



A U S T R A L I A

Understanding Multiple Sclerosis

AN INTRODUCTORY GUIDE





A U S T R A L I A

This Guide has been produced by MS Australia (MSA), the national peak body for people living with MS in Australia. Our role is to work on behalf of all state and territory based member organisations to provide a voice for people living with MS across Australia.

Multiple Sclerosis Australia
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What this guide covers

This guide was developed in collaboration with MS health professionals and in partnership with people living with MS.

This guide aims to:

- > Provide reliable introductory information about multiple sclerosis.
- > Increase your understanding of various treatment and therapeutic strategies that will enable you to proactively collaborate with your healthcare team.
- > Assist you to understand the brain health perspective on MS and how you can embrace a brain healthy lifestyle.
- > Share where you can access trusted information, research, support and advice, now and into the future of your MS journey.



2.8 million people are living with MS worldwide.

Introduction

Multiple Sclerosis (MS) is an incurable, chronic disease affecting the Central Nervous System (CNS) in which the body's own immune system mistakenly attacks and damages the fatty material – called myelin – around the nerves.

Because this damage can occur anywhere in the CNS, people with MS can experience a wide range of symptoms, unique to them, and can be affected differently at various stages in their life.

The diagnosis of multiple sclerosis often brings much confusion and many questions. This Guide aims to provide you with some introductory information, and we hope it will help you to transform this knowledge into action.

You play a key role in any decisions about your treatment options, support needs and care. There is no cure for MS as yet, but there are effective treatments and therapeutic strategies to help preserve brain and spinal cord tissue. There are also things that you can do to keep your brain as healthy as possible, including positive lifestyle choices that you can make now and into the future that will assist you to take control of your own health and wellbeing.

This guide is designed to give you a better understanding of MS and thus feel better informed to make the right choices for you and ultimately manage your MS as best you can.

What is MS?

Multiple Sclerosis (MS) is one of the most commonly acquired neurological diseases affecting the central nervous system (brain, spinal cord and optic nerve).¹



MS affects over 25,600 in Australia with 2.8 million diagnosed worldwide. Most people are diagnosed between the ages of 20-40, but it can affect younger and older people too. Roughly three times as many women have MS as men.²

MS is an inflammatory demyelinating condition.³ This means it is caused by damage to myelin – a fatty material that insulates nerves, acting much like the covering of an electrical cord. Myelin allows a nerve to transmit its impulses fast and smoothly, resulting in coordinated movements that we perform without thinking.

In MS, the loss of myelin (demyelination) results in disruption of the nerve's ability to conduct electrical impulses to and from the brain. This produces the various symptoms of MS. The sites or areas in the CNS where myelin is lost (plaques or lesions) appear as hardened scars. The term multiple sclerosis means 'many scars'.⁴

Key points:

- > MS will differ from person to person and will therefore be unique to you.
- > People experience MS in episodes often including gradual onset, recovery, acute stages or for some, a progressive decline of function. Not everyone will acquire a disability.
- > MS is not contagious. You can't give it to someone else.
- > MS is a lifelong condition but not a terminal one.
- > You can get MS at any age - even children can be diagnosed.
- > You can still get pregnant after a diagnosis of MS.
- > You can still actively participate in your community and workplace.
- > By educating yourself, you can play a key role in decisions about your own treatment and support needs.

¹ Compston A, Coles A. Multiple sclerosis. *Lancet*. 2008;372(9648):1502–1517

² Van der Mei, I, Taylor, B. Health Economic Impact of Multiple Sclerosis in Australia in 2017, August 2018

https://msra.org.au/wp-content/uploads/2018/08/health-economic-impact-of-ms-in-australia-in-2017_ms-research-australia_web.pdf

³ Rejdak, K, Jackson, S, Giovannoni, G. Multiple sclerosis: a practical overview for clinicians. *British Medical Bulletin*, Volume 95, Issue 1, 1 September 2010, Pages 79–104, <https://doi.org/10.1093/bmb/ldq017>

⁴ See MS International Federation at www.msif.org/about-ms/what-is-ms/

What are the symptoms?

MS symptoms are varied and unpredictable, depending on which part of the CNS is affected and to what degree.⁵

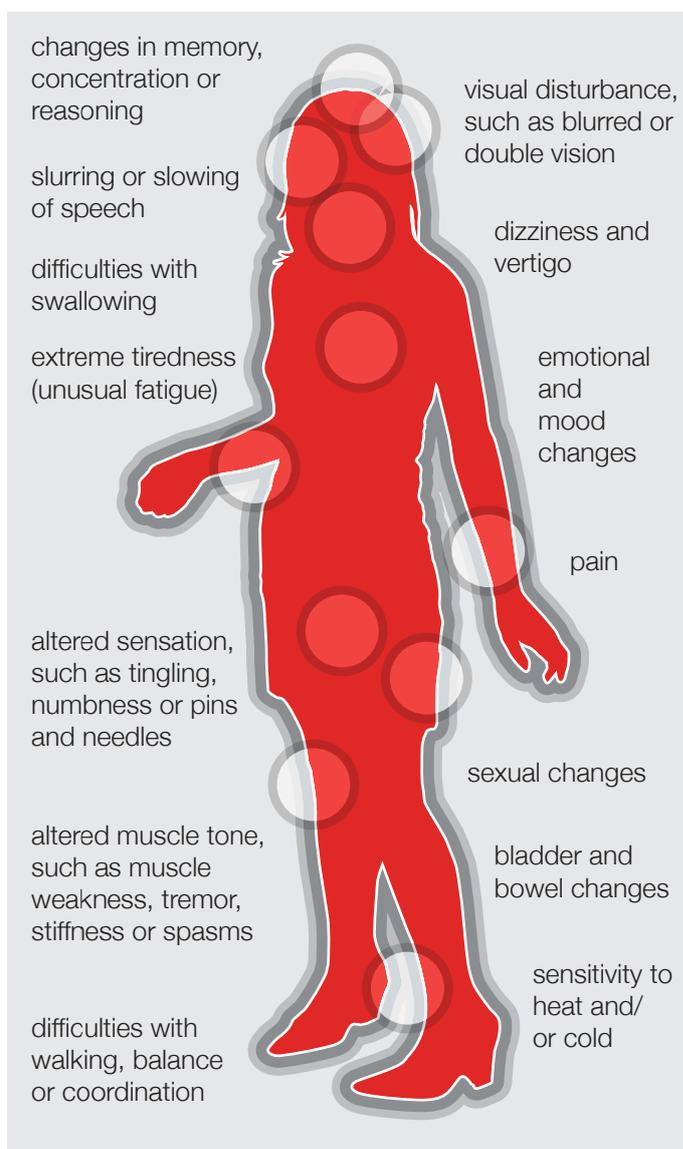
No two cases of MS are the same. Symptoms, depending on where lesions develop on the brain and spinal cord, can manifest in many different ways. Your symptoms may vary from day to day. Symptoms can also interact with each other.

Things to remember about MS symptoms, they:

- > Differ from person to person.
- > Are episodic, often with gradual onset, acute stages or progressive decline of function.
- > Can require constant adaptation, transitioning and adjustments.
- > Interact (triangulate) with other symptoms and cannot be assessed in isolation.
- > May vary and be unpredictable on any given day.
- > Interact with other co-occurring conditions or diagnoses causing a compounding effect.
- > Can be invisible, debilitating and result in a range of functional impairments.

Common symptoms of MS

The symptoms of MS can be both visible and invisible to others, are unpredictable and vary from person to person and from time to time in the same person. They may include:



⁵ de Sa JCC, Airas L, Bartholome E, Grigoriadis N, Mattle H, Oreja-Guevara C, O’Riordan J, Sellebjerg F, Stankoff B, Vass K, et al. Symptomatic therapy in multiple sclerosis: A review for a multimodal approach in clinical practice. *Ther Adv Neurol Disord*. 2011;4:139–168. doi: 10.1177/1756285611403646

What are the symptoms?

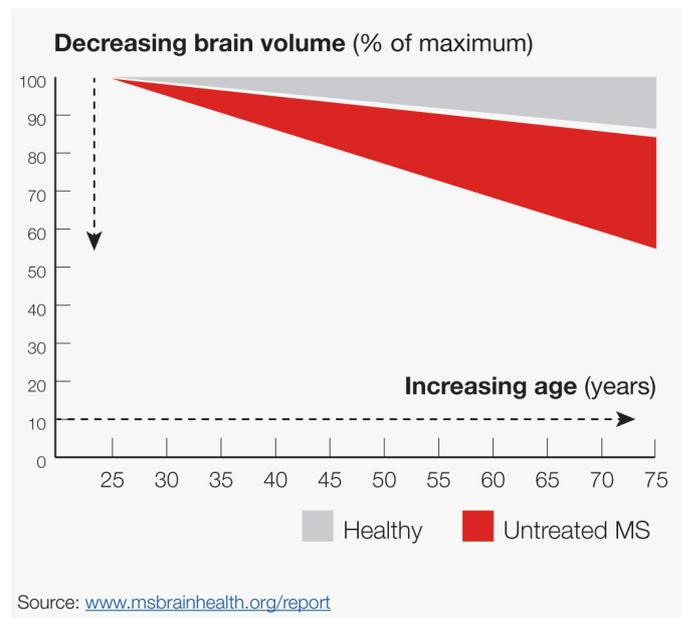
MS symptoms can be any combination of the five major functional impairments.

They include:

- > **Motor control** – unsteady movements (ataxia), muscular spasms and tremors, muscle weakness, impaired gait, coordination problems, speech and verbal difficulties (dysarthria and dysphonia), abnormal tone, hyper-tonicity, swallowing difficulties (dysphagia), breathing difficulties, heart problems, imbalance and impaired upper and lower limb function.
- > **Fatigue** – debilitating fatigue often in combination with heat sensitivity. Fatigue may impact other active symptoms, for example, ability to walk distances, concentration or ability to complete daily tasks and work.
- > **Other neurological symptoms** – including vertigo, pins and needles, nerve pain (neuralgia), ongoing pain, discomfort, visual disturbances including impaired vision (diplopia) and depth perception, involuntary eye movements (nystagmus) or partial or complete sight loss, heat sensitivity and the inability to regulate one's body temperature.
- > **Bladder and Bowel dysfunction** – including incontinence, failure to store or empty the bladder, urgency, nocturia, faecal impaction and constipation, diarrhoea and sexual problems.
- > **Neuropsychological symptoms** – including 'brain fog', impaired memory and concentration, changes in processing speed and ability, impaired executive (high level) function, personality changes, emotional changes, anxiety, depression, suicidal thoughts, and/or cognitive impairment and difficulties sleeping.

Brain atrophy

Healthy adults have a small amount of brain atrophy (decreased volume) due to natural ageing. This results in some nerve tissue becoming irreversibly destroyed. However, in many people with untreated MS, their brain atrophy occurs at a faster rate. A goal of treating MS is to prevent the brain and spinal cord damage that leads to brain atrophy.⁶



6 Giovannoni, G, Dhib-Jalbut, S, Hobart, J et al, 2017, Brain health: time matters in multiple sclerosis, Oxford PharmaGenesis Ltd, Oxford.

Functional reorganisation

Our central nervous system, just like anywhere else in our body, repairs itself after injury. Neuroplasticity is when the brain promotes recovery and repair through remyelination (resolving or repairing inflammation) and or reorganisation. Think of this as travelling on a highway and being redirected to take an alternative road or path due to roadworks. Your brain does something similar. While it is working on resolving the inflammation and repairing the myelin, your brain can redirect messages to other parts of your brain. This redirection is also called functional reorganisation which just means that your brain has the ability to adapt and change.⁷

Key points:

> An invisible disease

Multiple sclerosis is often referred to as an invisible disease as many symptoms might not be obvious to others. Family, friends and work colleagues may not recognise your challenges and symptoms because you don't "look sick". And you might be struggling to understand or explain your own symptoms to others.⁸ This Guide will hopefully provide you with a common language.

> A chronic disease⁹

Multiple sclerosis, like many other chronic diseases, does not have a one-size-fits-all solution. The disease might impact on a number of areas of your health and life. For most, MS is not a one-time occurrence and can at times be unpredictable. MS might require constant adjustment, management, monitoring and resilience. Similarly, it affects and impacts on those around you in different ways and at different times.



7 Tomassini, Valentina & Matthews, Paul & J Thompson, Alan & Fugle, Daniel & Geurts, Jeroen & Johansen-Berg, Heidi & K Jones, Derek & Rocca, Mara & G Wise, Richard & Barkhof, Frederik & Palace, Jacqueline. (2012). Neuroplasticity and functional recovery in multiple sclerosis. Nature reviews. Neurology. 8. 10.1038/nrneuro.2012.179.

8 <http://www.nationalmssociety.org/nationalmssociety/media/msnationalfiles/brochures/brochure-but-you-look-so-good.pdf>

9 <https://www.nationalmssociety.org/About-the-Society/News/New-Study-Resilience-in-People-with-Chronic-Disease>

How is MS diagnosed?

It is not easy to diagnose MS as no single test can positively tell if you have MS or not. The problem is that some early symptoms could also be caused by a number of other health conditions.¹⁰

Many people experience symptoms and know something is not right for some time before seeking a formal diagnosis. Some might see numerous medical professionals (GP, optometrist if their initial symptoms affect their vision, or specialists at their local hospital) before a formal diagnosis is made.

You might have had to describe your symptoms, how long you have experienced these symptoms and how severe they have been. You might have also been asked about your medical history or medication that you are taking.

Some of the most common early symptoms are:

> **Fatigue**

More than just being very tired. This is a type of tiredness that stops you from doing the things you always could do.

> **Stumbling**

Or loss of balance.

> **Unusual sensations**

Under your skin such as pins and needles (like when you have sat on your legs but the feeling doesn't go away) or numbness.

> **Slowed thinking**

> **Eyesight**

Problems with your vision.

GPs or optometrists may suspect MS but can't make a diagnosis of MS. Campaigns to raise awareness of MS amongst clinicians are ongoing, because an early referral to an MS specialist neurologist and diagnosis of MS has the potential to improve outcomes.

Time is critical to preserve brain volume and physical function. An early referral to a neurologist is essential.

It is best practice for clinicians and general neurologists to refer people suspected of having the disease to specialist MS neurologists. These specialists have access to the latest diagnostic criteria, facilities, and an experienced MS healthcare team who are best placed to guide those newly diagnosed with understanding their diagnosis, treatment and management options. They will also have aligned their prescribing guidelines with the latest treatment recommendations.

Frustratingly, for some, lengthy delays still occur between noticing the first symptoms and receiving a diagnosis. This lack of certainty can cause a lot of frustration, stress and worry, for you and your loved ones.

It is important to remember that whilst awaiting a diagnosis, clinicians can effectively treat your symptoms.

Interpretation and integration of patient history, a physical examination and results of imaging and laboratory testing by a clinician with expertise in MS is essential in making a reliable diagnosis.

10 Scolding N. The differential diagnosis of multiple sclerosis. *Journal of Neurology, Neurosurgery & Psychiatry* 2001;71:ii9-ii15.

How is MS diagnosed?

Tests to diagnose MS include:

- > **Neurological examination:** include checking your movement, coordination, vision, balance, reflexes and other functions of the senses. These tests not only suggest whether you might have MS, but can also indicate where in the CNS damage has taken place. You might also do a test to see how fast your nerve messages are travelling. This is called an evoked potentials (EPs) test and is often related to your eyes i.e. a visual evoked potentials (VEPs).
- > **Blood tests:** There is currently research work being done to develop a blood test for MS but it's not yet ready. Your neurologist might still ask you to provide him/her with blood tests as this may assist them to rule out other conditions.
- > **Magnetic Resonance Imaging (MRI):** This scan can detect scars or lesions in any part of your CNS. Sometimes they might inject a coloured dye (gadolinium) to determine if the scars or lesions might be related to MS or not. For a definite diagnosis of MS, this scarring has to happen in different points in time (often referred to as 'dissemination in time - DIT') and different parts of your CNS (referred to as 'dissemination in space - DIS'). It is recommended that an MRI is obtained in all patients being considered for a diagnosis of MS.
- > **Lumber puncture:** A small amount of fluid might be taken from your cerebrospinal fluid (CSF) to see (in laboratories) if there is any sign of oligoclonal bands (OCBs are not usually found in the CSF). The sensitivity of this test depends on the methods used. CSF examination can support MRI findings, increasing diagnostic confidence. CSF examination is strongly recommended when MRI evidence is insufficient, where laboratory tests are atypical of MS or for certain population groups i.e. children and older individuals. CSF examination is also recommended for those patients with clinically isolated syndrome (see page 8) where the presence of oligoclonal bands can be used as an independent predictor of a second attack, allowing for a diagnosis of MS to be made.

“

I'm relieved to be getting help for symptoms I've been experiencing for so long. I take each day as it comes and keep a positive outlook. Plus, the dog and cat are wonderful listeners. Mike

”

How is it diagnosed?

Clinically Isolated Syndrome (CIS)

Refers to the first clinical presentation of a disease characterised by inflammatory demyelination that could be MS.

CIS is diagnosed where a person, not known to have MS, provides evidence through their own reported symptoms corroborated with clinical observations that they are having an attack.

Clinical observations are obtained through objective clinical findings of an inflammatory demyelinating event in the CNS, with a duration of at least 24 hours with or without recovery and in the absence of fever or infection.

A diagnosis of MS can only be made if the person experiences another attack and any other cause is ruled out.

There is also a more complicated situation where someone can be diagnosed with Radiologically Isolated Syndrome or RIS where MRI findings suggest inflammatory demyelination in the absence of clinical signs of symptoms.¹¹

Children with MS

Although most people's onset of MS starts between 20-40 years, up to 10% of people experience their first MS symptoms before 16 years. The diagnosis of children and therapeutic strategies pose particular challenges.¹²

The emotional impact of a diagnosis of MS

A diagnosis brings as much confusion and questions as it does relief. You may experience a number of emotions, including frustration, anger, denial, sadness and finally acceptance. Feeling these emotions is natural and normal. And like MS, these emotions can come and go.

It's important to allow yourself to experience these emotions and recognise that it is part of your own journey of acceptance. Be kind to yourself. If your emotions are worsening or preventing you from performing your daily routine for two or more weeks, please see your doctor or talk to someone in your support team.

Appropriate drug treatment can reduce the potential damage caused by disease activity and brain atrophy. This is particularly important in the early stages of MS when the correct medications can reduce inflammation and the amount of new lesions and thus maximise brain health, your productivity and quality of life.¹³

Being informed about the disease, educating yourself about the available treatment options and strategies and surrounding yourself with a good supporting team, allow you to take back some of the control. Research in shared decision making, the collaborative process between a patient and healthcare provider, indicates that people will have greater outcomes if they feel educated and empowered to make proactive treatment decisions and advocate for themselves.¹⁴

¹¹ Yamout, B, Al Khawajah, M. Radiologically isolated syndrome and multiple sclerosis. *Multiple Sclerosis Related Disorder* 2017 Oct; 17:234-237. DOI: 10.1016/J.MSARD.2017.08.016.EPUB.2017 Aug 31

¹² Banwell, B et al. Multiple Sclerosis in Children: Clinical Diagnosis, therapeutic strategies, and future directions. *The Lancet Neurology*. 6(10):887-902, November 2007

¹³ Sormani MP, Arnold DL, De Stefano N. Treatment effect on brain atrophy correlates with treatment effect on disability in multiple sclerosis. *Ann Neurol* 2014; 75:43-9

¹⁴ Ben-Zacharia, A et al. Impact of shared decision making on disease modifying drug adherence in multiple sclerosis, *International Journal of MS Care*, 20(6):287-297, Nov 2018

How is it diagnosed?

Key points:

It is natural to wonder how MS will change your life or relationships. It is natural to have a lot of questions.

> **Educate yourself about MS.**

Find reliable, evidence-based (scientific) resources that will provide you with trusted information on MS.

> **Choose your support team.**

Work in partnership with your healthcare team and ask for information, support or time, when you need it. Collaborate with a healthcare team that specialises in MS if you are able to. Seek support from your state MS organisation (see page 21).

> **Be in tune with yourself.**

Make time each day to scan and notice how you are doing. Track your symptoms (physical, mental and emotional). Be kind to yourself. Practice mindfulness.

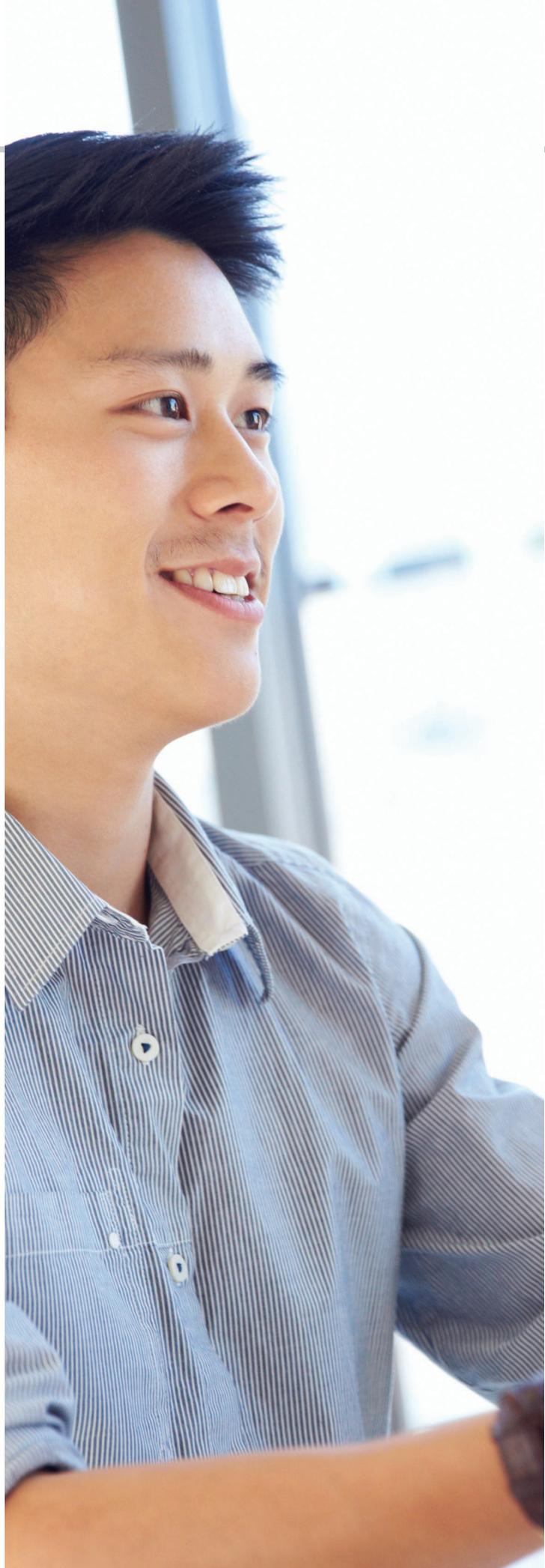
> **Strengthen your relationships.**

Good relationships are helpful to us all, even more so when challenged with a chronic illness. You might also find it helpful to talk to others with MS. Just remember everyone's experience is different. Allow those who love and care for you to help you. Don't be afraid to say how they can help or ask them what you need. And provide positive feedback. Be respectful and negotiate what works for both of you.

> **Take control.**

Cultivate a positive attitude and improve your coping skills. Learn to approach your challenges with positivity and even humour. Take control of those things you can manage. Learn to say no. Find a way of coping that works for you.

> **Plan for the unexpected.**



Types of MS

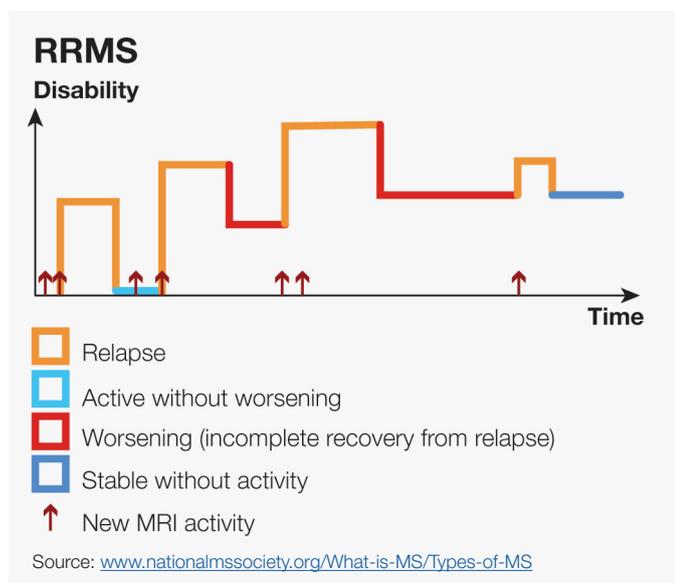
Accurate descriptions for the types of MS are considered important not only for communicating the likely course of the disease but also for treatment decisions.^{15,16}

1. Relapsing-remitting (RRMS)

Relapsing-remitting (RRMS) – this type of MS is the most common disease course characterised by clearly defined attacks or increased neurological activity followed by periods of complete or partial recovery. During periods of remission, all symptoms might disappear, however some might continue or become permanent. There is however no apparent ongoing accumulation of disability.

RRMS can be characterised as either **active** or **non-active** disease activity as well as **worsening** (a confirmed increase in disability over a specified period of time following a relapse) or **non-worsening**.

Approximately 85% of people with MS are initially diagnosed with RRMS.¹⁷

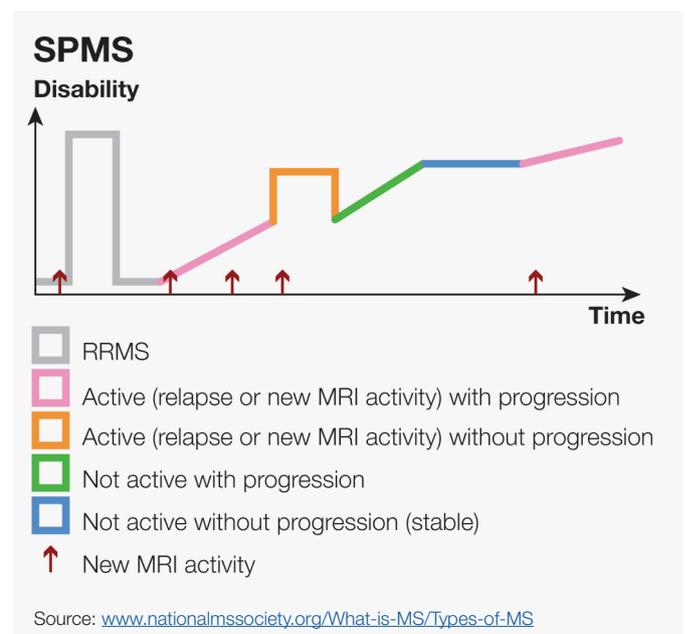


2. Secondary progressive (SPMS)

Secondary progressive (SPMS) – SPMS can follow an initial relapsing-remitting course. Some people who are diagnosed with RRMS will eventually transition to a secondary progressive course in which there is a slow and gradually progressive worsening of neurologic function (accumulation of disability) over time, independent of relapses.

With newer Disease Modifying Therapies available, there is a much lower risk of SPMS and onset of SPMS is on average more than 20 years after RRMS onset.¹⁸

SPMS can be further characterised at different points in time as either **active** (with relapses and/or evidence of new MRI activity) or **non-active**, as **well as with or without ongoing progression** (evidence of continued disease worsening over time).



15 Cutter, GR, et al. Defining the clinical course of multiple sclerosis: The 2013 revisions, *Neurology*, 2014; 83(3):278-286

16 Diagnosis of multiple sclerosis: 2017 revision of the McDonald Criteria. www.thelancet.com/neurology. Vol17 February 2018

17 See: www.nationalmssociety.org/What-is-MS/Types-of-MS

18 Weinshenker BG, Bass B, Rice GP, et al. The natural history of multiple sclerosis: a geographically based study. I. Clinical course and disability. *Brain*.1989;112(Pt 1):133-146

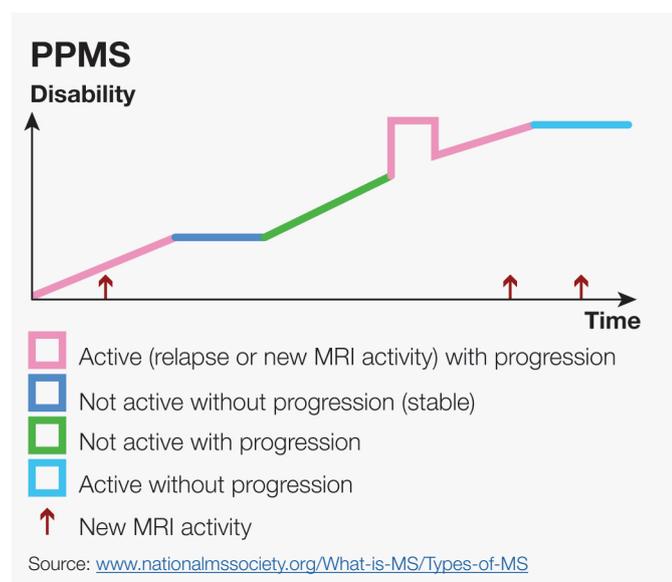
3. Primary progressive (PPMS)

Primary progressive (PPMS) – this type of MS is diagnosed when the condition follows a progressive course from onset, characterised by a worsening of neurological function (accumulation of disability) in the absence of exacerbations prior to clinical progression.

PPMS can have brief periods when the disease is stable, with or without a relapse or new MRI activity, as well as periods when increasing disability occurs with or without new relapses or lesions on MRI.

PPMS can be further characterised at different points in time as either **active** (with an occasional relapse and/or evidence of new MRI activity) or **non-active**, as well as **with progression** (evidence of disease worsening on an objective measure of change over time, with or without relapse or new MRI activity) or **without progression**.

PPMS involves much less inflammation of the type seen in relapsing MS.¹⁹ As a result, people with PPMS tend to have fewer brain lesions²⁰ than people with RRMS and more lesions in the spinal cord than in the brain, making PPMS more difficult to diagnose and treat than the relapsing form of MS.



Forms of MS at diagnosis: 12% PPMS, 3% unknown MS disease type, 85% RRMS. Many people diagnosed with RRMS will eventually develop SPMS.

PPMS tends to be diagnosed more in men than women and at an older onset age. PPMS is characterised by a considerably more rapid disease progression relative to RRMS.²¹ 12% of people with MS are diagnosed with PPMS.

“

I was diagnosed just over 12 years ago but I've lived with MS since my teens. Nothing is more frightening than knowing something is wrong but not knowing what it is. For me, diagnosis was a huge relief. Karen

”

¹⁹ Ingle GT, Sastre-Garriga J, Miller DH, et al. Is inflammation important in early PPMS? a longitudinal MRI study. *Journal of Neurology, Neurosurgery & Psychiatry* 2005;76:1255-1258.

²⁰ Dastagir, A et al. Brain and spinal cord MRI lesions in primary progressive vs. relapsing-remitting multiple sclerosis. *eNS.eNeurologicalSci.* 12 (2018)42-46

²¹ McKay KA, Kwan V, Duggan T, Tremlett H. Risk factors associated with the onset of relapsing-remitting and primary progressive multiple sclerosis: a systematic review. *Biomed Res Int.* 2015;2015:817238.

Why do people get MS?

There is no single cause of MS; however, studies have found a complex interaction between genetic susceptibility, environmental and lifestyle factors.

- > **Genetics:** MS is not, strictly speaking, a genetic or a hereditary condition and the majority of people who develop MS have no previous family history of the condition. If you have MS, it is by no means definite that your children will develop MS. Several genes (over 200) are believed to play a role in MS but they will only increase susceptibility to MS in combination with other environmental factors. Some research has also looked into the possibility that MS may be more prevalent in certain ethnic groups. Although MS appears to be more common in those considered Caucasian, it is not certain if this is linked to greater access to health services to identify and diagnose MS.²²
 - > **Infection:** A variety of viruses have been linked to MS, including Epstein-Barr (EBV), the virus that causes infectious mononucleosis (glandular fever). There appears to be some type of immune response triggered that predisposes someone to MS, rather than the EBV itself. By the time someone reaches adulthood, most people within the population have been exposed to this infection so on its own, it does not necessarily lead to or cause MS.
 - > **Geographic location:** MS is found to be more common in areas farthest from the equator, referred to as the latitudinal effect. However, prevalence rates may differ significantly among groups living in the same geographic area regardless of distance from the equator. In Australia, those living in northern Queensland are 2 times less likely to develop MS than those in Tasmania. The reasons behind this are still unclear, however, there is a possible link to exposure to ultraviolet (UV) radiation which diminishes as you move further away from the equator. Research into this possibility has focused on migration of people away from the equator to see if there might be an increased risk of developing MS. Ultraviolet light is known to have a number of impacts on the human body, including our immune system and plays a key role in the synthesis of vitamin D.²³
 - > **Vitamin D:** Numerous research studies have seen a correlation between Vitamin D levels and MS. Most of the vitamin D we need is made in our body in response to sunlight through exposure to UV radiation. Low levels of Vitamin D relate to an increased risk of developing MS, as well as negatively impacting on disease activity. The benefits of Vitamin D supplementation is an ongoing topic for scientific investigation.²⁴
 - > **Smoking:** It has been clearly shown that smoking significantly increases your chances of developing MS.²⁵ Smokers, and people exposed to second hand smoke, are almost two times more likely to develop MS and more likely to develop progressive forms of MS.
- The relationship between environmental, genetic and lifestyle factors are complex in determining who develops MS. But it is clear that MS is caused by early exposure to some environmental triggers in people who are genetically susceptible.²⁶

²² See <https://msra.org.au/news/role-genes-ms/>

²³ See <https://msra.org.au/news/unravelling-causes-ms/>

²⁴ Sintzel MB, Rametta M, Reder AT. Vitamin D and Multiple Sclerosis: A Comprehensive Review. *Neurol Ther.* 2017;7(1):59-85.

²⁵ Wingerchuk DM. Smoking: effects on multiple sclerosis susceptibility and disease progression. *Ther Adv Neurol Disord.* 2012;5(1):13-22.

²⁶ Libbey JE, Fujinami RS. Potential triggers of MS. *Results Probl Cell Differ.* 2010;51:21-42.

Why do people get MS?

Key points:

> **An auto-immune disease**

The immune system is made up of a complex network of cells that protects your body from foreign invaders like germs, viruses or bacteria. The immune system is tasked to keep you healthy, protect you from harmful things in your environment and prevent infections. In an auto-immune response, your body, mistakenly identifies its own cells as 'foreign invaders' and starts attacking and damaging its own tissue. Multiple sclerosis is one of a number of auto-immune diseases.²⁷

There are a number of therapeutic strategies available to control and successfully manage this auto-immune response.

> **An inflammatory disease:²⁸**

Inflammation is a normal, healthy response by your body to any injury or infection. Whenever you cut, bruise or hurt yourself or even when you get a cold, you're experiencing some form of inflammation. This acute response includes the release of antibodies and proteins, as well as increased blood flow to the damaged area. You might notice a reddening, swelling or might start to feel hot or even experience some level of pain. In the case of auto-immune conditions, inflammation may not go away and may become chronic, resulting in a number of inflammatory related symptoms.



²⁷ Wootla B, Eriguchi M, Rodriguez M. Is multiple sclerosis an autoimmune disease?. *Autoimmune Dis.* 2012;2012:969657.

²⁸ Losy J. Is MS an inflammatory or primary degenerative disease?. *J Neural Transm (Vienna).* 2013;120(10):1459-62.

What is a relapse?

A relapse is a relatively sudden episode of either new symptoms or a worsening of existing symptoms that continues for longer than 24 hours (i.e. not temporary) in the absence of a fever or other causes and is separated from a previous attack by at least 30 days.²⁹

A relapse can be experienced and symptoms can evolve over 1 to 7 days. It can plateau for several weeks and then it can take weeks to months to resolve or for your body to recover. Both the frequency and the severity of relapses are variable and unpredictable.

During pregnancy, women are less likely to have a relapse, although the risk of relapse increases in the six months after the birth. This is thought to be due to changes in the level of hormones, particularly oestrogen, in the body during and after pregnancy.³⁰

“

I could not have coped without my husband and the support of my lovely MS nurse. She was always at the end of the phone to answer any questions. Deanna

”

Where to go? Who should I talk to first?

A prompt response is advisable if you experience a potential relapse. A specialist MS nurse will be best placed to provide you with support, advice and information. Neurologists might have long waiting times and GPs would have to make a referral to a neurologist specialising in MS to get you the most suitable support. Alternatively you can present at an Emergency Department depending on the severity of your symptoms.

Clinicians will assess a relapse, considering your medical history, history of relapse symptoms (onset, severity, impacts on your daily life) and also try to eliminate other possible causes. However, finding a baseline to work from is not easy as it is hard to determine if someone has had a relapse or a pseudo-relapse (see below).

Doctors rely on the accuracy of patient information. It's therefore a good idea to keep a symptom diary and report changes to your health as early as possible. A relapse might indicate that you are on a treatment not suitable for you. It is not advisable to wait until your next scheduled check-up or neurological review. Now that we have treatments available that have improved efficacy, it is possible to ease symptoms as well as delay the progression of the disease and reduce the risk of relapses.

Identifying a pseudo-relapse

A pseudo-relapse also referred to as a pseudo-exacerbation is usually a temporary symptom flare-up that has nothing to do with the course of your disease, but happens because something has aggravated your condition, like a fever, infection, or hot weather or during or after times of intense stress.

29 Avasarala J. Redefining Acute Relapses in Multiple Sclerosis: Implications for Phase 3 Clinical Trials and Treatment Algorithms. *Innov Clin Neurosci*. 2017;14(3-4):38-40. Published 2017 Apr 1.

30 Dobson R, Dassan P, Roberts M, Giovannoni G, Nelson-Piercy C, Brex PA. *Pract Neurol*. 2019 Apr;19(2):106-114. doi: 10.1136/practneurol-2018-002060. Epub 2019 Jan 5. Review. <https://www.ncbi.nlm.nih.gov/pubmed/30612100> UK consensus on pregnancy in multiple sclerosis: 'Association of British Neurologists' guidelines.

What is a relapse?

Relapses indicate disease activity or symptom worsening.

Disease activity or relapses can be detected by MRI scans looking at new lesions, brain atrophy and looking at symptom worsening through a number of tests, including tests of cognition and functioning³¹.

Once a relapse is determined, the most suitable treatment response must be considered.

Treatment could be either or both:

- > **Medication:** based on your individual assessment and medical history (including your history of mental health) you might either receive oral steroids (which you can take at home) or intravenous steroids in hospital. Steroid medication (such as methylprednisolone) is often used to control the severity of an MS attack, by easing inflammation at the affected site.
- > **Rehabilitation:** assessment and referrals could be made for access to assistive technology, physiotherapy or other types of support within a multi-disciplinary MS care team.

Differentiating progression from a relapse:

People with secondary progressive disease types also have relapses. If symptoms are coming over months not days, it might be progression rather than an acute relapse.

Psychosocial impacts as result of relapse:

Due to the episodic and unpredictable nature of MS and relapses, you may experience a range of emotional responses. Adjustments and recovery might impact on your lifestyle, work and family life. Specialised MS services are in place to support you during this time.



31 Giovanni, G, Dhib-Jalbut, S, Hobart, J et al, 2017, Brain health: time matters in multiple sclerosis, Oxford PharmaGenesis Ltd, Oxford.

What treatments are available?

The key strategy or goal in managing MS, is to minimise relapses, eliminate inflammation, new lesions and brain atrophy at all stages of the disease. Treatment goals are also focused on restoring function and minimising the impact of symptoms on your day-to-day life.

Long-term research studies and real-world evidence from a number of databases and registries worldwide have shown that early intervention with disease modifying therapies leads to better outcomes in people with both clinically isolated syndrome and relapsing-remitting MS than those delaying treatment. This is especially important in the early stages of the disease.³²

Appropriate and individualised treatment can reduce disease activity.

“

Do your own research when it comes to your treatment options so you can make a reasonable and informed decision about what you would like to do.

Brian

”

Disease modifying therapies (DMTs)

Disease-modifying medications or disease-modifying treatments or immunotherapies) work by modifying the activity of the immune system to slow the frequency and severity of attacks to the central nervous system. This means the myelin sheaths are subjected to less damage. Immune suppressants are sometimes used, especially for people with progressive MS.

In Australia, people with MS have access to over a dozen different therapies, enabling neurologists to find the therapy that is right for you. A multidisciplinary MS team is best placed to provide an integrated and comprehensive approach to MS care. MS neurologists and MS specialist nurses can assist this decision and provide the information you need, as they have in-depth knowledge of the latest techniques and rapidly evolving treatment options.³³

The choice of therapy should be an informed, shared decision.

The decision to start a DMT is made together with your neurologist, carefully considering your MS disease course or type, your lifestyle, limitations, values, personal attitudes, life choices and the known side effects and potential risks and benefits of each of the therapies.³⁴

You need to understand the possible outcomes of not starting a treatment or choosing a treatment with less optimal outcomes; what the benefits are of early treatment; what your current treatment goal is and how to weigh this up against the potential risks of starting a particular DMT.

³² Giovannoni,G, Dhib-Jalbut,S, Hobart, J et al, 2017, Brain health: time matters in multiple sclerosis. Oxford PharmaGenesis Ltd, Oxford.

³³ <https://www.msaustralia.org.au/about-ms/medications-treatments>

³⁴ https://www.aan.com/siteassets/home-page/policy-and-guidelines/quality/quality-improvement/patient-handouts/15msshareddecisionmakingtool_pg.pdf

What treatments are available?

What you need to know

- > DMTs are not a cure for MS, but they can reduce how many relapses someone has and how serious they are.
- > Taking DMTs early in the course of active relapsing multiple sclerosis can prevent relapses, new brain and spinal cord lesions, and worsening neurological disability.
- > Some DMTs require a range of tests/assessments (according to their prescribing guidelines) that need to occur before they can be prescribed or treatment can be initiated.
- > DMTs have a variety of 'mechanisms of action' or ways in which they work. There are also different 'routes of delivery' or ways in which you take them i.e. pills, injections or infusions.
- > Each DMT is associated with a set of benefits and risks. Some DMTs are associated with potentially serious adverse reactions, and careful monitoring is required, usually through a specialist MS clinic.³⁵

You should continue taking your prescribed DMT unless:

- > Together with your prescribing neurologist, you determine that the current DMT is not adequately controlling or stabilising your disease.
- > You are experiencing a number of adverse side effects - apart from the initial adjustment period - and you are advised by your neurologist to change your medication.
- > You are unable to manage taking the particular DMT due to your lifestyle or individual needs.
- > A more appropriate treatment becomes available.

It can be frustrating if treatments aren't right for you or do not work as well as you would have liked. Choosing a different therapy should be an evidence-based decision between you and your healthcare professionals.

The choice of treatment, management and decisions about available therapies suitable for you, rely on your ability to **seek the information and support you require**. Ensure that you take the time you need to feel well informed to collaborate on the right treatment strategy for you.

Women who are pregnant or plan to become pregnant, or who are breastfeeding should discuss their plans with their healthcare provider, so that they can decide together the best and safest treatment plan.

Seek regular reviews to evaluate your current treatment and disease activity and to ensure that safety parameters are routinely monitored. Regular clinical evaluation and monitoring provides a strong evidence base for therapeutic strategy and treatment decisions.

Most people with MS find it useful to actively manage their health with a proactive approach to DMTs and **in combination with other brain healthy strategies**.

35 http://iomsn.org/wp-content/uploads/2016/07/CP_V12N1_2017and2018.pdf

Other brain health strategies

There are a number of things that you can do to keep your brain as healthy as possible.

An international group of researchers, patient organisations, clinicians and MS health professionals have produced a guide called *'Brain health: a guide for people with multiple sclerosis'*.³⁶

This guide was produced after recommendations made from the report, *'Brain health: time matters in multiple sclerosis'*, namely:

- 1. Take control and request the highest possible care from health professionals**
- 2. Follow a number of therapeutic strategies and make positive lifestyle changes to maximise your own brain health**

“

It does get easier to come to terms with MS. Initially it feels like you never will, but you do. Jodie

”

The following therapeutic strategies are recommended:

- > **Lead a brain healthy lifestyle** (see pages 19 and 20).
- > **Have a plan to monitor your MS disease activity to check if your treatment is working.** Help to monitor your MS by keeping a diary or an app, noting what seems to affect your health and wellbeing. This might include symptoms, treatments, side effects and other diseases. Prepare for your appointments and look for resources that can help you have these conversations.
- > **Be informed, take charge and share in decisions about your own health and wellbeing.** Explain to healthcare professionals what is important to you and what you want to achieve with treatment. Ask questions until you feel understood and well informed.
- > **Have some urgency in getting support** / or referrals to neurologists specialising in MS.
- > **Prompt diagnosis is very important** to access early treatment with disease modifying therapies (DMTs), when appropriate. Also be confident to discuss the possibility of disease activity and know that this might be ongoing even when you are feeling better.
- > **Understand the importance of brain health at all stages of the disease.**

36 <https://www.msbrainhealth.org/article/brain-health-a-guide-for-people-with-ms>

What is a brain healthy lifestyle?

You can make positive lifestyle choices that can help you keep your brain as healthy as possible.

Here are some positive steps you can take, informed by research and others living with MS:^{37 38 39 40}

1. Keep as active as you can

Higher levels of aerobic fitness are associated with faster information processing and preserving brain tissue volume.⁴¹ Many of the symptoms associated with MS can be reduced through physical exercise.⁴²

2. Keep your mind active

Education, reading, hobbies and artistic or creative pastimes can help protect against cognitive problems in MS when pursued over the long term.

3. Keep your weight under control

There is strong evidence that increased body weight and obesity is associated with higher numbers of MS lesions. Numerous studies have shown that being overweight/obese, particularly during adolescence, is associated with a 2-3 fold increase in the risk of developing MS.

There are a number of diets and 'protocols' out there that can make this area confusing to navigate. Not all are based on peer reviewed research. This area continues to be of interest but it requires a lot more research. It's best to find out what works best for you and have an individualised and open minded approach. You can ask to be referred to a dietician specialising in MS, if you need professional support and advice.

37 Amator,MA, Durfuss,T, Hemmer,B et al. Environmental modifiable risk factors for multiple sclerosis: Report from the 2016ECTRIMS focused workshop. Multiple Sclerosis Journal. First Published January 6, 2017 view: <https://doi.org/10.1177%2F1352458516686847>

38 Pepper,G, Butzkeuven,H, Dhib-Jalbut,S et al. Brain health: a guide for people with multiple sclerosis. view: <https://www.msbrainhealth.org/article/brain-health-a-guide-for-people-with-ms> View web page: <https://msra.org.au/news/unravelling-causes-ms/>

39 Briones-Buixassa L, Milà R, M^a Aragonès J, Buñill E, Olaya B, Arrufat FX. Stress and multiple sclerosis: A systematic review considering potential moderating and mediating factors and methods of assessing stress. Health Psychol Open. 2015;2(2):2055102915612271. Published 2015 Nov 4. doi:10.1177/2055102915612271

40 FRAGOSO, Yara Dadalti. Modifiable environmental factors in multiple sclerosis. Arq. Neuro-Psiquiatr. [online]. 2014, vol.72, n.11 [cited 2019-02-27], pp.889-894.

41 <https://www.msaustralia.org.au/living-with-ms/expert-blog/exercise-and-ms>

42 Dorans KS, Massa J, Chitnis T, Ascherio A, Munger KL. Physical activity and the incidence of multiple sclerosis. Neurology. 2016;87(17):1770-1776.

What is a brain healthy lifestyle?

4. Avoid smoking

Smoking is associated with decreased brain volume in people with MS. Smoking has also been associated with higher relapse rates, increased disability progression, more cognitive problems and reduced survival compared to not smoking at all. For people who already have MS, there is good evidence that stopping smoking reduces the risk of disability progression. Smoking is known to cause an increase in inflammation, and chemicals in smoke can also directly alter the function of some immune cells, potentially contributing to the development of MS.⁴³

5. Watch how much you drink

Higher levels of alcohol are associated with disability progression and reduced survival in people with MS.⁴⁴

6. Avoid Stress⁴⁵

MS by itself can be stressful. However, studies have linked severe stress with an increase in MS relapses. It's good to find strategies in your life to reduce your overall stress levels. Surround yourself with positive people and things you enjoy doing. Practice self-compassion. Mindfulness-based interventions have been shown to have some benefits to the quality of life of those living with MS.⁴⁶

7. Reorganise your life and priorities

Learn how to say no. Make adjustments and be kind to yourself. Accept your own limitations and re-prioritise what is important for you. Being resilient means experiencing the ups and downs of life but showing flexibility in how you respond to those life challenges. Recognise your strengths and supports and build on those. Work towards regaining and maintaining your goals for your family, life and health.

8. Find your support team

Be the CEO of your life. Decide which areas of your life you can delegate. Nurture supportive relationships. Ask for support and assistance from those close to you but also from those in your professional network. Where possible, always try to use healthcare professionals who specialise in MS.⁴⁷

9. Continue taking other medicines that your doctor has prescribed

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

“

Whatever you're feeling - it is okay. The only thing you don't have to feel is alone, as there are many of us out there with MS living full and happy lives. Don't be afraid to talk to us. Alison

”

⁴³ <https://msra.org.au/news/unravelling-causes-ms/>

⁴⁴ <https://www.msaustralia.org.au/about-ms/help-keep-your-brain-healthy>

⁴⁵ Yaribeygi H, Panahi Y, Sahraei H, Johnston TP, Sahebkar A. The impact of stress on body function: A review. EXCLI J. 2017;16:1057-1072. Published 2017 Jul 21. doi:10.17179/excli2017-480

⁴⁶ Simpson R, Booth J, Lawrence M, Byrne S, Mair F, Mercer S. Mindfulness based interventions in multiple sclerosis--a systematic review. BMC Neurol. 2014;14:15. Published 2014 Jan 17. doi:10.1186/1471-2377-14-15

⁴⁷ <https://www.msaustralia.org.au/wellbeing-ms/social-psychological>

Additional Reference: Atlas of MS 2020, Multiple Sclerosis International Federation, September 2020, www.atlasofms.org

Where can I get further information or support?

As the national peak body for Australians living with MS, we work closely with the state MS organisations to help you connect with the right support and services. Your state and territory MS organisations are:

MS Limited

Victoria, NSW, ACT and Tasmania

T: **1800 042 138**

E: msconnect@ms.org.au

www.ms.org.au

MSWA Western Australia

T: **1300 097 989**

E: communications@mswa.org.au

www.mswa.org.au

MS Society SA & NT

South Australia and Northern Territory

T: **1800 812 311**

E: msassist@ms.asn.au

www.ms.asn.au

MS Queensland

T: **1800 177 591**

E: info@msqld.org.au

www.msqld.org.au

MS Research

MSA also works closely with our partner, MS Research Australia. MS Research Australia is the largest Australian not-for-profit organisation dedicated to funding, coordinating, educating and advocating for MS research as part of the worldwide effort to solve MS.

www.msra.org.au

Stay connected:

Join us on our social media platforms, **Facebook** and **Twitter** and link to the MSA website to receive news updates, connect with peers, read our blog Uninterrupted or blog for us, keep up to date with events and more.

www.msaustralia.org.au



A U S T R A L I A

About MS Australia

MS Australia (MSA) is the national peak body for people living with MS in Australia. Our role is to work on behalf of all state and territory based member organisations to provide a voice for people living with multiple sclerosis across the country to support the development of:

- > Research
- > Advocacy and awareness
- > Communication and information
- > Services provided by our member organisations
- > International collaboration.

MSA advocates across all stakeholders, governments and communities, on behalf of our members, to represent people who are diagnosed with the disease, their carers and the broader MS community.

MSA works closely with partner organisation, MS Research Australia – the largest not-for-profit funder and coordinator of MS research in Australia.

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