MS Society

Managing MS relapses

We're the MS Society and we're here for you. Funding world-leading research, sharing information, making voices heard and campaigning for everyone's rights.

Together we are a community.
And together we will stop MS.

We rely on the generosity of people like you to fund our vital work. If you would like to make a donation, you can do so by:

- Calling us on: **0300 500 8084**.
  Lines are open Monday to Friday, 9am – 5pm
- Visiting us at: **donate.mssociety.org.uk**
- Posting your donation to: MS Society,
  Carriage House, 8 City North Place,
  London N4 3FU.
- Please make cheques payable to the 'MS Society'.

Managing MS relapses

Contents

A word from Rosie, who has MS

'Is it a relapse?' I think this is the scariest question I have ever asked myself. And I ask it a lot.

Most of my relapses occurred before I was diagnosed. I had some of the obvious symptoms, like loss of vision. But more often they were subtle changes that I tried to explain away. I spent a fortune replacing all my shoes before I discovered they weren't why my feet kept going numb.

What was clear was that I was struggling. I was quite angry back then. I understand now that was because I wasn't coping.

I'm less anxious now. Knowledge is definitely power when it comes to managing relapses.

I keep a written track of my symptoms. That way I don't worry about missing significant changes. I can focus on more fun things.

It's taken a year to fully recover from my last relapse. I still have symptoms - like echoes - of the more intense impairments I had. They get louder if I'm ill or stressed.

But I've started to get a sense of the symptoms that are familiar. They're like old (not so welcome) friends who pop back into your life from time to time. If something comes along that doesn't feel familiar, that's when I need to talk to my MS nurse.

Being more open and honest has helped me cope with relapses. I talk on forums, to my friends, family… sometimes to my cat! You manage relapses much better if you let people know what's going on.

Living with this uncertainty can destabilise your life. But learning more about relapses has helped me regain a sense of control.

Rosie

Five things to know

1. Relapses are a sign that your MS is active, but not all flare-ups of symptoms are relapses
2. Tell your neurologist or MS nurse if you think you're having a relapse. They can help you get the right treatment
3. Steroids can get you over a relapse faster, but not every relapse is treated with steroids
4. There are things you can do to reduce your risk of relapses
5. A disease modifying therapy (DMT) can cut down how many relapses you have. It also makes ones that you do get less serious

About this booklet

Most people with multiple sclerosis (MS) have relapses at some stage.

This booklet explains what a relapse is, what makes them more likely and what to do if you have one. We cover disease modifying therapies (DMTs), which can cut down how many relapses you have.

We also look at help available to get over relapses, and how to plan ahead.

With the information and tips in this booklet we hope you'll feel a bit more in control over your relapses.

Don't forget you can contact the MS Helpline to talk about anything to do with MS.
Call **0808 800 8000** (closed weekends and bank holidays).
Email
helpline@mssociety.org.uk
Or private message through our Facebook page at
facebook.com/MSSociety

You can also ask questions about relapses and get support from other people living with MS at **mssociety.org.uk/forum**

One last thing: if you see a word **in bold**, it means you'll find it explained at the back of the booklet.

> **"The hardest thing about relapses is wondering when - and if - you'll recover, or if your MS is getting worse. But the best thing to do is: ask advice, and take one day at a time. Try to be positive, look after yourself more, and rest a lot."**
>
> Sammy

What is a relapse?

A relapse is when you suddenly get new MS symptoms – or old ones come back or get worse.

A relapse can last days, weeks or sometimes even months. You might recover completely afterwards. Or you might be left with some lasting symptoms or disability.

A relapse can be a small inconvenience that's soon over. But a severe one can take months to recover from, and have a bigger and more lasting impact.

You might hear people call their relapses a 'flare-up' of their MS. Doctors sometimes call a relapse an episode, attack, flare-up or exacerbation.

Knowing for sure it's a relapse

It can be hard to be sure whether symptoms getting worse are actually a relapse. It could just be part of the normal ups and downs of your MS.

An MS relapse is when:

- you have new or worsening symptoms that have lasted longer than 24 hours

and

- it's been at least 30 days since the start of your last relapse

and

- there's no other reason your symptoms might have got worse, like infection, stress or changes in temperature for example.

So your doctor or MS team will check for these things to decide if it's a relapse. With time, lots of people say they get more expert in their own MS and get a better feel for what is or isn't a relapse.

You can't predict a relapse. But certain things might make them more likely. See page 36 to find out more.

If it's not a relapse, it could be what's called a '**pseudo-relapse**' causing your symptoms. Read more about that on page 16.

Who gets relapses with MS?

Most people who get relapses have a type of MS called relapsing remitting MS.

Some people with other types of MS also get relapses, though that's less common. The other main types of MS are both called 'progressive MS': primary progressive MS and secondary progressive MS.

Relapsing remitting MS

About 85% of people with MS have relapsing remitting MS when they're first diagnosed.

With relapsing remitting MS, you have relapses followed by recovery ('remission'). Usually your disability or symptoms don't get worse between relapses. But relapses can leave lasting effects.

Changes over time

People with relapsing remitting MS can experience their disability gradually getting worse.

As time goes on your body finds it harder to repair the damage each relapse brings. So your disability or symptoms can get worse, especially if you don't start treatment.

Recent studies also show that change is possible even when you aren't having relapses at all, though this is usually very gradual and might not cause symptoms.

Treating MS early

If you're diagnosed with relapsing remitting MS, you should be offered treatment with a disease modifying therapy (DMT) as soon as possible.

These can mean fewer relapses, and slower progression of your MS.

We have more about DMTs on page 36.

Progressive MS

Progressive MS means the symptoms get gradually worse even when there are no relapses. There are two main types of progressive MS.

Primary progressive MS

About 10 to 15% of people with MS are diagnosed with primary progressive MS. It is possible for people to have relapses with this type of MS, though most people don't.

Secondary progressive MS

Secondary progressive MS is a stage of MS which comes after relapsing remitting MS for many people.

It's when there are no longer obvious periods when symptoms go away or get better (remissions). Instead, symptoms or disability get steadily worse.

Some people with secondary progressive MS still have relapses, but not everyone does.

How soon this change to secondary progressive MS happens varies widely from person to person.

Before disease modifying therapies (DMTs) came along, it took around 20 years on average.

But thanks to today's MS drugs this is changing:

- fewer people are likely to go on to secondary progressive MS

- and for people who do, it could take longer to happen

You can find out more about managing progressive MS with our booklet 'Understanding progressive MS', on our website, and from our MS Helpline.

'Active' MS

If you do have relapses, your MS might be described as 'active'.

Relapsing and progressive types of MS might both be described as 'active' if you have a relapse. Or if your neurologist can see signs of new MS damage on an MRI scan.

If you have active MS, your neurologist will probably recommend you take a DMT.

What’s happening in my body with a relapse?

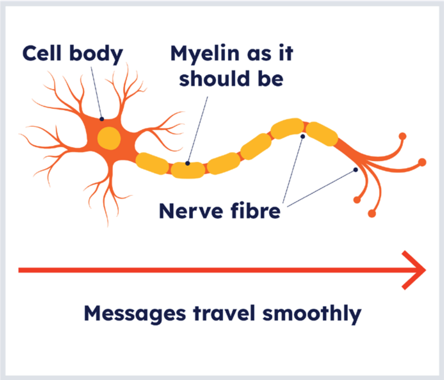
A relapse is a sign that your **immune system** is attacking nerves in your **central nervous system** (brain or spinal cord).

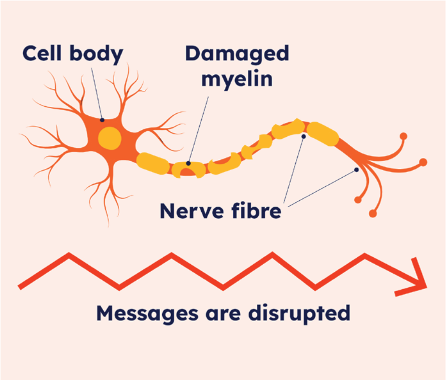
Around your nerves there’s a protective covering called **myelin**. When your brain sends messages to other parts of your body, signals travel along your nerves. Myelin helps these signals move faster along the nerve.

During a relapse, your **immune system** mistakenly starts attacking this myelin. It sends white blood cells to strip myelin from your nerves (**demyelination**). This damages the myelin and causes **inflammation** to the nerve.

Nerves with damaged myelin aren’t as good at passing on signals from your brain.

These messages are slowed down, or can’t get through at all. This causes your MS symptoms.





If the inflammation keeps happening or it goes untreated, the nerve may eventually stop working.

If your nervous system can't find another effective route for the messages, this will permanently affect the part of your body that this nerve controlled.

During and after a relapse a new **lesion** (area of damage) can usually be seen on an MRI scan of your brain or spinal cord.

MS can still be causing inflammation and damage to nerves even when you're in remission, it just doesn't always trigger a relapse.

How come I can get better after a relapse?

Early on in your MS, your body does its best to repair any damage. It covers the damaged nerve with new myelin. This is called remyelination.

This repair explains why your relapse symptoms often get better, or even clear up altogether.

The new myelin tends to be thinner, so doesn't work as well. After you've got over the relapse, signals might not travel along the nerve as easily as before.

This can leave you with some of the symptoms or disability you had during the relapse.

Your body tries to cope in other ways, too. It sends signals by other routes, using different nerves to avoid the ones with missing myelin.

Or a different part of your brain takes over from the part affected by the relapse.

But your body finds it harder after each attack to repair the myelin and reroute nerve signals.

Over time, the damage to nerves builds up which can make MS symptoms worse.

How will a relapse affect me?

Relapses are unpredictable. You won't know when one will happen, what symptoms it'll cause, or how long it'll last.

Relapses come on over a few hours or days. Sometimes people notice a new symptom when they wake in the morning.

Symptoms depend on which of the nerves in your brain or spinal cord are affected.

For example, an attack on your spinal cord can cause muscle weakness or bladder symptoms. An attack on your **optic nerve** will affect your eyesight.

There's no such thing as a typical relapse. But these are the most common ways relapses might affect you:

- extreme tiredness or exhaustion (fatigue)
- numbness, pain or tingling in a part of your body
- dizziness or problems with walking, balance or coordination
- your arms or legs become weak
- problems with memory, thinking or concentration (often called 'brain fog')
- muscle spasms
- pain
- problems with your eyesight
- bladder or bowel changes
- speech changes or problems with swallowing

An attack in one area of your brain or spinal cord means you'll only get symptoms in one part of your body.

An attack in several areas means you could get lots of different symptoms.

How long will it last?

A relapse might last a few days, weeks or sometimes, months. For most people it's over within a month. Taking steroids can speed up your recovery (see page 22).

How often will I get them?

How often you get relapses varies from person to person. It's impossible to predict exactly how many relapses you'll have over a period of time.

You might go for years without having any. Or you may be unlucky enough to get several in a year.

On average though, people with relapsing remitting MS might expect one or two relapses every couple of years.

Being on a disease modifying therapy (DMT) should mean you get fewer, and maybe none at all. See more about this on page 36.

Relapses become less common as you get older.

Will I get back to how I was before?

You'll get better after a relapse, but it's impossible to say if you'll make a full recovery.

Rehabilitation can help you get back some or all of the things your body could do before the relapse (see page 26). But you could be left with some lasting effects.

Is it definitely a relapse?

Having a flare-up of your symptoms doesn't always mean you're having a relapse. What you're feeling may be the normal ups and downs of your MS. This is sometimes called a 'pseudo-relapse'.

'Pseudo' means 'false' or 'not real'. The symptoms and how you feel are real, but the cause isn't the same as a relapse.

With a pseudo relapse, there's no new **lesion** or damage to the **myelin** in your brain or spinal cord that's causing the symptoms.

With a **pseudo-relapse**, your symptoms are usually ones you've had before, or are existing symptoms that have got worse.

You'll often be able to identify a trigger for a pseudo-relapse. Once you remove, or deal with, the trigger, your symptoms should improve again.

If you're not sure whether you're having a relapse or a pseudo-relapse, you might sometimes be able to identify and deal with the trigger before contacting your MS team.

If you're concerned about anything, always get in touch with a healthcare professional.

Things that can trigger pseudo-relapses

Your body getting hot

A rise in your body temperature, even by less than one degree, can make MS symptoms worse. You might hear this effect from heat called Uhthoff's sign or Uhthoff's phenomenon.

We think a big reason this happens is because messages aren't able to travel so easily along your nerves when they get warmer. Especially if the MS has damaged the protective myelin sheath.

Your body temperature might rise if.

- the weather or the room you're in is too warm
- you have a hot bath or shower
- you're exercising
- an infection raises your temperature or gives you a fever
- you're on your period

Once you cool down, your symptoms will ease off – often within minutes or hours.

Tips: to keep your body from overheating:

> drink ice cold drinks or suck on ice cubes or ice pops

> wear MS **cooling garments** (special vests, neck or wrist wraps)

> get into an air-conditioned room

> have a lukewarm shower or bath

> carry a pocket fan

> dip your feet and hands in cool water

> in warm weather wear light clothes that 'breathe' and a brimmed hat

We've got expert articles and tips for managing the effects of heat on our website (search 'temperature').

Tiredness or lack of sleep

Fatigue, overdoing things and not getting enough sleep can make MS symptoms worse for a while. Your MS nurse or neurologist can help if there are things stopping you sleeping like bladder problems or leg spasms.

Tips: Try our online fatigue management course for ways to manage your fatigue levels and other tips. **mssociety.org.uk/fatigue-course**

Also on our website we've got more about sleep and MS, including a podcast series (search 'sleep').

Stress

Stress can cause your symptoms to flare up. Your GP may be able to help with this. Make sure you're getting enough sleep, and make time to see friends and do things you enjoy.

If you have anxiety, maybe along with depression, your doctor might suggest a talking therapy (such as seeing a counsellor). This can work well, especially together with an antidepressant or anti-anxiety medication.

We look at stress again on page 40.

Tips: We've got lots of information on our website about complementary therapies and holistic approaches to living with MS.

Search 'alternative' to find info and tips about meditation, aromatherapy, **mindfulness**, massage, pilates, yoga and more.

Infections

Minor infections including urinary tract infections (UTIs), stomach bugs, coughs and colds, can make MS symptoms worse. This might be partly due to your body temperature going up.

Rest and look after yourself if you have a viral infection. Once it clears up, you should feel better again. But if you continue to feel bad, contact your MS nurse or team. Some infections might trigger a relapse, or cause other problems if not treated.

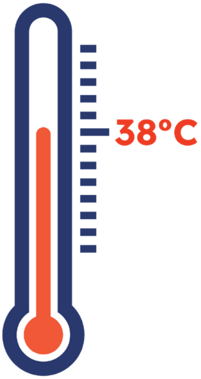
Tips: Read about managing and avoiding urinary tract infections on our website (search 'bladder'). We've also got information about vaccinations for infections like flu and COVID (search 'vaccines').

Periods

Some women feel their MS symptoms get worse a week or so before their period starts.

Around this time your hormone levels change and body temperature goes up. This rise in temperature could explain why MS symptoms get worse.

Tips: Find out more about periods and MS on our website (search 'periods').

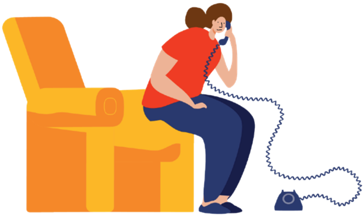


I think I'm having a relapse. What should I do?

Sometimes people get in touch with their MS team straight away. Sometimes they feel they can wait a day or two to see if it feels like a relapse.

When you decide to let someone know, they'll let you know the next steps. For example, checking if it is a relapse, and then how to manage it.

Even if you manage a relapse without treatment from a healthcare professional, do let them know if you have a relapse (see below, 'Reporting your relapse').



MS nurse or neurology team

If you've got an MS nurse, you should get in touch with them if you're worried about sudden new symptoms. If you don't have an MS nurse, contact your neurology team and tell them you think you're having a relapse – and how it's affecting you.

GP

Your GP can check for infections, like a urinary tract infection (UTI) for example. Checking for an infection helps to see if it might be a relapse or a **pseudo-relapse**. But it also means you can get the infection treated if there is one.

Hospital care

Relapses are rarely so bad that you to need to go to a hospital's Accident and Emergency (A&E) department. It could be necessary if you're in intense pain, you can't see in both eyes, or the relapse means you can't walk.

Relapses aren't life-threatening. But if you ever feel your life is in danger for any reason, calling an ambulance or going to A&E is the right thing to do.

A very bad relapse can mean a stay in hospital. This is usually decided after you've seen your neurologist through the normal channels, not after a trip to A&E.

Reporting your relapse

Don't keep a relapse to yourself. It's important your neurologist, MS nurse or GP know about it. It can help your MS care if they know how many relapses you have, and how they affect you.

For example:

- they might offer you steroids to help you get over your relapse sooner
- it might affect whether you can have a DMT and what type you can have. Even if you're already on a DMT, there might be another that works better for you.

It's a good idea to note down your symptoms, so that you won't forget what's happened. It'll help to keep your neurologist or MS nurse updated.

If you talk to your GP about a relapse, they should let your neurologist or MS nurse know it's happened.

Tips: Tell your neurologist or MS nurse if any of your MS symptoms change.

Track your symptoms with a diary, notebook or an app on your phone.

The **abilitynet.org.uk** website has a list of some MS apps you could try.

Steroids and other treatment

Not all relapses need to be treated. You might let your body recover in its own time. If you're offered steroids for a more serious relapse, it's your choice whether to take them.

Steroids

'Steroids' is short for corticosteroids. They dampen down **inflammation** in your body. They're not the same as anabolic steroids. These are the ones that athletes sometimes use to build muscle.

Steroids for MS have cortisone in them. Your body makes its own cortisone to calm down inflammation. Corticosteroids contain a man-made version of this.

Steroids can speed up your recovery, shortening a relapse by about two weeks. And they may reduce how severe your symptoms are too. But they don't always work for everyone every time, and they can cause side effects.

Will I be offered steroids?

You may not be offered steroids for symptoms like fatigue or some sensory symptoms like tingling or numbness. But it depends on the impact your symptoms are having on your day to day life.

You're more likely to be offered steroids if a relapse stops you doing the day-to-day things you need to do. For example, if your eyes are affected or you can't walk – or if a relapse is causing you a lot of distress.

Important to know
People who take steroids don't make a better long-term recovery than people who don't take them. Whether you have them or not, the chances of a relapse leaving you with lasting effects are the same.

Tablets or infusion?

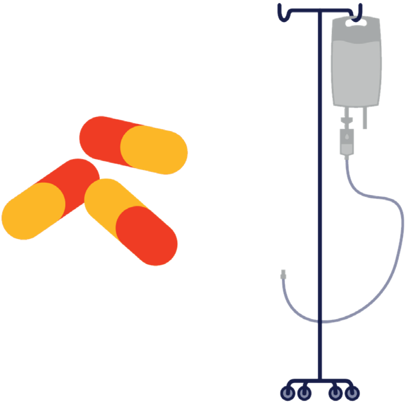
You usually get steroids as tablets to take at home. But sometimes you might be offered them as an **infusion (a 'drip')** in hospital. You'll have the steroids through a thin tube that goes into a vein in your hand. You may have steroids as an infusion if you can't get on with taking steroid tablets, or if you have a particularly severe relapse.

Steroid tablets work just as well as an infusion. No matter how you have them, you need to start as soon as possible – no later than two weeks after the relapse starts.

How long do I take steroids?

If you take steroids for a relapse:

- with tablets you'll take them for five days. The usual dose is 0.5g (500mg) of methylprednisolone once a day
- with an infusion you'll have it over three to five days. The usual dose is 1g (1000mg) of methylprednisolone each day



Side effects

Steroids can cause side effects, but for most people these are mild. They go once you stop taking them. They can include:

- a taste in your mouth like metal (mints can help)
- headaches
- difficulty sleeping (taking your tablets in the morning can help)
- an upset stomach or feeling sick
- mood swings, including depression, feeling very ‘up’ or agitated
- a faster heartbeat (palpitations)
- flushing (you go red in the face)
- an increased appetite
- water retention – this can cause swollen ankles, needing to pee more often, bloating, and short-term weight gain
- acne

Taking steroids increases your risk of getting infections, including urinary tract infections. Tell your doctor about any sign of an infection (like a sore throat, cough or fever).

And if you have diabetes, taking steroids may affect control of your blood sugar levels. You should monitor this more closely.

Taking steroids for long periods of time can cause more serious side effects. These can include diabetes and your bones becoming thinner and more likely to break.

For this reason, you’ll usually only be given a short course of steroids, and your doctor might want to limit how many times you take steroids in a year.

Steroids are strong drugs. So doctors won’t give you a supply to keep at home for any relapses you might get in the future.

Pregnancy and breastfeeding

If you have a relapse while you're pregnant which stops you doing your normal activities, it is possible to have treatment with steroids. Your doctor can discuss the latest advice and guidance with you.

You can also have steroids while you're breastfeeding. Talk this over with your MS team. You might be advised to wait a couple of hours or so after having the steroids before breastfeeding your baby.

Tip: If you're on a DMT and are given steroids, don't stop taking your DMT.

Plasma exchange

If you have a severe relapse and steroids don't work for you, you may be offered a treatment called plasma exchange.

In plasma exchange, blood is taken from a vein, usually in your arm. A machine separates the liquid part of your blood (plasma) from your red and white blood cells. This plasma is thrown away.

Your blood cells are mixed with new fluid made from blood given by a donor. This mixture is put back into your body through a blood transfusion.

Plasma exchange 'cleans' your blood of the **antibodies** that play a part in your immune system's attack on your nerves. This can speed up your recovery. It won't change your MS in the long run though.

You have plasma exchange in hospital, but you don't usually stay overnight. You may need two or three treatments each week over two weeks or more. Each session lasts two to four hours.

Getting over a relapse

There's a range of services and health care workers to help you get back on track after a relapse. But above all, take things easy.

Rest

You'll need to take things easy for a while to get over a relapse. Don't try to carry on as normal, or do everything yourself. When a relapse is pushing your fatigue levels up, you'll struggle with day-to-day chores.

You might feel awkward asking friends and family, but people are often happy to help if you explain the situation.

Before exercising again, give your body time to get its strength back. When you feel strong enough, pace yourself and listen to your body.

> **"I've given up my attitude of 'head down, keep going'.**
>
> Rosie

When rest and steroids aren't enough

You should be offered treatment in a hospital if your relapse is severe, or it's hard to manage at home.

Your MS team or neurologist can advise on any help they can offer with your symptoms. They might recommend **rehabilitation** to get back any function you've lost since the relapse. This covers things like physiotherapy, occupational therapy, speech and language therapy, and neuropsychology.

You could get rehabilitation in several different parts of a hospital or at a day centre near where you live.

Help from other medical professionals

Occupational therapy

An occupational therapist (OT) comes up with practical suggestions to help you do your everyday activities (like washing, dressing and eating). They also help with fatigue, balance or tremor.

OTs can teach you ways to deal with memory, thinking and concentration problems, too.

They might suggest equipment that can help and changes you can make in your workplace or at home.

> **“OTs are great at working out what really matters to living your life day-to-day, and helping you do it!”**
>
> Rosie

MS nurse

An MS nurse can give you advice about your relapse symptoms. They coordinate help from others, too. For example, they can get a prescription for steroids through a doctor. Your nurse is your link between hospital and specialist services, including social care.

MS nurses usually see people in clinics, but some make home visits. They answer questions by email or phone as well.

If you don’t have an MS nurse, you find your nearest one on the MS Trust website (search ‘services near me’). You might be able to contact one yourself, or your GP may need to refer you.

> **“I see my MS nurse every month because of my treatment. It makes a big difference just chatting about how things are going. I always leave feeling a little lighter.”**
>
> Rosie

Continence nurse or adviser

A continence service helps if a relapse is affecting your bowel or bladder. It's part of a local hospital, clinic or health centre. The staff can test and treat you for bladder or bowel problems, fit catheters and give you continence products.

Ask your GP, neurologist or MS nurse to refer you, or you might be able to refer yourself.

> **"My continence nurse is a star. She deals with everything in a matter of fact way. My first appointment felt like a weight had been lifted off my shoulders."**
>
> Caroline

District nurse

A district nurse (or community nurse) can help with lots of different health needs. They often work away from hospitals, linked to GPs. They can come to your home if you need care like dressing wounds and dealing with bowel or bladder issues.

Physiotherapy

Physiotherapy can help you get your strength and balance back and move around better. A physiotherapist suggests exercises or equipment to help with everyday activities. Your GP or MS nurse can refer you. In some areas a GP won't be able to refer to a 'neuro-physiotherapist' who specialises in neurological conditions like MS. You might need to ask your MS nurse or neurologist to make that referral.

Speech therapy

A speech and language therapist (SLT) can support you if a relapse has affected how you speak, eat, drink or swallow. They'll draw up a treatment programme and suggest exercises or equipment that might help.

They can also help if you're struggling to find the right words, or if it's hard to follow a conversation or concentrate.

Your GP, MS team or MS nurse can make a referral. You can also refer yourself to your local SLT service.

Neuropsychology

A neuropsychologist helps if you're having problems with how you think, your memory or concentration (known as 'cognition').

They can help with depression and anxiety too, especially if these last longer than a couple of months.

Neuropsychologists teach techniques to help you cope better. These can improve your memory and attention span. Your GP or MS specialist can refer you if this is available where you live. If it's not, your GP will know of local counselling support.

Help from social services

Social care is the help you get from your local council (or in Northern Ireland from your local Health and Social Care Trust). This can be in the form of services, support, money or equipment that helps you live an independent life.

It can also cover:

- changes to your home to make life easier
- help with things like washing, cleaning, getting dressed, shopping or getting out and about
- information and advice
- support for family members who look after you

Some services (like information and advice) are free, but most people pay something towards the others.

To access social care, you'll need to contact the social services department of your local council or Trust. You can find contact details on their website.

You might be referred by a health care professional to social services if a relapse means you – or your family carer – need support.

When you speak to social care services, say you'd like a 'needs assessment for social care'. That means you want them to check if you qualify to get support, and, if you do, what kind of help you need.

The law says your council or Trust must do this assessment for anyone who seems to need support. So don't be put you off from asking them to assess you.

If your council or Trust agree you need social care, and later your symptoms or disability improves, you must let them know. They might then change (or stop) the help they give you.

Find out more about social care services on our website (search 'social care').

Emotional impact

A relapse can trigger difficult feelings. It's a reminder that your MS hasn't gone away, and of how fragile your health can be.

A relapse might make you think about how your MS could be in the future. Maybe you hoped that taking a DMT would put an end to your relapses. It can be a blow if you then get one.

A relapse often forces someone to admit they need help. This can be hard to accept, especially if you don't like asking for it.

Anger and grief

A relapse can leave you with short-term or permanent symptoms and disability. This can trigger anger, depression, or feelings of grieving for what you've lost.

It's normal to react this way, but usually these feelings won't last.

Regret

Relapses are unpredictable and not anybody's fault. But if you believe something triggered a relapse, you might have regrets or blame yourself.

This is an understandable reaction, but no one's to blame for a relapse. Dwelling on what might have caused it won't undo what's happened.

Instead, it could help to learn from the past and focus on doing what you can to reduce your risk of a repeat. And go easy on yourself.

Someone to talk to

Your MS nurse, GP, counsellor, neuropsychologist or an occupational therapist can all help you deal with the emotional effects of a relapse.

Our MS Helpline on **0808 800 8000** can give emotional support to anyone living with MS. Page 49 explains how to reach them by email or online if you prefer. Family members, your partner and friends can use the Helpline as well. So can employers or anyone else who might want to understand more about MS.

Ask the Helpline or use our website to find out about services and support we offer in each UK nation.

We can also explain how to access emotional support from other providers (on our website, search 'help with emotional support').

Being ready for another relapse

Relapses are unpredictable. If another one happens, it makes sense to have plans in place.

Speak to your MS team or MS nurse about how to be more prepared. Making a plan now will be easier than once a relapse is underway. By then you could be exhausted by fatigue, or find it hard to think straight.

Make a list of people you can call on. This can be medical staff who look after your MS, family, friends and others who might help with practical things.

Family

If you have children, think about what childcare you can put in place if you can't look after them. Have you explained to them how a relapse might affect you? Would it be better to do this before one happens, rather than when you're ill?

Prepare a plan if you have elderly parents or a disabled relative that you normally take care of.

And if you've got pets, who will look after them during a relapse?

Home

Identify what jobs will need doing and who can help. This includes cleaning, gardening, grocery shopping, cooking and laundry.

If you think you'd need help at home during a relapse, ask your MS nurse or GP for advice.

If you live on your own, you could prepare in case a relapse stops you leaving the house. Stock up on things like toilet roll, toiletries, pet food, tinned or frozen food – things that are easy to prepare.

Work

Check your rights at work before a relapse happens. This includes sick pay, sick leave, **disability leave** and return to work policies.

Look into ‘**reasonable adjustments**’. These are changes the law says your employer must put in place if a relapse (or MS in general) affects you at work.

If your employer doesn’t know you have MS, ask yourself: would it be better to tell them before you get a relapse?

You’ll have a clear mind, and your symptoms will be stable. Telling them in the middle of a relapse will be tougher. Their reaction could be less positive.

We have information on ‘Work and MS’ for you and employers – on things like sick pay, telling your employer, fit notes, going back to work, and reasonable adjustments. Search ‘work’ on our website.

Driving

You might no longer feel safe behind the wheel during or after a relapse. Driving might become impossible. Ask someone else in advance if they’d drive you during a relapse and while you recover.

When you're first diagnosed with MS, you should tell the DVLA (Driver and Vehicle Licensing Agency). In Northern Ireland it's the Driver and Vehicle Agency (DVA). Find out more on our website (search 'driving').

When a relapse, or MS in general, affects your eyesight, you don't usually need to tell the DVLA or DVA if it only affects one eye.

But you must tell them about a problem with both eyes, including double vision. You must tell your insurance company, too.

Read more and check the rules at **gov.uk/driving-eyesight-rules**

Your GP or MS nurse can advise you if it's still safe to drive, and if you need to get in touch with the DVLA or DVA.

Your nearest driving assessment centre can check your coordination, eyesight and muscle strength. Find the nearest one, and more information about driving at **drivingmobility.org.uk/find-a-centre**

If a relapse is very severe

If a relapse hits you very hard, information in our 'Advanced MS' handbook might be useful. It covers things like:

- going into and leaving hospital
- social care
- money matters and benefits
- equipment to help you move around and with day-to-day tasks
- bathing and going to the toilet
- help and advice for whoever looks after you during the relapse

To order a free copy see 'Further Information' on page 49.

This information is also on our website (search 'advanced MS', or 'going to hospital' for that topic).

What affects my risk of relapse?

Relapses often happen for no obvious reason. But there are certain things that may affect your risk of getting them.

These include:

- taking a DMT
- smoking
- infections
- pregnancy and breastfeeding

Disease modifying therapies (DMTs)

Disease modifying therapies (DMTs) aren't a cure for MS, but they can reduce how many relapses someone has and how serious they are. They can also slow down the damage caused by MS that builds up over time.

There are different types of DMTs. Depending which one you have, they might reduce the number of relapses you get by between 30 and 70%.

What does this mean? If you were getting 1 relapse every 2 years before taking DMTs:

- A 30% drop would mean you now get 1 relapse every 2½ to 3 years
- A 70% drop would mean now getting 1 relapse every 7 years

This is an average, so some people may get relapses more frequently than this, and some people may get fewer (or none at all).

How do I get DMTs?

Speak to your MS team about DMTs. Usually only a neurologist can prescribe them, but an MS nurse can discuss what's available with you.

There are around 20 DMTs for MS available on the NHS. They're mostly taken either as a pill, an injection or an infusion. Depending on how your MS affects you, you might have a choice between different DMTs.

Most DMTs are for people with relapsing remitting MS. But there are now DMTs for some people with progressive MS too.

On our website we've got a DMT decision tool which can help you explore your DMT options and prepare for conversations with health professionals (search 'DMT decision tool').

If you're not online, our MS Helpline on **0808 800 8000** can explain more about DMTs.

Tips: DMTs work best if you start early in your MS. But, so long as you qualify for a DMT, it's never too late to take one.

Check out our videos of six people explaining their decision to start a DMT at **mssociety.org.uk/treatmentstories**

Try our DMT decision tool to explore your options **mssociety.org.uk/dmt-tool**

Are side effects making you think of stopping your DMT? Speak to your MS team about help sticking with it. Or it might be possible to change drugs.

Smoking

Smoking can make everyday MS symptoms worse, and make relapses more likely. Smoking makes chest infections, colds and flu more likely too, and these can also trigger relapses.

DMTs can be very important in managing relapses and the underlying damage caused by MS.

But a DMT won't protect you against the harm from smoking. Studies for several DMTs have shown that smokers have more relapses than non-smokers who take the same DMTs.

Smoking can also speed up how fast people become disabled, and how early the MS develops from relapsing remitting MS into secondary progressive MS.

The good news is, studies have shown that quitting smoking might prevent everyday symptoms getting worse.

And other research clearly shows that quitting leads to a slow down in how fast your disability gets worse. In fact, it slows it down to the rate we see in people who never smoked.

Find out more on our website (search 'smoking').

Tip: if you quit for 28 days, you're five times more likely to quit for good.

Find support with stopping at **nhs.uk/better-health/quit-smoking**

Infections

Having an infection, including flu and urinary tract infections, can increase your risk of a relapse.

So if you can take reasonable measures to avoid infections, you might also reduce your risk of having a relapse.

Vaccinations can help protect you against infections such as flu, pneumonia and COVID. This may in turn reduce your risk of getting a relapse. You should be offered a flu vaccine every year if you have MS.

> **"The first winter after I was diagnosed I caught the flu and had several relapses. A flu jab is such a simple thing to do but it could make a huge difference. It could've saved me from months of illness."**
>
> Rosie

Most people with MS can safely have most vaccinations available.

Researchers have looked at the results of many different studies to see if vaccines cause relapses. The evidence doesn't show that vaccines cause relapses.

If you've recently taken steroids, or you're taking certain DMTs, there are some vaccines you might not be advised to take. Talk to your neurologist or MS nurse about which vaccines to get.

Some everyday things can reduce your risk of many infections:

- avoid touching your eyes, mouth and nose
- stay away from people with cold or flu symptoms when possible
- regularly wash your hands with soap and water (for at least 20 seconds), especially before eating or preparing food

If you do develop an infection, let your GP or MS team know so that if it needs treating that can happen promptly.

Find out about the latest available vaccines on our website (search 'flu jab').

Tips: People with MS and their main family carers qualify for a free flu jab each autumn.

Read tips on avoiding bladder infections on our website (search 'bladder').

Pregnancy

Research shows that MS seems to be less active during pregnancy. This is especially true during the last three months (the 'third trimester'). Hormone changes probably play a role in this positive effect.

For most people, the risk of having a relapse is lower when they're pregnant. But this risk can go up if you stop taking certain DMTs. That's because stopping the treatment outweighs the effect of being pregnant.

If you're thinking of getting pregnant, or you discover you are, discuss your DMT options with your neurologist. That way you can decide what's best for you and the baby. Some DMTs can't be used when you're pregnant but others can.

Relapse risk after the birth

Until recently, research showed the risk of a relapse soon after the birth was higher than before pregnancy.

But newer research doesn't show this increased risk to the same degree. This could be because neurologists can now give more advice about DMTs before, during and after pregnancy.

The research shows average risks, and your risk of a relapse will be different to someone else's. So it's worth discussing your risk and DMT in advance with your neurologist.

Breastfeeding

If you choose to breastfeed your baby, this may also reduce your risk of relapse. If you usually take a DMT, check with your neurologist or MS nurse whether it's safe to do so while breastfeeding.

Fertility treatment

Recent research suggests IVF fertility treatment doesn't increase the risk of relapses during the process. The evidence for this was strongest for people who keep taking a DMT until the embryo is implanted in the womb.

Your neurologist can discuss this with you before you start any fertility treatments.

Other things to consider

Scientists have looked at several other things that might affect how many MS relapses people get.

There isn't always enough evidence to say for sure whether they do make a difference. But the things listed below can also affect general health and wellbeing. And anything you can do to give your general health a boost may help you to cope better with MS relapses.

Stress

Over the years, many studies have looked at whether there is a link between stress and MS getting worse.

The evidence is not absolutely clear. But many experts believe stress might be one of many factors which increase the risk of a relapse.

And many people affected by MS say stress is a factor in bringing on a relapse for them.

Whether it helps to prevent relapses or not, learning ways to get better sleep, calm anxiety and lower stress levels can help you to feel better.

We've got lots about managing stress and anxiety on our website, including exercise, Pilates and yoga videos, sleep podcasts and how to find support for anxiety and low mood.

If you're not online, give our MS Helpline a call to find out more.

Vitamin D

There's no hard evidence that vitamin D helps with relapses. Some studies show being low in this vitamin is linked to having more relapses. Or that extra vitamin D reduced the number of relapses. But other studies have shown no benefits.

For general health, it's recommended that all adults in the UK consider a vitamin D supplement during the darker months of the year. And some people are advised to take one all year round.

You might want to talk to your neurologist about vitamin D. There's no specific dose recommended for everyone with MS. But some neurologists advise higher doses than the 10 micrograms a day which is suggested for every adult.

Very high doses could be harmful, though, so speak to your MS team about what might be right for you.

Tips: Boost your vitamin D level by getting out in the sun during spring and summer (take care not to burn)

Speak to your GP or MS team about your vitamin D levels. They might test you to see if you need extra, and give you the right amount of supplement.

Find out more on our website (search 'vitamin D').

Diet

At the moment there isn't enough evidence to recommend any particular diet for everyone with MS.

But if you feel better eating a certain way, it could be a change that works for you. And following a healthy, balanced diet is important for your general health and managing your MS.

Your MS team or a dietitian can help make sure you get the nutrients you need in your diet.

And we've got lots more about food, drink and nutrition in our booklet 'Diet and MS' or on our website (search 'eating and drinking').

Exercise

You might need to take it easy and rest if you have a relapse, but at other times exercise can help you stay as fit and healthy as possible.

Regular activity or exercises can also help with managing some MS symptoms, including fatigue, balance difficulties and low mood.

Lots of people with MS notice symptoms get worse when they get hot, and then return to normal as the body cools down. To avoid this effect, you might find ways to stay cool while you exercise.

Discover more about finding exercise that's right for you, and ways to stay cool on in our booklet 'Moving more with MS'. Or on our website (search 'stay active' and 'temperature').

Useful organisations

MS Society

As well as our Helpline (see page 49) we have lots of ways you can get support and information including:

MS Society forum

The message board on our website connects you with others with MS. They can share what's worked for them:
mssociety.org.uk/forum

Our national, local, and online support

There's lots of different support available around the UK and online. Find out more at **mssociety.org.uk/local** or give us a call on the MS Helpline.

MS National Therapy Centres

A network of UK centres offering a range of therapies, including physiotherapy and counselling
msntc.org.uk

MS Together

A charity focussing on people aged 18-35 affected by MS. They host virtual and in-person social and support events.
mstogether.org

MS Trust

MS charity whose website includes a map of local MS services.
0800 032 3839
mstrust.org.uk

Shift MS

An online community of people with MS. Users share, support and interact with each other through their website.
shift.ms

New words explained

antibodies

These are made by your **immune system** to help kill things like viruses and bacteria. In MS your body makes harmful antibodies. With **plasma exchange**, they're taken out of your blood to help you recover from a serious relapse. That's sometimes used if steroids don't work

central nervous system

The name for your brain and spinal cord. Nerves carry messages between them both to control how parts of your body work

cooling garment

Special vests, neck and wrist wraps that stop your body overheating for three to four hours. Inside many are cooling packs of a special gel or ice. With others, you soak them in water to activate them, or they're battery powered

demyelination

That's when, during a relapse, your white blood cells strip away the myelin covering around nerves in your brain or spinal cord

disability leave

Time off for medical appointments or recovery time (for example, after a relapse). Your employer should record it separately from sick leave. Not all work places have this, but you could still ask for it

immune system

How your body defends you against things that give you infections or diseases (like viruses or bacteria). In MS this system goes wrong and attacks your **central nervous system**

New words explained

inflammation

When your **immune system** reacts to attack or damage, it sends more blood and immune cells to the damaged area. When MS causes inflammation in your brain or spinal cord, it starts to damage nerves there, triggering MS symptoms

infusion (or 'drip')

When a drug is put into you through a needle that goes into a vein in your arm, leg or hand

lesion (also called a 'plaque')

Areas of damage caused by MS in your brain or spinal cord. Lesions can be seen on MRI scans

mindfulness

A type of meditation. You focus on the present, your breathing and how you feel. You become more aware of your body, thoughts and feelings. It helps with stress, anxiety, depression and managing emotions

myelin

A fatty covering around a nerve which protects it and helps messages move along it faster. When you have MS, your **immune system** attacks myelin

neuroplasticity

How your brain changes, adapts and reorganises itself when nerves in it have been damaged. If an area of it is damaged by MS, another part can take over to do what the damaged bit once did. After a relapse, **rehabilitation** can train your brain to do this

optic nerve

A bundle of nerves that link the back of your eye to your brain. In MS this can become inflamed, causing sight problems

plasma exchange

A treatment for severe relapses when steroids won't work. It 'cleans' your blood by replacing plasma (the liquid part of your blood) with the plasma from someone who's given blood. Harmful antibodies are removed, speeding up your recovery

pseudo-relapse (or pseudo-exacerbation)

When symptoms similar to a relapse are caused for a short while by a trigger such as heat, stress or an infection. Unlike a real relapse, a pseudo-relapse isn't a sign of a new **lesion** in your brain or spinal cord. Symptoms stop when the trigger is taken away

reasonable adjustments

Changes at work that the law says your employer must make. They stop you being at a disadvantage because of a disability compared to other people at work

rehabilitation

Training your brain or body to get back functions lost after a relapse. It covers things like physiotherapy, occupational therapy and speech therapy

New words explained

remission

The time between relapses when your MS symptoms get better or go away completely

remyelination

When, after a relapse, your body replaces the damaged myelin covering around nerves in your brain or spinal cord

steroids

Short for corticosteroids. They dampen down inflammation in your brain or spinal cord during a relapse. They're man-made versions of the hormone cortisone that your body makes to deal with inflammation

urinary tract infection (UTI)

An infection in your bladder, kidneys or urethra (the tube your pee comes down as it leaves your bladder). In MS, it's often caused when your bladder doesn't empty properly, allowing bacteria to grow in the pee left in it. UTIs are treated with antibiotics

Further information

MS Helpline

Our MS Helpline gives emotional support and information to anyone living with MS. And through the helpline you can also access our:

- **MS nurses**
- **MS benefits advisers**
- **MS legal advisers**
- **Move more with MS service**
- **short breaks service**

We can provide information in different languages through an interpreter service. And by text relay and British Sign Language interpreters.

Find out more at **mssociety.org.uk/helpline**

0808 800 8000
(Mon-Fri 9am to 7pm except Bank Holidays)

helpline@mssociety.org.uk

Or direct private message us on Facebook (Mon-Fri 9am to 7pm) **facebook.com/MSSociety**

Resources

Our award winning information resources cover every aspect of living with MS.

You can read them online or download at **mssociety.org.uk/publications**

You can order printed resources from our online shop at **onlineshop.mssociety.org.uk** or call **0300 500 8084** and select option 4.

About this resource

With thanks to all the people affected by MS and professionals who contributed to this booklet.

We'd love to hear what you think about this information at **mssociety.org.uk/yourviews**

References

Email us if you’d like to know the references for this information at **supportercare@mssociety.org.uk**

Photography

Credit for photography belongs to Rebecca Cresta (p7), Robert Moane (p32) and Simon Rawles (p43).

This resource is also available in large print.

Call **0300 500 8084**
or email
shop@mssociety.org.uk

MS Society

Contact us:

MS Helpline
Freephone 0808 800 8000
(weekdays 9am-7pm)
helpline@mssociety.org.uk

MS National Centre
020 8438 0700
supportercare@mssociety.org.uk

MS Society Scotland
0131 335 4050
enquiries-scotland@mssociety.org.uk

MS Society Northern Ireland
028 9080 2802
nireception@mssociety.org.uk

MS Society Cymru
0208 438 0700
mscymru@mssociety.org.uk

Online
mssociety.org.uk
/MSSociety
@mssocietyuk
/mssocietyuk
mssocietyuk

Registered with FUNDRAISING REGULATOR

Trusted Information Creator
Patient Information Forum

BK05

This title will be reviewed within three years of publication (March 2028).

Multiple Sclerosis Society (MS Society UK) Registered charity in England and Wales number 1139257 And in Scotland registered charity number SC041990. Registered as a limited company in England and Wales (07451571)