

# MS Perspectives™

Volume 6, Issue 2

Practical Insights on  
Multiple Sclerosis

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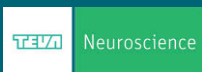
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A vast field of sunflowers stretches across the landscape under a bright sun in a clear blue sky. The sun is positioned in the upper right quadrant, creating a lens flare effect. The sunflowers are in full bloom, with bright yellow petals and dark brown centers. The field extends to a low horizon line, with a gentle rise in the distance.

“Eyes that do not cry,  
do not see.”

—SWEDISH PROVERB

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# Managing Fatigue **AND** Other Symptoms **TO** Improve Your Quality of Life



**T**he main goals of multiple sclerosis (MS) therapy are to reduce the accumulation of disability and brain lesions and the frequency of relapses with disease-modifying therapies (DMTs). Still, an equally important goal is to improve the quality of your life by controlling the symptoms—such as fatigue, sleep issues, low vision, poor mobility and balance, spasticity, memory and thinking problems, pain, and mood disorders—that can come with MS.

To manage symptoms, it's first important to be aware of them, says Aliza Ben-Zacharia, DrNP, ANP-BC, of Mount Sinai School of Medicine and one of *MS Perspectives'* advisors. For instance, fatigue is a major problem, affecting at least 2/3 of people with MS. "People often tell me that fatigue is the most disabling feature of their MS," she says.

"Fatigue can have multiple causes besides being related to the MS itself," continues Barbara Green, MD, director of the West County MS Center in St. Louis, Missouri and an *MS Perspectives'* advisor. "It can be related to sleep issues, to bladder problems that make it difficult for people

to sleep well through the night, or to other medical diseases or side effects from the combinations of drugs that people with MS are taking.”

## ***Getting to the Cause of Fatigue: A Step-by-Step Approach***

Dr. Green takes a methodical approach to determining the cause of fatigue in people with MS. As a first step, she considers whether fatigue is related to the drugs patients are using. She looks to see if they’ve started any new medications (including natural or herbal supplements) or if the doses of any medications have recently been increased. “Combinations of drugs, their doses, and when you take them can affect your sleep and cause fatigue and other side effects,” she explains.

“In addition, if you swap a brand-name drug for a generic, you might experience fatigue because your body may absorb that formulation differently or it may have additives that don’t agree with you.”

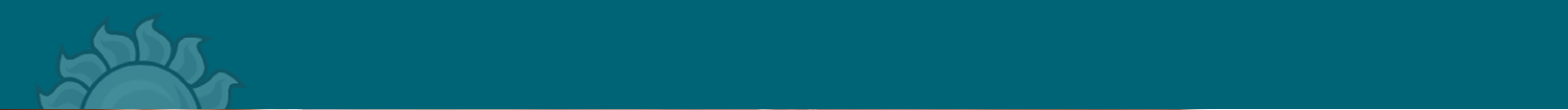
Next, Dr. Green considers whether fatigue is related to another medical condition, such as anemia (an iron deficiency), thyroid disease, or depression. “Treating those issues may resolve the fatigue,” she says.

Third, she evaluates whether fatigue is associated with poor sleep habits and sleep disorders, such as insomnia, restless legs syndrome, sleep apnea, bladder issues that

# FYI

*Did you know that...*

- ***Managing your MS symptoms is as important as stopping the progression of disability and minimizing the chance of relapse.***
- ***Common symptoms include fatigue, sleep issues, low vision, poor mobility and balance, spasticity, memory and thinking problems, pain, mood disorders, and bowel and bladder issues.***
- ***Fatigue, the most commonly reported and most disabling symptom of MS, can be related to the MS itself or to a host of other medical and lifestyle issues.***



cause people to get up a lot during the night, or hot flashes that wake women up during menopause. These problems can affect people with MS as well as those without MS. In addition, MS-related symptoms such as neurogenic bladder disorders and spasticity can disrupt sleep.

### Investigating Sleep Issues

Between 25% and 54% of people with MS have problems getting to sleep and staying asleep, which can have direct effects on how much energy you have during the day and whether or not you feel fatigued. “When I find out patients are sleeping poorly, the first thing I do is ask them about their sleep habits,” says

Dr. Green: “When do they go to bed? How many hours of sleep do they get? Do they get up at night to go to the bathroom or are they awakened by hot flashes, snoring (their partner’s or their own), or restless legs? Is anything going on in their lives that is making them feel stressed out and preventing sleep, such as a new job that has odd hours? Are they drinking coffee or alcohol in the evening, which can interfere with sleep?”

If any of these questions raise a red flag about sleep hygiene, there are many lifestyle changes that can be made to improve your sleep, such as:

- Keep to a regular sleep/wake schedule, going to bed and waking up at the same time each day.
- Avoid napping during the day.
- Only go to bed when you feel sleepy.



- Don't eat, read, or watch TV in bed—use the bed only for sleep and sex.
- Avoid stimulants such as caffeine and nicotine 4 to 6 hours before bedtime.
- Exercise regularly—it can boost your daytime energy and help you sleep better.
- Take a warm bath, meditate, or do yoga or other gentle relaxation exercises within an hour of bedtime to get you ready for sleep.
- Remove all bright lights from your bedroom—such as from a TV or a digital alarm clock—that can disrupt your ability to sleep.


### The Nightly Call of the Bladder

Both men and women can have trouble holding their urine overnight, again due to their MS, or to lifestyle habits that irritate the bladder, says Tracy Walker, FNP-C, of the MS Institute at Shepherd Center in Atlanta, and an *MS Perspectives*' advisor. "This



can interfere with their sleep, because it can be difficult to fall back asleep after they've gotten up to use the bathroom. Usually, these problems can be managed by following some lifestyle tips, but there are also numerous drugs we can prescribe to relieve symptoms," she says. (See the box "Managing Your Bladder" on page 8 for what you can do to soothe your bladder.)

Finally, if Dr. Green finds that fatigue is not being caused by another of these other conditions or persists after treatment of other issues, she considers whether it is a direct result of MS. In these cases, you will be taught energy-conservation techniques, says Dr. Ben-Zacharia: Pacing yourself, scheduling activities around the times when you have the most energy, and taking rest breaks. "Listen to your body and recognize when it says you've had enough for the moment," she advises. On the other hand, you will be encouraged to exercise as an energy-boosting strategy. "It's a



common misconception that exercise will make you more tired,” she says. “In fact, if you start to do aerobic exercise gradually and properly, and you combine it with strength-training exercises to improve your muscle tone, exercise can

actually improve your energy level.”

Several medications can also be prescribed, such as antidepressants and stimulants. Likewise, a supplement called acetyl-L-carnitine may help to reduce MS-related fatigue.

## MANAGING YOUR BLADDER

- **Avoid foods, drinks, and other substances that can irritate your bladder**

- Reduce or eliminate bladder irritants such as caffeine, alcohol, and spicy foods from your diet, and don’t smoke.

- **Be smart about your fluid intake**

- If you tend to drink a lot of fluids, reduce the amount to less than 2 liters daily.
- Drink less fluid in the evening if you frequently wake up during the night to go to the bathroom.
- Drink cranberry juice or take cranberry tablets to make your urine less friendly to bacteria and infections.

- **Train your bladder**

- Schedule regular bathroom breaks during the day—don’t hold it until you are ready to burst but don’t go too frequently either!

- **Do pelvic floor muscle exercises to strengthen the muscles that support the bladder**

- To find the pelvic floor muscles, tighten and loosen the muscles that you use to control urination.
- If you have urgency and frequency incontinence, where you have to urinate frequently and suddenly, do 5 to 10 quick squeezes of the pelvic muscles every time you visit the restroom. This can reduce leakage and the feeling of urgency.
- If you have stress incontinence, where you leak urine, twice a day squeeze the pelvic floor muscles and hold for a count of 10. (Count aloud and if your voice changes while you’re doing this exercise, that means you’re using your stomach muscles and not your pelvic floor muscles. Ask your MS clinician for guidance on how to find the right muscles to strengthen.)

- **If you are on an intermittent catheterization program, always catheterize before bedtime to prevent leaks that could wake you up**



# Safely Using Complementary AND Alternative Medicine (CAM)

By Barbara Bishop, MS, ANP-C, MSn, CNRN

**S**urveys suggest that three out of four people with MS try complementary and alternative medicine (or CAM), such as special diets, exercise regimens, acupuncture, reflexology, foods, and herbs. Seventy-five percent of people with MS are using at least one form of CAM at any one time. They may turn to CAM therapies because of the fear of disability, the lack of a cure for MS, and the unpredictability of the disease. CAM therapies may help people to feel like they are gaining control of the disease with more natural and less-intrusive remedies than conventional pharmaceutical medications.

Whatever your reason for using CAM therapies, you always need to ask some key questions about a specific intervention:

- What does it involve?
- How effective is it?
- How and why does it work?
- Are there any risks?
- What is the cost?

Once you have this information, if you

decide to move forward with a CAM therapy, keep these recommendations in mind:

- Always tell your healthcare provider you are using a CAM therapy.
- Don't replace a proven pharmaceutical therapy with a CAM therapy.
- Keep a log of what and how much you are taking and share that with your MS clinicians.



## ***Herbal Products Versus Pharmaceutical Drugs***

Herbal products may have many benefits, but they need to be used with caution because:

- They often have not been strictly researched (if at all).
- They can act in a similar way to prescription drugs (and some drugs are actually derived from herbs and plants).
- They can have unwanted side effects/interactions that haven't been identified or recognized.

- They may interact with prescription and over-the-counter drugs.
- They may contain multiple active ingredients in imprecise amounts, so you're

not sure if you're getting sufficient doses.

- They may claim to be "all natural" but that does not mean they are "all safe."

**The bottom line:** Both traditional and CAM therapies can have benefits for your MS symptoms, but be sure you discuss them with your MS clinicians so you're using them safely.

### CAM Resources

**Herbs at a Glance: A Quick Guide to Herbal Supplements** by the National Center for Complementary and Alternative Medicine and National Institutes of Health.

<http://www.nccam.nih.gov/health/herbsataglance.htm>

**Complementary and Alternative Medicine and Multiple Sclerosis** by Allen Bowling, MD, PhD

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

**Aubagio®**, Genzyme Corporation:  
[www.aubagio.com](http://www.aubagio.com), 855-MSONE2ONE (855-676-6326)

**Avonex®**, Biogen Idec:  
[www.avonex.com](http://www.avonex.com), 800-456-2255

**Betaseron®**, Bayer HealthCare:  
[www.betaseron.com](http://www.betaseron.com), 800-788-1467

**Copaxone®**, Teva Neuroscience:  
[www.sharesolutions.com](http://www.sharesolutions.com) or  
[www.copaxone.com](http://www.copaxone.com), 800-887-8100

**Extavia®**, Novartis:  
[www.extavia.com](http://www.extavia.com), 888-NOW-NOVA (888-669-6682)

**Gilenya™**, Novartis:

[www.gilenya.com](http://www.gilenya.com), 800-GILENYA (800-445-3692)

**Rebif®**, EMD Serono/Pfizer Inc:

[www.ms lifelines.com](http://www.ms lifelines.com), 877-447-3243

**Tecfidera™**, Biogen Idec:

[www.tecfidera.com](http://www.tecfidera.com), 800-456-2255

**Tysabri®**, Biogen Idec:

[www.tysabri.com](http://www.tysabri.com), 800-456-2255

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

**MS Views & News**

[www.msviewsandnews.org](http://www.msviewsandnews.org)

**MS World**

[www.ms world.org](http://www.ms world.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

# Consortium of Multiple Sclerosis Centers' Meeting

In the previous issue of *MS Perspectives*, we highlighted some important studies on multiple sclerosis (MS) presented at the American Academy of Neurology meeting. In this issue, we continue with our meeting update, this time with news from the Consortium of Multiple Sclerosis Centers' (CMSC) meeting, held in Orlando, Florida in May.



## Education Equals Adherence

**The study:** MS nurse Sarah Militello of the West County MS Center in St. Louis, Missouri, presented a poster of a five-step educational protocol developed at her center for helping people take the oral drug Gilenya™ (fingolimod) regularly and safely. She found that before the center started the educational process, only 29% of patients were taking Gilenya™ as prescribed and receiving the appropriate follow-up exams (such as lab tests and eye exams). After they initiated

the protocol, 81% of patients were taking the drug properly and having the necessary follow-up tests. "It's important that patients are well-informed when they start a drug," she said, "and they often have a ton of questions, so one of the keys to our success has been a 1-hour educational session scheduled after we know their insurance will pay for the drug or they can otherwise afford it." The session focuses on the risks and benefits for them, and if they're a good candidate for the drug. "The process has been successful for both our patients and the MS center staff in helping people do well on Gilenya™," she said, adding that they are applying it with modifications to the prescription of other MS drugs.

**What it means to you:** The more education and information you receive about any MS drug you're taking, the better you'll be at taking it—and hopefully, the better it will work for you.

## Three Times Weekly Copaxone® Is Effective

**The study:** Dr. Omar Khan of Wayne State University and colleagues from Russia, Poland, and Buffalo, NY, presented results of the



## The NARCOMS Patient Registry: Get Heard!

**H**ave you heard of the MS patient registry, known as the North American Research Committee on Multiple Sclerosis (NARCOMS)? NARCOMS was founded in 1993 by the Consortium of Multiple Sclerosis Centers (CMSC), and is a standing project of the CMSC. "It now contains data on over 36,000 people with MS," says Lisa Skutnik, Chief Operating Officer of the CMSC, "and is unique in medicine in that it is a large database of patient information that can be used to conduct research studies on the disease, its treatment, and insurance, employment, and disability issues."

NARCOMS is actively looking for more patients to enroll, so if you'd like to contribute to this important research effort, you can go to the NARCOMS website at <http://narcoms.org/> or call 800-253-7884. Once you've registered, you will be sent surveys in the Fall and Spring that take about 30 minutes to complete. As a thank-you for your participation, you'll receive NARCOMS NOW magazine, which offers insights into the results of the most recent surveys, MS news updates, and interviews with prominent people in the MS field.

Glatiramer Acetate Low Frequency Administration (GALA) study, which showed that three-times-a-week injections of a higher dose of Copaxone® are safe and effective in managing relapsing-remitting multiple sclerosis (RRMS). The study was conducted in over 17 countries with 1,404 subjects for 1 year. The regimen reduced the risk of relapses by a third (34%) compared with a placebo injection, as well as the number of new and total MS lesions seen on magnetic resonance imaging (MRI) scans. As with daily Copaxone® therapy, the most common adverse effect of the drug was soreness and redness at the site of the injections.

**What it means to you:** This more convenient disease-modifying therapy (DMT) for RRMS may be available in 2014.

## *Infusible Drug Effective in People with Very Active Relapsing-Remitting MS*

**The study:** Dr. Stephen Krieger of Mount Sinai Medical Center in New York City gave a presentation about the infusible drug alemtuzumab, which appears to be very effective at suppressing inflammatory activity in people with RRMS, particularly early in the disease course. The study looked at people who were still experiencing disease activity while on a DMT. One hundred and one people received infusions of alemtuzumab on 5 days at the start of the study and then on 3 days a year later, and were compared to 42 people who received injections of Rebif® (interferon beta 1a) three

times a week. Twenty-four percent of the people who received alemtuzumab had no MS disease activity (no relapses, no new lesions on MRI scans, no advancing disability) over the course of the 2-year study, while all of the people receiving Rebif® had relapses or other signs of active disease. The researchers noted that alemtuzumab meets the needs of people who don't respond to existing DMTs, but that must be balanced with the recognition that use of the drug may lead to serious immune disorders such as thyroid and kidney disease.

**What it means to you:** This new type of DMT, to be called Lemtrada, may be available in late 2013 or early 2014 for people who do not respond to other, safer DMTs.



# Ask the Clinician

**Q.** I was diagnosed with relapsing-remitting multiple sclerosis (MS) a couple of years ago. I had a tough time initially dealing with the diagnosis, and even now sometimes I have bouts of terrible sadness and then anger at myself for being down. Will these feelings ever go away?



*Kristina Seymour*

**A.** An MS diagnosis is life-altering on many levels, and not just immediately after you hear the news. Many patients become depressed for the first few months, and then reach a place of acceptance as they navigate beyond the initial shock and grief.

But that's not the end of the story. Sometimes people relapse into maladaptive ways of thinking and acting and then, as you describe, become angry at themselves for feeling down. In our groups, they ask "Why am I so sad about having MS again? I've already accepted it! I've already been sad about it."

The process of grief has been identified as the experience of loss in which one goes through stages of denial, anger, bargaining, depression, and acceptance. But acceptance is fragile, given the unpredictable nature of MS, its symptoms, and its impact on your life. As a result, grief can re-emerge at different times, bringing on intense

sadness, which can catch you off-guard because you don't expect it. This may lead you to become increasingly frustrated with yourself for wallowing or allowing yourself to sink into grief again. A helpful question in this situation is to stop and say, "Why am I this sad again now?" The key word here is "now." This question can help you to identify the current situation that may have triggered the sadness and the re-emergence of grief in regard to your MS.

Here is a story of how one man used this "now" question to get to the heart of his grief: The man had been diagnosed with MS at the age of 32 and was shocked and depressed for about 2 months. Eventually, however, with the right medical and professional help, he reached a place of acceptance. He was now 40 and in a wheelchair, and he could not drive independently anymore. Still, he was doing great up until recently, when he found himself increas-



ingly frustrated at the smallest things. He would even start crying suddenly, though he didn't know why. Why was he sad and angry *now*, seemingly out of the blue? Through a collaborative discussion, he and his therapist identified that he was distraught because his 15-year-old daughter was learning to drive—and he had been looking forward to teaching her this skill since she was a young child. When he realized how normal it was for him to grieve this loss, he was able to allow himself to feel sad and let go, and eventually the anger and tears subsided.

When many people think of grief, they think that it pertains to losing a loved one through death. Grief, however, is not just about death; rather, it is about loss. People with MS may experience loss in the following areas:

- loss of a healthy body-image and their perceptions of themselves;
- loss due to an inability to engage in their former hobbies;
- loss of a former career; and
- loss of reaching previously set life goals.

A re-emergence of grief can be associated with the anniversary of your diagnosis, important dates, or developmental markers (for yourself, your children, or other important family members,

friends, or colleagues). Developmental tasks in life such as a daughter getting married, which would traditionally require the father to walk her down the aisle, may occur with the ebb and flow of life and prompt grief regarding the new-found loss.

It's important to recognize that grief is not a simple, linear process that you can check off your to-do list, but rather a multifaceted and malleable concept, much like life and much like the symptoms of MS. Often, simply the awareness of the process of grief enables you to let go of any anger towards yourself for "being this sad again," allowing you to experience the emotions that need to be released so you can grieve the loss. Then, you can accept where you are in your life right now, and you can feel less stuck and more empowered.

It may be difficult for you to work through these feelings on your own, in which case I urge you to see a therapist or counselor to help you overcome this re-emergence of grief. If you don't know someone yourself, ask your MS clinician for a referral.

— Kristina Seymour, MA  
Doctoral Candidate  
Pain Institute at Shepherd Center  
Atlanta, Georgia



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