

MSAA

Winter/Spring 2013

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Bringing Information to People with Multiple Sclerosis

The Hidden Symptoms of MS



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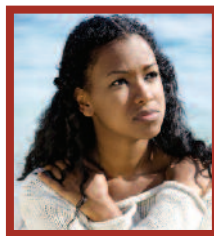
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WHAT'S THIS?

QR-code enabled smartphone users may scan this image to view this issue of *The Motivator* on their mobile device.



The Multiple Sclerosis Association of America is a leading resource for the entire MS community, improving lives today through vital services and support.

MSAA strives to provide useful, up-to-date information on matters of concern to MS patients and their families. This material is intended for general informational purposes only, and it does not constitute medical advice. You should not use the information presented as a means of diagnosis or for determining treatment. For diagnosis and treatment options, you are urged to consult your physician.

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A portion of this magazine has been printed on recycled paper using soy-based ink.



Douglas G. Franklin

A New Website, A New Mission

I have many new and exciting changes to announce for MSAA! These important initiatives have been in development for the past year, and appropriately for the spring season, have recently come to fruition.

The first item I want to announce is our new mission statement: “The Multiple Sclerosis Association of America is a leading resource for the entire MS community, improving lives today through vital services and support.” We also have a new tagline: “Improving Lives Today!” And finally, I am pleased to announce the launch of our new, user-friendly website at mysaa.org. All of these exciting developments will help us to build awareness of not only MS, but also the important services and support that we provide to the MS community.

MSAA’s new homepage features a newsfeed, social media links, and more features designed to inform and assist users



The launch of our completely redesigned and rewritten website, at mysaa.org, was a significant accomplishment. This offers easy-to-navigate sections, with highlights such as:

- A new homepage featuring an MS newsfeed, social media plugins, direct links to MSAA’s award-winning magazine, *The Motivator*, and our most recent *MS Research Update*, plus a full array of other options

mysaa.org



- An updated **About MS** section with information on disease-modifying treatments and symptom management; an overview covering topics such as who gets MS, types of MS, and what may cause MS; basic information for individuals who are newly diagnosed; and much more
- A new section titled **Manage Your MS** gives full details on MSAA's **Shared Management Tools (My MS Manager™, My MS Resource Locator, and S.E.A.R.C.H.™)**, as well as provides information on maintaining overall wellness when living with MS

Our new website also features: “MS Conversations,” MSAA’s blog for members of the MS community to exchange viewpoints and offer support; an extensive library of information – including MSAA’s published materials and MSi educational videos; access to information about all of MSAA’s programs and services (along with their applications); a calendar of events for MSAA activities across the nation; and more. Please be sure to visit our new website often!

In other MSAA news, as many of you know, **Swim for MS** is MSAA’s signature volunteer fundraising event! This program now features four-time Olympic Gold Medal Winner (and my niece) **Missy Franklin** as our Swim for MS Ambassador. Swim for MS provides the opportunity for anyone to create and arrange his or her own special Swim activity.

Anyone interested in participating may do so individually or recruit other swim enthusiasts to form a team. You will find several examples of creative ways to be a part of Swim for MS at www.SwimForMS.org. Most recently, two collegiate swimming programs, Seton Hall University and Ramapo College, hosted Swim for MS events during their Senior Day celebrations.

Both groups raised money for MSAA through their Swim for MS events. Seton Hall sold snacks at a stand during the meet, with all proceeds going to MSAA. Ramapo had a table where donations were collected directly from spectators who attended the meet. Many thanks for their efforts in raising much-needed donations for MSAA’s programs and services.

Now is the time to dive into action by signing up for **Swim for MS!** ♦

Doug Franklin joined MSAA as President & CEO in 1999. He has a distinguished career in nonprofit leadership and is a former national trainer in strategic planning for the Peter Drucker Foundation. A published international expert in social marketing and corporate social investment, he is a graduate of four universities. He currently serves on the National Board of the Key Philanthropic Organizations Committee of the American Society of Association Executives; on the Executive Committee of Health First – America’s Charities Board in Washington, DC; and as President of the Multiple Sclerosis Coalition.

A woman with blonde hair, wearing a red short-sleeved button-down shirt, is looking into a large, ornate mirror with a gold and black frame. She has her right hand near her ear and her left hand near her chest. The background is a patterned curtain.

The **HIDDEN** **SYMPTOMS** of MS

Managing the symptoms that those around you may not easily see or understand

Compiled and Edited by Susan Wells Courtney
Reviewed by Jack Burks, MD

We often hear people talk about the “hidden” or “invisible” symptoms of multiple sclerosis (MS). Many individuals with MS have difficulty explaining how uncomfortable they feel, especially when others around them remark that they don’t appear sick. Communicating the symptoms of MS that no one else sees can be difficult and even frustrating.

In this issue’s cover story, we address five symptoms that may be hard for others to see or understand: pain with MS; coping with fatigue; sleep issues (a contributing factor to fatigue); cognitive changes; and visual problems. Other symptoms could also fall under this category of “hidden” symptoms, but we limited our writing to just five areas,

so that we could provide adequate attention to each. Portions of the information provided are from previously published MSAA articles.

These sections have been co-written, reviewed, and edited by top MS experts outside of MSAA, and then reviewed again by MSAA’s Chief Medical Officer Jack Burks, MD. Please note that while specific treatment strategies and medications are listed, this information may not be considered as specific medical recommendations or advice. The details provided in this article are for informational purposes only, and readers are strongly urged to see their physician before making any changes to their treatment regimen, exercise routine, or any other aspect of their healthcare or lifestyle.

Pain with MS

Reviewed and edited by Heidi W. Maloni, PhD,
ANP-BC, CNRN, MSCN

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Pain with MS

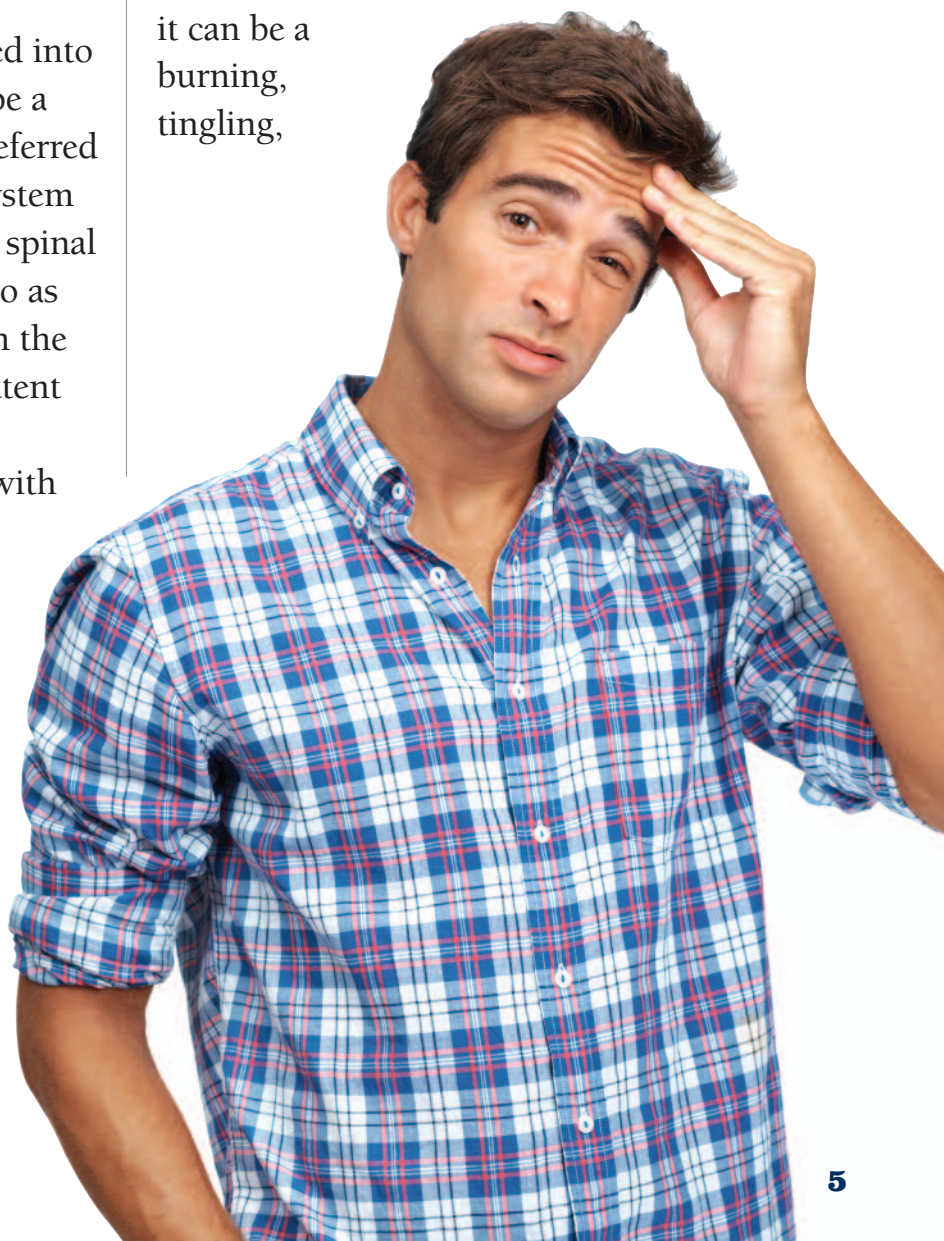
More than 50 percent of individuals with MS identify pain as a significant symptom. For many years, the medical community did not support the idea that pain could be caused by the effects of MS, but physicians today recognize that pain is a common symptom.

MS pain is mixed and may be divided into two different types. Pain from MS can be a direct result of damage to the nerves (referred to as “axons”) of the central nervous system (CNS), which consists of the brain and spinal cord. This first type of pain is referred to as **neurogenic**, and is caused by a lesion in the CNS. This type of pain may be intermittent or steady; spontaneous or evoked.

A second type of pain is associated with living with disability and its effects. This is referred to as **nociceptive**. Caused by any mechanism that stimulates a pain response, it can be mechanical, thermal, chemical, or electrical. Examples of this type of pain include musculoskeletal pain, lower-back pain, painful spasms, pain related to urinary-tract infection, pain of pressure sores, and even pain associated with disease-modifying drugs.

Neurogenic Pain

This type of pain lies within the axons (nerves) of the CNS that are either inflamed or are malfunctioning after the protective layer of myelin has been damaged. Nerve impulses may go off-track and spread to adjacent damaged nerve fibers, or nerve cells may become over stimulated and misfire. This type of “nerve excitability” is irritating to the nerve cells within the brain and spinal cord, often causing sudden and sharp pain. The sensation can be lightning-like and intermittent, or it can be a burning, tingling,



or a tight, “hug-like” feeling that can be continuous.

Surveys for patient pain indicate that the most common pain syndromes experienced in MS are: continuous burning in extremities; headache; back pain; and painful tonic spasms. **Examples of continuous MS pain syndromes include:**

- Steady dysesthetic pain, which is a burning, tingling, or tightening sensation, usually occurring in the legs and arms, but sometimes in the body; it is the most common chronic pain syndrome; it can be dull, nagging, or have a prickling sensation associated with warmth; it tends to be worse at night and after exercise; it is also aggravated by changes in temperature
- Severe spasms and spasticity (muscle tightness caused by impaired nerve impulses)

Examples of intermittent MS pain syndromes include:

- Chronic headaches, experienced by up to one-third of patients; more than half (54 percent) report headaches as a symptom at the time of diagnosis; migraines are three-times more common in MS than in the general population; headaches are not associated with disability or lesion burden
- Lhermitte’s sign, a shock-like sensation down the spine and legs when the neck is flexed; approximately 40 percent of individuals with MS experience this type of pain, although it usually does not require any treatment
- Optic neuritis, causing shooting pains in the eye

- Trigeminal neuralgia, a sharp facial pain brought on by a light touch or movement (occurring in roughly 2-to-5 percent of individuals with MS); up to one-third of these episodes can be bilateral (occurring on both sides of the face)

Non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen usually won’t work well on this type of pain. The over-stimulated nerves need to be calmed, and this may best be accomplished with anti-epileptic drugs, tricyclic antidepressants, and antispasticity drugs, to treat painful spasticity and spasms. Topical medications such as lidocaine gel or Zostrix® (capsaicin topical analgesic) may help reduce the burning and tingling. Optic neuritis is often treated with steroids to reduce the inflammation of the optic nerve. Non-pharmaceutical strategies may help to reduce the perceived severity of the pain. More information about specific treatments is provided later in this section.

Nociceptive Pain

This type of pain is usually less intense but can be long-lasting. For instance, weakness on one side of the body will cause someone to favor the other side and develop stiff joints; muscles can become twisted and cause the body to be unbalanced, frequently leading to muscle and joint pain. The same is true for spasticity (muscle stiffness) and spasms, as well as poor posture, with pain often occurring in the lower back. Even medications can sometimes cause painful side effects such as injection-site reactions, steroid-induced osteoporosis, and

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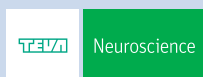
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degenerative joint disease.

Unlike neurogenic pain, neuromuscular pain may respond to NSAIDs, which includes ibuprofen (Advil® and Motrin®). Tylenol® (acetaminophen) may help with this type of discomfort too. Antidepressants are sometimes effective and their function is twofold: they may help to shift the perception of pain, while also elevating one's mood (living with chronic pain is known to increase depression, fatigue, and anxiety). Anti-spasticity medications may be used if spasticity and/or spasms are contributing to one's discomfort.

Non-pharmaceutical approaches include acupuncture, massage, tai chi, yoga, meditation, hydrotherapy, and physical therapy, among others. A physical therapist experienced with MS can be particularly useful in returning balance and good posture back to one's movement. Warm compresses can sometimes loosen a tight muscle or reduce lower back pain, while an ice pack is normally prescribed for a recent muscle injury or injection-site reactions. More information about specific treatments is provided later in this section on pain with MS.

MS experts caution their patients about chiropractic care as it can potentially aggravate the nerves of the back and neck. If back pain is severe, tests should be done to see if a pinched nerve, slipped disc, or other structural problem is at fault.

Monitoring Your Pain

The first step is to acknowledge your pain; only you know how severe and

persistent it is. The key is to work with your doctor to develop a pain-management plan. Chronic pain can become a quality-of-life issue, affecting not only how you feel, but also how you live your life. If pain continues despite treatment, clients should ask to be referred to a pain center, specifically one that is experienced with treating individuals with MS and can offer a team approach.

Pain with MS is a complex problem involving many issues. Keeping a “pain diary” and verbalizing precisely how the pain feels, where and when it occurs, and what factors increase, decrease, or change the pain, are crucial to an accurate diagnosis and optimum treatment plan. With a pain diary, you will be able to share with your doctor specific details about your pain that you might not otherwise recall or realize. To follow are some guidelines to what your medical professional will want to know.

The acronym OLD CART is used in medical schools and nursing schools to assess pain:

- Onset – when did your pain begin?
- Location – where does your pain occur?
- Duration – how long do your painful episodes last?
- Character – describe how the pain feels, i.e., is it sharp, dull, aching, burning, tingling, throbbing, etc.?
- Aggravating [factors] – what makes your pain worse?
- Relieving [factors] – what makes your pain better?
- Treatment – what are you doing, using, and/or taking to relieve your pain?

Please note that a few variations of OLD CART are used, including “OLD CARTS,” which adds an S for Severity (to rate the severity of the pain on a scale from 1 to 10).

Pain is also assessed by function or Pain Effects Scale, which evaluates the impact of pain on one’s quality of life. Factors considered include the following:

- Mood
- Ability to walk and move around
- Sleep
- Recreation
- Enjoyment of life

Treatments for Pain

A. DYSESTHESIAS

Dysesthesias are types of pain that are experienced as a burning or aching sensation. They are the most common types of pain seen in MS. The most frequently prescribed drugs used to treat this type of pain were originally developed as anti-seizure medications or antidepressants.

Pharmacologic Management

Anti-Seizure Agents, including (first-line, newer drugs) Neurontin® (gabapentin) and Lyrica® (pregabalin); (second-line) Tegretol® (carbamazepam) and Dilantin® (phenytoin)

Anti-Anxiety Agents, including Cymbalta® (duloxetine hydrochloride) and Klonopin® (clonazepam)

Tricyclic Antidepressants, including Elavil® (amitriptyline), Pamelor™ (nortriptyline), Norpramin® (desipramine), and others

As noted later in this section on pain, the drug tramadol (brand names include Ultram®, Ultram® ER, ConZip™, and Ryzolt™) may sometimes be used as a “rescue” drug for burning dysesthesias.

B. TRIGEMINAL NEURALGIA

Trigeminal neuralgia is a “lightning-like” stabbing pain in the face. It is the result of damage to the trigeminal nerve, which innervates (provides the nerve supply to) the side of the face. Trigeminal neuralgia can usually be treated with medications such as anti-seizure agents.

Pharmacologic Management (These include anti-seizure, anti-spasticity, anti-anxiety, and anti-pain medications)

First line: Tegretol® (carbamazepine)

Second line: Oxtellar XR™ and Trileptal® (oxcarbazepine); Lamictal® (lamotrigine); and baclofen (formerly available as Lioresal®)

Other options: Dilantin® (phenytoin), Klonopin® (clonazepam), Depakene® (valproic acid), Lyrica® (pregabalin), Neurontin® (gabapentin), and intranasal lidocaine

As noted later in this section, the drug tramadol (brand names include Ultram®, Ultram® ER, ConZip™, and Ryzolt™) may sometimes be used as a “rescue” drug for trigeminal neuralgia.

Surgical procedures

Surgical procedures to reduce pressure on the trigeminal nerve are possible in some situations.

C. LHERMITTE'S SIGN

Lhermitte's sign is a brief, stabbing pain that occurs when the neck is bent forward. It moves from the head down the spine, and usually lasts for less than a second. It may go away without specific treatment, as inflammation in the spinal cord decreases with other types of treatment or simply over time.

Non-Pharmacologic Management

A soft neck collar is often used to prevent the forward movement that triggers the pain.

Pharmacologic Management

Lhermitte's sign is not typically painful and does not require pharmacological management, as the risk of side effects from medication does not outweigh the benefits. New onset of Lhermitte's sign or a reappearance of Lhermitte's sign may indicate an MS exacerbation (or a new or worsening cervical-cord lesion). If Lhermitte's sign is an indication of an MS relapse, your physician may discuss prescribing steroids or other relapse treatment. Acthar® Gel (ACTH given via injection) is another option for treating MS relapses.

D. BACK AND OTHER MUSCULOSKELETAL PAIN

Back and other musculoskeletal pain in MS can have many causes, including spasticity. Pressure on the body caused by immobility, incorrect use of mobility aids, or the struggle to compensate for gait and balance problems may all contribute as well. An evaluation to pinpoint the source of the pain is essential.

Non-Pharmacologic Management

A variety of strategies may prove helpful in managing musculoskeletal pain. These may include heat, massage, ultrasound, evaluation of gait and seating by a physical therapist, and treatments for spasticity. A variety of relaxation techniques have proven helpful, as have acupuncture and acupressure. Acceptance and Commitment Therapy (ACT) may be of help. According to GoodTherapy.org, ACT uses mindfulness skills to develop psychological flexibility and helps clarify and direct values-guided behavior. Mindfulness-based interventions include therapies such as behavioral activation, hypnosis, and relaxation techniques.

Pharmacologic Management

Tylenol® (acetaminophen), or non-steroidal anti-inflammatory drugs (NSAIDs) such as Advil® (ibuprofen), may be helpful in managing a variety of types of musculoskeletal pain. Individuals taking these pain relievers should check with their doctor and follow prescribing instructions. Too much of these medications can cause serious side effects, including liver damage.

Botox® (botulinum toxin) can be effective in treating migraine headache, which is common in MS. Botox also helps other pain, including pain from muscle spasms in MS.

Complementary and Alternative Medicine (CAM) Therapies

Readers are advised to consult their physician before trying any new treatment, including these types of CAM therapies.

Acupuncture has been studied as a possible therapy for a number of MS symptoms. Pain is the one symptom that has shown a consistent positive response to this approach, and it may be effective when provided by an experienced practitioner. The technique involves inserting and manipulating fine needles in specific points on the body. According to traditional Chinese medical theory, acupuncture points are located along meridians through which chi (vital energy) flows. There is no known anatomic basis for the existence of acupuncture points or meridians, but the technique may work in certain specific situations.

Acupressure is essentially a variation of acupuncture, but involves applying physical pressure to acupuncture points. As with acupuncture, the points to which pressure is applied may or may not be in the same area of the body as the targeted symptom.

Guided imagery is a meditative process focused on self-healing, relaxation, and self-awareness. It is a relaxation technique that is based on the concept that the mind and body function as a single entity, and may help manage stress and reduce tension.

Biofeedback involves measuring bodily functions such as blood pressure, heart rate, skin temperature, sweat gland activity, and muscle tension. In theory, this ultimately allows you to increase your conscious control of what are normally unconscious physiologic activities. By providing you with information about physiologic functions that are normally not perceived at a conscious level, it is believed by some to allow people

to achieve control over these functions.

Both **yoga** and **tai chi** are based on traditional Asian medicine, and both have been shown to be of significant value in managing MS by allowing individuals to increase strength, flexibility, and balance. Several excellent books and videos are available that can help people develop a program that will assist in an overall management program for MS.

The medical use of **cannabis** (marijuana) is controversial since it has not been legalized nationally, but certain states have legalized its use by prescription through approved distribution centers. Studies with MS patients and cannabis for symptom relief are limited and the results have been mixed.

Additionally, there have been reports of adverse cognitive effects on people with MS. A recent report indicating that cannabis is associated with strokes in young people is also concerning. Your healthcare professional can help you to better understand the risks versus the benefits of cannabis in treating certain MS symptoms.

When Are Opioids Prescribed?

With certain diseases and conditions involving severe pain that is not responsive to other drugs, opioids are a type of drug that is sometimes prescribed. With MS, opioids are not as effective, and they are typically avoided. When these drugs are prescribed for any condition, doctors are cautious, as people become dependent upon them when used for a period of time. This is not a problem if managed correctly by the

prescribing doctor, and when discontinuing the drug, care is taken to do so gradually. However, some people will abuse this type of medication.

What are opioids? Opioids are all related to morphine, and include such familiar brand names as OxyContin® and Percocet® (both are brand names for the drug oxycodone), and Vicodin® (hydrocodone). Several other related drugs are members of the opioid family, including morphine, which is marketed under the brand names of Astramorph® and Avinza®. According to WebMD, “Opioid analgesics suppress your perception of pain and calm your emotional response to pain by reducing the number of pain signals sent by the nervous system and the brain’s reaction to those pain signals.”

Heidi W. Maloni, PhD notes, “Opioids are used in MS pain, but not as a first-line drug. I will often use the weaker opioid-drug tramadol (brand names include Ultram®, Ultram® ER, ConZip™, and Ryzolt™) as a “rescue” drug when the pain of trigeminal neuralgia becomes unbearable, or in cases of burning dysesthesias. I try very hard to avoid opioids.

“When are opioids indicated? When pain is moderate to severe, has significant impact on function and on quality of life, when non-opioids have been tried and failed, and very importantly, when the patient is agreeable to having opioids closely monitored, which may include signing a controlled-substance agreement, pill counts, and urine drug testing.

“A meta-analysis of opioid use in neuropathic pain from 1966 to 2004

indicated a significant effect on pain (reduction of 2 points on the Visual Analogue Scale) with those taking opioids compared to placebo. These were studies of short-term use. Use longer than six months has not been established from clinical trials. This means that in terms of treating neuropathic pain, the recommended efficacy and safety, abuse/addiction potential, and effects on quality of life, are not established. Three studies of opioids in MS pain showed a poor response to opioids or a response only at high doses. Side effects include constipation, nausea, dizziness, and drowsiness.”

Chronic opioid use can alter brain chemistry and can cause more intense pain. One study concluded that only a minority of the patients with central pain due to MS responded to morphine and only at high doses. Neuropathic pain is poorly responsive to opioids. Routine use of strong opioids in MS was not recommended. (Kalman et al; *Eur J Pain*. 2002;6[1] study on opioids and pain).

Dr. Maloni explains, “Those experiencing MS pain have the capacity to accept and manage their pain. By becoming more active, as well as seeking human interaction and support, one’s perception of pain may be reduced. Using techniques such as mindfulness, along with a careful use of medications – such as using low doses of several medications, to avoid side effects of excess drowsiness and constipation – are important strategies to help individuals who are coping with MS pain.”

Coping with Fatigue

Reviewed and edited by David Rintell, EdD,
Psychologist, Partners MS Center and Partners
Pediatric MS Center, Boston, Massachusetts

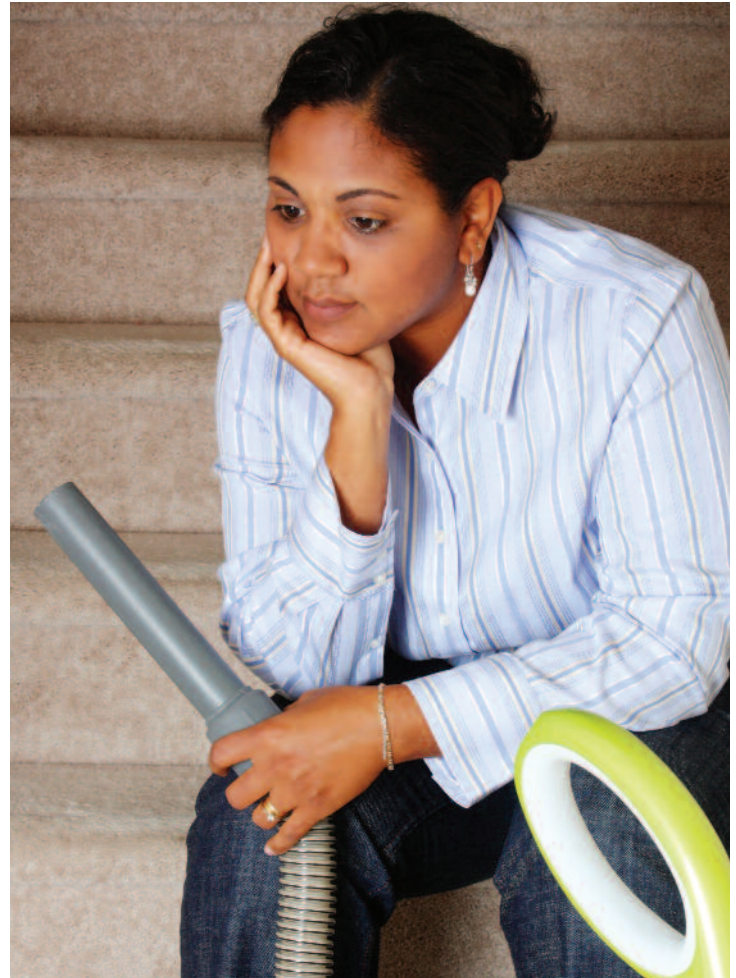
MS Fatigue

Fatigue has been described as an “overwhelming sense of tiredness.” Up to 80 percent of people with MS experience the disabling effects of fatigue. This overwhelming tiredness could occur any time in the course of MS, and it has not been shown to be related to measures of disability like the EDSS (Extended Disability Status Scale). Many people with MS find that fatigue increases as the day goes on, and worsens with a rise in body temperature, which might be caused by hot and humid weather.

Fatigue can be difficult for family members and friends to understand, because it is invisible to others. If fatigue is poorly understood, a person with MS who is experiencing fatigue might be characterized as “lazy.” Educating family, friends, and partners about MS fatigue is very important.

Many people with MS find that fatigue limits their enjoyment and participation in many activities. Fatigue can make performing tasks on the job or at home difficult. Although we do not know at this time what causes fatigue in MS, a number of influences on fatigue have been identified. Among others, these include depression, poor sleep, and sedating medications.

People who are depressed but do not have MS also frequently experience fatigue, and fatigue is one of the symptoms used to



diagnose depression. Much of MS fatigue is thought to be related to undiagnosed depression. As noted later in this section, medication that helps depression is also helpful for fatigue. Other common symptoms of depression are low mood, reduced interest, reduction in the enjoyment of activities that are usually enjoyable, a feeling of hopelessness, and irritability. If you feel that you might be experiencing depression, discussing this with your physician is important. Treating depression can also help with fatigue.

Sleep problems are very common in people with MS. They may lose sleep due to

bladder problems, limb movements, poor sleep habits, or depression. Sleep difficulties are thought to likely be another cause of depression.

Other Causes of Fatigue

Some fatigue experienced by people with MS is not actually caused by the MS. For example, a person might feel fatigued due to poor sleep, infection, medications, or depression.

Medications taken to solve other problems can contribute to fatigue. If you look at your pill bottles, some say, “May cause drowsiness” or “Do not operate heavy machinery while taking this medication.” These warnings indicate that the medicine is sedating, i.e., it can make you tired. Medications that are used to treat bladder dysfunction, spasticity, and pain can cause fatigue in MS patients. If this is the case and you are experiencing fatigue, a good place to begin is to review all of your medications with your physician.

Conserving Energy

People with MS who experience fatigue often feel as though their “batteries have run low” after doing some of their daily activities. A brief rest often serves to recharge the batteries, so it’s possible to finish the task. Planning one’s activities can help, such as trying not to go up and down the stairs more often than necessary, and other types of energy conservation can help.

One of the consequences of reduced activity and movement is deconditioning. It

is not advisable for a person with MS to rest more than necessary. In fact, while a person with MS may feel very tired after exercise, exercise is one of the best ways to build endurance and reduce fatigue.

Scheduling and planning ahead can be very helpful with saving energy. Listing activities in their order of importance enables a person to see clearly what needs to be done first and what can wait until another day – should all energy be used up before reaching the end of the list.

Those with limited energy can learn to accept that not everything will necessarily be completed when and how one prefers them to be done. In most cases, an unfinished job or activity will still be there the next day. By waiting, more energy and enjoyment will be found in accomplishing the task at a later time.

Scheduling sufficient periods for rest and alternating them with periods of physical exertion can be helpful, to avoid becoming too tired too quickly. Should you take on a project that is too much to handle at one time, divide it into smaller parts and schedule things accordingly. If this is not possible, you may want to have someone lend a hand to accomplish the task and avoid overexertion.

Energy-Saving Techniques

Efficiency and energy-saving techniques are very useful in combating fatigue while tackling household duties. Whenever possible – such as when cooking or cleaning – supplies should be arranged in advance so

FOR RELAPSING FORMS OF
MULTIPLE SCLEROSIS (MS)

HEY MS,

TAKE THIS!

GILENYA CUTS RELAPSES IN HALF

Not actual patients.

Only GILENYA® combines proven efficacy to cut MS relapses in half versus a leading injectable in a once-daily* pill.

GILENYA reduced the frequency of relapses by 52% in a 1-year study vs interferon beta-1a IM, and 54% in a 2-year study vs placebo.

Indication

GILENYA is a prescription medicine used to treat relapsing forms of multiple sclerosis (MS) in adults. GILENYA can decrease the number of MS flare-ups (relapses). GILENYA does not cure MS, but it can help slow down the physical problems that MS causes.

Important Safety Information

You should not take GILENYA if in the last 6 months you experienced heart attack, unstable angina, stroke or warning stroke, or certain types of heart failure. Do not take GILENYA if you have certain

types of an irregular or abnormal heartbeat (arrhythmia), including a heart finding called prolonged QT, as seen on a test to check the electrical activity of your heart (ECG) before starting GILENYA. You should not take GILENYA if you take certain medicines that change your heart rhythm.

*GILENYA can result in a slow heart rate when first taken. Your first dose will be given in a medical facility where you will be watched for at least 6 hours. If you stop taking GILENYA for more than 14 days after your first month of treatment, you will need to repeat this observation.

Please see additional Important Safety Information on next page.



READY TO TELL MS WHAT YOU REALLY THINK?

Go to gilenya.com to learn more. And join thousands of people taking a stance against their relapsing MS with GILENYA.



Important Safety Information

GILENYA may cause serious side effects such as:

- Slow heart rate, especially after your first dose. An ECG will be performed before and 6 hours after your first dose. Your pulse and blood pressure should be checked every hour while you stay in a medical facility during this time. If your heart rate slows down too much, you might feel dizzy or tired, or feel like your heart is beating slowly or skipping beats. Symptoms can happen up to 24 hours after your first dose. After 6 hours, if your ECG shows any heart problems or if your heart rate is still too low or continues to decrease, you will continue to be watched by a health care professional. If you have any serious side effects after your first dose, especially those that require treatment with other medicines, you will stay in a medical facility to be watched overnight and for at least 6 hours after your second dose of GILENYA the next day. If you have certain types of heart problems, or if you are taking certain types of medicines that can affect your heart, you will be watched overnight after you take your first dose. If you experience slow heart rate, it will usually return to normal within 1 month. Call your doctor or go to the nearest emergency room right away if you have any symptoms of a slow heart rate. If you stop taking GILENYA for more than 14 days after your first month of treatment, you will need to repeat this observation.
- Increased risk of serious infections. GILENYA lowers the number of white blood cells (lymphocytes) in your blood. This will usually go back to normal within 2 months of stopping GILENYA. Your doctor may do a blood test before you start GILENYA. Increased risk of infection was seen with doses higher than the approved dose (0.5 mg). Two patients died who took higher-dose GILENYA (1.25 mg) combined with high-dose steroids. Call your doctor right away if you have fever, tiredness, body aches, chills, nausea, or vomiting.
- Macular edema, a vision problem that can cause some of the same vision symptoms as an MS attack (optic neuritis), or no symptoms. Macular edema usually starts in the first 3 to 4 months after starting GILENYA. Your doctor should test your vision before you start GILENYA; 3 to 4 months after you start GILENYA; and any time you notice vision changes. Vision problems may continue after macular edema has gone away. Your risk of macular edema may be higher if you have diabetes or have had an inflammation of your eye (uveitis). Call your doctor right away if you have blurriness, shadows, or a blind spot in the center of your vision; sensitivity to light; or unusually colored vision.
- Breathing problems. Some patients have shortness of breath. Call your doctor right away if you have trouble breathing.
- Liver problems. Your doctor should do blood tests to check your liver before you start GILENYA. Call your doctor right away if you have nausea, vomiting, stomach pain, loss of appetite, tiredness, dark urine, or if your skin or the whites of your eyes turn yellow.
- Increases in blood pressure (BP). BP should be monitored during treatment.

GILENYA may harm your unborn baby. Talk to your doctor if you are pregnant or planning to become pregnant. Women who can become pregnant should use effective birth control while on

GILENYA, and for at least 2 months after stopping. If you become pregnant while taking GILENYA, or within 2 months after stopping, tell your doctor right away. Women who take GILENYA should not breastfeed, as it is not known if GILENYA passes into breast milk. A pregnancy registry is available for women who become pregnant during GILENYA treatment. Call 1-877-598-7237 or visit www.gilenyapregnancyregistry.com for more information.

Tell your doctor about all your medical conditions, including if you had or now have an irregular or abnormal heartbeat; history of stroke or warning stroke; heart problems; a history of repeated fainting; a fever or infection, or if you are unable to fight infections; eye problems; diabetes; breathing or liver problems; or high blood pressure. Also tell your doctor if you have had chicken pox or have received the vaccine for chicken pox. Your doctor may do a test for the chicken pox virus, and you may need to get the vaccine for chicken pox and wait 1 month before starting GILENYA.

Tell your doctor about all the medicines you take, including medicines for heart problems or high blood pressure or other medicines that may lower your heart rate or change your heart rhythm; medicines that could increase your chance of infections, such as medicines to treat cancer or control your immune system; or ketoconazole (an antifungal) by mouth. If taken with GILENYA, serious side effects may occur. You should not get certain vaccines while taking GILENYA, and for at least 2 months after stopping.

The most common side effects with GILENYA were headache, flu, diarrhea, back pain, abnormal liver tests, and cough.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see additional Important Safety Information on previous page.



Please see Brief Summary of Important Product Information on next pages.

MEDICATION GUIDE
GILENYA™ (je-LEN-yah)
(fingolimod)
capsules

Read this Medication Guide before you start using GILENYA and each time you get a refill. There may be new information. This information does not take the place of talking with your doctor about your medical condition or your treatment.

What is the most important information I should know about GILENYA?

GILENYA may cause serious side effects, including:

- 1. Slow heart rate (bradycardia or bradyarrhythmia) when you start taking GILENYA.** GILENYA can cause your heart rate to slow down, especially after you take your first dose. You will have a test to check the electrical activity of your heart (ECG) before you take your first dose of GILENYA.

You should stay in a medical facility for at least 6 hours after you take your first dose of GILENYA.

After you take your first dose of GILENYA:

- Your pulse and blood pressure should be checked every hour.
- You should be watched by a healthcare professional to see if you have any serious side effects. If your heart rate slows down too much, you may have symptoms such as:
 - dizziness
 - tiredness
 - feeling like your heart is beating slowly or skipping beats
- If you have any of the symptoms of slow heart rate, they will usually happen during the first 6 hours after your first dose of GILENYA. Symptoms can happen up to 24 hours after you take your first GILENYA dose.
- 6 hours after you take your first dose of GILENYA you will have another ECG. If your ECG shows any heart problems or if your heart rate is still too low or continues to decrease, you will continue to be watched.
- If you have any serious side effects after your first dose of GILENYA, especially those that require treatment with other medicines, you will stay in the medical facility to be watched overnight. You will also be watched for any serious side effects for at least 6 hours after you take your second dose of GILENYA the next day.
- If you have certain types of heart problems, or if you are taking certain types of medicines that can affect your heart, you will be watched overnight after you take your first dose of GILENYA.

Your slow heart rate will usually return to normal within 1 month after you start taking GILENYA.

Call your doctor or go to the nearest emergency room right away if you have any symptoms of slow heart rate.

- 2. Infections.** GILENYA can increase your risk of serious infections. GILENYA lowers the number of white blood cells (lymphocytes) in your blood. This will usually go back to normal within 2 months of stopping treatment. Your doctor may do a blood test before you start taking GILENYA. Call your doctor right away if you have any of these symptoms of an infection:
- fever
 - tiredness
 - body aches
 - chills
 - nausea
 - vomiting

- 3. A problem with your vision called macular edema.** Macular edema can cause some of the same vision symptoms as an MS attack (optic neuritis). You may not notice any symptoms with macular edema. Macular edema usually starts in the first

3 to 4 months after you start taking GILENYA. Your doctor should test your vision before you start taking GILENYA and 3 to 4 months after you start taking GILENYA, or any time you notice vision changes during treatment with GILENYA. Your risk of macular edema may be higher if you have diabetes or have had an inflammation of your eye called uveitis.

Call your doctor right away if you have any of the following:

- blurriness or shadows in the center of your vision
- a blind spot in the center of your vision
- sensitivity to light
- unusually colored (tinted) vision

What is GILENYA?

GILENYA is a prescription medicine used to treat relapsing forms of multiple sclerosis (MS) in adults. GILENYA can decrease the number of MS flare-ups (relapses). GILENYA does not cure MS, but it can help slow down the physical problems that MS causes.

It is not known if GILENYA is safe and effective in children under age 18.

Who should not take GILENYA?

Do not take GILENYA if you:

- have had a heart attack, unstable angina, stroke or warning stroke or certain types of heart failure in the last 6 months
- have certain types of irregular or abnormal heartbeat (arrhythmia), including patients in whom a heart finding called prolonged QT is seen on ECG before starting GILENYA
- are taking certain medicines that change your heart rhythm

If any of the above situations apply to you, tell your doctor.

What should I tell my doctor before taking GILENYA?

Before you take GILENYA, tell your doctor about all your medical conditions, including if you had or now have:

- an irregular or abnormal heartbeat (arrhythmia)
- a history of stroke or warning stroke
- heart problems, including heart attack or angina
- a history of repeated fainting (syncope)
- a fever or infection, or you are unable to fight infections. Tell your doctor if you have had chicken pox or have received the vaccine for chicken pox. Your doctor may do a blood test for chicken pox virus. You may need to get the vaccine for chicken pox and then wait 1 month before you start taking GILENYA.
- eye problems, especially an inflammation of the eye called uveitis.
- diabetes
- breathing problems, including during your sleep
- liver problems
- high blood pressure
- Are pregnant or plan to become pregnant. GILENYA may harm your unborn baby. Talk to your doctor if you are pregnant or are planning to become pregnant.
 - Tell your doctor right away if you become pregnant while taking GILENYA or if you become pregnant within 2 months after you stop taking GILENYA.
 - If you are a female who can become pregnant, you should use effective birth control during your treatment with GILENYA and for at least 2 months after you stop taking GILENYA.

Pregnancy Registry: There is a registry for women who become pregnant during treatment with GILENYA. If you become pregnant while taking GILENYA, talk to your doctor about registering with the GILENYA Pregnancy Registry. The purpose of this registry is to collect information about your health and your baby's health.

For more information, you can call the GILENYA Pregnancy Registry at 1-877-598-7237 or visit www.gilenyapregnancyregistry.com.

- Are breastfeeding or plan to breastfeed. It is not known if GILENYA passes into your breast milk. You and your doctor should decide if you will take GILENYA or breastfeed. You should not do both.

Tell your doctor about all the medicines you take, including prescription and non-prescription medicines, vitamins, and herbal supplements.

Know the medicines you take. Keep a list of your medicines with you to show your doctor and pharmacist when you get a new medicine.

Using GILENYA and other medicines together may affect each other causing serious side effects. Especially tell your doctor if you take:

- Medicines for:
 - heart problems or
 - high blood pressure or
 - other medicines that may lower your heart rate or change your heart rhythm
- Vaccines. Tell your doctor if you have been vaccinated within 1 month before you start taking GILENYA. You should not get certain vaccines while you take GILENYA and for at least 2 months after you stop taking GILENYA. If you take certain vaccines, you may get the infection the vaccine should have prevented. Vaccines may not work as well when given during GILENYA treatment.
- Medicines that could raise your chance of getting infections, such as medicines to treat cancer or to control your immune system.
- ketoconazole (an antifungal drug) by mouth

Ask your doctor or pharmacist for a list of these medicines if you are not sure.

How should I take GILENYA?

- Your first dose of GILENYA will be given in a medical facility where you will be watched for at least 6 hours after your first dose of GILENYA. See “**What is the most important information I should know about GILENYA?**”
- Take GILENYA exactly as your doctor tells you to take it.
- Take GILENYA 1 time each day.
- Take GILENYA with or without food.
- Do not stop taking GILENYA without talking with your doctor first.
- If you start GILENYA again after stopping for 2 weeks or more, you will start taking GILENYA again in your doctor’s office or clinic.

What are possible side effects of GILENYA?

GILENYA can cause serious side effects.

See “**What is the most important information I should know about GILENYA?**”

Serious side effects include:

- **Breathing Problems.** Some people who take GILENYA have shortness of breath. Call your doctor right away if you have trouble breathing.
- **Liver problems.** GILENYA may cause liver problems. Your doctor should do blood tests to check your liver before you start taking GILENYA. Call your doctor right away if you have any of the following symptoms of liver problems:
 - nausea
 - vomiting
 - stomach pain
 - loss of appetite

- tiredness
- your skin or the whites of your eyes turn yellow
- dark urine

The most common side effects of GILENYA include:

- headache
- flu
- diarrhea
- back pain
- abnormal liver tests
- cough

Tell your doctor if you have any side effect that bothers you or that does not go away.

These are not all of the possible side effects of GILENYA. For more information, ask your doctor or pharmacist. Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

How do I store GILENYA?

- Store GILENYA in the original blister pack in a dry place.
- Store GILENYA at room temperature between 59°F to 86°F (15°C to 30°C).
- Keep GILENYA and all medicines out of the reach of children.

General information about GILENYA

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use GILENYA for a condition for which it was not prescribed. Do not give GILENYA to other people, even if they have the same symptoms you have. It may harm them.

This Medication Guide summarizes the most important information about GILENYA. If you would like more information, talk with your doctor. You can ask your doctor or pharmacist for information about GILENYA that is written for healthcare professionals.

For more information, go to www.pharma.US.Novartis.com or call 1-888-669-6682.

What are the ingredients in GILENYA?

Active ingredient: fingolimod

Inactive ingredients: gelatin, magnesium stearate, mannitol, titanium dioxide, yellow iron oxide.

This Medication Guide has been approved by the U.S. Food and Drug Administration.

GILENYA is a trademark of Novartis AG.

Manufactured by:
Novartis Pharma Stein AG
Stein, Switzerland

Distributed by:
Novartis Pharmaceuticals Corporation
East Hanover, New Jersey 07936

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you may be sitting for most of the activity.

For instance, collecting all the ingredients at one time for a recipe enables the cook to prepare the food while sitting, using minimal effort. The same is true for cleaning, keeping supplies in one carrier and putting them in a safe place near the site of the next job.

Enough cannot be said about good planning. With respect to meals, selecting menus in advance with easy recipes can save both time and money. Before shopping for food, a list of all necessary ingredients for the week's meals may be written.

Becoming familiar with the local store and the aisles where individual items are located, can assist with saving energy as well. Better yet, if available and affordable, a food order can be delivered. Whenever possible, double portions of a meal may be prepared and the leftovers frozen for another day. This provides extra meals that require little time to prepare. Selecting easier methods of preparation, such as baking instead of frying, or using a microwave or crock pot, can really help to reduce the workload as well.

If the washer and dryer are not convenient to other rooms in your home, you can bring along things to do so you may sit nearby until the clothes are finished. Washing only one or two loads of laundry daily will spread them over the full week. This is far less stressful than doing several loads over the course of one day. Quickly removing clothes from the dryer and immediately folding or hanging them will help to keep clothes from wrinkling. When ironing is necessary, the clothes and board

can be arranged so the ironing may be done while sitting.

Frequently used items may be organized and hung or stored in easy-to-reach places, using pegboards, sliding drawers, Lazy Susans, and lightweight storage boxes. Trays and wheeled carts are indispensable for transporting food, dishes, laundry, and other bulky or heavy things around the house. When something heavy needs to be moved (without a tray or cart), sliding the item versus carrying it will save energy. If lifting a heavy object cannot be avoided, keep your back straight, stand with feet apart, and try to avoid straining muscles.

Another way to protect your back is to use chairs that provide support. When applicable, check that these are in the proper position with the desk, table, or countertop. Using a shoulder-phone device (a plastic piece that sits between the phone receiver and the shoulder) helps to avoid neck strain while talking on the phone. A speakerphone is especially useful if upper limbs are weak.

Planning also applies to personal tasks. When bathing, use a grab bar and have supplies and a tub seat in place (or within easy reach). This will help you to save energy. Clothing may be set out the night before it is needed. When dressing the following morning, clothes should go on the weak side first. When undressing, begin with the strong side.

If caring for a baby, working above the waist level to bathe, change, and dress the infant will be less strenuous. With toddlers, if they can do so safely, letting them stand on a stool or chair for dressing or washing reduces

physical strain. Disposable diapers require the least amount of work, while Velcro® or other fasteners on clothes are easier to manage than buttons. These types of fasteners also work well on clothing for individuals with limited movement or energy.

Most energy-saving techniques are little more than common sense and you might be surprised at how much physical strength is conserved by simply using these strategies. During all activities, try to have good light and ventilation so valuable energy is not spent straining to see clearly or taking a fresh breath. Spreading out activities while taking care not to do tiring tasks on consecutive days will also prove to be beneficial.

Relieving Fatigue through Cooling

Research has shown that nerves with damaged myelin are sensitive to changes in temperature. A rise in temperature may cause nerve conduction to be less efficient, whereas

a reduction in temperature may allow more signals to be transmitted across a damaged nerve.

The idea of cooling people with MS to alleviate symptoms has been researched and practiced for many years, but practical methods of cooling an individual had not been perfected until the 1990s. At this time, MSAA and NASA joined forces to develop and test a “cool suit.”

Cooling someone too quickly – such as taking cold baths or sitting close to the air conditioner – can cause shivering and vasoconstriction. This reaction does not help to alleviate MS symptoms. By slowly cooling down the body, an individual with MS may experience improvement in areas of physical performance, cognitive processing, and motor function. Cooling also significantly reduces fatigue, helping a person with MS perform his or her daily activities.

Exercise Can Boost Energy

Certain types of “easy exercise,” such as gardening and yoga (with your doctor’s approval), have been shown to boost energy levels, reduce stress, improve joint range of motion, help manage spasticity, and increase strength. Because of its natural buoyancy, water allows many men and women with MS to perform exercises they cannot do outside of the pool. Water exercise helps increase flexibility, strengthen the upper and lower extremities and trunk, improve ambulatory skills, increase coordination and balance, and condition the overall body to raise endurance levels and lessen fatigue.

For more information on the benefits of aquatic therapy and aquatic exercise for individuals with MS, please see the Health and Wellness column from the Summer/Fall 2012 issue of *The Motivator*. This may be found on MSAA’s website at mymsaa.org/publications/motivator/summer-fall12/health

Controlled cooling is now achieved through passive cooling garments. These are portable and allow the wearer to enjoy symptom relief indoors or out. Passive cooling garments, such as a vest and wraps for the neck, wrists, or ankles, use ice or gel packs to give people with MS immediate and simple relief from heat and certain MS symptoms. Some passive garments are dampened and chilled before use.

Cooling often provides temporary relief from fatigue and heat intolerance, as well as other MS symptoms. Cooling vests and accessory kits may be available through

MCAA (limitations apply). Anyone interested in MCAA's cooling program may visit mymsaa.org/msaa-help/cooling or call (800) 532-7667.

Medications for Fatigue

A number of drugs have been used effectively to manage fatigue. Many of them were first developed to treat other disorders such as alertness or depression. It should be noted that while these medications are used quite often with people with MS, they are not specifically FDA-approved for the treatment of multiple sclerosis.

MCAA's 2013

Art Showcase

MCAA is very proud to present our 2013 Art Showcase – celebrating the work of artists affected by multiple sclerosis.

In 2012, we received many wonderful submissions from across the country and are now delighted to share their work and their stories with you.

View the complete online gallery of artwork from participants in the Art Showcase – visit mymsaa.org/artshowcase2013



ANTIDEPRESSANTS

Selective Serotonin Reuptake Inhibitors (SSRIs) including Zoloft® (sertraline), Paxil® (paroxetine), and Prozac® (fluoxetine)

SSRIs (selective serotonin uptake inhibitors) are antidepressants. In addition to their use in treating depression, they may also help alleviate symptoms of fatigue.

These medications may need to be taken for several weeks before seeing an effect.

Wellbutrin® (bupropion) is an SNRI antidepressant (selective serotonin and norepinephrine reuptake inhibitor), and is one of the most energizing and most effective of the non-SSRI antidepressants against fatigue.

Tips to Conserve Energy

Use Adaptive Aids.

Reachers, dressing aids, and other adaptive equipment can significantly help conserve energy when dressing, bathing, and performing other household and personal activities. Many of these items may be obtained through MSAAs Equipment Distribution Program (limits apply). Please visit mysaa.org or call (800) 532-7667 for more information.

Shop from Home.

Rather than using valuable energy walking around stores, use catalogs or order items online. In addition to avoiding the crowds and exhaustion from walking through stores or malls, ordering clothes allows you to try them on at your leisure when your energy level is highest. Many grocery stores also offer online ordering with either free delivery or a minimal charge for delivery.

Take Fewer Steps.

Try to take care of as many things as possible in one room to eliminate extra trips.

Consider Telecommuting.

A great way to conserve energy is to reduce the amount of time spent traveling to and from work. Ask your employer about working part of the week from home.

Don't Get Overheated.

This can cause fatigue. Wear your cooling vest or other cooling apparel and try to go outside either early in the morning or later in the evening, when temperatures are at their coolest.

Learn to Delegate.

If cooking, shopping, cleaning, and doing the laundry drains your energy, talk with family members about sharing the load or consider hiring a cleaning or laundry service to take care of some of the chores. Let your family and friends know that you are counting on them for support, and tell them specifically what they can do to help. Remember, everyone benefits when your symptoms are lessened by conserving your energy.

STIMULANTS**Provigil® (modafinil)**

This is an oral medication that should be taken early in the day to minimize sleep disturbances. This drug promotes wakefulness, and was originally developed to treat narcolepsy, a neurologic condition associated with uncontrollable daytime sleepiness.

Nuvigil® (armodafinil)

This medication is a drug that is similar to Provigil and is also sometimes prescribed for the treatment of MS fatigue.

Amantadine

This generic medication was previously available as Symmetrel®. This is an oral medication that should be taken early in the day to minimize sleep disturbances. Amantadine is an antiviral medication used to prevent or treat influenza; it has also been used in Parkinson's disease. Its mechanism for relieving fatigue in some individuals with MS is unknown, although it may increase levels of the neurotransmitter dopamine in the brain.

Ritalin® (methylphenidate)

This is an oral medication that is usually taken 30 to 45 minutes before eating – or as your physician directs. Because it may cause difficulty sleeping, it is recommended that you take your last dose before 6:00 pm. Ritalin was originally developed as a treatment for attention deficit disorder (ADD), and has also been used to manage narcolepsy.

Dexedrine® (dextroamphetamine)

This is an oral medication that has been used to improve wakefulness, boost energy, and decrease fatigue and appetite.

Caffeine

Some people with MS find that caffeine, found in coffee, tea, or caffeinated soda, in moderation, can be helpful in managing fatigue. Unfortunately, caffeine is an irritant to the bladder, and can exacerbate urgency and frequency. Individuals should speak with their doctor about their intake of these beverages, to be sure they are not exceeding levels of caffeine that are appropriate for them.

Please note that stimulants and amphetamines are sometimes used for fatigue, and they can be helpful, but risks are involved with certain drugs. These should only be used when other treatments are not successful, and such drugs are prescribed cautiously.

Closing notes

David Rintell, EdD states, “The bottom line about fatigue is this: It is common and disabling. It can occur any time in the course of MS, and does not appear to be related to disability or lesion load on the MRI. Although there are theories about the cause of fatigue, we do not know what causes MS fatigue. We do know that much of fatigue can be accounted for by depression and sleep problems.”

Sleep Issues

Written by David Rintell, EdD,
Psychologist, Partners MS Center and Partners
Pediatric MS Center, Boston, Massachusetts

Sleep and MS

There is nothing like a good night's sleep to restore oneself physically, mentally, and emotionally. Unfortunately, more than half of people with MS experience difficulty sleeping. Inadequate sleep leads to fatigue, the most common and one of the most debilitating symptoms of MS. It also causes daytime drowsiness, lack of mental clarity, and a reduced ability to use one's resources to solve problems. Many possible causes of sleep problems for people with MS can be identified, including: bladder problems, depression, spasticity and frequent leg movements, difficulty changing position in bed, and poor sleep hygiene.

Causes of Sleep Problems in MS

Frequent Nighttime Urination

The need to urinate during the night, referred to as nocturia, is likely the most common culprit in sleep interruption for people with MS. Bladder problems are common in MS, and many people need to use the bathroom multiple times each night. Most people are able to regain sleep after getting up once, but it becomes increasingly difficult to sleep soundly when sleep is interrupted many times per night due to the need to urinate.

Fortunately, a number of solutions are available for urinary frequency in MS.



Consulting with a urologist (a physician who specializes in urinary difficulties) is an important first step. If you are having nocturia and/or the frequent or urgent need to urinate during the day, ask your neurologist to refer you to a urologist experienced with patients who have MS, and who has experience treating the symptoms of a neurogenic bladder.

Strategies to Help: Some people with the frequent and urgent need to urinate restrict their liquid intake, but this is not a healthy practice and can lead to other problems. Drink normally during the day, but have your last drink about three hours before going to bed. Drinks with caffeine stimulate the bladder, so reduce your caffeine intake, or drink caffeinated beverages only in the morning. Alcoholic beverages often cause nighttime urination, so do not drink alcoholic beverages late at night. You will find more information on caffeine and alcohol to follow.

Certain medications may help. Detrol® (tolterodine), Ditropan® (oxybutynin),

AMPYRA® (dalfampridine) is an oral medication that helps improve walking in patients with Multiple Sclerosis.

I will:

"The first thing I started to notice as my walking improved with Ampyra was my confidence in my ability to walk to meet my friends."

— Kristie Salerno Kent, diagnosed with MS in 1999.

Walk on.

Walking better matters. AMPYRA is the first and only medication shown in two clinical trials to improve walking in people with multiple sclerosis (MS). This was demonstrated by an increase in walking speed.

In these clinical studies, people who walked faster, regardless of treatment, reported improvements in their walking related activities. Not everyone responds to AMPYRA. Individual results may vary.

Can be taken in combination with your other MS therapies.

Visit Ampyra.com to find out more about a **FREE TRIAL**.

ampyra®

(dalfampridine) 10 mg
EXTENDED RELEASE TABLETS



Talk to your doctor to see if AMPYRA may be right for you.

New Safety Information

AMPYRA may cause serious allergic reactions, including rare occurrences of anaphylaxis.

Important Safety Information

Do not take AMPYRA if you have ever had a seizure or have certain types of kidney problems. Take AMPYRA exactly as prescribed by your doctor. You could have a seizure even if you never had a seizure before. Your chance of having a seizure is higher if you take too much AMPYRA or if your kidneys have a mild decrease of function, which is common after age 50. Your doctor may do a blood test to check how well your kidneys are working, if that is not known before you start taking AMPYRA.

In two pivotal trials 35% and 43% of patients taking AMPYRA responded to treatment vs. 8% and 9% of patients taking placebo.

AMPYRA should not be taken with other forms of 4-aminopyridine (4-AP, fampridine), since the active ingredient is the same.

For more information, please see the complete Medication Guide on the next page.

You are encouraged to report negative side effects of prescription drugs to the FDA.

Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

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MEDICATION GUIDE FOR AMPYRA® (am-PEER-ah) (dalfampridine) Extended Release Tablets

Read this Medication Guide before you start taking AMPYRA and each time you get a refill. There may be new information. This information does not take the place of talking with your doctor about your medical condition or your treatment.

What is the most important information I should know about AMPYRA?

AMPYRA can cause seizures.

- You could have a seizure even if you never had a seizure before.
- Your chance of having a seizure is higher if you take too much AMPYRA or if your kidneys have a mild decrease of function, which is common after age 50.
- Your doctor may do a blood test to check how well your kidneys are working, if that is not known before you start taking AMPYRA.
- Do not take AMPYRA if you have ever had a seizure.
- Before taking AMPYRA tell your doctor if you have kidney problems.
- Take AMPYRA exactly as prescribed by your doctor. See “How should I take AMPYRA?”

Stop taking AMPYRA and call your doctor right away if you have a seizure while taking AMPYRA.

What is AMPYRA?

AMPYRA is a prescription medicine used to help improve walking in people with multiple sclerosis (MS). This was shown by an increase in walking speed.

It is not known if AMPYRA is safe or effective in children less than 18 years of age.

Who should not take AMPYRA?

Do not take AMPYRA if you:

- have ever had a seizure
- have certain types of kidney problems

What should I tell my doctor before taking AMPYRA?

Before you take AMPYRA, tell your doctor if you:

- have any other medical conditions
- are taking compounded 4-aminopyridine (fampridine, 4-AP)
- are pregnant or plan to become pregnant. It is not known if AMPYRA will harm your unborn baby. You and your doctor will decide if you should take AMPYRA while you are pregnant.
- are breast-feeding or plan to breast-feed. It is not known if AMPYRA passes into your breast milk. You and your doctor should decide if you will take AMPYRA or breast-feed. You should not do both.

Tell your doctor about all the medicines you take, including prescription and non-prescription medicines, vitamins and herbal supplements.

Know the medicines you take. Keep a list of them and show it to your doctor and pharmacist when you get a new medicine.

How should I take AMPYRA?

- Take AMPYRA exactly as your doctor tells you to take it. Do not change your dose of AMPYRA.
- Take one tablet of AMPYRA 2 times each day about 12 hours apart. Do not take more than 2 tablets of AMPYRA in a 24-hour period.
- **Take AMPYRA tablets whole. Do not break, crush, chew or dissolve AMPYRA tablets before swallowing. If you cannot swallow AMPYRA tablets whole, tell your doctor.**
- AMPYRA is released slowly over time. If the tablet is broken, the medicine may be released too fast. This can raise your chance of having a seizure.
- AMPYRA can be taken with or without food.
- If you miss a dose of AMPYRA, do not make up the missed dose. Do not take 2 doses at the same time. Take your next dose at your regular scheduled time.
- If you take too much AMPYRA, call your doctor or go to the nearest hospital emergency room right away.
- Do not take AMPYRA together with other aminopyridine medications, including compounded 4-AP (sometimes called 4-aminopyridine, fampridine).

What are the possible side effects of AMPYRA?

AMPYRA may cause serious side effects, including:

- Kidney or bladder infections
- Serious allergic reactions, including anaphylactic reactions

See “What is the most important information I should know about AMPYRA?”

The most common side effects of AMPYRA include:

- urinary tract infection
- trouble sleeping (insomnia)
- dizziness
- headache
- nausea
- weakness
- back pain
- problems with balance
- multiple sclerosis relapse
- burning, tingling or itching of your skin
- irritation in your nose and throat
- constipation
- indigestion
- pain in your throat

Tell your doctor if you have any side effect that bothers you or that does not go away.

These are not all the possible side effects of AMPYRA. For more information, ask your doctor or pharmacist.

Call your doctor for medical advice about side effects. You may report side effects to the FDA at 1-800-FDA-1088.

How should I store AMPYRA?

- Store AMPYRA at 59°F to 86°F (15°C to 30°C).
- Safely throw away AMPYRA that is out of date or no longer needed.

Keep AMPYRA and all medicines out of the reach of children.

General Information about the safe and effective use of AMPYRA

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use AMPYRA for a condition for which it was not prescribed. Do not give AMPYRA to other people, even if they have the same symptoms that you have. It may harm them.

This Medication Guide summarizes the most important information about AMPYRA. If you would like more information, talk with your doctor. You can ask your pharmacist or doctor for information about AMPYRA that is written for health professionals.

For more information, go to www.AMPYRA.com or call 1-800-367-5109.

What are the ingredients in AMPYRA?

Active ingredient: dalfampridine (previously called fampridine)

Inactive ingredients: colloidal silicon dioxide, hydroxypropyl methylcellulose, magnesium stearate, microcrystalline cellulose, polyethylene glycol, and titanium dioxide.

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Ardsley, NY 10502
Issued 08/2012

This Medication Guide has been approved by the U.S. Food and Drug Administration.

AMPYRA® is a registered trademark of Acorda Therapeutics®, Inc. Manufactured for Acorda under license from Alkermes Pharma Ireland Limited (APIL), Athlone, Ireland, utilizing APIL's Matrix Drug Absorption System (MXDAS®) technology.

MXDAS® is a registered trademark of Alkermes Pharma Ireland Limited (APIL). U.S. Patent Nos.: US 5,540,938 and US 8,007,826

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Enablex® (darifenacin), Flomax® (tamsulosin), and Botox® (botulinum toxin) injections for certain bladder problems. DDAVP® (desmopressin) is a drug that is typically administered as a nasal spray, although an oral formulation is also available.

Depression

Depression interferes with one's ability to sleep. One of the main symptoms of depression is poor sleep. "Early morning awakening" is a common sleep problem in people who are depressed. People with this problem are able to fall asleep, but they wake up in the early morning hours and are unable to get back to sleep. Knowing the other symptoms of depression can help you to determine if depression is interfering with your sleep. Common signs of depression include:

- Feeling low or down
- Poor appetite or overeating
- Low energy
- Low self-esteem
- Difficulty with attention and concentration
- Feeling hopeless

Strategies to Help: The best treatment for depression in MS is the combination of counseling and medication. If you think you might be depressed, speak with your neurologist or primary-care doctor, or seek treatment from a mental-health provider. Exercise also helps depression, but is not a replacement for professional help.

Common medications for depression in people with MS include the SSRIs (selective serotonin reuptake inhibitors), including Prozac® (fluoxetine), Zoloft® (sertraline), Paxil® (paroxetine), Celexa® (citalopram), and Lexapro® (escitalopram). An SNRI antidepressant (selective serotonin and norepinephrine reuptake inhibitors), Wellbutrin® (bupropion), is also commonly used to treat depression in MS.

Spasticity

Spasticity is a common symptom of MS, which is characterized by muscles becoming tight and sometimes even rigid. Spasticity can be very uncomfortable or even painful, and limb movements may be associated with spasticity as well. Pain from spasticity can interfere with sleep.

Strategies to Help: Medications for spasticity include baclofen (formerly available as Lioresal®), Flexeril® (cyclobenzaprine), Zanaflex® (tizanidine), and Botox® injections for severe spasticity. Exercise and stretching can help to reduce spasticity, and a consultation with a physical therapist is recommended. If you or your partner notice that you are having a lot of limb movements and/or discomfort at night, consult your neurologist.

Sleeping Position

The human body was not designed to sleep in one position all night. Our skin and tissue experience a great deal of pressure from the weight of our bodies when we are asleep. We therefore must move and change

position multiple times during the night. When we change position, we wake up briefly, but if we are good sleepers we fall right back to sleep and don't even remember waking up. Some people with mobility problems due to MS have more difficulty moving around in bed at night. The pain and discomfort coming from the skin and tissues that are making contact with the bed can keep a person awake.

Strategies to Help: If turning in bed is difficult, install rails on one side of your bed,

so you can use your arms to change position. Sometimes partners arrange to turn the partner who has MS during the night. You should take care not to cause your partner to lose too much sleep with the task of turning you in bed. Speaking to your neurologist or physical therapist about this problem can be very useful.

Sleep Hygiene

We mostly think of habits when in the context of “bad habits,” such as smoking or chewing our nails. But habits can be either

Common Sleep Problems that Can Affect Anyone

Insomnia can occur for a number of reasons, including “**over-activation**,” where someone has too much on his or her mind to drift off to sleep. Specific or general worries, or an upsetting event, can often keep someone awake, and the worry of not falling asleep only worsens the problem. Naps can be helpful to re-energize people during the day, but too much napping will also contribute to nighttime insomnia.

Another issue is when a person's **biological clock and circadian rhythm**, which normally promote sleepiness during the dark of evening and wakefulness during the light of day, are not working properly. These can get off balance by not staying on a schedule, or from late-night activities, including shift work.

Sensory disruptions of noise or light during the night can interrupt one's sleep schedule as well, and taking steps to minimize these disturbances during times of sleep can be of help. Possible solutions include closing windows, installing shades or curtains that block outside

light, turning down the phone, and dimming or blocking inside light. Some people sleep better with the constant sounds of “white noise,” from a room fan or a CD designed for that purpose.

Sleep apnea is a serious disorder which occurs when a person's throat muscles relax too much and the airway is temporarily blocked. Overweight individuals are more prone to this disorder, and snoring can sometimes be a sign of the condition. While people with sleep apnea usually do not have trouble falling asleep, their breathing is affected once asleep, and the sudden inability to take a breath wakes them repeatedly throughout the night, sometimes as often as every 30 seconds.

Sleep apnea can be particularly dangerous since it affects breathing. For a proper diagnosis, a sleep study in your home or at a sleep center is often prescribed. Some overweight individuals lose weight once they are able to get adequate sleep, due to a decrease in the production of a hormone that promotes appetite.

bad or good habits, and good habits can help us sleep. The term “Sleep Hygiene” relates to our habits in the bedroom, in bed, and in relation to our sleep.

Consider “Susan,” a 34-year-old woman with MS. She is tired when she gets home from work, so she heats up some food, and then gets into bed to eat dinner. She then lays out her bills on the bed to determine which need to be paid, and pays her bills. Then she catches up on some work for her office. Susan has developed habits that make her bed a place of work, dining, and sometimes

turmoil (when she doesn’t have the money to pay her bills). Her bed is no longer a place of peace, comfort, and sleep.

“Jerry” is a 55-year-old man with MS who likes to watch TV late at night. Some days he goes to sleep at 1 am, but at other times, he goes to bed at 3 am or even later. He is almost always tired the next day, and as a result, takes a nap. His nap times can vary – sometimes they are for 15 minutes, and other times for an hour. His naps prevent him from feeling tired enough to go to bed by midnight, and he stays up late again.

...With or Without MS

Restless legs syndrome or RLS is a movement disorder that is not related to MS, but may occur more frequently in people with MS than in the general population. It is sometimes difficult to distinguish RLS from MS spasticity, so the actual prevalence of RLS in MS is not clear. When relaxed in a chair or bed during the evening, people with RLS feel uncomfortable and have the constant urge to move their legs.

Reducing consumption of alcohol, caffeine, and nicotine can be helpful for RLS. RLS can be a side effect of certain medications, and other medical conditions may cause RLS, so individuals who think they might have RLS should consult their neurologist. A number of medications are used to treat RLS, including Requip® (ropinirole). Other helpful strategies include stretching, taking warm or cool baths, applying hot or cold packs to the affected area, and limb massage.

Other sleep problems can include **sleep-walking**, **sleep terrors**, and **nightmares**, acting out physically while dreaming, waking up con-

fused, and even overeating while asleep.

Grinding teeth and/or **snoring** can have health implications and are disruptive to a partner’s sleep. Any underlying medical conditions that may affect sleep need to be investigated, diagnosed, and treated.

To encourage a good sleep regimen, experts recommend practicing a healthy lifestyle, which includes daily exercise, a healthy diet, limiting one’s alcohol and caffeine intake, and not smoking. Staying on a good sleep and waking schedule is important, as is preparing for sleep. For the latter, time should be allowed to finish household chores or take care of any loose ends before going to bed.

Writing down any concerns is a good way to put them aside until the next morning. Taking time to unwind and relax by reading a book, for example, can assist with falling asleep more naturally. Some individuals may find relaxation techniques, such as guided imagery, meditation, or biofeedback, to be of great help.

Strategies to Help: Many sleep problems in MS and in the general population can be solved by changing our habits about sleep, improving our sleep hygiene (or sleep habits). Below is an adaptation of the standard program to improve sleep hygiene:

1. Use your bed only for sleep and sex
2. Reduce stimulant use (caffeine) later in the day; avoid alcohol use in the evening
3. Go to bed at the same time every night
4. Stop working, making phone calls, or participating in any stressful activity two hours before bedtime
5. Set your alarm clock for eight hours after bedtime
6. When you get into bed, think about pleasant memories from the past; try to remember more and more details
7. If you haven't fallen asleep after 20 minutes, get out of bed
8. Once out of bed, sit in a comfortable chair in a quiet place and read something that is not stimulating; when you feel like you are ready to fall asleep, get back into bed, but repeat steps 6 and 7, as many times as needed
9. Discontinue napping during the day

With regard to alcohol, we know that drinking a small amount of an alcoholic beverage can help a person to fall asleep. What people often do not realize, however, is that alcohol has a “rebound” effect, causing people to wake up during the night. It also causes people to need to urinate more frequently during the night, another cause of

lost sleep.

Working with a trained psychologist on your sleep hygiene program is advisable, as a program often needs to be individualized or “tweaked” for each person, and adjusted over time. When people have tried to improve their sleep hygiene and have been unable to improve their sleep, they sometimes use medication to help them sleep.

You will find many advertisements on TV for sleep aids, and they all show a person refreshed in the morning. Most people who use “sleeping pills” do not wake up refreshed; instead, they wake up feeling drowsy.

There are alternatives to sleeping pills. An older form of antidepressants (tricyclics) is sometimes used because they are sedating. These types of antidepressants are not habit forming and a person can stop at any time. Many people find the supplement melatonin to be helpful. If used occasionally, antihistamines like Benadryl® (diphenhydramine HCl) can be taken for their sedating side-effects. But again, most sleep problems can be solved without medication.

If you are not sleeping well at night, finding solutions to your sleep problems is well worth the effort, so you can get a better quality and increased quantity of sleep. Most of us require 7 1/2 to 9 hours of sleep, and some require more. Without enough sleep, fatigue can become a big problem. But if you examine what is interfering with a good night's sleep, consult your physician, and take the necessary steps to resolve your sleep issues, you should feel better and experience less fatigue during the day. Sleep well!

Cognitive Changes

Reviewed and edited by Pat Bednarik,
MS, CCC-SLP, MSCS
Speech-Language Pathologist
Multiple Sclerosis Center at the
University of Pittsburgh Medical Center



Cognitive Changes with MS

Traditionally, cognitive issues were not believed to be a symptom of MS. In more recent years, researchers and physicians have come to find that roughly half of the MS population will experience some type of change in their cognitive abilities during the course of their disease.

The term “cognition” refers to a group of mental processes such as information processing, language, memory, visual perception/spatial skills, calculation skills, and executive functions (LaRocca, Sorenson and Fischer, 2000). These may be described as follows:

- Information-processing skills affect our ability to focus, maintain, and shift our attention from one thing to another without losing track of what we were doing, as well as managing incoming information quickly.
- Language refers to the ability to understand and use language appropriately in daily situations.

- Memory is a complex set of skills that involve learning, storage of information, and the ability to retrieve that information on demand.
- Visual perceptual/spatial skills allow us to do things such as recognize objects, draw, assemble things, and find our way around.
- Performing simple and complex math skills are involved in calculation abilities.
- Executive-functioning abilities enable us to get through our day by overseeing and coordinating tasks such as organization, planning, sequencing, problem solving, judgment, reasoning, monitoring our own behavior, etc.

The most commonly affected cognitive processes in MS are speed-of-information processing, memory, and executive functions. Other domains of cognition can also be affected depending on where lesions are located. However, rarely are all domains of cognition impacted by MS. Changes in cognitive abilities typically are clinically considered mild-to-moderate in severity,



Early treatment matters.

In clinical studies, early treatment with BETASERON® (interferon beta-1b) helped significantly delay the time to a second flare-up (conversion to clinically definite MS) compared with placebo.¹

INDICATIONS

BETASERON® (interferon beta-1b) is a prescription medicine used to reduce the number of relapses in people with relapsing forms of multiple sclerosis (MS). This includes people who have had their first symptoms of multiple sclerosis and have an MRI consistent with multiple sclerosis. BETASERON will not cure MS but may decrease the number of flare-ups of the disease.

IMPORTANT SAFETY INFORMATION

Do not take BETASERON (interferon beta-1b) if you are allergic to interferon beta-1b, to another interferon beta, to human albumin, or mannitol.

BETASERON can cause serious side effects, including:

Liver Problems Including Liver Failure. Symptoms of liver problems may include yellowing of your eyes, itchy skin, feeling very tired, flu-like symptoms, nausea or vomiting, bruising easily or bleeding problems. Your healthcare provider will do blood tests to check for these problems while you take BETASERON.

Serious Allergic Reactions. Serious allergic reactions can happen quickly and may happen after your first dose of BETASERON or after you have taken BETASERON many times. Symptoms may include difficulty breathing or swallowing, swelling of the mouth or tongue, rash, itching, or skin bumps.

Depression or Suicidal Thoughts. Call your healthcare provider right away if you have any of the following symptoms, especially if they are new, worse or worry you: thoughts about suicide or dying, new or worse depression (sinking feeling or sadness), new or worse anxiety (feeling uneasy, nervous or fearful for no reason), trouble sleeping (insomnia), acting aggressive, being angry, or violent, acting on

dangerous impulses, hallucinations, other unusual changes in behavior or mood.

Other possible serious side effects with BETASERON include:

Heart Problems. BETASERON may worsen heart problems including congestive heart failure. Symptoms of heart problems may include swollen ankles, shortness of breath, decreased ability to exercise, fast heartbeat, tightness in chest, increased need to urinate at night, not being able to lay flat in bed.

Injection Site Problems. Serious skin reactions can happen in some people including areas of severe damage to skin and the tissue below the skin (necrosis). These reactions can happen anywhere you inject BETASERON. Symptoms of injection site problems may include swelling, redness, or pain at the injection site, fluid drainage from the injection site, breaks in your skin or blue-black skin discoloration. Change your injection site each time you inject BETASERON as it will lessen the chance of you having a serious skin reaction. Avoid injecting BETASERON into an area of the skin that is sore, reddened, infected or has other problems.

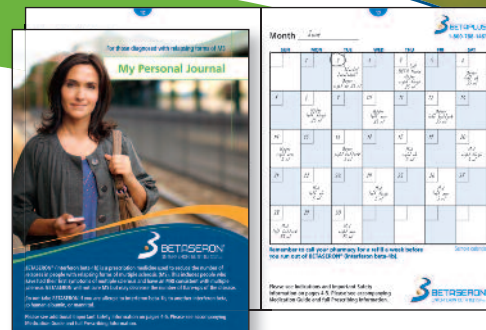
Flu-like Symptoms. BETASERON can cause flu-like symptoms including fever, chills, tiredness, sweating, muscle aches when you first start to use it. These symptoms may decrease over time.

So does ongoing support.

The BETAPLUS® support program brings BETASERON patients free 24/7/365 telephone access to MS-trained BETA Nurses, dedicated insurance assistance, an app that can help them track and plan their injections, and timely information and tools.

Visit **BETASERON.com** today

Sign up for BETAPLUS and get e-mails and information that could help you make a decision about RRMS therapy—plus a free personal journal to help you plan and track your treatment.



Taking medicines for fever and pain relief on the days you are using BETASERON may help decrease these symptoms.

Seizures. Some people have had seizures while taking BETASERON, including people who have never had seizures before. It is not known if the seizures were related to MS, to BETASERON, or to a combination of both. If you have a seizure after taking BETASERON call your healthcare provider right away.

Blood Problems. You may have a drop in the levels of infection-fighting white blood cells, red blood cells, or cells that help you form blood clots. If drops in levels are severe, they can lessen your ability to fight infections, make you feel tired or sluggish or cause you to bruise or bleed easily.

Risk to Pregnancy:

BETASERON can harm your unborn baby. BETASERON may cause you to lose your baby (miscarry). If you become pregnant while taking BETASERON call your healthcare provider right away. You and your healthcare provider should decide if you should continue to take BETASERON.

Most Common Side Effects:

The most common side effects of BETASERON include low white blood cell count, increases in your liver enzymes, headache, increase in your muscle

tension, pain, rash, problems sleeping, stomach pain, weakness. These are not all the possible side effects of BETASERON.

Tell your healthcare provider if you have any side effect that bothers you or that does not go away. Tell your healthcare provider about all the medicines you take and your medical conditions.

Please see brief summary of Medication Guide on the following page.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch or call 1-800-FDA-1088.

Reference: 1. Kappos L, Polman CH, Freedman MS, et al. Treatment with interferon beta-1b delays conversion to clinically definite and McDonald MS in patients with clinically isolated syndromes. *Neurology*. 2006;67:1242-1249.



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BETASERON[®]

(interferon beta-1b)
injection 0.3 mg

6800505BS
521-154-0002-13

Brief Summary of Medication Guide Betaseron[®] (bay-ta-seer-on) Interferon beta-1b (in-ter-feer-on beta-one-be)

This information does not include all the important information about Betaseron. For more information about Betaseron go to www.BETASERON.com.

What is the most important information I should know about Betaseron?

Betaseron can cause serious side effects, including:

- **liver problems including liver failure.** Symptoms of liver problems may include: yellowing of your eyes, itchy skin, feeling very tired, flu-like symptoms, nausea or vomiting, bruising easily or bleeding problems.

Your healthcare provider will do blood tests to check for these problems while you take Betaseron.

- **serious allergic reactions.** Serious allergic reactions can happen quickly and may happen after your first dose of Betaseron or after you have taken Betaseron many times. Symptoms may include: difficulty breathing or swallowing, swelling of the mouth or tongue, rash, itching, or skin bumps.

- **depression or suicidal thoughts.** Call your healthcare provider right away if you have any of the following symptoms, especially if they are new, worse, or worry you: thoughts about suicide or dying, new or worse depression, new or worse anxiety, trouble sleeping (insomnia), acting aggressive, being angry, or violent, acting on dangerous impulses, hallucinations, other unusual changes in behavior or mood.

What is Betaseron?

Betaseron is a prescription medicine used to reduce the number of relapses in people with relapsing forms of multiple sclerosis (MS). This includes people who have had their first symptoms of multiple sclerosis and have an MRI consistent with multiple sclerosis. Betaseron is similar to certain interferon proteins that are produced in the body. It will not cure your MS but may decrease the number of flare-ups of the disease.

It is not known if Betaseron is safe and effective in children.

Who should not take Betaseron?

Do not take Betaseron if you are allergic to interferon beta-1b, to another interferon beta, to human albumin, or mannitol. See the end of this leaflet for a complete list of ingredients in Betaseron.

What should I tell my healthcare provider before taking Betaseron?

Before you take Betaseron, tell your healthcare provider if you:

- have or have had depression (sinking feeling or sadness), anxiety (feeling uneasy, nervous, or fearful for no reason) or trouble sleeping
- have or have had liver problems
- have or have had blood problems such as bleeding or bruising easily, low red blood cells (anemia) or low white blood cells
- have or have had seizures
- have or have had heart problems
- are pregnant or plan to become pregnant. Betaseron can harm your unborn baby. Betaseron may cause you to lose your baby (miscarry). If you become pregnant while taking Betaseron call your healthcare provider right away. You and your healthcare provider should decide if you should continue to take Betaseron.
- are breastfeeding or plan to breastfeed. It is not known if Betaseron passes into your breast milk. You and your healthcare provider should decide if you will take Betaseron or breastfeed. You should not do both.

Tell your healthcare provider about all the medicines you take, including prescription and nonprescription medicines, vitamins, and herbal supplements.

Know the medicines you take. Keep a list of them to show your healthcare provider and pharmacist when you get a new medicine.

What are the possible side effects of Betaseron?

Betaseron may cause serious side effects. Call your healthcare provider right away if you have any of the serious side effects of Betaseron including:

- **See “What is the most important information I should know about Betaseron?”**
- **heart problems.** Betaseron may worsen heart problems including congestive heart failure. Symptoms of heart problems may include: swollen ankles, shortness of breath, decreased ability to exercise, fast heartbeat, tightness in chest, increased need to urinate at night, not being able to lay flat in bed.
- **injection site problems.** Serious skin reactions can happen in some people including areas of severe damage to skin and the tissue below the skin (necrosis). These reactions can happen anywhere you inject Betaseron. Symptoms of injection site problems may include:
 - swelling, redness, or pain at the injection site
 - fluid drainage from the injection site
 - breaks in your skin or blue-black skin discoloration

It is important for you to change your injection site each time you inject Betaseron. This will lessen the chance of you having a serious skin reaction at the site where you inject Betaseron. Avoid injecting Betaseron into an area of skin that is sore, reddened, infected or has other problems.

- **flu-like symptoms.** Betaseron can cause flu-like symptoms including: fever, chills, tiredness, sweating, muscle aches when you first start to use it

These symptoms may decrease over time. Taking medicines for fever and pain relief on the days you are using Betaseron may help decrease these symptoms.

- **seizures.** Some people have had seizures while taking Betaseron, including people who have never had seizures before. It is not known if the seizures were related to their MS, to Betaseron, or to a combination of both. If you have a seizure after taking Betaseron call your healthcare provider right away.

The most common side effects of Betaseron include: low white blood cell count, increases in your liver enzymes, headache, increases in your muscle tension, pain, rash, problems sleeping, stomach pain, weakness.

Tell your healthcare provider if you have any side effect that bothers you or that does not go away.

These are not all the possible side effects of Betaseron. For more information, ask your healthcare provider or pharmacist.

Call your doctor for medical advice about side effects. You may report side effects to FDA at 1-800-FDA-1088.

Keep Betaseron and all medicines out of the reach of children.

General information about the safe and effective use of Betaseron.

Medicines are sometimes prescribed for purposes other than those listed in a Medication Guide. Do not use Betaseron for a condition for which it was not prescribed. Do not give Betaseron to other people, even if they have the same symptoms that you have. It may harm them.

What are the ingredients in Betaseron?

Active ingredient: interferon beta-1b

Inactive ingredients: albumin (human), mannitol

Diluent contains sodium chloride solution.

Manufactured by:



Bayer HealthCare

Bayer HealthCare Pharmaceuticals Inc.
Montville, NJ 07045

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although even mild changes can be annoying and irritating in day-to-day functioning.

It's best to keep in mind that not all difficulties with cognition are a result of changes to the brain. Some brief examples of other influences on cognitive functions can be medication side effects, lack of sleep, depression, anxiety, stress, and fatigue. (Larocca, Sorensen and Fischer – *Multiple Sclerosis: The Questions You Have – The Answers You Need*, second edition, edited by Rosalind Kalb, published by Demos 2000.)

Strategies to Help Cope with Cognitive Issues

In the book, *Multiple Sclerosis: A Self-Care Guide to Wellness*, second edition (edited by Nancy J. Holland, EDD, RN, MSCN and June Halper, MSCN, ANP, FAAN; published by The Paralyzed Veterans of America and Demos Medical Publishing, LLC, 2005), one section is devoted to “Coping with Cognitive Changes.” It lists the different types of cognitive functions that may be affected by MS, which include difficulties with the following:

- Memory
- Abstract reasoning
- Information processing
- Word-finding
- Visual and spatial organization (such as driving or reading a map)
- Ability to shift between tasks
- Attention and concentration
- Organization and execution of complex sequences

To enhance one's ability to concentrate, this book recommends: identifying (and avoiding) distractions; establishing quiet time; determining a time when you are at your best and using that time to perform more complex tasks; learning energy-saving and pacing strategies; finding out how long your attention span can last and taking breaks while working when you know that your attention is no longer sharp; and breaking tasks down into sections so you don't have to complete a task all at once. Puzzles, meditation, and reading can also help enhance your ability to concentrate.

If having trouble processing information, ask those around you to not speak as quickly, allowing you time to assimilate the information. By letting family and friends know what is going on, they will be able to help you to cope with the cognitive challenges you may be experiencing.

If having trouble finding a certain word, the best idea is to wait and let the word come to you later. You may also try to talk more slowly, allowing yourself extra time to process information. Additionally, if you study and expand your vocabulary, you may have synonyms at your disposal to substitute for the words you can't find.

Other important strategies include getting organized. This can help substitute for any lapses in memory. For instance, use a journal and/or a calendar to help keep track of things you need to remember and appointments you need to keep. Use checklists for shopping and other tasks. Select a central place in your home to keep things that are

easily lost – such as glasses and keys – to help avoid the frustration and wasted energy of searching for lost items.

Another very helpful resource is Shelley Peterman Schwarz's second edition of her book, *Multiple Sclerosis: 300 Tips for Making Life Easier* (published by Demos Medical Publishing, LLC, 2005). In this edition, Ms. Schwarz presents tips that cover all the basics: from issues around the home and managing meals, to taking care of yourself, handling medical issues, and even travel.

The book also includes a section on improving memory and concentration.

Among others, some of her tips include:

- Write reminders (self-adhering Post-it® notes may be helpful) and put them where easily seen.
- Keep a small spiral notebook and a small pen or pencil with you to jot down things you need to remember.
- Use a gardener's apron while at home; it has big pockets and can carry the small notebook and other items (glasses, phone, etc.), allowing you to work "hands-free" around the house and conserve energy by not having to take extra steps to retrieve things.
- If you like gadgets, an electronic organizer (also known as a personal data assistant or PDA) can keep addresses and phone numbers, appointments, notes, to-do lists, etc.
- Your computer or cell phone can be programmed to alert you when you need a reminder for taking medicine, performing

a task, or attending a meeting.

- If you have trouble remembering if you have done a task, remind yourself by speaking out loud; for example, when leaving the house, say, "I'm locking the door," out loud, and this may help your memory.
- When running errands, plan your route in advance and write down the stops you need to make in sequence; this will help you to remember everything you need to do, saving time and energy.
- If you are out and need to remember something to do when you return home, call and leave yourself a message on your answering machine.

Focusing on the experiences one goes through with changes in cognitive function, *Facing the Cognitive Challenges of Multiple Sclerosis* (written by Jeffrey N. Gingold and published by Demos Medical Publishing, LLC, 2006), is an excellent resource. This book tells how the author came to find he had MS, and how he tried to conceal and cope with cognitive issues as well as other MS symptoms. Incredibly, he was trying to conceal these issues while working as a lawyer and continuing his roles as a devoted father and husband.

While telling his story, Mr. Gingold talks first-hand about the thoughts that went through his mind as he would unexpectedly encounter a lapse in memory, an inability to recall words, or find himself lost on a familiar road. He includes details about the other

symptoms he was experiencing, consulting doctors, going through the different tests involved with MS, and taking medication.

When taking a different path, his advice includes: if retiring from a career, choose to do something different that is challenging and interesting; don't think you are without options – many choices are available; keep your mind active by reading books, keeping a diary, and doing crossword puzzles to challenge your mind; sometimes you need to say “no” to requests from others to maintain clear thinking; ask for clarification, reminders, and direction when in a confusing situation; pause, relax and breathe calmly when having a temporary lapse in thinking; limit visual distractions and remove clutter from your home; and keep lists of daily responsibilities and activities.

Please note that all four books mentioned above: *Multiple Sclerosis: The Questions You Have – The Answers You Need*; *Multiple Sclerosis: A Self-Care Guide to Wellness*; *Multiple Sclerosis: 300 Tips for Making Life Easier*; and *Facing the Cognitive Challenges of Multiple Sclerosis*, are all available through MSAA's free Lending Library. Please see page 64 for ordering information.

Cognitive Testing and Rehabilitation

A baseline cognitive evaluation is important and can serve as the basis for a comprehensive management strategy by identifying cognitive strengths and weaknesses. This testing procedure is generally administered by a neuropsychologist

or other specialist (speech-language pathologist, occupational therapist, or psychologist) depending on the types of suspected problems as well as regional availability and practice of each discipline.

A variety of strategies have been designed to help improve cognitive function. These range from keeping simple task lists, to planning how you use your time to take on more complex tasks when you are at your best, to more advanced computerized programs designed to improve memory and other cognitive issues.

The results of a study on cognition were reported at the AAN's annual meeting in 2008. This study measured improvements in general memory, working memory, and processing speed in people who participated in a targeted cognitive rehabilitation program, compared to those who did not participate in a program. The results suggested a clinically statistical improvement. A recent study from Israel suggested that a computer-based cognitive training program (MindFit®) led to an improvement in memory skills in people with MS.

Other Options to Protect or Improve Cognition in MS Disease-Modifying Therapies

One of the best ways to maintain cognition is to do your best to avoid new lesions by taking a disease-modifying therapy (if you have a relapsing form of MS). A number of studies with these drugs have shown some benefit on protecting cognition. Ten disease-

modifying therapies are now approved for use by the United States Food and Drug Administration (FDA) for relapsing forms of MS. Please visit MSAAs website at mymsaa.org for specific information on these approved therapies.

Memory Medications and Supplements

People with MS and MS clinicians have hoped that medications such as those that help people with Alzheimer's disease might also benefit people with MS. Some of the Alzheimer's disease medications work to block the enzyme that breaks down the nerve signal messenger acetylcholine. This is the same chemical that is blocked by the bladder medication Ditropan[®] (oxybutynin). Although early reports suggested that the medication Aricept[®] (donepezil) might help cognition in MS, more thorough study has not proven this drug to be of benefit.

Additional studies of the Alzheimer's medications Exelon[®] (rivastigmine) and Namenda[®] (memantine HCl) also did not demonstrate a clear benefit. Some side effects may include stomach or bowel problems, mood changes, and urinary difficulty. Others had hoped that the herbal extract ginkgo biloba would be of benefit, however, preliminary studies have not demonstrated a benefit. Many other supplements are often promoted to help memory in the general population, but hard data is very limited even for people without MS. Discuss any drugs or supplements you may be taking with your healthcare team.

Treatment of Fatigue and Weakness

Treating fatigue when present may reduce its effects, but does it help memory? This is a difficult area to study due to the difficulties in measuring and documenting cognitive changes, as well as the subjective nature of fatigue management. Small trials of amantadine (previously Symmetrel[®]) used for fatigue have not been convincing for cognitive improvement. The medication Provigil[®] (modafinil) and Nuvigil[®] (armodafinil) are commonly used "off label" for MS fatigue and have also been used by some with attention disorders. Ampyra[®] (dalfampridine), studied in the 4-aminopyridine form also did not demonstrate improvement. Management of fatigue by both pharmacologic and non-pharmacologic means may be tried by some, and may include occupational therapy for energy-conservation techniques.

Hope for the Future

While there is currently no proven way to return the brain with its complicated pathways and connections to normal, researchers are actively involved with studying different methods to promote the survival of damaged brain structures, repair and regrowth of myelin, and even regrowth of nerve (axon) cells. While these future options may help, we already have ways to minimize the onset of cognitive problems. These include the ability to avoid aggravating factors, manage the challenges they present, adapt to these changes, and employ strategies to overcome cognitive issues whenever possible.

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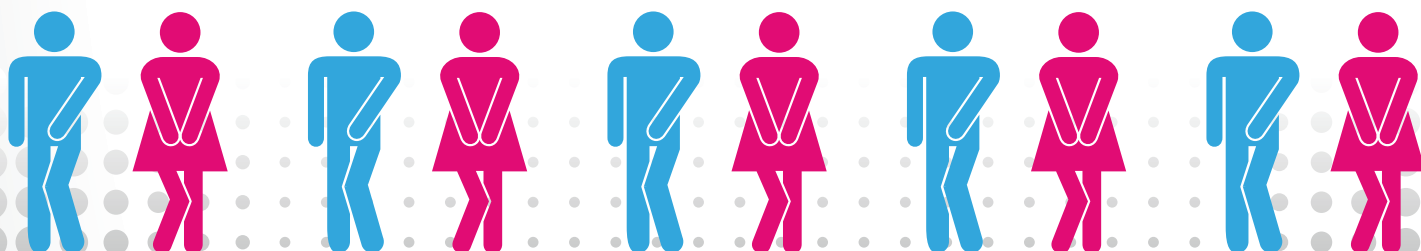
If you're a person living with multiple sclerosis and are suffering with urinary leakage, you may want to consider taking part in a medical research study.

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If you would like to know more about the study, please contact your local DIGNITY2 study team directly or visit the DIGNITY2 website at www.DIGNITY2study.com



Visual Problems

Reviewed and edited by Robert K. Shin, MD
Associate Professor of Neurology
Associate Professor of Ophthalmology and
Visual Sciences
University of Maryland School of Medicine



Visual Problems

Visual problems are common among those with MS and are often a first sign of the disease.

Optic neuritis is often the first symptom of MS. This occurs when inflammation and demyelination are present along the optic nerve (the nerve that connects the brain to the eye). A diagnosis of optic neuritis may suggest MS, but does not necessarily indicate that a person has or will develop MS. Symptoms of optic neuritis include the acute onset of any of the following:

- Decreased vision/blindness in one eye
- Blurred vision
- Graying of vision

Rarely are both eyes affected simultaneously with optic neuritis in MS. Pain with eye movement usually accompanies or precedes visual loss, and visual loss tends to worsen over the course of a few days before improving. Almost 55 percent of people with MS will have an

episode of optic neuritis (according to WebMD).

Many functions are involved in seeing an object. Two major components needed for effective vision are (1) the ability to correctly image what is seen and (2) the proper coordination of the muscles that surround the eye and control its movements. Either or both of these functions can be affected by MS.

The most common problems are decreased or blurred vision (caused by *optic neuritis*), double vision (*diplopia*), and shaking, involuntary movements of the eyes (*nystagmus*). While optic neuritis results from inflammation and demyelination along the optic nerve, double vision and involuntary eye movements are the result of lesions in the brain stem, a part of the nervous system between the brain and cervical spinal cord.

Inflammation along the optic nerve or in other areas of the brain and spinal cord is thought to be the cause of MS relapses, and if severe enough, is often treated with steroids

(described later). However, as with other symptoms, visual problems in MS can also be brought on by fatigue, an increase in temperature, stress, and infection. Managing these symptoms may help to improve any associated visual problems.

Types of Visual Disorders

Full loss of vision, decreased vision, or blurred vision frequently affects only one eye of a person with MS who is experiencing optic neuritis. Colors may appear washed out, and night vision may be particularly difficult. Sensitivity to contrasts in light or the presence of holes (*scotomas* or “blind spots”) may also occur. Occasionally, optic neuritis will cause pain upon movement of the affected eye.

Diplopia, also known as “double vision,” occurs when the muscles that control a particular eye movement are weakened and not coordinated. Although annoying, double vision usually resolves on its own without medical treatment. When diplopia comes on suddenly, it could indicate an acute attack.

Less common than diplopia, another disorder stemming from muscle weakness and loss of coordination around the eye is nystagmus. This is the uncontrolled side-to-side (horizontal) or up-and-down (vertical) movements of the eye. It can be asymptomatic (causing no visual problems) or severe enough to disturb vision. Objects may appear to jump or move unpredictably as the two eyes no longer coordinate well with each other. Nystagmus can be more of a nuisance than a major problem and is usually temporary.

Some individuals with MS may experience a *scotoma*, a disorder that causes a blind spot to appear in the center of vision. A different disorder, homonymous *hemianopsia*, occurs rarely, causing vision to be lost on the right or left visual fields of both eyes.

Treatment of Visual Disorders

Whenever a visual problem arises, an ophthalmologist or neuro-ophthalmologist should be consulted. At times, the doctor may decide that the best treatment is to wait for the inflammation to go down and to see if the visual symptoms disappear on their own, reserving steroid treatment for more severe attacks.

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If the symptoms are severe, intravenous steroid treatment may be used to reduce the inflammation and accelerate the recovery process. The same steroid treatment used to treat other types of MS relapses is often effective in shortening the duration of visual problems. These are usually given via intravenous injection (IV) for a few days, but steroids may also be given orally. An example of high dose steroids would be 1,000 mg of Solu-Medrol® (IV methylprednisolone).

Steroids may be administered two ways. As mentioned, a high dose of Solu-Medrol may be given through intravenous injection (IV), and this is often given daily for three to five days during an attack. Deltasone® (oral prednisone), Decadron® (oral dexamethasone), or Medrol® (oral methylprednisone) in a pill form may also be administered orally for several days after IV treatment, or they may be taken alone without an earlier IV treatment. While these corticosteroids may shorten MS attacks and help one to recover more quickly, no convincing evidence has been shown that corticosteroids can affect the long-term course of MS. Acthar® Gel (ACTH given via injection) is another option for treating MS relapses.

Another line of action is through disease-modifying therapies (DMTs). Presently, 10 disease-modifying therapies are FDA-approved for treating the relapsing forms of MS. Several studies have shown that these can reduce the number and severity of attacks, which in turn reduces the development of visual difficulties.

Several non-pharmaceutical options are

also available to help cope with visual changes. For instance, an eye patch is sometimes used to treat diplopia (double vision) when necessary, such as when driving or reading. An ophthalmologist may also offer additional ideas or treatments for specific visual symptoms. Examples include using yellow lenses to tone down light for those experiencing a light sensitivity, or prisms in eye glasses to redirect the image. In other instances, a patient may find ways to simply adjust – as by turning the head to allow better alignment of the eyes.

If visual problems persist, an ophthalmologist who specializes in low vision can help provide low-vision devices that include magnification and computer modifications. He or she can also design a variety of helpful strategies for managing daily activities.

Individuals with MS experiencing visual problems are often comforted by the fact that these symptoms are usually temporary. As with other MS symptoms, as noted earlier, please keep in mind that visual problems in MS may also be worsened by stress, fatigue, infection, certain medications, or an increase in temperature. When possible, avoiding situations that could worsen the symptoms of MS will also help to minimize the occurrence of visual issues. ♦

Editor's note: The details provided in this article are for informational purposes only. Readers are strongly urged to see their physician before making any changes to their treatment regimen.

What is the Cause of My Daily Headaches?



Dr. Jack Burks

Q: I was diagnosed with MS in 1994 and have been having daily headaches since last summer. In addition to my regular doctor, I have seen two neurologists as well as an ear, nose, and

throat (ENT) specialist. I have had SEVERAL magnetic resonance imaging (MRI) scans, computed tomography (CT or “CAT”) scans, and magnetic resonance angiogram (MRA) tests, and nothing has come up as to why I am having these headaches. Can you give me any direction?

A: Headaches can be caused by any number of factors, and without knowing all of your specific symptoms and giving you a complete

exam, I am not able to suggest any specific diagnosis. However, one mistake is that many people with MS automatically assume that any new issue may be attributed to their MS, and this is not always true. A headache, or any other new problem that arises, needs to be fully investigated to see what the actual cause may be.

Here are some examples of the wide variety of possible causes: headaches can be a dull ache at the back of the head and possibly caused by arthritis in the neck; some individuals with MS experience trigeminal neuralgia, which is a sharp facial pain brought on by a light touch or movement, and they may refer to this as a headache; if nausea and vomiting are present, or if your vision is affected, these can be signs of a migraine or vascular involvement; food allergies or caffeine are other types of common causes. Additionally, one’s emotions can also be involved. Anxiety and depression are among the most common causes of headaches. But please keep in mind that these are just a few examples of the countless types and causes of headaches, and I can’t begin to identify what may specifically be causing your daily headaches for the past year.

What I can tell you is that if you haven’t done so already, the next step in the process of finding out what is causing your headaches is to see a headache expert. This is usually a neurologist who specializes in the diagnosis and treatment of headaches. Your neurologist

To Submit Questions...

Please submit your questions to:

MSAA
Questions for Ask the Doctor
c/o Dr. Jack Burks
706 Haddonfield Road
Cherry Hill, New Jersey 08002

Readers may also send in questions via email to askdr@mysaa.org. Please be sure to write “Ask the Doctor” in the subject line.

may be able to recommend someone, or you may be able to find one through the National Headache Foundation's (NHF) physician finder. The website for the NHF is www.headaches.org, and you can also find a great deal of information on their site as well.

When seeing a headache specialist, he or she can find out about your symptoms specifically, and through tests, rule out many causes. You have already undergone several tests – so you already know what is NOT causing your headaches – and this is a great start. Sometimes a doctor will suggest that you keep a pain diary (mentioned on page 8 of the cover story's section on pain). This may help to provide more specifics on how the pain feels, where and when it occurs, and if it may be related to any type of activity. Sometimes a food diary, sleep diary, or other information can help provide direction for the specialist you are seeing.

Q: In the last issue, you answered a question regarding the appropriateness of stopping treatment with an MS disease-modifying therapy (DMT), since the questioner was not experiencing relapses. I thought my experience doing (almost) just that might add some anecdotal data.

I have been on my DMT since the mid-1990s. I switched doctors after a change in residence six years later. I had been free of both relapses and new lesions during those six years.

My new doctor put me on a different medication, and I thought this would be okay. After two months into my new

treatment, I had an exacerbation involving leg spasms, especially when trying to sleep. This is an issue that's still resolving itself to this day, more than a decade later.

I had to assert myself to get back to my original DMT afterwards, and I continue to be relapse and “new-lesion” free. I changed my doctor years later, however, and the new doctor I was trying out began tests and believed that my MS must have gone away, that my success couldn't be due to the long-term medication I was taking.

I didn't want to wait around to see his next big idea, as I had seen that “show” before. Long story short, like you said, “if it's not broken, don't fix it.” Clearly it is up to the individual to educate himself, ask many questions, and don't be afraid to change doctors.

A: Thank you for your illustrious example that may help a number of people going through the same circumstances. We don't know the precise mechanism that causes damage in MS or exactly why certain drugs may help one individual and not another, but we do know that many of the drugs have different mechanisms by which they work.

If someone finds that his or her MS is totally responsive to one drug, as in your case, the decision to switch to a different drug with a different mechanism, should be weighed very carefully before making a change. Your experience of an attack after six event-free years is a reminder that you don't get rid of MS, and that you need to continuously stay on a therapy that is right for you.

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Q: I have a strange question. My mother is having a hard time with the fact that I have MS. She simply wants it cured. She has a friend whom she works with, who also has a daughter with MS. Apparently, this young lady went to the Mayo Clinic and had her blood switched with “non-MS blood” I suppose. Is there any truth to this? I am going to stay with my mother for a week due to my being “laid-off” (fired) because of the MS. I just want to know the facts before we fight over this.

A: I agree with your mother, I want to cure MS too! However, at this time, not even the Mayo Clinic has a cure for MS. The good news is that treatments for MS are becoming more numerous and patients who stay under treatment are doing much better than before these treatments were introduced. For individuals with progressive forms of MS, research is ongoing to find effective treatments – and hopefully, new DMTs for this type of MS will soon be on their way to larger trials and eventually approval by the Food and Drug Administration (FDA).

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Regarding the daughter of your mother's friend, I assume she may be referring to plasmapheresis, also known as “plasma exchange,” which is occasionally used to treat a severe relapse. This is a procedure that extracts blood from the patient, sends it through a machine, and returns the blood to the body. Plasmapheresis works by removing or diluting elements of the plasma in the blood that may contain antibodies, which can increase the damage caused by MS.

This is not a long-term treatment for MS, nor is it a cure. It is usually used after steroids and the hormone ACTH have proven unsuccessful in treating an MS relapse. The effects of plasmapheresis are temporary, but it helps some patients to recover from a serious MS flare-up more quickly.

I would direct your mother to MSAAs website (mymsaa.org) so she may get a better understanding of MS and its treatments. Your mother may even benefit from counseling to help her adapt to the fact that MS (at this time) may not be cured. My best advice is to focus on your quality of life, reduce MS relapses, and know that positive family relationships are vital to one's long-term happiness. ♦

Dr. Jack Burks is an international MS neurologist, writer, lecturer, and researcher, who assists with the development of new MS therapies and advises patients, families, MS organizations, and healthcare groups. Dr. Burks is a clinical professor of neurology at the Florida International University in Miami. He has written and edited three MS textbooks, as well as numerous chapters and articles on MS.

Research News

American Academy of Neurology Meeting Highlights

Written by Jack Burks, MD

Edited by Susan Wells Courtney

The American Academy of Neurology's (AAN) 65th Annual Meeting took place in San Diego, California in March. This large medical conference presents the latest findings in research and treatments for neurological conditions, including multiple sclerosis (MS). While covering all of the studies relating to MS would not be possible in this issue of *The Motivator*, to follow are some important highlights.

General Studies

Adherence to a disease-modifying therapy (DMT) medication reduces the risk of MS relapses by 50 percent while increasing the number of individuals who are relapse-free at two years.

Women with MS who have had children may experience a slower rate of disability progression than women who have never been pregnant. More studies are needed to confirm these findings, and other disease factors may play a role in whether or not a patient becomes pregnant.

The **herpes zoster vaccine (HZV)** effect in MS was studied in 19 MS patients. These patients suffered no increase in MRI damage, nor had any clinical indication of increased MS symptoms at three months after the vaccination. This study suggests that the HZV is safe to use in MS patients.

FDA-Approved Disease-Modifying Therapies for MS

PEGylated Interferon beta-1a (peginterferon beta-1a) is a chemical modification of the interferon beta-1a (**Avonex**) molecule that allows it to be given subcutaneously (under the skin) every two or four weeks, in contrast to the current once-a-week, deeper, intramuscular injection. Studies are testing this experimental therapy for safety and effectiveness. If approved by the FDA, this would give patients the option of using a single-dose auto-injector with a prefilled syringe less frequently.

In a previous study (BENEFIT trial), patients with clinically isolated syndrome (CIS) were treated with **Betaseron**[®] (interferon beta-1b) or placebo for two years or until they were diagnosed with clinically definite MS (CDMS), at which time everyone was switched to Betaseron. A follow-up extension study at eight years showed both groups had stable or low disability levels, although the patients treated immediately with Betaseron following CIS had fewer relapses than those with delayed treatment.

The FDA-approved dose of **Copaxone**[®] (glatiramer acetate) is 20 mg given daily via subcutaneous injection. In this GALA study, patients received either a 40-mg dose three times per week subcutaneously, or a placebo. This experimental dose reduced relapses and MRI lesions compared to placebo. If FDA

approved, a less-frequent treatment option for Copaxone may become available.

Rebif[®] (interferon beta-1a) is being studied with the use of the RebiSmart[™] injection device, which is an electronic autoinjector that monitors drug adherence through an electronic dosing log. In a German study, it was found to have a 97-percent adherence rate at three months from the initiation of auto-injector use.

Data on small numbers of women who became pregnant within 90 days of taking **Tysabri**[®] (natalizumab) did not suggest any adverse effects on pregnancy outcome. The “C” recommendation (potential harm during pregnancy) stands. Women are not recommended to get pregnant while on Tysabri.

The higher dose (14 mg) of oral **Aubagio**[®] (teriflunomide) reduced both relapse rate and disability, while the 7-mg dose reduced relapses but not disability. Patients with fewer relapses prior to treatment had less disability while taking Aubagio.

A four-year patient-safety study with oral **Gilenya**[®] (fingolimod) showed no unexpected safety concerns, as well as a suggestion that disability may improve at four years on treatment. Those who switched to Gilenya prior to 12 weeks of discontinuing Tysabri, had a lower risk of relapsing than those who began therapy with Gilenya after 12 weeks of stopping Tysabri.

A combined analysis of the two **Tecfidera**[™] (dimethyl fumarate, BG-12) clinical trials showed that when given twice per day, Tecfidera reduced relapses and disability, while also having an acceptable safety profile. A

higher number of patients were free of disease activity versus placebo-treated patients over the two-year trial periods.

Experimental MS Therapies

In a three-year extension study of the oral drug **Laquinimod**, treated patients continued to have less risk of disability compared to placebo. Also, no new safety issues occurred.

Lemtrada[®] (alemtuzumab), a drug infused intravenously only three-to-five consecutive days for the entire first year, was more effective than Rebif in reducing overall disease activity. Adverse events, including thyroid and platelet problems, were consistent with previous studies.

Daclizumab (also known as Zenapax[®]), a monoclonal antibody given by injection, was shown to have less disease and MRI activity compared to placebo at one year. In the SELECT study, participants who were given a 24-week washout period (without treatment), and then reinitiated the drug, showed no evidence of rebound disease activity following the washout period.

MS patients on **Ocrelizumab**, a B-cell targeted monoclonal antibody, had low disease and MRI activity, which lasted at least 72 weeks after the last dose. No new safety concerns were experienced.

Vitamin D continues to be linked to MS and optic neuritis. Treatment with Vitamin D demonstrates positive immune-system changes with decreased inflammation and demyelination. African Americans with MS tend to have lower Vitamin D levels and more MS disability.

Studies in Progressive Types of MS

Fourteen primary-progressive MS (PPMS) patients were involved in clinical trials with the oral drug **Amiloride**, a potassium-sparing diuretic that may have neuroprotective activity. Preliminary results suggest positive effects on MRI and disability.

INFORMS is a double-blind, multicenter, study that will evaluate **Gilenya**[®] (fingolimod) 0.5 mg versus placebo in PPMS patients, over a flexible duration of three-to-five years. It will measure the time-to-sustained disability progression. The enrollment of 969 PPMS patients was completed in 2011.

A preliminary study with secondary-progressive MS (SPMS) patients evaluated the effectiveness of the oral statin drug, **simvastatin**. Preliminary results showed a positive influence on MRI and clinical disability outcomes. Further studies are necessary to confirm these results.

Siponimod (BAF312) is an oral drug that is in the same class of drugs as **Gilenya**, but it is not identical. A large study designed for SPMS patients is underway. A smaller study in relapsing-remitting MS (RRMS) was encouraging, based on relapse and MRI results.

Other Interesting Papers

High dietary salt was implicated in increased autoimmune neuro-inflammation by markedly boosting a Th17 helper T-cell driven autoimmune response in EAE (an experimental disease similar to MS in mice). Th17 is an immune-system cell (lymphocyte) involved with the inflammation that causes damage to the myelin and nerves with MS.

This Th17-boosting property of dietary salt is also seen in humans. The theory that salt may increase MS inflammation has far reaching practical dietary implications for MS patients.

Glucose levels (sugar levels in the blood) were found to be a predictor of the level of disability in MS patients. Further studies are needed to prove a causal relationship.

MS patients who **smoke** have an increased severity of MS. Reasons include the fact that smoking causes damaging changes in the immune system and blood pressure regulating system.

MS patients with certain **genetic patterns** (HLA-DRB1) have an increased level of spinal cord damage compared to MS patients without HLA-DRB1. This highlights the value of examining the brain and spinal cord with a microscope and linking findings to genetic factors.

Chronic Cerebrospinal Venous Insufficiency (CCSVI) has been proposed to cause MS damage due to blocked venous drainage from the brain. In this study, no difference was found in the proportion of MS patients with CCSVI compared to healthy people without MS. This study suggests that CCSVI is not more common in MS patients than in the general population.

Walking and gait were measured in MS patients on **Ampyra**[™] (dalfampridine) while first taking Ampyra, then while not on the drug, and again after the drug was reinstated. Researchers found that walking became worse for patients when not taking the drug, and improved when Ampyra was reinstated. ♦

Tecfidera Approved for the Long-Term Treatment of MS

Written by Susan Wells Courtney

Reviewed by Jack Burks, MD

The United States Food and Drug Administration (FDA) announced on March 27, 2013 that it approved Tecfidera™ (dimethyl fumarate, BG-12) as a first-line therapy for the long-term treatment of relapsing forms of multiple sclerosis (MS). Tecfidera is manufactured by Biogen Idec and is the 10th drug (and third oral medication) to be approved as a disease-modifying therapy (DMT) for the long-term treatment of MS. The approved dosage is 240 mg, taken in pill form twice daily.

Tecfidera may have a distinct **dual mechanism of action**. First, it is an immunomodulator (modulating or affecting how the immune system functions and exhibiting anti-inflammatory properties), and second, Tecfidera may have neuro-protective effects (potentially protecting the nerves [axons] and their myelin covering from damage).

The **Phase III DEFINE** placebo-controlled study enrolled 1,200 patients. Results showed a 49 to 50-percent reduction in the proportion of patients who relapsed during the study period compared to placebo, and a 34 to 38-percent reduction in the risk of sustained disability progression (for at least 12 weeks). The **Phase III CONFIRM** placebo-controlled study enrolled 1,232 patients. Results showed a reduction in relapse rates of 44 to 51 percent for Tecfidera compared to placebo. In

both studies, compared to placebo, individuals given Tecfidera had significantly reduced disease activity as shown on magnetic resonance imaging (MRI) scans.

The most commonly reported **side effects** were flushing and gastrointestinal events, such as diarrhea, nausea and vomiting, and abdominal pain. These occurred more often at the beginning of treatment, decreasing in frequency after the first one-to-two months on this medication.

Reduced white-blood cell (lymphocyte) counts were seen during the first year of treatment (lymphocytes are disease-fighting cells). The FDA recommends that prior to starting Tecfidera, and annually thereafter while still on the treatment, patients are given a complete blood count to monitor their ability to fight infection.

For More Information

Please see mysaa.org/news-msaa/840-tecfidera-approved for MSAA's full article on the approval of Tecfidera. Additional information on Tecfidera may be found by visiting www.tecfidera.com and or through Biogen Idec's patient assistance program at www.msactivesource.com or (800) 456-2255. In addition to MSAA's website (mysaa.org), individuals may call MSAA at (800) 532-7667 for more information about MS and its treatments. Questions to MSAA's Client Services Department may be emailed to MSquestions@mysaa.org. ♦

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A recent study¹ funded by the National MS Society, and published in the *Archives of Physical Medicine and Rehabilitation*, indicated that for ambulatory patients with MS, the **HFAD** significantly improved gait performance, as well as **improved strength** in the limb fitted with the **HFAD**. Furthermore, the use of the HFAD was found to result in **increased daily activity level**.

To purchase an **HFAD**, a physician's prescription is required for **both** the *Hip Flexion Assist Device* and for *Gait Training*.

1. Sutliff, Matthew H., PT; Jonathan M. Naft, CPO; Darlene K. Stough, RN; Jar Chi Lee, MS; Susana S. Arrigain, MA; and Francois A. Bethoux, MD. "Efficacy and Safety of a Hip Flexion Assist Orthosis in Ambulatory Multiple Sclerosis Patients." *Archives of Physical Medicine and Rehabilitation* 89 (2008): 1611-1617.



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Keep Cool This Summer

Spring is a time for all to enjoy the warmer, more-pleasant temperatures. Unfortunately, the hot and humid conditions of summer will quickly follow. As one of our most popular and longstanding services, the MSAA Cooling Equipment Program offers a variety of ice-pack vests and accessories to help lessen heat sensitivity and allow people to spend time outdoors, enjoying family gatherings, gardening, and a variety of fun, summer activities. To help meet our client's needs, cooling products also include smaller, lightweight vests that are easily hidden for discreet use and comfortable to wear while at

work, play, or participating in your favorite exercise.

As the summer temperatures begin to rise, so do the requests for cooling applications. To avoid possible delays due to high demand, MSAA encourages you to apply now before the summer cooling rush is upon us. If you are interested in receiving cooling items and have not received products from MSAA within the past five years, please download the Cooling Equipment application from mysaa.org/msaa-help/cooling or request a mailed copy by calling (800) 532-7667, extension 130.

Watch Our New Video about MS Relapses

Managing the unpredictability of multiple sclerosis is always challenging, especially for individuals with relapsing forms of the disease. When new symptoms appear or existing symptoms become worse, successful management involves accurately defining the relapse and understanding the best method of treatment.

Recognizing the need for additional awareness on this topic, MSAA is proud to announce the completion of its latest educational on-demand video, titled: *A Closer Look at The Importance of Treating and Managing MS Relapses*. Supported by an educational grant from Questcor Pharmaceuticals, this 40-minute video features neurologist and MS expert Dr.

Stephen Krieger of Mt. Sinai Hospital in New York City. In this relaxed, conversational-style interview, Dr. Krieger provides valuable insights into understanding the signs and symptoms of an MS relapse, guidance on when to discuss the onset of a flare up with a neurologist, and a thorough explanation of the various treatment options including steroids and other medications.

The video is now posted to the Multiple Sclerosis Information (MSi) section of the MSAA website and features a downloadable PDF transcript of the program. To view this new program along with other informative on-demand videos and archived webinars from the MSi library, please visit mysaa.org/videos.

Visit and Stay Well

Earlier this year, MSAA launched our completely redesigned and updated website: mymsaa.org. Our new website is not only more user-friendly, but also reflects our philosophy behind our shared-management programs. Including such programs as My MS Manager™ and My MS Resource Locator, these programs are designed to assist the patient and healthcare provider in working together to achieve the best possible health outcomes.

This comprehensive site features new sections and enhancements that provide more information, vital tools, and easier access for the entire MS community. Among the many new additions, our website includes a section

titled “Overall Wellness.”

Overall wellness is important for everyone – with or without a condition such as multiple sclerosis (MS). For individuals who are diagnosed with MS, taking care of your body and mind is vital to feeling and performing at your very best. In this section, MSAA offers a wealth of information on topics such as diet, exercise, women’s and men’s health, emotional support, complementary and alternative therapies, and many other subjects.

MSAA invites you to learn more about the “Overall Wellness” section as well as additional features to our exciting new website by visiting mymsaa.org. ♦



Will you join us? Over 36,000 people already have.

The non-profit NARCOMS Registry expedites MS research by providing a unique resource for investigators. We welcome your assistance in this global effort. Together we can make a huge difference in defeating MS!



We can learn about the complexities of MS by following disease and treatment patterns in a large group of people over several years. The information we gather is used only for research. Details submitted by the registry participants remain strictly confidential. There is **no cost** to you.

You will receive a complimentary subscription to the *NARCOMS Now* magazine on MS research, written specifically for NARCOMS participants. Enrollment is open to anyone diagnosed with MS over 18 years of age.

Sign up now at www.narcoms.org or call 800-253-7884 to request a survey. Our update surveys come via mail or online twice a year, each typically taking less than 20 minutes to complete. **That's it – thank you for supporting MS research!**

Swim for MS has Many Facets

“In helping others, we shall help ourselves, for whatever good we give out completes the circle and comes back to us.”

– Flora Edwards

Earlier this year I made my first contribution to MS Conversations (MSAA’s blog, located at blog.mymsaa.org) with my thoughts on giving, receiving, and service. In that entry, I spoke of the health benefits of volunteer work, quoting research that found people who volunteer and give of themselves have a greater chance of being happy and healthy than those who do not. In today’s busy society, this sounds like multi-tasking at its best – in helping others, we help ourselves.

As part of our Swim for MS initiative, MSAA offers a great way for you to help others, while helping yourself through fun and exercise. Swimming is known to be one of the best exercises for all ages and body types. It is especially good for those living with chronic illnesses like multiple sclerosis. For more information on the benefits of aquatic therapy and aquatic exercise for individuals with MS, please see the Health and Wellness column from the Summer/Fall 2012 issue of *The Motivator*. Visit mymsaa.org/msf12h to read this article on MSAA’s website. Individuals without internet access may request a copy by calling MSAA at (800) 532-7667.

The Swim for MS initiative has many facets. At its core is our goal to increase the

number of people with MS who are able to improve their quality of life through water-based exercise programs. In the next year, this initiative will work to educate individuals with MS on the benefits of aquatic exercise and to increase their opportunity to participate in water exercise.

MSAA is proud to have secured United States Olympic Gold Medalist Missy Franklin as our Swim for MS Ambassador. Missy’s accomplishments in swimming and her enthusiasm for being in the pool enable us to increase the marketing and promotion of the fundraising portion of Swim for MS. This is with the goal of increasing the number of volunteers participating and the donations generated in support of MSAA’s programs and services, including aquatic exercise.

Swim for MS encourages volunteers to swim laps or distances over a set period and collect donation pledges. These challenges can be done individually or through group swims by teams of young and old alike. Volunteers also raise funds through a variety of unique one-day events such as pool parties, water-volleyball tournaments, and cannonball challenges. Unlike more traditional MS fundraising activities, Swim for MS allows individuals with MS at any stage in their journey – from the recently diagnosed to those with limited mobility – to benefit from water exercise and assist in raising donated funds for a vital cause.

On our SwimForMS.org website, you can read the profiles of some of our swimmers. They can inspire you and give you great ideas for your own Swim for MS challenge. Read about a 7-year-old boy who spent his summer doing cannonballs into his backyard pool, making 500 jumps over the summer while raising money. Or see the high school student from Pennsylvania who hosted a 24-hour swim party to honor his teacher with

MS, raising more than \$1,700. And then there is the story of Jeannie, who has MS herself and credits her involvement with swimming for giving her back her health. Jeannie's synchronized Swim for MS included events at three pools and included the synchronized swim team where she is now a regular member. We would like to thank everyone who has or will participate in our Swim for MS program! ♦



IN MEMORIAM: GARY WALLACE

A tribute from colleague and friend, Doug Franklin

Gary Wallace passed away September 12, 2012 after battling a medical condition for many months. He is survived by his wife Roberta and his son Kevin.

He was MSAA's Vice President of Finance and Administration and joined the charity with me back in 1999 as my first new hire. Our early days together were challenging as MSAA was transitioning from a founder-led organization to a new, re-focused charity, built on a solid financial foundation with exemplary policies and procedures that earned us the right to use the Better Business Bureau's Wise Giving Alliance seal of approval. Gary was instrumental in helping us move forward and he always treated the charity's finances with care and support, ensuring MSAA grew within its means while remaining financially sound.

A quiet man with a gentle disposition, he worked tirelessly to help the charity grow. His fondness for his extended MSAA family was always apparent and he is sorely missed by all of his colleagues. His dry wit and love of a good joke was always on display.

Gary's love for golf is exemplified by the titling of our annual charity golf tournament in his memory. The MSAA Gary Wallace Memorial Tournament will be played this year on Monday, September 16, at Little Mill Country Club in Marlton, New Jersey. If you are interested in participating, please visit support.mymsaa.org/golfLM. Gary will be there with us in spirit this year, and his contributions to MSAA during his 14-year employment span will continue for many years to come. Rest in peace GW!

Health and Wellness

The Affordable Care Act and You

Major Changes In Healthcare Will Affect the MS Community – Are You Ready?

by Margaret Weisser, LSW • Edited by Peter Damiri

The Affordable Care Act (ACA) aims to increase the availability and affordability of health insurance for millions of Americans who lack coverage. The ACA initially began making changes in 2010; however, beginning in January 2014, this historic initiative will significantly impact a substantial number of individuals with multiple sclerosis (MS) and their families.

A number of changes have been made to the entire health-insurance system, not only in terms of greater access to insurance, but also with how insurance will be regulated and minimum standards of coverage. Open enrollment begins on October 1, 2013. While most Americans with manageable healthcare needs will find sufficient information regarding coverage options through state and federal resources, the MS community must be prepared to ask additional questions to ensure proper coverage.

As many of you know, MS is a highly individualized and expensive disease to evaluate, manage, and treat. Individuals with MS must consider an extraordinary number of factors when determining their healthcare coverage, including: the ability to access neurologists and other treating specialists; policy selections that impact the costs of deductibles, co-pays, and co-insurance; and drug formularies that classify MS medications

in various tiers, limiting access and restricting changes. Similar complexities and changes will potentially impact the costs of magnetic resonance imaging (MRI) scans, rehabilitation services, and adaptive equipment.

What if You Have Insurance Already?

Many individuals who have insurance currently may be thinking, “Will the ACA impact me?” The answer for almost everyone is a resounding, “Yes!” Some of the overarching benefits put into place by the ACA will assist all individuals with MS. These include the removal of pre-existing conditions, the elimination of dollar limits on annual and lifetime benefits for healthcare coverage, and benchmark plans that set minimum benefits standards on a broad array of health services.

Medicare recipients will see some changes in their out-of-pocket expenses as the Medicare Part D donut hole, which covers prescription medications, is incrementally lowered to finally “close” in the year 2020. At that time, Medicare recipients will pay 25 percent of the drug cost. This represents a significant cost savings, as before 2010, individuals in the donut hole were required to pay 100 percent of the cost of their medications until reaching the end of the donut hole.

Medicaid will also see changes as many more individuals on a low-income budget will become eligible for Medicaid. At the time this article was written, 27 states have already agreed to expand their Medicaid programs to include individuals up to 138 percent of the federal poverty level (FPL), which is \$15,415 per individual or \$26,344 per family of three in 2012. It is important to note that some states only expanded the Medicaid program for particular groups and not all individuals under the 138-percent FPL. Additionally, as of March 2013, seven states are still undecided on whether to expand the Medicaid program.

For individuals who live on a very limited budget, your residence may actually dictate what insurance resources may be available to you. If you are not sure whether you may qualify for Medicaid services beginning in January 2014, you will be able to find out directly through your state's Marketplace. When you input your income into the system, the Marketplace will identify whether you qualify for Medicaid in your state. If you qualify, your enrollment information will be sent directly to the correct state office.

Private insurance or employer-based insurance offers new options as well. Individuals who purchase insurance or receive insurance through an employer will also have new coverage options as Health Insurance Marketplaces (formerly Exchanges) open up to create an arena in which to shop for the best insurance policy. Employers with 50 or more full-time equivalent employees must automatically register their employees

for health insurance or pay a penalty. An employee can opt out of their company health-insurance plan in writing and formally choose to enter the Health Insurance Marketplace.

The Health Insurance Marketplace is an entirely new entity with 18 states choosing to independently run their own Marketplace, seven states selecting to provide a partnership Marketplace with the federal government, and 26 states opting to default to the federal government to run their Marketplace. The Marketplace is largely a web-based comparison platform (similar in concept to Orbitz or Travelocity) where people can enter their personal information and receive comparison data on health-insurance plans. Individuals will be able to compare the cost of the monthly premiums, deductibles, and expected costs and co-insurance fees for common procedures, medical equipment, and medications. If you do not have computer access, you will have opportunities to enroll by phone and in person.

Most plans offered through the Marketplace include three levels of service. They are commonly defined as:

Bronze: lower premiums, but higher out-of-pocket costs for health services

Silver: higher premiums than bronze, but more moderate out-of-pocket costs for health services

Gold: highest monthly premiums, but lowest out-of-pocket medical costs for health services

So, Why Do You Need to be Concerned?

Most individuals with average healthcare needs will be able to enter the Marketplace and locate a suitable plan within their price range. For individuals who purchase insurance in the Marketplace, many will qualify for a monetary credit to assist with their monthly premiums. This credit is determined when a person's income is entered into the Marketplace website. It is important to remember that if your income changes during the year, you must re-enter the Marketplace and update your income, as this might affect your coverage.

Individuals with MS need to consider many factors when selecting a plan that go far beyond the cost of the monthly premium. The challenges presented by a complex, chronic illness such as MS will require you to pay close attention to many areas of coverage, including the items listed below.

Medications: Medications that are specific to MS (the disease-modifying therapies and some symptom-management treatments) are considered specialty drugs. As a result, most of these medications are classified as Tier 3 or Tier 4, which indicates they have the highest co-pay levels. You will need to evaluate not only the cost of the co-pay or co-insurance for medications on those tiers, but also directly check with each insurance policy you are considering to see which MS medications are currently covered on that insurance drug formulary.

You should consider not only your current drug therapy, but what other medication(s) would be available to you if you need to

change drug protocols. Plans that cover fewer MS medications may be less desirable. Also, plans may list many of the MS medications as a "Step Therapy," which means you must fail another identified treatment option to qualify for that medication. Another important factor to understand and remember is that insurance companies can change their drug formularies at any time. The companies are required to notify customers of these changes, but it is in your best interest to inquire about the drug formulary when you renew your policy.

Diagnostic and follow-up testing (such as MRI): If specific tests, such as an MRI, are typically used in the management of your health conditions, you will want to evaluate how that procedure is covered to project out-of-pocket expenses. This entails evaluating the cost of the monthly insurance premium for plans at different coverage levels versus what the expected co-pay, co-insurance, and deductible costs will be for procedures or testing you may need on a regular basis.

Durable Medical Equipment (DME): Many individuals with MS may utilize DME's such as canes, walkers, wheelchairs, lifts, and scooters. If you know you need to replace an existing item or are looking to obtain multiple items to improve daily living, you should pay close attention to how these items are covered under the policy. This will ensure that you will have the coverage needed to obtain any items you may require.

Please make sure that you select wisely. If you select the "wrong" plan, you may not be eligible to change insurance policies again until the next open enrollment or until a



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specific qualifying “life-change” event takes place. Therefore, it is especially important to make the best choice possible based on your individual needs and circumstances.

These are just a few of the areas you may want to consider when selecting the best Medicare, Medicaid, or insurance plan for your specific needs. For more information and details about what you need to know, please visit the ACA section of MSAA’s

website at mymsaa.org/aca. On the website, we offer a list of common insurance terminology, how to navigate drug formularies for MS medications, a checklist of important questions to ask before purchasing a policy, and more. Anyone with additional questions may speak with an MSAA Helpline consultant by calling (800) 532-7667, extension 154. Questions may also be emailed to MSquestions@mymsaa.org. ♦

The temperatures are warming up and summer is just around the corner. Now is the perfect time to start planning your Swim for MS challenge!



What is Swim for MS?

Swim for MS is a national fundraiser in which volunteers are encouraged to create their own Swim challenge while recruiting online donations to support MSAA. Swim for MS is unique because MSAA does not plan the event - you do! As a Swim for MS volunteer, you have the opportunity to create and arrange your own special Swim activity. You can participate individually or recruit other Swim enthusiasts to form a team.

How do I Swim for MS?

You’ll find many fun and creative ways to dive into action and raise funds for MS. Popular Swim for MS activities fall into two main categories:

Go the Distance: individuals or teams set a challenge goal to swim a certain amount of laps, distance, or time during one day or over a set period of time (i.e., swim 500 laps in 30 days to raise \$1,000 for MS)

Make a Splash: participants turn fun pool activities into exciting fundraisers such as pool-volleyball tournaments, cannonball-jumping contests, and more! You can even dedicate your next birthday party as a Swim for MS Pool Party.

Please visit SwimForMS.org today or call (800) 532-7667, extension 157 to sign up!

Stories to Inspire

Hiking the Arizona Trail for Multiple Sclerosis

Foolishly, I told myself that I would not cry when I reached the border between Arizona and Mexico, thus having completed my journey of 817 miles through rugged mountains, water-deficient deserts, and stunning Ponderosa and Aspen forests that encompass the Arizona Trail. But my toughened trail demeanor that had been honed during the past three months was as elusive as the mountain lions I heard so much about but had yet to see.

After many months of long preparation and sacrifice, my dream finally became reality: I had walked 817 miles for multiple sclerosis.

Why, I was asked, would I hike 817 miles?

When I think of MS, I think of movement (and lack thereof), and how we are impacted by this sometimes physically debilitating disease. In my case, I was not impacted physically but was so emotionally. After my diagnosis in 2009, and after a period of time of fighting with these feelings, I realized I was not the only one who mourned an old existence. Because of MS, many former hikers, runners, and athletes could no longer perform as they had in the past, and the emotional impact of that realization can be staggering. This recognition inspired me to want to help others attain confidence and strength in their fight against MS.

As my husband Bob and I walked through

a blizzard of snow in the Grand Canyon, one April day in 2011, “Hiking for MS” was conceived.

Being avid hikers, it was a chance for us put our talents together and walk for those who might not be as fortunate (or could no longer hike themselves). The Arizona Trail had just conjoined its last individual segments, and to our knowledge no one with multiple sclerosis had yet walked the entire 817 miles as a thru-hiker (i.e., hiking the entire distance continually, without leaving the trail for any amount of time). If we succeeded, it would have taken us over two months to do so, barring any injuries or sicknesses.

After a few false starts that involved funding, our plans started coming to fruition. I had found another hiker to join me and we were slowly reaching our financial goals. I trained hard, driving my husband crazy with my obsessive need to work out. We set a date of September 11, 2012, in order to honor both those with MS, as well as those fallen heroes of 9/11.

After only a few weeks on the trail and having lost my hiking partner to injury, I realized that I had undertaken a huge task that I hadn't been fully prepared for. I had



by Shawn Feliciano

never thought of the possibility of my hiking by myself (Bob's main job was to drive to each meeting point, set up camp, and scout out the segments to come).

The Arizona Trail, although beautiful, can be quite treacherous. The difficulty in this hike was the lack of water, and for this reason Bob's job was of crucial importance. He had to make sure that he cached water for me, so that I would not have to carry the weight, especially during a long day hike. If he or I missed the rendezvous point, I could die from dehydration or exposure to the cold at night.

Hiking by myself meant that I had to be focused and present at all times, and we know how hard that might be for those with MS. I needed to have directional sense (which is one of the reasons that I had planned to hike with a partner); I had none. I was acutely aware that I had begun this hike during early fall, which meant that the bears had not begun to hibernate, and mountain lions still abounded. When there is more than one person hiking, there is less of a chance encounter with these animals, but as a lone hiker, and especially a small woman, I was an easy target. I was told that the "young and stupid" male mountain lions were the ones that were more likely to take a chance at a morsel like me.

And if that was not enough to scare me, I had to contend with the human element – especially as I reached areas that were more populated. A woman hiking by herself drew attention.

Despite these real and perceived obstacles, I faced each day with exuberance and a sense

of adventure. I had my days where I could not find the trail and had to retrace my steps. (The Arizona trail is a combination of trails and many are marked with old signage or unmarked – the Arizona Trail Association is working out these glitches).

One day, I was so turned around after trying to fruitlessly retrace my steps twice, that I hailed a family on horseback and begged for a ride. I wasn't technically on the Arizona Trail, hence the problem, so it was okay to hitchhike (I could still claim that I hiked the entire trail, and not ridden for any portion of it). For someone who was afraid of horses, my fear was quickly dispelled as I thought of the miles my feet would be spared. Fortunately, the family gave me a lift, riding double with the mom. We started getting into creek beds that were dry and very rocky. At this point, the horse was afraid, so she got off and coaxed the horse along, leading him through the difficult terrain. It was quite an adventure!

After more hours of useless hiking, I had but a couple of hours to retrace my steps to my starting point before dark. Cell coverage was sporadic during most of the hike, but came through during these crucial times. And luckily, Bob could drive back to that morning's drop-off point and spare me from having to spend a tentless night in the wild.

Many were the times in which I faced an impasse because of lack of signage, scouting the area in all directions in order not to make a rash decision. These times taught me about obstacles we each face at one time or another and what lessons we can glean from those times.

My mind had time to be still and so I learned how to be silent and appreciate myself; laugh at my blunders; have faith in others; overcome the pressures that the hike was having on my marriage. Some days the MS symptoms were worse than others and I would trip and fall more often. When I did I was grateful that I could do so, because I still have the ability to hike. And each day I walked for those who could not.

Originally, it was my intention to bring awareness and inspire others, yet it was I who was fortunate to be inspired by those who extended love and hospitality to me. Some of those I met on the trail, others wrote to thank me for encouraging and instilling hope, while new friends opened up their homes and volunteered their personal time to

hike with me.

After 80 days on the trail, I was blessed to have had my dad and brother, as well as my best friend from high school join me on this journey. My husband, who supported me throughout every phase of the entire hike (while wearing the driver, camp-setter, cook, and hiker hats in the process), was instrumental in my beginning and successfully completing the hike.

So, on that momentous occasion as I took my final steps towards the 817th mile marker, I remembered all of those with MS for whom I had walked, all those who had helped or wished us well, and all our dreams, trials, and tribulations; and the tears flowed joyfully.

Now, on to the next adventure! ♦



Spread the Word

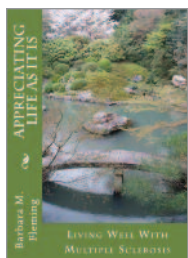
Facing the Cognitive Challenges of Multiple Sclerosis

SECOND EDITION

Written by Jeffrey Gingold
Published by Demos Health
MSAA Book # 158



Award-winning author Jeffrey Gingold is an attorney, husband, and father who also has MS. He has written several books on this topic, speaking candidly and descriptively about the unexpected cognitive challenges that MS has brought into his life. Giving precise details, Gingold explains how he feels when experiencing a sudden lapse in memory, the fears and confusion that stop him in his tracks, and the methods he has found to best resolve an otherwise panic-stricken moment.



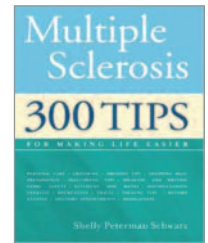
Appreciating Life As It Is: Living Well With Multiple Sclerosis

Written by Barbara M. Fleming
Published by CreateSpace
Independent Publishing Platform
MSAA Book # 13

Author Barbara Fleming was diagnosed with MS 30 years ago, and has worked as a library director, art instructor, and professional artist. Applying the theories of Dzogchen, a philosophy of Tibetan Buddhism, her book takes a more spiritual approach to living with MS. Meaning “great perfection,” Dzogchen is aimed at breaking up the negative thoughts that can interfere with the enjoyment of life, and developing a positive outlook that is full of potential, regardless of life’s circumstances.

Multiple Sclerosis: 300 Tips for Making Life Easier

Written by Shelley Peterman Schwarz
Published by ReadHowYouWant
MSAA Book # 60



Diagnosed with primary-progressive MS in 1979, Shelley Peterman Schwarz is well known in the MS community as well as at MSAA. She has been involved with several of our educational materials, and is also an award-winning author, columnist, and popular radio and TV personality. This large-print, second edition of her book provides time and energy-saving tips, techniques, and shortcuts to help individuals with MS to organize and simplify their lives.

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