Making Sense of MS

Multiple Sclerosis Trust MS

Relapsing remitting MS

What does it mean to be diagnosed with relapsing remitting MS?

Multiple sclerosis is a lifelong condition which affects the brain and spinal cord (the central nervous system). There are different types of MS and the type you're diagnosed with will depend on the pattern of your symptoms over time.

MS can be very broadly split into two types

- **relapsing remitting MS** – this is where new symptoms suddenly appear, or old symptoms reappear or become significantly worse, for a period of time. This is known as a relapse. Relapses can last anywhere between a few days, up to weeks or even months. In between relapses are periods of remission where you may have no symptoms, or your symptoms are relatively stable. Periods of remission can last from months to years until they're interrupted by a relapse.
- **progressive MS** – this is where MS symptoms gradually worsen and build up over time, known as progression. The rate at which symptoms become more severe varies; typically the changes are slow and gradual over a number of years, though for some it can be more rapid. There can also be periods of minor improvement or times when symptoms stay the same. Progression can occur from the outset of the condition (primary progressive MS), or it can develop following an initial relapsing remitting course (secondary progressive MS). You may also come across the term progressive relapsing MS (PRMS) where there is progression from the outset of the condition but also occasional relapses – this is an outdated term which is no longer widely used.

Each type of MS encompasses a wide range of experiences of the condition. Even with these definitions in place it can still be difficult to determine exactly what type of MS you have, particularly at the point of diagnosis and it may only become apparent over time as the condition develops.

This information is an introduction to relapsing remitting MS (RRMS) for those who are newly diagnosed. If you're not sure what type of MS you have, you might like to read this information alongside our information sheet on progressive MS. Keeping a diary, with notes on any new or worsening symptoms, can help your MS team to determine which type of MS you have if it's not initially clear.

Someone told me: "Remember that you've probably been living with this for some time. The only thing that's changed is that now you have a name for it." This really put things into perspective for me.

What is relapsing remitting MS?

The name reflects the pattern of symptoms which alternate between having relapses and being in remission.

Relapses are known by many other names including an attack, episode, flare up or exacerbation. When you're first diagnosed with MS it can be difficult to work out if you're having a relapse or not. This is because many MS symptoms can fluctuate day to day, so changes might be part of the everyday up and down pattern of MS rather than the start of a relapse.

To be classed as a relapse, any new or worsening symptoms must last for at least 24 hours. There mustn't be another reason why your symptoms may have worsened, such as having an infection or if your body temperature is raised. Also, a new relapse must occur at least 30 days after the start of a previous relapse. It can take a few days before you and your MS team are sure whether you're having a relapse or not.

Recovery from a relapse can vary widely. You may find that your relapse symptoms improve quickly, or it could be more gradual with your symptoms still improving three to six months later. Some symptoms might go away completely; but there is the possibility that some may only partially improve, remain unchanged, or become permanent.

During periods of remission, you may have no symptoms, or your symptoms could be relatively stable – although they may vary in intensity from day to day because of the fluctuating nature of MS.

For every 100 people diagnosed with MS, around 85 will be diagnosed with relapsing remitting MS. It is typically diagnosed when someone is in their 20s or 30s, although it can be diagnosed in children and older adults too. It's two to three times more common in women than men.

Other ways your MS might be described

Increasingly the way MS is described is changing. The following terms are being used more widely to describe what is happening at an individual level, at a specific point in time:

- **active** or **not active** – used in all types of MS to describe whether or not you're having relapses and/or if new lesions (characterised by inflammation and demyelination) can be seen on an MRI scan
- **worsening** or **stable** – used in people with RRMS following a relapse to describe whether their symptoms are worsening (incomplete recovery from a relapse) or stable (complete recovery from a relapse)
- **with progression** or **without progression** – used in people with progressive MS to describe whether symptoms are increasing or staying the same over a period of time.

MS is a really confusing condition. It helps to meet people who are going through the same thing as you. Information about support groups is invaluable.

Although you might think that active MS would only apply to someone with RRMS, it may also be used in progressive MS. Someone with SPMS may continue to have relapses, especially in the period when they're changing from a relapsing remitting pattern to a progressive pattern. Therefore, during a relapse or if inflammation is seen on an MRI scan, then their MS would be described as active. In PPMS, inflammation is seen to a lesser extent than in RRMS and SPMS, but it can be present – particularly in the first few years after diagnosis. Some people with PPMS also experience a single relapse.

After a relapse, if your MS symptoms return to the same level as they were before the relapse, your MS would be described as stable. If they've increased your MS would be described as worsening.

Relapse associated worsening or RAW (incomplete recovery from a relapse) and progession independent of relapses or PIRA (an increase in symptoms independent of relapses) are the terms used to describe the change towards a greater number and severity of symptoms that cause increasing difficulties.

What are the symptoms of relapsing remitting MS?

There's a wide range of possible symptoms which vary from person to person. At diagnosis you'll probably only have experienced a few of them and you won't go on to experience them all. The symptoms that you experience will depend on where MS has caused damage in your brain and spinal cord. This means that MS can be unpredictable, which can take some getting used to.

Some of the most common symptoms in RRMS around the time of diagnosis are:

- **problems with eyesight** – such as blind spots, double vision, or eye pain
- **altered sensations** – unusual feelings in the skin such as numbness, tingling or burning sensations, including a type of pain known as neuropathic or nerve pain
- **fatigue** – exhaustion which is out of all proportion to what you've been doing, it can be mental or physical tiredness
- **cognitive problems** – which might include problems with concentration, memory or planning.

Some symptoms of MS, such as fatigue and altered sensations, aren't always obvious to other people even though they may have a significant impact on your life. They're often referred to as invisible symptoms.

I take amitriptyline for nerve pain. It's helped considerably and has the added bonus of helping me sleep better too.

What treatments are there for relapsing remitting MS?

There's a wide range of treatment options available for individual symptoms. There are also drugs available to treat the underlying condition or change the course of the condition itself, known as disease modifying drugs, which may be appropriate for some people.

Symptomatic treatments

Symptomatic treatments help relieve the physical or mental symptoms of a condition. They don't treat the underlying cause or change the course of the condition itself. Symptomatic treatments for relapsing remitting MS include:

- **drug treatments** – such as medication for pain, spasticity and spasms, or bladder issues
- **therapies** – like physiotherapy to help with muscle stiffness, cognitive behavioural therapy for pain, anxiety or depression and occupational therapy to provide practical support to overcome any difficulties with day-to-day activities, so you can do as much as you can for yourself and live life as independently as possible
- **management techniques** – for example learning to pace yourself to minimise fatigue
- **rehabilitation** – which can improve day-to-day living if your symptoms are making this difficult. This will vary depending on your personal needs but might include services such as physiotherapy, speech and language therapy, cognitive rehabilitation therapy or you may be given aids and equipment by an occupational therapist that can help
- **complementary and alternative medicines (CAMs)** – for example acupuncture, Pilates and relaxation techniques such as mindfulness or meditation. These are treatments which fall outside conventional medicine but are generally accepted as being helpful in improving physical and mental wellbeing.

Disease modifying drugs

Disease modifying drugs (DMDs) work to decrease the attacks made by your immune system on your brain and spinal cord. The goal of disease modifying drugs in RRMS is to reduce the number and severity of relapses and slow down the build-up of disability, which can occur if you don't recover completely from a relapse.

There's increasing evidence that starting treatment with DMDs soon after diagnosis minimises the damage to your nerves and reduces disability progression. This helps you stay as well and active as possible in the longer term.

Your neurologist or MS nurse may raise the topic of DMDs but, if not, you could ask them whether they may be suitable for you, about the possible risks and side effects, and when to begin treatment. Although early treatment is recommended, you shouldn't feel pressurised into starting treatment before you're ready to make that decision.

The side effects of the DMDs sound scary when you first read about them. So far, the only downside I've experienced is flushing. To be honest the embarrassment of looking like a tomato for an hour a day is a small price to pay if it stops my MS progressing.

What happens in a relapse?

The immune system attacks the insulating layer around your nerves (myelin) in the central nervous system. This leads to inflammation along the nerves and the myelin can be damaged and stripped away (demyelination). These areas of damage are known as lesions. Messages passing along damaged nerves may travel more slowly, be interrupted, or may not get through at all. This can mean you suddenly experience new or worsening symptoms – a relapse.

Relapses can affect different areas or 'systems' of the body and your neurologist may describe your relapse according to how you are affected:

- **optic neuritis** – blurring of vision in one eye
- **sensory relapse** – persistent altered sensations in part of the body
- **motor relapse** – weakness in part of the body
- **cerebellar relapse** – loss of coordination
- **cognitive relapse** – affecting thinking and memory
- **mixed relapse** – where two or more of the above systems are affected.

As the inflammation calms down, the damaged myelin may be repaired (remyelination) to some extent, but messages may not pass along your nerves as quickly which is why some symptoms may persist.

Inflammation can cause lesions without resulting in a relapse. The damage may occur in a part of the central nervous system which doesn't lead to symptoms, or your brain may be able to adapt rapidly and re-route messages around an area of inflammation. These are known as silent lesions and can only be seen using MRI scans. These silent lesions are seen as an important marker of MS activity and a target for preventative treatment with disease modifying drugs.

When do relapses occur?

It's not possible to predict when, or how often, you'll have a relapse. Everyone's MS is different and so is every relapse. Some people have several relapses a year, but others go for years without having any. Some relapses may be more severe than others.

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

During pregnancy, most women find they experience fewer relapses, but the risk of relapse increases in the first few months after the birth. Pregnancy doesn't affect how your MS develops in the long term. If you're planning to become pregnant, or think you might be already, it's best to discuss this with your MS team or GP, as most medications aren't recommended during pregnancy.

Learn to listen to your body. Rest when you need to rest. Be kind to yourself and take help when offered.

What's not a relapse?

There are many reasons that your MS symptoms can get worse. It's unlikely that you're having a relapse if your symptoms improve after dealing with any of the following.

Infections – illnesses such as a cold, flu, stomach bug or bladder infection can cause symptoms to worsen. Take care of yourself as you usually would, such as resting, drinking plenty to avoid dehydration, taking suitable painkillers to lower a temperature and speak to your GP or MS team if you think you need antibiotics for a bacterial infection. Severe infections can trigger a relapse so, if you continue to feel unwell, contact your MS team or GP.

Heat or cold – if you experience temperature sensitivity, being too hot or cold may make your symptoms worse, so strategies to cool down, or warm up, to keep yourself at a more comfortable temperature may help.

Stress – feeling under pressure can make symptoms harder to live with. It's unlikely that you can remove all the sources of stress in your life but learning to identify what causes you to feel under pressure and finding ways that work for you to manage your stress levels can be helpful.

Tiredness – overdoing it can cause symptoms to increase, so it's important to try and pace yourself to avoid this. See if you feel better after taking some time to rest and relax.

Deconditioning – this is a loss of physical fitness that can be experienced due to a lack of exercise or long periods of inactivity such as bedrest. Your muscles become weaker and less toned, and your heart can't pump blood around the body as efficiently as it did before. As a result, any physical activity wears you out more quickly. This can happen in MS if you can't get around, or exercise, as easily as you used to and can be mistaken for your MS worsening. Deconditioning may respond to physiotherapy, regular exercise, or physical activity such as gentle stretches, walking upstairs or doing household chores.

Periods – some women find that their symptoms get worse in the days before their period. Usually, they feel better once bleeding has started.

What should I do if I am having a relapse?

If you think you're having a relapse, and your symptoms are mild, you might choose to wait and see if they improve. However, if you experience sudden difficulties, such as with your eyesight or mobility, it's more important to contact your MS team in case you need treatment.

Every MS service works differently so check with your MS nurse or neurologist in advance about what to do if you think you may be having a relapse. Some MS services have relapse clinics while others will discuss your concerns by phone or email.

It's important to tell your MS team about a relapse even if you're not on treatment and feel like you're generally managing well. This might be an opportunity to raise with them whether you want to continue as you are, or if you want to explore starting treatment with a disease modifying drug. If you're already on a DMD, a relapse could be an indication that your current DMD isn't keeping your MS under control, and you might want to discuss whether to continue with this treatment or look at switching to an alternative. Your team need to know about any relapses you have so they can give you the best information to help you make these decisions.

It can be worrying when symptoms feel worse but, if in doubt, contact your MS team. With time, you'll develop a better feel for whether you're having a relapse or not.

I have had IV steroid treatment for relapses in the past, which helped to calm everything down.

Treating a relapse

Not all relapses need treatment as symptoms will generally improve on their own. However, if your relapse is having a significant effect on day-to-day activities, such as using your hands or walking, you may be offered a short course of high dose steroids. Steroids reduce inflammation and can help speed up your recovery, but they won't change how much you recover in the long term.

Ideally, steroids should be started as soon as possible after your relapse has been confirmed. You will typically be given 0.5g of methylprednisolone daily as pills for five days, or 1g of methylprednisolone daily through a drip (intravenous infusion) for three to five days.

The side effects of steroids are usually mild and go away quickly once you finish the course of treatment. However, some people can feel quite unwell taking them, so it's best to talk it through with your MS team so you can decide on the best course of action for your situation. The most common side effects include a metallic taste, an upset stomach, difficulty sleeping and mood changes. If given too often, steroids can cause thinning of the bones, so treatment is usually limited to a maximum of three courses a year. Some neurologists prefer not to treat relapses with steroids at all.

Recovering from a relapse

Recovering is often a case of waiting to see what happens. Be kind and don't push yourself too hard while you're recovering. The following are some things to think about.

Home life – consider asking for extra support from family and friends. This might be help around the house or with collecting the kids from school. This can be hard if you're used to being independent but it's likely friends and family will be happy to help.

Working and studying – you may need to reduce your hours or take some time off. With a diagnosis of MS, the Equality Act entitles you to ask for reasonable adjustments to help you so it's worth speaking to your manager, human resources/occupational health team, or your education provider about the support and adjustments they can provide. This might be simple changes such as providing you with a car parking space nearer the building entrance if you're finding walking more difficult, starting work earlier/later to help with fatigue, or if you're having cognitive issues perhaps someone else could take notes for you in a lecture so you can focus on what is being said.

Feeling emotional – relapses are usually unexpected and can leave you feeling overwhelmed. This can be made worse if you're not sleeping well or by some medications, such as steroids. These feelings are likely to go away as you recover from the relapse, but if not, discuss them with your GP or MS team.

Your MS team may arrange a follow-up appointment to see how you're doing. You may have developed new symptoms during your relapse or been less active which can lead to deconditioning (muscle weakness). Specialist advice and support can help you identify any further treatment options to help you get back on track with your life.

I'd say don't try and make too many lifestyle changes at once. You're told to follow a healthy balanced diet, hard if you have a sweet tooth. You're told to exercise, hard if you don't enjoy it. Take it at your own pace.

Living with relapsing remitting MS

Living with relapsing remitting MS can mean living with a degree of uncertainty. A change in your symptoms doesn't always mean that you're going to have a relapse, or that your MS is getting worse, but you may be concerned about how well you'll feel on a particular day.

People living with MS say the best approach is to try and put your worries aside, live each day as it comes and deal with any symptoms or relapses if, and when, they happen.

Day-to-day living

It's important to look after your general health. This includes your physical health and your mental wellbeing. Eating a well-balanced diet, keeping your brain and body as active as possible, drinking sensibly to reduce the health risks from alcohol and not smoking can help you stay well. Taking these steps can also help manage some symptoms and reduce the risk of relapse triggers, such as severe infections. It's also important to go for all the usual health checks, such as cancer screening, and for any vaccinations you're offered. Taking good care of yourself will help you continue to do the things you enjoy, as well as the things you have to do.

You may be concerned that your RRMS will get worse very rapidly but this rarely happens. Some people find that their MS stays the same for many years or even decades.

Many people who are initially diagnosed with RRMS find that over time, the pattern of their symptoms change. They find they have fewer or no relapses, but their symptoms gradually worsen and accumulate over time, having more of an effect on everyday life. Their MS will be reclassified to secondary progressive MS (SPMS) to reflect this change.

MS isn't a terminal condition and it's unlikely to be a direct cause of death, but you will live with it for the rest of your life. If you're more severely affected, you might be more susceptible to developing infections or complications that affect your swallowing, breathing or circulation. So, it's important to keep as well as you can and seek treatment promptly when needed.

Most people with MS live into old age, although lifespan, on average, is about six years less than the general population, but this gap appears to be getting smaller all the time.

Diaries and reviews

It's recommended that you have a review of your MS once a year, this might be with your neurologist or your MS nurse, but if you have a relapse or are taking a DMD you might be seen more often. It can be good to look back over the previous year before your review to see if you need to discuss anything in particular with your MS team.

You might find it helpful to keep a simple diary to record your symptoms and any relapses. You could make a note of any new or worsening symptoms, when they happened and whether they went away or have persisted. You could include when you started (or stopped) any medication or treatment, whether you experienced any side effects and how much it helped relieve your symptoms.

I live very well with RRMS 6 years on from diagnosis. Make the most of your MS nurse and consultant. Don't be afraid to ask the silly questions. Make a note of your symptoms in daily life as you always forget during appointments.

A diary could be paper-based or you may prefer to use an app on your phone. It can be useful to use something that's easy to take with you to your appointments so you can share a summary with your MS team. They can then see at a glance what's happening with your MS and support you better. You can also add the dates and any outcomes of appointments in your diary so you have a record of what was said.

If you think your review is overdue, or you've experienced significant changes to your MS, you should consider contacting your MS team or GP to arrange to see them rather than waiting for the system to contact you.

Is there disability with relapsing remitting MS?

You may be concerned that relapsing remitting MS will impact on your ability to do what you want, when you want to. It's natural to worry about whether it will change your physical capabilities and if you will become disabled.

For many people with MS the changes occur slowly over many years. It doesn't mean that you will inevitably experience a rapid decline in your health or capabilities. However, regrettably some people experience a highly active or rapidly evolving form of RRMS. This is where you have frequent relapses that you don't fully recover from, which can lead to more significant disability.

What is disability?

Disability means different things to different people. The medical model of disability is around having a physical or mental condition that has an impact on your ability to do daily activities. This might relate to something as simple as having difficulty fastening a button, or putting in earrings, because of numbness in your fingers. Although this could be classed as a disability, many people who experience this wouldn't consider themselves disabled even though this symptom does impact on their lives.

Typically people consider disability to be difficulties with mobility, and tend to look for outward symbols such as a walking aid or wheelchair – unsurprising given that a wheelchair symbol is often used to represent disability. But disability is not just about mobility, it can include less visible symptoms such as fatigue or pain.

A social model of disability has also been developed which, rather than focusing on your condition, considers the barriers in wider society and your environment which effectively disable you. This might be negative attitudes, lack of understanding about your condition, or physical barriers such as steps which might prevent you accessing parts of a building, or a lack of public toilets making it difficult to go out if you have bladder issues. This model highlights the need for society to change to create equality, more independence and choice for everyone.

I have made a conscious effort to get fitter. It's important to me to be the best I can be for as long as possible for my children.

Will I become disabled?

As everyone's MS is different, it's not possible to predict how much your MS will affect you. It will be up to you to choose how you define yourself and whether you consider how MS has affected you to be disabling. Because the symptoms of MS can vary so much, you might have different views of yourself at different times.

Often living with relapsing remitting MS can mean finding different ways to enable you to carry on doing the things you enjoy. For example, you might choose to sit on a stool or chair to prepare food or do the ironing – this can help if you have balance issues, or it can be a way to conserve energy if you have fatigue which could mean you can still see friends or do some exercise later in the day.

Getting support

Although the concept of being disabled may feel uncomfortable or inappropriate, it can help you access support. The Equality Act covers you as soon as you're diagnosed with MS, even though you may not see yourself as disabled. It covers both physical difficulties and symptoms that affect your thinking.

This can be particularly helpful at work, for example if you need any adjustments made to be able to carry on with your role. This might include allowing you to return to work by gradually increasing your hours after a relapse or, if heat makes your symptoms worse, allowing you to sit in a cooler area of the office.

If you do have extra care or mobility needs as a result of living with MS, there may be benefits, grants or other financial support available to you. Some benefits are awarded based on the impact of your MS rather than being linked to your level of income or savings.

Going forward

Being diagnosed with relapsing remitting MS sets you on a lifelong journey. It will take time to learn about your MS, how to manage it well and to become your own expert.

None of us know what life has in store for us. It's good to live in the here and now and make the most of today. Try not to focus too much on what might happen or assume that MS will have an effect on a particular aspect of your life. This time and energy could be spent in a more positive way on something that's important to you right now.

Notes...

Got a question about MS?

Ask our Helpline Team on 0800 032 3839
or email ask@mstrust.org.uk

Scan to support the MS Trust

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Further information

Making Sense of MS information sheets:

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Making Sense of MS

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

MS Trust Information Team
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