

## Deciding what to do about multiple sclerosis

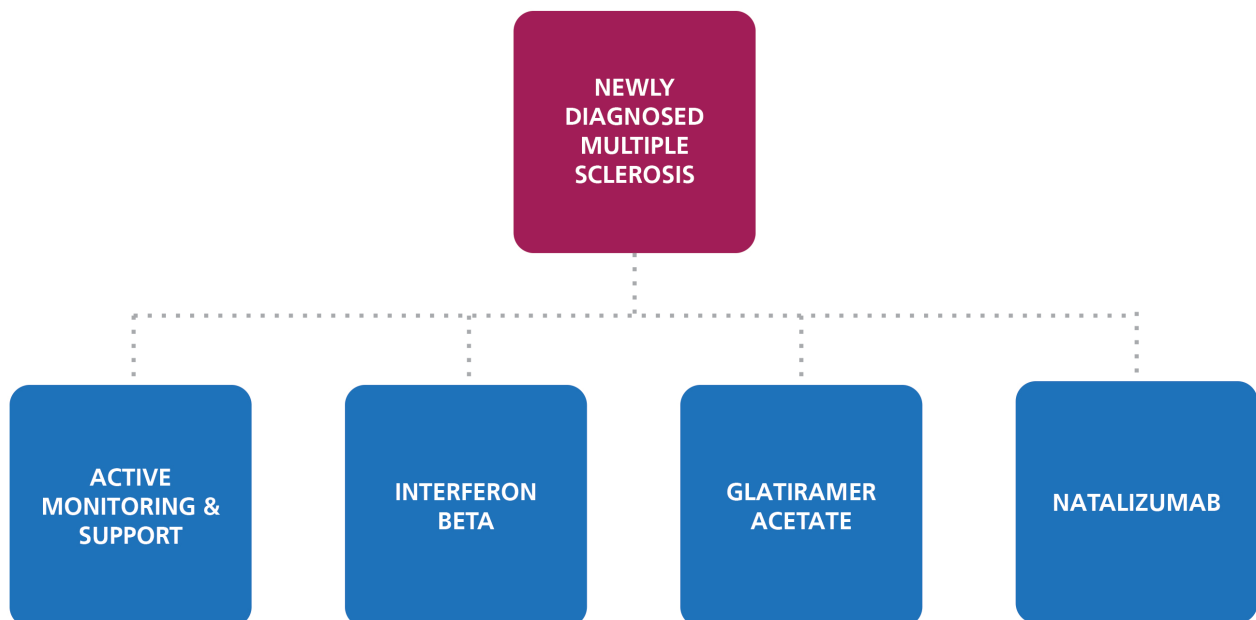
This short decision aid is to help people with multiple sclerosis (MS) and their health care team decide whether a disease-modifying drug is suitable for them, and if so which one. This decision aid is only for people with relapsing-remitting MS who have never used disease-modifying drugs before.

The four main treatment options are:

- Active monitoring and support
- Interferon beta
- Glatiramer acetate
- Natalizumab

Not everyone will be able to choose from all of these options. Some of these medications are not suitable for everyone. For example, natalizumab can only be taken by people who have severe relapsing-remitting multiple sclerosis that is getting worse quickly. MS specialist nurses or neurologists can help people decide which treatments are suitable for them.

Although active monitoring is listed as a distinct treatment option in this decision aid, everyone who has MS, whether they are taking disease-modifying drugs or not, will be actively monitored and provided with self-care support.



## What are my options?

	Active monitoring and support	Interferon beta	Glatiramer acetate	Natalizumab
<b>What is the treatment?</b>	<p>People have their condition and symptoms regularly reviewed. Although people won't be taking medication to control relapses, they can start taking medication if they have a relapse.</p> <p>All people with MS can have treatment to manage their symptoms including physiotherapy, occupational therapy, psychological support, advice to help them manage their own illness (self-management), and medicines to control symptoms. These medicines are different from disease-modifying drugs and are not covered in this decision aid.</p>	<p>Interferon beta 1a and interferon beta 1b are drugs based on naturally produced proteins that help calm inflammation. People taking interferon beta will have their condition and symptoms reviewed regularly, in the same way as people who choose active monitoring with no disease-modifying drug treatment.</p> <p>People may choose to take medicines to control their symptoms. These medicines can be taken alongside disease-modifying therapy. Medicines to treat symptoms are not covered in this decision aid.</p>	<p>Glatiramer acetate is a mix of substances called amino acids. This drug helps to calm the cells from the immune system that attack the coating around the nerves. People taking glatiramer acetate will have their condition and symptoms reviewed regularly, in the same way as people who choose active monitoring with no disease-modifying drug treatment.</p> <p>People may choose to take medicines to control their symptoms. These medicines can be taken alongside disease-modifying drugs. Medicines to treat symptoms are not covered in this decision aid.</p>	<p>Natalizumab is only recommended for people with severe relapsing-remitting MS that is getting worse quickly.</p> <p>Natalizumab is a drug that affects how the immune system works. It stops the white blood cells (one of the types of cells your immune system makes to help fight infection) passing from the blood into the brain and nervous system. People taking natalizumab will have their condition and symptoms reviewed regularly in the same way as people who choose active monitoring with no disease-modifying drug treatment.</p> <p>People may choose to take medicines to control their symptoms. These medicines can be taken alongside disease-modifying treatment. Medicines to treat symptoms are not covered in this decision aid.</p>

	Active monitoring and support	Interferon beta	Glatiramer acetate	Natalizumab
<b>What does treatment involve?</b>	<p>People who choose active monitoring usually have regular appointments with a healthcare professional to monitor their condition and symptoms. These appointments may be face to face, but can also be done by phone.</p> <p>Although people won't be taking medication to control relapses, they can start taking medication if they have a relapse.</p> <p>People may choose to take medicine to control their symptoms. These medicines are different from disease-modifying drugs and are not covered in this decision aid.</p>	<p>Interferon beta needs to be injected. Some types of interferon beta are injected under the skin, others into the muscle. How often a person needs injections varies between once a week and three times a week, depending on the type of interferon beta.</p> <p>People who use interferon beta need to have a secure storage area for their syringes and needles, and a special box to discard needles. Some types of interferon beta have to be kept in the fridge.</p>	<p>Glatiramer acetate needs to be injected under the skin every day. People who use glatiramer acetate need to have a secure storage area for their syringes and needles, and a special box to discard needles. Glatiramer acetate injections need to be stored in a fridge.</p>	<p>Natalizumab is taken as an intravenous infusion (a 'drip') into a vein, in hospital, every four weeks.</p>

	Active monitoring and support	Interferon beta	Glatiramer acetate	Natalizumab
<b>What is the effect on whether your MS gets worse?</b>	<p>Active monitoring will not help to slow or stop the rate at which disability becomes worse for people who have MS.</p>	<p>Interferon beta may slow the rate at which disability becomes worse for people who have MS. [1]</p>	<p>In a group of people with MS who were followed up for two years, glatiramer acetate did not slow the rate at which disability became worse.[2]</p>	<p>Natalizumab may slow down the rate at which disability becomes worse for people with MS.[3]</p>

	Active monitoring and support	Interferon beta	Glatiramer acetate	Natalizumab
<b>What is the effect on how many relapses you have?</b>	<p>Active monitoring does not affect how many relapses a person has or how often they have them.</p>	<p>In a group of people with MS who were followed up for two years, injections of interferon beta reduced the number of relapses they had by an average of about one third.[4]</p>	<p>In a group of people with MS who were followed up for two years, injections of glatiramer acetate reduced the number of relapses they had by an average of about one third.[5]</p>	<p>In a group of people with MS who were followed up for two years, natalizumab infusions reduced the number of relapses they had on average by about half.[6]</p>

	Active monitoring and support	Interferon beta	Glatiramer acetate	Natalizumab
What is the effect on your life and what you can do?	<p>People who choose active monitoring need to find time for regular appointments and check-ups.</p> <p>Active monitoring has no direct effect on what people can do. Other non-drug treatments may help someone with MS stay active.</p>	<p>Having fewer relapses and less disability may mean that people are able to do more, and to feel less anxious about their disease.[7]</p> <p>People who choose interferon beta need to find time for regular injections. They need to inject the drug themselves or with the help of a family member. They also need to consider practical issues like how to manage the injections, and how to store the medicines.</p> <p>People who choose interferon beta also need to have regular blood tests at first to make sure they are tolerating the drug well.</p>	<p>Having fewer relapses may mean that people are able to do more, and to feel less anxious about their disease.[8]</p> <p>People who choose glatiramer acetate need to find time for regular injections. They need to inject the drug themselves or with the help of a family member. They also need to consider practical issues like how to manage the injections, and how to store the medicines.</p>	<p>Having fewer relapses and less disability may mean that people are able to do more, and to feel less anxious about their disease.[9]</p> <p>People who choose natalizumab need to visit hospital once every four weeks for an infusion. This can take up to two hours.</p>

	Active monitoring and support	Interferon beta	Glatiramer acetate	Natalizumab
<b>What side effects or complications does the treatment have?</b>	Active monitoring is not likely to cause 'side effects', but choosing not to take disease-modifying drugs increases the chance of having a potentially disabling relapse.	About 48 in 100 people taking interferon beta have flu-like symptoms for up to a day after the injection. These symptoms usually stop altogether after a few months of treatment. About 28 in 100 people get fever, 50 in 100 people get a headache, and 62 in 100 people get skin reactions at the site of the injection, such as redness or itching.[10] These symptoms usually only last a short time after the injection.	About 15 in 100 people have an allergic reaction after at least one of their glatiramer acetate injections.[11]  Some people who have glatiramer acetate injections get a skin condition called lipoatrophy.[12]	About 2 in 1,000 people taking natalizumab get a serious brain condition called progressive multifocal leucoencephalopathy (PML). There is a blood test that can tell if you might be at risk of getting this condition. [13]  Natalizumab can cause liver damage. This damage is reversible when people change treatment.[14]  Other side effects include urine infections, tiredness, fever, rash, sinus congestion, swelling, and itching. [15] [16] Most of these symptoms only last a short time after the infusion.  About 10 in 100 people have an allergic reaction to natalizumab.[17] People who have an allergic reaction will need to change their treatment to a different drug.

## What are the pros and cons of each option?

People with multiple sclerosis have different experiences about the health problem and views on treatment. Choosing the treatment option that is best for the patient means considering how the consequences of each treatment option will affect their life.

Here are some questions people may want to consider about treatment for multiple sclerosis:

- How important is it for them to limit the number of relapses they have?
- Do they want to stop their MS getting worse for as long as possible, even if that means having injections or drips?
- Are they willing to start a treatment that will affect their daily life?
- Do they want to be active and independent for as long as possible?
- Are they willing to have a treatment that has a chance of serious side effects?
- Are they pregnant, breastfeeding, or planning to get pregnant in the near future?