Making Sense of MS

Multiple Sclerosis Trust MS

Progressive MS: an introduction

What does it mean to be diagnosed with progressive MS?

Multiple sclerosis is a lifelong condition which affects the central nervous system (the brain and spinal cord). 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

- **progressive MS** – this is where MS symptoms gradually worsen and accumulate 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.
- **relapsing remitting MS** – this is where new symptoms suddenly appear, or old symptoms reappear or become significantly worse, for anywhere between a few days up to weeks or even months. This is known as a relapse. 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.

Each type of MS encompasses a wide range of experiences of MS. 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 progressive MS 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 relapsing remitting 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.

What is progressive MS?

Progressive MS is a complex condition that varies widely from person to person and doesn't follow a set pattern, but the main feature is symptoms gradually worsening over time. However, there are clinical differences seen amongst people with progressive MS and it can develop in different ways, so definitions have been devised to try to broadly group individuals to reflect these differences.

I found it very scary at first, thinking tomorrow will always be worse than today. You have to give yourself time to get used to it and take one day at a time.

Traditionally progressive MS has been divided into the following types:

- **primary progressive MS (PPMS)** – where progression has occurred primarily from the outset of the condition
- **secondary progressive MS (SPMS)** – where progression has developed following, or secondary to, an initial relapsing remitting course
- **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, but you may come across it.

Progressive MS is typically diagnosed when people are in their 40s or 50s. Comparing primary progressive with secondary progressive MS, the age of onset is similar, so someone with primary progressive MS tends to develop symptoms at around the same age that someone with relapsing remitting MS typically moves into the secondary progressive stage of their MS.

A diagnosis of progressive MS is often a clinical diagnosis – based on your medical history and the symptoms you're experiencing, rather than on diagnostic tests. A neurologist might see a pattern of worsening symptoms but there might not necessarily be evidence of more lesions (demyelination and inflammation) on an MRI scan. Instead, the pattern is a move to a slow and progressive loss of the nerve cells themselves (neurodegeneration) which is thought to contribute to the nature of progressive MS.

Primary progressive MS

For every 100 people diagnosed with MS between 10–15 will be diagnosed with primary progressive MS. In PPMS symptoms gradually increase from the outset of the condition and it's rare to have any relapses. Equal numbers of men and women are diagnosed with PPMS.

Secondary progressive MS

Many people initially diagnosed with relapsing remitting MS go on to develop a progressive form of the condition. This is when the severity and frequency of relapses decrease or even stop altogether, but the level of permanent change in symptoms increases over time. This transition from RRMS to SPMS typically happens between 10–25 years after diagnosis. Secondary progressive MS is more common in women than men.

Only a small number of people are diagnosed at the outset with secondary progressive MS. This may happen if the initial relapsing remitting phase went undiagnosed, perhaps because lesions in the brain or spinal cord didn't lead to symptoms (silent) and were only subsequently seen on an MRI scan when current symptoms were investigated; or any relapses were so mild their significance was overlooked at the time or were attributed to another cause.

Don't think too far ahead because the only thing that's certain is things change. Don't frighten yourself with worst case scenarios.

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** – these terms are 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 to describe whether their symptoms are worsening or staying the same following 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.

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, so 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. In these circumstances PPMS would be described as active.

What are the symptoms of progressive 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.

For many people with progressive MS, the first symptom they experience is difficulty with walking. This might be stiffness, weakness or a heavy feeling in your legs which gradually gets worse and can lead to problems such as tripping on kerbs or when going up steps. You might also experience unsteadiness or problems with your balance and coordination which can contribute to walking difficulties.

Bladder and bowel issues, such as difficulties with going to the toilet or needing to go more often, are also common. They may also be linked to sexual problems such as maintaining an erection, loss of desire or less sensation in your genital area.

These symptoms are commonly seen together as they're all caused by lesions in the spinal cord.

I have hope that something more can be offered in the future to promote remyelination.

Some other common symptoms are:

- **fatigue** – exhaustion which is out of all proportion to what you've been doing, it can be mental or physical tiredness
- **spasticity and spasms** – stiffness of the muscles
- **cognitive problems** – which might include problems with concentration, memory or planning
- **emotional difficulties** – feelings of anxiety or altered mood
- **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.

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.

What treatments are there for progressive MS?

Often people with progressive MS are under the impression that there aren't any treatments for them. This is not true. There's a wide range of treatment options available for individual symptoms and, for some people with early or active progressive MS, disease modifying drugs may be appropriate.

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 progressive MS include:

- **drug treatments** – such as medication for pain, spasticity or bladder issues
- **therapies** – like physiotherapy to help with muscle stiffness, or cognitive behavioural therapy for pain, anxiety or depression, or 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.

I do a little exercise every day which makes me feel a bit more in control and hopefully keeps my muscles strong.

Disease modifying drugs

Disease modifying drugs (DMDs) treat the underlying condition, or change the course of the condition itself. The majority of DMDs available for MS aim 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. Until recently, DMDs were only used in people with MS who experience relapses. However, a small number of DMDs are now available for some people with progressive MS to slow down disability progression.

If you have SPMS, you may be offered a DMD if you're still experiencing relapses, or if your MS is showing signs of inflammatory activity on an MRI scan. This is where new or growing areas of damage (lesions) can be seen on the scan.

If you have PPMS, you may be eligible for a DMD if your MS is active, you've had the condition for 15 years or less (early), and you can walk at least 20 metres (with or without a walking aid).

If you have progressive MS and you're not experiencing relapses or your MS isn't active, then it's unlikely you'll be offered a DMD.

Living with progressive MS

Living with progressive MS can mean living with a degree of uncertainty. MS symptoms can sometimes get more or less intense, or fluctuate, over time. A change in your symptoms doesn't always mean 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 symptoms 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. 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 will help you stay well and manage some symptoms. It's also important to go for health checks, such as cancer screening, and any vaccinations you're offered. Taking good care of yourself will help you to continue to do the things you enjoy, as well as the things you have to do.

You may be concerned your MS will get worse very rapidly, but for most people the changes are very gradual over a number of years. MS isn't a terminal condition and it's rarely 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. This gap appears to be getting smaller all the time.

Before appointments I note the dates and duration of any symptoms and take a list of things to ask. I use the notes function on my phone when seeing my MS nurse.

Diaries and reviews

It's recommended that you have a review of your MS once a year but if you have a substantial change in your symptoms 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 keep a record of your symptoms. 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.

A diary could be paper-based or an app on your phone. It can be useful to use something that's easy to take 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, consider contacting your MS team or GP rather than waiting for the system to contact you.

Is there disability with progressive MS?

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

Although progression does mean that disability will continue to increase over time, for many people it will occur slowly over many years and doesn't mean that you will inevitably experience a rapid decline in your health or capabilities. A study in Canada that looked at progression in PPMS found that although 1 in 4 of the group needed assistance to walk seven and a half years after their symptoms began, 1 in 4 were still able to walk unaided after 25 years. However, regrettably for some people, MS can lead to significant disability.

What is disability?

Disability means different things to different people. The medical model of disability relates to a physical or mental condition and its impact on your ability to do daily activities. This might be 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.

Regular breaks and prioritising things you want to do, whilst accepting your limitations is important.

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.

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 progressive MS can mean finding a slightly different way 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 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. Social care services can carry out an assessment if you need support to help you maintain your independence.

Going forward

Being diagnosed with progressive 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.

Got a question about MS?

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

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Further information

Making Sense of MS information sheets:

About MS

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Information on our website:

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

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