

Talking about treatments

Questions to ask my MS specialist



My treatment choices

We're learning more about how multiple sclerosis (MS) affects people's bodies and the difference treatment can make. Drugs for relapsing types of MS such as Disease Modifying Therapies (DMTs) are developing all the time.

New evidence has changed what we understand about MS and how to treat it. Rather than waiting to see whether more relapses occur, DMTs should be offered as close as possible to diagnosis, before damage to the body has built up. So when you see your MS Nurse or Neurologist you might have questions. This checklist can help you get answers.

No matter what type of MS you have, official guidelines now say you should be offered a review with an MS specialist at least once a year.

What is a DMT?

If you have relapsing MS taking a DMT is a treatment that, over the years, is intended to change for the better ('modify') how your MS develops. DMTs offer you the chance to take control of your MS. To find out more about DMTs and other treatments download a copy of our new booklet DMTs for MS.

Who can I turn to for support?

- A local MS Nurse, especially if I need support taking my DMT
- Call the MS Helpline **0808 800 8000** – you can ask questions, or just talk about how treatment and DMTs make you feel.
- mssociety.org.uk/DMTs

My question checklist

When you see your specialist it's easy to forget questions that were on your mind. So take this to your next appointment to help you talk through what you want and how to get it.

This question is...	very important	need to know	not very important
Which DMTs can I have for my type of MS?			
What difference might a DMT make to my MS?			
Why are some DMTs not available to me?			
How likely am I to get side effects?			
How do I take DMTs?			
What tests will I need?			
Is it OK to be on treatment if I want to have a baby			
If I say no to a DMT now can I change my mind later?			
What are the latest treatments?			

What are the latest treatments?

Nearly all the DMTs we have at the moment only work with types of MS that have relapses. New drugs are being tested to see if they work for progressive (non-relapsing) types of MS.

We hope the first DMT that works against early primary progressive MS, ocrelizumab, will be available in the UK on the NHS by 2019.

HSCT

HSCT stands for haematopoietic stem cell transplantation. Stem cells are taken from your bone marrow and frozen. Next you take chemotherapy drugs to kill your harmful immune cells. Then your stem cells are put back into your blood stream. There they'll rebuild your immune system so that works as it should. Find out more about HSCT mssociety.org.uk/HSCT

If you are not happy with your treatment

You and your specialist should decide your treatment together, based upon which treatments are available to you at the time. If you're not happy with answers or your proposed treatment, you have the right to a second opinion.

This could mean having to travel to a different hospital and your treatment could start later. Talk this through with your specialist to see what this delay might mean to you.

Find out more about getting a second opinion or making a complaint:

mssociety.org.uk/gettingtreatment

Things to take to my appointment.

It is helpful to take a list of previous relapses, especially any you've had in the last two years. And to make and bring a list of any new symptoms that remain after your relapse.

- My list of questions
- Names and doses of medications I am taking
- Information about treatments I've seen and heard about
- A friend or relative to support me and ask questions
- Pen and paper
- Any letters or documents about my diagnosis and test results like MRI scans and lumbar punctures