

Brain health

A guide for people with multiple sclerosis

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About this guide

This short guide is a resource to help people with multiple sclerosis (MS) understand how they can keep their brains as healthy as possible and request the highest possible standard of care from healthcare professionals. It explains how people with MS can put into practice the recommendations from the report *Brain health: time matters in multiple sclerosis*.

This guide and the report were authored by an international group of people with insight into the reality of living with MS. The group included people with MS, representatives from patient organizations, clinicians, researchers, specialist nurses and health economists.

The group recommended a therapeutic strategy that involves:

- leading a brain-healthy lifestyle, including treating other diseases (page 3)
- a plan to monitor MS disease activity to see whether treatment is working (page 4)
- informed, shared decision-making (page 5)
- urgent referral to a neurologist and prompt diagnosis (page 6)
- early treatment with a disease-modifying therapy (DMT), when appropriate (page 6)
- understanding the importance of brain health at all stages of the disease (pages 7–8).

Although there is currently no cure for MS, our vision is to help people with the disease to take control and take positive action to maximize their lifelong brain health.

What can you do after reading this guide?

Everyone with MS

- Understand the brain health perspective on MS and embrace a 'brain-healthy' lifestyle.
- Explain to healthcare professionals what matters to you and what you want to achieve with treatment.
- Ask questions until you feel understood and well informed.
- Help to monitor your MS by keeping a diary of the things that affect your health and wellbeing, such as symptoms, treatment side effects and other diseases.
- Be informed about your MS so that you can share the decision-making about your treatment with your healthcare professionals.

People at/very near to diagnosis

- Ask for urgent referral to a neurologist (preferably one with a special interest in MS) and access to diagnostic services.
- Start treatment as early as possible with a DMT (if appropriate).

People with relapsing forms of MS

- Discuss monitoring your MS using magnetic resonance imaging (MRI) brain scans and ask about what the results mean for you.
- Be confident to discuss the possibility that disease activity may be ongoing even when you are feeling well.

Positive lifestyle choices can help to keep your brain as healthy as possible



Having a healthy brain that functions well is important for people with MS. Here are six positive steps you can take to keep your brain as healthy as possible, whatever your MS diagnosis.



Keep as active as you can

Higher levels of aerobic fitness are associated with faster information processing and preserved brain tissue volume.^{1,a} This suggests that being as active as possible may help to preserve brain health in people with MS.



Keep your weight under control

Obesity is associated with higher numbers of MS lesions (areas of intensive damage) than maintaining a healthy weight.²



Keep your mind active

Education, reading, hobbies and artistic or creative pastimes help to protect against cognitive problems in MS when pursued over a lifetime.³⁻⁷



Avoid smoking

Cigarette smoking is associated with decreased brain volume in people with MS,² as well as with higher relapse rates,⁸ increased disability progression,^{8,9} more cognitive problems¹⁰ and reduced survival¹¹ compared with not smoking.



Watch how much you drink

Unsafe levels of alcohol are associated with reduced survival in people with MS.¹¹



Continue taking other medicines that your doctor has prescribed

If you have other diseases, be responsible for monitoring and managing them, including taking any prescribed medications. Conditions such as high blood pressure, high cholesterol, heart disease and diabetes can worsen the MS disease course.

What can you do?

- **Embrace a brain-healthy lifestyle** that includes keeping physically active, keeping your weight under control, keeping your mind active, not smoking, watching how much you drink and taking any medications prescribed for you.

^aAlthough it is normal for healthy adults to lose small amounts of brain tissue as they get older, this process happens more quickly in people with MS (see pages 7–8).

Regular monitoring should be central to managing MS



Monitoring MS to see whether treatment is working is key to maximizing lifelong brain health. Just as a car comes with a plan for regular check-ups and services, the healthcare professionals who oversee your treatment should have a plan to monitor your MS – and to put information about you and your disease into a logbook that they discuss with you.

Relapses and disability progression indicate disease activity – and you can take positive action by helping to monitor them. It can be helpful to keep an MS diary of things that affect your health and wellbeing, such as symptoms (**Figure 1**),^{12,13} side effects and other diseases, so that you can share a full picture with your healthcare professionals.

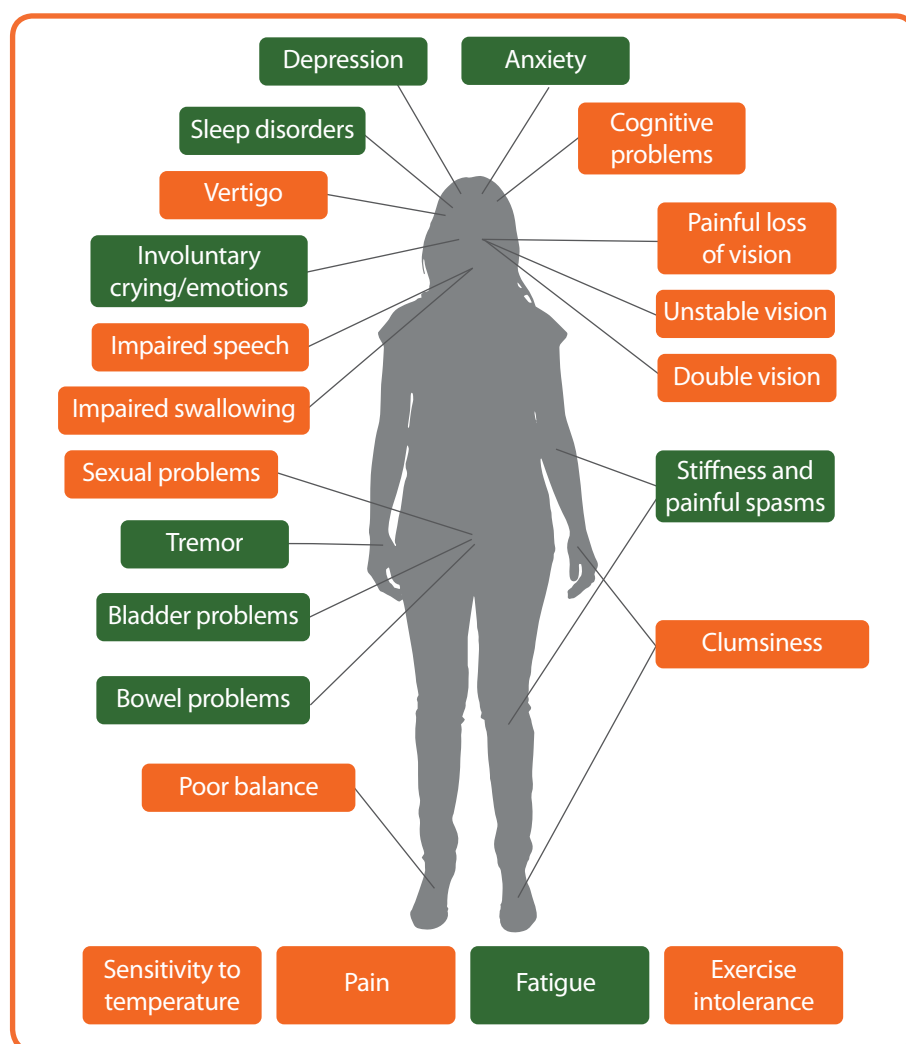


Figure 1. Take positive action. Look out for these symptoms,^{12,13} especially the ones shown in green, and keep an MS diary to discuss at appointments with your healthcare professionals.

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All MS disease activity damages tissue in the brain and spinal cord even if this doesn't immediately lead to a relapse (see pages 7–8, **Figure 2**). There is evidence that lesions (acute areas of damage) and brain tissue loss predict relapses and disability progression.¹⁴ MRI brain scans should therefore be used to look for new lesions. In some clinics it may also be possible to monitor brain tissue loss by using software that is becoming more widely available.

Regular monitoring of disease activity can give early warning that MS is not responding well to treatment. Timing is crucial, and clinical or MRI evidence that disease activity is poorly controlled should lead to a discussion about the possibility of switching to a DMT that acts on the body in a different way.

What can you do?

- **Keep an MS diary** of things that affect your health and wellbeing, such as symptoms, side effects and other diseases. Share this information with your healthcare professionals.
- **Discuss strategies for managing your MS**, such as leading a brain-healthy lifestyle and taking a DMT and medications that reduce symptoms.
- **Ask the healthcare professionals who oversee your treatment how they plan to monitor your MS.** Discuss scheduling regular MRI scans to see how active your disease is.
- **Ensure that you feel well informed about the results of your clinical assessments and MRI scans**, and ask those overseeing your treatment to discuss them with you.
- **Ask whether it is appropriate to switch to another DMT** if your MS is not responding well to treatment or if you experience unpleasant side effects.

You play a key role in decisions about your treatment



Choosing how to start treatment or when to switch to a different DMT should be an informed, shared decision in which you play an important role. You should feel able to discuss your values, needs, limitations, lifestyle, treatment goals and the likely disease course with your healthcare professionals. Topics of conversation may include employment, starting or extending a family, other lifestyle factors that are important to you, your attitude to risk and feelings about injections, and any other diseases for which you are being treated, including any side effects of your current medication. A discussion about the relative convenience, effectiveness, possible side effects and specific safety monitoring of the DMTs being considered is also important.

When people with MS feel well informed about their disease and its treatment¹⁵ and have good, open, trust-based relationships with healthcare professionals,^{16,17} they are more likely to continue with treatment – and therefore less likely to experience serious relapses.¹⁸ A well-informed and proactive collaboration with your healthcare team is therefore an important part of managing your MS successfully.

**What can you do?**

- **Be part of the decision-making process** together with your healthcare professionals. Explain what matters to you and ask questions until you feel well informed.
- **Prepare for your appointments by making notes about topics you would like to discuss**, such as your symptoms, likely disease course and treatment options.
- **Explain to your healthcare professionals what matters to you**, including your family and home, your job and hobbies, and what you want to achieve with treatment.
- **Look for other resources to help with these conversations.** Your local MS patient organizations may be able to help.
- **Continue to take any DMT that is prescribed.**

Time matters at/very near to diagnosis



Prompt diagnosis enables early treatment

To maximize lifelong brain health, treatment and management of MS need to start as early as possible – and this requires a prompt diagnosis. Generally, a person experiencing symptoms consistent with early MS will seek advice from their family doctor/primary care physician or a hospital. Once the possibility of MS has been recognized, an urgent referral needs to be made to a neurologist – a doctor who specializes in diseases of the nervous system.

MS is a complex disease. A neurologist with a special interest in MS, together with their team, will be best placed to provide a diagnosis and an integrated approach to care and management. Such neurologists have broad experience of the long-term management of MS and in-depth knowledge of the latest diagnostic criteria, treatment options and monitoring processes. MS specialist nurses are key team members in many services. They can help to improve knowledge, confidence and the ability to cope,¹⁹ provide emotional support²⁰ and are highly valued by people with MS.²¹

It is now possible to diagnose MS earlier than ever before, thanks to evidence from MRI brain scans.²² Diagnosis now happens at least 10 times more quickly than in the early 1980s,²³ and about one in five people who have had a single relapse can receive a firm diagnosis from their first MRI scans.²⁴ For others, further appointments for MRI scans and clinical examinations will ensure that a diagnosis can be made as soon as possible. A prompt diagnosis means that people with MS and their healthcare professionals can start to treat and manage the disease as early as possible.

What can you do?

- **Ask for urgent referral to a neurologist** if MS is suspected, preferably to one with a special interest in MS, or to an MS specialist clinic.
- **Request early access to diagnostic procedures**, including MRI.
- **Stay in touch with your MS team for ongoing monitoring** if you do not receive a diagnosis straight away.

Early treatment with a DMT can reduce disease activity



In people with relapsing forms of MS, starting treatment with a disease-modifying therapy (DMT) early in the disease course is associated with better long-term outcomes than delaying treatment.²⁵ Different DMTs act on the body in different ways and each is associated with a particular set of benefits and possible side effects. Choosing the most appropriate DMT for you is therefore something to talk about with your healthcare professionals (see page 5 for suggested topics), along with how to lead a brain-healthy lifestyle (see page 3).

What can you do?

- **Ask your healthcare professionals whether it is appropriate to start treatment with a DMT** and find out which options are available.

Background: the brain health perspective on MS



In MS, the body's immune system mistakenly attacks and damages tissue in the brain, spinal cord and optic nerve (the central nervous system). Although it is normal for healthy adults to lose small amounts of brain tissue as they get older, this process happens more quickly in people with MS (**Figure 2a**).^{26,27} For many people with the disease, this causes physical disability, fatigue and cognitive problems (e.g. difficulties with concentration, memory and learning new things).

MS is most often diagnosed in people aged 20–40 years. The exact range of symptoms experienced by each person can vary, depending on the locations of tissue damage in the central nervous system. In addition, for many people with MS, areas of intensive damage (known as lesions) may noticeably disrupt nerve function and lead to attacks of worsened symptoms and impairment (known as relapses). All lesions contribute to tissue loss even if they do not cause a relapse (**Figure 2b**).

The brain is a remarkably flexible organ. When learning new skills, such as speaking a foreign language or playing a musical instrument, it can recruit new areas to use for these tasks. In a similar way, if a part of the brain has been damaged, new areas can be recruited to help with the tasks previously performed by the damaged area. Thus, new areas of the brain can be recruited to compensate when MS causes damage to brain tissue.^{28,29}

The capacity of the brain to adapt is known as neurological reserve, and the more neurological reserve a brain has the healthier it is. However, it is now known that MS can be active even when someone is feeling well. Research has shown that only about one in 10 lesions leads to a relapse,^{30,31} and that other, less noticeable, damage can also be ongoing.³² So, even if someone is not experiencing new or worsened symptoms, the brain may be using up some of its neurological reserve to compensate for damage (**Figure 2c**). If all of its neurological reserve is used up, the brain can no longer recruit new areas and the symptoms of MS are more likely to progress (**Figure 2d**).

Neurological reserve is a valuable resource that plays a large part in having a healthy brain that functions well. The earlier sections of this document have explained how you can take positive action to maximize your lifelong brain health whatever your MS diagnosis.

What can you do?

- **Be aware that MS disease activity may be ongoing even when you feel well** and that this can threaten brain health.
- **Ask your healthcare professionals how they plan to monitor your MS** to see whether the disease is active (see page 5).
- Discuss with others, including your healthcare professionals, **why neurological reserve and brain health are important.**

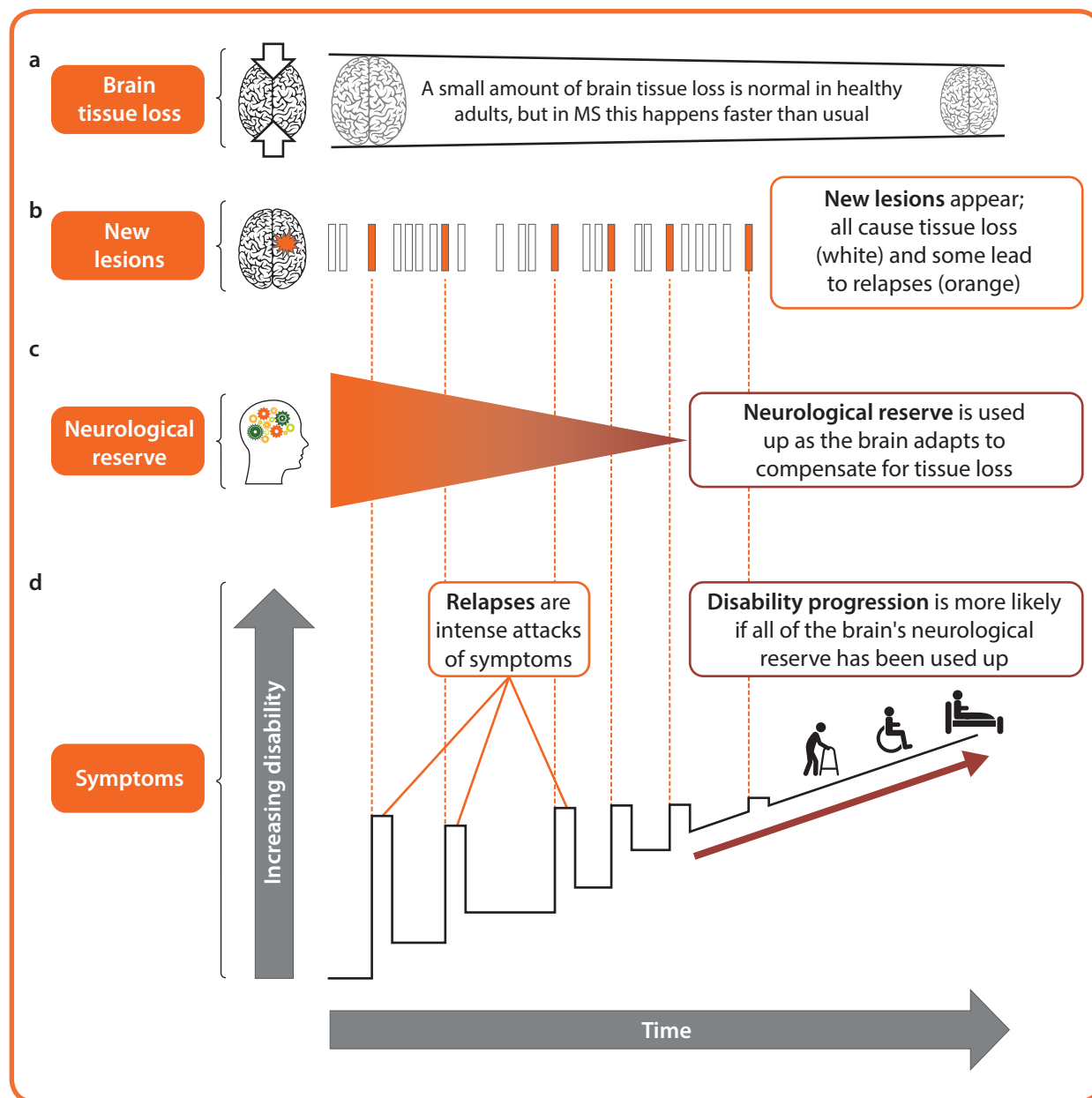


Figure 2. All MS disease activity leads to brain tissue loss which uses up valuable neurological reserve. **a.** MS disease activity causes lesions and other less noticeable damage that lead to faster brain tissue loss than usual. **b.** All lesions cause tissue loss; if a lesion noticeably disrupts nerve function, it also leads to a relapse (an attack of worsened symptoms and impairment). **c.** The brain uses up its neurological reserve as it recruits new areas to help with tasks previously performed by damaged areas. (Neurological reserve plays a large part in having a healthy brain that functions well.) **d.** The symptoms of MS are more likely to progress when all neurological reserve is used up.

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Further reading and support

MS Brain Health is calling for a radical change in the management of MS because time matters at every stage of diagnosis and treatment. You can register your support for the initiative and view other resources about brain health in MS at www.msbrainhealth.org.

The following websites provide links to many MS patient organizations that give support and information about living with MS.

- Multiple Sclerosis International Federation (MSIF):
www.msif.org/living-with-ms/find-ms-support-near-you/
- European Multiple Sclerosis Platform (EMSP):
www.emsp.org/members/

Endorsements

This guide explains how people with MS 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)

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