

Special Issue on  
Medication Adherence

Winter 2013

# IMIS Perspectives™

Volume 6, Issue 3

Practical Insights on  
Multiple Sclerosis

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Real-life Strategies  
for Taking Your MS  
Medication
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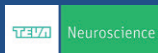
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“ Hope is the thing with feathers,  
That perches in the soul,  
And sings the tune without the words,  
And never stops at all. ”

—EMILY DICKINSON



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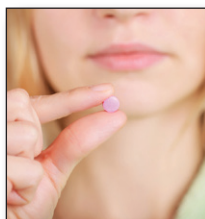
# MS Perspectives™

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# THE BEST MEDICINE:

## Real-life Strategies FOR Taking YOUR MS Medication

**H**aving a chronic illness such as multiple sclerosis (MS) and taking medication for it can be a challenge, to say the least. Oftentimes, people know they should be following their healthcare providers' instructions better, but they may not know how, they may forget the instructions, or they may not truly understand what's at stake. This issue of *MS Perspectives* addresses the whys and wherefores of people taking and not taking their MS medications, and offers tips on how you can not only improve your adherence to your healthcare providers' advice, but hopefully also your health.

### ***How big a problem is medication adherence?***

It is a common problem. In one study, one in 10 patients on injectable disease-modifying therapies (DMTs) missed more than 10 doses over a 6-month period. Another study found that up to 60% of people with MS discontinued their injectable treatment over a 2-year period. But injections aren't the only route of treatment that can cause lapses in medication use: People can also have trouble



adhering to the new oral MS drug regimens. “I find that having to remember to take a lot of different medications, what’s called ‘polypharmacy,’ is a big issue, especially for older adults,” says Barbara Green, MD, director of The MS Center of St. Louis in St. Louis, Missouri and an *MS Perspectives*’ advisor. “The more medications you have to take—MS drugs, blood pressure drugs, cholesterol drugs, diabetes drugs—the more complicated it becomes to take them correctly and on time.” Another *MS Perspectives*’ advisor, Tracy Walker, FNP-C, of the MS Institute at Shepherd Center in Atlanta, adds that “Many patients get tired of taking so many pills and decide to take only a few—but then they choose the wrong pills to stop. You

may not have symptoms if you discontinue taking your drugs for high blood pressure, cholesterol, or MS, but there is a silent, hidden risk of non-use.”



# FYI

*Did you know that...*

- ***Taking your MS medication correctly and on time can be a challenge, whether you’re using a pill, or an injected or infused drug.***
- ***All people with chronic illnesses—from diabetes to high blood pressure to heart failure—may not take medications as prescribed.***
- ***Barriers to correct and consistent usage of medications can include a lack of family support to assist with injections, cost, and insurance issues, among other things.***

## ***Is medication adherence just an issue for people with MS?***

No, you’re not alone! All people with chronic illnesses—from diabetes to high blood pressure to heart failure—may not take medications as prescribed. Adherence issues

can also affect people with acute (short-term) illnesses. “Think about people who are prescribed an antibiotic for 10 days—often, they don’t take the full dose because they start to feel better or they have side effects from the drug,” notes Barbara Bishop, MS, ANP-C, MSN, CNRN, a nurse practitioner with Virginia Beach Neurology in Virginia Beach, Virginia, and an *MS Perspectives*’ advisor.

### **Why do many people discontinue taking DMTs and other MS drugs?**

People discontinue taking medications or skip doses for a host of reasons—they experience side effects, they forget, they don’t think it’s helping them, they want to take a break from medications, they

have a fear of needles, or they don’t want to think about their illness.

“I think the greatest reason that people discontinue an MS drug is because they don’t fully understand the rationale for taking the drug—exactly what it can and cannot do,” says Dr. Green. It’s also difficult to deal with the unpredictable nature of MS and frustrating not being able to tell whether you would remain stable without the drug or your disease would progress.

### **What are barriers to taking MS medications?**

Unfortunately, there are many barriers to taking medications regularly. An absence of family support to assist with injections, cost and insurance

## HOW FAR WE’VE COME

The first case of MS is noted in a Dutch nun, Saint Lidwina of Schiedam



**1860s**

A variety of MS treatments are tried, including rest cures, bleeding, horseback riding, gold chloride, zinc, sulfate, silver nitrate, strychnine, and electrical stimulation



**1946**

A panel convened by the NMSS develops specific criteria for diagnosing MS



**1970s**

**1421**



Dr. Jean-Martin Charcot names the disease “sclerose en plaques”

**1860s-1900s**



Sylvia Lawry founds the group that will become the National Multiple Sclerosis Society (NMSS)

**1965**



Steroids are used to treat MS relapses



issues, a lack of access to a pharmacy, cognitive problems, emotional problems such as depression, and even, in some cases, language barriers are some key issues.

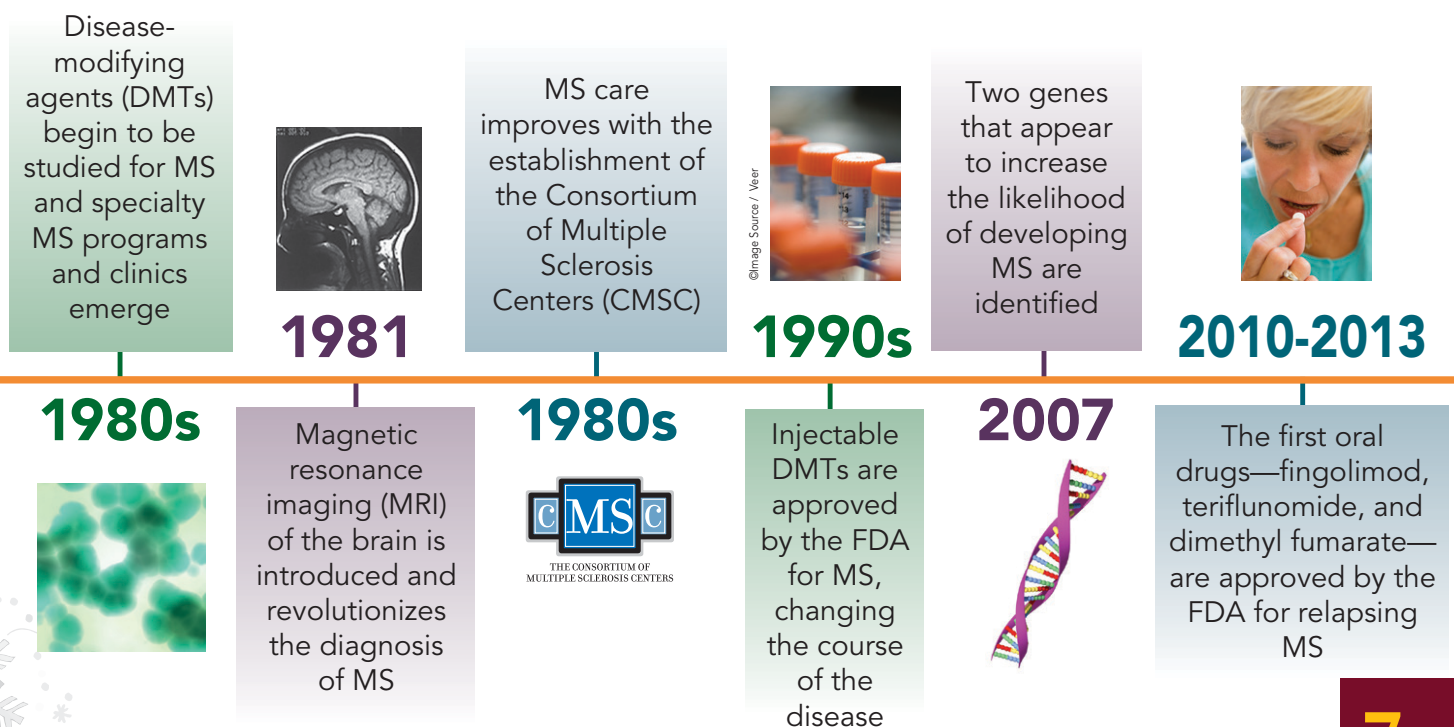
## ***Is missing or delaying medication a problem?***


Yes, since several studies suggest that not taking DMTs regularly increases your risk of disability. For example, a study of 632 patients with relapsing-remitting MS (RRMS) found that people who discontinued DMTs had more physical disability at 2 years than people who stayed on therapy. Other studies show that delaying medication use after the diagnosis of a clinically isolated syndrome (CIS) or MS can lead to permanent damage to the nervous system.

The key message: Have realistic expectations about treatment. DMTs can't completely stop MS, reverse the damage that's already been done, or prevent all relapses, but research does show that patients who are on treatment and stay on treatment continue to do better over time compared with patients who start treatment later or who frequently interrupt or stop treatment, or who take extended drug holidays (lasting months to years).

## ***What about taking too much medicine? Is that ever a problem?***

Sometimes, yes. People may forget a dose of their DMT and then try and catch up, says Ms. Bishop. "Some of these





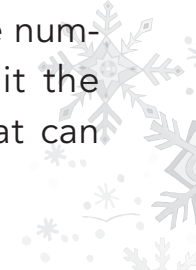
medications have very narrow therapeutic windows and if doses are taken too close together, they may become toxic or cause side effects. That's why it's so important to talk with your healthcare provider about your dosing schedule and what to do if you miss a dose."

## ***What are the available options for DMT?***

There are numerous options for DMT for relapsing forms of MS today, from injectables to oral and infusible drugs. Still other medications are in the pipeline, such as the infusible drugs ocrelizumab and alemtuzumab (the latter is a once-yearly infusion that was approved this past September for use in Europe). This means that if one medication is not working for you and your MS, you may have other options to try.

Trials are also underway with a number of drugs, such as ocrelizumab, fingolimod (Gilenya<sup>®</sup>), and natalizumab (Tysabri<sup>®</sup>), for the treatment of progressive forms of MS.

**Injectable drugs.** Even though most people perceive a pill as a better treatment option, injectables are still a staple of MS treatment. The reason? They have an excellent long-term safety record that doesn't exist with new drugs. Although they work in different ways from one another, both glatiramer acetate (Copaxone<sup>®</sup>), which is administered daily, and the interferons (Avonex<sup>®</sup>, Betaseron<sup>®</sup>, Extavia<sup>®</sup>, and Rebif<sup>®</sup>), which are administered every other day to weekly, have similar benefits. They all reduce the number and severity of relapses, limit the brain and spinal cord damage that can





## Holly: How I Take My MS Medication

**H**olly has been on an injectable medication for 10 years for her relapsing-remitting MS, ever since being diagnosed at the age of 32. “I’ve been pretty stable on this drug, and I’ve gotten used to doing the injections in the evening,” she explains. “I figure that if I was a diabetic, I’d have to give myself insulin shots, so this is a similar scenario. It doesn’t bother me.”

Holly actually works as a nurse with other people with MS. “I’ve learned from people who have lived with MS for 20 years or more that you’re going to have some down days, but if you do what your doctor tells you to and try to stay positive, you’ll be okay,” she says.

To remember to take her shots, Holly sets her cellphone alarm. Her husband also reminds her. When she gets down to her last four doses, she automatically calls the pharmacy for a refill, so she always has the medication in the house.

**Lesson to be learned:** Use reminders to help you take your medication—whether that’s a cellphone alarm or app, tying your medication use to your regular schedule, or relying on a family member to help you.



be seen on magnetic resonance imaging (MRI) scans, and delay the progression of MS. (Note: A three-times-weekly higher dose of Copaxone® is being studied, as is a twice-monthly subcutaneous injection of Avonex®.)

**Infusible drugs.** The infusible drug mitoxantrone (Novantrone®) is approved to treat different forms of MS (both relapsing and progressive types), but is

rarely used today. Natalizumab (Tysabri®), which is delivered monthly by infusion for relapsing forms of MS, is more typically the infusible drug prescribed. It is effective in reducing the rate of relapse and the progression of disability, but it can suppress the immune system, which in a small percentage of patients can lead to a risk of the serious infection known as progressive multifocal leuko-

## John: How I Take My MS Medication

**J**ohn was diagnosed with relapsing MS at the age of 24 and is now 32. He started on an injectable disease-modifying treatment (DMT) and continued with it for 8 years with no relapses or changes noted on his magnetic resonance imaging (MRI) scans. Unfortunately, earlier this year, he developed a serious staph infection in his leg as a result of injecting. Over the past year, his MS clinician has switched him to an oral medication, and although he did a good job giving himself three injections a week, he prefers the daily pill. "I'm terrified of needles, so I would have to get myself psyched up to give myself an injection," he recalls. "I never missed a dose, but I do find it easier to use the daily pill."

John recalls that "When I was first diagnosed with MS, I was totally in denial about it. I had been active my whole life, so I just didn't accept that I could have a disabling disease." Despite that denial, John *did* completely accept that he needed a disease-modifying drug and took it without resentment or doubt that it would help him, which gave him the motivation to stay on track with his injection schedule.

Now, John recognizes that it's important to not only take his pill on a daily basis, but to also have follow-up tests to make sure the drug isn't causing any issues. "I try to stay disciplined," he says. "I work every day, I eat healthy, I exercise, I take my medication, and I have no issues. I am very fortunate."

**Lesson to be learned:** Even if you can't see the benefits of the medication, you have to trust that it is doing its job "behind the scenes." Studies consistently show that people who start DMTs early in their disease course and continue with them have less progression of MS and less disability down the line.





cephalopathy (PML). Over the past few years, however, researchers have made progress in identifying the people who are most at risk for PML and identifying how best to protect them.

**Oral drugs.** Three disease-modifying oral drugs have been approved for relapsing forms of MS to date: Fingolimod (Gilenya®) was the first to be approved in 2010, followed by teriflu-

nomide (Aubagio®) in 2012 and dimethyl fumarate (Tecfidera®) in 2013. The three drugs work in different ways from one another and from the injectable and infusible DMTs. On-going studies are monitoring the safety and effectiveness of these drugs, and in some cases, whether they are of value for people who are at high risk for developing MS or in progressive forms of the disease.

### Support Programs for MS Disease-Modifying Therapies (DMTs)

**Aubagio®, Genzyme Corporation:**  
[www.aubagio.com](http://www.aubagio.com), 855-MSONEZONE (855-676-6326)

**Avonex®, Biogen Idec:**  
<http://www.avonex.com/multiple-sclerosis-support.xml>, 800-456-2255

**Betaseron®, Bayer HealthCare:**  
<http://www.betaseron.com>, 800-788-1467

**Copaxone®, Teva Neuroscience:**  
<http://copaxone.com/AboutSharedSolutions.aspx>, 800-887-8100

**Extavia®, Novartis:**  
<http://www.extavia.com/info/PatientSupport/Patient-support-program.jsp>, 888-NOW-NOVA (888-669-6682)

**Gilenya®, Novartis:**  
<http://www.gilenya.com/c/go-program>, 800-GILENYA (800-445-3692)

**Rebif®, EMD Serono/Pfizer Inc:**  
[www.mslifelines.com](http://www.mslifelines.com), 877-447-3243

**Tecfidera®, Biogen Idec:**  
<http://www.tecfidera.com/support/ms-support-services.html>, 800-456-2255

**Tysabri®, Biogen Idec:**  
<http://www.tysabri.com/ms-support-services.xml>, 800-456-2255

### MS News, Support, and Self-Help Groups

**MS Views & News**  
[www.msviewsandnews.org](http://www.msviewsandnews.org)

**MS World**  
[www.msworld.org](http://www.msworld.org)

**Multiple Sclerosis Association of America**  
[www.msassociation.org](http://www.msassociation.org), 800-532-7667

**Multiple Sclerosis International Federation**  
[www.msif.org](http://www.msif.org)

**Multiple Sclerosis Foundation**  
[www.msfocus.org](http://www.msfocus.org), 888-MSFOCUS

**National Multiple Sclerosis Society**  
[www.nationalmssociety.org](http://www.nationalmssociety.org), 800-344-4867

# Staying Safe on Your MS Medication



Barbara J. Green, MD

**W**hether you are taking your MS disease-modifying therapy (DMT) by self-injection, intravenous infusion, or by mouth, it is crucial to pay attention to the safety recommendations that will keep you healthy over the long term. If you start a new medication, you should receive careful education about it with regard to treatment outcomes, side effects, and needed testing. Additional counseling should occur if you report any adverse effects or if you experience an unex-

pected or a planned pregnancy.

In the table on the next page, you'll find a list of important pretreatment and follow-up evaluations recommended for the available DMTs. Always be sure to report any new symptoms or side effects to your MS provider as these could prompt additional needed laboratory or other testing. Also ask your MS doctor or nurse about recommendations for follow-up visits, which are crucial for early detection of safety issues and lack of drug efficacy.





Medication	Pretreatment Testing	Ongoing Treatment Monitoring
Aubagio®	MRI brain scan; CBC and CMP tests; TB skin or blood test—and if positive, a chest radiograph	MRI, LFT, CBC test, and skin check at the intervals recommended by your clinician
Copaxone®	MRI brain scan	MRI at the intervals recommended by your clinician and skin checks for severe/painful injection-site reactions as needed
Gilenya®	MRI brain scan; CBC, CMP, thyroid, and VZV titer tests; ECG; eye exam	MRI, CBC test, LFT, skin check, and eye exam as ordered by your clinician; ECG at the start and finish of the First Dose Observation period
Interferons (Avonex®, Betaseron®, Extavia®, Rebif®)	MRI brain scan, CBC, CMP tests	MRI, CBC test, LFT, and thyroid function test as ordered by your clinician, and skin checks for severe/painful injection-site reactions as needed
Tecfidera®	MRI brain scan; CBC and CMP tests	MRI, CBC and CMP tests as recommended by your clinician
Tysabri®	MRI brain scan; JC virus antibody test; CBC and CMP tests	MRI, JC virus test, CBC test, LFT, and skin check at the intervals recommended by your clinician

CBC=complete blood count; CMP=complete metabolic panel; ECG=electrocardiogram; LFT=liver function test; MRI=magnetic resonance imaging scan; TB=tuberculosis; VZV=varicella zoster virus (chickenpox).

# Ask the Clinician



Tracy Walker

**Q.** I know I should follow my healthcare providers' instructions better, but I don't. Help!

**A.** Whether it's taking medication, exercising regularly, following a specific diet, or wearing a brace—it's the million dollar question. *Why don't we "just do it"?* Research tells us that between 20% and 50% of people don't take their medications. Is it just human nature to resist instruction or procrastinate? Or is it that medical providers don't explain things clearly or educate their patients well enough? Perhaps our stressful lifestyles and fast-paced society are to blame, making it difficult to stay on track? Maybe some of all of the above?

How can we help ourselves and others find wellness even in the face of chronic illness and a crazy schedule? Well, I am still trying to answer that million-dollar question—and let me know if you have it figured out! In the meantime, my patients and life have taught me a few things that nursing school didn't cover:

**1. Ask "why?"** Why is this right for me or why not? Knowledge is power

and is often the first step in getting where you want to be. Write your questions down in advance of your medical visit and take a friend or family member with you. At the end of the visit, don't hesitate to ask for instructions in writing if you are not sure you understood everything.

**2. Use the tools you have available to help you follow the plan even when life gets stressful.** Whether it's an app for your smart phone (check out Copaxone iTracker™ and myBETA-app™) that can help you remember to take your medication, a note on the refrigerator, or a friend who will call and keep you accountable or cheer you up when life gets tough, make use of your resources. Also take advantage of the free nursing support programs offered by the pharmaceutical companies that make DMTs (see the box entitled "Support Programs for MS Disease-Modifying Therapies" on page 11).



**3. Be honest.** Tell your healthcare providers if you're struggling to follow a prescribed treatment regimen. They can help you figure out your personal barriers to successful treatment and possible ways of overcoming them. If all else fails, they may be able to

recommend another treatment option (which is the beauty of having so many different disease-modifying drugs for MS available).

**4. Connect tomorrow to today.** Many times we tell ourselves we will start that medicine tomorrow, start that exercise program tomorrow, start eating healthier tomorrow. The next thing we know, tomorrow has turned into 6 months later. Remind yourself that reaching your health goals for tomorrow means doing what you need to do *today*.

**5. Believe in yourself!**

Sometimes we get so frustrated with ourselves when we don't do everything perfectly that we lose sight of the positive steps we have taken. Give yourself a pat on the back for taking your medicine today and celebrate the positive.

—Tracy Walker, FNP-C  
Nurse Practitioner  
MS Institute at  
Shepherd Center  
Atlanta, Georgia



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