Making Sense of MS

Multiple Sclerosis Trust MS

Someone I know has MS

An introduction to multiple sclerosis for people who know someone with the condition

If someone you know has recently been diagnosed with MS, you may like to learn more about the condition. This information answers the most commonly asked questions about MS.

This resource aims to support a wide range of people, including the partner of someone recently diagnosed with MS, the wider family, friends and work colleagues. Not all of it will apply to you – it depends on the kind of relationship or interactions you have with the person with MS.

What is MS?

MS stands for multiple sclerosis which is a condition that affects the brain and spinal cord (the central nervous system). 'Sclerosis' means scarring or hardening of tiny patches of tissue. 'Multiple' is added because this can happen in more than one place.

It's estimated that around 130,000 people in the UK have MS. Every week, roughly 130 more people are diagnosed with the condition.

MS is a lifelong condition, but it is rarely fatal. It isn't infectious or contagious so it can't be passed on to other people. At the moment, there's no cure but there's a wide range of treatments. Although MS can cause some disability, most people never need to use a wheelchair on a regular basis.

Most people with MS live into old age although their lifespan, on average, is about six years less than the general population. This is because people who are more severely affected by MS are more likely to experience complications, such as chest infections and swallowing difficulties. Having MS also increases the risk of comorbidities (having more than one health condition), such as high blood pressure and cholesterol, which can also contribute to reduced lifespan.

What's happening in the body?

The immune system is the body's natural defence system which helps fight against infections.

Most people have heard of MS, but they don't really know what it is. Their attitudes probably won't change unless it touches their lives more directly, until they know what MS looks like and what it can do.

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

When this damage happens, messages don't pass along the nerves as efficiently as they used to so messages can be delayed or sometimes may not get through at all. These areas of damage cause the symptoms people with MS experience.

What are the symptoms?

There's a wide range of possible symptoms. Most people experience a small number around the time of diagnosis and won't go on to experience them all. Some of the most common are:

- fatigue (a kind of exhaustion which is out of all proportion to the task undertaken)
- problems with eyesight
- unusual feelings in the skin (such as pins and needles, numbness or burning)
- memory and thinking problems
- walking difficulties (such as tripping, stumbling or weakness).

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 be upsetting to someone who is feeling very unwell but looks OK to others. They may feel that they're not believed when they say their symptoms are causing them difficulties. It's often more helpful to ask someone how they are, rather than assume they're OK.

MS symptoms can be misunderstood. Slurred speech or walking unsteadily can be symptoms of MS but may be mistaken for drunkenness. Reduced performance in the workplace could be due to MS-related fatigue but may be misinterpreted as laziness. Keep an open mind and chat things through so that you're clear whether MS is the cause of their difficulty and, if so, whether you can do anything to help.

Is everyone's MS the same?

No, MS affects everyone differently. If you've previously known someone with MS, you may be tempted to think that you know what it's like. However, it's best to begin with an open mind and not make comparisons.

Some people will have few symptoms for many years, but others will be more severely affected. MS is very unpredictable from day to day and even from hour to hour. It's not possible to say exactly how someone's MS will develop in the long term as everyone's MS is different.

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.

Many people who are newly diagnosed experience relapses. This is where new symptoms suddenly appear, or existing symptoms significantly worsen. These symptoms usually come on over a period of hours or days, reach a climax, and then gradually improve over a few weeks or sometimes months. Some symptoms may never go away completely.

What’s it like to be diagnosed with MS?

For some people, diagnosis with MS happens rapidly, especially if symptoms began very suddenly. Others may have experienced symptoms on and off for years and have been trying to find the cause. By the time other health conditions have been ruled out, they may be largely expecting their diagnosis. Consequently, reactions vary widely.

They may feel shocked, surprised, worried, tearful, depressed, angry or be in denial. Some people feel a lack of emotion or as if it’s happening to someone else. Others may feel relieved that they’ve finally found the cause of their symptoms. Many people will feel very different emotions at different times and moods can change very rapidly. This is likely to feel uncomfortable for them and, perhaps, for you too.

However, it’s understandable as they’ll need time to learn about MS and what it might mean for them.

Shortly after someone with MS is diagnosed, they may need to make important decisions about their treatment options. It’s useful to be aware that this is something they may also be having to think about at the difficult time following diagnosis.

Dealing with uncertainty about the future

As MS is an unpredictable condition, receiving a diagnosis can be overwhelming and leave people feeling stressed or worried about their future, especially in the weeks and months following the diagnosis. Learning to live with the unknown and not knowing what the future will bring can be challenging.

It’s normal for people to need time and space to adjust to their diagnosis. Do be patient if your partner, relative, friend or colleague isn’t ready to talk just yet.

People who’ve lived with MS for a while often say that learning to live each day as it comes, finding things to appreciate and avoiding comparing their life to others can all help them to move forward.

How might I feel about their diagnosis?

You’ll have your own response to the news of their diagnosis which will depend, in part, on how close you are to the person who has been diagnosed.

You may experience one or more of a whole range of reactions – from concern or empathy to shock, surprise, anxiety, anger, helplessness, or fear for the future. You may feel no emotion at all to begin with or it may seem like the whole thing is unreal.

Emotions change from week to week, day to day and sometimes minute to minute.

Their diagnosis may affect your own mood, so remember to take care of yourself too. There's no correct way to react and your emotional response to the news may be completely different from theirs.

You'll need time to adjust. You may find that your feelings are very different at different times. You may believe that you must stay strong for others, but it can be helpful to share how you feel with someone else. This could be with a friend, family member or an online group. It could be with the person with MS, although you will need to be sensitive as they'll be dealing with their own emotional response to the diagnosis.

Is it OK to talk about their MS?

Some people are happy to talk about their MS. Others find it difficult, especially if it hasn't been long since they were diagnosed. There may be a careful balance to strike between needing to discuss issues and respecting their wish for privacy.

As far as possible, you should let them take the lead, as they'll know what aspects they're comfortable talking about, who with and when they feel able to do this. You may find that they're ready to talk on some days but not others. Above all, it's helpful to keep the lines of communication open.

Whether you can tell other people about their diagnosis is a tricky topic. Ideally, you should talk this through with the person with MS and then respect their wishes. They may be happy for you to talk to others but it's more likely that they'll want to be in control of who knows what and when.

You may discover information about treatments for MS that you'd like to share. Some of these may be legitimate but others may be at an early stage of development, hyped up, a scam or possibly harmful. Be particularly wary of anyone who claims they can cure MS as, at the moment, there is no cure. Sharing information is usually helpful but try not to push too hard. Not all treatments are appropriate for everyone. The person with MS will want to make sure they're doing the best for themselves by discussing treatment options with their health professionals.

What's it like to live with MS?

We can give you some examples of how MS can affect daily life. However, MS symptoms are different for each individual so it can be helpful to explore how MS affects your relative, friend or colleague personally.

- Fatigue is an overwhelming feeling of mental and/or physical exhaustion. It's very different from the tiredness that people without MS may experience following heavy exercise or a busy day at work. Someone with MS may have energy at the beginning of the day, but then fatigue may kick in quite suddenly and much sooner than ordinary tiredness. As this can happen quickly and unexpectedly, they may not be able to say in advance that they'll run out of energy. They may need to rest quietly, go home or ask for help.

I've been frequently touched by the consideration and concern shown to me by my friends. Some don't know how to react, of course, but almost all of them have been brilliant throughout.

- Some people with MS may experience visual problems, such as blurred or double vision, or blind spots. Problems with eyesight can't usually be corrected with glasses. People may find it difficult to drive or to read.
- Strange sensations, like numbness, burning or pins and needles, can occur in different areas of the body. If the hands are affected, then it may make it more difficult to hold objects safely. If someone has numbness in their feet, this can make it harder to feel the floor when walking which can increase the risk of falls.
- Heat often makes MS symptoms worse, so it's important to keep cool on a hot day or turn the central heating down. However, some people find that their symptoms worsen in cold weather, so keeping warm by layering up can also be important.
- It may be difficult to walk as far, or as fast, as before. A tendency to trip may mean it's important to concentrate on walking, instead of walking and talking at the same time.
- Needing to go to the toilet quite suddenly, or more often, is common. If someone with MS experiences bladder or bowel issues, they may be concerned about the availability of public toilets when they're away from home.
- Sometimes MS can slow down the thinking process, known as cognition. It may be harder to remember the right word or where something has been put. MS can reduce concentration and the ability to think through a complex task. Reducing distractions, like turning off the TV or going to a quiet room, can really help. Also, giving someone more time, and not putting pressure on them, can make a huge difference.

As MS is so unpredictable, many people learn to be flexible and manage their symptoms and the consequences if, and when, they arise. It can be helpful if those around them take the same flexible approach.

How can I help?

It's better to ask someone how they'd like you to help, rather than trying to work it out for yourself. They may suggest something you hadn't even thought of. It can be helpful to show you care – perhaps with a hug, a text, a bunch of flowers or by phoning regularly. You may also be able to do something more practical.

Try to resist the temptation to take over and overprotect someone. This can leave the person with MS feeling smothered and like they've lost control. Instead, ask how you can help and take their lead, rather than making assumptions. This will ensure you're supporting them in a way that feels right for them.

Not everyone will need or want help. Some people don't like a lot of fuss and will prefer to continue their life exactly as before. Others may only need help when they're going through a relapse or feeling particularly unwell. What support you can provide will depend on your relationship with them and whether you live together, nearby or at a distance.

You may have the kind of lifestyle that allows you to be flexible and step up to help out at short notice. Then again, more structured

MS factors heavily in my working life and the decisions I make every day. But this hasn't always meant shelving my plans; it's meant adjusting my plans along the way, which takes some getting used to.

support, where you take on a task that needs to be done on a regular basis – like cutting the grass or doing the grocery shopping – may fit better with your life.

Could you give them a lift to their appointments or take them out shopping if they find driving difficult? Perhaps you could pick up their kids from school and let them stay for tea. There are endless ways that you can be of help.

Although you'll have the best of intentions, it's important to think very realistically about what you can reliably offer and make this clear. This could save embarrassment on both sides and avoid a mismatch of expectations.

Try to be alert to the limitations that MS can impose. For example, someone may feel OK when you arrive but may suddenly get very tired and need to rest alone. This isn't a reflection on your visit, just a common consequence of living with MS. Doing regular short visits can be less tiring than fewer longer visits.

If someone you work with has MS, the support they may need will depend on how their MS affects them personally. Many people who've recently been diagnosed may worry about how the condition will affect their working life. Employers can help support an employee with MS by asking if there's anything they can do to help them at work and by offering to make reasonable adjustments. This may include a dedicated parking space near the entrance to the office, more flexible working hours, or a desk in a cooler or quieter part of the office. It's particularly important for employers to keep communication channels open so if anything changes with the person's MS, which results in them needing more support at work, they feel comfortable raising this.

There is no formula for what the best approach is as everyone's affected differently by MS. A willingness to listen and help, and sensitivity to their individual needs and wishes, are the cornerstones of providing appropriate support.

How can I learn more about MS?

It's important to use reliable sources of information relevant to the UK, like the MS Trust, other MS charities and health professionals, together with NHS and government websites. Sites with out of date, unreliable or misleading information can be difficult to spot, as they may sound very convincing especially when you're new to the topic.

At the MS Trust, we produce practical, reliable, evidence-based information, which is available online and in print, and covers a whole range of topics, from how MS is diagnosed to treatment options and living well with the condition.

Ask us

The MS Trust helpline is here to answer your questions about MS. We specialise in health information and can usually point you in the right direction for information on other topics related to living with MS.

You can reach us by emailing ask@mstrust.org.uk or by calling free on 0800 032 3839 (Monday to Friday, 9am to 5pm).

Life goes on, maybe not exactly as we'd planned or dreamed it would. MS makes you stop sweating the small stuff and puts things into perspective.

Information from the MS Trust

This information is part of Making Sense of MS, a group of resources providing introductory information on the topics that are most relevant to people who've recently been diagnosed. You can read them in print or online and then follow the pointers to more detailed information if you need it.

Going forward

It may have been a surprise to learn that your partner, family member, friend or colleague was diagnosed with MS. Remember that they're still the same person and will very often want to be treated in the same way as before.

Try not to worry too much about what might, or might not, happen or assume that MS will have an effect on some particular aspect of your lives. This time and energy could be spent in a more positive way on something that's important right now.

Got a question about MS?

Ask the MS Trust helpline
on 0800 032 3839
or email
ask@mstrust.org.uk

Further information

🕮 Making Sense of MS information sheets:

Treating MS symptoms mstrust.org.uk/455
Disease modifying drugs: an introduction mstrust.org.uk/442
MS and your feelings mstrust.org.uk/447
Making Sense of MS: newly diagnosed with MS mstrust.org.uk/448

ⓘ Information on our website:

MSTV: YouTube channel for young people affected by MS
mstrust.org.uk/MSTV
Working life mstrust.org.uk/work
A to Z of MS mstrust.org.uk/a-z
Making Sense of MS mstrust.org.uk/msos

🕮 Other publications from the MS Trust:

Talking with your kids about MS mstrust.org.uk/316
Kids' guide to MS mstrust.org.uk/286
MS Trust information services mstrust.org.uk/483

Printed publications can be ordered for free or downloaded from our website. Alternatively, they can be ordered by calling 01462 476700. Contact the MS Trust helpline if you'd like any information about the reference sources used in the production of this publication or a large print version.

Multiple Sclerosis Trust
Spirella Building, Bridge Road
Letchworth Garden City
Hertfordshire SG6 4ET

T. **01462 476700**
T. **0800 032 3839**
E. **ask@mstrust.org.uk**
W. **mstrust.org.uk**

Registered charity no. 1088353

Making Sense of MS

This information is part of a set of resources for people who are newly diagnosed with MS. You might like to look at our introductory resource, Making Sense of MS: newly diagnosed with MS, which answers the questions most commonly asked around the time of diagnosis.

MS Trust Information Team
Someone I know has MS (Order code: 441)

This edition published 2022

This publication will be reviewed in three years.

441 - Someone I know has MS MS.06.22.2K

Produced by verdicottsdesign.com