



## MULTIPLE SCLEROSIS

# FIVE QUESTIONS FOR... STARTING A DISEASE-MODIFYING THERAPY FOR MULTIPLE SCLEROSIS (MS)

Shared decision-making helps you and your doctor discuss options and make decisions together. Health care decisions should consider the best evidence and your health care goals. This guide will help you and your doctor talk about:

- Disease-modifying therapy for MS
- The risks and benefits of starting a drug
- Additional steps you can take to live well with MS

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### 1. WHAT IS A DISEASE-MODIFYING THERAPY?

The term “disease-modifying therapy” or DMT refers to treatments that are intended to decrease the number of MS relapses, reduce new brain lesions, and hopefully delay disability. Examples of DMTs are listed below. Relapses (also known as attacks, flares, or exacerbations) are periods of new or worsening symptoms that come on over hours to days, last more than 24 hours, and occur when you do not have a fever or infection. A brain lesion is an injury to the tissue in your brain. MS disease activity can cause brain lesions, and new lesions may lead to more symptoms. Everyone is different, but common MS symptoms include vision problems such as decreased vision or double vision, movement problems and muscle weakness, numbness, tingling, bladder or bowel control problems, tiredness, sexual activity problems, depression or anxiety, coordination problems, pain, and forgetfulness or slowed thinking.

DMTs are thought to act by reducing inflammation caused by the immune system, which is your body’s protection system to fight infections and toxins. DMTs are not meant to make you feel better and are different from the medicines used to treat the common MS symptoms. Medicines used to decrease common symptoms help with things like walking difficulties or bladder issues, but do not change your disease process. Examples of these types of drugs include dalfampridine for walking, baclofen for spasticity, gabapentin for pain, and oxybutynin for bladder control.

### 2. WHEN SHOULD I THINK ABOUT STARTING A DMT?

Most doctors believe that DMTs should be started as early as possible because the available medical evidence shows that MS may cause brain damage early, even before there are signs of disability. DMTs do not repair damage that has already happened or reverse lesions, but they may reduce relapses and new lesions. Reducing relapses and new lesions likely delays the onset of disability.

### 3. WHAT ARE OTHER THINGS SHOULD I DO IF I HAVE MS?

Every patient with MS should follow a healthy diet and wellness plan with their neurologists and MS team that includes exercise. Depending on your condition, your team may also talk to you about starting dietary supplements, like vitamin D, as well as tobacco cessation if you smoke.

## 4. WHAT DMTS ARE AVAILABLE?

Many DMTs are available and come in pill, injection, or intravenous forms. An injection is a quick shot given through needle either under the skin or into the muscle. Intravenous medications are given through a needle in a vein, often over an hour or two in an infusion center or a doctor's office. All DMTs have potential side effects or safety concerns that should be discussed with your health care team; many of the DMTs require routine monitoring as well. Because DMTs are not approved for use in pregnancy, if you are a woman who is pregnant or thinking of becoming pregnant, tell your doctor.

DMT NAME	HOW THIS IS DRUG IS RECEIVED	WHO MIGHT BENEFIT*	SIDE EFFECTS MAY INCLUDE
Beta interferon 1b subcutaneous (Betaseron <sup>®</sup> , Extavia <sup>®</sup> )	Injection under the skin every other day	Patients with relapsing and remitting MS	Fever, aches and pains, headaches, injection site redness and irritation, injection site ulceration, low blood counts, liver abnormalities, liver failure (rare), weight loss, depression
Beta interferon 1a subcutaneous (Rebif <sup>®</sup> )	Injection under the skin three times a week	Patients with relapsing and remitting MS	Fever, aches and pains, headaches, injection site redness and irritation, injection site ulceration, low blood counts, liver abnormalities, liver failure (rare), weight loss, depression
Beta interferon 1a intramuscular (Avonex <sup>®</sup> )	Injection into a muscle once a week	Patients with relapsing forms of MS	Fever, aches and pains, headaches, injection site pain, low blood counts, and liver damage
Beta interferon 1a intramuscular (Plegridy <sup>®</sup> )	Injection under the skin once every other week	Patients with relapsing forms of MS	Fever, aches and pains, headaches, injection site pain
Glatiramer acetate (Copaxone <sup>®</sup> )	Injection under the skin three times a week (40mg) or daily (20mg)	Patient with relapsing and remitting MS	Injection site redness and irritation, skin dimpling at injection sites, post-injection reactions that may include anxiety, rapid heart rate, shortness of breath starting a minute or two after injection and lasting up to 30 minutes
Mitoxantrone (Novantrone <sup>®</sup> )	Infusion into a vein once every three months	Patients with relapsing forms of MS	Infection, rare chance of leukemia, and rarely given because of dose related heart damage with heart failure
Natalizumab (Tysabri <sup>®</sup> )	Infusion into a vein once every 28 days	Patients with relapsing forms of MS	Allergic reactions, potential of brain infection including progressive multifocal leukoencephalopathy (PML)
Fingolimod (Gilenya <sup>®</sup> )	Pill once a day	Patients with relapsing forms of MS	Slowed heart rate after first dose, lung problems, swelling of the back of the eye, viral infections (rare but includes PML), high blood pressure, and liver damage
Teriflunomide (Aubagio <sup>®</sup> )	Pill once a day	Patients with relapsing forms of MS	Liver damage, infections, hair thinning, diarrhea Women who are or may become pregnant should not take as there is a chance of birth defects
Dimethylfumarate (Tecfidera <sup>®</sup> )	Pill taken 2 times a day	Patients with relapsing forms of MS	Stomach upset with nausea, abdominal pain and diarrhea (in some patients), flushing or reddening of the skin, liver damage, low blood counts, viral infections (rare but includes PML)
Alemtuzumab (Lemtrada <sup>®</sup> )	Infusion into a vein given for 5 days in a row and then for three days one year later	Patients with relapsing forms of MS	Given infrequently and to those who have tried two or more DMTs without success before Allergic reactions, thyroid disease, bleeding disorders, autoimmune diseases, infections Risk of increased cancers requiring yearly skin and thyroid tests

For more information regarding safety and side effects, visit Medline Plus at [nlm.nih.gov/medlineplus/medlineplus.html](http://nlm.nih.gov/medlineplus/medlineplus.html).

\*Medications that are prescribed "off label" may not be approved treatments for your diagnosis. Ask your doctor to describe the risks and benefits of these options.

## 5. WHAT THINGS SHOULD I TALK TO MY DOCTOR ABOUT BEFORE STARTING A DISEASE-MODIFYING THERAPY?

Before making the decision to start a new drug, review the following with your doctor and obtain a written summary of your visit, which includes recommendations and next steps.

### QUESTIONS

### ANSWERS OR OTHER QUESTIONS YOU HAVE

- What are the potential risks, side effects, and benefits? \_\_\_\_\_
- Who will give me an injection or infusion? \_\_\_\_\_
- What worries me about starting a DMT? \_\_\_\_\_
- If I start a DMT, how long do I have to keep taking it? \_\_\_\_\_
- Who do I talk to, if I start a DMT and have side effects? \_\_\_\_\_
- What if I don't start a DMT? \_\_\_\_\_
- Where can I find out how much these DMTs will cost, and if my insurance will pay for them? \_\_\_\_\_
- Are there programs to help me pay for these drugs? \_\_\_\_\_
- Are there clinical trials? \_\_\_\_\_
- If I start this DMT, does that mean I cannot be in a clinical trial? \_\_\_\_\_

Answers and Other Questions You Have

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## References

Visit [NationalMSSociety.org](http://NationalMSSociety.org) if you would like more information on your diagnoses of MS.

Disclaimer: The American Academy of Neurology recognizes that specific patient care decisions are the prerogative of the patient and the physician caring for the patient, based on all of the circumstances. This statement is provided as an educational service of the AAN. It is based on an assessment of current scientific and clinical information. It is not intended to include all possible proper methods of care for a particular neurologic problem or all legitimate criteria for choosing to use a specific procedure. Neither is it intended to exclude any reasonable alternative methodologies.