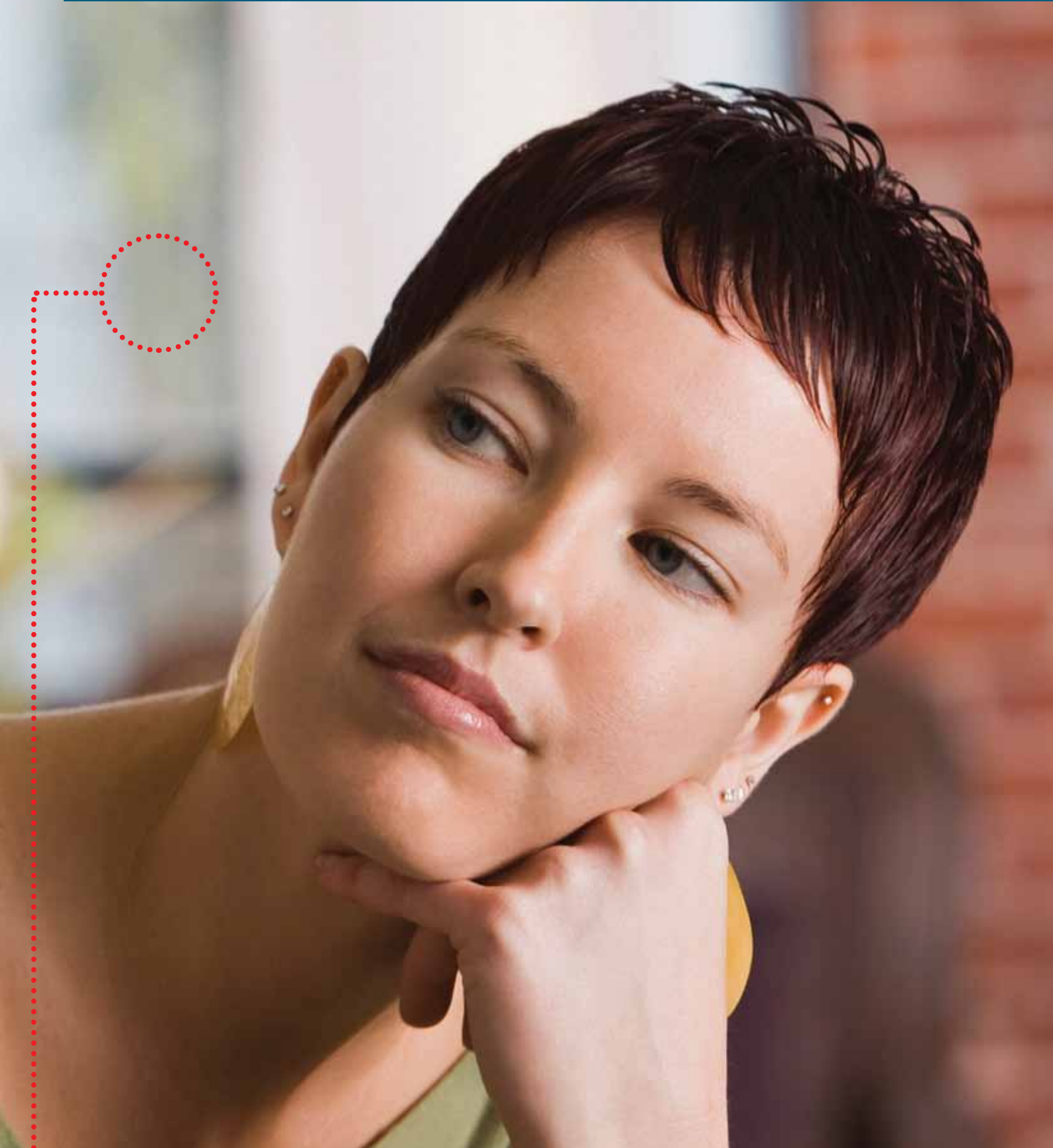




# Understanding MS

An Introduction for People Living with MS



Freecall™ 1800 042 138

[www.msaustralia.org.au](http://www.msaustralia.org.au)

**MS Australia** strives for a world without multiple sclerosis (MS) through quality research and for service excellence to people with MS, their family members and carers.

**MS information and support line:** 1800 042 138  
**[www.msaustralia.org.au](http://www.msaustralia.org.au)**

**Understanding MS: An Introduction for People Living with MS**  
**ISBN:** 978-0-9871186-4-6

**Published by:** Multiple Sclerosis Australia **ABN:** 51 008 515 508

**Disclaimer:** Information contained in this booklet should not be used for individual medical advice. Readers must seek their own medical advice as required.

**© Multiple Sclerosis Australia 2012**

All materials in this booklet is copyright and may not be reproduced in whole or in part without the express permission of Multiple Sclerosis Australia.

## **Contents**

<b>Introduction</b>	<b>02</b>
<b>Adjusting to a diagnosis</b>	<b>03</b>
<b>What is MS?</b>	<b>06</b>
<b>Medical treatments</b>	<b>15</b>
<b>Living well with MS</b>	<b>17</b>
<b>MS research</b>	<b>20</b>
<b>Where to from here</b>	<b>21</b>
<b>Glossary of terms</b>	<b>22</b>
<b>Bibliography</b>	<b>24</b>

# Introduction

**If you** are reading this booklet, you have probably just been diagnosed with multiple sclerosis (MS) or you have decided it is time to find out more about MS.

MS is a condition that affects the central nervous system (or CNS) which is made up of the brain, spinal cord and optic nerve. People with MS can experience a wide range of symptoms and can be affected differently at various stages in their life. While there is no cure for the condition, there are treatments and support available which can help to reduce its impact and symptoms.

After receiving a diagnosis of MS you may be asking yourself 'what do I do now?' This booklet is designed to help you gain a better understanding of MS and introduce you to the support available to help you live well. It may be useful to share this booklet with your significant others who would also like to know more about MS.

There are many misunderstandings about MS in the general community and online. With the current treatments available, MS does not necessarily lead to significant disability. What you imagine may happen can be far scarier than what you will experience. Knowledge is power and this booklet will inform you and direct you to sources of support.

Taking in too much information at once can sometimes be overwhelming. Try and read this booklet at a pace you find comfortable. Perhaps you can turn to the chapters you are ready to read and leave the others for a time when you are feeling less apprehensive. Remember, most people with MS learn to cope with the disease and continue to live a full and happy life.

MS Australia provides an easily accessible information and support line service, as well as a range of programs and services to help you deal with your diagnosis and the effect it may have on your life. Contact us on 1800 042 138 (Freecall™) to speak to one of our experienced staff. If you speak a language other than English and require an interpreter service, please turn to page 21 for more information.

## **This booklet is designed to assist by:**

- addressing some of the feelings and emotions you may experience at the time of diagnosis and throughout your journey.
- providing reliable introductory information about MS.
- directing you to sources of support and informing you of the treatments available that can help to reduce the impact and symptoms of the disease.
- encouraging you to live a full and meaningful life despite your diagnosis.

# Adjusting to a diagnosis

**For many** people a diagnosis of MS can be daunting. It is important to remember that you can have a full and meaningful life with MS.

Being diagnosed with a chronic condition is one of life's major challenges, so don't expect it will be easy to accept your diagnosis right away. It may take time. How much time is not something that can be pre-determined, as each person's experience will be different.

## Initial reactions

Initial reactions to a diagnosis can include a wide range of feelings, including shock and fear or even relief because you now have an explanation for the symptoms you have been living with. In this chapter you will find some of the common initial emotions you may experience after learning you have MS.

It is important to remember that these feelings are normal and you are entitled to have them. You will not necessarily experience all of them and they may not occur in any particular order. These feelings may also come and go. Over time you may have other reactions which will be determined, in part, by the types of symptoms you experience and the impact these symptoms may have on your lifestyle.

Although this situation may seem like one of the hardest things you have had to deal with, be mindful that you have, most likely, experienced other challenges in your life and you dealt with those challenges using your coping skills and inner strength. It is also important to acknowledge no-one is to blame for what is happening and MS is not caused by factors you or anyone else have any control over. If you feel these emotions are impacting on your wellbeing or relationships, speak to someone about how you are feeling. MS Australia or your GP can provide advice about seeking further support.

## Anger/resentment

It is common to feel angry or resentful toward MS itself because it has taken something away or made life difficult. You may feel angry that others are healthy and you have been diagnosed with an illness. You may even feel angry about your family's reaction to the

diagnosis or their lack of understanding about the symptoms you are experiencing.

## Blame and guilt

A diagnosis of MS can lead to guilt and often drive you to seek a reason for what has happened. You may attempt to blame someone or something for your diagnosis.

## Denial

Denial is quite common at the time of diagnosis, when you or your family members are trying to hold on to your existing lifestyle or behave as though nothing has happened.

## Fear and anxiety

It is natural to have fears about the future – how your family will cope financially, emotionally and as a unit. Given MS can be unpredictable, you may also be feeling anxious.

## Frustration

Finding the time and energy to deal with a new challenge can be frustrating. Postponed activities, rearranged schedules and a slower pace can all add to the stress.

## Grief

A person commonly experiences grief when they lose something that is important to them – a particular way of doing things, a valued activity, their sense of security or general wellbeing. As MS can bring with it some unexpected changes, grief may be one of the emotions you experience.

## Isolation

You may feel alone at times, particularly if MS creates distance between you and your relatives or friends. It is common to feel isolated from your family or that living with MS is a journey you must take on your own. This is not usually the case. In fact, your family and friends can offer you great emotional and practical support. You do not have to face the challenges of MS alone.

## Sadness and depression

Sadness is a feeling that may be brought about by a sense of loss after diagnosis, the changes that might take place due to MS or by the unpredictable nature of MS. Depression can cause a person to lose interest in life, feel like a burden



and worry about the worth of life itself. Clinical depression does not come and go, it can last for weeks. If you are feeling depressed, try speaking to your GP or a trusted friend. Sharing your feelings and seeking the right support can often help to ease the situation.

### **Go easy on yourself**

Eventually, you will start to find small ways of adapting and adjusting to the presence of MS in your life. Being adaptable does not mean giving up your plans, priorities or goals; it means finding what works for you so your life is as enjoyable as possible, even with the changes and challenges MS may bring.

Consider seeking support if you feel you are not yourself and your emotions are impacting on your day-to-day life. Consulting with a clinical psychologist or counsellor can be helpful during this difficult time.

### **Communicating with the people in your life**

The way different family members feel about life with MS may not necessarily be the same, or you might not all experience similar feelings at the same time. Many of the people around you will have different reactions to the news of your diagnosis. They may also experience anxiety, sadness, grief, anger and guilt. Respecting each individual's coping style and communicating openly can be helpful.

Partners, family, carers and close friends will be important in helping you to both adapt to the news and learn how to live with the changes. Talking about powerful and personal emotions may be hard, but it is healthy to find a way to share them. At the same time, a family needs to acknowledge there may be occasions when one of you is unable to express thoughts and feelings. It is not unusual for yourself, or others, to feel as though you need some time alone. You may even find it easier to talk to someone outside your immediate circle, such as a GP or another health professional.

Some of the family members you talk to about MS will probably have many questions and it is best to be as prepared as possible. For example, telling a child about MS will be different to telling a teen.

You will need to take into consideration the child's age and personality. Younger children may only need a brief and simple explanation and maybe some examples, such as "Mummy has a problem called MS and this means she is a bit wobbly when she walks". Older children and teenagers will need as much information as they would like to know. It is also a good idea to encourage them to speak to someone they trust when they have issues or concerns.

The booklet series *Family Matters: For Families and Friends of People Living with MS* is available on our website and may be a good starting point for those who are close to you so they can begin to understand more about MS.

### **Disclosing your diagnosis**

There may be instances where you will want to invest more thought into the decision to tell someone about your diagnosis. You may or may not wish to tell friends, acquaintances or those in your workplace about your MS when you are still adjusting to the news yourself.

Telling your employer or manager will need a very different approach again. Some people choose to tell employers about their symptoms rather than the condition itself. Be clear about why you choose to tell someone about your symptoms or that you have MS. There may be certain outcomes as a result of letting people know this information, and things can get awkward if you regret telling a friend or colleague.

Importantly, many people successfully continue to work despite a diagnosis of MS. For more information about employment support services and disclosing your diagnosis, contact our information and support line.

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

” – Jodie

## **Educating yourself about MS**

Understanding MS and having some knowledge about the condition can help you to feel in control. This can be helpful, especially because MS itself can often be unpredictable.

Some people may find too much information overwhelming, while others can only relax when they feel they know everything there is to know. Ensure you are educating yourself at your own pace, as you are ready.

Your neurologist, GP and MS Australia are examples of reliable sources that can provide accurate, up-to-date information about the most effective ways to treat MS and manage symptoms.

*Some frequently-asked questions about MS include:*

### **How will my MS develop?**

This is one of the most commonly asked questions; however, nobody can predict the future so it is a difficult question to answer. A number of factors, including age of onset, type of MS, the nervous system pathways involved and frequency of relapses, will have a role to play in terms of individual outcomes (prognosis). Finding out as much information as you can about MS, including how to deal with the most common symptoms and what treatment options are available, will help you to manage your condition.

### **Will I need a wheelchair?**

For the vast majority of people with MS, the answer to this question will be no. Rapid progression is rare and after 20 years most people with relapsing-remitting MS (see 'Types of MS' on page 9) will not need to use a wheelchair on a regular basis.

### **Am I going to lose my independence?**

For most people the answer is no. Many people with MS continue to enjoy an active and independent life years after diagnosis.

### **Do people who don't have MS live longer?**

Again, nobody can predict the future. Many factors contribute to life expectancy (see 'How will my MS develop?'). Studies show people who don't have MS live approximately 8–12 years longer.

However, these studies don't take into account the introduction of disease-modifying drugs (see 'Medical treatments for MS' on page 15). There is one study, involving the drug Betaferon, indicating a longer life expectancy. Although it is natural to experience a sense of loss for the life you had planned, MS is not the devastating diagnosis many people fear. Managing your general health and lifestyle, as well as MS symptoms can make a difference in terms of life expectancy.

### **How do I find reliable information about MS?**

Naturally, you will want to know the causes of MS and all the treatment options available beyond what your neurologist may have discussed with you. There is plenty of information about MS online, including claims of various 'cures' for the condition. Much of this information is someone's opinion rather than information based on evidence. Evidence-based medicine refers to treatments that have been tested by applying a method agreed to by researchers and that have been effective over many years. For reliable MS or MS-related information, please contact our information and support line, or visit our website.

### **After an MS diagnosis**

Even though MS is unpredictable you can learn to understand what affects your condition, how to make the most effective use of the medications and resources available to you, and some of the lifestyle changes you can make. Together, these factors may help you to have a healthier and more manageable life with MS.

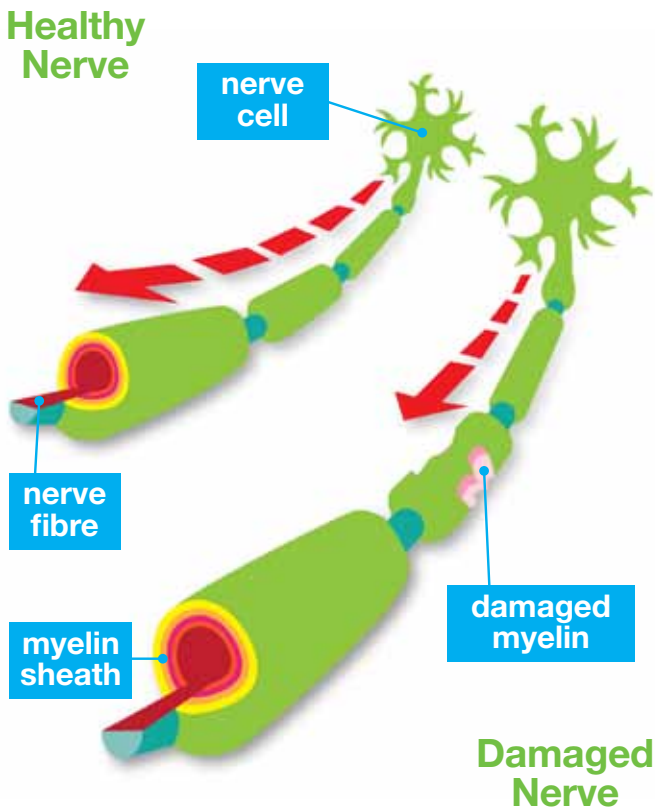
Every day you use problem-solving skills: You get to your appointments on time; decide what groceries you need to purchase to feed yourself and your family; set goals and overcome stress. Basically, you are managing your life. Managing your life means you actively work or improve on factors within your control to ensure you are better able to deal with the unpredictable or unchangeable factors in your life.

Managing your life with MS means you are best placed to face the challenges that living with this condition might bring. There are a range of strategies, as well as healthcare professionals (see 'Your healthcare team' on page 17) to assist you along your journey.

# What is MS?

## What is MS and what is happening inside my body?

The central nervous system (or CNS) is part of the body's communication system. It is made up of the brain, spinal cord and the optic nerve, which mostly consist of nerve cells called neurons. Electrical signals travel along the neurons in the central nervous system, carrying messages to all parts of the body. Nerve fibres known as axons are the part of the neuron that pick up electrical signals and deliver them to the next neuron. Most axons are tightly wrapped in a white fatty material called a myelin sheath. This acts like insulation, allowing the electrical signals to travel rapidly without being interrupted or distorted.



## What is demyelination?

Demyelination is damage caused to myelin by recurrent attacks of inflammation. Demyelination ultimately results in nervous system scars, called lesions, which interrupt communication between the nerves and the rest of the body.

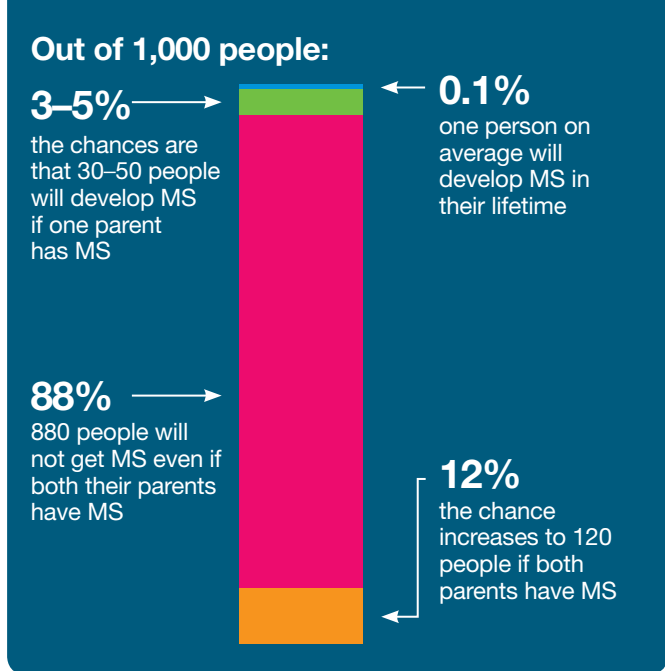
The role of the immune system is to identify or remove viruses, anything harmful that enters the body, or dead and damaged cells. In MS, the immune system attacks myelin. This may be because something occurs which causes the immune system to react, or because there are issues with the myelin and the immune system is trying to clean up the damage. When the immune system continues to attack one area, it causes inflammation. Inflammation may cause a relapse in MS (see 'What is a relapse?' on page 13).

Damage in different parts of the central nervous system will interrupt different messages and lead to different symptoms. For instance, damage in the part of the spinal cord which is responsible for your toes might mean you experience numbness in that part of your body, or damage in the part of the brain responsible for balance might mean you experience dizziness. The common symptoms of MS are covered in detail from page 10.

## Things you may like to know about MS:

- Statistics show that one in 20 Australians will be touched by MS through a family member, colleague or friend who is living with the disease.
- It is estimated that over 23,000 people in Australia have MS, and 75 per cent are women.
- 2.5 million people are living with MS worldwide.
- MS is the most common disease of the central nervous system in young adults.
- Diagnosis of MS is typically between 20 and 40 years, although onset of symptoms may be earlier.





### Genes

MS is more common in people who have a relative with MS, but you do not inherit MS in the same way you inherit hair colour. If you had an identical twin with MS, meaning you shared 100 per cent of your genes, your risk of developing MS is approximately 25–30 per cent. If you have a parent with MS, your risk of developing MS is less than five per cent.

Researchers have identified a number of genetic variations which are associated with MS, but more research is needed to understand exactly what role these genes play. Current research suggests the relationship between these genetic variations and a person's risk of developing MS is complicated. In some cases, how a person's particular gene variant affects them depends on the environment in which they grow up.

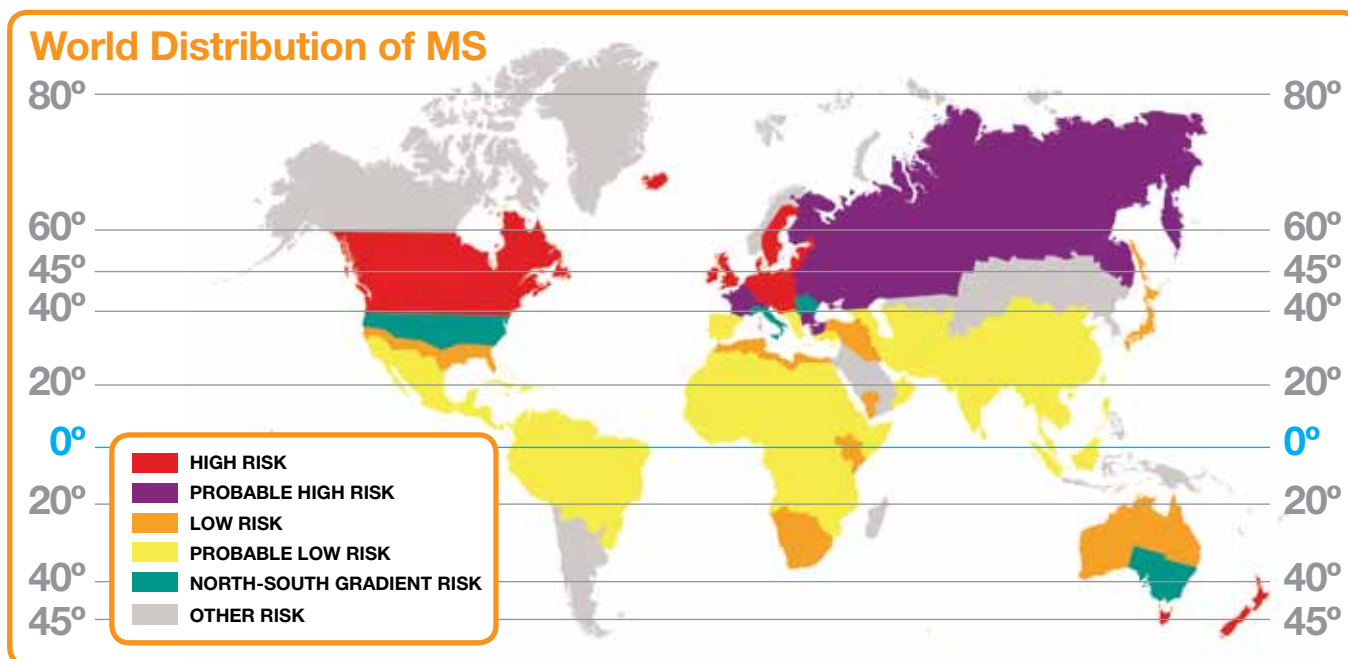
MS is more common in people who have had certain common infections (i.e. glandular fever) than in people who have not had these infections. This has led researchers to suspect that people whose genes make them susceptible to MS may have an immune system that responds in an unusual way.

### The environment

Researchers have identified many things in the environment which make a person more likely to develop MS. One of the earliest environmental factors to be identified is the latitudinal effect. This refers to the fact that MS is more common the further away you are from the equator (shown in the map below at zero degrees).

The equator is an imaginary line on the Earth's surface that is equal distance from the North Pole and the South Pole. It divides the Earth into the Northern Hemisphere and the Southern Hemisphere. Near the equator there is little distinction between summer, winter, autumn or spring, and temperatures in this area are usually high throughout the year.

In Australia, more than 23,000 people have MS and it is more common in Tasmania than in Queensland. Research in places like Australia, where people with similar backgrounds live in very different climates, has helped to demonstrate that at least part of this difference is caused by the environment and not just a person's background.



## How is MS diagnosed?

When a person has symptoms that are similar to the symptoms of MS, a neurologist – a specialist who treats diseases of the brain, spinal cord and nerves – will need to collect a detailed medical history, order a range of tests, and perform a physical examination to check certain reflexes and responses. This information is then used to determine what is happening within the central nervous system, what may have happened in the past, and whether a person meets the international criteria for a diagnosis of MS. This involves excluding any other possible causes for the symptoms the person is experiencing.

If the results do not meet the criteria for a definitive diagnosis of MS, a doctor may diagnose clinically isolated syndrome (see page 10) or they may not be able to make a definite diagnosis.

For some people it takes many years to be given a diagnosis and they may need to be monitored for a while; however, for others, a diagnosis is given when they first experience symptoms. In some instances there may even be enough information for a doctor to identify a particular type of MS. It is important to remember the process is different for everyone.

### What is a lesion?

There are a number of conditions in which neurons are demyelinated, or lose their myelin. MS is different from other demyelinating conditions in that myelin is removed from neurons in concentrated areas. On an MRI scan, these show up as spots called lesions. Lesions show an abnormal change in the structure of an organ due to disease or injury. MS lesions can occur anywhere in the central nervous system. Generally, especially early in the disease, the body is able to repair myelin damage.

## International diagnostic criteria

The criteria used to diagnose MS are agreed upon by an international committee of experts. The criteria specify the evidence a doctor needs to make a diagnosis of MS. The most important detail required is evidence of lesions in different parts of the central nervous system, at different times, with no alternative explanation other than MS. The criteria are updated regularly as better technology becomes available and as researchers learn more about MS. Today, an accurate diagnosis of MS can be achieved much quicker than it was in the past.

## Medical history

Once diagnosed with MS, many people realise their symptoms actually started many years before. That is why medical history is important. A person's neurologist will usually ask about any symptoms experienced in the past. Some of the symptoms might be evidence of existing lesions and lesions in different parts of the central nervous system. People are sometimes doubtful about telling their neurologist about symptoms, particularly unusual ones like tingling sensations or dizziness. It is important to remember neurologists are specialists who understand the central nervous system and the unusual symptoms it can produce.

## Magnetic resonance imaging (MRI)

MRI scans are a specific type of diagnostic imaging used to produce images of the brain or spinal cord. On the scans, areas of damage may show up as spots known as lesions. If there are lesions, your neurologist will examine what type of lesions they are as well as their location. More than one lesion might be evidence of lesions in other parts of the central nervous system. Different types of MRI scans can also be used to provide different types of information. Some MRI scans can show older lesions which are remyelinating, or areas where scarring has occurred at a different time.

## Blood tests

Your neurologist may order a range of blood tests. Generally these will be to exclude other possible causes of your symptoms. MS cannot be diagnosed by a single blood test, but test results can contribute information to the diagnostic

process. They can also provide important information your neurologist will need to prescribe treatments.

### Lumbar punctures

A lumbar puncture (sometimes called a spinal tap) is a test which involves taking a small amount of fluid from your spine using a needle. The fluid is then sent to a laboratory to test for a number of things that can help the neurologist to build a picture of what is happening inside your body. One of the things your neurologist might be looking for is oligoclonal bands, which can provide evidence of inflammation occurring in the central nervous system.

### Evoked potentials (EPs) and visual evoked potentials (VEPs)

Evoked potentials are tests which measure the time it takes for messages to travel along nerve fibres to the brain. If messages are delayed, it can indicate scarring to nerves even if you are not experiencing symptoms. Visual evoked potentials (VEPs) provide information about how well messages are travelling along your optic nerve. These tests measure the time between when you are shown an image to when the message registers in the part of your brain that processes information from your eyes. VEPs are one of the more common EPs used to diagnose or monitor MS. Your doctor may order other types of EPs such as somatosensory evoked potentials, which measure messages travelling from your skin, or auditory evoked potentials, which measure messages travelling from your ears.

### Types of MS

MS varies greatly from person to person and everyone with MS will experience the disease differently. However, there are categories used to describe the broad pattern of the disease experienced by most people.

The most commonly used categories of MS are relapsing-remitting multiple sclerosis (RRMS), secondary progressive multiple sclerosis (SPMS) and primary progressive multiple sclerosis (PPMS). The three types of MS (along with relapsing progressive MS, which is used much less frequently now) were identified by an international committee in 1996 as a broad way

of classifying a disease which varies greatly in each individual person. They describe the disease pattern and not the severity of the individual disease course.

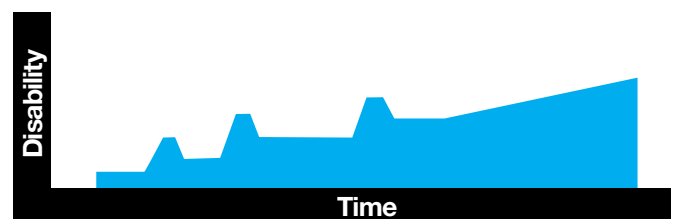
Other categories which are used less often describe the severity of the disease, such as benign or malignant MS, or the areas affected, such as spinal MS.

### Relapsing-remitting MS (RRMS)



The majority of people with MS (approximately 85 per cent) are initially diagnosed with RRMS. The main feature of RRMS is the fluctuation in symptoms. Relapses (also called exacerbations, attacks, flare-ups or episodes) are periods when symptoms get worse and remission is when they improve. Relapses are changes in old symptoms or the appearance of new symptoms which last more than 24 hours. Some relapses resolve quite quickly, while others can take weeks or months to subside. Many relapses will fully resolve, while others may have an impact on your long-term function. Relapses in RRMS are caused by inflammation, which occurs when the immune cells attack myelin. People with MS may also experience changes in their symptoms from day to day but this is not the same as a relapse.

### Secondary progressive MS (SPMS)



Over time, most people who have RRMS will find they have fewer relapses. At this time, their disease may be categorised as SPMS. After 25 years a portion of people initially diagnosed with RRMS will be described as having SPMS. Some people with a SPMS pattern of disease will still have relapses, others will not. The main feature of SPMS is a

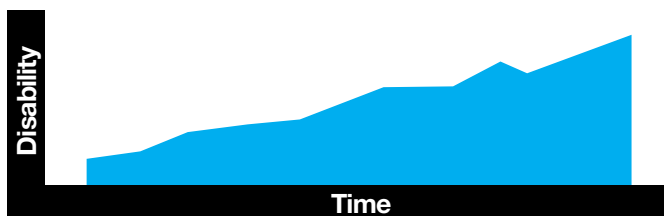
“

**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

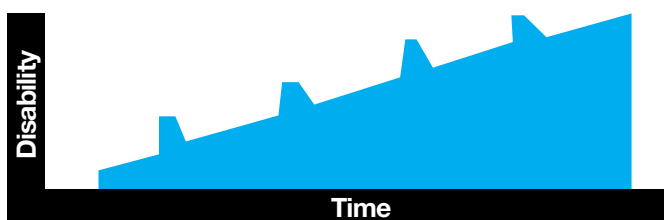
more constant pattern of symptoms. Relapses tend to reduce or disappear but a person's function generally decreases. For some people the loss in function can be rapid, while for others it can be very gradual.

### Primary progressive MS (PPMS)



Some people diagnosed with MS will not experience clearly defined relapses. This is usually described as PPMS. People with PPMS represent about 10 per cent of all those with MS. The main feature of PPMS is a constant pattern of symptoms from the time of diagnosis. There may be periods where symptoms are stable or even improve, but overall loss of function tends to increase. As with SPMS, for some people the loss of function can be rapid, for others it can be very gradual.

### Progressive relapsing MS (PRMS)



PRMS is defined as progressive disease from onset, with clear acute relapses (with or without recovery) with periods between relapses characterised by continuing progression. Although the least common of the types, recent clinical trials of progressive MS have provided ample evidence for this form of MS. The behaviour of PRMS is similar to that of SPMS.

### What is clinically isolated syndrome (CIS)?

For a definitive diagnosis of MS to be made, a neurologist needs to identify evidence of disease activity in different parts of the central nervous system and at different times. When a person experiences one event of demyelination they may be diagnosed with CIS. Some people will recover from an episode of CIS, others will have a second episode (or relapse) at which time they will be diagnosed with MS.

There are different features which may show up in MRI scans or other tests which may suggest that a person with CIS is more or less likely to have another episode and therefore 'convert' to clinically definite MS. For people with signs of converting from CIS to MS, there is increasing evidence to show that disease-modifying treatments used for MS can slow the progression from CIS to MS.

### Common symptoms and their management

When myelin is damaged, messages travelling along the nerve fibre may be altered or may not reach their destination. This is what causes the symptoms of MS.

As mentioned in 'What is MS?' (page 6), MS symptoms may be different for each person and symptoms can change over the course of time. It is also important to remember not all health issues are MS related.

However, there are common symptoms that may be experienced in varying degrees by many people with MS. Managing your symptoms can be much easier if you work with your healthcare team to develop a personal management strategy. This can help you to minimise the impact of symptoms on your life and enable you to get on with your daily routine.

Below is a list, in alphabetical order, of some of the more common symptoms of MS.

### Bladder issues

Bladder issues are a common symptom of MS but can often be under-reported. Issues can include:

- not being able to completely empty the bladder.
- reduced bladder capacity or storage.
- a combination of both.

There has been much research into bladder symptoms and, as a result, many problems can now be effectively managed. It is important to discuss them with your GP or MS nurse who can then provide you with advice or a referral to a continence adviser.

### Bowel concerns

Bowel concerns can occur in MS. The most common of these concerns is constipation, which relates to difficulties with emptying the bowel. There are also medications that can cause constipation. It is important to discuss any issues of constipation with your GP.

Treatments for mild constipation may include eating a high-fibre diet, drinking approximately one and a half to two litres of water each day, regular exercise and developing a regular time of day for opening the bowels.

### Fatigue

Fatigue is one of the most common symptoms of MS and can often have a major impact on people's lives. People can experience fatigue that interrupts their daily life or prevents them from working and have no other symptoms.

Being an 'invisible' symptom of MS, fatigue is often misunderstood by family members, carers, friends or colleagues. They may assume the

person with MS is depressed or just not trying hard enough, so it is important to communicate about fatigue and make sure those around you understand its impact. Many medications are also known to cause or worsen fatigue.

Fatigue is a major cause of early departure from the workforce, but working on strategies and making adjustments to the way you go about your day can make a significant difference. For example, including regular rest periods, grouping activities and attending to more strenuous tasks when your energy is at its peak can help to minimise the effects of this symptom on your life.

### Memory and thinking (cognition) concerns

Memory and thinking issues can occur with MS. Some people say their concentration levels falter, making it difficult to complete tasks or find the right word when in conversation.

Altered mood or depression may also cause memory issues, as can heat and fatigue. Whatever the cause, there are many strategies available to assist in dealing with these issues so it is important to discuss them with your GP or MS nurse. Some of the strategies used effectively by many people are simple things like keeping a diary or using a calendar, making lists, or writing reminders on whiteboards. Ask for a referral to a neuropsychologist or occupational therapist if you need more help with managing this symptom. (see 'Your healthcare team' on page 17).

“

**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

### Mood and emotions

Changes in mood and emotion are relatively common in people with MS. It may be related to nerve damage, but more commonly people can experience anger, sadness and stress when dealing with a diagnosis of MS or dealing with the challenges that MS can present.

It is not unusual for all people to experience periods of sadness and distress which can result in irritability and sleeping problems. Many people find attending support groups helpful. Sharing thoughts and ideas with people who have a greater awareness of what you are going through can be very positive. Our organisation runs support groups in many locations. To find out more, contact our information and support line.

It is also important to keep talking openly to family and friends so they have some idea of what you are experiencing. If these changes begin to affect your life and last longer than you expected, talk to your GP. They may offer advice or refer you to a clinical psychologist or counsellor if required.

### Pain

Approximately 60 per cent of people with MS experience pain. Pain can be a result of damage in the central nervous system and can be experienced in various forms.

Muscular and lower-back pain is also experienced by people with MS. This is often a result of altered posture or walking problems placing stress on joints and ligaments. Exercises, medications or a combination of both can help with managing pain so it is important to discuss this symptom with your GP.

For more information about addressing pain in MS, read our booklet *Managing Pain: For People Living with MS*, available on our website.

### Sensory changes or altered sensations

MS can cause numbness, tingling or pins and needles. Some people may also experience a prickly or burning sensation over areas of skin. It may affect a small part of the body or a larger area such as an entire arm or leg.

“

**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

### Sexuality and intimacy

Sexuality and intimacy can be affected by MS. This may be a direct result of nerve damage in the central nervous system, which can cause changes such as reduced libido, vaginal dryness or erection issues. Symptoms such as fatigue, weakness and pain may also have an impact on sexual response and desire. Stress, not talking freely, anxiety and embarrassment are also contributing factors when it comes to sexuality and intimacy.

Although they may seem embarrassing, many of the physical problems with sex can be addressed so it is important to discuss these with your GP or MS nurse. In some instances, counselling may be appropriate to help manage this issue. It is just as important to talk with your partner and maintain open communication as this will help to avoid misunderstandings and ensure you are both aware of each other's concerns.

### Temperature or heat intolerance

Temperature or heat intolerance occurs in MS. Many people with MS find that on hot days or when their body temperature increases after exercise, their symptoms get worse. This is temporary and when the body cools down the symptoms are reduced again (see 'What could mimic a relapse?' on page 13). The effect of heat on MS symptoms is not a result of further damage or inflammation in the central nervous system.

Many things can help to decrease the effect of heat. They include: cooling hats, garments and neck ties; carrying out chores in the cooler parts of the day; staying in a cool environment and avoiding outings on extremely hot days.

### Visual disturbances

If the nerve from the eye becomes inflamed or damaged by MS it can cause visual disturbances. This is called optic neuritis. The effects of optic neuritis can include blurred or dimmed vision, the loss of some vision in the eye and pain behind the eyeball. Sometimes eye movements may be affected.

Optic neuritis is usually temporary and most people recover well. Sometimes a course of steroids may be helpful, so it's important to report any visual problems to your GP.

### Weakened muscles

In MS, the disruption of messages travelling along the nerves can result in weakened muscles, particularly in the legs and arms. This loss of strength can cause walking and balance difficulties, and tasks that were once done without any problem may become harder. Fatigue may also have an impact on muscle weakness.

Developing appropriate strengthening exercises with a physiotherapist or exercise physiologist can help. An occupational therapist can also advise on aids and techniques to help make the most of available strength and ability.

“

**All of us are unique with this illness. What works for one won't always work for the other. Mindset is vital! Defy MS, never let it get the better of you and seek as much information on what's available to you**

”

– Reece

### What is a relapse?

A relapse is formally defined as the development of new symptoms or the temporary worsening or recurrence of old symptoms, which is not caused by an infection or any other cause, and lasts more than 24 hours.

When new inflammation and/or damage to myelin occur in the brain and spinal cord, a person with MS may experience a relapse. A relapse may also be referred to by other names such as exacerbation, bout, attack, flare-up or episode.

Common symptoms associated with a relapse may include issues with balance, bladder, eyesight, fatigue, memory and thinking, and mobility.

A relapse needs to occur at least 30 days after any previous episode to be considered a new relapse. A relapse may occur quickly with a sudden and intense onset of symptoms, or gradually, with symptoms appearing over a few days or weeks. While some people may experience mild symptoms, for others they may be more noticeable. The period between relapses is known as remission, which can vary greatly from a month to years.

Although the definition of a relapse may seem quite complicated, it is important that you try to understand what a relapse involves so you can discuss it with your healthcare team.

### How do I know if I am having a relapse?

Most people with MS will have a range of fluctuating symptoms at any given time, so it can be hard to tell if an increase in symptoms is part of the variability of the condition or if it is a relapse. Changes in symptoms should be discussed with your neurologist. Your neurologist needs to be aware of symptom changes to determine how often you are having relapses and if your current treatment is working for you.

There are times when even neurologists can find it difficult to diagnose a relapse and sometimes they can only be diagnosed in hindsight. This is because anything which causes an increase in a person's core body temperature can temporarily increase MS symptoms (see 'What could mimic a relapse?' on page 14).



### What could mimic a relapse? (pseudoexacerbation)

An increase in a person's core body heat can cause relapse-like symptoms. This is known as a pseudoexacerbation. A pseudoexacerbation is a temporary worsening of symptoms. It does not indicate new inflammation or damage to myelin but is brought on by other issues. A range of factors can cause a pseudoexacerbation. They include other illness or infection, exercise and an environment that is too warm.

Effortful exercise can cause relapse-like symptoms because it results in a temporary increase in your core temperature. Research shows that relapse-like symptoms usually settle within half an hour of stopping exercise and cooling down. Resting and taking a cold drink or shower should help to bring down the body's core temperature and reduce heat-related symptoms.

If the increase in symptoms is due to an infection, it is essential that you see your GP and treat the underlying cause of the infection to reduce the symptoms. Once the infection is identified and treated, the relapse-like symptoms will usually settle within a day. Nevertheless, it is important to note that infection can sometimes trigger a relapse so look out for urinary tract, and cold or flu infections.

### How long does a relapse last?

Relapses differ widely from person to person, and the symptoms, severity, frequency and length of a relapse will often vary over time within the same person.

Although the experience of having a relapse can be overwhelming, relapses may often be mild and the symptoms can resolve within a few days or weeks. Occasionally it may take a few months, and while some people may regain full function after a relapse, others may experience some ongoing reduced function.

### How do I prepare for a relapse?

The symptoms of MS are unpredictable and it's hard to know what to expect. Being prepared can help to reduce your stress when a relapse occurs. One of the ways to ensure you are prepared is to be aware of the support and services around you.

Make sure you know who to call on during these times, whether it is your GP, neurologist, MS nurse, family members, friends or your local support network.

As well as being prepared, don't lose hope. Relapses can take you by surprise and the symptoms may be difficult to deal with, but you don't have to lose your independence or stop doing the things you love most. Remember, the aim is to live your life as best you can despite the symptoms of MS.

*Managing a Relapse: For People Living with MS is a practical and useful publication available on our website.*

“

**I am continuing to learn how to listen to my body – to know when I need to take time to rest or to get more exercise – and to remember that relapses happen but not to freak out if I have a sore hand for a day**

” – Dani



# Medical treatments

**It is** important to know that there is a difference between the disease-modifying drugs used to help treat MS itself, and the medications that may be used to help treat an MS relapse.

## Disease-modifying drugs

Disease-modifying drugs, also known as immunotherapies, are the recommended available treatments for relapsing-remitting MS (RRMS). Although there are currently no medical treatment options for people with the primary progressive and secondary progressive forms of MS, there is currently much research going on in this area.

Disease-modifying drugs work to reduce disease activity in the central nervous system. There is no treatment to cure or stop MS, but these medications may help in reducing the frequency

and severity of relapses in RRMS. They may not make you feel any better and they will not generally stop all MS symptoms, but they may be able to help control the course of MS.

In fact, research shows that commencing treatment early not only reduces relapse rates, but it may also slow the accumulation of nerve damage and may prevent some of the loss of function you can accumulate over time. This is why your neurologist may have spoken to you about commencing treatment soon after diagnosis.

For information about the most current disease-modifying treatments available for MS, please visit our website or contact our information and support line.

## Considering medical treatment?

Treatment is generally advised for people diagnosed with RRMS to reduce the frequency and severity of relapses and to slow the progression of the disease. While there are benefits to starting treatment as soon as possible, it is also important to take enough time to consider your treatment options.

When committing to a treatment course you will need to consider the long-term nature of your commitment and ensure it fits in with your lifestyle. That is not to say you cannot ever change the treatment you initially decide on. However, it is recommended you give the treatment a reasonable period of time to allow your body to adjust to it before contemplating a change to another medication. Your neurologist or MS nurse will be able to go over all the options in detail to assist you in making a choice that will best suit you.

## Pregnancy and medications

As with all medications for MS, it is important to talk to your neurologist, especially if you are considering pregnancy or if you become pregnant.

If you are taking a disease-modifying medication and discover you or your partner are pregnant, make an appointment to discuss the matter with your neurologist as soon as possible as he/she will be able to advise you on how the guidelines relate to your personal situation.



**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**

**”** – *Bosco*

There is limited data about the effects of these therapies in pregnancy, so generally it is recommended women stop taking disease-modifying medications while pregnant. However, this is a decision you will need to make with your neurologist and the people supporting you, as each individual circumstance is different.

*Deciding on Motherhood: For Women Living with MS* is a publication designed to assist women with making a decision about pregnancy after a diagnosis of MS. This helpful publication is available on our website.

### Support, education and follow-up

Whichever treatment option you choose to commence, your MS nurse will assist you in all aspects of the treatment including teaching you to give yourself an injection, helping you manage any side effects you may experience, ensuring you know when and what follow-up tests may be required, and assisting you to manage any symptoms that are causing you difficulty. An MS nurse will continue to follow-up with you for as long as you require assistance.

### Treatment of relapses

The most common medications used to treat a relapse are corticosteroids (steroids). They are used to manage intense relapses by easing inflammation in the affected area. Your doctor or neurologist is the best person to communicate with about the medications you should be taking during a relapse.

### How do steroids work?

Steroids are drugs that mimic the effect of hormones that are naturally produced in the body. When steroids are given so that they exceed the body's natural levels they can suppress inflammation, reducing the signs and symptoms of inflammatory conditions such as MS.

Unlike disease-modifying drugs, these drugs only treat the symptoms of a relapse not the disease itself. They can help settle the symptoms you are experiencing, and in some cases, reduce the length of a relapse and help you recover sooner.

### What steroids are available for treating relapses?

The most common steroids used for MS relapses are methylprednisolone (Solu Medrol, Depo-Medrol) which is administered intravenously and prednisone (Panafcort, Sone) which is given in an oral form.

### How will I know if I need steroid treatment?

It is important to note that relapses will be assessed on an individual basis. Your GP or neurologist will need to consider a number of factors including your symptoms, the severity of the relapse and the functional loss you are experiencing, as well as the side effects of the steroid treatment.

It is essential to report your relapses to your neurologist to ensure you are receiving the best possible treatment for your MS.

“  
**I think it is important to know that things are forever improving in the way of treatments. It sure gave me confidence when I was diagnosed**

” – Brooke

# Living well with MS

**MS can** have a profound impact on all areas of life and each person will feel differently about when they are ready to manage these areas.

It is important to remember there are ways for you to improve and enhance your life regardless of the limitations MS can sometimes pose. By taking a close look at the things that are important to you as a person and ensuring you are making healthy lifestyle choices, you can manage your MS and take control of your life.

You can live well with MS. Health professionals from MS Australia can help you to adopt a holistic approach in the management of your condition. A holistic approach takes into account your 'whole person' – your psychological, physical and social needs – and considers such things as stress, physical activity, symptom management, family and relationship concerns, and the medical management of your MS.

A holistic approach can help to ensure you maintain your overall health and wellbeing, leading to a better quality of life for you and your family.

## Your healthcare team

Health professionals are an essential tool in your efforts to adapt to life with MS. You should feel comfortable about seeking out this kind of support as it will make a difference to the way you manage and cope with some of the challenges MS can bring. There are many healthcare providers who can assist you in all areas of lifestyle management, specifically with managing the symptoms of MS such as those outlined under 'Common symptoms and their management' (page 10).

Your *neurologist and GP* will help with the medical management of your MS, and your MS nurse will help you manage your medications and symptoms. When visiting your neurologist or GP it is easy to forget questions you may have, so write them down in a notebook as you think of them and take them with you on your next visit. It may also be helpful to take someone with you to the consultation to ensure any new information is well understood. At times like this, two heads can be better than one, especially if there is a lot to take in. Your neurologist will write to your GP

after seeing you so they are updated on any new information relating to you.

*MS Australia's client services team, an MS nurse or social worker* can work with you to devise strategies that address your MS-related concerns. They can also assist you to access various health and community services and advocate on your behalf.

*An occupational therapist (OT)* can assist you to address any temporary functional difficulties you are having at home or work, as well as provide you with fatigue-management advice. They can help if you are having difficulty with tasks you are normally able to do, or tasks you need to do to manage your life and responsibilities.

*A physiotherapist or exercise physiologist* can devise tailored programs to help you increase your physical strength and fitness and optimise mobility, balance and coordination. In the event of a relapse, physiotherapists can advise you on the appropriate level of exercise and devise a fitness regime to follow as you recover.

*Clinical psychologists, social workers and counsellors* can assist you to manage stress, anxiety and depression and will help you to manage the impact of MS on your relationships.

*Neuropsychologists* are concerned with understanding how the brain works in the areas of thinking, memory, behaviour and personality.

“

**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

There is also a focus on how changes in the brain affect these areas. Neuropsychologists can help you identify which brain functions, if any, have changed and they can advise on ways to manage such changes.

This list of health professionals is by no means exhaustive and, throughout your journey with MS, you may need to consult a number of different health professionals to address your concerns. They will work with you, and together, to ensure all aspects of your individual situation – including your physical and emotional wellbeing – are addressed.

### Diet

Dietary guidelines for Australian adults recommend a balanced diet low in saturated fat, sugar and salt, and including foods from the following food groups: fruit, vegetables and legumes, breads and cereals, lean meats and dairy.

There are a number of diets published in books and on the internet which report specific benefits for people with MS. Scientific support for any particular ‘MS diet’ is generally limited. However, this does not mean changing your diet will not make you feel healthier. Any changes that lead you to consume more fresh foods, particularly fruits and vegetables, and less saturated fat and sugar are likely to have a positive effect on your general health. There are also changes to your diet which are likely to impact on specific symptoms of MS, such as bowel problems or fatigue.

“  
**My diet is better, I exercise every day, eat lots of fish and manage the symptoms as they occur. The irony is, I live a healthier life than I ever did before diagnosis**

” – Robert

Anyone planning to severely restrict or remove entire food groups from their diet should consider seeking the advice of a dietitian or nutritionist. Not only do different food groups provide particular nutritional value on their own, combining a variety of food types can improve the nutritional value of a particular meal. A dietitian or nutritionist can provide advice on how to ensure you are still meeting your individual nutritional requirements when you either choose to, or need to, restrict or remove food groups from your diet.

### Vitamin D

There is significant evidence that people who are deficient in vitamin D are at an increased risk of MS. It is recommended people with MS have their vitamin D levels assessed through their GP.

People with MS commonly take vitamin D supplements. Vitamin D can also be attained from foods such as sardines, salmon, tuna, sunflower seeds, eggs and safe exposure to sunshine.

### Physical activity

Physical activity is essential to everyone’s general health and wellbeing. Inactivity in people with or without MS can result in numerous risk factors which may lead to heart disease and diabetes.

In people with MS, inactivity may aggravate or exaggerate the impact of symptoms such as muscle weakness and fatigue. It is important to remember that regular activity will keep you flexible, fit and healthy, as well as help you strengthen your bones and maintain muscle. Physical activity and exercise can also improve mood and reduce depression. Increasing evidence shows exercise benefits the immune system. It may also help recovery from a relapse and prevent long-term problems with muscles or posture.

Given each person’s symptoms and abilities vary, a physical assessment by a physiotherapist or exercise physiologist that understands MS will help you find which exercises will provide the most benefit.

### Looking to the future

Ensuring you participate in activities that are enjoyable and achievable can be beneficial for

“

**Don't ever let anyone tell you that you can't do something because you have MS. You may not be able to do it in the same way you once did, but you can still have dreams. You just need to modify the way you go about achieving them and the expectations you have of yourself**

” – Karen

your health and wellbeing. Set goals and take small steps to achieving them. Remember to treat yourself and give yourself some credit when you achieve those goals. Planning activities in advance, so you have things to look forward to, can also be worthwhile. The idea is to remain focused on the good things in your life and the things that you can do.

### Cigarette smoking

People with MS who smoke appear to experience a faster progression of their disease. Studies have shown that MS disability progressed more quickly in smokers, and quitting may delay MS progression. Further research has found links between smoking and brain tissue damage observed on imaging scans, and that the risk for developing MS increased with more years of smoking. If you have MS it is better not to smoke. For assistance, talk to your GP or pharmacist or call Quitline on 137 848.

### Stress and anxiety

Stress is a part of daily life, whether or not a person has MS. It is normal to feel anxious about having MS and how it will affect your life. Many people with MS say they experience more symptoms during stressful times. When the stress

lessens, their symptoms seem less troubling or less severe. In times of stress the body sets up many mechanisms to deal with its effects, more energy is required to think, problem-solve and handle daily life.

Learning to recognise what makes you feel stressed can help you to manage it. Even boredom can be cause for stress – keeping the mind and body active is essential. There are many simple things you can do to lessen the stress you may feel such as learning as much as you can about MS, putting time aside each day for rest and relaxation, joining a support group, talking to a counsellor, and talking to family and friends.

### Complementary therapies

Complementary therapies are therapies which can be used in conjunction with your conventional treatment. They aim to improve your general wellbeing and quality of life, and can help you to deal with some of the side effects of your illness.

Complementary therapies are not considered part of mainstream medicine, but you may have heard about some of the more common forms such as vitamin supplements, acupuncture, massage, relaxation, tai chi and yoga.

Complementary therapists tend to focus on you as a whole person – both your physical and emotional health – not just the parts of your body that are affected. If you are interested in exploring complementary therapies, it is important you consult your GP and neurologist to ensure any new treatment you choose to undertake will not affect your medications or your symptoms. Most healthcare professionals are more than happy to include complementary therapies into a person's healthcare portfolio.

It is not advised that you stop taking prescribed medications or change your dosage without the knowledge and approval of your treating neurologist or GP.

# MS research

**Researchers** working across a range of different fields are continuing to find out more about how MS works, bringing the possibility of more effective treatments and ultimately a cure even closer.

Given MS is a complex disease, various areas of study form part of the research taking place today. The answers are likely to come from a combination of these different scientific areas.

## Epidemiology

This area of research looks at which groups of people have MS and tries to understand what some of the triggers of MS might be. The 'environmental' factors investigated might include viruses, smoking, sun exposure, vitamin levels and more. It also aims to see if today's groups are different to past groups who have had MS.

## Genetics

The role of genetics is considered to be a factor in the MS equation. Researchers aim to find out what genes might make people susceptible to MS, what role individual genes play in the disease process and how genes interact with environmental factors.

## Immunology

The immune system plays an important role in MS. Understanding the different components of the immune system and which particular immune cells play a role in the disease may lead to new treatments that better target the disease process.

## Regenerative medicine

This area of research aims to answer the following questions: How does the body repair myelin? Is there a way to promote myelin repair in MS? How and why do nerve axons degenerate? Can they be protected?

## Neuropathology

This is the study of brain tissue to investigate the different stages of the disease and the cells and molecules involved. Scientists want to know what might be happening before the immune system starts to attack the myelin, and what is happening in the lesions as they try to repair the damage.

## Clinical and applied

This area aims to ensure people with MS stay as well as possible for as long as possible. It

asks questions like: Is there a more effective medication? What type of exercise is best for these symptoms? Are there strategies people with MS can use to cope with symptoms?

## Pharmacology

Pharmacology is the study of drugs. It involves examining the interactions of chemical substances with living systems, and understanding the properties of drugs and their actions. The study of pharmacology in MS interacts with many of the different areas of study mentioned in this chapter, as they begin to reveal potential 'targets' against which to design new drugs.

## Biomarkers

Biomarkers are biological substances that can be detected, for example in blood urine or cerebrospinal fluid, and provide an indication of a biological or disease state. Researchers are investigating possible biomarkers to help accelerate diagnosis and better predict the course of the condition (prognosis). Biomarkers will also allow researchers to track treatments and their effect on MS, and will be useful in clinical trials to speed up the development of new treatments.

## Multiple Sclerosis Research Australia (MSRA)

Australian researchers are working to answer many of the questions we still have about MS.

The MS Australia research arm, Multiple Sclerosis Research Australia (MSRA), seeks to support innovative research to find treatments for MS, and ultimately, a cure. MSRA's research strategy aims to accelerate research activity in areas where Australian scientists can have the greatest impact in worldwide MS research. Working in partnership with, and encouraging collaboration between Australia's top (university-based) medical research centres, MSRA funds research focused on three main areas: Better diagnosis and treatment of MS; prediction and prevention of MS; and the promotion of cell repair and regeneration.

You can learn more about MSRA and MS research at [www.msra.org.au](http://www.msra.org.au)

# Where to from here?

## How we can help

MS Australia offers a variety of programs to help you effectively manage and cope with MS. We aim to assist you, as well as your family members and carers to live well.

Living with MS can be challenging at times, but you don't have to face these challenges on your own. By registering with us, you can gain access to information on MS and MS-related issues, as well as assessment and referral services that connect you to vital community support resources.

Visit [www.msaustralia.org.au](http://www.msaustralia.org.au) for the contact details of MS Australia offices and services in your state. Our information and support line (1800 042 138) is also available five days a week to help answer all your MS-related questions and assist you with any concerns you may have.

## Information in languages other than English

MS Australia is committed to ensuring the service we provide meets the individual needs of people with MS, their families and carers in a manner which is sensitive to their gender, religion and cultural or linguistic background.

MS Australia can arrange for an interpreter to be available for most programs and services. We may suggest an interpreter for particular appointments, or you can make a request for an interpreter.

The Multiple Sclerosis International Federation (MSIF) also provides information resources in several languages (see 'Other useful resources').

### Telephone interpreter service

To speak with MS Australia staff via a telephone interpreter service, please contact the Translating and Interpreting Service (TIS) on 131 450. Ask for an interpreter who speaks your language and ask to be put through to 1800 042 138 (local call charges apply from landline phones, higher charges from mobile and public phones). Please let staff know if you would like them to call you back.

## National Relay Service

If you are deaf, or have a hearing or speech impairment, contact us through the National Relay Service:

### TTY users

Call 133 677 and ask for 1800 042 138.

### Speak and Listen users

Call 1300 555 727 and ask for 1800 042 138.

### Internet relay users

Connect to the NRS ([www.relayservice.com.au](http://www.relayservice.com.au)) and ask for 1800 042 138.

## Other useful resources

If you would like to learn more about MS, there are a range of publications and websites you can access. We have included some of the most useful ones here:

For publications and resources developed by MS Australia visit [www.msaustralia.org.au](http://www.msaustralia.org.au) or contact our information and support line: 1800 042 138 (Freecall™)

Visit [www.msra.org.au](http://www.msra.org.au) for information about research initiatives in Australia and around the world

*MS in Focus* is an informative publication developed by the MS International Federation (MSIF) and explores a speciality area of MS in each edition [www.msif.org](http://www.msif.org)

The MS Trust is a charity providing a range of free and useful information for people affected by MS, as well as health professionals working with MS. Visit [www.mstrust.org.uk](http://www.mstrust.org.uk)

[www.nationalmssociety.org](http://www.nationalmssociety.org) is the website of the MS Society USA

[www.mssociety.org.uk](http://www.mssociety.org.uk) is the website of the MS Society UK

# Glossary of terms

**Antibody** – Also known as an immunoglobulin, an antibody is a protein produced in the body and used by the immune system to identify and neutralise foreign objects such as bacteria and viruses.

**Autoimmune** – When a disease occurs because the body misrecognises part of its own tissue as foreign and attacks that tissue, causing damage.

**Axon (nerve fibre)** – The long threadlike part of a nerve cell along which impulses are transmitted between cells.

**Benign** – In the medical sense, this term means mild or not causing serious damage.

**Blood-brain barrier** – A protective membrane that controls the passage of substances from the blood into the central nervous system.

**Central nervous system (CNS)** – Made up of the brain, spinal cord and optic nerve, the CNS is the body's main control system. MS occurs within this system.

**Demyelination** – Damage caused to myelin by recurrent attacks of inflammation. Demyelination ultimately results in nervous system scars, called lesions, which interrupt communications between the nerves and the rest of the body.

**Equator** – The equator is an imaginary line on the Earth's surface that is equal distance from the North Pole and the South Pole. It divides the Earth into the Northern Hemisphere and the Southern Hemisphere (shown as zero degrees on maps). Near the equator there is little distinction between summer, winter, autumn, or spring and temperatures in this area are usually high throughout the year.

**Evidence-based medicine** – A systematic process of appraising and using current research findings. It is a process that includes formulating a clear clinical question of patient needs; searching the current literature; evaluating the literature; deciding which studies are valid and useful to the patient; and applying the findings and evaluating the outcome.

**Function** – To work or operate in a proper or particular way.

**Gadolinium** – A chemical compound given during MRI scans that helps distinguish new lesions from old.

**Gene** – A hereditary unit, consisting of a sequence of DNA that occupies a specific location on a chromosome and determines a particular characteristic in an organism.

**Holistic** – An approach that treats the whole body rather than just dealing with a particular issue caused by a disease or symptom.

**Immune system** – A system made up of many organs and cells, that defends the body against infection, disease and foreign substances.

**Immunosuppressive** – Able to suppress some or all of the functions of the immune system.

**Incidence** – The number of new cases of a disease or condition occurring in a given population in a given period. See prevalence.

**Inflammation** – The body's response to injury, infection or other attacks.

**Interferons** – A group of proteins made by cells when they are infected with a virus to help prevent nearby cells from being infected. Types of interferons modulate the immune system and have been shown to reduce the number of exacerbations in relapsing-remitting MS.

**Intravenous** – Denoting or relating to an injection into a vein.

**Latitudinal effect** – Research has identified the latitudinal effect in the prevalence of MS, finding that MS is more common in people who live further away from the equator (see equator).

**Lesion** (or plaque) – An abnormal change in the structure of an organ due to disease or injury.

**Lymph nodes** – A small ball or an oval-shaped organ of the immune system, distributed widely throughout the body including the armpit and



stomach and linked by lymphatic vessels. They filter or trap foreign particles and are important in the proper functioning of the immune system.

**Lymphocytes** – The lymph fluid inside of lymph nodes contains lymphocytes, a type of white blood cells, which are continuously recirculated through the lymph nodes and the bloodstream.

**Myelin** – A fatty material insulating nerve cell fibres in the brain and spinal cord. Myelin facilitates the smooth, high-speed transmission of electrochemical messages between these components of the central nervous system and the rest of the body. In MS, myelin is damaged through a process known as demyelination, which results in distorted or blocked signals.

**Nerve fibre** – See axon.

**Neurologist** – A specialist who treats diseases of the brain, spinal cord and nerves.

**Neuron** – Also known as a nerve cell, a neuron is an electrically stimulated cell that processes and transmits information by electrical and chemical signalling.

**Oligodendrocytes** – Oligodendrocytes are cells in the nervous system responsible for producing a fatty substance that insulates nerve fibres (see myelin).

**Oligoclonal bands** – Oligoclonal banding is a test to look for inflammation-related proteins in the cerebrospinal fluid; the clear fluid that flows in the space surrounding the spinal cord and brain. Oligoclonal bands are bands of immunoglobulins seen in the cerebrospinal fluid (CSF) that may suggest inflammation of the central nervous system. Oligoclonal bands may be a sign of MS.

**Prognosis** – A prediction of the probable course and outcome of a disease.

**Somatosensory** – Of or relating to the perception of sensory stimuli from the skin and internal organs.

# Bibliography

1. ABS. Profiles of Disability. Cat. No. 4429.0. Canberra: Australian Bureau of Statistics 2012.
2. Better Health Channel. Complementary Therapies. Viewed May 2012 at [http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Complementary\\_therapies](http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Complementary_therapies)
3. Biology Online Dictionary. Viewed May 2012 at <http://www.biology-online.org/dictionary>
4. Correale J, Fiol M and Gilmore W. The risk of relapses in multiple sclerosis during systemic infections. *Neurology* 2006 Aug; 67(4):652–9.
5. Compston A & Coles A. Multiple sclerosis. *The Lancet* 2008 Oct; 372 (9648):(1502–17).
6. Dalgas U, Stenager E, Jakobsen J, *et al.* Fatigue, mood and quality of life improve in MS patients after progressive resistance training. *Mult Scler* 2010 Apr; 16(4):480–490.
7. Dodd, KJ, Taylor NF, Denisenko S, *et al.* A qualitative analysis of a progressive resistance exercise programme for people with multiple sclerosis. *Disabil Rehabil* 2006 Sep; 28(18):1127–34.
8. Ebers GC. Environmental factors and multiple sclerosis. *Lancet Neurol* 2008; 7:268–277.
9. Ebers GC. Natural history of multiple sclerosis. *J Neurol Neurosurg Psychiatry* 2001; 17:16–9.ii.
10. Hadgkiss EJ, Jelinek GA, Weiland TJ, *et al.* Health-related quality of life outcomes at 1 and 5 years after a residential retreat promoting lifestyle modifications for people with multiple sclerosis. *Qual Prim Care* 2010; 18(6):379–89.
11. Jagannath VA, Fedorowicz Z, Asokan G V, *et al.* Vitamin D for the management of multiple sclerosis. *The Cochrane Library* 2010; 12. Viewed May 2012 at <http://www.update-software.com/BCP/WileyPDF/EN/CD008422.pdf>
12. Krupp LB. Fatigue in multiple sclerosis: definition, pathophysiology and treatment. *CNS Drugs* 2003; 17(4):225–234.
13. Lublin FD, Goldsmith SC, Dickinson CG. Introduction to the disease courses of MS. *MS in Focus* 2009; 14:4–6.
14. McDonald WI, Compston A, Edan G, *et al.* Recommended diagnostic criteria for multiple sclerosis: Guidelines from the international panel on the diagnosis of multiple sclerosis. *Ann Neurol* 2001; 50:121–7.
15. McLeod JG, Barnett MH, Macaskill P, *et al.* Long-term prognosis of multiple sclerosis in Australia. *J Neurol Sciences* 2007; 256:35–8.
16. McLeod JG, Hammond SR, Halpike JF. Epidemiology of multiple sclerosis in Australia with NSW & SA survey results. *MJA* 1994; 160:117–22.
17. Mhyr KM, Riise T, Vedeler G, Nortvedt MW, *et al.* Disability and prognosis in multiple sclerosis: demographic and clinical variables important for the ability to walk and awarding of disability pension. *Mult Scler* 2007; (7) 59–56.
18. Multiple Sclerosis Trust (UK). First thoughts. Viewed Dec 2011 at <http://www.mstrust.org.uk/information/aboutms/firstthoughts.jsp>
19. New Studies on Smoking and MS: Surprising Results? National MS Society (USA). Viewed May 2012 at <http://www.nationalmssociety.org/multimedia-library/E-newsletter/september-09-enews-research/index.aspx>
20. Polman CH, Reingold SC, Banwell B, *et al.* Diagnostic criteria for multiple sclerosis: 2010 revisions to the McDonald criteria. *Ann of Neurol* 2011; 69(2):292–302.
21. Polman CH, Reingold SC, Edan G, *et al.* Diagnostic criteria for multiple sclerosis: 2005 revisions to the "McDonald Criteria". *Ann of Neurol* 2005; 58(6):840–6.
22. Poser CM, Paty DW, Scheinberg L, *et al.* New diagnostic criteria for multiple sclerosis: Guidelines for research protocols. *Ann Neurol* 1983; 13:227–31.
23. Rietberg MB, Brooks D, Uitdehaag BMK, Kwakkel G. Exercise therapy for multiple sclerosis (review). *The Cochrane Library* 2011; 1. Viewed May 2012 at <http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD003980.pub2/full>
24. Sadovnick AD, Ebers GW, Wilson RW, *et al.* Life expectancy in patients attending multiple sclerosis clinics. *Neurology* 1992; 42(5):991–4.
25. Shams PN and Plant GT. Optic neuritis: a review. *International MS Journal* 2009; 16(3):82–89.
26. Smith RM, Adeney-Steel M, Fulcher G, Longley WA. Symptom change with exercise is a temporary phenomenon for people with multiple sclerosis. *Arch Phys Med Rehabil* 2006 May; 87(5):723–7.
27. Thomas PW, Thomas S, Hillier C, *et al.* Psychological interventions for multiple sclerosis (review). *The Cochrane Library* 2009; issue 1. Viewed May 2012 at <http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD004431.pub2/pdf>
28. Tremlett H, Yousefi M, Devonshire V, *et al.* Impact of multiple sclerosis relapses on progression diminishes with time. *Neurology* 2002 Nov; 73(20):1616–23.
29. Tsui A & Lee MA. Multiple sclerosis and pregnancy. *Curr Opin Obstet Gynecol* 2011 Dec; 23(6):435–9.
30. World Health Organization and Multiple Sclerosis International Foundation. *Atlas multiple sclerosis resources in the world.* World Health Organization 2008.



AUSTRALIA

[www.msaustralia.org.au](http://www.msaustralia.org.au)

**Freecall™**  
**1800 042 138**

© MS Australia 2012