my MS roadmap

Symptoms and diagnosis

This resource is designed to help you navigate conversations with your healthcare team and better understand MS; from diagnosis, through to starting treatment, and beyond.

How to use this guide

Within this document, you will find:

- Questions you may like to ask your healthcare team
- Common misconceptions clarified
- Key terminology explained in plain language

This document focuses on symptoms and diagnosis; however, everyone's care pathway is different, so feel free to explore the different **myMS roadmap** documents, for different stages of MS, at your own pace, and in any order you like.

Diagnosis

The symptoms of MS can be similar to other conditions, so it can be hard to reach a diagnosis quickly. Learn more about what you can expect and how you can better prepare for your next steps below.

Questions to ask

Why can it take so long to confirm a diagnosis of MS?	Diagnosing MS can be difficult as many MS symptoms are also common in other health conditions. This means that it can take time to confirm that your symptoms have been caused by MS rather than any other health condition.
How can I prepare for a future with MS?	The treatment and management of MS has improved dramatically over the last decade, and people with MS are usually able to live long and full lives. However, some adaptations to your lifestyle and home may be needed to help you to keep doing the things that matter most to you.
How can I ensure I am still able to work and socialize?	Having an open, positive conversation with your doctor about your priorities for the future can really help them to identify and guide you towards strategies that could help you to maintain your lifestyle as long as possible

What can I do, other than take medication, to help manage my health in the long term?	Looking after your physical and mental health, as well as leading a healthy lifestyle is very important. There may be specific lifestyle choices that are more important to implement early on, in order to improve or maintain your lifestyle in the future; these can be discussed with your doctor.
What does ‘progressive’ mean?	You may hear your doctor talk about MS as a ‘progressive disease’. This is not necessarily the same as being diagnosed with ‘progressive MS’ but refers to the fact that your MS is always changing. Your doctor may be able to recommend some resources that will help you better understand the difference.
What should I do now that I have an MS diagnosis?	Getting a diagnosis of MS can be overwhelming, and it’s not uncommon to feel confused or left in the dark. Asking questions, such as ‘what should I do now?’, can help you to feel more in charge and remind your doctor to keep you informed along the way.
Where should I look for reliable information about MS and how to manage it?	There is a huge amount of online information about MS; the volume can be overwhelming, and not all of it is accurate. Your doctor will be able to guide you to information and resources that have been developed or validated by experts – both healthcare professionals and other people living with MS.

Common misconceptions

MS only affects white people	MS is most common among white people, but it does also affect those from other racial and ethnic background and communities. One study in the UK looked at the ethnicity of people with MS and found over 25% to be Black and around 14% to be South Asian.
MS is caused by physical trauma or mental stress	Although physical trauma and stress may trigger symptoms in someone with MS, they aren't necessarily direct causes. MS does not occur as a result of something you've done.
MS only affects young women	Most people with MS are diagnosed between the ages of 20 and 50 years. Men account for 1 in 4 cases – that's around 25%. In addition, around 1 in 10 people with MS are diagnosed in childhood or teenage years, and around 1 in 20 are diagnosed over 50 years of age.
Each person's pathway with MS is the same	Everyone's experience with MS is different. Your symptoms are dependent on where in your brain the nerves become damaged, and so sometimes it can be difficult for doctors to predict how your MS might change over time. However, it is important to be open and honest with your MS team; the more you share, the better they can support you with your particular MS journey.

Fatigue is just tiredness	Fatigue is one of the most common symptoms for people with MS. Unlike the everyday tiredness that you might feel after a busy day, fatigue can leave you feeling exhausted out of proportion to your activity – a night’s sleep may not leave you refreshed. This is totally normal. Your doctor can help you find ways to cope, such as how to pace yourself and how to plan, prioritize and delegate tasks.
Having MS means I will have to give up work	Although some people with MS may find their work more difficult after being diagnosed, you are entitled to reasonable workplace adjustments. For example, greater flexibility in working hours, having a quiet area for rest nearby, or working from home. You cannot get fired for having MS and there are tools to support explaining your needs to your employer.
MS will be passed onto my children	Although it is more likely to see MS develop in an individual who has a biological relative with the condition, MS is not typically considered a hereditary condition; however, investigations are ongoing.

Useful terminology

Disease-modifying therapy (DMT)

A DMT may work to change the course of your MS over the long term, to reduce the severity and number of relapses you experience, and to slow accumulation of disability. There are a growing number of effective DMTs available, and a variety of other medicines and non-drug treatments can be used to treat or alleviate symptoms.

Multiple sclerosis (MS)

MS is a neurodegenerative autoimmune condition that develops when your own immune system mistakenly attacks healthy parts of your body; in this case, the protective coating called myelin that surrounds your nerves and helps them to function properly. It is usually accepted that there are three main types of MS – relapsing-remitting (RRMS), primary progressive (PPMS) and secondary progressive (SPMS) – although you may also hear it described as ‘active’ or ‘smoldering’ too.

Primary progressive MS (PPMS)

PPMS is the least common type of MS, affecting about 10-15% of people with MS. It is characterized by a worsening of symptoms from the beginning, without early relapses or remission periods.

Progressive MS

Progressive MS is a type of MS where symptoms gradually worsen over time, without periods of remission in between. MS may be progressive from diagnosis (primary progressive MS) or may become progressive after a period of relapsing-remitting MS (secondary progressive MS).

Progression

Progression in MS can be difficult to define and is not necessarily the same as being diagnosed with ‘progressive MS’. Instead, it refers to the fact that your MS is always changing. These changes might be the development of a new symptom or the worsening of existing symptoms and are usually independent from a relapse.

Relapse

A relapse (also sometimes called an 'attack', 'exacerbation' or 'flare') is a short period of time (at least 24 hours) in which you experience new or worsened symptoms. These symptoms then get better or even disappear again. If symptoms get better but do not fully go away, the impact this has on you is called residual disability.

Relapsing-remitting MS (RRMS)

RRMS is the most common type of MS, affecting around 85% of people with MS. It is characterized by the person experiencing relapses (development of new or worsening symptoms), followed by periods of recovery or ‘remission’ when symptoms get better or even disappear again. If they get better but do not fully go away, the impact that this has on you is called residual disability.

Secondary progressive MS (SPMS)

Some, but not all, people originally diagnosed with relapsing-remitting MS, may progress to SPMS. This means that their disease course has changed, and rather than experiencing relapses, their symptoms now gradually worsen over time, without periods of remission in between.