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## Multiple sclerosis (MS)

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### Summary

- Multiple sclerosis (MS) is an incurable, chronic disease.
  - If you have MS, your immune system mistakenly destroys tissue in your brain, spinal cord and optic nerves.
  - The symptoms of MS vary over time and are unpredictable. No two people will experience the same symptoms.
  - Medications for MS either ease specific symptoms or slow down the progress of the disease.
  - There are lifestyle changes you can make that will improve your overall health while living with MS.
  - MS is a complex disease. It is best, where possible, to seek support and advice from healthcare professionals that specialise in MS.
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### What is multiple sclerosis (MS)?

Multiple sclerosis (MS) is an incurable, chronic (ongoing) and complex disease in which your body's immune system mistakenly attacks itself. This is known as an autoimmune response.

With MS, the immune system attacks and damages the fatty material (myelin) that insulates the nerves of your central nervous system (the brain, spinal cord and optic nerves). This is known as demyelination.

Healthy myelin acts like the covering of an electric cord. It protects your nerve fibres and allows them to transmit impulses (messages) quickly and effectively.

Demyelination causes inflammation and scarring (multiple sclerosis means 'many scars'). The formation of these scars, known as plaques or lesions, affects your nerves' ability to transmit messages between your brain and other parts of your body.

Demyelination can occur anywhere in the central nervous system. For this reason, everyone's experience of MS is unique. People with MS can experience a **wide range of symptoms**, and can be affected differently at various stages in their life.

After demyelination occurs, the brain works to repair the tissue and resolve the inflammation. While doing so it can redirect messages to other parts of your brain. It's a bit like travelling on a highway and being redirected to take an alternative road or path due to roadworks.

Even though the brain works to repair damaged tissue, the repair is often incomplete and some nerve tissue is irreversibly destroyed. This leads to a decrease in brain volume, known as brain atrophy.

Healthy adults have a small amount of brain atrophy due to natural ageing, but in many people with untreated MS, brain atrophy occurs at a much faster rate. MS treatment aims to prevent the irreversible damage that leads to brain atrophy.

### MS is a common disease

Over 2.3 million people live with MS worldwide, and there are over 25,600 people living with MS in Australia. On average more than 10 Australians are diagnosed with MS every week. Three quarters of all people with MS are women.

Multiple sclerosis is the leading cause of disability in young adults. Diagnosis of MS mostly occurs between the ages of 20 and 40 years, although children can also be diagnosed with the disease.

### Types of MS

MS can progress in different ways. Knowing the type of MS you have can help you understand the course your MS is likely to take, and help you make informed treatment decisions.

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The different types of MS are:

- **relapsing-remitting MS (RRMS)** – this type of MS is the most common. It is characterised by clearly defined attacks (called active disease activity) followed by periods of complete or partial recovery (referred to as non-active disease activity, or remission). During periods of remission the disease does not appear to progress. At this time, all symptoms might disappear (non-worsening), or some might continue or become permanent (worsening). Approximately 85 per cent of people with MS are initially diagnosed with RRMS
- **secondary progressive MS (SPMS)** – this type of MS is diagnosed when an initial relapsing-remitting (RRMS) phase is followed by a 'progressive' phase in which the disease progresses and continually worsens. Attacks and partial recoveries may continue to occur throughout this phase. There is no clinical test to show when RRMS changes to SPMS
- **primary progressive MS (PPMS)** – this type of MS is diagnosed when the condition follows a progressive (continually worsening) course from the beginning. It is characterised by increasing disability, usually without periods of remission (recovery) or acute attacks. 10 to 15per cent of people with MS are diagnosed with PPMS.

## Symptoms of MS

The symptoms of MS are varied and unpredictable, depending on which part of the CNS is affected and to what degree. No two cases of MS are the same.

Symptoms may vary from day to day and symptoms can also interact with each other. The symptoms of MS can be both visible and invisible to others.

**MS symptoms** can be a combination of problems with the following areas:

- **motor control** – difficulties with walking, balance or coordination, muscle spasms or tremors, muscle weakness, slurring or slowing of speech, swallowing difficulties, breathing difficulties, heart problems and dizziness or vertigo
- **fatigue** – extreme tiredness, often in combination with heat sensitivity which can impact on your physical, emotional and mental abilities
- other neurological symptoms – visual disturbances (such as blurred or double vision or changes in depth perception, partial or complete sight loss), altered sensations such as pins and needles or numbness, neurological pain, sensitivity to heat or cold, or discomfort
- **bladder and bowel dysfunction** – including incontinence (leakage from the bladder or bowel), needing to urinate more or less often, urgency, needing to urinate frequently during the night, constipation, diarrhoea
- **neuropsychological symptoms** – including 'brain fog', impaired memory and concentration, changes in processing speed and ability, impaired cognitive function, personal and emotional changes, anxiety, depression and difficulties sleeping.

Multiple sclerosis is a chronic disease requiring constant adjustment, management, monitoring and resilience. Similarly, it affects and impacts on those around you in different ways at different times.

## What causes MS?

There is no single cause of MS, however studies have found a complex interaction between genetics, environment and lifestyle factors:

- **genetics** – several genes are believed to play a role in MS. Having one of these genes might increase your chances of getting MS, but other environmental factors are also involved
- **infection** – a variety of viruses have been linked to MS, including Epstein-Barr virus, the virus that causes **glandular fever**
- geographical location – MS is more common in areas further from the equator. This is referred to as the latitudinal affect. The reasons for this are still unclear. There is a possible link to exposure (or lack of exposure) to ultraviolet light
- **vitamin D** – numerous studies have shown a correlation between vitamin D levels and MS. Low levels of vitamin D may increase the risk of developing MS, and may also negatively impact on outcomes once

someone is diagnosed

- **smoking** – smoking and exposure to second hand smoke significantly increase your chances of developing MS. You are twice as likely to develop MS and more likely to develop progressive forms of MS if you smoke or are exposed to second-hand smoke.

## How is MS diagnosed?

Diagnosing MS can be difficult, as some of the early symptoms (such as fatigue, stumbling, unusual sensations, slowed thinking or problems with eyesight) can also be caused by a number of other health conditions. There is no single test for MS.

If your doctor or neurologist thinks you may have MS, they will refer you to a specialist MS neurologist. Specialist MS neurologists have access to the latest **diagnostic tools** and facilities, and an experienced MS healthcare team. This team can help you understand your new diagnosis, treatment and management options.

Even if you are still waiting for a diagnosis, your healthcare team can effectively treat your symptoms.

Tests to diagnose MS include:

- neurological examination – this might include an ‘evoked potentials’ test, which measures the speed at which messages travel along the nerve pathways in your CNS
- blood tests – to rule out other causes
- **magnetic resonance imaging (MRI)** – to look for scarring (plaques or lesions) in your brain and spinal cord
- lumbar puncture – to test your cerebrospinal fluid (CSF). CSF examination can support MRI findings and help rule out other diseases.

If scarring is found in the CNS, to confirm a diagnosis of MS a neurologist will look for evidence that the scarring happened at different points in time (often referred to as ‘disseminated in time – DIT’) and in different parts of your CNS (referred to as ‘disseminated in space – DIS’).

To achieve the best possible outcomes for people with MS, it is recommended that delays in diagnosing MS be minimised and that goals for treatment and ongoing management of MS be set early in the course of the disease.

Being informed about MS will enable you to participate in decision making about your treatment. Research has shown that a collaborative decision-making process between patient and healthcare provider leads to the best health outcomes.

## What are MS relapses?

A relapse is a relatively sudden episode of either a new symptom or a worsening of an existing symptom that:

- continues for longer than 24 hours
- cannot be explained by other causes (such as an infection)
- is separated from the previous attack by at least 30 days.

Relapse symptoms can evolve over one to seven days. They can then plateau (reach a state of little or no change) for several weeks. It can then take months for your body to recover. How often you have a relapse, and how severe they are, can be variable and unpredictable.

If you think you are experiencing a relapse, see your specialist MS nurse as soon as possible. They will be able to guide you through the relapse and provide you with support.

Use a diary to keep a record of your symptoms. Accurate patient information is useful to your doctor in treating and managing your MS. A relapse might indicate that your treatment is no longer suitable.

If it is determined that you are having a relapse, your treatment team will need to consider the most suitable treatment response. This might include both medication and rehabilitation options.

Due to the episodic (on-again, off-again) nature of MS and relapses, you and your loved ones might experience a range of emotional responses. **Specialised MS support services** are available to support you during this time. These include employment advice and support.

## How is MS treated?

There are no medications to cure MS. At all stages of the disease, MS treatment aims to:

- minimise relapses
- eliminate inflammation
- prevent the formation of new lesions
- minimise brain atrophy
- restore function
- minimise the impact of symptoms on your day to day life.

### **Specialist MS healthcare team**

If you have been diagnosed with MS your GP will work together closely with the local MS specialist team to provide your care. This team will consist of a neurologist, an MS specialist nurse and a number of other allied health practitioners, if needed, including an occupational therapist, physiotherapist and incontinence nurse.

Your specialist MS healthcare team will discuss with you:

- the aims of treatment
- which treatment might be most suitable for you
- the pros and cons of the different treatments available
- brain health lifestyle changes that you can make to improve your health outcomes.

They will help you establish ways of coping, adapting to and managing your MS.

### **Medication treatments**

**Medication treatments** available include disease modifying therapies and symptomatic treatments.

**Disease modifying therapies** (also called DMTs or immunotherapies) work by modifying the activity of your immune system to slow the frequency and severity of attacks on your CNS. You can take DMTs in pill form or as injections or infusions.

The decision to start a DMT should be an informed and shared decision, made together with your specialist MS neurologist. It should take into account:

- the type of MS you have
- your current treatment goal
- your lifestyle choices
- the potential risks of treatment.

Studies have shown that early diagnosis and treatment intervention with DMTs leads to better outcomes in people with MS than delaying treatment. Studies have also shown that best outcomes are achieved if there are clear treatment goals set, which are regularly monitored and reviewed.

Symptomatic treatments are used to treat relapses or specific **MS symptoms**.

### **MS treatment reviews**

It is recommended that you have:

- regular treatment follow-ups
- six-monthly treatment reviews to look at how your current treatment approach is working
- an MRI scan at least once a year – to check for evidence of disease activity.

### **Brain healthy lifestyle treatments**

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

- keeping your weight under control
- adopting a healthy diet
- avoiding smoking

- limiting alcohol intake
- keeping your mind and body as active as possible
- learning some **ways to manage stress** – MS can cause stress because of its unpredictable nature, but stress in turn can increase your risk of a relapse.

If you have an intolerance or sensitivity to cold or heat that worsens your symptoms, it can be managed by adopting a number of strategies – talk to your MS healthcare team.

### **Complementary therapies and MS**

Medications and physical therapies can be complemented by other therapies. Be cautious when investigating a complementary therapy and be sceptical of 'miracle cure' claims.

Always **ask your MS healthcare team for advice** before starting any complementary treatment, as some complementary treatments may have negative interactions with medications you may be taking.

### **Where to get help**

- Your specialist MS healthcare team (including a specialist MS nurse, a neurologist and other allied health practitioners as needed – for example an occupational therapist, physiotherapist and incontinence nurse)
- Your **GP (doctor)**
- Your local **MS organisation** for MS specific advice, services and support
- **MS Australia** and MS Research Australia [<https://msra.org.au/>] for up to date and trusted information

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