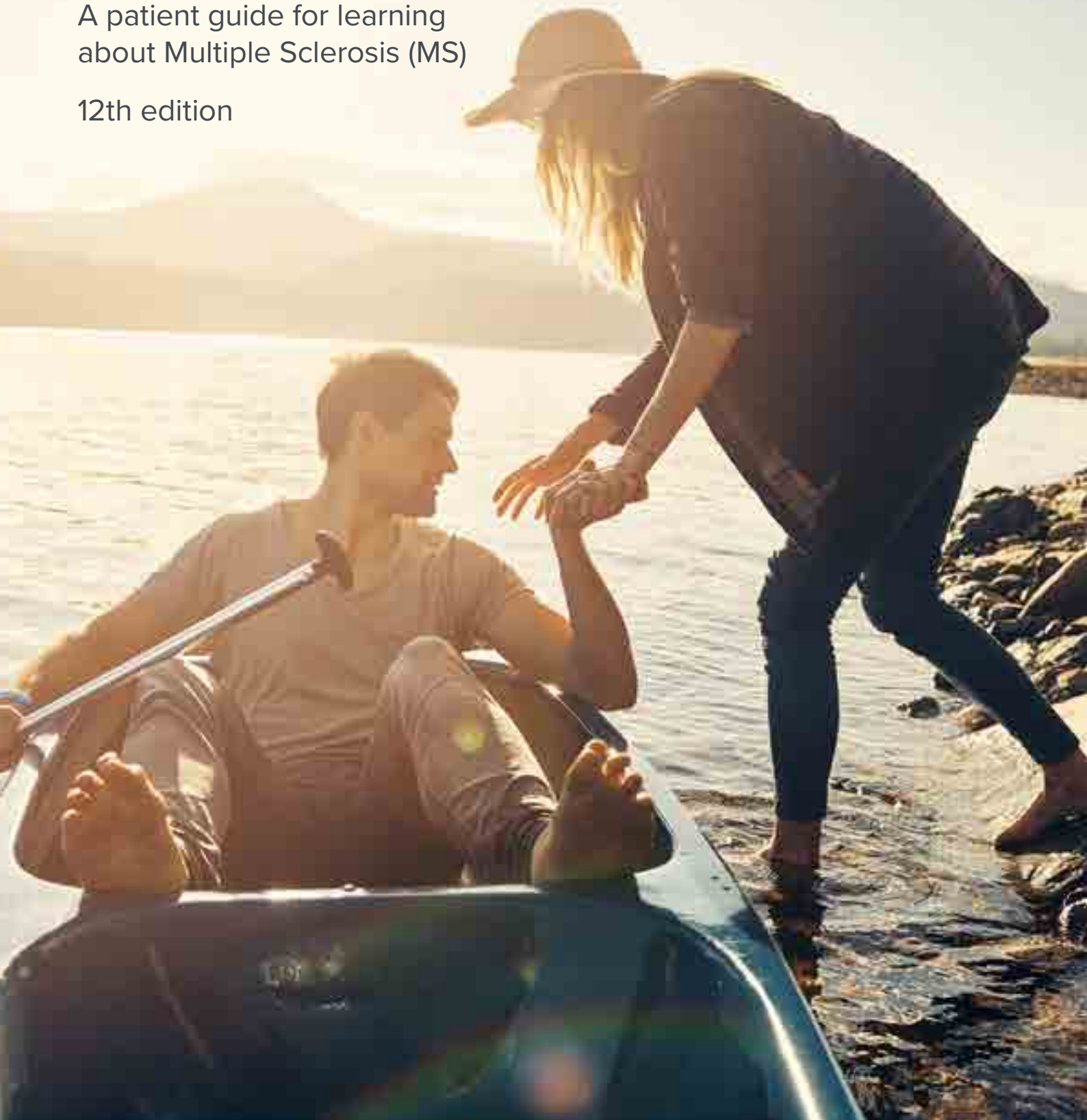


What is MS?

A patient guide for learning
about Multiple Sclerosis (MS)

12th edition



'What is MS? A patient guide for learning about MS' has been developed on behalf of Biogen Australia and New Zealand.

Biogen would like to thank Professor Allan Kermode, Consultant Neurologist, Sir Charles Gairdner Hospital in Perth and Tim O'Maley RN, Nurse Practitioner at MS Queensland for their expert opinions and critique of this booklet.



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Biogen Australia Pty Ltd, ABN 30 095 760 115
Macquarie Park, NSW 2113, Sydney, Australia.
Biogen NZ Biopharma Limited
188 Quay Street, Auckland, New Zealand.

Disclaimer: While every effort has been made to ensure the accuracy and validity of the information presented in this book, it is not intended to take the place of professional medical advice. Your primary source of information should always be your doctor and other healthcare professionals who are involved in your care. You should follow medical practitioners' instructions at all times and contact your doctor if you have any questions about your condition or its treatment.

Introduction

If you or someone close to you has recently been diagnosed with multiple sclerosis (MS), it's natural that you may be feeling upset and overwhelmed.

Having MS means adapting to changing situations. Having some knowledge about the condition, and about what support is available if you need it, can be helpful at this time.

This book has been put together to give you some general information about MS, including the common symptoms and its diagnosis. It also contains some practical tips for adapting to the changes associated with MS, which will help you stay positive and get the most out of life.

Biogen has produced this booklet as a community service for people with MS, their families, carers and other interested people. This information does not constitute medical advice. For specific information about MS as related to you or someone else you know, please talk to your neurologist, general practitioner (GP), MS Organisation or other health professionals involved in your care.



What is MS?

MS is a chronic disease where myelin, which covers some nerves in the brain and spinal cord (Central Nervous System [CNS]), becomes damaged. This may cause a range of symptoms affecting sight, movement, balance and/or other physical functions. MS is most commonly diagnosed between the ages of 20 and 40 years.^{1,4}

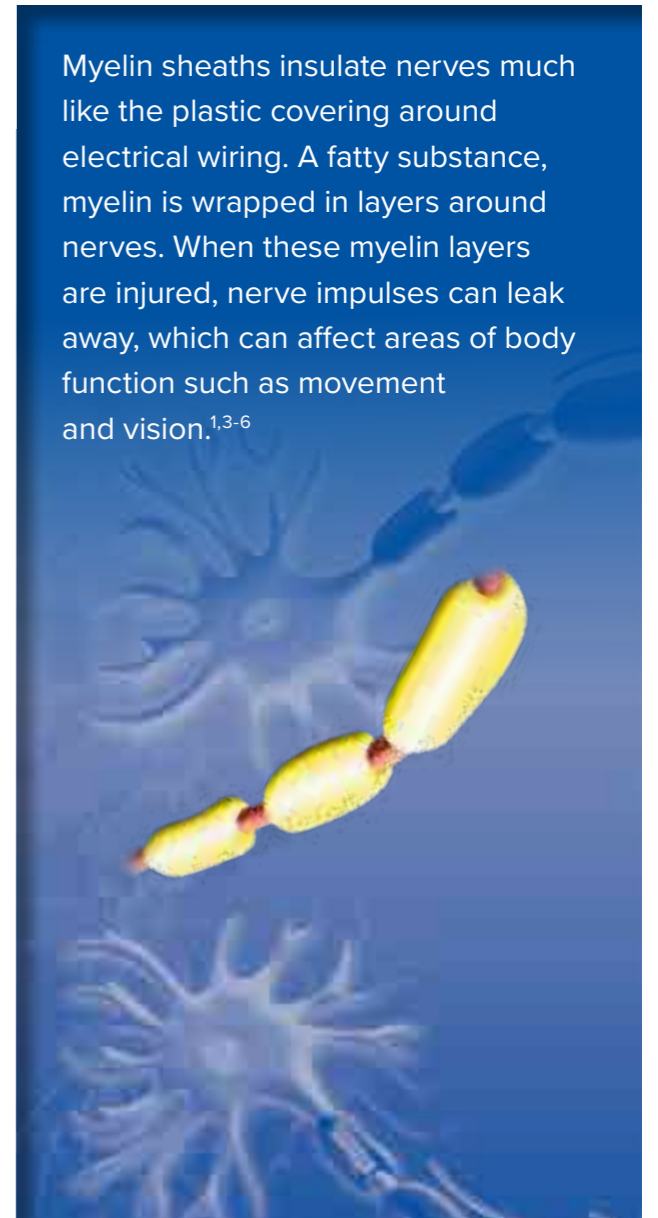
Functions of the CNS

The CNS consists of the brain and spinal cord and optic nerve, which control bodily functions by sending out and receiving electrical signals along nerves to all parts of the body. These signals (impulses) control all of our voluntary and involuntary movements, as well as sensations, such as sight, touch, smell, hearing and taste.^{1,3-5}

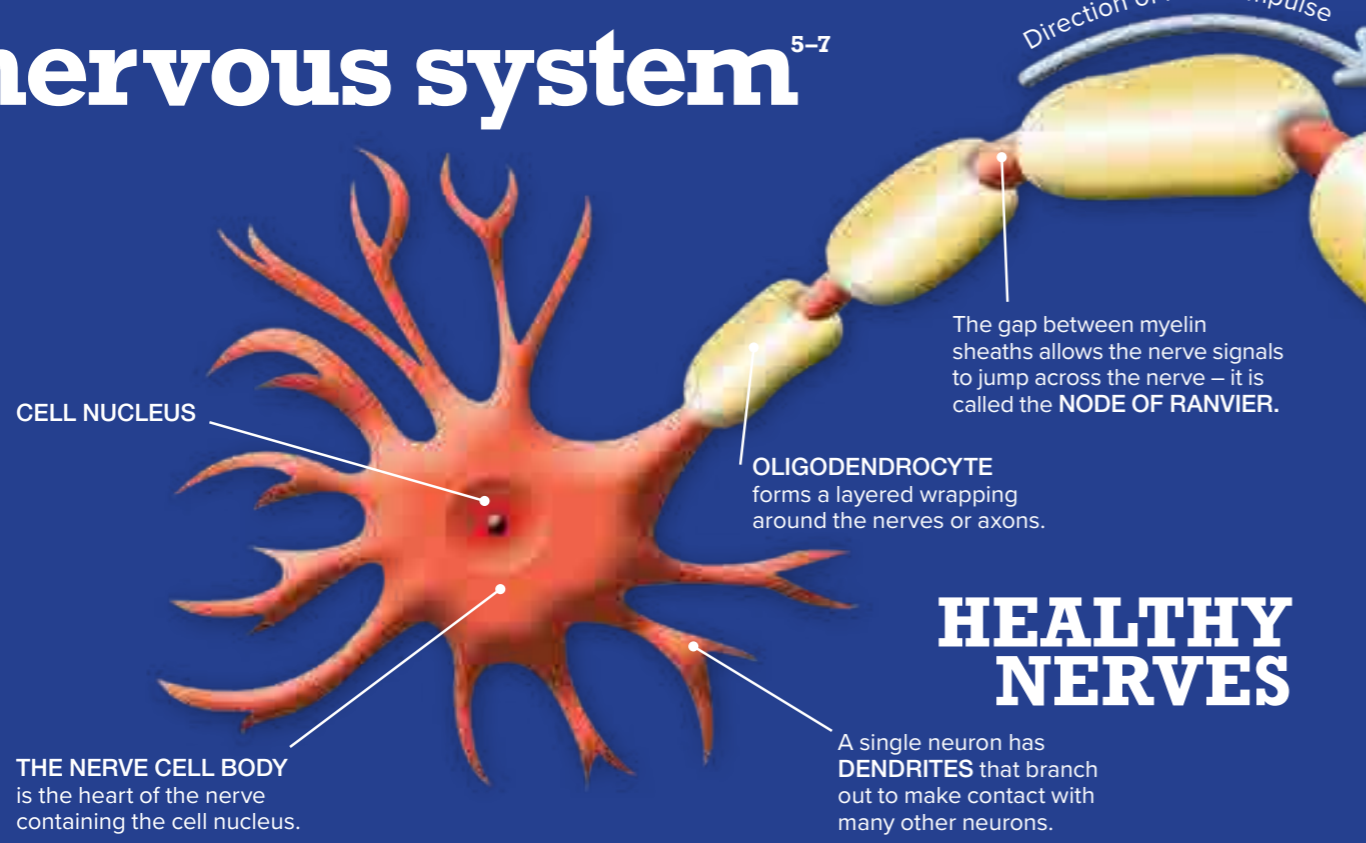
Most nerves inside and outside the brain are wrapped in layers of a fatty substance – called myelin – that forms an insulating cover, called the myelin sheath. The myelin sheath allows the electrical impulses of the nervous system to travel quickly and accurately along the nerve fibres (axons) to and from different parts of the body. This process permits smooth, rapid and co-ordinated movements to be performed, with little conscious effort, as well as the accurate interpretation of sensations the body receives. If the myelin sheath is damaged and scarred by inflammation, the nerves do not conduct impulses normally.^{1,3-6}

MS is a disorder in which the body's own immune system seems to cause damage to the nerves in a person's brain and spinal cord.³

Myelin sheaths insulate nerves much like the plastic covering around electrical wiring. A fatty substance, myelin is wrapped in layers around nerves. When these myelin layers are injured, nerve impulses can leak away, which can affect areas of body function such as movement and vision.^{1,3-6}

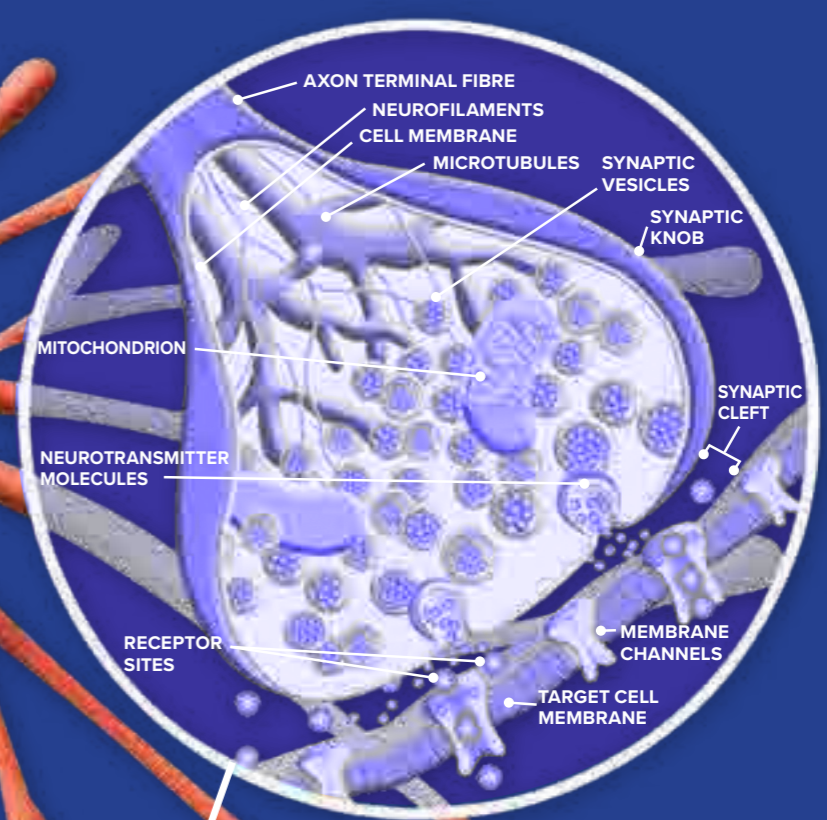


A look at the nervous system⁵⁻⁷



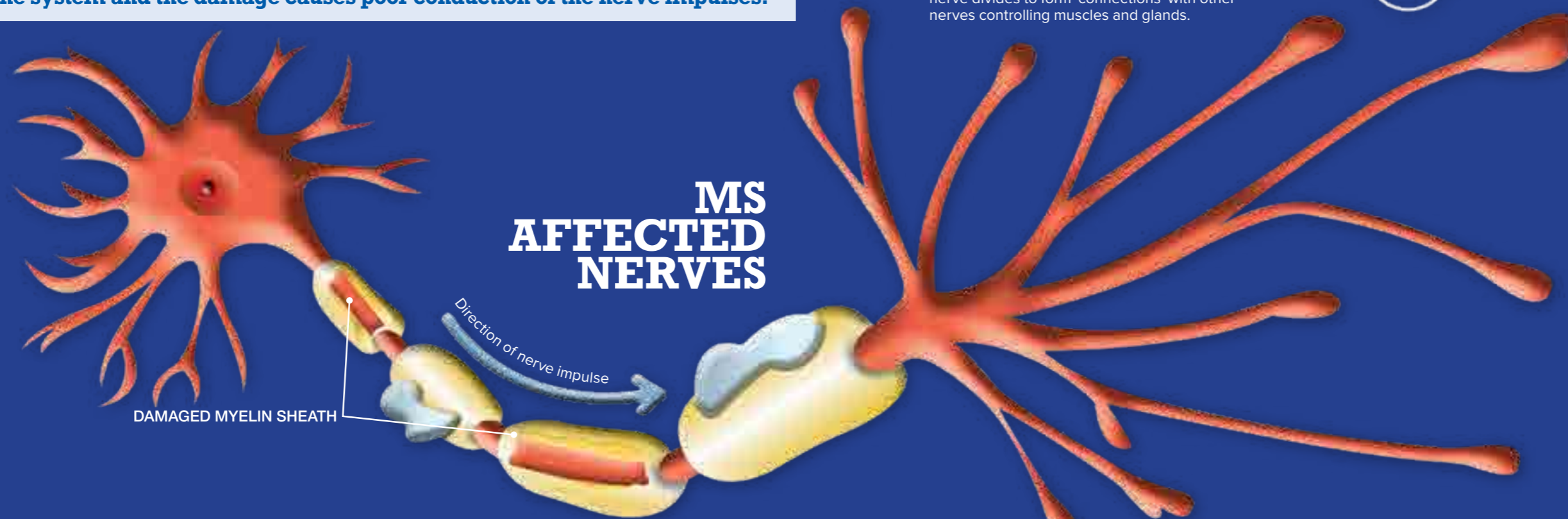
MYELIN SHEATH insulates the nerve fibre or axon. It is formed by oligodendrocytes.

NERVE FIBRES or **AXONS** carry the body's electrical impulses away from the cell body to glands and muscles.



AXONS are nerve fibres, which can be up to a metre long. Axon terminals are where the nerve divides to form 'connections' with other nerves controlling muscles and glands.

At the heart of the nervous system, neurons act like electrical wiring. They receive signals and carry that signal from one part of the body to another via the central nervous system. In MS, the myelin sheath is 'attacked' by the body's immune system and the damage causes poor conduction of the nerve impulses.



A **MACROPHAGE** is one of the cells of the immune system that attacks and removes the damaged sections of myelin, causing poor or non-existent electrical conduction.

What is MS?

What happens when you have MS?

Multiple sclerosis gets its name because multiple areas of the brain and spinal cord are affected and the disease causes the development of sclerosis (scar tissue) in damaged areas of the brain and spinal cord.^{1,6}

In cases of MS:^{1,5-7}

- The cells in the CNS that are responsible for making and maintaining the myelin sheath appear to be attacked by the body's immune system, causing inflammation and swelling
- The myelin of affected nerves then begins to break down (a process called demyelination) and can gradually disappear, being replaced by scar tissue (a process known as sclerosis or plaque formation)
- The flow of electrical impulses along affected nerve fibres therefore becomes disrupted or even blocked
- This results in symptoms, such as muscle weakness, which may affect any part of the body.

Who gets MS?

MS is usually first diagnosed between the ages 20 and 40 years in Australia and 20 and 50 years in New Zealand, and about three times as many women have MS as men.^{3,4}

In Australia, an estimated 25,600 people have MS.³ In New Zealand, there are approximately 4,000 people diagnosed with MS.⁴ Research suggests that MS may be more common in some types of ethnic groups, such as Caucasians.³

It is not known whether the increasing prevalence of MS is due to doctors making earlier and more accurate diagnoses or other environmental factors.⁴

Partially demyelinated nerve fibres do not operate correctly, causing symptoms such as muscle weakness that may affect any part of the body.^{1,6,7}

Causes of MS

Unfortunately, there is no single cause of MS. Studies have shown that a combination of genes, and environmental and lifestyle factors may contribute to the development of MS.³

Family history

MS is not inherited from your parents, with most people who develop MS having no known family history. There are, however, a number of genes (in combination with other environmental factors) that may be involved in increasing a person's susceptibility to developing MS.³

Infection

A number of viruses have been linked to MS, including the virus that causes glandular fever (Epstein-Barr Virus). However, by the time adulthood is reached, many people have had glandular fever, and so just getting the virus does not necessarily mean you will develop MS.³

Smoking

It is well-understood that smoking can significantly increase the likelihood of developing MS. In fact, people who smoke or inhale smoke second-hand are two times more likely to develop MS.³

Geographic location

Interestingly, MS is more common in regions further away from the equator. In Australia for example, people living in Northern Queensland are two times less likely to develop MS than people living in Tasmania. The exact reason why geographic location impacts the development of MS is still unclear, but lower amounts of ultraviolet light and a decrease in levels vitamin D in the body (which you get from the sun) may play a key role.³



Symptoms of MS

Not everyone with MS will experience the same symptoms. MS symptoms can also be unpredictable and quite diverse depending exactly where the central nervous system is affected.³

There are five main parts of function MS can affect. These include: motor control, fatigue, bladder/bowel dysfunction, neuropsychological symptoms and neurological symptoms.³



Some common MS symptoms³

- Memory changes, including changes in concentration
- Slurring/slowing of speech
- Difficulties swallowing
- Extreme tiredness (this is different to usual everyday fatigue)
- Altered sensation (tingling, numbness, pins and needles)
- Altered muscle tone (weakness, tremors, stiffness, spasms)
- Difficulties walking, balance problems or coordination issues
- Visual disturbances (blurred or double vision)
- Dizziness and vertigo
- Emotional and mood changes
- Pain
- Sexual changes
- Bladder and bowel changes
- Heat and/or cold sensitivity



Fatigue

This is a very common symptom that occurs in ~80% of people with MS. This type of fatigue can interfere with a person's ability to function and is not like normal everyday tiredness.^{4,8,9}

Numbness and tingling

Numbness can occur in the face, body, arms or legs and is commonly one of the first symptoms of MS.⁸

Weakness

The weakness experienced in MS usually results from damage to the nerves that stimulate the muscles, or because some muscles are not being used as much anymore. This is usually managed with rehabilitation and the use of mobility aids.⁸

Walking difficulties

Difficulties walking is usually due to other symptoms of MS, such as muscle weakness, spasticity and fatigue. Usually, any walking issues can be aided by physiotherapy and walking aids.⁸

Spasticity

This includes a variety of different symptoms, such as feelings of stiffness and involuntary muscle spasms. These spasms can occur in any limb, but are more common in the legs.⁸

Vision problems

Having vision problems is often seen at the onset of MS. Blurred vision, poor contrast or pain in one eye should be evaluated quickly by a doctor.⁸

Bladder and bowel problems

Bladder dysfunction is common and occurs in at least 80% of people with MS. Bladder issues can usually be managed well with medications, watching fluid intake and sometimes catheterisation. Additionally, constipation and loss of bowel control can also be a symptom associated with MS.⁸

Cognitive changes

This refers to high-level brain functions, including the ability to process information, learn/remember new information, focus and accurately perceive the surrounding environment.⁸

The symptoms of MS can be unpredictable and diverse.³ If you experience any new or worsening symptom(s) or are worried, please speak to your neurologist who will be able to help introduce management strategies.

How is MS diagnosed?

MS is not easy to diagnose. There is no single test for MS and the disease presents differently in each person. In addition, other diseases of the CNS are often associated with similar symptoms to MS.³

MS is typically diagnosed by observing symptoms over a period of time, combined with the results of medical tests. That is why there is often a delay between the first appearance of symptoms and a confirmed diagnosis of MS.³ General practitioners or optometrists (if initial symptoms affect vision) may suspect MS, but unfortunately they cannot make a diagnosis. Neurologists who specialise in MS are best trained to provide a diagnosis and prescribe a treatment plan.³

Some common medical tests that help to diagnose MS include:³

- Magnetic resonance imaging (MRI) – a scan of the brain and spinal cord
- Lumbar puncture – to collect cerebrospinal fluid (CSF) from around the spine for analysis
- Neurological examination – to examine your senses and function.

A definitive diagnosis of MS is made when a person has evidence of two separate MS attacks at different times and/or lesions in the brain and spinal cord that show previous attacks.¹ Doctors follow specific diagnostic criteria for MS and this is one of the reasons why it can sometimes take time to determine whether a person has MS, and if so, the type of MS.^{1,6}

Doctors may suspect MS in people who develop coordination and movement problems, numbness or changed sensations such as pain or tingling, and/or sudden blurred or double vision.^{3,4,6}

Neurological examination

This includes checking your movement, coordination, vision, balance and reflexes. Doing this type of examination not only helps to diagnose MS, but may also look at how far MS has progressed and whether damage to your central nervous system has already occurred. To specifically test for damage to your nerves, your neurologist may perform what is called an evoked potentials test. This test looks at how fast messages are travelling from parts of your body to your brain.^{1,3,6}

MRI

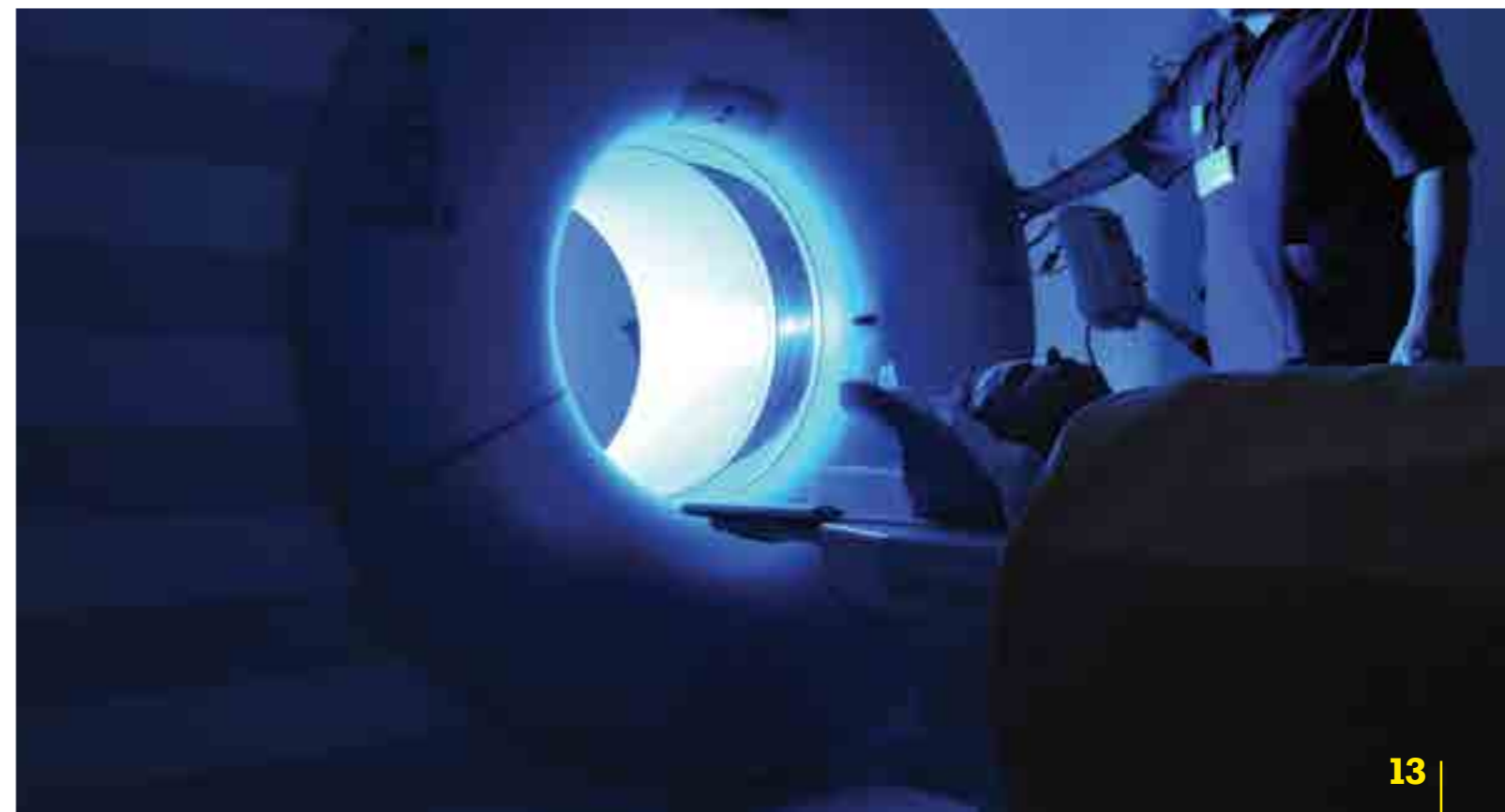
MRI involves the use of a strong magnetic field to create detailed pictures of the brain and spinal cord. MRI scans can reveal areas of inflammation and scarring in the brain, even before a person has developed symptoms. They can also be used to monitor changes in the brain over time.^{1,3,4,6}

This information is for educational purpose only and is not intended to be used for any self-diagnosis purposes nor to replace the advice of your neurologist or healthcare professional.

Lumbar puncture

A lumbar puncture involves a small amount of cerebrospinal fluid (CSF) taken from inside your spine to examine if any specific proteins are present. CSF is used in conjunction with other tests to help diagnose MS.^{3,4}

A definitive diagnosis of MS is made after at least two separate attacks and/or lesions in the brain and spinal cord that indicate previous attacks.¹



Coming to terms with a diagnosis of MS

Coming to terms with a diagnosis of MS may take some time. Following the diagnosis, it is common to experience emotions such as shock, fear, sadness or anger. Some people become depressed or have trouble sleeping and eating. If a person's symptoms are only mild or appear to have resolved completely, they may even doubt or deny the diagnosis of MS. For others, the diagnosis may adversely affect their confidence and self-esteem.

Having MS can be a challenge and it may take a while before the implications of the diagnosis become clear to you. It may mean that you have to consider changes to your lifestyle or environment. An immediate concern can be deciding whether to tell other people, such as family members, friends, work colleagues or employers, and when to do so.

Talking to your neurologist, a counsellor, psychologist or MS nurse can help you to deal with some of these feelings and issues. These people will also be able to assist you in developing suitable strategies to deal with your condition. You might also benefit from talking with other people who have MS, either one-on-one or as part of a support group. Your local MS Organisation will be able to assist you in this regard.

Most importantly, if you have been diagnosed with MS, remember that a number of approved treatments are available. Although they cannot cure the disease, they may help to manage symptoms, reduce the risk of relapse, slow the development of disability and disease progression.

Don't be afraid to share your concerns with people who can help, such as your neurologist, a counsellor or a MS nurse. Remember that there are treatments to help manage symptoms, reduce relapses and slow the development of disability.



Different types of MS

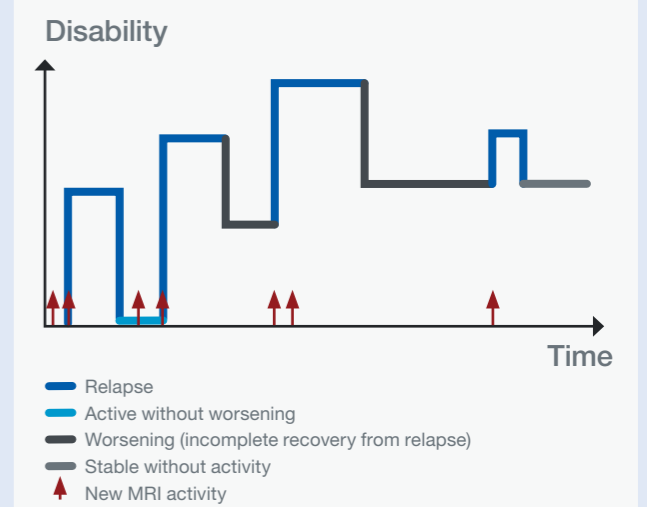
Both the symptoms and the course of MS can vary considerably from person to person. The condition may progress or regress unpredictably. Some people have only mild symptoms throughout their lives, while others have episodic attacks that cause residual effects or progressive worsening. In about a quarter of cases, having MS will not greatly affect a person's daily life.^{1,3,4,6}

Relapsing Remitting MS accounts for approximately 85% of new diagnoses in people who are first diagnosed with MS.^{3,4}



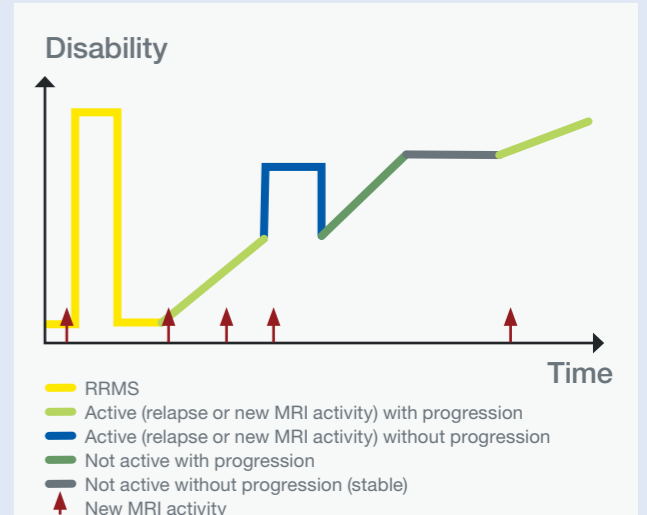
1) Relapsing remitting MS (RRMS)

RRMS is the most common disease course, where defined attacks or increased neurological activity is followed by periods of complete or partial recovery/remission. During these periods of recovery, all symptoms may go away, but some may also remain permanent.^{3,9-12}



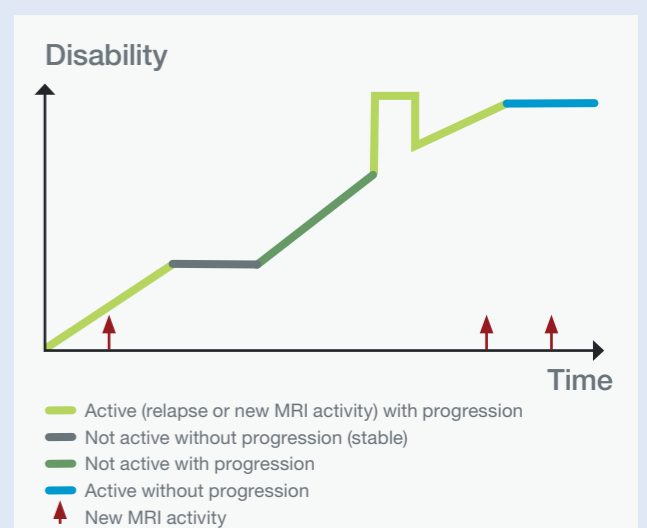
2) Secondary progressive MS (SPMS)

Initially, SPMS can follow the same course as RRMS. For some people with RRMS, they will at some point transition to this secondary progressive course of MS defined by the slow and progressive worsening of neurological function (this means an accumulation of disability over time that is not associated with relapses).^{3,9-12}



3) Primary progressive MS (PPMS)

This type of MS follows a progressive course from onset/diagnosis, without any remissions. In PPMS, you can have periods where the disease is stable, with or without relapse or new MRI activity. You can also have periods with increasing disability with or without new relapses or lesions on MRI.^{3,9-12}



Images adapted from Lublin FD. 2014¹¹ and Lublin FD et al. 2014.¹²



What is an MS relapse?

A relapse is usually defined as a new symptom or deterioration of an existing symptom that lasts for more than 24 hours. Relapses are also often called exacerbations or 'attacks'.^{3,4}

When the inflammation responsible for a relapse subsides, repair of the myelin sheath can begin to take place. When this occurs, the severity of relapse symptoms tends to decrease and the relapse symptoms may disappear altogether.^{1,3,4,6}

Remission defines the period during which a person's MS is stable and there are no new symptoms. It is important to remember that, even during remission, individuals may have ongoing symptoms related to previous MS relapses or problems. The timing, frequency and severity of relapses may be quite unpredictable.^{4,6}

The important thing to remember about any MS relapse is that an affected person will generally experience improvement afterwards. Severity of symptoms may decrease and the body may begin to repair damaged nerve tissue. However, recovery from a relapse may be incomplete and the amount of recovery can also vary from relapse to relapse.^{3,4,6}

A relapse is usually defined as any new symptom, or a deterioration of an existing symptom, which lasts more than 24 hours. The important thing to remember is that an MS relapse is generally followed by some level of recovery, with the symptoms either completely or partially disappearing.^{3,4}

Pregnancy and MS

For people with MS, there are several issues to consider when planning to have children.

MS is not automatically passed on to children, but the exact transmission risk is not known. If one parent has MS and decides to have a family, there is only a small chance that the child will develop MS over his/her lifetime; the risk is estimated to be around 4–9.8%.^{13,14}

Interestingly, when a woman with MS becomes pregnant, her MS is generally less active and relapses tend to occur less frequently. However, during the first three months after the birth of a child, relapses can become more frequent. It is not possible to predict what will happen for individual women, but it is important to try to be prepared for any eventuality. Overall though, the risk or relapse is similar to that of a woman with MS who is not pregnant.^{6,14,15}

You should consult your neurologist if you are planning to start a family or become pregnant while taking medication for your MS.

Finally, be aware that bringing up children may present additional challenges when one of the parents has MS. You may need extra help because of general fatigue, the flare-up of MS-related symptoms or when symptoms progressively accumulate.

Trauma and MS

There is no evidence that trauma or extreme stress causes MS, triggers symptom and flare-ups or affects the progression of MS in any way. What is known is that some people with MS don't cope easily with their symptoms when they are exposed to stress. However, it is important to understand that psychological or emotional factors, including stress, do not appear to directly affect the course of MS.^{16,17}



Vaccinations

Recent studies have shown that vaccinations do not increase the long-term risk of development MS.¹⁸ It is also important that you speak to your neurologist about any vaccinations you are due to receive as most people with MS should still be able to receive most vaccinations.¹⁹



Treatment of MS

Although there is no cure for MS, research is ongoing to develop treatments that might better prevent or limit the damage, symptoms and disability caused by the disease. Doctors now have a much better understanding of how MS develops and how symptoms are produced. These advances have led to new approaches to treatment, including the development of medication that can help to modify the course of the disease.³



The aim of medication when treating MS is to either provide relief of symptoms or to reduce the risk of relapses and MS progression.²⁰ The type of medication prescribed by your neurologist depends on a number of factors, including the type of MS.²⁰

Corticosteroids (steroids)

Steroids are to help control the severity of an MS attack. They work by reducing inflammation.²⁰

Immunosuppressants

Medications that dampen down your immune system can sometimes be prescribed for people with MS, usually those with progressive MS.²⁰

Disease-modifying therapies (immunotherapies)

These medications work by modifying how active the immune system is. The goal of immunotherapy is to slow the frequency and severity of MS attacks on the central nervous system, meaning that the myelin sheaths are not damaged as often or as severely.²⁰

Always consult your neurologist if you have any questions about your MS treatment.

People with MS may be taking a number of medications to treat certain symptoms associated with MS. As with all medications, you may experience some side effects. It is important that you share any concerns you have with your neurologist before starting or during any of your treatments. If you develop any side effects you think are a result of your medication that is concerning, you should seek the advice of your neurologist as soon as possible.



Living with MS:

Tips for getting
the most out of life



Living with MS: Your Body

Regular exercise

Research suggests that exercise can help to improve the overall health of people who have milder MS, as well as help those with more severe MS stay as mobile as possible.⁴

Exercise can also help manage some of the symptoms associated with MS, such as fatigue, muscle stiffness, anxiety, depression and bladder/bowel problems.⁴

Before starting any new exercise program, it is important to consult with your neurologist to determine what is appropriate for you as some exercises may make some existing MS symptoms worse.⁴

Maintain a healthy weight

Maintaining a healthy weight is important. There is a lot of evidence to show that increased body weight and obesity are linked to more MS lesions. Even though there are a number of diets available on the internet, you should always speak with your neurologist who can refer you to an appropriate healthcare professional like a dietitian.³

There are many positive changes you can make to help you feel in control of your lifestyle, as well as maintain your overall health and wellbeing.

Don't smoke

Cigarette smoking adversely affects the progression of MS and has been linked to higher relapse rates, increased disability progression, more cognitive problems and reduced survival.³

- If you have MS, it is advisable not to smoke
- Call or visit the website of your local Quitline:
 - Australia:
13 78 48
www.quit.org.au
 - New Zealand:
0800 778 778
www.quit.org.nz

Living with MS: Your Body *(cont'd)*

Minimise fatigue

You can do many things to help minimise fatigue and/or the impact of fatigue on your life; for instance, you can:^{4,9}

- Do regular exercise (this may help to reduce fatigue)
- Prioritise activities and learn to pace yourself (this can help you to make the most of the energy you have)
- Plan your activities in advance (e.g. before going out, find out where the nearest parking is; ask for a restaurant table close to the entrance; consider booking a wheelchair if going on an outing where lots of walking may be required)
- Develop a daily routine that suits you (e.g. if you are more tired at the end of the day, do more strenuous tasks earlier and plan to rest in the afternoons)
- Be energy-efficient (e.g. organise your surroundings so that frequently used things are within easy reach; use a portable phone; sit down while doing tasks such as cooking; plan menus before going shopping; take advantage of lifts and escalators; use parking spots for people with disabilities)
- Eat regularly (skipping meals may reduce your energy levels)
- Delegate whenever possible (i.e. accept and ask for help from family and friends; get outside help for routine cleaning and ironing).

Monitor your bladder and bowel function

Bladder and bowel problems are common in people with MS. The good news is that there are lots of things you can do to help minimise bladder problems if you experience them. For instance, you can:^{4,9}

- Drink plenty of water during the day (about 2 litres) and minimise fluid intake in the evenings
- Try to urinate regularly
- Limit your intake of alcohol, coffee and soft drinks that contain caffeine
- Tell your neurologist about symptoms, such as an inability to hold urine or difficulty emptying the bladder (medications are available to help with these conditions).

To help minimise bowel problems, you can:

- Make sure your diet contains plenty of fibre, such as fruit, raw vegetables and wholemeal bread
- Be active every day, whenever possible.

Make the most of the energy you have by prioritising what is important to you, making sure you balance rest periods and activity.

Reduce your body's sensitivity to temperature

Many people with MS report a worsening of symptoms following an increase in temperature or after exercise.^{3,4,9}

It is important to understand that a rise in body temperature does not make MS more aggressive or progressive; it can simply lead to a temporary worsening of pre-existing symptoms (i.e. until the person cools down) and doesn't cause lasting damage.^{3,4,9}

There are several things you can do to help minimise these effects; for instance:^{3,4,9}

- Avoid extremes of temperature
- Avoid exercising in the heat of the day
- Do regular exercise for shorter periods, rather than doing long sessions less frequently
- Make the most of air-conditioned places during very hot weather
- Consult your neurologist if you are sensitive to temperature.



Living with MS: Your mental health

Do things to reduce anxiety

It is normal to feel anxious about your condition and how it will affect your lifestyle.^{3,4,9}

There is also a lot you can do to help minimise these feelings; for instance:^{3,4,9}

- Learn more about your disease (e.g. speak with your neurologist, GP, other healthcare professionals and/or MS societies)
- Find a support group, to meet and talk to others who have MS, share experiences and ask questions about how others cope with symptoms that worry you
- Plan ahead (e.g. before you go on an outing, phone ahead to find out about parking, nearby bathrooms and air-conditioning etc.)
- Avoid isolating yourself from others (i.e. maintain regular contact with family and friends)
- Set aside regular time to relax and perhaps try massage or meditation
- Enlist the help of friends and family to deal with MS-related problems
- Talk with a counsellor about coping strategies
- Be cautious about information or advice from well-meaning friends, as it may make you unnecessarily anxious and concerned.

Maintain your self-esteem

Living with MS can affect how you see yourself. You may experience periods of low self-esteem and/or lack the self-confidence you used to have.

There are many things you can do to help improve your self-esteem; for instance:

- Continue to value yourself and what you have to offer
- Set yourself goals and be prepared to take small steps to achieve them
- Praise yourself when you achieve your goals
- Try to plan things in advance, so that you always have something to look forward to
- Take time out for yourself, as well as spend time with supportive friends and family
- Participate in regular activities that are enjoyable and achievable
- Try to remain positive (i.e. look at your situation as a fresh beginning and focus on the good things in your life).

If you have any concerns, always consult your neurologist or other healthcare professional. They are there to help.

Use memory aids

In some cases, MS can affect particular mental functions, such as a person's memory, ability to plan, foresight and judgment.^{3,4,9}

There are many things you can do to help address memory problems; for instance:^{3,4,9}

- Keep a diary or organiser and use it to record appointments, phone numbers and driving directions
- Make lists (i.e. when shopping, planning the day's activities)
- Keep a family calendar at home and record family members' appointments and commitments
- Organise your environment so that things remain in familiar and set places
- Let family and friends know that you are having trouble with your memory, so that they can help you
- Ask people to keep directions simple
- Repeat information and write down important points
- Consult your neurologist for an evaluation if you are having increased trouble remembering things or organising daily activities, experiencing lapses of judgment or if it is becoming harder to stay focused on specific tasks.



Address mood swings or feelings of depression

If you are experiencing mood swings or depression, it is very important to talk with your neurologist. Depression can be effectively treated in a number of different ways (e.g. via the use of appropriate professional counselling and/or antidepressant medication).^{3,4,9}

You should also try to:^{3,4,9}

- Remain involved or engaged with family and friends (i.e. avoid isolating yourself)
- Continue to participate in regular and enjoyable activities.

Living with MS: Your sex life

Intimate relationships can change when a person has MS. Relationships often change because of poor communication or misunderstandings, rather than the direct consequences of MS.^{3,4,9}

Do not hesitate to talk with your doctor or nurse about strategies to deal with the physical changes that can affect your sex life; for instance:^{3,4,9}

- If you are too tired for sex, choose a time of day when you usually have more energy and, if practical, have a rest beforehand
- Try different positions to compensate for weak or tight muscles
- Let your partner know if your skin is oversensitive or if you have areas of numbness, so that they can stimulate other erogenous zones

- If you are worried about incontinence, go to the toilet before intercourse
- If you have vaginal dryness, lubricating jelly can be useful
- Use of muscle relaxants can help to reduce leg spasms (spasticity)
- Discuss male sexual-related issues with your doctor, as there are now several different treatments available
- Try to be open and honest with your partner, and be prepared to experiment
- If you use a catheter, talk with your doctor about your options regarding sexual activity.

Living with MS: Your relationships

A diagnosis of MS can increase the stress on relationships with family and friends. It is important to communicate your feelings to family and friends, and let them know how you are feeling. Many people choose not to tell their friends or colleagues, as they fear these people will see them differently.^{3,4,9}

Your partner

- Acknowledge your partner's feelings and anxieties about your condition
- Work together to overcome difficulties
- Talk with a counsellor or social worker if you are worried about the effect your MS is having on your relationship, especially if you are concerned that there is a burden on your partner or that you are becoming more dependent on your partner
- Encourage your partner to have time out for themselves, even if this means getting some help from friends or other family members.

Your children

- Listen to and acknowledge your children's questions, and take time to talk to them about your condition
- Don't hide the truth about your condition
- Let them know that you get frustrated or angry at times
- Educate your children about MS, giving straightforward and honest explanations (provide age-appropriate explanations to each child)
- Consider the child's preferences when deciding how to best explain things (i.e. some children may prefer to read a book about MS while they are alone, while others may prefer to sit with you and watch a video about MS)
- Involve your child, by asking him/her to help out around the house, assist with shopping, or walk the dog, and so on
- Consider family counselling.



Living with MS:

Your daily activities

Regardless of how long you have had MS or the symptoms you currently have, it is important to use your energy efficiently throughout the day. The following suggestions may help.^{3,4,9}

Shopping

- Shop with a friend or carer (this can help to reduce the stress and fatigue of shopping)
- Shop at times of the day when you have more energy, and rest afterwards
- Take advantage of home delivery services
- Order groceries over the internet
- Say 'yes' to friends who offer to do some shopping for you.

Cooking and housework

- Sit down to prepare meals
- Try sitting on a high stool with a footrest to cook
- Encourage children to put away their own toys and involve them in daily tasks
- Use electronic aids, such as food processors, electric cutting knives and can openers
- Spread tasks over a period of time, rather than trying to do everything at once.

Personal care

- Sit down while washing and showering
- Use an electric toothbrush and floss holder
- Sit down while dressing.

Going out

- Plan ahead (i.e. before going out, call and ask about the closest place to park)
- When going to a restaurant, ask for a table that is easily accessible and close to the entrance (or bathroom if necessary)
- If going to a large complex or park, consider using a wheelchair if required.



Your home & environment

There is much you can do to make your home more accessible and safe. The following suggestions may help.^{3,4,9}

Around the home

- Make sure floor surfaces are not slippery (e.g. ensure that carpets and rugs are on non-slip pads; fix any loose floor boards)
- Store frequently used items within easy reach to reduce reaching and bending
- Install handrails for stairs
- Consider installing handrails in the shower or bath
- Ask an occupational therapist to assess your home and recommend changes that will make your home more accessible.

Safety

- Keep a portable or mobile phone within reach
- Keep batteries and torches in accessible places
- Establish a network of friends and family who can help you, if and when you need it
- Have night lights around your home
- Have a strategy for evacuating your house in the event of fire and practice it several times per year
- If you have trouble with your hearing, get a smoke detector with a visual signal.



Living with MS: Your work

Work is very important to most people but symptoms such as fatigue or issues with walking or balance may present challenges for you.^{3,4,20}

There are many things you can do to help minimise the impact that having MS might have on your ability to work; for instance:^{3,4,9}

- If you get tired in the afternoons, try to do as much as you can during the morning and rest at lunch time
- If you start to feel tired, try taking a short break and do some mild exercise that may help to wake you up
- Sit in a chair with arm rests and good back support
- Arrange your desk so that frequently used things are within easy reach
- Make sure your chair is at the correct height to maintain good posture
- Make sure that you have good lighting over your work area
- If parking is available, arrange to have a spot close to the entrance of your building.

You may have questions about when and who to disclose your diagnosis to at work. Your neurologist, MS nurse or MS Organisation can help with these questions.



Living with MS: Your leisure time



It is always very important to set aside time for fun activities, whether you have MS or not. Such activities may be creative, social, physical and/or intellectual, and can help to take your mind off your MS.^{3,4,9}

People who have MS are advised to:^{3,4,9}

- Do things that are achievable and fun
- Do some things that include friends and family, as well as things for yourself
- Do occasional spur-of-the-moment things (if/when practical)
- Take time out to rest and relax on a daily basis.

Frequently asked questions about MS



Living with MS

How do I know my MS is getting worse?

This is a difficult question to answer. In general terms, the appearance of a new symptom often indicates the occurrence of an MS relapse or 'attack'. Although it is very common for people with MS to experience various symptoms that may come and go, like tingling, tiredness and poor balance, these sensations are not necessarily a sign that your MS is getting worse. Similarly, urinary problems or other symptoms may be due to something other than your MS. If you are concerned it is best for you to speak to your neurologist.^{4,9}

Can the nervous system repair itself after a relapse?

The nervous system is capable of repair after an MS relapse or 'attack'. The medical research community is working hard to identify and develop treatments that might assist or optimise this repair process.^{1,3,4,9}

What is optic neuritis and is it always a symptom of MS?

Optic neuritis is caused by inflammation in the nerve that connects the eye to the brain. Optic neuritis is a very common symptom of MS and, in many cases, is the first symptom that appears. However, it is important to remember that not all people with optic neuritis will go on to develop further symptoms of MS.^{4,9}

Can trauma affect the course of MS?

There is no evidence that trauma affects the course of MS. Some MS symptoms may increase the chance of an accident, however; speak with your healthcare team about ways to manage your symptoms and reduce your risk of injury.⁶

Can MS cause emotional symptoms?

MS can cause a variety of emotional symptoms. Indeed, emotional symptoms are considered to be an important part of the condition. Emotional symptoms in MS often require treatment in their own right and failure to accept their existence and have them treated may well compromise your MS treatment.^{3,4,9}

Can stress cause an MS attack?

There is no scientific proof that stress can cause an MS attack. However, as a general principle, most doctors feel that it is both logical and reasonable to manage stress, because it can have other adverse effects on a person's health.^{3,6,9,14}

Do any illnesses, such as a cold, trigger MS attacks?

There is reasonable evidence to show that a variety of infections may trigger MS relapses.^{3,4,6,9}

I love jogging, but sometimes my MS symptoms flare up afterwards: Is jogging doing any damage or accelerating the progression of my MS?

There is no evidence that exercising worsens MS and, in fact, the reverse is now thought to be true. The reason that some pre-existing symptoms may worsen with exercise is related to the body's core temperature. Exercise causes an increase in body temperature, which affects the function of the nervous system. With rest and cooling, the symptoms disappear.^{3,4,9}

Are there any types of exercise I should avoid?

All exercise is helpful, although it is logical for individuals with coordination or balance problems to avoid any exercise or sport that could result in a fall or injury. It may be reasonable to avoid extreme exercise where temporary muscle tiredness and weakness from the extreme effort may be more pronounced because of your MS and may cause you to get hot.^{3,4,9}

Will a special diet help my MS?

This is controversial. Some believe that a balanced diet is the most appropriate for patients with MS. Extreme diets may result in undesirable weight loss, while exclusion diets may result in other health issues. These questions would be best discussed directly with your neurologist or a qualified dietitian.^{3,4,9}

What particular vitamins and minerals should I be taking to help my MS?

Currently there is not enough evidence to support the use of any dietary supplements for people with MS.

You can obtain the vitamins and minerals you need from a balanced diet. A balanced diet, such as one based on the Australian Dietary Guidelines for the general population, will help you meet important nutritional needs.²¹

Right before I have my period, my MS symptoms worsen: Is there any correlation?

This phenomenon has been observed by some healthcare professionals.⁹ Discuss this further with your neurologist.

I love taking bubble baths but sometimes I 'tingle' afterwards: Can I still do this?

When bathing try not to let the water get too hot; hot temperatures can worsen MS symptoms. If MS affects your leg strength and balance, you should take care when getting in and out of a bath.^{3,4,9}

MS is not contagious and cannot be transmitted from person to person.³

Can I get a flu shot if I have MS?

Recent studies show that having an influenza vaccination does not increase a person's risk of MS relapse. However, you should always discuss this issue with your doctor before arranging to have a vaccination.¹⁷

Can I still drive with MS?

Possible factors that can affect driving could be associated with having problems with arm, leg or specific visual functions, resulting in safety concerns when driving. If these issues apply to you, or you have related questions, you should discuss them further with your neurologist.⁹

If I have MS, can I drink alcohol?

There is no evidence that alcoholic beverages are any more harmful for people with MS than they are for people without the disease. However, alcohol can temporarily worsen MS symptoms such as fatigue and coordination, impact some medications used to manage MS and its symptoms, and increase the risk of developing other health conditions that could worsen MS.^{3,4}

Is MS ever fatal?

In most cases, MS does not markedly affect a person's life expectancy.^{3,4,9}

For people who have relapsing remitting MS, what does being in remission actually mean?

The term remission applies to individuals who are not developing new MS symptoms. If a patient has pre-existing symptoms, which have been present for some time, then they are in remission. Being in remission does not mean being symptom-free.^{3,4,9}

My friends ask whether you can catch MS: what should I say?

MS is not transmissible. Detailed studies demonstrate that MS cannot be passed from person to person.³

I have read a lot about sunlight and MS: What should I be doing in this regard?

This issue remains the subject of some debate. There is some indirect epidemiological evidence that suggests higher sun exposure during childhood and early adolescence is associated with a reduced risk of MS due to Vitamin D levels. Insufficient ultraviolet radiation may therefore influence the development of MS.^{3,4,6} It is best to ask your neurologist for more information on this.

Health professionals and MS management

A wide range of different health professionals work with people who have MS.⁴

Your general practitioner (GP) will refer you to a neurologist, a type of specialist who treats problems related to the nervous system. A neurologist will perform neurological examinations to assess your strength, co-ordination, sensation and reflexes, and will also refer you for specialised tests, such as MRI scanning, lumbar puncture and nerve conduction tests (i.e. using evoked potentials).

Your neurologist may also continue to see you on a regular basis, to monitor your condition and make any necessary changes to treatment. A specialist MS nurse can provide specific education and training about MS medications and the possible side-effects of treatment, in addition to offering useful information and advice about the likely impact of MS on your daily life.

MS nurses may be contacted through your local MS Organisation, larger metropolitan hospitals or via your neurologist. Some private nursing agencies can also provide an immunotherapy training service.

You may need to see other medical specialists while living with MS. Some of these additional specialists are listed in the table on the next page.



SPECIALIST	TREATMENT ROLE
Counsellor/ Social Worker	Can help to reduce the impact of MS on your personal, family, social and work relationships
Dietitian	Can help to devise a diet that best suits your specific needs and circumstances
Gynaecologist	Can help to address specific women's health concerns
Occupational Therapist	Can help to analyse daily routines and offer advice about how certain activities may be modified to better suit your specific needs or circumstances; can also recommend specific adaptations for the home or workplace
Ophthalmologist	Can help to address visual problems
Pharmacist	Can dispense and help provide information about the medications you have been prescribed
Physiotherapist	Can help to devise tailored exercise programs, designed to improve or maintain strength, mobility, balance and co-ordination
Psychologist/ Psychiatrist	Can help to address anxiety and other mood disorders, including depression
Rehabilitation Specialist	Can assist in co-ordinating physical rehabilitation and offer specific advice about how to preserve or maximise mobility
Sex Therapist	Can help to address sexual problems or difficulties
Speech Therapist	Can help to improve a person's ability to swallow or speak
Urologist	Can help to address urinary symptoms and some male sexual problems

Additional resources & information



This book has hopefully given you some basic information about MS, as well as some practical and positive suggestions for making the most of your abilities.

You can get further information from your neurologist or other healthcare professionals, and there are several national and state MS Societies that may also be of assistance to you.

MS Organisations in Australia

MS Australia

W: msaustralia.org.au

ACT/NSW/VIC/TAS

MS Limited – MS Connect

W: ms.org.au

QLD

MS Queensland

W: msqld.org.au

SA/NT

The MS Society of South Australia and Northern Territory – MS Assist

W: ms.asn.au

WA

MSWA

W: mswa.org.au

MS Organisations in New Zealand

MS New Zealand

W: msnz.org.nz

Northland MS Society

W: tiaho.org.nz/tiaho_support/northland-multiple-sclerosis-society-inc/

MS Auckland

W: msakl.org.nz

MS Waikato

W: mswaikato.org.nz

Bay of Plenty MS Society

W: bopms.co.nz

Rotorua MS Society

T: 027 925 3245 or 0276277621

E: msrotoruadistricts@gmail.com

Gisborne/East Coast MS Society

T: 06 868 8842

E: office.ms.gisborne.eastcoast@gmail.com

Hawkes Bay MS Society

W: hawkesbaymultiplesclerosis.org

Taranaki MS Society

W: mstaranaki.co.nz

MS Wanganui

W: mswanganui.org.nz

MS Central Districts

W: mscentral.org.nz

Wellington MS Society

W: mswellington.org.nz

Additional resources & information *(cont'd)*

Marlborough MS Society

T: 03 578 4058
E: mmss@xtra.co.nz

Nelson MS Society

W: msnelson.org.nz

West Coast MS Society

T: 03 768 7007
E: mspdwestcoast@gmail.com

MS & Parkinson's Society of Canterbury

W: ms-pd.org.nz

South Canterbury MS Society

W: mssouthcanterbury.org.nz

Otago MS Society

W: msotago.org.nz

Southland MS Society

T: 03 218 3975
E: info@mssouthland.org.nz

**Can't find a
New Zealand MS society close to you listed here?**

Go to:
msnz.org.nz/contact-your-regional-society/
and enter your region.

Websites

A great deal of information about MS can be found on the internet, but the quality of information can be variable. It is important to discuss any treatment issues or concerns with your neurologist or other health professionals.

Useful websites include:

MS Australia
www.msaustralia.org.au

MS Society of New Zealand
www.msnz.org.nz

Multiple Sclerosis
International Federation
www.msif.org

Note: These website addresses are provided for your convenience only. The websites listed (and any website linked to them) are not operated or controlled by Biogen Australia Pty Ltd or Biogen NZ Biopharma Limited and therefore Biogen Australia Pty Ltd and Biogen NZ Biopharma Limited are not responsible for the content found on them.

Glossary

Autoimmune reaction:

A process by which the body's immune system attacks its own tissues

Axon:

Part of a nerve cell which transmits the nerve signal, some axons are protected by a myelin sheath

Central nervous system (CNS):

The brain, spinal cord and optic nerve; controls the main bodily functions

Cerebellum:

The part of the brain that controls balance and co-ordination

Cerebrospinal fluid (CSF):

Fluid surrounding the brain and spinal cord; a sample of CSF is taken during a lumbar puncture

Clinically isolated syndrome:

A patient presents with a single demyelinating event, such as optic neuritis (visual disturbance) or a spinal cord symptom (e.g. weakness, sensory impairment), that may also be associated with changes on MRI that are suggestive of MS

Demyelination:

Process by which the myelin sheath around nerve fibres is destroyed, resulting in disruption of the flow of messages from the brain and spinal cord to other parts of the body and back again

Evoked potentials:

Technique used for measuring the speed at which signals travel along nerves

Exacerbation:

Also known as a relapse or 'attack'; an acute worsening of the signs and symptoms of a disease or an occurrence of new neurological sign or symptom

Immune system:

The system that protects the body against disease-producing organisms and other foreign substances

Incontinence:

Loss of control of urine or bowel movements

Inflammation:

Process causing swelling, pain and/or redness, which is part of the body's response to damage

Lumbar puncture:

Procedure in which a needle is inserted into the CSF space in the lower back and a sample of fluid is taken for analysis

Magnetic resonance imaging (MRI):

A diagnostic procedure in which a strong magnetic field is used to scan and create detailed pictures of a part of the body (e.g. the brain and spinal cord)

Myelin:

Fatty substance that surrounds some nerve fibres (axons), protecting and insulating them; helps electrical impulses to travel along the nerve fibre with speed and accuracy to the required parts of the body

Nerve impulse:

Electrical signal that passes along a nerve fibre (axon)

Neurogenic/neuropathic pain:

Pain resulting from abnormalities of central (CNS) or peripheral nerves

Optic neuritis:

Inflammation of the optic nerve (nerve that controls the ability to see)

Placebo:

An inactive substance that is usually administered to a patient to compare its effects with those of an active drug

Plaque:

Also known as sclerosis; a localised area of scar tissue

Relapse:

A deterioration in an illness; includes either the development of new symptoms or the sudden worsening of older symptoms

Remission:

Temporary recovery from disease (may last for years)

Spasticity:

Involuntary tightening of muscles (spasm), which stops them from relaxing

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Biogen Australia Pty Ltd,
ABN: 30 095 760 115, Macquarie Park NSW 2113

Biogen NZ Biopharma Limited,
188 Quay Street, Auckland, New Zealand TAPS Approval No: BG1161.

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