

# MS EMPOWERMENT SERIES

SHARED DECISION MAKING IN MULTIPLE SCLEROSIS



## LONG-TERM BENEFITS OF MS TREATMENT

*What Can Be Gained by  
Staying on Therapy?*



An educational series for people with multiple sclerosis (MS) developed in conjunction with the International Organization of MS Nurses (IOMSN)

Provided through educational grants from Bayer Healthcare Pharmaceuticals, Mallinckrodt, Sanofi Genzyme, Teva Pharmaceuticals, and Genentech, a Member of the Roche Group.

*“An MS nurse told me that when she first started out, a lot of her patients were a lot more disabled. She talks about the ‘waiting room full of wheelchairs’ that she doesn’t really see anymore. It’s encouraging to hear about a change in the impact of this disease.”*

— JOAN M., DIAGNOSED WITH MS IN 2008

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Developed by Delaware Media Group in conjunction with the International Organization of MS Nurses (IOMSN)

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## Hello, and welcome!

This brochure offers a brief overview of the benefits of starting and continuing disease-modifying therapy for MS.



As a neurology nurse specialist for over 30 years, I have been privileged to interact with many hundreds of people affected by MS and their loved ones. I often feel that I am learning as much from my patients as they are learning from me! Becoming more informed about the condition and how it affects each individual is one of the most important parts of the relationship between the MS nurse and the patient and family.

This MS Empowerment Series was developed for the International Organization of MS Nurses (IOMSN) to guide the conversation between you and your MS nurse specialist or other healthcare professional. However, the conversation does not stop here. Every person with MS is unique and is affected in different ways. The ideas and resources in this brochure can be used to discuss your own needs and set goals for managing your condition.

I have been inspired by many individuals over the years who have faced and overcome the barriers they encounter. I hope these materials help to inform, guide, and inspire you.

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# LONG-TERM BENEFITS OF MS TREATMENT

## WHAT CAN BE GAINED BY STAYING ON THERAPY?

Disease-modifying therapies (DMTs) are recommended to slow the progression of MS. Many people who start DMT want to know how long they will need to stay on the treatment.

### How Long Do I Need to Stay on the Medication?

MS is a chronic disease, meaning that it involves long-term or even lifelong treatment. The available drug treatments limit the damage to the central nervous system (CNS) that occurs with MS, but they do not “cure” the disease or eliminate the source of the damage. In addition, these treatments do not repair damage that has already occurred. Researchers are looking for ways to better protect the brain (*neuro-protection*) and repair damage (*neurorepair*). Until this work is successful, most MS treatments must be taken over long-term periods to protect from CNS damage.

### How Do I Choose the Right Treatment?

MS is a complex disease that is expressed differently in different people. Some people with MS may have difficulty walking, but for others the main problems are fatigue, or bladder dysfunction, or impaired vision. The severity of MS varies as well. You might have multiple acute “attacks” or relapses in a year (a sign of a more aggressive course) or go several years between




relapses. Therefore, no one treatment is right for everyone.

There are a number of different ways to administer MS therapies, including:

- Oral (by mouth).
- Injectable. Injected with a needle, either subcutaneously (SC, under the skin) or intramuscularly (IM, into the muscle).
- Intravenous. An intravenous (IV) infusion is administered into your vein, often at a specialized medical facility.

Your choice of treatment might be based on whether one of these methods seems more comfortable for you. But, you should also consider:

- whether your MS is aggressive and may require a “high-efficacy” treatment



*“Most people don’t know I have MS unless I tell them. But just because you can’t ‘see’ MS doesn’t mean it doesn’t affect me. People may judge me and think that I don’t have a disability—or that I don’t need a special parking sticker because I can walk. I just tell them, ‘I have MS, so I have good days and bad days’ or ‘I get tired quickly.’”*

— EMILY S., DIAGNOSED WITH MS IN 1996

- the safety of the drug and how it may affect your body
- how often blood tests and other follow-up steps are required
- whether you have medical conditions that prevent you from using a certain treatment

Your MS healthcare provider will go over the choices with you to help you pick a treatment that best suits your condition. The currently available MS agents are shown in the **Table** on page 8. To learn more about each of the ther-

apies, the National Multiple Sclerosis Society (NMSS) offers a good overview (see Resource box). You can also learn a lot from the patient support services provided by the manufacturer of your MS therapy. These programs vary from phone counseling to in-person support in which trained nurses meet with you in person to help establish a personal treatment plan.

### **Should I Wait Before Starting a Treatment?**

For many people with MS, starting DMT early has lasting benefits. We talk about the best “window of opportunity” for treating MS. This window is in the early stages, when MS activity is thought to involve more inflammation of the CNS. All of the available MS drugs target the disease in slightly different ways, but many of them work to limit or prevent CNS inflammation. This has been shown to prevent relapses, new lesions or worsening lesions in the brain and spinal cord MRI scans, and atrophy (shrinking) of the brain due to the loss of nerve cells.

Many people who participated in the early clinical trials of MS medications have been evaluated over the years to see how long-term treatment has affected their MS. In one early trial of MS therapy, participants were started out on an interferon (one of the few medications available at the time) or took a placebo for 2 years before they were switched to interferon therapy. Some 20 years later, we see that the treatment helped control the disease in both groups. However, those who received **early treatment** had:

**Table. Available Disease Modifying Therapies for Multiple Sclerosis\***

<b>Administration Method</b>	<b>Generic Name</b>	<b>Brand Name</b>	<b>Dosage Schedule</b>
Injectable	Interferon beta-1b	Betaseron Extavia	Every other day
	Interferon beta-1a IM Interferon beta-1a SC Peginterferon beta-1a	Avonex Rebif Plegridy	Once per week 3 times per week Every 2 weeks
	Glatiramer acetate	Copaxone 20mg Glatopa (generic) Glatiramer 20mg (generic) Copaxone 40mg Glatiramer 40mg (generic)	Once daily   3 times per week
	Daclizumab	Zinbryta	Once per month
Oral	Fingolimod	Gilenya	Once daily
	Teriflunomide	Aubagio	Once daily
	Dimethyl fumarate	Tecfidera	Twice daily
Intravenous (IV)	Natalizumab	Tysabri	Every 4 weeks
	Alemtuzumab	Lemtrada	Cycle 1: 5 consecutive days (One year later) Cycle 2: 3 consecutive days
	Ocrelizumab	Ocrevus	Every 6 months

\*As of January 2018  
IM=intramuscular; SC=subcutaneous

- Slower disease progression (delaying or avoiding the need to use a cane or other device for walking support)
  - Longer time until the onset of secondary progressive MS (more years before SPMS, or no conversion to SPMS)
- Fewer relapses each year

Remember, much of the neurologic damage in MS occurs “under the surface,” meaning that it can’t be detected in a doctor’s exam or on a standard MRI. You might not notice some of the effects of the damage because other parts





of your body or brain help to compensate—a concept called “functional reserve.” With the passage of time, the disease causes more unseen damage and functional reserve tends to be reduced, so more symptoms can affect you.

### **When Should I Change My Treatment?**

Because MS is a long-term disease, your body may respond differently to medications as time passes. This means a treatment that currently helps to control the disease might not have the same benefits in the future. A change in therapy may be necessary due to:

- *Efficacy*: the DMT is no longer controlling MS activity: this may mean a relapse on therapy, or an MRI showing new signs of inflammatory activity

- *Safety*: you have a complication that affects the safety of the drug for you, or side effects are intolerable and are affecting your daily life
- *Adherence*: you have difficulty taking to the therapy as prescribed. For some people who inject their drugs, “needle fatigue” occurs over time.
- *Advances*: a new therapy becomes available that is a better fit for you
- *Payment*: there is a change in the insurance coverage for the medication

Changes in therapy need to be approved by your healthcare provider, and in most cases need to be authorized by the insurance company or organization paying for the medication.

### **Can I Take a Break from Treatment?**

“Drug holiday” is a term sometimes used to refer to a short or even prolonged pause in treatment. You might feel you need a “drug holiday” for several reasons:

- You feel the treatment is not working the way you thought it would
- You feel that the risks outweigh the benefits
- Side effects are affecting your quality of life
- You feel like you have been on treatment for a long time

If you are considering stopping or taking a break in your MS treatment, discuss your reasons with an MS nurse or other healthcare professional. You may find there is a reasonable

solution for your problem, or even a legitimate reason to take a break. Some reasons might be that you're planning a pregnancy, or taking time between a change in therapy (sometimes called a "washout period"). Your healthcare provider should discuss with you whether the risks of MS disease activity might be too great to have a gap in treatment.


### **If I Haven't Had Relapse for a While, Do I Even Need Treatment?**

If your MS seems quiet, is it because you have a mild course, or because the medications are doing their job? This is a tough question to answer, so the next question is, is it worth the risk? There are data showing that nonadherence (not taking medications) and breaks in treatment increase the risk of relapses and progression of disability in MS. If we compare populations of people who have had MS for 20 years or more, those who have taken DMT have much greater benefits in the prevention of disability compared with untreated persons. This means less need for devices to help in walking, slower onset of progressive stages MS, and longer overall survival.

### **If I Have Secondary Progressive MS (SPMS), Do I Need a DMT?**

This issue is unclear for many people with MS. SPMS is a stage that occurs in many people after relapsing MS has become more advanced. Relapses usually slow or stop, but symptoms and disability may progressively worsen.

Many of the MS DMTs are approved for use in people with SPMS who have evidence of



*"I keep a journal of my MS journey, and when I look back on older entries I realize how much the treatment has helped me over time."*

— DIANE C., PHILADELPHIA AREA

inflammatory activity (relapses, or new MRI activity). However, many MS experts advocate continuing on a DMT (or switching to a different drug) for all or most patients with SPMS. This may help to prevent silent damage in the CNS. Several investigative therapies are being studied specifically for SPMS.

### **The Importance of a Healthy Lifestyle**

To many, it may seem that since MS is the overriding health problem, why worry about the small stuff? In fact, steps that you take to maintain your health can make a significant difference in how MS affects your body. Some of these steps include:

- Maintaining a healthy weight and diet
- Refraining from (or quitting) smoking
- Exercise/fitness activities recommended by your MS specialist
- Stress management techniques (including getting enough sleep)

# RESOURCE LIST

Resource	Source/Contact Information
<b>Consortium of MS Centers (CMSC)</b> An organization for MS care professionals that also provides many valuable resources for people with MS.	Website: <a href="http://www.mscares.org">www.mscares.org</a> Email: <a href="mailto:info@mscares.org">info@mscares.org</a> (201) 487-1050
<b>National Multiple Sclerosis Society (NMSS)</b> The largest MS advocacy group in the U.S., with the vision of "A World Free of MS."	Website: <a href="http://nationalmssociety.org">nationalmssociety.org</a> Email: <a href="mailto:contactusnmss@nmss.org">contactusnmss@nmss.org</a> (800) 344-4867
<b>Multiple Sclerosis Association of America (MSAA)</b> A national nonprofit organization dedicated to improving lives through vital services and support.	General Information email: <a href="mailto:webmaster@mymsaa.org">webmaster@mymsaa.org</a> MS questions email: <a href="mailto:MSquestions@mymsaa.org">MSquestions@mymsaa.org</a> Phone: (856) 488-4500 Helpline: (800)-532-7667 ext. 154
<b>Multiple Sclerosis Foundation (MSF)</b> A national nonprofit organization offering support groups and grant-based assistance.	Email: <a href="mailto:support@msfocus.org">support@msfocus.org</a> Phone: (888) 673-6287
<b>North American Research Committee on Multiple Sclerosis (NARCOMS)</b> An international patient registry service to collect information about living with MS that can be utilized by researchers to further the advancement of MS care.	Email: <a href="mailto:MSregistry@narcoms.org">MSregistry@narcoms.org</a> Phone: (800) 253-7884





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