

What is MS?



100,000 people live with multiple sclerosis in the UK.
Every one of them shares the uncertainty of life with MS.

The MS Society is the UK charity fighting to improve treatment and care to help people with MS take control of their lives.

We're a world-leading funder of MS research. We've already made important breakthroughs, and we're now at the start of a generation of MS research that holds incredible promise.

With your support, we will beat MS.

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MS is a significant part of me, but it is far from the most interesting part. It's just a facet.

– *Helen*

MS is not going to go away. So I just have to get on with it and make the most of my life.

– *Sylvia*

I have not had the life that I wanted, but the life I have led with MS has allowed me to meet some wonderful people. They haven't been able to ignore MS either, but they have made the best of the life they have been blessed with. – *John*

It doesn't have to mean a life sentence. Yes, it's serious and yes, it does change your life... but you can still enjoy your life. – *Louisa*

What is MS?

Multiple sclerosis (MS) is a neurological condition that affects the brain and spinal cord (the central nervous system). In MS, the body's immune system turns against itself and, instead of fighting off infection, starts attacking the myelin coating surrounding the nerve fibres in the brain and spinal cord.

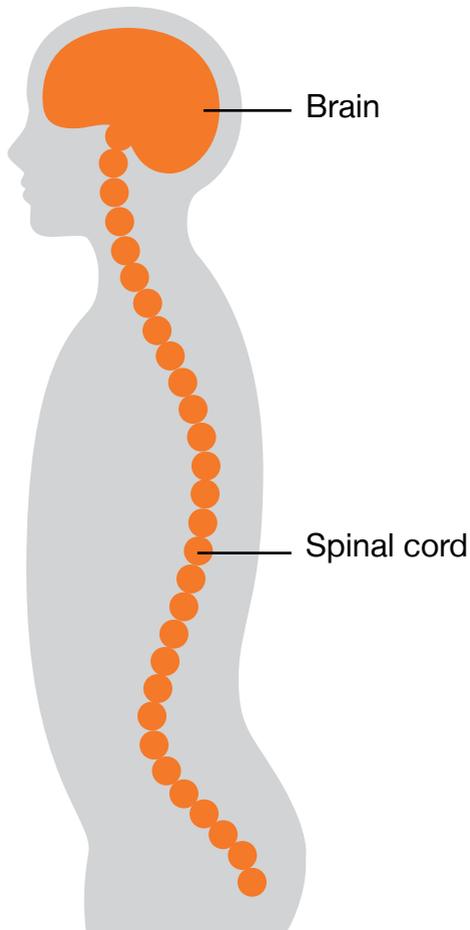
MS is a very individual condition: no two people are affected in the same way. The symptoms someone has will depend on which parts of their brain and spinal cord are affected. There are many different symptoms of MS, and it's unlikely that anyone will have all of them.

In this booklet, we explain what MS is and how it can affect someone. We look at the risk factors for developing MS, how it is diagnosed, the different types of MS, and the treatments available for managing the condition and its symptoms. We also signpost to further sources of information and support from the MS Society, and explain how we can help.

 Where you see this symbol, this means there's an MS Society information resource that covers the topic in more depth.

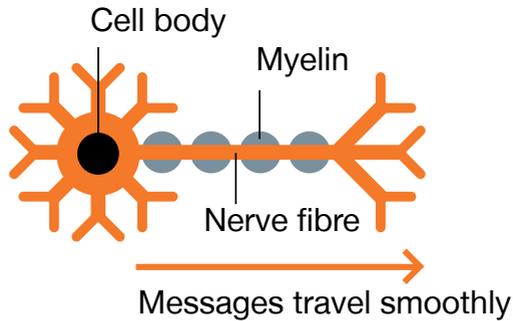
MS and the central nervous system

The central nervous system is made up of your brain and spinal cord. The brain controls your bodily functions, such as movement or thought. Messages pass to and from the brain to all parts of your body, controlling both conscious and unconscious actions. The spinal cord is the central pathway for these messages.



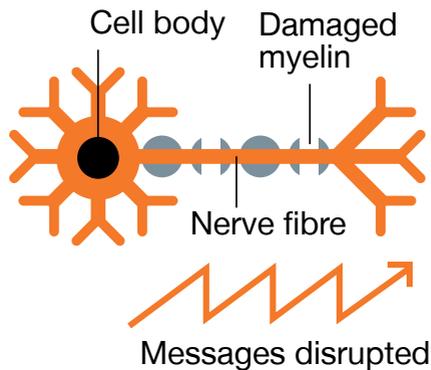
Inside the brain and spinal cord, messages travel along nerve fibres which are coated with a fatty substance called myelin (Fig 1). Myelin is a protective layer which helps messages travel quickly and smoothly.

Fig 1: Myelin



When the myelin is damaged by an attack from the immune system, this disrupts the messages in the brain and spinal cord (Fig 2). Messages can slow down, become distorted, jump from one nerve fibre to another or not get through at all.

Fig 2: Demyelination in MS



What's going on?

One way to understand what is happening in MS is to think of the nervous system as an electrical circuit.

Your brain and spinal cord are the power source – the mains electricity at home. The different parts of your body are the lights, computers, TV and so on. In order to work, these appliances need electricity, just like your body's actions depend on messages from your brain.

The nerve fibres in the brain and spinal cord are the wires behind the walls, linking everything together. Plastic insulation protects the cables in the same way that myelin protects the nerve fibres.

If the insulation becomes damaged then the appliances might not work properly. There could be interference on the TV. The light might flicker on and off. This is what's happening in MS – damage to the insulation affects the way things work.

As the central nervous system links all bodily activities, many different symptoms can appear in MS. It depends on which part of the brain or spinal cord is involved, and the function of the affected nerve. There's more about the different symptoms of MS on page 12.

MS means that I'm constantly adapting my lifestyle to accommodate the condition, quite often on a daily basis. I'm constantly aware of its impact on my family and friends. – *Eiona*

Who gets MS?

There are about 100,000 people in the UK who have MS – that's around one in every 600 people.

MS is usually diagnosed between the ages of 20 and 40, although it can occur at any age. Children can develop it, although this is rare.

Women are more likely to have MS than men: there are roughly three times more women than men with MS in the UK. We don't yet know why that is, although research continues to try to find the answer.

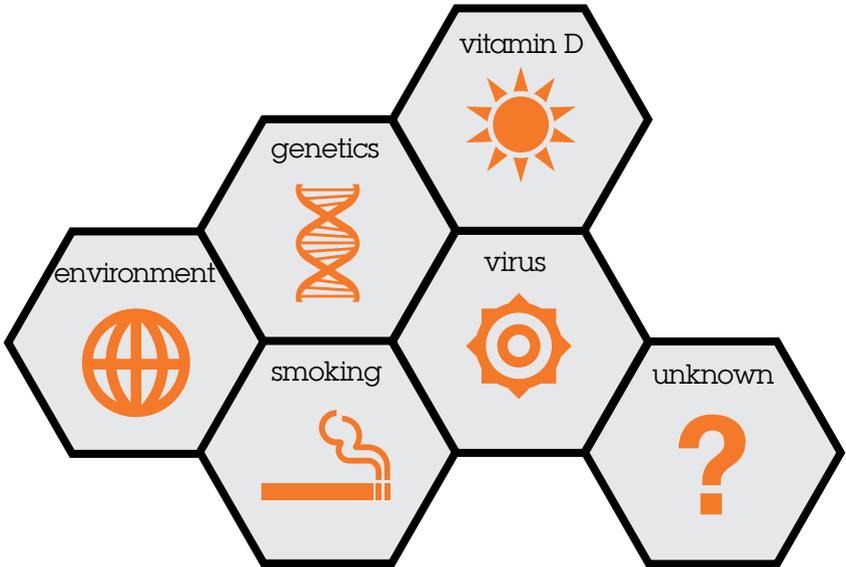
Pregnancy and MS

The majority of women who have MS are diagnosed in their 20s and 30s, at a time when they may be thinking about starting a family. MS doesn't affect fertility, so it shouldn't stop a woman from having a baby. However, being pregnant will affect the treatment a woman can have for her MS.

 [Read more – Women's health](#)

MS is most common in people whose ancestors come from northern Europe. However, people of all ethnic, cultural and social backgrounds can develop MS.

What causes MS?



We don't know for sure why someone develops MS, though there appear to be a number of risk factors – both genetic and environmental. It's likely that a combination of these factors is involved.

We do know that MS is not infectious – it can't be caught or passed from one person to another.

Genetic factors

MS is not directly inherited like some other conditions – it isn't caused by one faulty gene.

However, there does appear to be a genetic element to it. Research into the genetics of MS has so far found over 50 genes that may make someone more likely to develop MS.

But not everyone who has these genes will get MS.

While MS can occur more than once in a family, it's more likely that this won't happen. Even the identical twin of someone with MS only has a 30 per cent chance of developing MS as well. And a child of someone with MS has just a two per cent chance of having MS themselves.

So, while there is a genetic element to MS, it's not the whole story.

 [Read more – Genes and MS](#)

Environmental factors

MS is more common in areas that are furthest away from the equator. There are relatively few people with MS in places like Malaysia or Ecuador, but many more in the UK, northern USA, Canada, Scandinavia, southern Australia and New Zealand.

This suggests there is something in the environment that plays a role in MS. Research has so far discovered a number of environmental factors that are linked with MS, but more work is needed before we can definitely say they are involved in causing MS.

Three of these possible environmental factors are vitamin D, viruses and smoking.

Vitamin D?

We've known for a long time that MS is more common in areas away from the equator. Researchers have been looking into why this is – and one possible answer is vitamin D.

Vitamin D is known as the sunshine vitamin, as it is produced by our bodies in reaction to sunlight. A growing body of research suggests that low levels of vitamin D, particularly during childhood or before birth, may be a factor that affects someone's risk of developing MS. This hasn't been proved, and more research needs to be done before we can be sure.

 [Read more – Diet and nutrition](#)

Viruses?

Research has looked at whether viruses or bacteria may be a factor in developing MS. Although no single virus has been identified as definitely contributing to MS, there is growing evidence that a common childhood virus, such as the Epstein Barr virus (which can cause glandular fever), may act as a trigger.

This theory is still unproven. Many people who do not have MS would also have been exposed to these viruses. So, just like genes, viruses are unlikely to be the whole story.

Smoking?

A number of studies have looked at smoking in relation to MS, and have found that smoking appears to increase someone's risk of developing MS. It's not yet clear exactly why this is, although one theory is that the chemicals in the cigarette smoke affect the immune system.

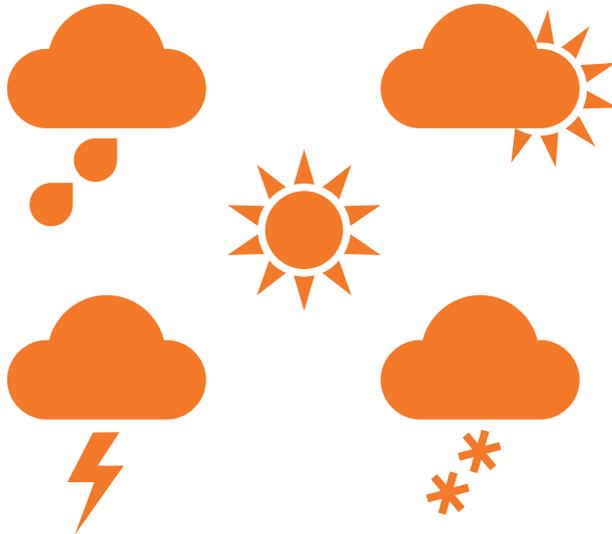
There is still more we need to know about the link between smoking and MS. This includes whether the risk increases the more someone smokes, how smoking interacts with other risk factors for MS and whether smoking also affects progression in MS.

Something else?

We've discovered a lot about the potential causes of MS, but there's still lots more to learn. Research is going on all over the world – including projects funded by the MS Society – to find out more. Once we know why someone develops MS, we will be closer to being able to stop it from occurring in the first place. Read more about the latest research into the causes of MS at www.mssociety.org.uk/research

What are the symptoms of MS?

MS is complex, and has many possible symptoms. Most people will only experience a few of them, and it's unlikely that anyone will experience all of them.



Trying to predict MS symptoms can be like trying to predict the weather. They can vary enormously from one day to the next – even from one hour to the next. They might last for a few hours, or for days, weeks or months. Some symptoms may not have a clear-cut beginning, and they may persist. Some people find certain triggers make their symptoms temporarily worse, or make old symptoms reappear – heat, stress, exertion or tiredness, for example.

Common symptoms

- Fatigue – an overwhelming sense of tiredness making physical or mental activity difficult or even impossible
- Sensory problems – such as numbness or tingling of the hands or feet
- Visual problems – such as blurred or double vision, or a temporary loss of sight in one or both eyes
- Dizziness – sometimes called vertigo
- Pain
- Loss of muscle strength and dexterity
- Problems with walking, balance and coordination
- Muscle stiffness and spasms – tightening or rigidity in particular muscle groups, sometimes known as spasticity
- Difficulties with speech and swallowing
- Bladder and bowel problems
- Problems with memory and thinking, also known as ‘cognitive problems’ – such as forgetting names
- Sexual problems

 We have information booklets on each of these symptoms, and you can also find out more on our website.

I would never patronise my wife or anyone who has MS to say, ‘I know how you feel.’ As I have no idea at all and no two people with MS are the same. – *Ron*

Invisible symptoms

Some MS symptoms are obvious to other people, while others aren't.

It might be easy to tell if someone with MS has problems walking, for example, but not that they are fatigued or in pain. These 'invisible' symptoms can be difficult for other people to understand, and frustrating for the person with MS to try to describe, or to explain how they are affected. Some people with MS say this can be a particular problem at work, especially if they appear to 'look so well'.

It's important to remember that these symptoms are just as real as any other and to avoid making assumptions about the person with MS, for example, mistaking fatigue for laziness.

How is MS diagnosed?

MS is complex and, as mentioned on page 12, can cause many different symptoms, so it's not easy to diagnose. There's also no single, simple test – like a blood test, for example – that can tell whether someone has MS. It's hard to pinpoint exactly when MS begins, and the early signs and symptoms are different for everyone. The symptoms of MS can also be symptoms of other conditions, so doctors will need to explore a range of possible causes for them.

MS can only be diagnosed by a neurologist. If you or your GP notice unexplained symptoms and are concerned that you might have MS, you will need a referral to a neurologist for further diagnostic tests. There's more information on these different tests below.

 [Read more](#) – *Getting the best from health care services*

I felt relieved when told...A big weight off my shoulders. Nothing had changed within those split seconds, so I went off on holiday and decided to throw myself wholeheartedly into learning about it when I got home. – *Eleanor*

Different tests

A diagnosis of MS involves a number of different tests, some of which may need to be repeated. It's not uncommon for a diagnosis of MS to take several months – or even longer – which can be a worrying time.

As well as testing for MS, doctors may need to test for other conditions that are similar to MS. This may include blood tests to reveal certain antibodies, and inner ear tests to check balance.



What are they looking for?

To diagnose MS, a neurologist follows guidelines called the McDonald criteria. They are looking for evidence of damage to the central nervous system that has:

- occurred on different dates
- affected at least two different places in the central nervous system

Neurological examination and history

The neurologist asks questions about past and present symptoms and problems. They also carry out a physical examination to check if movements, reflexes and sensory abilities – such as eyesight – are affected. Even if a neurologist strongly suspects MS at this stage, other tests are needed to confirm it.

MRI (magnetic resonance imaging)

MRI scanners use strong magnetic fields to create an image of someone's brain and spinal cord. If there are areas of inflammation or damage, or 'lesions', these show up on the scan.

Before I was diagnosed I was really worried about how I felt... Getting a diagnosis from my consultant was numbing, but not for long. – Aleks

To scan the brain and spinal cord, the person lies on a bed which then slides into the centre of the MRI scanner. The process takes anything from 10 minutes to an hour. It's painless, although it's quite noisy and some people feel a little claustrophobic.

The results of the MRI scan confirm a diagnosis in over 90 per cent of people who have MS.

Lumbar puncture

People with MS often have antibodies in the fluid that surrounds the brain and spinal cord. These antibodies are a sign that the immune system has been active in the central nervous system. The procedure used to get a sample of this fluid is called a lumbar puncture.

A lumbar puncture involves inserting a needle into the space around the spinal cord and drawing out fluid. You will be offered a local anaesthetic, but the procedure can still be uncomfortable. Many people get a strong headache afterwards. Newer, smaller needles cause less discomfort, although they're not yet being widely used.

Thanks to advances in other diagnostic tools, particularly MRI, lumbar punctures are not carried out as often as they used to be.

Evoked potentials

These tests measure how quickly messages travel between the brain, eyes, ears and skin. Small electrodes attached to the head monitor how brain waves respond to what the person has seen or heard. Messages are slower if myelin damage has occurred.

I'd had what I now know was optic neuritis about 6 years previously and I'd had a scan then. My eye problem had cleared up and I didn't ask any more questions. So when I was given the MS diagnosis, it came as a real shock. – *Rachel*

A diagnosis of MS

Receiving a diagnosis of MS can often be a life-changing moment. For some people, a diagnosis of MS can be overwhelming, frightening, confusing or distressing. For others it can be a relief, particularly if they've had symptoms for a long time. All of these reactions – and more – are perfectly normal.

However someone reacts to a diagnosis, there is support available – from our local branches, our MS Helpline and our information resources.

0808 800 8000 (9am–9pm, Monday–Friday)
www.mssociety.org.uk/near-me

 [Read more](#) – *Just diagnosed and Living with the effects of MS*

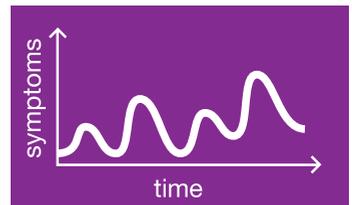
Are there different types of MS?

While everyone's MS is different, most people's experiences will fall into one of a number of broad types. For some, their MS is characterised by periods of relapse followed by remission. For others, it follows a progressive pattern. However, the lines between the different types are not always clear – it's not always obvious what type of MS someone has, and no two people, even with the same type of MS, will follow exactly the same pattern.

The three main types of MS are explained below – relapsing remitting, primary progressive and secondary progressive.

Relapsing remitting MS

In relapsing remitting MS, people have relapses or attacks of symptoms that occur for a period of time – days, weeks or months – and then improve, either partially or completely. Around 85 per cent of people with MS are diagnosed with this type.

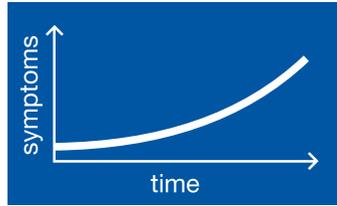


In the early stages of relapsing remitting MS, symptoms can go away completely between relapses – this is known as remission. However, sometimes there may be residual damage to the myelin, or even to the nerve fibre itself. This damage can mean that symptoms don't always disappear completely.

 [Read more – Managing a relapse](#)

Primary progressive MS

People with primary progressive MS don't have any distinct attacks or remissions, but begin with subtle problems that slowly get worse over time. Their MS is progressive from the start.



Around 10 to 15 per cent of people with MS have the primary progressive form. They tend to be diagnosed slightly later in life than people with the other forms – usually in their 40s or later. And, unlike relapsing remitting MS, men are just as likely to have primary progressive MS as women.

Some people who have progressive MS from the start also have relapses on top of the clear progression. This is called progressive relapsing MS.

Read more – *What is primary progressive MS?*

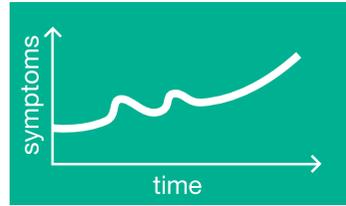
Proportions of people diagnosed with each type of MS



- Relapsing remitting MS, 85%
- Primary progressive MS, 15%

Secondary progressive MS

Many people with relapsing remitting MS go on to have secondary progressive MS. If someone's MS symptoms have become progressively worse over a period of at least



six months, independent of any relapses, they can be said to have moved on to secondary progressive MS.

Roughly 65 per cent of people with relapsing remitting MS will have developed secondary progressive MS 15 years after being diagnosed.

It isn't always easy for doctors to tell when someone has moved on to the secondary progressive phase of MS. Some people continue to have relapses in addition to progressive deterioration, while others don't.

Although no-one's MS starts out as secondary progressive, it is possible for someone to be told they have this type at the time of diagnosis if they've had unexplained symptoms for some time.

 [Read more – What is secondary progressive MS?](#)

Of the people diagnosed with relapsing remitting MS, after 15 years



- 65% will have moved onto secondary progressive MS
- 35% won't have moved onto secondary progressive MS

Benign MS?

Some people may be told that they have 'benign' MS, perhaps because their symptoms have been quite mild. However, this can sometimes be misleading.

'Benign' MS is a label that can only be applied when looking back at the course of someone's MS over a period of at least 10 to 15 years. If someone has had MS for many years and it hasn't worsened, and they have little or no disability, they might be said to have 'benign' MS. It's difficult to give exact figures, but probably between 10 and 30 per cent of people with MS fit this broad description.

However, 'benign' doesn't mean that someone's MS has been completely problem-free, or that it will continue in that way. Someone could still have a relapse even after many years of inactive MS.

This disease will not define me any more than the colour of my hair. I want to be described as a husband, a father, bright, witty, knowledgeable and kind. That's all. – *Martin*

Can MS be treated?

Yes. Although there's no cure for MS yet, there are different ways to manage it.



This can include treatments for individual symptoms or relapses. It might also include psychological therapies, such as cognitive behavioural therapy, to help adjust to living with MS or with managing symptoms such as fatigue. There are also drugs that aim to reduce the number of relapses someone has. It can also include more lifestyle options such as diet, exercise and complementary and alternative therapies.

Managing symptoms

There are many treatments available for managing the different symptoms of MS. These treatments may not always make the symptom go away, but they can often make it easier to deal with.

Drug treatments can be helpful, but there are other approaches too – such as physiotherapy for muscle stiffness, or occupational therapy for tremor. Many different health and social care specialists can be involved in managing symptoms. These include occupational therapists, physiotherapists, continence advisers, psychologists, and speech and language therapists.

Read more – Find out more about managing the symptoms of MS in our information booklets and on our website.

Taking control

Many people with MS say that taking an active role in how they manage their MS helps them to feel in control. This might involve learning more about their symptoms and paying attention to what makes them worse and what helps them; working with health and social care professionals to try out different treatments; and having the knowledge and confidence to choose the treatment that's right for them. This approach is often referred to as self management.

Managing relapses

If someone has a particularly disabling, distressing or painful relapse, they might be prescribed steroids – called ‘corticosteroids’. Steroids can help to speed up recovery from a relapse. These are usually taken as tablets, or through a drip (intravenously).

Whether or not someone has had steroids, they may also benefit from rehabilitation after a relapse. Rehabilitation can combine many different approaches including physiotherapy, occupational therapy, dietary advice, employment services, support for care at home, and so on.

 [Read more – Managing a relapse](#)

When I tell people I have MS, the first thing they do is tell you that they understand because of someone they know with MS. They don't, because they don't have my MS. – *Jane*

Disease modifying drugs

If someone has relapses with their MS, then disease modifying drugs may be an option for them. These drugs aren't a cure for MS, but they can reduce the number of relapses or attacks that someone has.

There are a number of different drugs currently available on the NHS. They each have eligibility criteria, usually based on the number of relapses someone has had.

 [Read more – Disease modifying drugs](#)

What about progressive MS?

People often ask why there aren't treatments and therapies to slow or stop progression. One reason for this is because, until recently, scientists simply haven't had the same understanding of what's behind progressive MS as they have with relapsing remitting MS.

But that's all changing. Advances in technology – such as more powerful MRI scanners – mean that it's now possible to do the kind of research needed to find the right treatments. As a result, research is focusing more on finding treatments to halt progression, or even to reverse the damage that's already happened. There's more about the latest research at www.mssociety.org.uk/research

There are lots of things I just don't do anymore. However my life had another big change a few months after my diagnosis. I met my future husband and although in some respects the brakes were put on in my life, in others I did the things I had always hoped for. – *Rachel*

Complementary and alternative therapies

Many people with MS use complementary therapies to help relieve particular symptoms, or to feel better. The kinds of therapies used by people with MS include acupuncture, yoga, meditation, massage, hyperbaric oxygen therapy, homeopathy and osteopathy – although this isn't an exhaustive list.

There's not much research evidence behind many complementary therapies, but that doesn't necessarily mean that people don't get any benefit from them. Some people with MS say that using a complementary therapy has made a difference to how they feel, but they are not for everyone. As is often the case with MS, it's very individual.

It's always a good idea to check with a health care professional before trying out a complementary therapy.

 [Read more – Complementary and alternative medicines](#)

What about stress?

Many people with MS say that stress affects how they feel. Although there does seem to be a link between stress and MS, it's not conclusive – partly because it's so difficult to define what we mean by stress, and partly because everyone reacts to stress in different ways.

Reducing stress as much as possible can help with general health and wellbeing – although it's impossible to avoid it completely, and some stress can actually be positive, for example, helping you to get something done on time.

Diet

Eating a healthy, balanced diet can improve someone's general health and quality of life, which is particularly important when living with a long-term condition like MS.

Some people say that following a specific diet has made a difference to how they feel, perhaps by reducing the number of relapses they have, or by improving their overall quality of life. But other people don't feel this way. There is no conclusive evidence that special diets are effective at managing MS. For most people with MS, the best diet is a healthy, varied one.

 [Read more – Diet and nutrition](#)

Exercise

Regular exercise can help with managing symptoms and to prevent longer-term problems. Being active doesn't have to mean going out and playing a sport – it's all about people finding the right activities to suit them and their abilities.

 [Read more – Exercise and physiotherapy and Exercising with MS DVD](#)

I manage my time carefully due to fatigue but I sometimes have a day where I sail through without much difficulty at all. Those days are precious and I really appreciate them. People without MS would just take that for granted! – *Ellie*

How can the MS Society help?

We support thousands of people affected by MS – people who have a huge range of interests, aspirations and backgrounds.

Over 300 local branches offer support and information across the UK www.mssociety.org.uk/near-me

Our freephone MS Helpline offers confidential emotional support and information on 0808 800 8000.

Our award-winning information resources cover every aspect of living with MS
www.mssociety.org.uk/publications

Message boards on our website offer the chance to connect with other people affected by MS
www.mssociety.org.uk/forum

Research we fund helps to get us a step closer to beating MS. We are the biggest charitable funder of MS research in the UK. We fund world-class research to find the cause and cure for MS, as well as research into symptom relief and developing services to make a difference to people's lives in the here and now.

To find out more about the research projects we fund, and to read the latest research developments, go to www.mssociety.org.uk/research

Get involved!

To find out more contact your national office or use the UK contact details below.

Join us – members can receive local and national magazines and newsletters, and get involved locally and nationally. Be as involved as you like. Just by being a member, you strengthen the voice of people with MS.

www.mssociety.org.uk/joinus

020 8438 0759

Help us raise vital funds

www.mssociety.org.uk/fundraising

0845 481 1577

Volunteer

www.mssociety.org.uk/volunteering

020 8438 0944

Campaign with us, locally and nationally

www.mssociety.org.uk/campaignscommunity

020 8438 0700

Get involved in research

www.mssociety.org.uk/research

No-one gave me any information or help then, which made things worse and made me worry more. I was just sent away with the diagnosis. Thankfully I contacted the MS Society for information and the MS Society Helpline for some much needed help. – *Carole*

Join the MS Register



The UK MS Register is a unique project aiming to revolutionise our understanding of MS and the impact it has on the lives of people with MS. There are many things we know about MS, but so much more that only people with MS can tell us. How many people are there with each type of MS? How does it affect them? What services are most needed?

That's where the UK MS Register comes in. This groundbreaking work combines clinical and NHS data with the first-hand experiences of people with MS, to build a rich picture of what it's like to live with MS. Knowing this could transform the development and delivery of research, care and services for people with MS.

Anyone over the age of 18 with a confirmed diagnosis of MS can join the UK MS Register: www.msregister.org

About this booklet

Written by Jude Burke

With thanks to the many health care professionals and people affected by MS who contributed to this booklet.

Disclaimer

We have made every effort to ensure that the information in this booklet is correct. We do not accept liability for any errors or omissions. The law and government regulations may change. Be sure to seek local advice from the sources listed.

If you have any comments on this information or the work of the MS Society, please send them to infoteam@mssociety.org.uk.

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Fourth edition, June 2013

This title will be reviewed within three years.

References

A list of references is available on request, and all cited articles are available to borrow from the MS Society library (there may be a small charge). Contact the UK Information team, or visit www.mssociety.org.uk/library

The MS Society provides this information free of charge but if you would like to help cover the cost, which will help towards our essential work, please call 0800 100 133 or visit the fundraising section of our website to make a donation. Anything you can give will be greatly appreciated.

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