

Brain health in multiple sclerosis

A nursing resource

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This guide explains how nurses can put into practice the recommendations from the report *Brain health: time matters in multiple sclerosis*, which can be found at www.msbrainhealth.org/report.

As of 22 August 2018, the full report has been endorsed by the following organizations. Endorsements received since this date can be found at www.msbrainhealth.org.

- Accelerated Cure Project for Multiple Sclerosis
- ACTRIMS (Americas Committee for Treatment and Research in Multiple Sclerosis)
- American Association of Neuroscience Nurses
- Australian and New Zealand Association of Neurologists
- BCTRIMS (Brazilian Committee for Treatment and Research in Multiple Sclerosis)
- Consortium of Multiple Sclerosis Centers
- Czech Multiple Sclerosis Society (Unie ROSKA)
- ECTRIMS (European Committee for Treatment and Research in Multiple Sclerosis)
- European Brain Council
- European Multiple Sclerosis Platform
- Francophone Multiple Sclerosis Society (Société Francophone de la Sclérose en Plaques)
- German Multiple Sclerosis Society (Deutsche Multiple Sklerose Gesellschaft Bundesverband e.V.)
- International Multiple Sclerosis Cognition Society
- International Organization of Multiple Sclerosis Nurses
- International Society of Neuroimmunology
- Italian Multiple Sclerosis Association (Associazione Italiana Sclerosi Multipla)
- Japan Multiple Sclerosis Society
- LACTRIMS (Latin-American Committee for Treatment and Research in Multiple Sclerosis)
- MENACTRIMS (Middle East North Africa Committee for Treatment and Research in Multiple Sclerosis)
- MexCTRIMS (Mexican Committee for Treatment and Research in Multiple Sclerosis)
- MS Nurses Australia Inc
- Multiple Sclerosis Association of America
- Multiple Sclerosis Association of Kenya
- Multiple Sclerosis Australia
- Multiple Sclerosis Coalition
- Multiple Sclerosis Foundation (USA and Puerto Rico)
- Multiple Sclerosis International Federation
- Multiple Sclerosis Ireland
- Multiple Sclerosis Research Australia
- Multiple Sclerosis Society (UK)
- Multiple Sclerosis Society Malaysia
- Multiple Sclerosis Society of Canada
- Multiple Sclerosis Society of Greece
- Multiple Sclerosis Society of New Zealand
- Multiple Sclerosis Spain (Esclerosis Múltiple España)
- Multiple Sclerosis Trust (UK)
- National Multiple Sclerosis Foundation of the Netherlands (Nationaal MS Fonds)
- National Multiple Sclerosis Society (USA)
- New Zealand MS Research Trust
- Norwegian Multiple Sclerosis Federation (Multippel Sklerose Forbundet)
- PACTRIMS (Pan-Asian Committee for Treatment and Research in Multiple Sclerosis)
- Polish MS Society (Polskie Towarzystwo Stwardnienia Rozsianego)
- RIMS (European Network for Rehabilitation in Multiple Sclerosis)
- RUCTRIMS (Russian Committee for Treatment and Research in Multiple Sclerosis)
- Shift.ms
- Swedish Neurological Association (Neuroförbundet)
- UK Multiple Sclerosis Specialist Nurse Association
- United Spinal Association
- The Work Foundation (UK)

About this guide

This concise guide to brain health in multiple sclerosis (MS) is a resource for nursing professionals. It explains how nurses can put into practice the recommendations from the report *Brain health: time matters in multiple sclerosis*.

This guide and the report are authored by an international multidisciplinary group, including specialist nurses, clinicians, researchers, health economists, people with MS and representatives from patient organizations. We recommend a therapeutic strategy (**Figure 1**) that involves:

- an understanding of the importance of brain health at all stages of the disease (pages 2–3)
- a brain-healthy lifestyle (page 4)
- informed, shared decision-making (pages 5–6)
- early treatment with a disease-modifying therapy (DMT), when appropriate (pages 5–6)
- strategies to monitor and assess treatment effectiveness (pages 7–8).

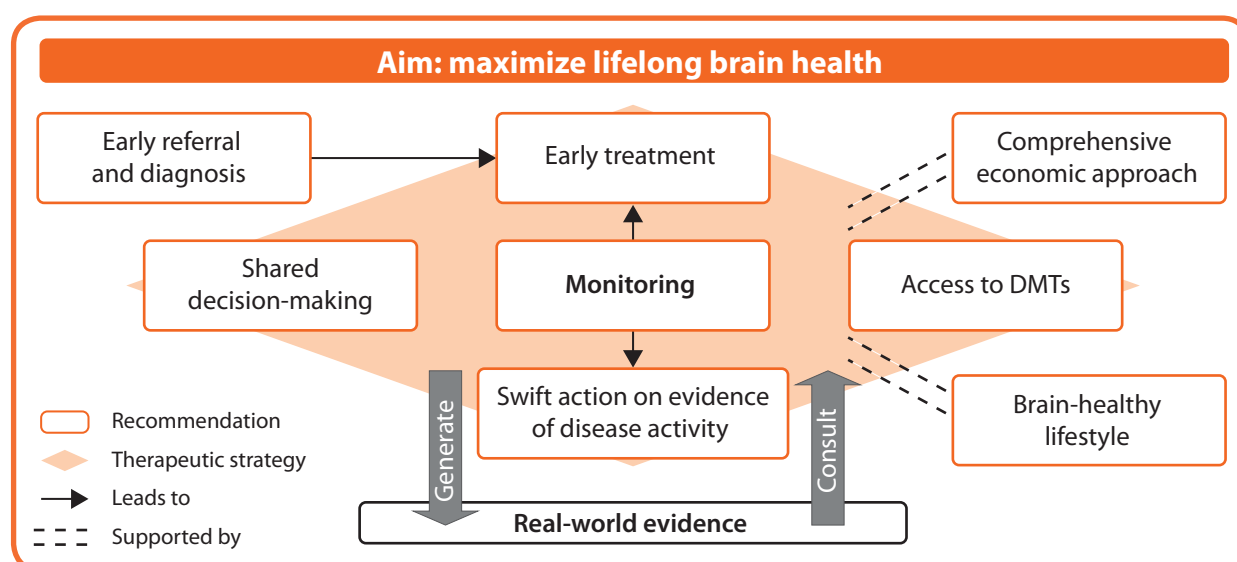


Figure 1. Overview of a therapeutic strategy based on regular monitoring that aims to maximize lifelong brain health while generating robust real-world evidence.

DMTs, disease-modifying therapies.

Nurses play a key role in the care and support of people with MS

"My MS nurse is my lifeline. Without her I would be lost. She gives me as much or as little as I request."

Nurses with specialist knowledge of MS play a pivotal role within MS clinical services, which includes:

- provision of education and information about MS, DMTs and wellness strategies
- support and counselling
- implementation of DMT safety and effectiveness monitoring programmes
- symptom assessment and management
- case management and clinical care.

This guide includes suggestions for how you can implement relevant recommendations from the *Brain health: time matters in multiple sclerosis* report in your clinical practice.

The brain health perspective on MS

In MS, the body produces an immune response against its own tissue in the brain, spinal cord and optic nerves, causing inflammation, destruction of myelin and nerve degeneration. This results in long-term damage that can cause physical disability, fatigue, cognitive impairment and emotional problems. Even at low levels of physical disability, MS may lead to considerable personal and societal costs, and these costs increase as disability progresses. Therefore, there is a strong individual and global health economic argument for maintaining brain health in people with MS.

The range of symptoms experienced by people with MS varies, depending on the locations of tissue damage in the central nervous system. Areas of intensive tissue damage (lesions) can noticeably disrupt nerve function and lead to clinical attacks (relapses), with new symptoms and impairments or worsening of existing ones. However, many new lesions occur without associated clinical symptoms. As people age, it is normal to lose small amounts of brain tissue (referred to as 'brain volume loss' or 'brain atrophy'); however, this process happens more quickly in people with MS than in healthy adults (**Figure 2a**).^{2,3} Even in the absence of clinical symptoms and relapses, it is thought that all lesions may contribute to long-term functional changes and accelerated brain atrophy. In the long term, tissue loss in MS – in lesions and the whole brain – leads to an increase in disability and in the severity and number of symptoms.

The brain is a remarkably flexible organ; it can recruit new areas to allow acquisition of new skills or to compensate for damage. When MS causes damage to brain tissue in one area, new areas are often recruited to help with the tasks previously performed by the damaged area.^{4,5} The capacity of the brain to adapt in this way is known as **neurological reserve** – this correlates with brain volume – and the more neurological reserve a brain has, the healthier it is (**Figure 2b**).

Time is critical

It is now known that MS can be active even when someone is feeling well. Research has shown that only about one in ten lesions (as detected by magnetic resonance imaging [MRI]) leads to a relapse (**Figure 2c**),^{6,7} and that other, less noticeable, damage can also be ongoing, without clinical symptoms occurring.⁸ So, although a person with MS may be asymptomatic, the rate of brain atrophy can be accelerated and neurological reserve may be depleted to compensate for subclinical damage. As neurological reserve is depleted, the capacity of the brain to recruit new areas decreases and the symptoms of MS and associated disability are more likely to progress (**Figures 2d, 2e**).

Neurological reserve is a valuable resource that plays a large part in having a healthy, well-functioning brain. Intervention should aim to maximize the brain health and physical functioning of each individual with MS. This guide gives further information on how you can contribute to helping people with MS maximize their lifelong brain health.

What can you do in your nursing practice?

- **Educate colleagues and people with MS** about why neurological reserve and brain health are important.
- **Provide prompt support** for people with suspected or newly diagnosed MS, and for those who are living with a diagnosis of MS.

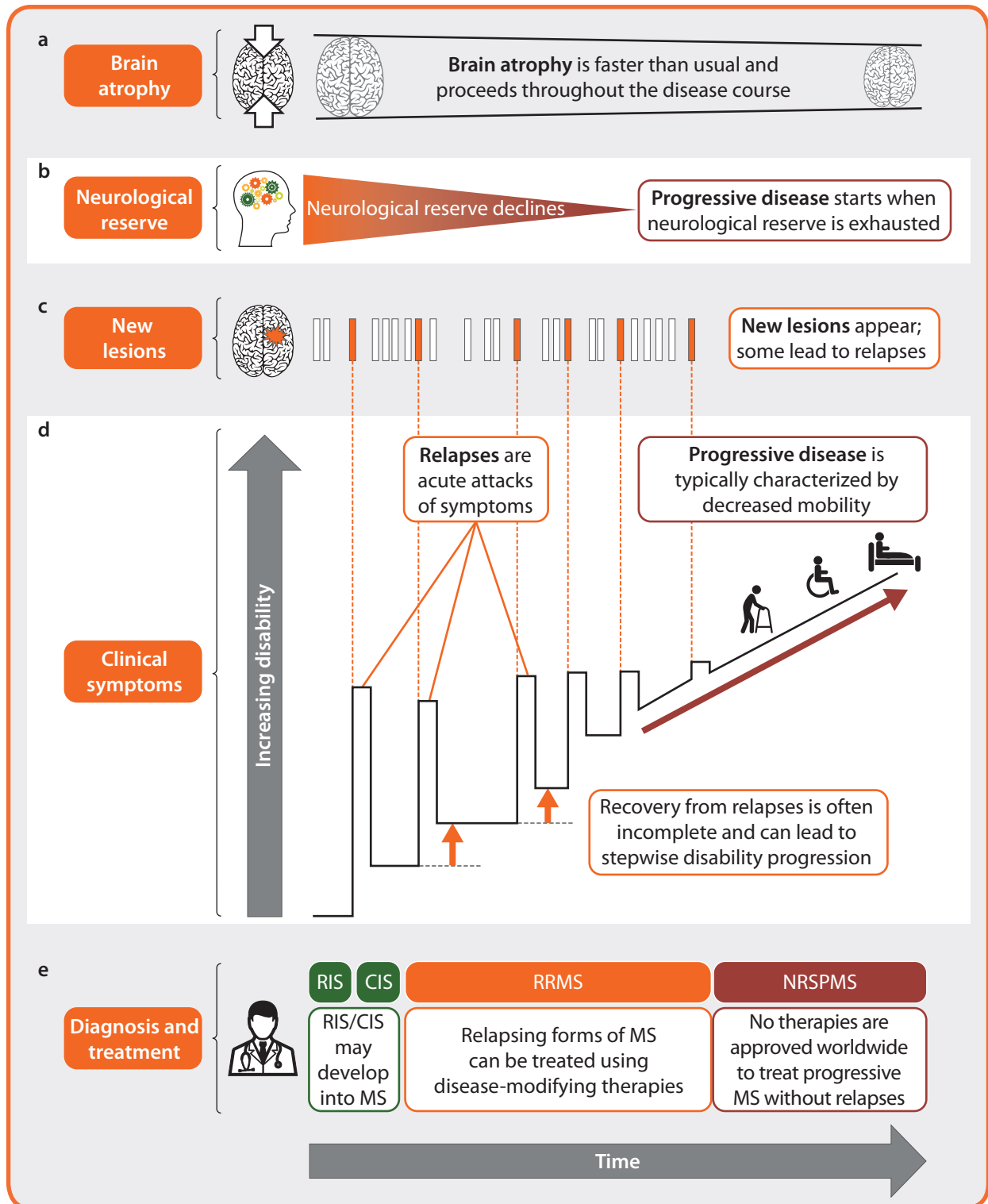


Figure 2. The damage caused by MS typically leads to relapses followed by progressive disease.

a. The brains of people with MS atrophy more rapidly than those of healthy people as a result of damage caused by the disease. **b.** The brain can use its neurological reserve to compensate for damage by remodelling itself. However, when its neurological reserve is depleted, the clinical symptoms of the disease may progress.

c. MS causes lesions – acute areas of damage to the brain and spinal cord that accumulate over time. If a lesion noticeably disrupts nerve function, it leads to a relapse (an attack of clinical symptoms).

d. A typical MS disease course involves relapses, followed by progressive disease, which may involve progression of physical disability and cognitive decline.

e. Disease-modifying therapies are most effective in the early stages of the disease when relapses, new lesion accumulation and inflammation are still present. Therefore, early intervention with disease-modifying therapies is key to improving outcomes for people with MS.

CIS, clinically isolated syndrome; NRSPMS, non-relapsing secondary progressive multiple sclerosis; RIS, radiologically isolated syndrome; RRMS, relapsing–remitting multiple sclerosis.

Positive lifestyle choices can help to maximize lifelong brain health

Treating and managing MS requires a comprehensive approach. The following lifestyle factors can contribute to maximizing lifelong brain health in people with MS, whatever their MS diagnosis.



Avoiding smoking

Cigarette smoking is associated with decreased brain volume in people with MS,⁹ as well as with higher relapse rates,¹⁰ increased disability progression,^{10,11} more cognitive problems¹² and reduced survival,¹³ compared with not smoking.



Cardiovascular fitness

Higher levels of aerobic fitness are associated with faster information processing and preserved brain tissue volume;¹⁴ therefore, aerobic exercise should be a part of managing MS.



Maintaining a healthy weight

Being overweight or obese is associated with an increased lesion burden compared with maintaining a healthy weight.⁹



Intellectually enriching activities

Education, reading, hobbies and artistic or creative pastimes help to protect against cognitive problems in MS when pursued over a lifetime.^{15–19}



Limiting alcohol

Alcohol abuse is associated with reduced survival in people with MS.¹³



Minimizing comorbidities

Conditions such as high blood pressure, high cholesterol, heart disease and diabetes can worsen the MS disease course.^{9,20,21}

What can you do in your nursing practice?

- **Educate people with MS about the importance of maximizing lifelong brain health** with positive lifestyle measures.
- **Provide people with MS with written information** to support discussion and enable gradual learning. You can download a one-page summary of the lifestyle guidance above at www.msbrainhealth.org/resources/article/six-ways-to-lead-a-brain-healthy-lifestyle.
- **Encourage people with MS to adopt and maintain a brain-healthy lifestyle** and assist them in developing practical strategies for their individual circumstances.
 - In particular, MS nurses can work collaboratively with people with MS and their primary care physicians or other healthcare professionals to minimize comorbidities and promote adherence to management plans.
- **Empower people with MS by providing relevant information about local support**, such as smoking cessation services, exercise classes, weight loss groups and guidance from a dietitian.

Nurses can help to empower people with MS

Being diagnosed with a chronic, unpredictable, progressive incurable disease can cause distress and impose substantial personal costs on both the individual with MS and their family. MS-related cognitive impairment, depression, anxiety and fatigue are common and may be present with or without more obvious clinical symptoms. Nurses are well placed to establish trust and rapport, and to provide support and counselling for people with MS.

When people with MS have good, open, trust-based relationships with healthcare professionals^{22,23} and feel well informed about their disease and its treatment,²⁴ they are more likely to continue with their treatment – and therefore are less likely to experience serious relapses.²⁵ Hence, a well-informed and proactive collaboration between people with MS and their healthcare professionals is an important part of managing MS successfully.

What can you do in your nursing practice?

- **Educate people with MS about their disease**, about their role in shared decision-making and about the impact that their choices may have on their brain health.
- **Empower people with MS to participate in decisions** about their treatments and healthcare.
- **Educate people with MS about the importance of maximizing their lifelong brain health** by making positive lifestyle choices, as well as taking appropriate drug treatments.

Early intervention with a DMT can reduce disease activity

In people with relapsing forms of MS, starting treatment with a DMT early in the disease course is associated with better long-term outcomes than delaying treatment (**Figure 3**).²⁶

What can you do in your nursing practice?

- **Explain the benefits of early intervention with a DMT**, the likely consequences of inadequate or suboptimal treatment, and the goal of minimizing disease activity while optimizing safety.
- **Assess and identify areas of concern in treatment adherence** and help to develop individualized plans to promote adherence to treatments.

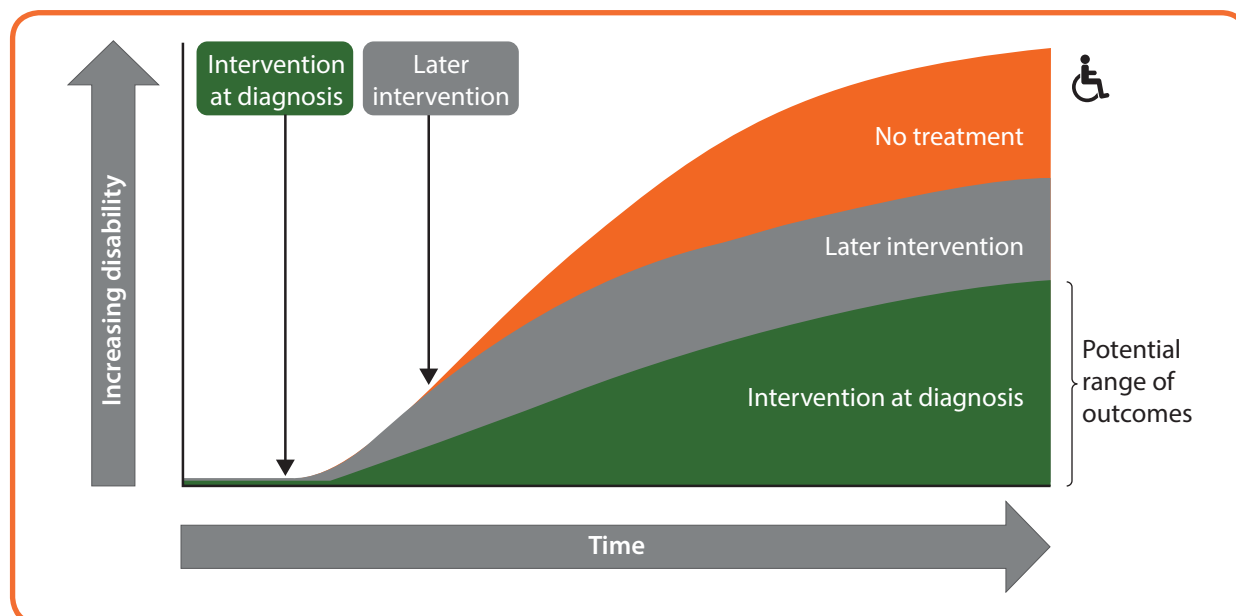


Figure 3. Early intervention with a DMT in people with MS and CIS is thought to give the best long-term outcomes. CIS, clinically isolated syndrome; DMT; disease-modifying therapy.

Decisions about DMTs should be shared and well informed

Shared decision-making is a collaborative process in which clinical evidence and the values and preferences of the person with MS are taken into account. Numerous DMTs with different mechanisms of action are available for the treatment of MS. Each is associated with a particular set of potential benefits, possible side effects and safety concerns. When making treatment decisions, all parties should consider various factors, including employment status, family planning, lifestyle factors, likely adherence to therapy, attitude to risk, aversion to or physical limitations affecting self-injection, and existing comorbidities. Choosing the most appropriate DMT should be a shared decision between the person with MS and their healthcare professionals.

What can you do in your nursing practice?

- **Help to select the optimal DMT for the individual person with MS**, by discussing with them the mechanism of action, relative effectiveness, convenience and side effects of the treatments available in your region.
- **Provide evidence-based resources** and tools to help people with MS and their families understand the benefits and risks of the various treatment options available.
- **Ensure a shared decision-making process** about options for initiating or switching DMTs that includes dialogue between people with MS and their healthcare professionals.
- **Encourage your colleagues and people with MS to consider the full range of DMTs available** in your region, to maximize the opportunities for finding the optimal treatment for each individual.

Regular monitoring is central to managing MS

Monitoring MS disease activity to evaluate treatment effectiveness is key to maximizing lifelong brain health. **Figure 4** shows both the clinical and subclinical indicators of MS disease activity that can be monitored in clinical practice.

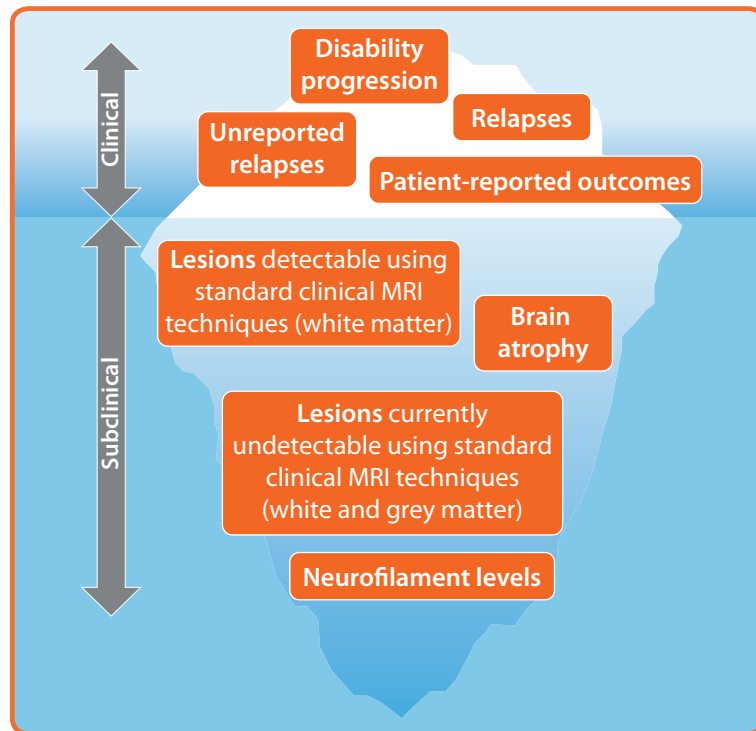


Figure 4. Monitoring disability progression and relapses can be supplemented by assessment of other measures of disease activity.

Neurofilaments are released when nerve damage occurs; blood neurofilament levels have the potential to be used as an indicator of subclinical disease.

MRI, magnetic resonance imaging.

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European Federation of Neurological Societies/European Neurological Society Joint Congress of Neurology, 31 May–3 June 2014, Istanbul, Turkey. © Gavin Giovannoni 2014.

All disease activity damages tissue in the central nervous system, even if there is no evidence of clinical relapse or disability progression. Regularly monitoring disease activity using MRI can give an early warning that MS is not responding well to treatment; disease activity in the form of lesions and brain tissue loss can predict relapses and disability progression.²⁶ MRI or clinical evidence that disease activity is poorly controlled should prompt discussion about the possibility of switching to a DMT with a different mechanism of action (**Figure 5**).

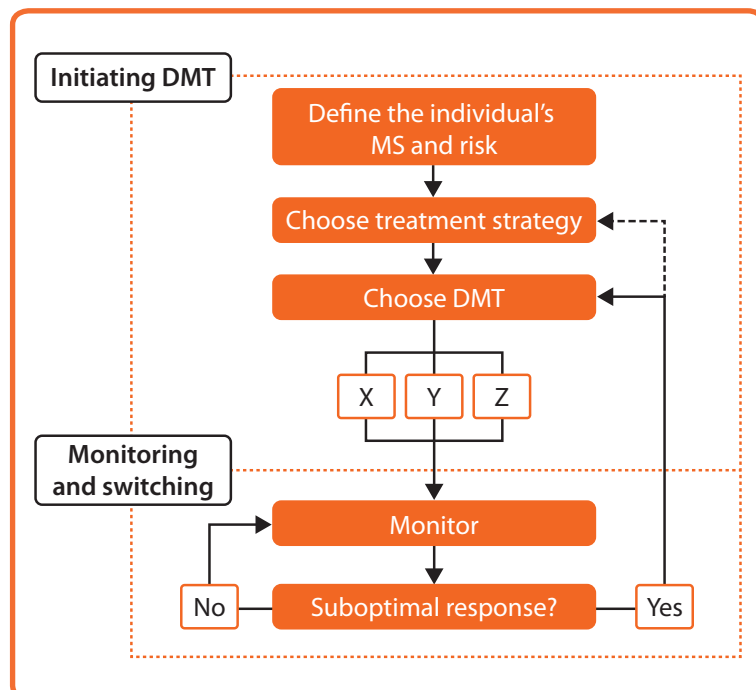


Figure 5. Monitoring is crucial to identifying a suboptimal response to treatment and enabling timely switching to a different disease-modifying therapy.

X, Y and Z represent DMT options.

DMT, disease-modifying therapy.

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What can you do in your nursing practice?

- **Encourage people with MS to monitor their disease** by keeping an MS diary or using a monitoring app to record factors that affect their health and well-being, such as symptoms, side effects and other diseases, and facilitate open disclosure.
- **Participate in the development and implementation of strategies that support active monitoring of disease activity** and of DMT safety in people with MS; this will help with rapid identification of suboptimal treatment.
- **Act swiftly on suboptimal control of disease activity** by initiating a discussion about the possibility of switching to a DMT with a different mechanism of action.
- **Discuss the possibility of switching to a DMT with a different mechanism of action** when clear MRI evidence of disease activity is available, even if there is no clinical evidence of disease activity (relapses or disability progression).
- **Actively participate in setting up and maintaining a database** to record patient demographics, relapses, neurological evaluations, MRI results and courses of treatment. Databasing provides a tool for monitoring in everyday clinical practice and improving treatment strategies in your service, as well as contributing to creating long-term real-world evidence for MS management.

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Further resources and training for nursing professionals with an interest in MS

International Organization of MS Nurses (IOMSN; www.iomsn.org) is the largest nursing organization specializing in MS and provides free resources on all aspects of MS nursing.

MS Nurse Professional (www.ms nursepro.org) is a European-focused, e-learning training curriculum for nurses beginning their career in the field of MS. It is led by the European Multiple Sclerosis Platform (EMSP) in collaboration with IOMSN and RIMS (European Network of Rehabilitation in Multiple Sclerosis).

MS Nurses International Certifications Board (www.ms nicb.org) offers certification by examination for nursing professionals providing care in MS and provides resources for further learning.

MS Brain Health has more free resources online at www.ms brainhealth.org.

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"Nurses play a crucial role in MS. Wherever they are in the world, this concise publication offers them clear guidance on how to provide even better advice in areas such as early treatment, monitoring and maintaining brain health, and healthy living, all of which can influence quality of life for people with MS."

Peer Baneke,
Multiple Sclerosis International Federation

"This report encompasses the ongoing challenges faced by people with MS and presents realistic strategies for improving patient care."

Samantha Colhoun,
UK Multiple Sclerosis Specialist Nurse Association

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