

The logo for MS Society, featuring the letters 'MS' in a bold, orange font followed by the word 'Society' in a smaller, black font, all contained within an orange triangle pointing to the right.

MS Society

A portrait of a woman with dark, curly hair, wearing glasses and a brown leather jacket with a thick fur collar. She is smiling slightly and looking directly at the camera. The background is a soft-focus indoor setting.

Managing your relapses

The MS Society is here to make life better for people with MS, through research, campaigning and support.

We can see a future where nobody needs to worry about MS getting worse.

We believe that, together, we can stop MS.

mssociety.org.uk/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: mssociety.org.uk/donate
- Posting your donation to: MS Society, National Centre, 372 Edgware Road, London NW2 6ND. Please make cheques payable to the ‘MS Society.’

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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.

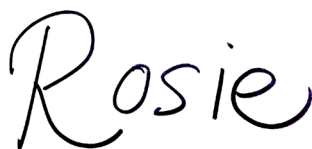
It's taken a year to fully recover from my last relapse. I still have symptoms - like echoes - of the

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.

A handwritten signature in black ink that reads "Rosie". The letters are cursive and fluid, with a large, prominent 'R' at the beginning.

Five things to know

- 1 Relapses are a sign that your MS is active. But it can still be active and causing damage even when you're not having relapses or any other symptoms
- 2 There are things you can do to reduce your risk of relapses
- 3 A disease modifying therapy (DMT) is the best way to cut down how many you have. It also makes ones that you do get less serious
- 4 Steroids get you over a relapse faster. But the chances of it leaving you with lasting effects are the same, whether you take steroids or not
- 5 Always let your neurologist or MS nurse know if you think you're having a relapse. They can then make sure you're getting the right treatment



About this booklet

Most people with multiple sclerosis (MS) have relapses at some stage. This booklet explains what's happening during one, what makes them more likely, and ways to cut how many you have.

It also looks at help available to get over relapses, and how to be more prepared for them.

There are people whose job it is to help you get over a relapse if you need them. You'll read about them and the services they offer.

With the information and tips in this booklet hopefully 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 them on **0800 800 8000** (closed weekends and bank holidays).

Or email them at helpline@mssociety.org.uk or send a private

message through our Facebook page [facebook.com/MSSociety](https://www.facebook.com/MSSociety). Use the 'send message' tab under the main picture.

You can also ask questions about relapses and get support on our online forum 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. Then you make a recovery.

A relapse can last days, a few weeks or sometimes months. Then it all goes away again. Or the symptoms mostly get better but you're 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 big and lasting impact.

You hear people call their relapses a flare-up of their MS. Doctors might call a relapse an episode, attack, (acute) exacerbation or a demyelinating event.

Knowing for sure it's a relapse

For you and your neurologist or MS nurse it can be hard to be

sure that you're having a relapse. Symptoms getting worse might just be part of the ups and downs of your MS.

So your neurologist or MS nurse uses this test to decide if it's a relapse:

1. Have your new or worsening symptoms lasted longer than 24 hours? ✓
2. Have 30 days gone by since your last relapse or flare-up of your MS symptoms? ✓

Answer 'yes' to both questions, and the next thing is to rule out an infection (they can make MS symptoms worse). So your doctor will test and treat you for things like bladder infections.

If you have no infections, and there's no other explanation for your symptoms getting worse, then it must be a relapse.

If it's not a relapse, on page 38 you'll find another explanation for your MS symptoms getting worse.

Why is this happening?

A relapse is a sign that your MS has become more active. It shows that your **immune system** is attacking nerves in your brain or spinal cord.

Around your nerves there's a fatty covering called myelin. It protects them from damage.

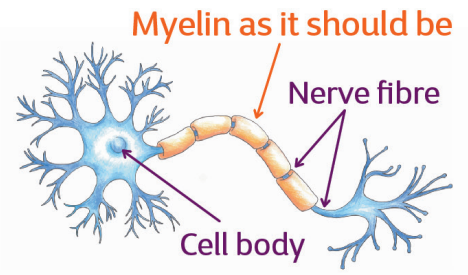
When your brain sends messages to other parts of your body, signals travel along your nerves. Myelin helps these signals move faster along the nerve.

During a relapse your immune system wrongly thinks this myelin shouldn't be there, so attacks it by mistake.

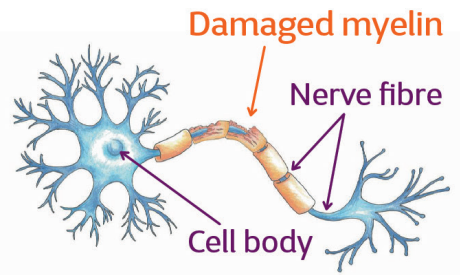
It sends cells to strip myelin from nerves. White blood cells (B cells and T cells) carry out this attack. This damages the myelin and causes **inflammation** to the nerve.

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, eventually the damage can make the nerve die. This will permanently affect the part of your body that this nerve controls.



Messages travel smoothly



Messages are disrupted

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. But when a lesion happens, it won'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. So, over time, you get a build-up of damage to your nerves, and your MS symptoms get worse.



What can I expect?

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. You might even wake up one morning and find you have a new symptom.

Symptoms depend on where in your brain or spinal cord your immune system attacks the nerves.

For example, an attack on your spinal cord can affect your walking or bladder. 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 (MS fatigue)
- numbness, pain or tingling in a part of your body
- dizziness or problems with walking, your balance or coordination
- your arms or legs become weak

- your memory, thinking or concentration suffer (often called 'brain fog')
- muscle spasms
- pain
- problems with your eyesight
- your bladder or bowel don't work like they should

An attack on just one area of your brain or spinal cord means the relapse affects only one part of your body. An attack on different parts of them causes symptoms in other bits of your body.

“I felt isolated. I didn't know what to do and what would happen. That's when I spoke to my MS team, who supported me through everything. Just having an understanding ear on the other end of the phone or email was like a comfort blanket.”
Chris

How long will it last?

A relapse might last a few days, weeks or months. For most people it's over within a month. Taking steroids can speed up your recovery (see page 25).

How often will I get them?

You can never know how many relapses you'll get over a set length of time. You might not have many at all over the years. Or you may be unlucky enough to get several in a year.

People with relapsing MS might expect on average 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.

Relapses become less common the older you get. Some of this is a direct result of ageing. But it's also because relapses usually become rarer (or stop altogether) as relapsing MS turns into secondary progressive MS.

This change tends to happen about 15 to 20 years after

someone's diagnosed with relapsing remitting MS. DMTs might slow this down.

Will I get back to how I was before?

You'll get better but it's not possible to say if your recovery will be 100%.

Rehabilitation can help you get back some or all of the things your body could do before the relapse (see page 29). But you could be left with some lasting symptoms or disability.

You might be wondering: if I have more relapses than other people, will I end up with more disability in years to come? Unfortunately studies haven't been able to answer that for certain.

In the next chapter we look at how to lower your chances of a relapse.

“OK, let's admit it: relapses are scary. Yes, there's the physical impact. But there's also a massive emotional impact as well.”

Tom



What causes relapses? Can I avoid them?

Relapses often happen for no reason. But we know that three things definitely make you more likely to have them.

These are:

- not treating your MS with a DMT
- smoking
- infections

Not treating your MS

Treatment with a disease modifying therapy (DMT) can make the biggest difference to your chances of getting relapses.

The least hard-hitting drugs can cut them by a third. And the hardest-hitting ones can reduce them by up to 70%.

If you do still get a relapse, a DMT can make it less serious. If your treatment is working really well, there may be no signs that your MS is active. Then you might get no relapses.

Find out more about these treatments, including how much each one reduces relapses, in our DMT booklet 'Disease modifying therapies (DMTs) for MS'. Visit mssociety.org.uk/dmts or to order a free copy see page 46.

I have progressive MS and still get relapses

People with primary or secondary progressive MS don't usually get relapses, so aren't offered DMTs. But some still get them and they do qualify for a DMT.

For early primary progressive MS (with relapses or inflammation seen on MRI scans), there's the drug ocrelizumab (brand name Ocrevus).

If you have secondary progressive MS and still get relapses, you can have beta interferon. A new drug, siponimod, will also hopefully be available in the UK in 2020.

My last relapse was ages ago. Is my MS still active?

Even if you've not had a relapse for a while, your MS can still be active and causing damage that you won't notice.

The time between relapses, when your symptoms get better, is called remission. Doctors used to think MS wasn't active during remission. But thanks to MRI scans we now see that MS can still cause inflammation and damage to nerves when you're in remission.

The good news is that DMTs can reduce this silent damage too.

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
- 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 you more likely to get relapses. It makes chest infections, colds and flu more likely too. These can also trigger relapses.

Smoking also makes your everyday MS symptoms worse, and can speed up how fast you become disabled. And some

DMTs work less well if you smoke. You get more relapses while taking them than people who don't smoke.

Stop smoking and these risks quite quickly drop to those of someone who doesn't smoke. Find more on this at mssociety.org.uk/smoking

Tips

- If you quit for 28 days, you're five times more likely to quit for good
- Find support with stopping at nhs.uk/smokefree

**“We all know
cigarettes
are bad for you.
But I had no idea
smoking makes
MS worse, too.”**
Lawrence

**“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

Infections

Infections caused by a virus (and perhaps bacteria, too) can cause a relapse. One study found that, after having flu, around one in three people had a relapse within six weeks.

Vaccination can protect you against flu, tetanus and the liver infection hepatitis B.

Stays in hospital put you at risk of infections. Anything that keeps you out of hospital helps, such as quickly treating bladder infections.

You can avoid a lot infections if you:

- avoid touching your eyes, mouth and nose. Stay away from people with colds or flu
- wash your hands with soap and water often (for at least 20 seconds).
- or use hand sanitizers or hand-wipes with at least 60% alcohol in them.
- handwashing cuts your risk of things like colds by about 20%
- get a doctor to check any infection you might have – sooner rather than later

Tips

- People with MS and their family carers qualify for a free flu jab each autumn from their GP
- Tips on avoiding bladder infections are in our booklet ‘MS and your bladder’. Order a free copy (see page 46) or find it at: mssociety.org.uk/bladder

Other possible triggers

It’s possible – but not proved beyond doubt – that stress and being low in vitamin D might also cause relapses.

Stress

Lots of people say stress triggers their relapses. We can’t be totally sure this is true, but quite a few studies back this idea up.

In studies that found a link the relapses happened up to six weeks after a stressful event.

Stress affects our **immune systems**, the system that also

causes relapses. So it's easy to see how there might be a link.

Stress also makes you run down, affects your sleep, and leaves you more open to infections, which can trigger relapses or make MS symptoms worse.

Check out page 40 for tips on how to de-stress.

A few studies have also found that poor sleep may be linked to relapses.

Vitamin D

We get vitamin D from some food like oily fish. But our skin makes most of what we need when we're in the sun. In the UK this happens only in the summer as winter sun isn't strong enough.

Some studies show if you're low in vitamin D, you're more likely to have relapses. Some show that taking extra vitamin D can help you have fewer of them.

But other studies haven't shown either of these things.



It's not yet been proved whether extra vitamin D lowers your risk of relapses. So there are no official recommendations on taking it that apply to all people with MS.

But official **ABN** guidelines do recommend that all women of childbearing age and who have MS should take extra vitamin D.

That said, many neurologists give this vitamin to their patients anyway. In the right doses it does no harm, and may do some good.

We'll have results from more vitamin D studies in a few years.

Relapses and what you eat

Some people believe what they eat can cut their relapses. They limit or cut out red meat, grains, gluten, dairy products or fats – or any combination of these.

At the moment there's no hard evidence that special diets make relapses less likely. Read more at mssociety.org.uk/diets

Download our booklet 'Diet and nutrition', or order a copy (see page 46). Speak to your doctor about major changes to your diet. You may need supplements if you cut out some foods.

Tips

- We can boost our vitamin D levels by being in the summer sun (but without burning) and eating fish like mackerel, sardines and salmon
- But many people with MS are so low in vitamin D that they can't get the extra they need just from food or sunshine. They need a supplement
- Speak to your GP or MS team about your vitamin D levels. They'll test you to see if you need extra, and give you the right amount of supplement
- Any supplement you take needs to be vitamin D3. Vitamin D2 isn't as good at boosting your vitamin D levels.

Relapses and having a baby

The chance of a relapse goes down if you're pregnant.

Your body makes more hormones (like oestrogen), which make your immune system less active. This stops your body rejecting the baby. A knock-on effect is that your risk of a relapse normally drops.

During the three months after you give birth, hormone levels return to normal. In the days before DMTs this made the risk of a relapse go up.

But a study in 2019 found that, because of DMTs, this rise doesn't seem to happen anymore.

Your neurologist can advise you based on how active your MS is and what DMT you've been taking. They might recommend that very soon after you've given birth you start taking a DMT again – or that you keep taking your DMT through pregnancy and after it.

Some studies (but not all) show breastfeeding (and no bottle feeding at all) for the first couple of months means less chance of a relapse.

Some DMTs aren't safe to take if you want to breastfeed, but ABN guidelines encourage mums with MS to breastfeed if they can.

Some fertility treatments use hormones so might trigger a relapse. But, again, this isn't certain.

If you're interested in fertility treatment, experts say you shouldn't let this put you off it.

No extra risk

Studies show that none of these make a relapse more likely:

- exercising
- surgery (including having a general anaesthetic)
- suffering an injury
- being vaccinated against flu, hepatitis B and tetanus

The flu jab is seen as safe for people with MS. Lots of studies have found no evidence that it raises your risk of a relapse.

The Yellow Fever vaccine does make relapses more likely, but there's no strong evidence other vaccines do. But some should be avoided if you're on certain DMTs.



I think a relapse has started. What should I do?

Once you suspect a relapse has begun, how soon do you contact someone?

You might do this straight away. But some people wait a couple of days in case what they're feeling turns out to be a **pseudo-relapse** caused by something else (see page 38).

When you decide to let someone know, contact a member of your MS team. This could be:

Your MS nurse



Not everyone has one, but for many people their nurse is the first person to turn to.

You can phone or email them.

They might want to talk things through over the phone, or see you in person.

If you're not sure whether you're having a relapse, they can help you work this out.

Your neurologist



If you don't have an MS nurse, phone your neurologist.

When you're put through to their secretary, it's important to say that you think you're having a relapse and describe how it's affecting you.

Once your neurologist (or MS nurse) knows you're having a relapse, they'll tell you what to do next.

A relapse clinic



Some hospitals have relapse clinics, maybe one day a week, staffed by specialists like neurologists and MS nurses. You can turn up without much notice.

These clinics offer treatments like steroids, either to take at home or have through an **infusion** (a 'drip') at the clinic.

Your GP



If there's no alternative, make an emergency appointment with your GP (family doctor). They can check for infections that need treating and might give you steroid tablets.

Your GP needs to let your neurologist or MS nurse know that you've had a relapse. This information could affect your treatment with a DMT.

Accident and Emergency (A&E)

Relapses are rarely so bad that you to need to go to a hospital's A&E department.

Exceptions would be if you're in intense pain, 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 that your neurologist, MS nurse or GP know about it. That's because:

- they might offer you steroids to help you get over it sooner
- reporting a relapse might affect the DMT treatment you can have

Your neurologist needs to keep track of how many relapses you have, and how serious they are.

You can only start on a DMT if you have a certain number of relapses over a year or two. If you've not qualified for a DMT up until now, a new relapse could mean you can now start treatment with one.

Already on a DMT? Then a new relapse might mean your treatment's not working and it's

time to think about switching to a harder-hitting one.

Keep a record of your symptoms,

so that you won't forget what's happened. It'll help to keep your neurologist or MS nurse updated.

Tips

- Tell your neurologist or MS nurse if any of your symptoms change
- Track your symptoms using a diary, notebook or an app that you download onto your phone like these:

SymTrac (novartis.co.uk/symtractm) – iPhone (iOS) and Android platforms

MS Management (<https://play.google.com/store/apps/details?id=com.confidosoft.msapp>) – Android only

MS Notes Journal (<https://play.google.com/store/apps/details?id=mslogbook.android.mslogbook.android>) – Android only



Steroids and other treatment

Not all relapses need to be treated. If it's not serious, you might let your body recover in its own time. If 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 don't build muscle like anabolic steroids.

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

Steroids can speed up your recovery, shortening a relapse by about two weeks. But they don't always work for everyone every time. Some people can have an allergic reaction to them.

You won't get steroids for symptoms like fatigue or milder ones like tingling or numbness.

You're offered steroids if a relapse is serious and stops you doing the day-to-day things you need to do.

Examples would be 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

You usually get steroids as tablets to take at home. Or you might have them through an

infusion (a ‘drip’) in hospital. Then you take in the steroids through a thin tube that goes into a vein in your hand.

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

It’s possible to be allergic to steroids but for most people any side effects are mild. They go once you stop taking them. You might get:

- a taste in your mouth like metal (mints can help)
- headache
- a ‘buzzy’ feeling with extra energy, making it hard to sleep. This is why you take them in the morning. You could ask your doctor for something to help you sleep
- 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)

- a bigger appetite
- water retention. This can cause swollen ankles, a need to pee often, a general bloated feeling, and short-term weight gain
- infections, including **urinary tract infections**. Tell your doctor about any sign of an infection (like a sore throat, cough or fever)
- high levels of sugar in your blood or pee (if you have diabetes your doctor will talk to you about your insulin levels)
- acne (which goes when you stop the steroids)

Take steroids for longer and side effects can be more serious. This can lead to diabetes, or your bones become thinner and more likely to break.

Because of this your doctor might avoid giving you steroids more than three times a year.

A course of steroid tablets lasts five days. Each dose is **0.5g (500mg)** of methylprednisolone (brand name Medrone)

With an infusion you'll have it over three to five days. Each dose is **1g (1000mg)** of methylprednisolone.

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.

If you're a woman who's pregnant, you can be treated with an infusion of steroids if a relapse stops you going about your day-to-day life.

If you need steroids, you don't have to stop 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.

“Steroids I find are a necessary evil: effective, but be prepared for side effects. You'll eat anything that isn't nailed down! And remember - you will sleep again, eventually.”
Christine

Steroids by infusion

You might have an infusion instead of tablets if you:

- have a severe relapse
- need to go into hospital because steroid tablets don't work (or you can't take them for some reason)
- have other health conditions that steroids might make worse like diabetes or depression

“I took them once for optic neuritis. They gave me awful stomach problems and made me very angry. Considering they only slightly reduce the length of the relapse, I wouldn't take them again for that problem.”

Sammy

Tip

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



Plasma exchange

Plasma exchange is an option if a relapse is severe and steroids don't work, or if you're allergic to them.

Blood is taken from a vein, usually in your arm. A machine separates the liquid part of your blood (plasma) from the red and white blood cells in it. 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 speeds up your recovery. It won't make your MS any better in the long run though. Only a DMT can do that.

Plasma exchange happens in a hospital. 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

Time and taking things easy can get you 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.

“I've given up my attitude of 'head down, keep going.'”
Rosie

You might feel awkward asking friends and family, but people are usually 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. Listen to your body.

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 care for you at home.

Your MS team or neurologist will decide what help you need 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 neuro-psychology.

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

“Don't go through a relapse by yourself. Involve your family, friends, counsellor or MS nurse. If you need support, ask for it.”
Tom

Help from other medical professionals

Occupational therapy



An occupational therapist (OT) comes up with practical suggestions that save you energy. They help you do things in a better way (like washing, dressing and eating).

They also help with fatigue, balance or tremor. OTs teach ways of dealing with memory, thinking and concentration problems, too.

They might suggest equipment and changes to where you live or work. Occupational therapy isn't just about where you work. It's also about how you manage at home.

“I saw an occupational therapist who gave me brilliant fatigue advice. This really improved my quality of life. She was invaluable.”

Sammy

MS nurse



An MS nurse can give you advice about your relapse symptoms.

They also coordinate others to help. For example, they can get a prescription for steroids through your GP.

Your nurse is your link between hospital and specialist services, including social care.

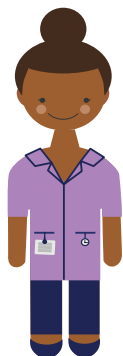
MS nurses usually see people in clinics, but some make home visits. They answer questions by email or phone as well.

If you don't have an MS nurse, find your nearest one at [mstrust.org.uk/about-ms/ms-services-near-me](https://www.mstrust.org.uk/about-ms/ms-services-near-me). You may be able to contact one yourself, or your GP may need to arrange a referral.

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

Rosie

Continence nurse or advisor



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.

“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

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

District nurse



A district nurse (or community nurse) can help when you need a nurse for other things. They often work away from hospitals, linked to GPs.

They can come to your home to give quite complicated 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.

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 now struggling to find the right words, or it's hard to follow a conversation or concentrate (like when you're reading).

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

Neuro-psychology



A neuro-psychologist helps with problems a relapse causes 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.

Neuro-psychologists teach techniques to help you cope better. These can improve your memory and attention span. You can learn how to recall words better.

Your GP, MS team or MS nurse can make a referral. 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 help you get from your local council (or in Northern Ireland from your local health and social care trust).

It can be 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 just 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.

You may be referred to social services if a relapse means that you – or your family carer – need support.

If what you need can't be provided at home, or your relapse is severe, you should be offered treatment in hospital as an inpatient.

Get in touch with the social services department of your council (or, in Northern Ireland, your trust). Say you want to be assessed for social care.

Contact details are on your council's (or trust's) website.

If you appear to need help, the law says they must do an assessment of what you need.

If you get social care, and later your symptoms or disability improve,

the law says you must let them know. They might then change (or stop) the help they give you.

There's more information in our social care booklets for Scotland, Northern Ireland, England and Wales. Order a free copy (see page 46) or find them at mssociety.org.uk/social-care

Emotional impact

A relapse can trigger difficult feelings. It can be 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 might 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 you to admit you 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 (or others might blame themselves).

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

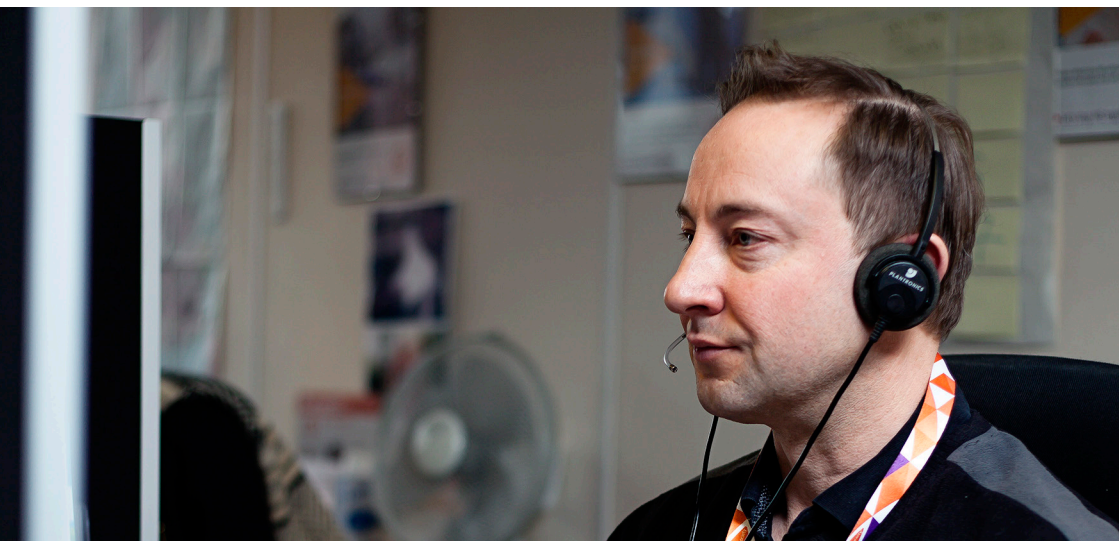
Instead learn from the past, focus on avoiding a repeat, and go easy on yourself.

Someone to talk to

Your MS nurse, GP, a counsellor, a neuro-psychologist or occupational therapist can all help you deal with the emotional fallout from a relapse.

People on the MS Helpline on **0808 800 8000** are trained in giving emotional support. Page 42 explains the different ways you can contact them. Family members and your partner can use the Helpline as well.

If you live in Northern Ireland, our centre in Belfast offers a counselling service. Find details at mssociety.org.uk/northern-ireland-counselling



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 even 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, what childcare is in place if you can't look after them?

Have you explained to them how a relapse might affect you? It's better to do this before one happens, rather than when you're ill.

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

If you've got pets, who'll look after them during a relapse?

Home

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

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

Live on your own? Then make preparations in case a relapse stops you leaving the house.

Stock up on things like toilet roll, toiletries, pet food, tinned or frozen food, including meals that don't need much preparing.

Work

Check your rights at work before a relapse strikes. 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) leaves you with a disability.

If you work and 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.

Our booklet 'Work and MS' has information on things like sick pay, fit notes, going back to work, and reasonable adjustments.

Order a free copy (see page 46) or read about these things at mssociety.org.uk/work-and-you

Driving

You might no longer feel safe behind the wheel during or after a relapse. Driving might even become impossible.

Ask someone else in advance if they'd drive you during a relapse and while you recover.

When you were first diagnosed with MS, you should've told this to the DVLA (Driver and Vehicle Licensing Agency). In Northern Ireland it's the Driver and Vehicle Agency (DVA) you tell.

Find out more at: mssociety.org.uk/driving

When a relapse, or MS in general, affects your eyesight, you don't 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 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 Mobility Assessment Centre can check



your coordination, eyesight and muscle strength.

Find the nearest one, and more information about driving after you've been ill, at

drivingmobility.org.uk/information/returning-to-driving/

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 your 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 46.

When it's not a real relapse

It's often not clear if you're having a relapse. What you're feeling may be just the normal ups and downs of your MS, or something called a 'pseudo-relapse'.

What if, using the definition on page 8, you're not having a relapse?

Then a pseudo-relapse (or pseudo-exacerbation) is the likely explanation of this sudden flare-up of your symptoms.

'Pseudo' means 'false' or 'not real'. Your symptoms will feel very real – so will the worry that your MS is getting worse. But, unlike a real relapse, a pseudo-relapse causes no lasting harm.

That's because no new **lesion** or damage to the **myelin** in your brain or spinal cord is happening.

It can be hard to know if it's a pseudo-relapse or the real thing.

This should get easier the longer you have MS.

Signs of a pseudo-relapse are:

- it has a trigger you can usually identify. Symptoms go once the trigger is no longer there
- it doesn't last long (under 24 hours)
- you can have several of them in a short period of time (over a week or during a month)

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

If you get a new symptom, this could be a sign of a real relapse.

So always tell your MS nurse or neurologist about a new symptom.

Things that trigger pseudo-relapses

Your body getting hot

If your body heats up, even by less than one degree, MS can stop messages travelling easily along your nerves.

That makes symptoms worse. This is called Uhthoff's sign or phenomenon.

The nerves in your brain and spinal cord have a covering of **myelin**. This normally protects the nerve from rises in temperature.

If MS damages the myelin, heat stops the nerve working as well as it should.

Your body can overheat 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. Check your temperature to see if you're fighting an infection.

If you cool down, your symptoms will ease off within hours.

Tips

To keep your body from overheating:

- drink ice cold drinks or suck on 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

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 with things stopping you sleeping like bladder problems or leg spasms.

Check our website for our an online tool that helps you manage your fatigue levels and other tips at

mssociety.org.uk/about-ms/signs-and-symptoms/fatigue/managing-fatigue

Stress

You can learn ways to calm anxiety and lower stress levels. These include regular exercise, meditation, relaxation techniques, mindfulness and yoga. Your GP can suggest things locally.

A good night's sleep helps too, as does spending time with friends or on a hobby.

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.

Tips

- Our booklet 'Complementary and alternative medicine' covers relaxation, like meditation, aromatherapy and massage
- We have exercise and yoga webpages and videos at **mssociety.org.uk/care-and-support/everyday-living/staying-active**
- Find out more about mindfulness at **mssociety.org.uk/mindfulness**

Infections

Even a minor infection can make symptoms worse without causing a proper relapse.

As you fight an infection, your body temperature goes up, making MS symptoms worse for a while. Treat the infection and symptoms go away.

Urinary tract infections (UTIs) are common triggers. Get infections



looked at sooner rather than later as they can lead to a proper relapse.

Our booklet 'MS and your bladder' tells you the signs to look out for and how to avoid UTIs.

Find it here mssociety.org.uk/bladder or see page 46 for how to get a free copy.

Periods

Lots of women feel their MS symptoms get worse a week or so before their period. Some studies back this up, but others don't.

Around this time your hormone levels change and your body temperature goes up by one degree.

This could explain why MS symptoms get worse. Cooling garments and our other tips can keep your body temperature down.

Treatment for a pseudo-relapse

You won't be given steroids as there's no inflammation in your nerves to treat. Instead just take away what's triggering your symptoms, and rest.

Useful organisations

MS Society

MS Helpline

Our helpline offers emotional support and information to anyone affected by MS. Talk to them in confidence about your MS and how it affects you.

Call them on **0808 800 8000** (closed weekends and bank holidays) or email them at **helpline@mssociety.org.uk**

You can also send them a private message by visiting our Facebook page **facebook.com/MSSociety**. Use the 'send message' tab under the main picture.

Living Well with MS sessions

A course of four weekly meetings for people living with MS, either face to face or online.

Chat, share experiences and learn ways to support yourself to live well with MS. Find details at: **mssociety.org.uk/living-well-sessions**

Our groups

Through our 270 local groups you'll

find out about local services and get support. Find your nearest group at: **mssociety.org.uk/near-me**

MS Society forum

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

MS National Therapy Centres

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

Other organisations

MS Trust

A charity offering information for anyone affected by MS: Freephone Information Service: **0800 032 3839**

mstrust.org.uk

Shift MS

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

shift.ms

New words explained

Association of British Neurologists (ABN) – the UK professional organisation for MS specialists. It recommends how people with MS should be treated

antibodies – these are made by your **immune system** to help kill things like viruses and bacteria. In MS your body makes harmful antibodies. During **plasma exchange** they're taken out of your blood to help you recover from a serious relapse 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

continence service – staffed by specialist nurses and based in a hospital, clinic or health centre. It treats bladder and bowel problems

cooling garment – special vests, neck and wrist wraps that stop your body overheating for three to four hours. Inside are cooling packs of a special gel or ice. Or you soak

them in water to activate them, or they're powered by battery

demyelination – when, during a relapse, 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). Good employers record it separately from sick leave. Not all work places have this, but you could still ask for it

exacerbation – another word for a relapse

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**

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. This causes 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**’) – an area 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 our 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 adapts and reorganises itself when nerves in it are damaged. If an area of brain is damaged by MS,

another part can take over to do what the damaged bit once did.

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 if steroids won’t work. It ‘cleans’ your blood by replacing plasma (the liquid part of your blood) with 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

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 that can be in your kidneys, bladder or urethra (the tube your pee comes down as it leaves your bladder). 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

Resources

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

To order email:

shop@mssociety.org.uk or visit
mssociety.org.uk/publications

MS Helpline

The free MS Helpline offers confidential emotional support and information for anyone affected by MS, including family, friends and carers.

Information is available in over 150 languages through an interpreter service.

0808 800 8000

(closed weekends and bank holidays)

helpline@mssociety.org.uk

About this resource

Thanks to all the people affected by MS and professionals who contributed to this booklet, in particular the following MS clinical nurse specialists: Melissa Chowdhary, Del Thomas and Adrienne Cox.

If you have any comments on this information, please send them to: resources@mssociety.org.uk

Disclaimer: We have made every effort to ensure that the information in this publication is correct. We do not accept liability for any errors or omissions. Availability and prescribing criteria for drugs in various parts of the UK may change. Seek advice from the sources listed.

References

A list of references is available on request. Call **0300 500 8084**.

Photography

Photography: Rebecca Cresta (cover and p34), Simon Rawles (pages 10, 18 and 41), Jonathan Simpson (p21) David Dunne (p6), Amit Lennon (pages 15, 28 and 37), Alex Grace (p13) and Paul Moane (p24)

This resource is also available in large print.

Call **0300 500 8084**
or visit **mssociety.org.uk/publications**

Contact us



MS Helpline

Freephone 0808 800 8000

(closed on weekends and bank holidays)

helpline@mssociety.org.uk

MS National Centre

0300 500 8084

info@mssociety.org.uk

supportercare@mssociety.org.uk

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facebook.com/MSSociety

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