

Multiple
Sclerosis
Trust

MS

MS: what does it mean for me?



A positive
and practical
introduction
to MS

MS: what does it mean for me?

Multiple sclerosis (MS) is complex and unpredictable. If you have recently been diagnosed with the condition, you will almost certainly have a number of questions about how it will affect your life. In our experience, one of the best ways of learning to adjust to your new circumstances is to have access to clear and accurate information. The aim of this booklet is to do just that – to provide a practical introduction to MS and to help you to maintain a positive attitude to managing your MS.

There is not enough space to cover all aspects of MS in detail, but the MS Trust can provide more detailed information on the topics covered in this book as and when you want them. Details of some other useful sources of information and support can be found at the end of this book. For a complete list of our publications, contact the MS Trust at the address inside the back cover or visit our website www.mstrust.org.uk, from which many of our publications can be downloaded.

The MS Trust would like to thank all the people with MS who were involved in the development of this booklet.

Written and edited by: MS Trust Information Team

MS: what does it mean for me?

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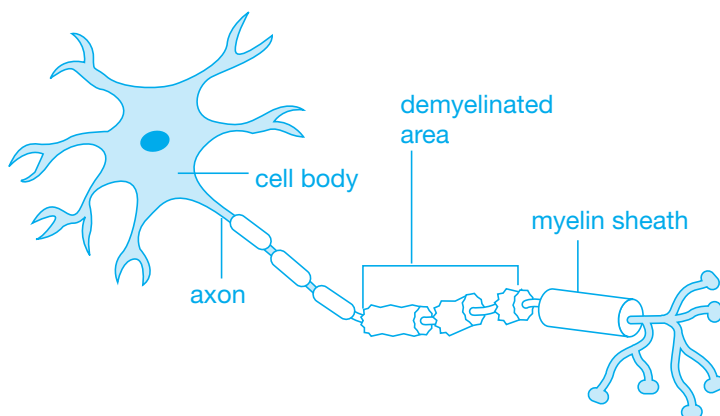
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What is MS?

MS is the most common disease of the central nervous system affecting young adults. The central nervous system comprises the brain and spinal cord. Together with the nerves connecting to the rest of the body, they form the body's communication network.

Nerve cells (**neurons**) contain nerve fibres (**axons**), which are surrounded by a protective sheath of fatty protein called myelin. This protects the nerves in the same way that insulating material protects an electric wire. In MS, damage or scarring occurs to the **myelin sheath**. This damage (called **demyelination**) disrupts the way in which messages, or nerve impulses, are carried to and from the brain and so can interfere with a range of the body's functions.

A nerve cell or neuron



The term 'multiple sclerosis' comes from 'sclerosis', which means 'scarring' and 'multiple', which relates to the sites of the scarring, which can occur in different places throughout the brain and spinal cord.

The symptoms experienced depend on the position and extent of the scarring or lesions within the central nervous system and on how much damage has occurred, so no two people with MS will have exactly the same set of symptoms.

In the earlier stages of MS, the central nervous system can often repair areas of damaged myelin or reroute messages via different pathways of neurons thereby avoiding the damaged areas. This explains why episodes of symptoms (relapses) can be followed by weeks, months or even years when symptoms improve or disappear (remission). However, if the area of damage becomes too large, communication with that specific part of the central nervous system may become permanently blocked.

What are the common symptoms at the time of diagnosis?

- fatigue
- loss of vision in one eye
- blurred or double vision
- dragging a foot
- weakness of limbs
- reduced coordination
- balance problems
- numbness, pins and needles, burning sensations



What causes MS?

The cause of MS is not yet fully understood but is thought to be a combination of environmental and genetic factors. One theory is that some people have certain groups of genes that make them more likely to develop MS. It may be that an external factor, such as a virus, triggers a reaction in those with this genetic predisposition causing the immune system to malfunction and attack its own myelin.






First thoughts...


You're told you have MS, what thoughts go through your head?

When you are first diagnosed with MS, you may experience a variety of emotions, ranging from shock and disbelief to anger and fear, even – for some people – relief that at last they have a diagnosis. You will probably need answers to a number of important questions, such as:




“How will my MS develop?”

This is one of the most commonly asked questions, but unfortunately due to the varied and unpredictable nature of MS it is impossible to answer with any certainty. For further information on long-term prognosis see page 14.



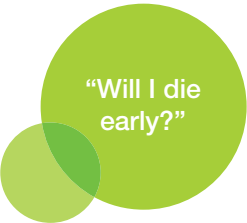
“Will I be severely disabled?”

For the vast majority of people with MS, the answer to this question will be no. Rapid progression is rare and most people with MS will never need to use a wheelchair on a regular basis.



“Am I going to lose my independence?”

Again for most people the answer is no. Most people with MS continue to enjoy an active life many years after diagnosis.



“Will I die
early?”

Most people with MS will live just as long as anybody else.

Although it is natural to experience a sense of loss for the life you had planned, MS need not be the devastating diagnosis that many people fear, particularly if you have access to good information and to the right treatments and support from health and social care professionals.





Key facts about MS

- More than 100,000 people in the UK have multiple sclerosis (MS)
- More women than men are diagnosed with MS
- MS is not inherited, but family members do have a slightly higher risk of developing MS (see page 26)
- It is usually diagnosed when people are in their 20's and 30's
- MS is a disease affecting the central nervous system (the brain and spinal cord)
- Symptoms can come and go and can vary greatly in terms of severity
- There may be periods of relapse of varying length and severity
- Everyone's MS is different
- MS is not a fatal condition
- It is neither infectious nor contagious
- Most people diagnosed with MS will not need to use a wheelchair on a regular basis
- At present, there is no cure for MS but this certainly doesn't mean that the symptoms of MS cannot be treated



Diagnosing MS

Getting a diagnosis of MS can be a long and difficult process, not least because the symptoms of MS are common to many other conditions. Many people with MS say that handling the uncertainty during and following diagnosis is harder than coping with any of the symptoms they ever experience. Knowing what to expect during the diagnostic procedure and understanding what the various tests are looking for can help to make the process easier to deal with.

There is no one test or procedure that can be used to accurately diagnose MS on its own. Diagnosis is usually based on a history of symptoms (perhaps an unexplained episode of blurred vision years before, or pins and needles in the hands or feet) and on the results from a series of tests. Doctors need to rule out other possible causes of symptoms before they can confirm a diagnosis of MS.

If you experience symptoms for the first time, and then they improve or disappear, neurologists often prefer to wait for a second relapse, or for symptoms to become more severe, before giving a definite diagnosis.

Medical (clinical) history

Your doctor will ask about your medical history and symptoms and may perform some simple physical examinations.

MRI scanning

Magnetic resonance imaging (MRI) scans are used to identify any areas of scarring in the brain or spinal cord.

Evoked potentials

These are simple electrical tests, usually carried out on vision, which can detect a delay in messages between the eyes and the brain.

Lumbar puncture

This procedure involves drawing off a sample of fluid from around the spine and testing for abnormalities that can indicate MS.

It is important to note that the above tests do not always give a definitive result. For most people with MS, an MRI scan will show some lesions or areas of inflammation, but a small proportion of people do have a 'silent' MRI. Similarly around 5% of people with MS will have a negative lumbar puncture result.





Types of MS

MS is a complex and unpredictable condition that varies from person to person and does not follow a set pattern. Symptoms can come and go from day to day but there can also be relapses followed by periods of complete or partial remission. For other people, MS can be more progressive in nature.

MS is often divided into four different types:

1 Benign

Benign MS is associated with very occasional relapses, with good recovery in between and minimal symptoms over many years; therefore it can only be diagnosed retrospectively. Some neurologists estimate that more than 20% of people with MS have this benign form of the condition. The long-term prognosis for a person with benign MS is generally good, but there can be exceptions and some people do find their benign MS worsens in later life.

2 Relapsing remitting

Initially, about two thirds of people have relapsing remitting MS. They experience relapses on average once or twice per year, with good or complete remission in between. However, there is a tendency for symptoms to worsen very gradually over time.

A relapse is a significant worsening or re-occurrence of a symptom, or group of symptoms, lasting for more than 24 hours, in the absence of an infection. Relapses are also referred to as exacerbations, episodes and attacks. Symptoms usually appear over a short period of time (hours or days), but can last for anywhere between a few days to many months. The severity of a relapse can also vary from mild to more severe.

A remission is a period of recovery, when symptoms become less severe or disappear altogether. Periods of remission can last any length of time, sometimes even for years.

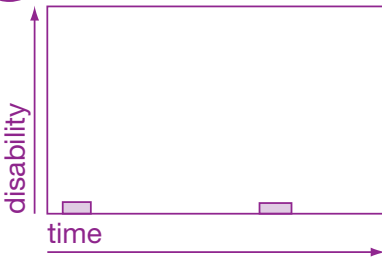
3 Secondary progressive

People who start off with relapsing remitting MS may go on to develop a progressive form of the condition. The transition usually occurs somewhere between five to 20 years after diagnosis, but you can change from relapsing remitting MS to secondary progressive MS at any time. The severity and frequency of the relapses decrease, but disability slowly increases.

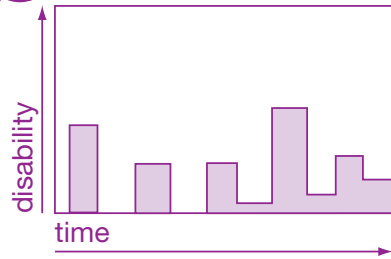
4 Primary progressive

About 10-15% of people experience symptoms right from the start that become progressively worse over a period of years without remission.

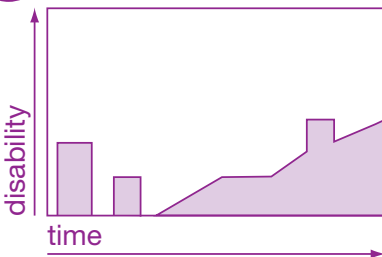
1 Benign



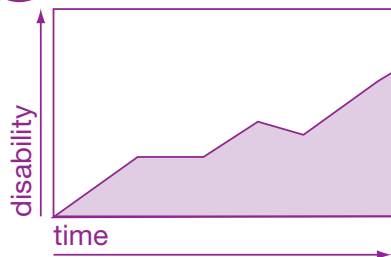
2 Relapsing remitting



3 Secondary progressive



4 Primary progressive



It is important to note that it is not always possible to determine which type of MS you have when you are diagnosed – this may only become apparent over time. The course of MS is very varied and unpredictable, which makes it impossible to say with any certainty how your MS might develop.

Research has shown that some early symptoms, particularly those affecting sight and sensation, as well as long intervals between relapses, suggest a more positive long-term outlook or prognosis.

Remember whatever type of MS you have, it is unlikely to shorten your lifespan.





Health professionals involved in the management of MS

Because of the wide range of possible symptoms that can be experienced in MS, a multidisciplinary team of specialist health professionals may be involved in your treatment. The roles of just some of these health professionals are described below.

GP

Although by definition not experts on MS, GPs are knowledgeable in dealing with some symptoms. They also have an important role in referring you to, and liaising with, other members of the specialist multidisciplinary team.

Neurologist

A neurologist is involved in the diagnostic procedure and determining what medical treatment may be appropriate. A list of specialist MS centres in the UK and the neurologists within those centres can be found on the MS Trust website:

www.mstrust.org.uk/map

MS specialist nurse

MS nurses are often the first point of contact to discuss any MS-related concerns. They liaise with, and can refer to, other members of the multidisciplinary team ensuring continuity of care.

Physiotherapist

Physiotherapists are involved in the assessment of movement to help improve mobility. They can provide advice on exercise. They can also have a role in the management of some types of pain.

Occupational therapist (OT)

The main role of an OT is to assess your ability to perform daily activities and provide aids or adaptations, for example to help conserve energy, if they are needed. They also have an important role in teaching fatigue management strategies.

Continence advisor

This is a nurse who specialises in bladder and bowel problems. Their role is to assess the nature of any problem and provide advice on appropriate medication or other management strategies.





Living with the symptoms

Key facts

- MS can cause a wide variety of symptoms, but most people only experience a small number of these
- Symptoms can come and go
- Some symptoms are very responsive to treatment; others are more difficult to manage
- No two people with MS experience the same symptoms to the same degree

Some symptoms, such as pain and fatigue, can worsen temporarily, for example during hot weather, whilst exercising, or if you have an infection. Sometimes it can be difficult to distinguish transient symptoms such as these from the onset of a relapse.

It is also important to remember that not all the symptoms you experience will necessarily be connected to your MS. You are still susceptible to all the ailments experienced by the general population.

Some of the more common symptoms are listed here, with an indication of how they can be treated or managed. If you are experiencing these symptoms and they are causing you problems, ask your GP for help or to refer you to the appropriate specialist. There is no need to put up with them - don't suffer in silence!

Visual disturbances

Optic neuritis, or inflammation of the optic nerve, is often the first symptom of MS. Eye problems can include temporary loss of vision, double vision, pain and reduction in colour vision. Steroids may be used to keep these symptoms under control.

Fatigue

An overwhelming sense of exhaustion and weariness is a very common symptom of MS. It can be particularly difficult to cope with since it is effectively an 'invisible' symptom that will not be obvious to other people. You may need to explain that fatigue is a specific symptom of MS and that you are not being lazy! There is a lot you can do to minimise the effects of fatigue, for example, by using time management and energy conservation techniques, by pacing yourself and by alternating periods of activity with rest. An occupational therapist can advise on the best ways to manage fatigue.

Bladder and bowel problems

Bladder problems include needing to empty the bladder more frequently and more urgently than usual. The most common bowel problem is constipation. Although these symptoms can be distressing and embarrassing, remember that they are usually very responsive to treatment. Ask your doctor to refer you for specialist continence advice.

Pain

For some time pain was not recognised as a symptom of MS, but more recently it has been acknowledged that there are two types of pain that can occur in MS. Pain may be neuropathic, ie caused directly by damage to the nerves. It is associated with stabbing pains, extreme skin sensitivity and burning sensations. The second type of pain, known as musculoskeletal pain, is not caused directly by MS but can develop through altered posture and positioning and is triggered by damage to tendons, ligaments, muscles or bones. In order to treat pain effectively, it is important to identify the cause. For example, nerve pain may be best managed using drugs, whilst musculoskeletal pain is best treated by a physiotherapist and/or occupational therapist.



Spasm

Nerve damage can cause muscles to contract into tight, often painful spasm. This symptom is not only distressing, but if it is not treated effectively, the functioning of the muscles can be affected. Therapists and doctors both play an important role in the management of spasm and may recommend a combination of exercise and drug therapy.

Mobility problems

Difficulties with walking can be caused by balance or coordination problems, dizziness, muscle stiffness (spasticity) or weakness. A multidisciplinary team should manage this aspect of MS and input from a physiotherapist is very important.



Drug therapies

Drug therapy is now an established part of managing MS, and it is vital that specialist assessments are undertaken early in the disease course. Currently, there are three areas in which drug therapies are used:

Drugs to treat relapses

Steroids are sometimes given for a few days; they can either be administered orally by tablet or as a solution into a vein (intravenously). While there is no evidence that steroids make any difference to the long-term course of the condition, they can be effective at speeding up recovery from relapse.

Drugs that modify the disease course (DMDs)

Four beta interferon products, Avonex, Betaferon, Rebif and Extavia may be prescribed for the treatment of relapsing remitting MS and also for secondary progressive MS if relapses are still occurring.

Another disease-modifying drug, glatiramer acetate (Copaxone), also for relapsing remitting MS, has similar effects to beta interferon, although it acts in a different way.

All these drugs reduce the number, duration and severity of relapses for many people, and may also slow the progression of disability. All are self-injected under the skin or into a muscle, once or several times a week, depending on which drug is prescribed.

For further information on this topic, please ask for a copy of our booklet on disease modifying drug therapies.

Natalizumab (Tysabri) is a disease modifying drug licensed only for use in people with highly active relapsing remitting MS. It is given intravenously once every four weeks.

Request a copy of our factsheet for more information about natalizumab.

Drugs to treat symptoms

Drugs are available to treat some specific symptoms of MS, although some symptoms are more responsive to treatment than others. Symptoms where drug therapies are often used include: bladder problems, spasms, spasticity and pain.

Our understanding of the best ways of managing MS is improving all the time and several potential new drug therapies are in development.



Complementary therapies

Many people with MS use complementary and alternative medicines (CAMs) as a way of relieving symptoms or improving wellbeing. These include yoga, touch therapies (eg reflexology, massage, aromatherapy), homoeopathy, hyperbaric oxygen therapy, acupuncture, dietary changes, supplements, herbal remedies, relaxation and meditation techniques.

It is difficult to measure how effective a particular therapy is for MS, whether drug or non-drug, since MS varies so much from person to person, and from day to day. It is also hard to conduct trials that measure the effect of CAMs and much of the evidence for their use is anecdotal, ie based on individual experiences.

Many people with MS find that CAMs can help not only to ease some symptoms, but also to improve general wellbeing. When you may feel as though you have lost control of your own body, just knowing that you are doing something for yourself can be a positive step.

A word of caution

There is a widespread belief that CAMs must be safe since they are 'natural' but this is not necessarily true. Always check that your practitioner is properly trained and has the appropriate qualifications for the therapy they are offering, and find out whether they are registered with their professional association or regulatory body if they have one. Also make sure that you are fully aware of the cost of any treatment and how long it is likely to last.

Remember that CAMs can interact with conventional therapies. For example, the popular herb St John's Wort, which is used to treat depression, can make some prescription medicines, including the contraceptive pill and some conventional antidepressants, work less well. So, it is a good idea to inform your doctor of your plans and to let your therapist know that you have MS. It's worth remembering too that no complementary therapy can currently offer a cure and to be wary of anyone who makes this claim.



Some further questions

Is there anybody I need to tell that I have MS?

If you have a driving licence you must tell the DVLA (Driver and Vehicle Licensing Agency) that you have MS. They will send you a questionnaire to assess the impact of MS on your driving performance. The DVLA may need to talk to your doctor about your condition. If there is no medical reason to prevent you from driving, a full licence will be retained. You must also tell the DVLA if your MS worsens; this may require a reassessment.

Insurers require that you declare any relevant information, medical or otherwise. If you fail to do so, you run the risk of their refusing any claims. If you are in any doubt, check with your insurer about what you are required to disclose.

Choosing when and how to inform family, friends and colleagues about your MS is a personal and complex decision. There is no legal obligation to inform your employer that you have MS unless you are in the armed forces, work on a plane or ship, or your condition presents a health and safety risk. However, you must not mislead your employer and you must answer medical questions honestly. More information on telling people about your MS can be found in our factsheet 'Talking about MS to family, friends and colleagues'.

Further information about working with MS can be found in our booklet 'At work with MS', or you may want to speak with the Disability Employment Advisor (DEA) at your local Job Centre.

What will make my MS worse?

First and foremost, MS is unpredictable so it is difficult to know what, if anything, might trigger a relapse for you. You may find that specific factors, such as fatigue or increased body temperature (due to a hot bath, hot climate or perhaps an infection) can worsen symptoms and occasionally even cause a relapse. On the other hand, they may have no effect on your MS whatsoever.

Some people worry that receiving a vaccination, for example against flu, or when travelling abroad or having a general anaesthetic can make their MS worse. In fact, there is no evidence to suggest that someone with MS should avoid either being vaccinated, or having a necessary operation. Similarly, there is no link between the use of prescribed medications, such as the contraceptive pill or HRT, and a relapse of MS.

What happens if I get pregnant?

If you are considering getting pregnant, it is natural to want to know how pregnancy will affect your health and whether your baby is likely to develop MS.

A woman with MS is less likely to have a relapse during pregnancy, although the risk of relapse increases in the six months after the birth. However, pregnancy has no long-term effect on the course of MS and you are no more likely to experience miscarriage, stillbirth, birth defects or infant death than a woman who does not have MS. Further information can be found in our factsheet 'Pregnancy and parenthood'.

Will my children get MS?

MS is not inherited in the same way as the colour of your eyes, which is passed down through the genes. However, it is now generally accepted that if there is MS in the family, you are more likely to have a genetic predisposition to MS than someone who does not have MS in their family. This means that if a parent has MS, their children will have a greater risk of developing the condition, although the risk is still very small.





Sources of further information and support

We hope that this book has been helpful. When you are diagnosed with MS, the most important thing is to have access to accurate information and specialist help. Some people with MS can rely on the support of an expert multidisciplinary team of health professionals, backed up perhaps by an excellent local self-help group, right from the moment of diagnosis. Others are less fortunate and have to seek out help for themselves. Rest assured that help is out there – the secret is in knowing how to access it.

At the MS Trust, we believe that helping people to access the right information at the right time is the most important part of our job. We provide that information directly to people with MS themselves, and we provide it indirectly by educating and informing nurses and other health professionals who then pass on their knowledge to people with MS.

Our experienced information team is on hand to answer questions and to research specific topics on your behalf. We have a wide range of specialist topic-related publications and also organise regular Internet chatroom sessions, with the opportunity to put your questions to a panel of experts. Our contact details can be found inside the back cover - we look forward to hearing from you.

Details of some further sources of information and support can be found overleaf.

Online support groups

shift.ms

An online community set up for people in their 20's and 30's (or with a younger attitude)

www.shift.ms

MS People UK

An online community for those with MS, their families and friends

www.ms-people.com

Legal advice

Citizens Advice Bureau

Offers free, confidential, impartial and independent advice, including benefits, legal matters and employment rights

www.citizensadvice.org.uk

Department of Work and Pensions

The government department that oversees the benefits system. The website has information on the range of benefits available

www.dwp.gov.uk

Equality and Human Rights Commission

The Equality and Human Rights Commission is a good source of advice if you feel you may have been discriminated against at work or elsewhere

www.equalityhumanrights.com





Contact information

Neurologist:

Neurologist's secretary:

Telephone number:

MS specialist nurse:

Telephone number:

GP:

Telephone number:

MS Trust Information Team: 0800 032 3839

Other useful numbers:



MS Trust information service

Helping you find the information you need

We hope that you have found this information helpful. The MS Trust offers a wide range of publications, including a newsletter **Open Door**, which provides an ongoing update on research and developments in MS management. In addition it contains articles from people with MS and health professionals.

For a full list of MS Trust publications, to sign up for Open Door and much more visit our website at **www.mstrust.org.uk**

If you would like to speak with someone about any aspect of MS, contact the MS Trust information team and they will help find answers to your questions.

Freephone

0800 032 3839 (Lines are open Monday – Friday 9am-5pm)

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All our services are provided free within the UK. If you have found this information valuable, please help us to help others; any donation, however small, is much appreciated.



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