my MS
roadmap

Family, work life and planning for the future

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 family, work life and planning for the future; 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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Planning for the future

Although it can be a tricky subject to raise, having an open conversation about what the future might bring could help you to develop strategies to maintain your lifestyle. Read the content below to learn how you can start creating your own personal plan.

Questions to ask

Are there ways to work on or improve my cognition to help reduce the impact on my day-to-day life?	Fatigue is one of the most common factors reported by people with MS as affecting their cognition. There are steps and adaptations you can make to improve your cognitive reserve and manage your long-term cognition; discuss your options with your doctor.
What adaptations can I make in my home life to help me as my MS progresses?	Small adaptations to your daily life can have a big impact in the long run. These may be changes to your car, such as switching to an automatic vehicle, or adjustments around the home, such as installing a second banister rail on the stairs to help you balance. Having these conversations with your doctor can help you plan and maintain your lifestyle as long as possible.
What can I do, other than taking a disease-modifying therapy, to maintain my health in the longer term?	A healthy lifestyle can positively impact your MS. Eating healthily, maintaining regular exercise, reducing alcohol intake and not smoking are all positive steps to take, alongside managing your stress levels. Complementary therapies may be helpful for making these changes. You should talk to your doctor to understand the options available to you.

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Common misconceptions

I can’t do anything to slow my progression	In addition to taking your disease-modifying therapy (DMT), a number of lifestyle changes may positively impact your MS symptoms, including changing your diet, stopping smoking or introducing regular exercise. You should speak with your doctor about the options that might be most appropriate and feasible for you.
I will have to stop work and hobbies because of my MS	As time goes by you may find that your MS changes and progresses, but this does not necessarily mean you need to stop doing the things you love. Having an open conversation with your doctor about priorities for the future can really help them to identify and guide you towards strategies to help maintain your lifestyle as long as possible.

Family and work life

Many people with MS are concerned about how their MS may affect their family and work. Read the content below to learn how you could be supported through these challenges.

Questions to ask

How can I tell my employer about my MS? Do I have to tell them?	You don't have to tell your employer about being diagnosed with MS, unless it will affect your ability to work and perform. However, it might help your employer to make any reasonable workplace adjustments and support you in the long run. You cannot get fired for having MS and there are tools to support you with explaining your needs to your employer.
What kind of reasonable adjustments can I ask for at work?	There are steps you can take to reduce the impact of your MS on your work and make your working environment more comfortable. These may include greater flexibility in your working hours or allowing you access to a quiet place for rest. Your doctor can help you find reliable sources of information about your employment rights and support you having these conversations.
Will I have to stop driving?	Many people with MS are concerned about whether their MS means they will have to stop driving. The good news is that most people with MS continue to drive as before. Sometimes you may need to make adjustments, for example switching to an automatic vehicle. Speak with your doctor about how you can make long-term preparations for driving with MS.

How can I explain my MS to my children?	While there isn’t a perfect way to explain your MS, you know your family best and when the right time and place might be to do this. Your doctor can help you plan what you might want to say and point you in the direction of useful resources to help you explain.
Will my MS affect me having children?	People with MS generally do not have more difficulty conceiving than people without MS. However, some disease-modifying therapies (including those taken by the father) are not recommended in pregnancy. You should tell your doctor if you are planning to have a baby or have become pregnant.
How might pregnancy affect my MS symptoms?	It is perfectly normal to be concerned about how your MS might be affected during pregnancy. Interestingly, some studies show that women may have fewer relapses during pregnancy. However, you may want to speak to your doctor about how to manage symptoms such as fatigue, balance, back pain or bladder control.

I am already on an MS treatment and want to start a family. Can I keep taking my MS medication during pregnancy and breastfeeding?	Many disease-modifying therapies are not recommended for use during pregnancy and breastfeeding, and so you may be advised to stop taking your treatment before you try to conceive. However, this does not apply to all disease-modifying therapies, and your doctor will consider the balance of risk to you and your baby in order to find the best solution. You should tell your doctor if you are planning to have a baby, have become pregnant, or plan to breastfeed.
I am not on an MS treatment yet and want to start a family. Should I not start a disease-modifying therapy?	You should let your doctor know you want to start a family before you try to conceive or begin treatment. Your doctor can discuss which treatments may be right for you.
What will happen after I've had my baby?	Similar to how your body changes during pregnancy, your body changes again after birth. This is true whether or not you have MS. You may be more tired and so it will be important to consider whether you might need additional support. Speaking with your doctor about what to expect can help you put plans in place, such as asking family and friends to help out once you are home with your baby.
Where can I go for support with managing young children?	Managing young children can be exhausting for anyone, regardless of having MS. However, some of your MS symptoms may makes things more difficult. Talk with your doctor about how you can plan and manage your day-to-day activities to help alleviate some symptoms, such as fatigue.

Common misconceptions

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.

Useful terminology

Cognition

Cognition refers to all sorts of 'thinking' processes, such as attention, learning, reasoning, memory, understanding, planning and making decisions. About half of people with MS experience changes in their cognitive abilities. Sometimes people with MS describe the experience as having 'brain fog', when they may be struggling to organize their thoughts.

Cognitive reserve

When parts of the CNS are damaged by MS, creating lesions or scars, you do not always develop a new symptom (see silent lesions). This is because of cognitive reserve – you can think of this as your brain's 'flexibility' or 'adaptability'. If you have a good cognitive reserve, your brain will find ways to overcome the damage, for example by sending messages via different routes.

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.

Fatigue

Fatigue is one of the most common symptoms of 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 pacing yourself, and planning, prioritizing and delegating tasks.