



Questions and Answers about Early Treatment

What treatments are there for relapsing MS?

There are now 11 disease modifying therapies (DMTs) for relapsing MS. How effective they are, their side effects and how you take them are all different. The more effective treatments tend to have more serious side effects.

DMTs can reduce the number of relapses you may have and reduce the damage MS causes and that builds up (accumulates) over time. This means that taking a DMT can delay the damage to your body getting worse compared to if you don't take a treatment. This is true even if you have not been having relapses. Information on DMTs should be given to you by health care professionals when you are diagnosed. You can also get information from the MS Society at www.mssociety.org.uk

What are the benefits of early treatment?

Even when you're not having a relapse MS may carry on attacking your body, leading to nerve damage that can't be put right. Taking DMTs cannot undo this damage to nerves, but they help prevent it and lower the number of relapses you have too.

This means that the earlier you start treatment, the better.

How early is early treatment?

Your neurologist should begin talking about what kind of treatment is right for you as soon as you're diagnosed. If you decide to start treatment, it should be offered as close to diagnosis as possible. This view is supported by the Association of British Neurologists (ABN) in their recently updated MS prescribing guidelines.

The discussion about your treatment should then carry on at your six week follow up appointment and in the six month period after this. During this time you and your neurologist should make a treatment plan and decide what your treatment should look like.

Who qualifies to be treated early?

If you have a relapsing form of MS, you could qualify for treatment. There are 11 DMTs licensed for MS so speak to your neurologist or MS nurse about which one's right for you.

Can I get early treatment if diagnosed with progressive MS?

DMTs are not prescribed for people with progressive MS who do not have relapses. If managing your MS with a DMT isn't possible, there are treatments available to manage your symptoms. Progressive MS is our top research priority and that of the global research community – with new knowledge being gained, new projects funded and clinical trials running, there's hope on the horizon. You can find lots of information on progressive MS research on our website.

<http://www.mssociety.org.uk/ms-research/projects/progressive-ms>

What treatments are there for progressive MS?

Right now there are no DMTs for non-relapsing progressive MS that can slow or stop it getting worse, but research is being done to find them. You can read about current research into progressive MS on our main website.

If you can't treat your MS with DMTs, there are [treatments, self-management techniques and complementary therapies](#) you can try to help manage your symptoms.

What are you doing for people with primary progressive and secondary progressive MS?

Finding treatments for progressive MS is the MS Society's number one research priority. More importantly, it's a global priority.

The UK MS Society is a leading member of the Progressive MS Alliance, a network of MS charities from around the world that are united to achieve one key goal: **to speed up the development of treatments for progressive MS.**

In 2014 it launched 22 innovative research projects and plans to invest €22.4 million between 2014 and 2019.

The MS Society also has a [progressive MS forum](#), support can be found through our Helpline and local branches and centres, while [grants](#) and a [Short Breaks scheme](#) can also be applied for,

What does this mean for someone with MS now?

We know about the benefits of treatment but there are some other important developments in treatment and care for people with relapsing forms of MS.

[New best practice guidelines for MS](#), from NICE (National Institute for Health and Care Excellence), recommend that people with MS have at least one review of their condition each year and have one person making sure a team of people with different skills are working together to provide your care and treatment.

The Association of British Neurologists (ABN) recently updated their guidance on how MS should be treated. They recommend:

- treatment starting as close to diagnosis as possible
- making a joint decision on which treatment to use
- and using MRI as part of an ongoing review

If you have a relapsing form of MS, you may wish to contact your neurologist or nurse to make sure you're receiving the best treatment and support package that you can get – this is true whether or not you're already on treatment or in regular contact with your MS team.

I have just been diagnosed and my neurologist didn't mention treatment. What should I do?

You have a right to ask for an appointment to speak to your neurologist about your options. Both NICE (National Institute for Health and Care Excellence) and the Association of British Neurologists (ABN) recommend that information about treatment options is given to you at diagnosis and in the weeks and months that follow.

You can prepare for the appointment by looking at our information on the treatments available and the questions you might want to ask. You find them here www.mssociety.org.uk/earlytreatment If you aren't happy with your care you can always ask for a second opinion. The NHS has guidance on how to do this which can be found [here](#).

I do not have regular appointments with a neurologist/MS nurse, what should I do?

If you are not under the care of an MS specialist nurse or neurologist, you should go back to your GP and ask for a referral.

Is taking early treatment less worthwhile if you are an older patient?

In some trials of DMTs, the results showed that they tended to be more effective in people of a younger age. But this doesn't mean that older people won't see benefits from DMTs, or wouldn't benefit from early treatment.

What happens if you don't have treatment early? I've had MS for x number of years and haven't had treatment.

DMTs are now known to help prevent the damage to nerves that builds up over time in relapsing remitting MS. DMTs can't undo any damage to nerves that has already happened, which is why the earlier you start treatment, the better. But this doesn't mean that starting a treatment later will not have any benefits.

The most important thing is to speak to your MS nurse or neurologist about what your options are.

What happens if I've had treatment and stopped it? What does early treatment now mean for me?

It is important to have a conversation with your MS nurse or neurologist about your treatment options, as restarting treatment may still have benefits.

I had treatment early but I have since/recently taken a break from treatment – what does this mean for me now?

It is important to have a conversation with your MS nurse or neurologist about your treatment options.

I was diagnosed with relapsing remitting MS two years ago but still haven't had any treatment, is it too late to get a DMT?

No. The evidence shows that starting treatment can slow down how your MS progresses, helping to prevent the damage to nerves that builds up over time. DMTs

can't undo any damage to nerves that has already happened, which is why the earlier you start treatment, the better. Starting a treatment later can still have benefits.

I've been told I had a CIS. Are there any treatments for CIS? Can early treatment stop me from getting MS?

DMTs can be used to treat [clinically isolated syndrome \(CIS\)](#). There is some evidence showing that taking a DMT can delay or lower your chances of getting MS.

Not everyone who is diagnosed with CIS goes on to get MS. This can make it more difficult to decide whether to take a treatment.

There are three situations where within 12 months of a person having CIS their neurologist might, after talking through the benefits and side effects, recommend starting treatment:

1. MRI scans show signs of MS
2. MRI scans show that another relapse (attack) is likely
3. Your spinal fluid shows signs you have MS

At the moment only beta interferons and glatiramer acetate can be used to treat someone with CIS.

Speak to your neurologist or MS nurse regarding whether treatment would be appropriate for you.

What should my next steps be? How do I choose which treatment to take?

It's important to know about all the treatments open to you. Information on DMTs should be given to you by health care professionals when you are diagnosed. You can also get information from www.mssociety.org.uk/earlytreatment and our Helpline on 0808 800 8000.

Which treatment you choose will be a joint decision between you and your neurologist.

What effects do the newer treatments have over a long time?

All of the licensed DMTs have become available in the last 20 years, and some of the newer treatments have only become available within the past 5 years. Evidence is clearer around the long term benefits of older therapies, but much less clear for the newer therapies. We do have a good understanding of the more general benefits

of using these treatments over a long time, but it will take years to gather specific long term evidence for new treatments.

It's important we carry on collecting more information on what each treatment does – that's why we're asking people with MS to share their experience of taking a DMT to patient registries such as the MS Register at www.ukmsregister.org

Why do some people have doubts about the benefits of early treatment?

Some neurologists and MS nurses haven't been supportive of treatment with a DMT in the past. One of the reasons may be because in 2002 NICE (National Institute for Health and Care Excellence) stated the cost of beta interferon and glatiramer acetate was more than the benefit they bring and should not be used on the NHS. Also, some people felt there's not a lot of information on the newer DMTs. Data published from the MS Risk Sharing Scheme in 2010 made some people believe even more that use of DMTs in MS couldn't be justified.

Because of this, some people with MS don't start treatment at all, while others have been encouraged to 'wait and see' how their MS develops before they make their decision. We now know that to slow down the damage caused by MS, people should be offered a treatment as soon as possible after diagnosis. The more recent data from the Risk Sharing Scheme, for years four and six (announced in 2014, but published in 2015), should reinforce new professional treatment guidance and help to change attitudes to and practice around the use of DMTs in the management of MS.

You should speak to your neurologist or MS nurse about which treatment is best for you. If they have doubts, you can make them aware that recent ABN guidelines support treatment starting as soon after diagnosis as possible.

In order to help you when you talk to your neurologist, the MS Society has developed a checklist of things to bring up at appointments. Download it at www.mssociety.org.uk/earlytreatment

You can ask your GP or another healthcare professional, such as a neurologist, for a second or further opinion if you are not satisfied. The NHS has guidance on how to do this which can be found [here](#).

What is the Risk Sharing Scheme?

It is essentially a patient access scheme for treatments. It was set up in 2002, in response to a NICE* decision that two licensed MS medicines were not cost effective and should not be made available on the NHS. Following lobbying by the MS community, a compromise was reached: certain DMTs for MS would be made

available on the NHS. These were beta interferon (brand names Avonex, Betaferon and Rebif) and glatiramer acetate (brand name Copaxone).

It was agreed that the Department of Health and drug companies would pay for these DMTs and the infrastructure needed to give them. The treatments are available to people with MS who meet the Association of British Neurologists (ABN) criteria. The Scheme then monitors the cost and benefits of those treatments over a ten year period.

* The National Institute for Health and Care Excellence (NICE) provides national guidance and advice to improve health and social care. Their technology appraisals guidance assesses the clinical and cost effectiveness of health technologies, such as new pharmaceutical products. The NHS is legally obliged to fund and resource medicines and treatments recommended by NICE's technology appraisals.

Why is treating people early seen as important now?

A number of sources of clinical evidence on early treatment have been building up for some time, and in response the MS Society brought together a group of experts to look at the long-term benefits of early treatment and to reach a consensus. This group met in November 2014 and included people affected by MS, neurologists, MS nurses and other healthcare professionals. They strongly agreed that the evidence confirms the importance of treating with DMTs as close to diagnosis as possible. The consensus paper can be found at www.mssociety.org.uk/earlytreatment

Why has the MS Society announced this news several months after the consensus meeting was held?

After reaching our position on early treatment by looking carefully at the evidence with neurologists, MS nurses and people with MS, we also wanted to make sure it was shared by other organisations in the MS community, such as Shift MS and MS Trust. We also wanted our recommendation to have the backing of the Association of British Neurologists (ABN). The ABN has recently included the recommendation to treat with a DMT as close as possible to diagnosis in their [new prescribing guidelines](#), published in June. Additionally, a global consensus on the value of early treatment has been reached by experts and an international report will be published in October. The MS Society was invited to sit on the working group for this report.

We also wanted to make sure we were fully prepared to support people with MS when we announced this new consensus. This includes a number of information resources to support people in responding to this news.

What are you doing to make sure my doctors and nurses know about this news?

The MS Society Treat Me Right campaign is fighting for people with MS to get the right treatment, at the right time, no matter where they live. This includes getting treated early.

The MS Society is working hard to make sure health care professionals, professional organisations, civil servants and politicians know about the long term benefits of early treatment. This will mean they'll be able to change how people in the NHS prescribe these drugs.

I tried treatment and suffered bad side effects. What can I do?

Three new treatments have been given the go-ahead for use on the NHS, making a total of 11 DMTs now available. How you take them, how well they work and their side effects are all different.

If you find the side effects are too much on one drug, you can speak to your specialist. It might be possible to change to another DMT. Read more at www.mssociety.org.uk/earlytreatment and speak with your MS nurse or neurologist about the new treatments that might be available to you.

Why have the MS Society only now decided that early treatment works? Why hasn't this always been the case? How long has this been known about? I could've done something sooner but I waited to see how my MS progressed. Now I'm worried I've made the wrong decision

It takes time to collect information on how safe a treatment is and how well it works. Our understanding of the biology of MS has moved on a great deal over the last 15 years. This has improved our understanding of the damage that can be happening without someone experiencing obvious relapses.

Evidence has been building in recent years to show the potential long term benefits of taking a DMT early. But until now questions remained about whether there was enough evidence to make changes in policy and practice.

Now we know the benefits, we want people with relapsing forms of MS to be offered a treatment as close as possible to their diagnosis. If you have a relapsing form of MS it is important that you speak to your neurologist about your options and which treatment could be right for you.

If you find this upsetting and would like to talk more, please call our freephone telephone number on 0808 800 8000.

What does this mean for women who want to have children and go on treatment? What should I do if I'm thinking of having a family?

Doctors generally say you shouldn't take DMTs while you're pregnant. You should talk about best treatment options with your neurologist or MS nurse. Together you can decide on the best plan for you when you're thinking of having children. Further information can be found [here](#).

This is good news for drug companies. Have they had a hand in what you're saying about early treatment?

All the information and support we give, and everything we campaign for, is based on real evidence.

The drugs industry has no influence over what's in our information, campaigns or the research we fund. We only work with drug companies when we're certain it's in the best interests of people with MS. Companies weren't involved in the consensus paper we helped draw up about early treatment.

But the drugs industry does put money into the development and operation of clinical trials of new treatments.

We are totally open about any money we get from drug companies. This makes sure that we keep our independence. In 2014, support from drug companies made up just 1% of all the money we get. [Read our full policy on working with industry](#).

Why is MRI scanning so important?

MRI (magnetic resonance imaging) has made diagnosing and tracking MS better. When MS causes lesions in your brain or spinal cord, this can be picked up by MRI scans.

If you're affected by CIS or MS, you should have regular MRI scans to check how it's developing, as recommended by the ABN (Association of British Neurologists) guidelines. This helps when making decisions about the right treatment for you. You and your neurologist together will decide what this course of treatment will look like, and what sort of DMT to use

Right now there aren't any licensed treatments for progressive MS that can slow it down or stop it getting worse, but we are funding research to find them. You can read about current research into progressive MS on our main website. If managing your MS with DMTs isn't possible (either because you have progressive MS, you're

pregnant, or you just don't want to take them) there are treatments and complementary therapies that can help manage your symptoms.

My neurologist or MS nurse has never told me if my MS has progressed from relapsing remitting. I don't really know what type of MS I have. What should we be doing to be certain about this? Will this make a difference on how well DMTs may work for me and if I can get them?

Relapses, someone's disability getting worse and lesions on the brain and spinal cord are all signs neurologists look for so they can measure what your MS is doing. A neurologist specialising in MS is in the best position to decide what these mean for a person with MS and whether treatment is likely to be beneficial.

MRI scans can be useful for understanding the damage caused by MS and whether treatment is working for someone. Regular MRI scans should be used to help you and your neurologist make decisions about treatment.

Whether you are eligible for a DMT is dependent on your type of MS – only people with relapsing MS should be treated with DMTs. If you're not sure what type of MS you have and what treatments might be open to you, make an appointment with your neurologist or MS nurse. If you aren't happy with your care you can always ask for a second opinion.

The NHS is already financially overstretched. Increasing the numbers on treatment will be expensive. How will the NHS afford it?

Although these treatments cost the NHS to begin with, they have been found to be worth the cost by NICE (National Institute for Health and Care Excellence) and the Department of Health (and their equivalents in Scotland, Wales and Northern Ireland). It's really important that people get the right treatments at the right time, no matter where they live.

Your information about who can have DMTs is different from what I've heard from other places. And my specialist doesn't agree with you. Why is that?

Who can have a DMT depends on two things: firstly the guidelines which advise MS specialists about who should get them, and, secondly, how each specialist interprets these guidelines. Some guidelines are more restrictive than others and some neurologists are more cautious in how they follow the guidelines.

MS treatment has three main sets of guidelines:

1. ABN (Association of British Neurologists) guidelines. These are the most recent ones (July 2015) and most accurately reflect how MS specialists are prescribing DMTs today. They're less restrictive than other guidelines. They also match the goal of offering people treatment as close as possible to when they're diagnosed (which the ABN, the MS Society and other MS organisations fully support).
2. NICE (National Institute for Health and Care Excellence) guidelines. NICE produce individual guidance on how to use each DMT and these are used by many MS specialists when they make decisions about prescribing these drugs. NICE also have general guidelines about treating MS but they don't cover DMTs. These were last updated in October 2014 and will be updated again at the end of 2016.
3. NHS England commissioning policy on DMTs. This covers what MS treatment the NHS is willing to pay for in England. The latest version came out in May 2014. It tends to follow the NICE and other Department of Health advice on the various DMTs.

Also in Scotland, Wales and Northern Ireland there are separate guidelines for some DMTs.

When it comes to who can have DMTs, there's a difference between what the MS Society says and what the NICE and NHS England guidance say (and what organisations such as the MS Trust say). All agree that DMTs should be offered if you have 'active' MS. At the moment NICE, NHS England and the MS Trust define 'active' MS as usually meaning two or more relapses in the last two years. This is also given as a definition in the ABN guidelines. We at the MS Society now define 'active' MS as when you've had a **recent relapse and/or have had MRI scans showing new signs that your MS is active (you have new lesions)**.

The change is because the 2015 ABN guidelines recognise that more and more MS specialists are changing their definition of 'active' MS. These guidelines say: "Increasingly, clinicians are starting treatments in people whose disease is judged 'active' because of a single recent relapse and/or on radiological grounds" (ie, signs on MRI scans). The ABN says this includes newly diagnosed people and people who have new lesions on MRI scans but who haven't had a relapse.

The MS Society supports this move towards treating people earlier. We also recognise that the ABN recommendation that people with MS are offered treatment as close to when they were diagnosed as possible is less easy to meet if specialists stick to the 'two relapses in two years' definition. Insisting people have multiple relapses before giving them a DMT could mean they suffer damage which cannot be put right later.

Another difference between what the MS Society is saying and what is recommended by others is around how early some individual drugs (eg,

alemtuzumab) are used. We say these drugs can be used by a wider group of people; for example, using them as someone's first DMT. This is based on how the ABN guidelines describe how some specialists prescribe the drugs (some specialists follow what the licence for each drug allows not just what NICE guidance recommends). At the end of the day your specialist has a degree of freedom about how he or she interprets the various DMT guidelines.

If your MS specialist says you don't qualify for a DMT he or she could very well be correct as each drug is licensed to be used in particular situations. Or they could be staying with the older guidance about two relapses in two years. Or they could be sticking closely to NICE or NHS guidelines instead of interpreting them less restrictively. And the decision of your specialist will have to take into account what they believe the NHS locally will pay for you to have.

You have the right to a second opinion if you're not happy with the answer or treatment you're given. Your specialist should be happy to arrange for you to see another neurologist at the same hospital. You can also get advice on getting a second opinion from www.nhs.uk (search for "how to get a second opinion" – but include the quote marks). If you're having problems getting an MS drug check out our *Access to medicines* guides at www.mssociety.org.uk/treatmeright