

A man with short dark hair and glasses is sitting on a brown couch, smiling. He is wearing a yellow t-shirt with a blue graphic that says "EAST VS WEST" and "DECEMBER, 1972". A small white dog is sitting on the couch next to him. The background shows a window with wooden blinds. An orange triangle is overlaid on the bottom left of the image, containing the text "Understanding relapsing remitting MS".

**Understanding
relapsing
remitting MS**

We're the MS Society. Our community is here for you through the highs, lows and everything in between. We understand what life's like with MS.

Together, we are strong enough to 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 Chris, who has MS

When I was diagnosed with relapsing MS, like most people, I was shocked. I went into my shell a lot, and it took me a long time to tell anyone about my condition.

But gradually, over time, I've learnt to open up a lot more about my condition. The MS Society has been a great help. I think the information on the MS Society website is a great place to start to help you come to terms with your diagnosis.

This booklet answered a lot of my questions about relapsing remitting MS. And I'm always checking the MS Society Facebook page as well, often getting into discussions with other followers about various topics!

I know that when I do have relapses, I really need to take it easy, but it's hard when real life gets in the way. My support network of family makes this much easier, though.

MS has changed my life, but it hasn't stopped me from doing what I want to do. That's the main thing, and I'm determined that this will continue.

Chris

Five things to know

- 1** MS isn't infectious – you can't catch it – and, we don't yet fully understand why you get it. But, we do know that factors such as your genes, your lifestyle and your environment may be involved
- 2** With relapsing remitting MS, you have a pattern of relapses (symptoms getting worse) followed by recovery ('remission')
- 3** People often recover well from a relapse, with complete remission. But around half of all relapses may leave some lingering problems
- 4** Relapses often last a number of weeks, and possibly even months
- 5** Taking a disease modifying therapy (DMT) can mean fewer and less serious relapses, and it could slow down your MS



About this booklet

In this booklet you'll find information about relapsing remitting MS (often just called relapsing MS). This is the most common type of MS - around 85% of people with MS are diagnosed with this type.

It's not unusual to feel shocked, frightened and worried about your future after receiving a diagnosis of relapsing remitting MS. Knowing more about MS can help you feel more in control of what's happening. We hope this booklet will make you feel less uncertain or worried.

Living with MS has real challenges but a lot has changed since the first effective treatments became available in the nineties. What we know about MS is growing all the time. Research into even better treatments is making progress, new ones keep being launched, and recently we've seen some major breakthroughs.

Life with MS these days is less about what you can't do, but more about what you can do. At the MS Society we're here to help you or the person you know with MS find ways to live out your plans and hopes.

In this booklet, we explain what relapsing MS is, how to manage your condition and how to access the information, treatments and support you need to do this.

One last thing. Where you see a word in bold in this booklet, it means you can turn to the back and find it explained.

Relapsing remitting MS explained

Multiple sclerosis (MS) affects the **nerves** in your brain and spinal cord (also known as your **central nervous system** or **CNS**).

Think of your central nervous system as a pathway by which messages travel between your brain, spinal cord and other parts of your body. For instance, when you walk, messages must travel from your brain to your leg muscles. If that pathway becomes damaged, their journey may become slower, distorted or even blocked. That's what causes MS symptoms. You might experience several or a few different symptoms, depending on the part of the central nervous system that's affected.

Not only are there differences in MS symptoms between individuals, but also how and when you experience them can

be different. The most common symptoms are fatigue, muscle weakness, difficulty walking, bladder problems, pins and needles, dizziness, muscle spasms, pain, visual disturbances and difficulties with memory. But, you may never experience all of these symptoms, and it's very unlikely that you'd get them all at once.

For more about symptoms, visit our website mssociety.org.uk/what-is-ms/signs-and-symptoms or read our booklets 'Just diagnosed' and 'What is MS?'

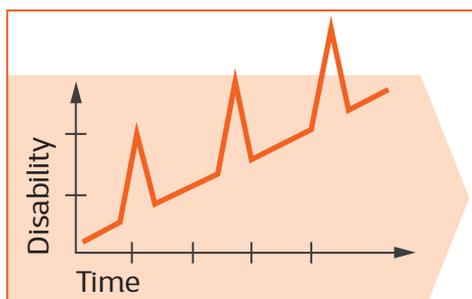
Types of MS

There three main diagnoses of MS: relapsing remitting, secondary progressive and primary progressive.

Relapsing remitting MS

When people are first diagnosed with MS, about 85% are

diagnosed the relapsing remitting type of MS. With this type of MS you have a pattern of **relapses** (symptoms getting worse) followed by recovery ('remission'). Your disability doesn't get worse between relapses but after each relapse it can end up worse than before. As time goes on your body finds it harder to repair the damage each relapse brings. So your disability is likely to get worse, especially if you don't start treatment.



With progressive MS, there are no periods of remission and the condition gradually gets worse over time. But, the speed at which this happens varies greatly and it's not yet possible to predict exactly how it will affect one person.

“When you’re diagnosed, it can feel like your whole world is crumbling. But my family and friends were really supportive. I talked to them about it as much as I felt I needed to, and over time I began to realise that life was still good.”

Ali

What are relapses?

Most people diagnosed with MS get relapses to begin with. A relapse is when, after a period when your MS was stable, your **immune system** attacks your nerves. This causes **inflammation** to the **myelin** coating around them. This damage stops signals travelling along the nerves like they should and causes symptoms of MS. An example of a relapse could be blurred or no vision or not being able to lift a leg.

To be classed as a relapse, these symptoms need to last for 24 hours or more, and not be caused by an infection. They would also need to happen at least 30 days after any previous relapse. A relapse may be called by other names, such as an attack, exacerbation, flare-up, acute episode or clinical event.

For days, weeks or months the symptoms you had already may get worse or new ones appear. Your body does its best to repair the damaged myelin. Then symptoms can get better or go completely. This recovery is called 'remission'. But you might be left with some disability. As time goes on it gets harder for your body to repair the damage after each relapse.

Doctors used to believe that during remission MS wasn't causing any harm. But we now know that even when you're not having a relapse, MS can be damaging your nerves.

“Get as much information as you can about the condition - but from reputable sources. There's a lot of rubbish out there on the internet, so be careful where you look.”

Chris

How many people have relapsing remitting MS?

There are roughly 1.3 million people worldwide who have relapsing MS out of 2.3 million with any type of MS. In the UK, there are about 130,000 people living with MS. When they were first told they had MS, 85% of them were diagnosed with the relapsing remitting type.

Who does it affect?

In the UK people are most likely to find out they have MS in their 30s, 40s and 50s. But the first signs of MS often start years earlier.

MS affects nearly three times as many women as men for reasons we don't yet understand.

Pregnancy and relapses

If you're pregnant and have MS you're less likely to have a relapse, although the risk of relapse increases during the six months after the birth. This is probably due to changes in hormone levels during and after pregnancy. In the long-term, pregnancy doesn't affect how someone's MS develops. Most medications are not recommended during pregnancy so if you are planning to become pregnant, or think you might be already, you should discuss this with your MS nurse or doctor.

Diagnosing relapsing remitting MS

MS is complex and can cause many different symptoms, so it's not easy to diagnose. It's hard to pinpoint exactly when MS begins, and the early signs and symptoms are different for everyone.

It's not uncommon for a diagnosis to take several months, and frustratingly it can take even longer. A range of other possible causes need to be explored and many different tests need to be carried out.

The tests

Neurological examination

Your neurologist may carry out simple tests for balance, movement, coordination, reflexes or vision.

MRI scan

An **MRI scan** creates images of cross-sections of the brain and spinal cord, showing any scars (or **lesions**) that may be caused by MS.

Lumbar puncture

Under local anaesthetic, a needle is inserted into the space around your spinal cord to take a small sample of fluid, which is then tested for abnormalities associated with MS. You can find more information on ways people are diagnosed on our website.

Move to secondary progressive MS

Most people with relapsing remitting MS will eventually develop secondary progressive MS. It varies widely from person to person, but on average, around 65 per cent of people with relapsing remitting MS will develop secondary progressive MS 15 years after being diagnosed.

With this type of MS, you no longer have clear periods when your disability stops or gets better (relapses and remissions) and your disability gets steadily worse. But, determining this isn't straightforward. It can take months to recover from a relapse, which can leave permanent damage. This doesn't necessarily mean that the condition has progressed.

The Expanded Disability



EDSS
0.0

EDSS
1.0

EDSS
2.0

EDSS
3.0

EDSS
4.0

EDSS
5.0

Normal
examination

No disability
but clear
signs of
impairment

Minimal disability

Moderate
disability

Able to walk
without aid

Your neurologist may use a clinical tool called the Expanded Disability Status Scale. This measures levels of disability on a scale of 0 to 10, as well as asking you how your ability to complete certain tasks has changed. Sometimes an MRI scan is used to check for certain changes in your central nervous system.

In the past, before DMTs came along, it usually took around 20 years for relapsing MS to change

into secondary progressive MS. But thanks to today's MS drugs this is changing:

- fewer people are likely to go on to secondary progressive MS
- for those that do this could take longer to happen

In a small number of cases, some people are not diagnosed with MS until their condition has reached the secondary progressive stage.

Status Scale (EDSS)



Death

EDSS
6.0

EDSS
7.0

EDSS
8.0

EDSS
9.0

EDSS
10.0

Help needed to walk 100 metres

Essentially restricted to wheelchair

Disability impacts daily activities

Essentially restricted to bed much of the day

Bedridden and unable to communicate effectively or eat/swallow

Progressive relapsing MS

A small number of people with either type of progressive MS also experience relapses as well as progression.

Read more about all forms of progressive MS in our booklet, 'Understanding progressive MS'.

How fast will your condition progress?

The short answer is that nobody knows. MS is unpredictable and no two people are affected by MS in the same way. There's no standard pattern that your MS will follow. Even knowing what type of MS you have will not tell you how it will develop.

It's impossible to tell when your next relapse will be, how quickly your MS will progress or what part of your body will be affected. Symptoms can occur randomly – at any time, in any order. Being tired, stressed, ill – for example, having a cold – or feeling too hot can make you feel worse. These feelings affect how you experience your symptoms and don't

necessarily mean that your MS is progressing.

Your symptoms can change from day to day, or hour to hour, for no obvious reason. You may also find you have days, weeks, months and sometimes years when you feel fine, with no real symptoms.

This unpredictability, and not knowing what the future holds, can be one of the hardest parts of living with MS. It can take some time to come to terms with it, but there's support available.

If you want to talk to someone, our MS Helpline is available weekdays from 9am to 9pm on **0808 800 8000** (closed in the weekend and on bank holidays). Our local groups also offer direct access to a support network of experienced volunteers.

You can read more about the emotional effects of MS in our booklet, 'MS and your emotions'.



What's going on in your body?

MS is a complex condition that isn't yet fully understood. But, we do know it's an autoimmune condition. This is when your **immune system**, which is meant to protect you from infections, gets confused and mistakes a part of your body for an 'invader' such as a virus, and attacks it.

In the case of MS, it affects your central nervous system, which consists of the brain and the spinal cord. The central nervous system is the control centre of the body, governing every function, from unconscious actions like breathing and arousal to conscious actions such as movement, bladder, bowel and sex.

The spinal cord receives information from around your body and passes it on to your brain, which analyses and stores it. Your brain then sends out

messages to parts of your body, instructing it to perform various tasks. For instance, if you want to walk over to the other side of the room, your brain will send instructions to your leg muscles.

Message interruption

These messages are sent by electrical impulses transmitted by **nerves**, which are covered by a fatty substance called **myelin**. The myelin has two functions: it protects the nerves and it ensures that the messages travel smoothly and quickly to the correct destination.

But in MS, your immune system mistakes myelin for an 'invader'. As a result, it allows its white disease-fighting cells out of the bloodstream, through the blood-brain barrier and into the central nervous system, where it attacks myelin and the cells that make myelin (oligodendrocytes).

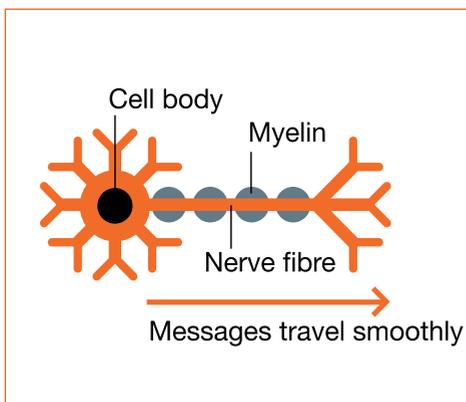
As the myelin becomes damaged, something happens to the nerves' ability to send messages efficiently and quickly. This is what leads to symptoms. And because the central nervous system governs all your bodily functions, symptoms can be incredibly wide-ranging, depending on the area that's affected.

A useful comparison

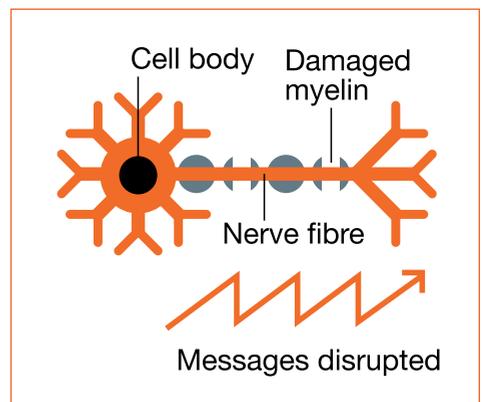
It can be easier to understand the mechanism underlying MS if you compare what is happening in the central nervous system with something that's familiar in everyday life, such as your water pipe system at home.

Imagine that your nerves are like water pipes, sending water (messages) around your home (body). The protective myelin around your nerves is the lagging. Just as lagging helps to insulate your pipes, ensuring that hot water is delivered efficiently, the myelin insulates the nerves, allowing the messages to arrive swiftly to the right destination. And, as lagging also protects the pipe from damage, myelin helps protect the nerve.

In MS, sections of the lagging (myelin) on the pipes (nerves) get damaged and fall off, leaving the pipes exposed. If the lagging continues to be damaged, the



Myelin as it should be. Messages travel smoothly



Myelin damaged. Messages are disrupted

pipes become vulnerable and when a cold winter comes along, they may crack and burst. If the pipes are not repaired, the water pipe system becomes less efficient.

Why did I get it?

We still don't know what the exact cause of MS is.

What we do know is that there's not just one single reason why you got MS. Instead, there are probably a number of different reasons, or factors, involved – your genes, your environment and your lifestyle.

Your genes

MS is not directly inherited like some other conditions. It isn't caused by one faulty gene. But, there does seem to be a genetic element to it.

Research into the genetics of MS has so far identified over 100 genes that may play a role in MS. But not everyone who has these genes will get MS.

While MS can happen more than once in a family, it's more likely that it won't happen. Even the identical twin of someone with MS only has a 30% chance of developing MS as well. This tells us that even if you have the same genes, you're unlikely to develop MS.

So, while there's a genetic element to MS, it's not the whole story.

Your environment

We know that you're more likely to get MS if you live further away from the equator and don't get much sun. There are fewer people with MS in places like Malaysia or Ecuador, but many more in the UK, northern USA, Canada, Scandinavia, southern Australia and New Zealand.

This tells us there's something in the environment that plays a role in MS.

More and more evidence shows that low levels of vitamin D during your childhood may increase your chances of developing MS. Vitamin D is known as the

sunshine vitamin, our bodies produce it when sunlight shines on our skin.

Recent research tells us that certain bacterial or viral infections may act as a potential trigger for MS, including the Epstein-Barr virus (also known as the kissing disease or mononucleosis), which causes glandular fever.

This doesn't mean these infections cause MS, but they could add to your chances of developing it. And just because you've had the Epstein Barr virus doesn't mean you'll get MS as most people carry it.

Your lifestyle

Smoking

Studies suggest that smoking could increase risk, possibly by affecting the immune system. Smoking is also linked to going from relapsing MS to progressive MS at a faster rate. So, just as for everyone else, it's a good idea not to smoke and to stop if you do.

“I used to play a lot of sports. Rugby was my main one, but I can't play any more. I still take my son to training every week and get involved with lots of aspects of the club. I also lift weights - I go to the gym most days. It's important to do what you can, when you feel up to it.”

Bruce

Obesity

Studies have found that being very overweight (**obese**), especially when a child or young adult, is linked to MS. This could be because being very overweight can:

- make you low in vitamin D
- make your immune system overactive and cause **inflammation** inside your body

- other reasons we don't understand yet

Of course, not everyone who's obese gets MS and not everyone who got MS is or was very overweight. But if your risk of getting MS is on your mind, your weight is a risk factor you can change.

MS is no-one's fault

Hearing about things that may cause MS might make you ask: 'Could I have done something to avoid it?' But you couldn't because we don't know for sure which things come together to cause MS in each person. In the past we all knew much less about what might cause MS. So you weren't in a position to do anything to stop it.

“Since my diagnosis, my family has become even more important to me. I spend as much time as I can with my partner and children. They’ve come to terms with my condition now as well. I think it’s brought us all together and made us stronger. I’m really thankful for their support.”

Ali



Coming to terms with your diagnosis

Being diagnosed with any lifelong condition can have a huge emotional and psychological impact, even if you were expecting the diagnosis.

It's not unusual to feel shocked, frightened, vulnerable and worried about the future. You may feel totally devastated or you may be in denial. You may feel angry, tearful, confused, overwhelmed, anxious, depressed, withdrawn or all those things in the weeks and months afterwards.

There's no right or wrong way to react. Each person's response is as individual as their symptoms but it's generally recognised that many people go through a grieving process for the loss of the life they had expected. This is a normal, emotionally healthy response.

Don't beat yourself up if you are still struggling to come to terms with the diagnosis for some time afterwards. It can take many months and even years to do this.

You may be worried about your ability to carry on working and how this will impact on your finances. You may also be concerned about the effects of your condition on your family, especially if you have young children. See What can help, below, for getting help on practical matters.

Positives

You may feel relieved to have a diagnosis that explains the many and seemingly unrelated symptoms you have been having. Now you have a diagnosis, you can get access to MS services, support and other forms of help.

What can help

Some people want to find out as much about MS as soon as possible. Others don't feel ready to take in lots of new information. But you feel, it's important to know how to get hold of information if you want it.

Information

Guidelines from the National Institute for Health and Care Excellence (NICE) recommend that written information about MS and how to manage symptoms should be made available when you're diagnosed. You should also be advised about local support groups and services, relevant social services, national charities, and any legal requirements or rights. If you haven't received this, ask your GP, MS nurse or contact our free helpline (see below).

You may also find some of our following free booklets useful:

- Living with the effects of MS
- Just diagnosed
- MS and your emotions

If doing your own research, check that your information source is reputable. This is especially important with regard to health products and treatments. If in doubt, check with your MS nurse, neurologist or GP. Or read 'I've got nothing to lose by trying it', a free guide by charity Sense about Science, which you can download from our website.

Support

- Groups – Many of our local groups have regular support group meetings, plus each group has an MS support officer who can offer guidance on local services. There are also national support groups, including for minority groups.
- MS helpline – We offer emotional support plus practical information by our free helpline (**0808 800 8000**).
- Online forums – Our forums offer a way to share experiences and support with others affected by MS. community.mssociety.org/uk/forum



Talking therapies

Counselling, psychotherapy and cognitive behavioural therapy (CBT) all offer ways to help you come to terms with your diagnosis and deal more positively with challenges. They allow you to talk about your feelings in a safe environment with someone who is trained to help you in a positive way. But, a recent study showed better results for CBT in helping people adjust to the early stages of MS. CBT uses practical problem-solving techniques to help you change how you think and behave.

You may be able to get talking therapies through your GP or MS nurse. But, access on the NHS can be limited. Counselling is available from some regional MS Therapy Centres or you may be able to access it at a discounted rate through your local MS Society group.

“I try and keep a positive outlook. I may have my MS, but my MS doesn't have me. I don't think having this condition has to make your life worse. Focus on what you can do, not what you can't.”

Chris

Otherwise, you can find a qualified counsellor or psychotherapist through the British Association for Counselling & Psychotherapy (BACP). See the back of this booklet for contact details.

**www.itsgoodtotalk.org.uk
01455883300**

For more about emotional support, visit the Support section of our website or call our free MS Helpline: **mssociety.org.uk/ms-support/emotional-support
0808 800 8000**

Managing relapses

It's not possible to predict when **relapses** will happen or how often. Every person's MS is different and so is every relapse. Some people experience several in a year but others will go for many years between relapses.

As the number and timing of relapses is beyond your control, the best strategy is to manage them well when they happen.

Will I recover completely from a relapse?

People often make a very good recovery from a relapse, with complete remission. However, this is not always the case and around half of all relapses may leave some lingering problems, however slight.

This is because, if the damage to **myelin** is severe, then some symptoms remain, though

they may still improve over the following months.

Our understanding of how MS attacks the body is changing. MS specialists used to think that once a relapse was over the attack, the damage to your brain and spinal cord stops and no new damage was happening. But now we know that even when you aren't having relapses MS can still be causing damage.

This damage can be happening even if there are no signs of it that you might notice, such as a relapse. That's why treatment with a disease modifying therapy (DMT) should be offered to you as close to when you're diagnosed as possible.

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

If you think you're having a relapse, you should contact your GP or MS nurse (if you have one) as soon as you can.

Before they can say your symptoms are definitely caused by a relapse, they will need to check for other possible causes for them. They will probably ask you lots of questions about your symptoms and how they're affecting you, your general health and your activity over the last few days. They will also need to test for possible infections, such as bladder infections.

It's important that your neurologist knows you're having a relapse, as it may affect your eligibility for disease modifying therapies (DMTs). Your GP or MS nurse can pass this information on to your neurologist, if you're not able to.

If you're not in regular contact with a neurologist, you should still make an appointment to see your GP. They will be able to refer you back to a neurologist, if that's what you want.

What treatment can I have for a relapse?

Treatments include **disease modifying drugs (DMTs)**. Taking

a DMT can mean fewer and less serious relapses, and it could slow down your MS.

You'll find more on DMTs on page 34.

Some milder relapses won't need any special treatment (just keep on taking your DMT). You can speed up how fast you get over more serious relapses with a short course of **steroids**. These are taken as a pill or through a 'drip' that goes into a vein. Like any drug, though, steroids can have side effects. Speak to your GP, MS nurse or neurologist for more information about side effects.

Whether a relapse is treated or not doesn't make any difference to how much permanent disability it could leave you with. Rehabilitation after a relapse can help get you over it. This includes physiotherapy, occupational therapy, advice on what you eat and support at work and with help in your home.

See our booklet ‘Managing a relapse’ for more information on treating relapses.

Recovering from a relapse

How well you will recover from a relapse, and how long it will take varies from person to person. Relapses often last a number of weeks, and possibly even months. The worst of your symptoms will usually go away once the **inflammation** has gone down.

However, some symptoms may linger on. This is due to damage to the myelin coating or the nerve fibres themselves, which disrupts messages passing along them. Over time – particularly in the early stages of MS – your body may be able to repair some of this damage. As a result, you may find your symptoms continue to improve after the relapse is over.

Planning ahead

Putting a few simple things in place while you are in remission could make things easier for you and those around you if a relapse happens. Think about:

- A contact number (GP or MS nurse) who you can call for medical advice
- Do my friends or family know who to contact and what to say if I am taken ill? This might include informing your workplace or school as well as health or social care professionals
- In case I go into hospital, have I got a list of drugs that I usually take (for MS or any other condition), or any other details that might affect how I receive care?
- Setting up a power of attorney (PA) as someone could be temporarily unable to communicate their wishes while experiencing a relapse

Pseudo-relapses

Sometimes your symptoms might get worse for a short time without an increase in MS activity. This is called a 'pseudo-relapse'.

Pseudo-relapses are often caused by a rise in body temperature. This might be because of an illness or infection, exercise or simply being in a hot environment.

When your body temperature rises, this can slow down the

speed of messages transmitted along nerve fibres. If the myelin coating around the nerve fibres or the **nerves** themselves have been damaged, this slowing down can make your symptoms worse, or make old symptoms reappear.

These pseudo-relapses are not thought to cause long-term harm. Once whatever is causing your body temperature to rise has gone away, you should find your symptoms go away too.



Managing your condition

You should receive information about symptom management when you're diagnosed, but symptoms and needs change over time so you should also be offered a management care plan.

This should include a single point of contact, usually an MS specialist nurse, to coordinate care and help you and your family access the right health and social care services for you.

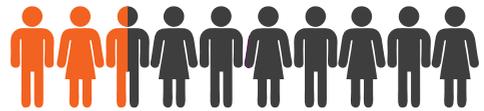
A range of health professionals including physiotherapists, occupational therapists, speech and language therapists, psychologists, dieticians, social care and continence specialists can help with symptom management. Your MS nurse or GP can refer you.

Treating symptoms

There are many treatments, including drugs, devices and therapies that can help with

symptoms, from muscle pain, stiffness, spasms and poor balance to continence issues, difficulties with speech, swallowing, sight, memory and thinking, and sexual function.

Drug treatments licensed over recent years include Fampyra (fampridine), a tablet that's been found to improve walking speed and ability by up to 25% in four out of 10 people.



and injections of botulinum toxin (commonly known as 'botox') for overactive bladder. There's also Sativex (nabiximols), an oral spray derived from cannabis, which can reduce muscle spasms.

Ask your MS nurse, neurology nurse, GP or neurologist about symptoms. Even if there are no drug treatments, a health professional can advise you on

appropriate therapies or coping strategies.

- Free access to Sativex and Fampyra, which is not deemed cost-effective by NICE, is limited across the UK. If you're having problems accessing licensed treatments, find out more about our Treat me right campaign at www.treatmerightms.org.uk

Self-management programmes

Tried and tested techniques are used to help you deal with MS challenges. Topics may include managing symptoms such as fatigue or pain, action-planning, problem-solving, exercise, healthy eating and relaxation techniques. See our website or ask your local MS Society group or MS nurse what's on offer near you.

Rehabilitation

Its aim is to help you maintain function, staying as active and independent as possible. It may involve helping you deal better

with fatigue, improving mobility, addressing continence issues, or tackling sleep problems or side effects from medication. It encompasses a multi-disciplinary approach, where you benefit from the input of several health professionals, depending on your needs.

“I try to walk as much as possible, resting when I need to. I know it's 48 steps to the bus stop and 103 to the shop. I always plan the quickest route because if I overdo it I'll fall and my legs become like rubber.”

Ronny

Local services

Your local MS Society group can tell you about the services in your area. These may include free or discounted exercise classes, care services, carers' groups, shop

mobility schemes, transport and disability schemes.

Quit smoking services

There's now good **evidence** that smoking can speed up the progression of MS. Ask your GP about your local NHS Stop Smoking Service or visit www.nhs.uk/smokefree

Lifestyle changes

Suitable exercise

Short bursts of moderate aerobic exercise, like walking or steady cycling, have been shown to help improve fatigue and quality of life in people with MS. Many people find resistance exercise (stretching, yoga and weights) less challenging. A physiotherapist can advise on the best exercises for you. There's a free downloadable Exercise and physiotherapy booklet and a free DVD, Exercising with MS, which you can order or watch online, plus a library of exercise DVDs. Details of how to order these can be found on page 38.

Healthy eating

Certain diets are promoted as effective therapies for MS but there's no clinical research that supports this. But a healthy, balanced diet will help you stay as well as possible. Find out more in our booklet Diet and nutrition.

“Pilates exercises are designed to build up core stability so they're ideal for us MSers, as it can help improve your balance and walking. When I get physio after a relapse the exercises I get given are always based on Pilates exercises, and I find they help my standing and walking.”

Dan

Therapies

Cognitive behavioural therapy (CBT)

This therapy, which focuses on specific, practical problem-solving techniques, can help you to manage fatigue, as well as dealing with anxiety and depression.

Cognitive rehabilitation therapy

This is designed to help combat the problems with memory, attention span or concentration that occur in between 50 to 60% of people with MS. It's provided by occupational therapists and psychologists in a group or on a one-to-one basis.

Relaxation

Some research suggests that relaxation techniques, including meditation and mindfulness, can help reduce fatigue, anxiety and stress and improve working memory, attention and planning abilities. The Mental Health Foundation charity has details of courses, including an online course that has been found to be effective in reducing stress, anxiety and depression.

Visit www.mentalhealth.org.uk for more information.

Complementary therapies

Some people report that hyperbaric oxygen therapy, in which you breathe in pure oxygen under increased air pressure, helps relieve symptoms. However, scientific studies don't support this, and there are some associated risks.

Many people find that other complementary therapies such as reflexology and massage can help with relaxation, and these are often available at MS therapy centres, spas and health clubs, or you can find details of qualified practitioners through the relevant professional bodies.

Always discuss treatment options, whether orthodox or complementary, with your GP, neurologist or other professional. Some, such as herbal remedies, may interfere with drug treatments. Find out more in our booklet *Complementary and Alternative Medicine (CAMs)*.

Disease modifying therapies (DMTs)

Disease modifying therapies (DMTs) are also called ‘disease modifying drugs (DMDs). They aren’t a cure, but they could make a big difference to your MS. DMTs offer many people with MS the chance to take more control of it and their lives.

Nearly all the DMTs we have at the moment only work with types of MS that have **relapses**. New drugs are being tested to see if they work against progressive (non-relapsing) types of MS. We hope the first one that works against primary progressive MS, ocrelizumab, will be available in 2017 or 2018.

Some DMTs are taken as tablets, some as infusions, or drips, and some as injections.

What could a DMT do for me?

DMTs won’t cure your MS and they can’t undo any disability you

already have. Tackling this is a top priority for research. But taking a DMT can mean you have:

- fewer relapses
- relapses that aren’t as serious
- a slow down in how fast your disability gets worse
- less build-up of damage (**lesions**) in your brain or spinal cord (seen on an **MRI scan**)

In fact, if treatment works very well there may be no signs that your MS is active at the moment. That means:

- you’re no longer having relapses
- your disability isn’t getting worse
- MRI scans show lesions in your brain have stopped growing and/or there are no new ones
- your brain isn’t shrinking any faster

All our brains get a bit smaller as we get older but with MS this can happen faster. DMTs can stop this for many people.

How do I get DMTs?

DMTs can only be prescribed by a neurologist or, in some places, by a consultant nurse.

Your MS specialist follows guidelines about which DMTs you can have. He or she will bear in mind:

- how many **relapses** you've had in the last year or two
- how bad they were
- have you tried another DMT but it didn't work for you
- how active your MS is

In the past guidelines said that to get a DMT you needed to have 'active' MS and this meant at least two relapses in the last two years. But **ABN** guidelines from 2015 say more and more MS specialists see 'active' MS as meaning you've had just one recent relapse and/or MRI scans that show new damage (**lesions**) in your brain.

DMTs available for relapsing remitting MS

The following DMTs are available for relapsing remitting MS (generic name for the drug, followed by its brand name, in brackets):

- alemtuzumab (Lemtrada)
- beta interferons (Avonex, Betaferon, Extavia, Rebif, Plegridy)
- daclizumab (Zinbryta)
- dimethyl fumarate (Tecfidera)
- fingolimod (Gilenya)
- glatiramer acetate (Copaxone)
- natalizumab (Tysabri)
- teriflunomide (Aubagio)

For more on DMTs check out our booklet **Disease modifying therapies (DMTs)** for MS. We also have factsheets for each drug at mssociety.org.uk/dmts

New words explained

Central nervous system – your brain and spinal cord. Nerves carry messages between the two that control how parts of your body work.

Immune system – how your body defends you against things that give you infections or diseases (like virus and bacteria). In MS this system goes wrong and it 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, making it swollen. When inflammation of the brain and spinal cord is left untreated it starts to damage it, leading to MS symptoms

Lesions (also called ‘plaques’) – areas of damage caused by MS in your brain or spinal cord. They slow down or stop messages travelling down nerves, affecting your control of parts of your body. Lesions can be seen on MRI scans

MRI scans – pictures of inside your brain or spinal cord made by ‘magnetic resonance imaging’. They show where MS is causing damage through inflammation and damage to the myelin around the nerves

Myelin – a fatty covering that protects parts of your nerves. When you have MS myelin is attacked by mistake by your immune system. This interrupts messages that travel along your nerves and that control parts of your body, causing the symptoms of MS

Nerves – bundles of fibres along which signals travel from your brain or spinal cord. These nerve signals control how parts of your body work and make sure your thinking and memory work correctly

Neurological symptoms – we talk about neurological symptoms when we want to describe symptoms you might have as a

result of the effect your MS has on your nervous system. Some of these symptoms include blurred vision, difficulty walking, weak muscles and fatigue.

Obese – being very overweight. Defined by the NHS as a body mass index (BMI) over 30 and over. Find out your BMI at www.nhs.uk/Tools/Pages/Healthyweightcalculator.aspx

Plaques – see lesions

Relapse – a flare up or attack of your MS when you get new symptoms or old ones get worse. Symptoms then go away, get less noticeable or they can become permanent

Scientific or clinical evidence
– we use the term evidence to describe when tests have been done to prove a (medical) claim does or doesn't work. Usually, the larger the test, the more reliable the proof is. When we say there is 'little evidence' we mean that there have been few tests and/or tests with a small number of persons.

Steroids – are used to reduce inflammation and make your immune system less active. They're man-made versions of the hormones you normally produce in your adrenal glands (two small glands that sit on top of your kidneys).

Further information

Library

For more information, research articles and DVDs about MS contact our librarian.

020 8438 0900

librarian@mssociety.org.uk

mssociety.org.uk/library

Resources

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

020 8438 0999

shop@mssociety.org.uk

[mssociety.org.uk/](https://mssociety.org.uk/publications)

[publications](https://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

(weekdays 9am–9pm, closed on bank holidays)

helpline@mssociety.org.uk

About this resource

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

If you have any comments on this information, please send them to: resources@mssociety.org.uk or you can complete our short online survey at surveymonkey.com/s/MSresources

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. Seek advice from the sources listed.

References

A list of references is available on request, and all cited articles are available to borrow from the MS Society library (there may be a small charge).

Contact the librarian on **020 8438 0900**, or visit mssociety.org.uk/library

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This resource is also available in large print and audio.

Call **020 8438 0999**
or email shop@mssociety.org.uk

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