient.

The DMDs discussed in this session are used as maintenance escalation therapies or immune reconstitution therapies. These treatments can be given either orally, via injection or as an infusion therapy.

### Maintenance escalation therapies

Maintenance escalation therapies for MS are administered continuously without interruption and can vary in frequency from daily to every six months. Their primary goal is to induce long-term remission, but disease recurrence often necessitates treatment changes. These therapies include interferons, glatiramer acetate, natalizumab, S1P modulators, and anti-CD20 therapies.

### Immune reconstitution therapies

Immune reconstitution therapies aim to reset the immune system by reducing autoimmune cells and allowing healthy cells to repopulate without autoimmune activity. Examples include alemtuzumab, cladribine, and autologous haematopoietic stem cell transplant (AHSCT). These treatments provide a ‘reboot’ of the immune system to achieve long-term disease control.

### DMDs in Australia & New Zealand

As of 2026, there are 14 DMDs funded under the PBS in Australia and 8 DMDs funded under Pharmac in New Zealand.

**Read more about the DMDs available in Australia**

**Read more about the DMDs available in New Zealand**

In 2025, Monash University led the development of the **Consensus recommendations on multiple sclerosis management in Australia and New Zealand: part 1** to guide best practice MS management in Australia and New Zealand. The guidelines provide evidence-based information to inform healthcare professionals and people living with the disease.

**Read the full Consensus Guidelines**

**Listen to a podcast about the consensus guidelines**

## Choosing a disease modifying drug

### Role of the MS Nurse

MS Nurses play a critical role in the use of DMDs by people with MS including:

- Providing individualised patient education,
- Organising continuous treatment (whether via infusions or prescriptions),
- Monitoring patients through blood tests, MRIs, and follow-up consultations, and
- Providing patient advocacy.

Building a trusting relationship with patients with MS is essential, especially given the uncertainty around the best treatment for each individual, which often involves trial and error. Patients should be empowered to communicate openly about side effects or DMD treatment fit issues, and MS Nurses must be flexible in advocating for patient preferences even when these differ from initial medical recommendations.

Conversations about MS and its treatments can be challenging for some patients. Patients may be at various stages of their disease journey, with differing levels of knowledge and comfort regarding treatments. Some may come well-informed, while others prefer minimal information.

### Contraception & family planning

It is important to tailor communication to individual needs, including discussing contraception and family planning explicitly and sensitively. Specific questions about contraception use are necessary to ensure safety when starting DMDs.

Family planning is a critical consideration in MS care, as the disease predominantly affects women in their prime reproductive years. Evidence suggests women with two or more children tend to have better MS outcomes[1]. Despite this, some patients receive discouraging advice about pregnancy.

MS Nurses should support patients' reproductive choices, provide information on DMDs that are safe during conception and pregnancy, and develop plans for medication adjustments if pregnancy occurs unexpectedly. This support helps normalise family planning as part of living with MS and can reduce patient anxiety.

## Treatment decision factors & patient education

Treatment decisions vary widely based on disease activity, patient age, family planning, lifestyle, side effects, risks, and logistical considerations. Neurologists may offer options or direct treatment plans, and patients' readiness to engage with medical information differs.

Educating patients about treatment options should be personalised, using diverse methods such as conversations, printed materials, emails, or follow-up calls. Ongoing education is important as patients' circumstances and preferences can change over time

## Risks of untreated MS

Untreated MS can lead to progressive physical disability, cognitive impairment, reduced quality of life, relationship difficulties, unemployment, and shortened life expectancy by 6 to 8 years. DMDs aim to delay or prevent disability and improve long-term prognosis, although predicting disease course remains challenging. A patient's reasons for declining treatment, such as risk aversion or comorbidities, are valid and must be respected.

## Side effect management

Side effects are an inevitable part of DMDs, and their management requires honest communication and individualised approaches. A patient's tolerance for side effects varies, influenced by treatment frequency and severity.

MS Nurses should regularly assess side effects, provide reassurance when symptoms are typical, and explore alternative treatments if side effects significantly impair a patient's quality of life.

Early treatment phases may worsen some MS symptoms temporarily due to immune system adjustments. Support from MS Nurses and infusion teams is vital, and misinformation from social media should be addressed cautiously.

### Scenario 1

*A patient calls you three weeks after starting their DMD saying 'I feel awful, I want to stop'.*

The MS Nurse needs to talk with the patient and explore why they are saying this. Here are some things to consider:

- What are side effects that they experiencing? Can these be managed?
- Can you give them the reassurance that what they are feeling is not actually unusual at this point in time?
- Did they understand everything about the DMD when you first spoke about it? You might have to provide more information about the DMD and discuss if this really fits with their lifestyle
- Has the DMD had an impact on their immune system? For example, do they have a bladder infection?
- Is there currently very hot weather that could be impacting them?
- Is there another medication they are meant to be taking alongside the DMD? Are they taking that?
- What else is going on in their life? Stress, anxiety and depression can have a real impact on people living with MS. What lifestyle changes can you recommend?
- Are they having any other issues with symptoms that are not related to the DMD?
- Do they need referral to any other members of the healthcare team?

It is important not to dismiss the person's feeling and deal with their individual situation. Most of all they are seeking reassurance from their MS Nurse. Remember to follow up to see how the patient is going after this initial conversation.

**Learn more about symptom assessment & management in Part 2: The Nuts & Bolts of MS**

## Generic medications

The MS treatment landscape is continuously evolving and there are an increasing number of generic DMDs available for people with MS.

Generic medications contain the same active ingredient as the brand name medication and are to be taken in the same dose and frequency as the brand name medication.

Generic medications can become available when a brand-name medication's patent protections have expired. The original brand product has a certain patent life and after this ends, other manufacturers can apply for a license to manufacture and market a generic version. These generic versions must meet the same standards of quality, safety and effectiveness as the original brand.

## Biosimilar medications

Biosimilar medications are highly similar versions of original biologic drugs. While biosimilars are not exact copies, they are designed to be as close as possible in terms of safety, effectiveness, and quality. A biosimilar will have the same type of active ingredient as the original drug.

Due to the complexity of biologics, creating an exact replica is challenging, but biosimilars undergo rigorous testing to ensure they perform similarly to the original product. They must also get approval from the relevant Regulatory Agency (such as PBS or Pharmac)). This means that a person living with MS should have the same clinical response to the biosimilar as they would to the original treatment.

## Steroids

Steroids (also known as corticosteroids), once a common treatment for MS relapses, are now used more sparingly and primarily for significant relapses affecting vision or mobility. They help reduce inflammation at the affected site, providing symptom relief. Taking steroids will not have any impact on a patient's level of recovery from a relapse or the long-term course of their MS.

Methylprednisolone is the most common form of steroid and can be taken as tablets or by intravenous infusion (drip) over a number of days. Not everyone experiences side effects when taking steroids, however some patients may experience a metallic taste, indigestion, difficulty sleeping, mood swings or altered mood and flushing of the face.

It is important to explain to the patient the benefits and potential side effects of taking steroids and support them in deciding the best course of action.

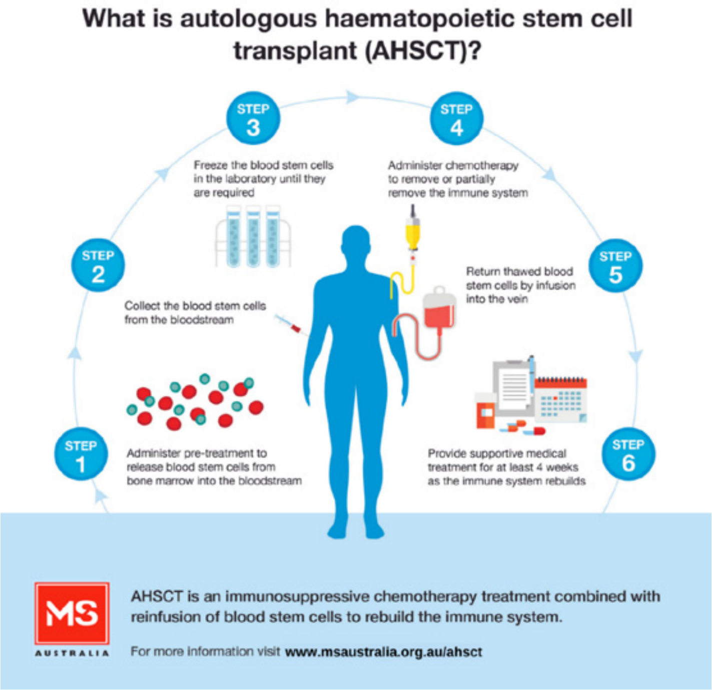
## Stem cell transplants for MS

Autologous haematopoietic stem cell transplant (AHSCT) is a potent immune therapy that can induce sustained remission in some MS patients who have failed other DMDs. The procedure involves harvesting the patient's blood stem cells, administering high-dose chemotherapy to ablate the immune system, and reinfusing the blood stem cells.

AHSCT carries potential serious risks, although treatment-related mortality and complications have reduced substantially with improved patient selection and protocols. In Australia and New Zealand, access remains limited and is typically provided through specialised centres with defined eligibility criteria.

Some patients may choose to travel overseas for AHSCT, particularly if they do not meet the inclusion criteria to undergo the treatment in Australia or New Zealand and may be reluctant to disclose this to their healthcare team. AHSCT is a complex medical procedure requiring significant follow-up care both in the immediate weeks following treatment and longer term. It is important that the patients feel supported by their MS Nurse to disclose and reassured that they will be provided with ongoing care.

**Read more about AHSCT and where to access it in Australia**



What is autologous haematopoietic stem cell transplant (AHSCT)?

AHSCT is an immunosuppressive chemotherapy treatment combined with reinfusion of blood stem cells to rebuild the immune system.

For more information visit **www.msaustralia.org.au/ahsct**

## Complementary and alternative therapies

Complementary and alternative therapies are important adjuncts to MS management, supporting a multi-pronged, long-term approach. Patients often use these therapies to gain a sense of control and improve wellbeing.

Common evidence-based recommendations include diet changes, regular exercise, smoking cessation, mental health awareness, and mindfulness practices such as Tai Chi, yoga and Pilates.

There are a range of complementary and alternative therapies that have no evidence base for MS, however, they may provide some relief for patients. It is important that patients are aware of the risks associated with therapy and the impact on their MS symptoms, MS treatments and comorbidities.

Most complementary therapies are compatible with DMDs. MS Nurses should discuss complementary and alternative therapies openly to build trust and guide patients towards evidence-based options while recognising some unproven or expensive treatments are self-limiting.

**Complementary therapies** are a range of approaches to care aimed at enhancing quality of life and improving wellbeing, that are generally used in conjunction with conventional medical treatments.

**Alternative therapies** are treatment options outside the orthodox range, that may be used in place of conventional treatments.

### Living well with MS guides

Originally developed in 2020, MS Australia updated the *Living Well with MS* guides to incorporate new wellness content supporting people living with MS to make informed lifestyle decisions that promote better health and wellbeing and support day-to-day living with MS.

These resources include two guides – one for people living with MS and one for health professionals – informed by the latest research and real-life experience.

The guide for health professionals brings together the latest evidence on modifiable lifestyle factors in MS, offering practical insights and evidence-based interventions to support MS management, clinical conversations, and shared decision-making to improve health outcomes for people living with MS.

**View the guides**

**Learn more about modifiable lifestyle factors in Part 4: Regaining Control**

## Shared decision making in MS care

Shared decision making is a collaborative process between patients and healthcare teams to select appropriate treatments. It requires understanding the patient's priorities, lifestyle, and preferences, such as medication administration methods and timing.

Overwhelming patients with excessive information should be avoided and instead the MS Nurses should tailor discussions to help narrow treatment options. Ongoing feedback and support are crucial as patients' needs and decisions evolve over time.

Respecting patients' choices, including breaks from medication or preference for natural approaches, is essential, as is clear communication about the long-term goals of therapy.

Remember that the words you use with patients matter. 'Treatment', 'therapy' and 'medication' can mean different things to different people. For example, a patient might not be taking a DMD, but they are actively managing their MS through exercise, nutrition, and other strategies – for this patient they are on a 'therapy'. Always use language that respects the patient's choices and keeps the person at the centre, letting their priorities guide conversations and recommendations.

### Scenario 2

*A patient tells you they want to stop their DMD and try natural approaches because they're worried about the side effects.*

To approach this conversation using the principles of shared decision making, the MS nurse can start with the following discussion questions:

- Why do you want to stop the medication?
- Are there side effects that we haven't address properly for you?
- Is the medication still fitting with your lifestyle?

Important things to consider in the conversation:

- Make the patient feel respected and assure them that if they absolutely need to stop the DMD, they will be supported to do this
- Is there information you can give on the DMD to support their decision? For example, is this is a medication you can take a break from without a lot of risk?
- Are there things that were not considered when the medication was first administered that should be addressed now?
- Is there an alternative DMD that would better suit them? For example, do they want a DMD that is delivered every six months instead of every month?

**Shared decision-making is about respecting the person and their choices.**

## Conclusion

MS treatment is complex, and the best care is always individualised. Across the MS journey, nurses play a central role in building trust, providing tailored education, organising and monitoring the use of DMDs, and supporting people to manage side effects and uncertainty.

This session has outlined the current treatment landscape, including maintenance and immune reconstitution therapies, alongside the use of steroids for significant relapses and the value of complementary strategies that support wellbeing. Above all, effective care relies on shared decision-making, listening first, matching information to the person's readiness, and balancing benefits, risks, lifestyle and family planning considerations.

Finally, the language we use matters, using respectful, person-centred wording helps protect trust, acknowledge the work people already do to live well with MS, and keeps their priorities at the centre of every conversation.

## Reference

1. Ponsonby, A.L., Lucas, R.M., van der Mei, .IA., Dear, K., Valery, P.C., Pender, M.P., Taylor, B.V., Kilpatrick, T.J., Coulthard, A., Chapman, C., Williams, D., McMichael, A.J., Dwyer, T.. Offspring number, pregnancy, and risk of a first clinical demyelinating event: the AusImmune Study. *Neurology*. 2012 Mar 20;78(12):867-74. doi: 10.1212/WNL.0b013e31824c4648.

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.