MS Trust

Making sense of MS

— A guide for people newly diagnosed with MS

How we can help

Publications

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Contents

Making sense of MS

Finding good, reliable information you can trust is important, particularly when you're newly diagnosed with MS.

Learning about MS can help you take control and feel more secure in what may feel like uncertain times. The Making Sense of MS resource aims to answer the most commonly asked questions after diagnosis. You can take your time and gather information at your own pace, perhaps starting with the topics that are most important to you.

This book is part of the Making Sense of MS resource. It gives an overview on the topics that people living with multiple sclerosis (MS) have told us are the most useful for those new to MS. It contains information on these key topics:

- **What is MS?** – an overview of what MS is, why it happens and what the symptoms are.
- **What happens after diagnosis?** – looks at how you might feel after diagnosis, who you need to tell and where to get support.
- **Making the most of appointments** – looks at how to get the best out of appointments with health professionals, questions you might ask and ideas that might help you prepare for appointments.

- **Living well with MS** – practical information on living well with MS including diet and lifestyle, exercise and fatigue, stress and relaxation, and symptom management.

At the end of each section we direct you to where you can find further information if you'd like to explore a particular topic in more depth. Some topics may never be relevant to you.

As part of the Making Sense of MS resource you can also request further information sheets on the following topics:

- **MS and your feelings** – answers the most commonly asked questions about emotional responses to a diagnosis of MS.
- **Telling people about your MS –** looks at how to approach telling partners, friends, family and colleagues about your MS.

- **Someone I know has MS** – this information sheet is designed to support people with a family member, friend or colleague who has been diagnosed with MS; it gives an overview of what MS is, what it's like to be diagnosed and live with MS.
- **Relapsing remitting MS** – explains what it means to be diagnosed with relapsing remitting MS.
- **Progressive MS** – looks at what it means to be diagnosed with a progressive form of MS.
- **Treating MS symptoms** – an introduction to the range of treatments that are available to manage the symptoms of MS.
- **Disease modifying therapies** – answers the most commonly asked questions about disease modifying therapies.

At the MS Trust we produce a wide range of information for people living with MS.

When you're ready for more information visit our website, search our A-Z, download one of our publications or contact us and we can email or post a publication to you.

Our Helpline Team are her for you when things are getting difficult. They can provide you with information or signpost you to other sources of support. You can call them on **0800 032 3839** or email **helpline@mstrust.org.uk.**

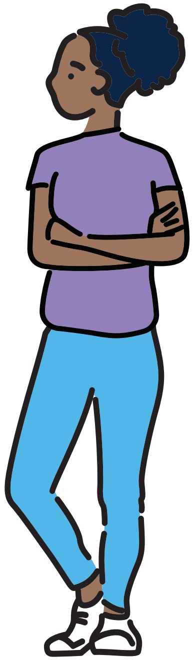
1. What is MS?

If you've just been diagnosed with multiple sclerosis, you'll probably have many questions about the condition and what it could mean for you. Here we answer some of the most frequently asked questions after diagnosis.

Multiple sclerosis is a condition which causes damage to your brain and spinal cord (the central nervous system). 'Sclerosis' means scarring and refers to the damage to the nerves caused by MS. 'Multiple' is added because this can happen in more than one place.

How common is MS?

- It's estimated that over 150,000 people in the UK have MS which is about one in every 500.
- Every week nearly 135 more people are diagnosed.
- It's nearly three times more common in women than in men.
- Most people are diagnosed in their 20s and 30s but it can be diagnosed in younger and older people.
- MS isn't infectious or contagious so you can't catch it or pass it on to other people.



What's happening in my body?

Your immune system is your body's natural defence system which helps your body fight against infections.

Your central nervous system contains nerve cells which process information and communicate messages to and from different areas of your body triggering a response, such as lifting your foot when walking or contracting the muscles in the bladder wall so you can empty your bladder.

In MS your immune system mistakenly attacks your central nervous system. When the attack happens, the immune system targets the protective covering around your nerves (called myelin). This covering is there to protect your nerves and help messages travel along them smoothly.

When myelin is damaged (called demyelination) messages don't pass along your nerves as efficiently as they used to so messages can be delayed or sometimes may not get through at all. These areas of damage are called lesions and they cause the symptoms you experience.

> “I'd spent so many sleepless nights googling symptoms and what my MRI results meant that when my neurologist confirmed it was MS, I was glad I finally knew what was going on.”

After an attack your body is able to repair itself to some extent. In the earlier stages of MS, your body has the ability to replace the damaged myelin (called remyelination), although it tends to be thinner than unaffected myelin so the messages may not travel as fast as they did before. Your brain also has the ability to reroute messages to avoid an area of damage so that messages can still get through – this is known as plasticity.

MS is thought to be an autoimmune and neurodegenerative condition. Autoimmune because your body is attacking healthy cells and neurodegenerative because the loss of myelin can leave nerves exposed and more vulnerable to long-lasting damage.

What are the symptoms?

In MS, it's only the nerves in the brain and/or spine that are damaged. However, because these nerves control the functions of the whole body, MS can cause a wide variety of symptoms. Most people will usually experience only a small number around the time of diagnosis and you may never experience all the possible symptoms of MS.

Symptoms vary from person to person and from day to day. This can make your MS rather unpredictable. It's completely normal for it to take some time to adjust and adapt to this unpredictability going forward in your life.

Some of the most common symptoms around the time of diagnosis are fatigue (a kind of exhaustion which is out of all proportion to the task undertaken), unusual feelings in your skin (such as pins and needles, numbness or burning), problems with eyesight, memory and thinking problems, and walking difficulties (such as tripping, stumbling, weakness or a heavy feeling in your legs).

Other possible symptoms that can happen in MS include muscle stiffness and spasms, bladder and bowel problems, and sexual difficulties.

Many of these symptoms may be invisible to other people. This can mean you look well to others when you're actually feeling very unwell. Sometimes it can be useful to explain to your family and friends when you're feeling like this as it may not always be clear to them.

If you experience new symptoms, it's important to get them checked out by your MS nurse or GP. They may be part of your MS but they could have some other cause. Like everyone else, it's good to go for routine health tests such as for blood pressure, diabetes and cancer screening.

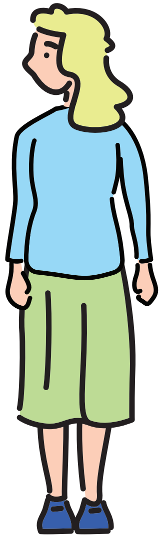
What's causing these symptoms?

MS symptoms will usually correspond with the areas of your brain and spinal cord that have been damaged, although this isn't the case for all symptoms.

Symptoms like muscle stiffness and bladder problems are linked to nerve damage in the spinal cord, whereas loss of balance or dizziness are caused by damage to an area in the back of the brain called the cerebellum which controls movement, balance and posture.

Other symptoms, such as fatigue, are not linked to a specific area of damage in your brain or spine. Instead fatigue is thought to be due to nerve messages from the brain and spinal cord having to cope with, and work around, the areas of damage caused by MS. It therefore takes more energy for your body to send and deliver these messages to other parts of the body, like the muscles in your arms and legs, causing a build-up of fatigue.

Is everyone's MS the same?



No, everyone's MS is different. MS is divided into three main types:

- relapsing remitting MS
- secondary progressive MS
- primary progressive MS.

Some neurologists prefer to divide MS into relapsing MS and progressive MS so you may come across this classification too. Sometimes there can be some doubt as to which type you have, especially when you're first diagnosed.

Your neurologist may have told you which type of MS you have. If not, you can ask your neurologist or MS nurse at your next appointment although they may not know yet. Keeping a diary with brief notes on any new or changing symptoms can help your neurologist better understand the type of MS you have.

Relapsing remitting MS (RRMS)

About 85 in 100 people are diagnosed with relapsing remitting MS. This type of MS is characterised by periods where your symptoms flare up (relapses) followed by periods where your symptoms are relatively stable or you may have no symptoms at all (remission). These periods of relative stability can last from months to years until they are interrupted by a relapse.

Relapses are episodes of new or worsening symptoms lasting at least 24 hours, but usually anything from a few days to a number of weeks or months. Some relapses are relatively mild but some are more severe. Symptoms usually improve and may go away completely as the body repairs itself. Relapses may be treated with steroids in the first few days to speed up recovery, particularly if symptoms are having a big impact on your everyday life.

Every relapse is different and it isn't possible to predict when relapses will happen or how often. This is one reason that MS is often described as unpredictable. If you have relapses, talk to your neurologist or MS nurse about whether you're eligible for a disease modifying therapies (DMTs). These can decrease the number and impact of relapses.

Secondary progressive MS (SPMS)

Most people who are initially diagnosed with relapsing remitting MS find that, over time, their MS changes. They have fewer or no relapses but their disability is increasing. This is called secondary progressive MS.

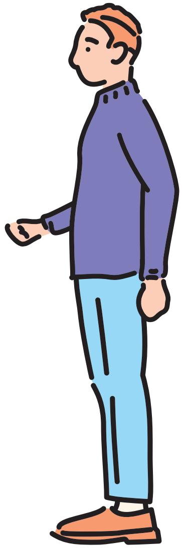
Some people are already experiencing secondary progressive MS when they receive their diagnosis as the relapsing remitting stage went undiagnosed.

Primary progressive MS (PPMS)

Between 10 and 15 in 100 people are diagnosed with primary progressive MS. In this type of MS disability increases from the beginning. It's unlikely that you'll experience any relapses, although they can still happen in PPMS.

'Progressive' is the word used to describe the change towards more disability in MS. Although disability increases in progressive MS, the rate at which this happens varies from person to person and you may have times of improvement and times when symptoms stay the same.

> "The diagnosis of MS meant I would get started on treatment and that brought hope that I would get relief from my symptoms."



Other terms used to describe your MS

As well as these types of MS, you may also hear your neurologist using other terms to describe the activity of your MS. Increasingly neurologists are using the terms:

- active/not active
- worsening/stable
- with progression/without progression.

Active or not active is used in all types of MS to describe whether or not you're having relapses and/or if new lesions can be seen on an MRI scan. For instance, if you have RRMS and you're experiencing relapses, your MS would be considered active. Alternatively if you have PPMS and no new lesions could be seen on an MRI scan, your MS would be termed not active.

Worsening or stable is used in people with RRMS to describe whether your disability is increasing or staying at the same level following a relapse.

With progression or without progression is used in people with PPMS and SPMS to describe whether your level of disability is increasing or staying the same over a period of time.

Can MS be treated?

At the moment, there is no cure for MS but there is a wide range of possible treatments which you can discuss with your health professionals.

Symptomatic treatments

There are lots of treatments available to treat the symptoms of MS.

This includes drug treatments, therapies (such as physiotherapy and occupational therapy), self-management techniques and rehabilitation.

Disease modifying therapies

There are also medicines that can treat the underlying condition of MS – these are called disease modifying therapies. These work to reduce the number and severity of relapses you may have, and slow down the build-up of disability over time.

Complementary therapies

Some people with MS choose to use complementary therapies alongside their conventional medicine to help improve their physical and mental wellbeing. These therapies include things like yoga, massage, reflexology and mindfulness.

Why me?

You may wonder whether you did something to cause your MS or if you could have stopped MS from happening to you. The answer to this is ‘no’ as the causes of MS are not well understood so no one could have advised you how to prevent your MS.

The cause of MS is a very active area of research and it seems likely that a number of different factors must come together to trigger MS. It’s thought that genes make up around half the risk of getting MS. More than 230 genes have been found that each increase the risk of developing MS to a small degree. None of them directly causes the condition itself and someone with MS will have a combination of many of these genes.

Other factors are in the world around us and there is some evidence that lack of sunshine may play a part. Other possibilities include being exposed to certain common viruses, smoking and obesity.

However no one knows for certain. It’s thought there is still some kind of trigger which hasn’t been identified yet that causes (or activates) MS in those who have a higher risk because of their genes.

Will my family get MS?

MS is not considered an inherited condition as it’s not passed on in a predictable way like some conditions, such as haemophilia or muscular dystrophy, and many people have no previous family history of MS. Some genes make it more likely that someone develops MS but having these genes is definitely not enough on its own as other factors are needed to trigger the condition. This means that the risk of another member of your family getting MS is small.

Can I have children?

MS rarely affects a woman’s ability to get pregnant, carry a child or give birth. A woman with MS is less likely to have a relapse during pregnancy, although the risk of relapse increases during the six months after the birth. Pregnancy does not affect how someone’s MS develops in the long term.

There is no evidence that MS affects male fertility directly although sometimes symptoms include erectile dysfunction.

If you're planning to have children, it's best to discuss this with your MS nurse or your GP, especially as most medications are not recommended during pregnancy.

How much will MS affect me?

After diagnosis, it's natural to wonder what MS might mean for your future. Everyone's MS is different so no one can predict how much your MS might, or might not, affect you.

MS is a lifelong condition but it is rarely fatal. Most people with MS live into old age although their lifespan, on average, is about six years less than the general population.

Will I become disabled?

It's possible that MS may impact on what you can do in the future and you may need to adapt to these changes and learn to do certain activities in your life differently.

Although MS can cause some disability, most people never need to use a wheelchair on a regular basis. The treatment and care of people with MS is improving so people diagnosed with MS today can expect a better quality of life than was possible previously.

Some people find that their MS only has a small impact on their daily lives and they can continue with their usual hobbies and working life. They may show no obvious signs of their condition. Others have more intrusive symptoms which can have a much bigger impact and may result in reducing working hours or needing more help around the home.

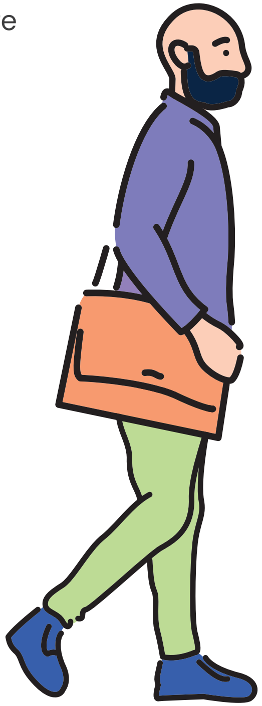
If you already know someone with MS, you may be tempted to assume that your MS will be the same as theirs. This is unlikely as everyone's MS is different. This is true even if you are closely related to them.

If you are more severely affected you may get more infections than healthier people and can develop complications that affect breathing and circulation. This can decrease your life expectancy so it's important to keep as well as possible and seek treatment promptly.

> “
> Life goes on, maybe not exactly as you'd planned or dreamed it would.
> ”

Looking forward

MS affects everyone differently so it is not possible to predict exactly how your MS will develop. It's natural to wonder about the future but being diagnosed with MS may not change your plans significantly so don't feel pressured into making life changing decisions too soon after diagnosis.



2. What happens after diagnosis?

Now that you've been diagnosed with MS, what happens next?

Now that you've been diagnosed with MS, what happens next? You could be feeling a range of emotions about the diagnosis and be wondering if that's normal. You may be concerned about how life might change or be unsure about who you have to tell. This information looks at these issues and how to obtain support going forward.

You and your diagnosis

Everyone responds differently to being diagnosed. It's not unusual to experience many powerful emotions as you learn to live with MS. Feelings can change from day to day but you can learn to work through your feelings in your own way, in your own time. Feelings of shock, denial, fear, anger, anxiety, loneliness, sadness, uncertainty and guilt are all a normal part of coming to terms with a diagnosis of a lifelong condition like MS. You may feel a sense of relief or acceptance, especially if you've spent a long time trying to find out the reason for your symptoms. You may experience a complete lack of emotion or feel numb.

There's no right or wrong way to react, it's very personal to you. How you react and adjust to living with MS often follows how you respond to and face other problems in your life, but learning about the possible emotional effects of a diagnosis of MS can help you cope.

If you're really struggling to come to terms with your diagnosis let your GP or MS nurse know, they'll be able to talk it through with you, or refer you to further support such as a counsellor or neuropsychologist.

What will happen next?

MS is a highly variable condition that affects everyone very differently, and MS teams around the UK work in slightly different ways, so what happens next will depend on a number of factors.

- What you'd like to happen. There will be choices you can make.
- What support your MS team can offer and how soon. You might meet your MS nurse immediately after diagnosis, but it's more usual to have to wait several weeks.
- How active your MS is at the moment. You might want to look at symptomatic treatments or whether disease modifying therapies that aim to alter the course of your MS are an option.
- What else is going on in your life at the moment.

> “I didn’t tell my friends and family until a couple of months later when I had adjusted to the news. This was on a one-to-one basis so I could deal with any emotion, including my own.”

The people you have to tell

There are only a few people and organisations that you must tell about your diagnosis straight away.

If you drive, you must tell the DVLA (Driver and Vehicle Licensing Agency) who issue driving licences as MS is a notifiable medical condition which may affect your ability to drive safely. They will send you a form to fill out and may contact your doctor or ask for an assessment. You may be able to keep a full licence, or you may be issued with a short-term medical driving licence for between one and five years, at which point you’d then be reassessed. Your licence may be revoked if the DVLA thinks you can no longer drive safely because of your MS symptoms.

The second group that you may need to inform are companies that have issued you with insurance, including most health and motor insurance policies. Check the small print of your policy to see if you need to tell them straight away or only when you come to renew the policy. If you’re not sure, give them a call as not informing them could risk making the policy invalid. You may be able to claim under some health or critical illness policies as soon as you’re diagnosed.

Lastly, in some jobs, for example if you’re in the armed forces or drive a passenger or heavy goods vehicle, you’ll need to tell your employer straight away. Some jobs require a certain standard of eyesight or medical fitness. Check your contract or employee handbook to see if this applies to your job.

After that it’s entirely up to you who you tell, when you tell them and how much you disclose. You might find you want some time to yourself to adjust to your diagnosis and learn more about MS before you share your diagnosis with other people, whether this is family, friends or colleagues. When you feel the time is right for you we have many information resources available that you can share with children and adults to help them understand your MS.

Will life change?

Life doesn’t stop at diagnosis, although it may feel that way at first. Your work or education, family and social lives will continue, but perhaps not in quite the same way as before. You’re probably worried that MS will make a big difference to your life and the choices you have. It’s not possible to predict exactly how you’ll be affected or how it will impact on your future, as everyone’s MS is different.

Some of the things you might need to think about are simple everyday things like learning to plan around symptoms such as fatigue. Other things might be more life transforming such as deciding whether to start or add to a family, or whether to make changes at work such as reducing your hours or moving jobs entirely. Just as everyone does, you’ll need to review your options and make choices or changes from time to time.

Getting support

Support from health professionals

Who you see, and how often, will depend on how active your MS is, what symptoms you're experiencing, what treatments are available and how your local MS service works. Your own preferences should also be taken into account, where possible.

You'll probably see some health professionals who specialise in MS, like an MS nurse, and possibly some who specialise in a particular treatment, such as a physiotherapist. You should see your neurologist for an annual review and your GP may be involved in some of your MS care, as well as looking after your general health.

Support comes in many forms, whether this is prescribing medication, providing practical advice or equipment, or counselling for the emotional impact of living with MS.

Your next appointment

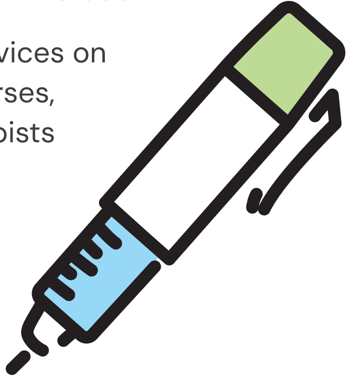
When you were diagnosed, you may have been told who you'd see next and when. If this didn't happen, you could ask your neurologist's secretary, MS nurse or GP if an appointment letter doesn't come through within about a month. You shouldn't be left in limbo, perhaps feeling anxious, for too long.

In some areas, people meet their MS nurse immediately after diagnosis. In others, you're given more time to adjust to your diagnosis and to think about what questions you might want to ask, or what your needs might be, before you see the nurse. Unfortunately, not all areas have an MS nurse. If this is the case for you, your GP will have an important role in your care.

Some services can offer appointments at short notice if your MS becomes more active or if you think you might be having a relapse. You may be able to contact your MS nurse by email or phone, although you might have to leave a message.

It can be good to write your questions down before your appointment so you don't forget anything. If you want, you could take someone with you to your appointment, both as moral support and a second pair of ears, that way you can compare your understanding of what was discussed afterwards. You can find out more about making the most of appointments later in the book.

You can find details of your local MS services on our online map, it gives details of MS nurses, hospitals with MS services, physiotherapists and occupational therapists (amongst others) where they're available.



> “After four years in ‘limboland’, a definite diagnosis enabled me to know for sure what I was dealing with and to get on with my life.”

Is it an emergency?

MS symptoms rarely cause an emergency, although initially when you experience new and unknown symptoms it might feel like one. Your MS team will understand that you’re anxious about your MS, especially in the early days after diagnosis, and will support you to get used to its unpredictable nature. It’s important to let your MS team know if you’re experiencing new symptoms or think you’re having a relapse, so that treatment can be considered.

Ask your MS nurse and neurologist about the best way to contact them with your concerns or questions.

Support from family and friends

Naturally your family and friends will want to help or look after you, but it needs to be done in a way that’s acceptable to you. It can be helpful to explain how you feel about your MS and how unpredictable it can be. It’s good to have support in place but you also need to feel in control of your own life.

Support from the MS community

You might be keen to share your experiences or ask questions of other people with MS, or you may prefer to focus on your existing network of family and friends. It’s a very personal choice. Experiences can be shared face-to-face through support groups or online through social media and blogging.

Exploring treatment options

Your health professionals may suggest starting treatment soon after diagnosis. This may be to help with individual symptoms, or to reduce the impact of relapses if you have relapsing remitting MS. You may feel ready to make treatment decisions straight away, but if you need more time your MS team should support you with this.

The earlier you start treatment, generally the more effective it’s likely to be. However, a few months delay is unlikely to be critical unless your MS is very active.

Treating symptoms

Treatments are available for the symptoms of MS no matter what type of MS you have. Talk about the options for treating any symptoms you’re experiencing with your health professionals. Treatment might involve taking medication, therapies such as physiotherapy, or a combination of both.

Disease modifying therapies

Until recently, disease modifying therapies (DMTs) were only used in people with MS who experience relapses to reduce the number of them, their impact and the MS disease activity seen on MRI scans. However, certain disease modifying therapies are starting to become available for some people with progressive forms of MS.

Looking after yourself

Support from other people is helpful but there's a lot you can do yourself to be as well as possible. You might like to review your lifestyle and consider making changes. You can find out more about this later in the book.

Some people with MS find that complementary therapies can help them manage their MS as well as giving them a sense of control over their body. Commonly tried therapies include aromatherapy, massage, mindfulness, Pilates, reflexology, Tai Chi and yoga.

Initially it can be difficult to judge if any changes to your health are MS related or not, but this becomes clearer with time. You're still susceptible to other illnesses and conditions, so it's important to keep up with your normal health screening appointments. Don't accept that everything is due to your MS if you believe otherwise.

Moving forward

Different people have different challenges. It's normal to need time and space to adjust to your diagnosis. Maintaining a positive outlook and getting good, reliable information you can trust can make a big difference; so can being flexible and taking a problem solving approach.

People who've lived with MS for a while say that learning to live each day as it comes, finding things to appreciate and avoiding comparing your life to others can all help you move forward. Some people highlight the good things that have come out of their diagnosis such as looking after their general health better through diet and exercise, choosing a new life path they didn't anticipate, meeting different kinds of people and learning to think more creatively.

The choices are yours to make! You have the option to take control of the things within your power, whilst learning to accept the things you can't control. These can all help you learn to live well with your MS.

> "The choices are yours to make! You have the option to take control of the things within your power, whilst learning to accept the things you can't control. These can all help you learn to live well with your MS."

3. Making the most of appointments

Appointments with your MS team provide you with an opportunity to ask questions and discuss treatment options to help you manage your MS.

The time available is usually quite limited so this information provides some suggestions on how to make the most of your appointments and get the best from your MS team.

How does the healthcare system work?

In an ideal world, you'd be able to see any health professional whenever you liked, for as long as you needed. In reality, this isn't possible as NHS resources are limited. MS services are structured differently around the UK so it's a good idea to ask how things work where you are.

Some health professionals are based at MS specialist centres which are usually based in large hospitals supporting people from a wide region. Other health professionals are based in local hospitals or may travel from the specialist centre, perhaps once a week, to run an MS clinic. Some services are community-based so they may be associated with a GP practice or another local centre. So you may find yourself going to different places to see various members of your MS team.

The health professionals involved in supporting you will vary according to your individual symptoms and whether you experience relapses or not.

Some of them will be MS specialists whilst others may be specialists in the management of a particular symptom (such as pain), or a particular treatment or approach (for example, physiotherapy).

Who is in my MS team?

MS health professionals often work together as part of a multidisciplinary team (MDT). Each member has a particular area of expertise so you'll only be referred to those that are appropriate to your needs. If you'd like to find more details about your local MS service, take a look at our online map.

MS nurses

After diagnosis, most people are referred to see an MS nurse. The nurse specialises in supporting people with MS and is likely to be your regular point of contact. Some MS nurses also support people with other neurological conditions so they may be called a neurology nurse or something similar.

The main role of your MS nurse is to provide you with support and clinical advice to help you manage your MS. They can talk with you about treatments for specific symptoms and suggest self-management strategies you could try for symptoms like fatigue and pain. They can also refer you on to other services, like physiotherapy, psychology or continence services, if necessary.

Some MS nurses specialise in particular treatments, like the disease modifying therapies.

> “After diagnosis, most people are referred to see an MS nurse. The nurse specialises in supporting people with MS and is likely to be your regular point of contact.”

How often you contact your nurse will depend on what's happening with your MS. You might want to contact them if you think you're having a relapse, if there's a symptom you're really struggling with, or if you're experiencing side effects with a new medication.

Most MS nurse services can be contacted by phone. You usually have to phone the service, leave a message and an MS nurse will get back to you, usually within a few days. Each service will have a timeframe in which they aim to respond.

Unfortunately, not all parts of the UK have an MS nurse service. If this is the case where you are, you may have to rely more on your GP to help you with symptom management and referrals to other services.

Neurologists

You probably saw a neurologist for your diagnosis. Some neurologists support people with a wide range of neurological conditions whilst others specialise just in MS. If you were diagnosed by a general neurologist you might want to consider transferring your care to an MS specialist neurologist. A specialist will have more experience in treating MS but you may have to travel further to see them at an MS specialist centre. However, some specialist neurologists have satellite clinics at local hospitals so it's worth asking what the arrangement is where you live.

> “Don't have hundreds of questions. Prioritise three really important ones for you. Do your research first and be calm so you can hear and take in your health professional's answers.”

GPs

You may know your GP well through your consultations over the years and they're still there to support you. Your GP is probably the most accessible member of your healthcare team and can respond quickly to provide some medications, for example, antibiotics for a urine infection. They can also refer you into other services if you don't have an MS nurse.

However, most GPs aren't specialists in MS so they may need to consult your neurologist before prescribing some treatments or refer you to specialist services. Your GP may be able to investigate whether any new symptoms are part of your MS or have some other cause.

Other health professionals

You may be referred to other specialists depending on your particular symptoms. As symptoms vary so much from one person to another, the health professionals who may be involved in your care are from a wide range of disciplines. It's unlikely you'll encounter them all.

They could include a physiotherapist, speech and language therapist (SLT) or occupational therapist (OT). A physiotherapist can help by suggesting exercises to help improve muscle stiffness, spasms and weakness, or advising on good posture when sitting, standing or lying down. An SLT can help with communication and swallowing problems. An OT can give practical pointers on lifestyle changes or adaptations and equipment that may help you in your daily life.

For some people, seeing a counsellor or neuropsychologist can be helpful, especially if you're finding it difficult to adjust to your diagnosis or if you're experiencing persistent low mood. A neuropsychologist can also help with cognitive symptoms like poor memory or concentration.

You may be referred to other services with their own specialist doctors, nurses and allied health professionals. These could include specialist teams for fatigue, spasticity, pain, diet, continence or rehabilitation.

You!

You are at the centre of your MS management team and have an important role to play. You'll have choices to consider when it comes to your treatment. How you choose to manage your MS is a very personal decision.

You can become an expert patient by building up your knowledge of MS and its management. You can ask your MS team questions and expect support to decide the best course of action for you. Everyone with MS is different so you'll want to find the best healthcare plan for you personally.

Preparing for your appointment

You should have regular appointments with your MS nurse and neurologist to review your MS. How often you see them will depend on how active your MS is, and on the capacity of your local MS service, but at least once a year is recommended.

Some services are able to offer appointments at short notice if your MS becomes more active or if you think you're having a relapse.

Preparing before an appointment can help you make the best use of the time available. Sometimes, the time allocated doesn't feel long enough – this can be frustrating for both you and your health professional. They'll be anxious to discuss the most important issues first, just like you.

Typically, a GP has around 10 to 15 minutes for an appointment, a neurologist or MS nurse may have 30 minutes, although this will vary from one service to another and may also depend on what's happening with your MS. It's reasonable to ask how long your appointment is scheduled to last so you can fit in your priorities without running out of time.

It may not be possible to provide answers to all your questions but, by being prepared, you'll be best placed to cover the topics you want to discuss. If it doesn't all get discussed in the meeting, your health professional may be able to contact you later with further information. You might like to think about:

What has happened since your last appointment?

- It may help to keep a diary to record any new or worsening symptoms, when they happened and whether they went away or are still troubling you.
- You could use your diary to prepare a simple timeline so your health professional can see at a glance what's been happening with your MS. Too much detail can make it hard to spot the things that are most important.
- Is there anything else in your life that they need to know about, like pregnancy or plans to move out of the area?

What's bothering you most?

- Is it accepting your diagnosis and what it might mean for you?
- Is it a particular symptom? Is it new or causing more issues than before? Does it stop you doing things that are important to you?
- Are you having difficulties with any medication? Do you find it hard to remember to take it? Are you experiencing any side effects?
- Are you feeling anxious or low in mood? Is it hard to cope at the moment?
- Do you need some written information, or an explanation, so you can understand your MS better?
- Would you like to know about sources of support, perhaps at work or with childcare, or to meet other people with MS?

What are your priority topics for the appointment?

- You could write them down in order. Between three and five works well.

- Be specific and think in advance whether you're hoping for a particular outcome, but remember to be open to other possibilities that may be suggested.

Who might go with you?

- You don't have to have another person with you but it can be helpful. They can be an extra pair of ears and keep notes of the conversation which you can refer back to afterwards.
- It doesn't have to be the person closest to you. Choose someone who'll support you well.

Do you need to do more background reading?

- Reading about your particular symptoms, possible treatment options, lifestyle changes, relapse management or the experiences of others might make it easier to understand what is suggested to help you or to decide which option you'd like to take, if there is a choice.

> “Make sure you’re not afraid to ask your neurologist to explain things clearly. I think they forget sometimes that we’re not experts or medical professionals ourselves.”

In the appointment

It’s a two-way discussion

Any consultation should ideally be a joint discussion between you and your health professional. Explain clearly what you’ve experienced, what you’d like to happen and anything that you don’t understand or would like repeated. It’s important to be open about how you feel and what your priorities are. Being realistic is important too.

Your health professionals may have their own list of priorities and these might be different from yours. They may raise things that you hadn’t thought of or didn’t know about. It’s not unusual for some of their topics to overtake some of the priorities on your own list.

You might feel a range of emotions during your appointment, such as feeling upset, anxious, overwhelmed or even angry. This is normal and your health professional will be used to these reactions so try not to worry too much if you do become emotional.

Your health professional will do their best to support you whilst ensuring the conversation remains productive so you get the most out of your appointment.

Making decisions together

Shared decision making is when you work with, and are supported by, health professionals to make decisions about your treatment, based on the best possible information. There may be times when you’d like a lot of support in making decisions and others when you want to be more independent.

Of course, you’re only one side of the equation. Some doctors and nurses are more willing to debate the best course of action, some will leave the choice entirely to you, but others prefer to give clear-cut advice about what they think is most appropriate.

Each of you brings something important to the conversation. Your health professional will have knowledge and experience in managing MS, whilst you’re the expert on your own values, expectations and priorities, and only you know how your body is feeling.

It’s good to ask

The appointment is for your benefit so make the most of it. Don’t be afraid to ask about anything that’s important to you even if it might feel trivial or embarrassing. It’s very likely that someone else has asked a similar question before so you’re unlikely to take your health professional by surprise.

Don’t worry about asking for information to be repeated, explained in a different way or written down for you. It’s important that you come away from the appointment with everything you need.

In many situations, asking three key questions works well. They are:

1. What are my options?
2. What are the pros and cons of each option?
3. How do I get support to help me make a decision that is right for me?

Support might be printed or online information. It could mean referral to another health professional with more relevant expertise. Maybe you might want time to think things over and then have another appointment to take things forward. Or you might want to involve family or friends.

Your health professionals might not be able to answer all of your questions. Not everything has been discovered about MS and they may not be able to say what is happening, or may happen, to you. Sometimes, they may be able to find out the information that you need or can point you to other sources of support like the MS Trust.

After the appointment

It can be helpful to keep some basic notes about appointments and the ups and downs of your MS. You might like to keep:

- a record of names, locations, phone numbers and email addresses for your health professionals
- the dates of appointments with brief notes on what was discussed and decided
- copies of letters to you or your health professionals
- a simple symptom diary, which includes when you started or stopped any medication, and records any relevant events in your life like infections or times of stress.

You could also keep the notes you made when preparing for an appointment, any notes made by you (or the person who went with you) during the appointment, and any information leaflets you've been given about MS.

4. Living well with MS

Everyone knows the value of looking after their general health, both mental and physical, but this can be especially important when you live with a long-term condition like multiple sclerosis. This information looks at some changes to your lifestyle that could help you live better with your MS.

The benefits of living a healthy lifestyle

Being diagnosed with a long-term condition is often a prompt to look at the aspects of life that we're all encouraged to manage well – such as eating a balanced diet, exercising more, reducing stress and looking after your mental wellbeing, finding a good work-life balance, whether you smoke or not and how much alcohol you drink.

Even if MS isn't currently having much of an impact on your day to day life, you might want to consider making sure you're as well as possible so you're best placed to deal with any relapses, new symptoms or other challenges that may happen in the future.

If you're already experiencing symptoms that are impacting on your usual lifestyle, perhaps fatigue or mobility issues, you may already recognise that making some changes to your lifestyle could be beneficial.

If you're ready to make some changes, it's helpful to be realistic about what fits into your way of life. Perhaps think about introducing changes one at a time rather than trying to do everything at once, that way it's more likely that you'll be able to maintain those changes over the longer term. It's up to you to decide if you want to make any changes to your lifestyle – it's your life and your MS, but here are some suggestions you might want to think about.

Making a start

Learning to live with MS can take a while and you might not be ready yet to think about making changes.

Once you are ready, thinking about the following aspects of your lifestyle might be a good place to start.

- How well balanced is your diet?
- Do you exercise enough or is MS affecting what exercise you can do?
- Do you smoke or vape?
- Do you think you drink too much?
- Do you take any recreational drugs?
- Are there any particular symptoms which are causing you difficulties which might be managed better?
- Are you feeling stressed?
- Are you keeping your mind active?
- Are you managing to balance the demands of work and home-life?
- Do you feel you're getting enough sleep?

You could also think about the following.

- What gives you pleasure or what do you enjoy doing?
- What are the positives in your life?
- Who do you enjoy spending time with?
- What's most important to you?

After considering these things and when you're ready to explore making some changes, you could start to note down how this might be achieved.

- What would you like to happen?
- Where could you make a start?
- What are the changes you think would be easiest for you to introduce first?
- Is there anyone who could support or advise you?
- Is there anything that is urgent that you should focus on?

Living with MS day to day

The advice for people with MS is the same as for everyone when it comes to a healthy lifestyle – eat a balanced diet, exercise regularly, drink sensibly to reduce the health risks from alcohol and don't smoke.

Doing as much as you can, or want to do, will help keep your mind and body as active and strong as possible. Simple changes can make a big difference, for example, choosing a healthier snack such as a piece of fruit or unsalted nuts rather than chocolate or a biscuit, walking up the stairs rather than taking the lift at work, having two or three alcohol-free days each week, or reading a chapter of your book before bed to help you unwind.

Diet

There is a wide range of views on what constitutes a good diet for people with MS. Diet is a notoriously difficult area to research and high quality evidence as to whether any particular diet is beneficial for MS is in short supply.

Government advice on what makes a balanced diet is just as relevant to people with MS as it is to the general population. However, many people with MS choose to try an alternative diet to see if it has any beneficial effects on their MS. It can give a sense of control that you're trying something that might help you. If you're interested in looking at making dietary changes, there are a few things that you might want to think about.

- Cost – is it affordable?
- How much time will it take to prepare meals?
- Will it affect your ability to eat with friends or family both at home and socially?
- Perhaps most importantly consider whether the diet is nutritionally balanced – does it involve cutting out major food groups?

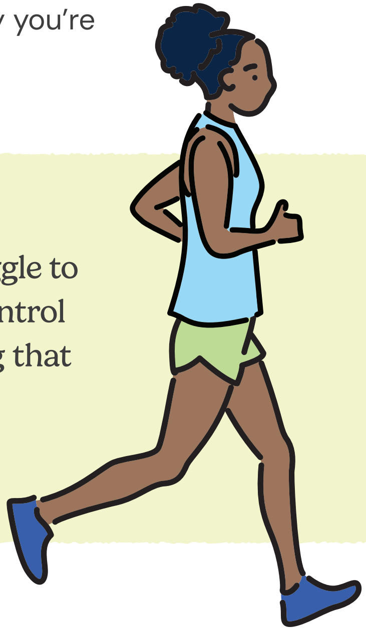
Exercise

Taking regular exercise can help you improve your overall fitness and maintain a healthy weight, but did you know it can also help with MS symptoms such as fatigue, bowel problems and muscle spasms? Exercise helps maintain both your strength and flexibility, builds your endurance and it can also have a positive impact on your mental wellbeing. So keeping as active as possible is really important, even if it's simply carrying out day to day tasks rather than following a formal exercise programme.

There are lots of different types of exercise that you could try. If you'd like to try and become more active so you can build your strength, you could take a gentle approach by trying yoga, Pilates or Tai Chi which focus on flexibility and balance – some exercises may even be done sitting or lying down.

Or you may prefer higher intensity activities such as dancing, swimming, cycling or running. The main thing is to choose something that you think you'll enjoy, perhaps think about getting a friend to join you, that way you're more likely to commit to doing it regularly.

> "I exercise (despite the fact that I struggle to walk!) because it's something I can control in the face of this uncontrollable thing that is happening to me."



If you need further advice or support about starting a new exercise regime, you could ask your GP or neurologist to refer you to a physiotherapist with expertise in MS.

Brain health

Keeping your brain active is important in MS. A healthy brain can help you remember, learn, plan and concentrate. It also increases your brain's ability to improvise or find different ways to carry out a job – this is known as cognitive reserve. Increasing your cognitive reserve is important right from the point of diagnosis with MS as it will help you maintain thinking and memory skills for as long as possible. Taking medicines as prescribed is also important.

There are lots of activities that can help stimulate or challenge the brain. The most important thing is to find something you enjoy – just like exercise! The following are just a few ideas of some activities that can encourage abstract thinking, problem solving skills, developing strategies, sequencing or organisation:

- reading for fun
- learning a new language
- playing board or card games
- listening to music
- playing a musical instrument or singing
- keeping a journal
- puzzles such as crosswords, word searches or Sudoku
- brain training games or apps
- arts and crafts such as painting, knitting, crocheting or sewing.

A healthy brain is better able to compensate for some of the damage caused by MS as it can reroute messages or adapt healthy areas of your brain to take on new functions.

> “A healthy brain is better able to compensate for some of the damage caused by MS as it can reroute messages or adapt healthy areas of your brain to take on new functions.”

Smoking

Nobody would argue that smoking is good for you, but there's increasing evidence that smoking is a significant risk factor in MS. It's been linked to an increased risk of developing MS and to a faster rate of disease progression in those with MS who do smoke. It also puts you at greater risk of other autoimmune conditions and lung cancer.

If you do smoke it's never too late to quit! If you can give up, many of these risks can be reduced. There's a range of support programmes available which could help you stop. A pharmacist or your GP can discuss what might work for you if you're not sure where to start.

Vaping (inhaling the vapour produced by an e-cigarette or similar device) is often seen as a 'healthier' option than smoking, but this claim isn't supported for people with MS. It's thought that like smoking, vaping could affect the blood-brain barrier and the cells lining the lungs. So if you do want to give up using nicotine replacement products, it might be better to try patches or lozenges rather than vaping.

Fatigue

Many people with MS experience fatigue. This can mean even simple everyday tasks are exhausting, let alone entertaining thoughts of trying to do some exercise. However, as well as maintaining muscle strength, exercise has been shown to improve fatigue in people with MS, so although you may not be able to do the same level of activity as before, you might well see a positive impact on your fatigue levels if you try to include some form of exercise – however big or small – in your daily routine.

Fatigue can also make other symptoms, such as pain, feel worse or harder to deal with. Learning to pace yourself and prioritising the most urgent or important things on your 'to-do list' can make a big difference, perhaps even leaving you with enough energy to go and exercise or do something else that you enjoy.

Further information

Scan here to find out more or go to **mstrust.org.uk/information-support/newly-diagnosed**

> “I am a bit more gentle on myself, I say “no” more often – to work and friends. I try not to burn the candle at both ends and get good rest.”

Fatigue can be mental as well as physical, so it's just as important to take breaks from activities like reading or using a computer.

If you're really struggling with fatigue there may be a fatigue management team that you can be referred to for more advice on pacing, planning and exercise. Ask your GP or MS nurse.

Sleep

Some people with MS find they have difficulty getting to, or staying, asleep which leaves them feeling sleepy during the day. This can impact on your work and personal life, and leave you with lower energy levels and difficulties with concentration, memory and low mood. It can also make other MS symptoms feel worse if you're struggling to sleep and feel tired.

Establishing a regular bedtime routine and adopting good habits such as avoiding stimulants like caffeine and alcohol late in the day can make a big difference, as can staying off devices such as mobiles or tablets in the hour before bed.

If there are symptoms that are disrupting your sleep, such as getting up to go to the loo, it's worth speaking to your GP or MS team to see if they can be better managed. Similarly talk with your team if any medications you're taking have side effects that are making sleep more difficult.

Stress and relaxation

Many people, whether they have MS or not, experience stress. There are many things that can make people feel under pressure, such as deadlines at work, or caring for family members. It can be stressful adapting to a diagnosis of MS and experiencing new symptoms.

Everyone has their own way of dealing with stressful situations, but it can help to take a practical approach to managing stress. First you need to identify what's causing it and then you could think about how you could manage your stress better. The following ideas might help.

- Making changes. Are there any changes you can make that could help reduce your stress, such as planning ahead or enlisting the help of others?
- Taking a calmer approach. Are there any techniques you could employ to help you feel less stressed? Perhaps mindfulness or relaxation techniques, or simply going for a walk or listening to music to remove yourself from the stressful situation for a short time.
- Being kind to yourself. Give yourself permission to rest or relax without feeling guilty. Taking a step back and focusing on doing something for you might change your perspective on the problem.
- Getting another person's perspective. Discussing your worries with someone you're close to, rather than keeping things to yourself, can put things in a different light as well as allowing you to support each other.

It's probably not possible to remove all the sources of stress in your life, but the above suggestions may help you manage stress more successfully.

Feeling anxious, low or depressed

Depression, low mood and anxiety are common in MS. These symptoms can arise as a consequence of coming to terms with the diagnosis of MS and learning to live with the ups and downs of a long-term condition, or as a direct result of an MS lesion in the area of the brain which controls mood.

It's natural to feel down sometimes and it can be helpful to talk through with family or friends how you're feeling. But if it carries on for more than a few weeks, you might want to seek professional advice. You may find you're able to speak more openly about how you're feeling with someone who's not close to you, such as your GP. They may suggest seeing a counsellor or neuropsychologist, taking medication, or a combination of both.

Symptom management

If your symptoms are being managed well it can have a positive impact on your sense of wellbeing, so if you have new or worsening symptoms it can be a good idea to contact your MS team for advice. Some symptoms can't always be got rid of completely, sometimes it's a case of managing them as well as possible to reduce their impact on your everyday life. If you find one medication or approach isn't working well, you could ask if there are other options. It's important to keep taking medication as prescribed to get the best benefits from it.

Many people with MS find their symptoms are affected by temperature. You may notice that your symptoms feel worse when it's hot, although some people find the cold makes their symptoms flare up too. Strategies such as layering clothing and using fans, ice packs or hot water bottles can help your body temperature return to normal. When it's back to normal, your symptoms should quickly reverse.

Infections, such as a chest or bladder infection, can also aggravate your symptoms but they should subside once the infection has cleared.

It's important to remember that not all symptoms may be due to MS. You're still susceptible to other conditions, so it's best to have them checked out and to go for all the usual health checks, such as cancer screening, and for any vaccinations you're offered.

Living with MS in the longer term

It's not unusual to feel stressed or unsettled about the future, especially in the weeks immediately after your diagnosis. It's best to take your time to consider the future, and not make any major life decisions at times of crisis. You may want to wait until your MS is more stable and better managed.

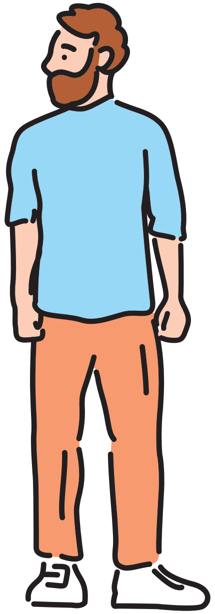
Working with MS

People often worry about working with MS, but many people stay in work until retirement. There are benefits to working in addition to being paid! It's a way of gaining skills and knowledge, feeling valued and pursuing your goals. For many people it's a route to socialising or meeting new people.

In most jobs you're not required to tell your employer about your MS diagnosis. However, it can help you access support and get adjustments made at work if you need them, such as sitting in a quieter area of the office or having an allocated parking space closer to the building you work in.

When things feel difficult

There may be times when you need some practical support, for example, if you're having a relapse or struggling with a particular symptom. Asking for help can be hard at first, especially if you're used to being independent. Generally it's better to be honest with people rather than trying to pretend that everything is ok when actually it's not, that way hopefully you can get some support in place.



Often family and friends want to help, but aren't sure what to say or do for the best. They may not realise the impact of your symptoms, especially invisible symptoms such as pain or fatigue. It can be helpful if you give them specific requests such as *"Could you wash up after the evening meal, as I don't have any energy left by the end of the day?"* or *"Could you have the kids overnight on Saturday so I can have a rest on Sunday morning?"* rather than *"Could you help around the house a bit more?"* or *"Could you look after the kids sometime?"*

Are there things that you do that could be done differently, such as getting groceries delivered rather than doing the food shop yourself? Sitting down to do the ironing or batch cooking on good days? Or could you afford a cleaner or gardener so that's one less thing you have to take care of?

At work could you delegate any tasks you're finding difficult, for example, could someone else take the minutes of a meeting so you can focus on what's being said? Or could you work from home sometimes to avoid the commute? Or a simple change such as moving to a desk closer to the toilets could make things easier for you.

If things are getting really difficult, or you're struggling to find the support you need, contact your MS team.

Our Helpline Team are her for you when things are getting difficult. They can provide you with information or signpost you to other sources of support. You can call them on **0800 032 3839** or email **helpline@mstrust.org.uk.**

Take control

Although professional help is important, there's lots that you can do for yourself. Adopting a healthier lifestyle is just one aspect of learning to live well with MS. Hearing other people's experiences and sharing tips for living well with MS can be helpful too.

Remember that you don't have to be a superhero who deals with everything, but you don't have to be a victim of MS either. You just happen to be a person who has MS. Many people say the mantra "I have MS but it doesn't have me" is a good one to live by.

> "Don't frighten yourself with worst case scenarios. Just be in the now because that's the only thing that's guaranteed."

About the authors

Health Information Team, MS Trust

MS Trust brings together expertise from every angle to help everyone feel more in control of their MS today and every day.

Through trusted information and compassionate support, the training of new MS healthcare professionals, and research rooted in real experience – we're here for every MS. Every day.

Thank you

MS Trust would like to thank all the health professionals and people living with MS who have made this book possible through sharing their experiences or reviewing the text.

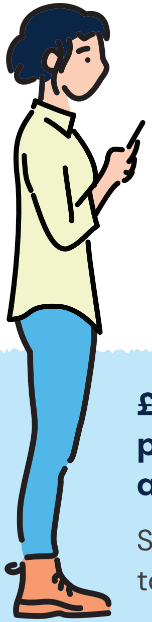
Bibliographical information

MS Trust Health Information Team
Making Sense of MS: newly diagnosed with MS

This publication will be reviewed in three years.

Further information

Scan here to find out more or go to **mstrust.org.uk/information-support/newly-diagnosed**



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