



# Explaining MS to others

## You may find it helpful to share this information with others if you've just been diagnosed with multiple sclerosis

If someone you know has recently been diagnosed with MS, you may like to know more about the condition. This information answers the most commonly asked questions about MS. The  symbol will point you to further online resources and the  symbol indicates printed publications which can be ordered for free or downloaded from our website.

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 that you have with the person with MS.

Resources to explain MS to children can be found here:

-  *Talking with your kids about MS* [mstrust.org.uk/family-t](https://mstrust.org.uk/family-t)
-  *Kids' guide to MS* [mstrust.org.uk/family-k](https://mstrust.org.uk/family-k)
-  *Young person's guide to MS* [mstrust.org.uk/family-y](https://mstrust.org.uk/family-y)

## 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.

Over 100,000 people in the UK have MS which is about one in every 600. Every week, nearly 100 more people are diagnosed with MS.

MS is not a terminal illness but it is a lifelong condition. It isn't infectious or contagious so it can't be passed on to other people. At the moment, there is no cure but there is a wide range of treatments. The majority of people with MS will not need to use a wheelchair full time. Multiple sclerosis is rarely fatal. On average people with MS live about six years less than the general population.

 *About MS* [mstrust.org.uk/440](https://mstrust.org.uk/440)

## What are the symptoms?

There is 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



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are fatigue (a kind of exhaustion which is out of all proportion to the task undertaken), stumbling more than before, unusual feelings in the skin (such as pins and needles or numbness), slowed thinking, or problems with eyesight.

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 that their symptoms are causing them difficulties. It's often more helpful to ask someone how they are, rather than assume they are 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.

 [Treating MS symptoms mstrust.org.uk/455](https://mstrust.org.uk/455)

## Is everyone's MS the same?

No, MS affects everyone differently. If you have 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 a fresh point of view 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. Also, it's not possible to say exactly how someone's MS will develop in the long term.

Many people who are newly diagnosed experience relapses, which are periods of new or particularly bad symptoms that begin suddenly. These symptoms usually improve and may go away completely, although this may take a few months.

## 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 be shocked, surprised, worried, tearful, depressed, angry or in denial. Some people feel a lack of emotion or as if it's happening to someone else. Others may feel relieved that they have finally found the cause of their long-standing 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.



There may be a careful balance to strike between needing to discuss issues and respecting their wish for privacy.

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

 [What happens after diagnosis? mstrust.org.uk/456](https://mstrust.org.uk/456)  
 [MS and your feelings mstrust.org.uk/447](https://mstrust.org.uk/447)

## How might I feel about their diagnosis?

You will 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, amongst others. You may feel no emotion at all to begin with or it may seem like the whole thing is unreal. Their diagnosis may affect your own mood, so remember to take care of yourself too. There is no correct way to react and your emotional response to the news may be completely different from theirs.

You'll need time to adjust and may find that your feelings are very different at different times. You may believe that you have to 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 will be dealing with their own emotional response to 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's not 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 will know what aspects they are 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 will 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.



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.

## What is 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. Someone may have energy at the beginning of the day, but then fatigue kicks in much sooner than ordinary tiredness. This can happen suddenly so they may not be able to say in advance that they will run out of energy. They may need to rest quietly, go home or ask for help.
- Problems with eyesight can't usually be corrected with glasses. Someone may have blurred or double vision, or blind spots. It may be difficult to drive or to read labels in the supermarket.
- Numbness or pins and needles can occur in different areas of the body. If the hands are affected, then using a knife and fork may cause some difficulty or appear as clumsiness.
- Heat often makes symptoms worse, so it's important to keep cool on a hot day or turn the central heating down. However, some people find that cold makes their symptoms worse.
- It may be difficult to walk as far, or as fast, as before. A tendency to stumble 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. Trips out may need to be organised so that toilets are always close by.
- 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 may be 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.

Not everyone will need or want help. Some people don't like a lot of fuss or will prefer to continue their life exactly as before. Others may need help only 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.



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You may have the kind of character and lifestyle that allow you to be flexible and step up to help out at short notice. Alternatively, you may prefer a more structured commitment, where you take on a task that needs to be done on a regular basis, like cutting the grass or doing the grocery shopping.

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. The possibilities are endless.

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.

There is no formula for what is the best approach as everyone is 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.

 [Living well with MS \*mstrust.org.uk/443\*](https://mstrust.org.uk/443)

 [Working and studying with MS \*mstrust.org.uk/457\*](https://mstrust.org.uk/457)

## 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 unreliable or misleading information can be difficult to spot, as they may sound very convincing especially when you are new to the topic. The MS Trust's information is certified by the Information Standard so you know it can be trusted.

### Ask us

The MS Trust Enquiry Service is here to answer your questions. 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 [infoteam@mstrust.org.uk](mailto:infoteam@mstrust.org.uk) or by calling free on **0800 032 3839** (Monday to Friday, 9am to 5pm).

## Got a question about MS?

Ask our Enquiry Service

on 0800 032 3839

or email

[infoteam@mstrust.org.uk](mailto:infoteam@mstrust.org.uk)

## 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 have recently been diagnosed. You can read them in print or online and then follow the pointers to more detailed information if you need it.

📄 *Making Sense of MS* [mstrust.org.uk/msos](http://mstrust.org.uk/msos)

📄 *A to Z of MS* [mstrust.org.uk/a-z](http://mstrust.org.uk/a-z)

📖 *MS Trust resources brochure (We're here to help)* [mstrust.org.uk/resource](http://mstrust.org.uk/resource)

## The bottom line

It may have been a surprise to learn that your partner, family member, friend or colleague was diagnosed with MS. Remember that they are 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 is important right now.

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 Enquiry Service if you'd like any information about the reference sources used in the production of this publication or a large print version.



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### 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, which answers the questions most commonly asked around the time of diagnosis.

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*Explaining MS to others* (Order code: 441)

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