my MS
roadmap

Starting treatment and changing treatment

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
- **Terminology** explained in plain language
- **Common misconceptions** clarified

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.

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Starting treatment

Starting treatment for your MS can be a daunting time, and you are likely to have lots of questions for your healthcare team. Make sure you get the most out of these conversations by reading through the content below.

Questions you might like to ask

How do I take this medication?	Therapies for MS come in a number of forms and dosing routines. They may be oral (taken by mouth), injectable or infusions (delivered directly into the bloodstream). Your doctor will be able to talk you through exactly how, and when, to take your particular medication.
I have just been diagnosed with MS and I am feeling generally OK; do I really need to start medication?	MS is a ‘progressive’ disease, which means that the symptoms you experience may change over time. Taking a disease-modifying therapy can help to prevent or reduce the severity and number of any future relapses you may experience, and slow any accumulation of disability. It is generally accepted that the earlier you start, the better the results.
What effects can I expect to see from taking this medication?	MS is often managed by a variety of treatments. Some are intended to change the long-term course of your disease (disease-modifying therapies), whilst others may be shorter-term solutions to help with a particular symptom. It can be helpful to understand which is which in order to manage your expectations, and also be aware of any possible side effects.

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What should I do if I’m not happy with my medication?	Unfortunately, sometimes a treatment may not provide the results you had hoped for, your circumstances may change or you may experience side effects. Being open and honest with your doctor is important to help them find the right treatment for you. It is important to never stop taking your medication without consulting with your doctor first.
What types of disease-modifying therapy can and can’t I have, and why?	Not all disease-modifying therapies are suitable for everyone. Based on the evidence from clinical research trials, each one will be approved for certain types of MS. Your doctor will be able to make a recommendation about what might be the best fit for you.

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Common misconceptions

Everyone experiences side effects from their disease-modifying therapy	All drugs, even those you buy without a prescription, can cause adverse events or ‘side effects’ because everyone’s bodies react differently to things in our environments; not all people will experience side effects the same way, and different people may experience different side effects.
I can’t change my disease-modifying therapy once I’ve started	Everyone’s bodies react differently to different medications. If you start a disease-modifying therapy and find you are experiencing side effects, it is not as effective as hoped, or your circumstances change (e.g. you want to start a family), you can speak to your doctor about switching to something that may work better for you.

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Treatment change

There are many reasons why one particular disease-modifying therapy might not be quite right for you, but this doesn't mean that another one won't be a better fit. Read the content below to help prepare for any conversations with your healthcare team about making a switch to your treatment plan.

Questions you might like to ask

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.
Why is my treatment not working?	There is no 'one-size-fits-all' approach for treating MS; everyone's experience is different and there are a number of reasons why one particular drug might not be right for you. This does not mean that something else won't be more effective. You should speak with your doctor about the options available.

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Common misconceptions

I am not eligible to take part in clinical trials.	If you and your doctor are thinking about changing your disease-modifying therapy, one option could be to participate in a clinical trial for a new medicine in development. Different trials will look for different types of people, so if you would be interested in taking part in research, speak to your doctor to find out what options might be available to you.
Once one MS treatment does not work, the others won't either.	Each disease-modifying therapy works in a different way and has different benefits and risks, so just because one doesn't work for you, it doesn't mean that another one won't. You can speak with your doctor to find the right one for you.
There are no management or treatment options for secondary progressive MS	While some medications may not be appropriate if you have secondary progressive MS, there are now many complementary and alternative medicines, and other treatment options available. Your doctor will be able to provide more information about these.
Treatment success is measured and defined by MRI activity	MRI scans can indicate whether a treatment is having an effect on your lesion load; however, a 'successful' treatment is different for everyone. Success may be based on whether your symptoms and side effects are manageable, your quality of life is stable or your treatment burden is acceptable (e.g. if you are finding the number of hospital visits exhausting). Be honest and open about what is important to you.

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Useful terminology

Adverse event or side effect

An adverse event is an unwanted change in your health (such as a new symptom), which is experienced after you have taken a medicine or non-drug treatment. If this happens, you should tell your doctor immediately, as they will need to work out whether the change is related to your drug, your MS or something else.

Clinical trial

A clinical trial is a research project that investigates the effect of a treatment (e.g. a drug, surgical procedure or diet) or device (e.g. a pacemaker) to understand whether it is safe and effective.

Complementary and alternative medicines (CAMs)

Between 1 in 3 and 1 in 2 people with MS use at least one CAM regularly, such as aromatherapy, herbal medicine, or mindfulness and meditation. CAMs can offer direct medical benefits, alleviate stress, or offer psychological help. Always tell your doctor if you plan to use a CAM as some can interact negatively with your MS therapies.

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.

Magnetic resonance imaging (MRI)

MRI scanning is a medical imaging technique that uses magnetic fields to create an image of your brain or spinal cord (or another part of your body). MRIs are often used to diagnose MS as they allow your doctor to see if you have developed any demyelinating lesions, which appear as white or black spots on the scan, depending on the type used.

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.

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Relapsing-remitting MS (RRMS)

RRMS is the most common type of MS, affecting around 85% 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.

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