Talking about treatments

Questions to ask my MS specialist



My treatment choices

We're learning more about how MS affects people's bodies and the difference treatment can make. Disease Modifying Therapies (DMTs) are developing all the time for types of MS that are active. 'Active' means you get relapses, or your MRI scans show new lesions. Relapsing remitting MS is 'active' and some types of progressive MS are.

New evidence has changed what we understand about MS and how to treat it. If you have relapsing MS, you should be offered a DMT as close as possible to your diagnosis. This is instead of waiting to see whether you get more relapses, and before more damage to your body happens. 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?

A DMT is a treatment that, over the years, is intended to change for the better ('modify') how your MS develops. If your MS is active, DMTs offer you the chance to take more control of it. To find out more about DMTs and other treatments, download a copy of our booklet DMTs about MS or check our info at

mssociety.org.uk/DMTs

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.

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?			

Find out about the latest treatments?

You can find out about the latest treatments any time from our website. We'll explain what the research shows, and who night get them through the NHS.

mssociety.org.uk/about-ms/treatments-and-therapies

Or call our MS Helpline on 0808 800 8000.

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.

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☐ 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

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This title will be reviewed within three years of publication.

