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MSAA

The MOTIVATOR

Winter/Spring 2009

Bringing Information to People with Multiple Sclerosis

Symptom Management Update

An overview of the many strategies, therapies, and medications used to manage MS symptoms

The MOTIVATOR

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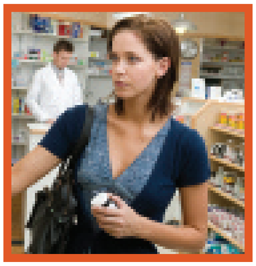

COVER STORY

DEPARTMENTS

MSAA
MULTIPLE SCLEROSIS ASSOCIATION OF AMERICA

The Multiple Sclerosis Association of America's mission is to enrich the quality of life for everyone affected by multiple sclerosis.

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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Up Front

By Douglas G. Franklin
MSAA President and CEO

Douglas G. Franklin

At the same time that this issue of *The Motivator* is being printed and mailed, MSAA is hosting several public education events across the country. This is all part of "MS Awareness Month," which occurs in March of each year. I encourage you to visit our website, **www.msassociation.org**, to learn about events in your area – not only in March, but throughout the year. While on our site, please take a moment to view one of our free educational videos in our MSi video library, read one of our award-winning publications, or look at the many volunteer opportunities available.

Also in March, I am traveling with six other members of the MS Coalition (MSC) to the National Multiple Sclerosis Society (NMSS) Public Policy Conference in Washington, DC. This conference provides an excellent opportunity for so many of us to gather in one room and discuss the issues facing everyone affected by MS. Our three days of meetings culminate in a march to "The Hill," where we hope to again shine a light on the needs of the MS community to members of Congress.

> **"MSAA will continue to work tirelessly toward fulfilling our mission to enrich the quality of life for everyone affected by MS, especially at a time when our clients may be in greatest need of our assistance."**

I would also like to note that these are challenging economic times for all of us, and we are inspired by the degree of support MSAA's donors and clients have shown. Please know that we will continue to work tirelessly toward fulfilling our mission to enrich the quality of life for everyone affected by MS, especially at a time when our clients may be in greatest need of our assistance. ◆

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.

Symptom Management Update

A comprehensive overview of strategies and medications used to manage MS symptoms, along with initial findings on many experimental treatments presently being studied

Written by Diana M. Schneider, PhD
Edited by Susan Wells Courtney
Reviewed by Jack Burks, MD and Randall T. Schapiro, MD

Based on the positive review to the "MS Research Update" articles that appeared in the Summer 2007 and 2008 issues of *The Motivator*, this article expands the coverage of MS management to discuss the second arm of the MS treatment spectrum, the management of the many symptoms of the disease. Although most of the media attention given to MS focuses on the disease modifying agents, many of the symptoms of MS can and should be managed effectively. The article is organized by symptom, and discusses both non-pharmacologic and pharmacologic approaches. For each medication, we have provided basic information on usage, dose, and effect. This is not a complete list and not all studies and their research are included.

The information provided is based on a wide range of sources, including the extensive journal literature on MS and its management, a review of ongoing clinical trials, and papers presented at major national and international meetings dedicated to neurologic conditions and MS. These include the annual meetings of the American Academy of Neurology (AAN), the Consortium of Multiple Sclerosis Centers (CMSC), and the American and European Committees for Treatment and Research in Multiple Sclerosis (ACTRIMS and ECTRIMS).

Editor's note: MSAA does not endorse or recommend any specific products or therapies. Readers are advised to consult their physician before making any changes to their medication, diet, exercise, or other regimen.

General Comments and Discussion

Multiple sclerosis (MS) may be associated with a wide variety of symptoms, which can occur in almost any combination and vary widely among individuals. These symptoms are managed with both rehabilitation strategies – including physical and occupational therapy – and a range of pharmacologic agents.

Many people with MS take multiple medications, and it is important that any physician prescribing any new drug know ALL of the medications you are currently taking. This is especially important for those drugs that have either a depressant or stimulant effect on the central nervous system (CNS). Such depressants include the benzodiazepines and other tranquilizers, sedatives, prescription medications used for pain, antihistamines, and alcohol. Stimulants include drugs used to manage fatigue.

Some drugs are used to manage more than one symptom. For example, some antidepressants are also effective in managing fatigue, and a number of agents originally developed as anti-seizure medications are helpful in managing pain and spasticity. For these multi-use agents, we have included the drug under its major indication, and cross-referenced it as appropriate.

Many – even most – of the medications used to manage the symptoms of MS were first developed for use in other conditions, or the same symptom in people who do not have MS. When a drug has been approved by the United States' Food and Drug Administration (FDA) for use in one condition, physicians may use it on an "off-label" basis in other situations, whose symptoms may resemble that of the one for which the drug was originally approved. Because FDA approval includes a detailed review of safety and reliability testing, the physician can be reasonably confident that the side effects of the drugs are well known.

We note recommended dosages for drugs wherever guidelines exist, although each individual responds differently and optimal dosages may be outside this range depending on a variety of factors. In the case of many drugs used off-label, the dosage may be different than that used for the original condition for which the drug was approved, and will be adjusted for each individual to maximize therapeutic benefit and minimize side effects.

All drugs have side effects, and it can be difficult to determine the specific cause of any new side effect to a specific agent if you are taking multiple medications. Many of the drugs used to treat MS have side effects that

include dizziness, sleepiness, fatigue and weakness, confusion, and gastrointestinal disorders. Most of these symptoms disappear as your body becomes used to the medications. However, report any sudden changes in your physical or psychological health to your physician to rule out an unusually severe effect of a new medication.

Just as the symptoms of MS differ from one person to another, how an individual reacts to a certain treatment will differ from person to person as well.

In most cases, medications used to treat any symptom of MS should not be discontinued abruptly. These medications are usually tapered off gradually, as indicated by your healthcare provider, and some drugs may have severe side effects if suddenly stopped. Please consult a physician before making any change to your medications. In the event of a severe or allergic reaction to a drug, contact a medical professional or seek emergency help immediately.

A Word about Complementary and Alternative Medicine (CAM)

The term "CAM" can be broadly defined as therapies that are somewhat outside of the medical mainstream, and used to manage various symptoms or illnesses. Some, such as acupuncture, have been the subject of major studies that have shown a positive effect on specific symptoms. Others, such as tai chi, yoga, and meditation, are generally beneficial to many people, not just those with MS. Still others, including a wide variety of herbs, should be used with caution as they have the potential to interact with medications that you may be taking. Don't begin any program or supplement without first discussing with your physician or nurse whether the therapy might affect your MS adversely or interact with your current medications.

In the pages to follow are the most commonly reported symptoms of MS, along with the different strategies used in treating these symptoms. Just as the symptoms of MS differ from one person to another, how an individual reacts to a certain treatment will differ from person to person as well.

Often a physician will need to try different therapies, dosages, and even combinations, before finding the treatment plan best suited for a specific patient. The following information is not to be used to determine treatment, but rather to inform readers of the different treatment strategies available. As noted earlier, MSAA does not endorse or recommend any specific products or therapies. And as always, please consult a physician before making any changes to your treatment regimen.

At the conclusion of this listing is a page of resources for more information. This includes books, videos, and MSAA publications. Readers looking for more information or support are also encouraged to speak with one of MSAA's Helpline consultants by calling (800) 532-7667.

SECTION 1: FATIGUE

Fatigue is one of the most common symptoms of MS. The term is generally used to refer to a "lassitude" characterized by an overwhelming sleepiness that often comes on suddenly. A number of strategies and medications may be helpful.

NON-PHARMACOLOGIC MANAGEMENT

Energy conservation

You may be able to see a pattern to your fatigue. For example, many people find that their fatigue is at its worst in the afternoon. You can learn to plan your activities to take advantage of those times when you tend to have the most energy, and to pace your activities to allow for rest periods. An occupational therapist can help you conserve your energy by balancing activity and rest, so that you are able to enjoy the things you most want to do.

Cooling

Because many people with MS are heat-sensitive and find that their fatigue is increased in hot weather or in warm indoor environments, a variety of cooling techniques have been found useful. These include swimming in cool water, taking cool drinks on warm days, using air conditioning, and using cooling apparel or other accessories. MSAA has a Cooling Equipment Distribution Program, which provides various types of apparel (such as vests, neck wraps, and wristbands) to individuals who qualify. These types of products may also be purchased through various retailers.

Manage Secondary Causes

Fatigue can result from a variety of metabolic and hormonal conditions, sleep deprivation, depression and anxiety, and a variety of medications. It is important that your health provider address these problems with a comprehensive checkup if you are experiencing fatigue. Stress management techniques such as meditation may be helpful in managing fatigue. Because deconditioning, contributes to fatigue, exercise – especially aerobic exercise in moderation – may also be helpful in decreasing fatigue.

PHARMACOLOGIC MANAGEMENT

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.

Provigil® (modafinil)

This is an oral medication whose usual dose is 100 to 200 mg daily, although dosages up to 400 mg are sometimes needed. It 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.

Reports of the drug's effectiveness in MS have been mixed. Its use in MS was first based on a 2002 study from Ohio State University showing improvement in 65 patients with a dose of 200 mg per day. A more recent randomized, placebo-controlled, double-blind study in Germany was performed in 121 patients who had a high baseline score on the Fatigue Severity Scale (FSS) and an Expanded Disability Status Scale (EDSS) score of less than 7. Initial evaluation of the data showed significant improvement in fatigue, cognitive impairment, and walking. However, a study comparing modafinil to antidepressant therapy in 64 patients found that antidepressant treatment was more effective as measured by a number of test criteria.

Side effects most commonly seen are headaches, insomnia, nausea, and constipation.

Amantadine

This generic medication was previously available as Symmetrel®. This is an oral medication whose usual dose is 100 to 200 mg daily. The drug 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.

Side effects include rashes, dizziness or lightheadedness, insomnia, nausea, and constipation.

Ritalin® (methylphenidate)

This is an oral medication whose usual dose is 10 to 60 mg daily, 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.

Methylphenidate was originally developed as a treatment for attention deficit disorder, and has also been used to manage narcolepsy.

FATIGUE (continued)

A Phase I trial in 2003-2005 enrolled 80 patients with either RRMS or SPMS. It evaluated the effect of methylphenidate on cognition, not fatigue, but the link between the two supports its use for fatigue.

Side effects include nausea, dizziness, insomnia, severe or persistent headache, high blood pressure, and tachycardia (rapid heart rate); it should not be taken by individuals with serious heart problems.

Dexedrine® (dextroamphetamine)

This is an oral medication whose usual dose is 5 to 40 mg daily. This is a stimulant that has been used to improve wakefulness, boost energy, and decrease fatigue and appetite.

Side effects are similar to Ritalin® and include nausea, dizziness, insomnia, constipation, high blood pressure, and rapid heart rate.

Cylert® (pemoline)

Pemoline was withdrawn from the United States' market in 2005 due to rare but severe liver damage, resulting in death or liver transplant.

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

SSRIs are antidepressants, and are discussed in the section on Depression (page 24); managing the effects of depression may also alleviate symptoms of fatigue. These medications may need to be taken for several weeks before seeing an effect.

Side effects include drowsiness, mouth dryness, headache, nausea, and sleep difficulties.

Caffeine

Caffeine taken as coffee, tea, or caffeinated soda, in moderation, can be helpful in managing fatigue. Individuals should speak with their doctor about their intake of these beverages, to be sure they are not exceeding levels of caffeine or sugar that are appropriate for them.

SECTION 2: SPASTICITY

This common symptom of MS usually affects the muscles involved in walking and maintaining upright posture. With normal muscle function, opposite muscles work in opposite directions, meaning that one muscle pulls while the other relaxes. Spasticity is a condition that occurs when opposite muscles both contract or relax at the same time, causing an increase in muscle tone. This can often lead to muscle stiffness, muscle spasms, reduced joint mobility, and related discomfort. It also contributes to fatigue, because more energy is required to perform daily activities.

NON-PHARMACOLOGIC MANAGEMENT STRATEGIES

Manage Secondary Causes

Because spasticity may be worsened by a variety of other MS symptoms and non-MS-related conditions, it is important that spasticity be managed as part of a comprehensive strategy. Common MS symptoms that contribute to an increase in spasticity include fatigue, stress, heat, urinary tract and other infections, and pain. Therapies designed to relieve these symptoms may result in significant improvement in spasticity.

Stretching and Range of Motion Exercises

A physical therapist can develop a specific stretching and range of motion (ROM) exercise program for your specific issues. Aquatic exercise may also be helpful.

Orthotics and Walking Aids

Simple devices such as an ankle-foot orthosis (AFO) may help walking by relieving the effects of foot-drop and by reducing spasticity.

PHARMACOLOGIC MANAGEMENT

A variety of pharmacologic agents can be helpful in managing spasticity, some of which are used “off label.” This means that they have been approved for use in other conditions, but have also been shown (for example) to be effective in spasticity management for individuals with MS, despite not being specifically approved by the FDA for this purpose. Optimal management is sometimes achieved by combining several medications, which has the benefit of reduced side effects.

Baclofen (formerly available as Lioresal®)

This is an oral medication whose escalating dose is usually begun at 5 mg daily, with a typical effective dose of 30 to 90 mg daily; some individuals may require higher doses. Most doctors start with a low dose and increase it gradually. Discontinuation of the drug is also done by gradually lowering the dose to avoid seizures. This is the most commonly prescribed drug used to manage spasticity, and most people with MS respond well to it.

Side effects include drowsiness, dry mouth, and lightheadedness. Again, the drug should not be stopped abruptly, as seizures, hallucinations, and/or agitation may result.

Zanaflex® tablets and Zanaflex Capsules® (tizanidine hydrochloride)

This oral medication is available as tablets or capsules, however, these have slightly different formulations from each other and from the generic versions, so you should not switch without consulting your physician. The starting dose is usually 2 to 4 mg daily, gradually increased to a maximum of 36 mg daily. It is particularly useful for nighttime spasticity, and is often combined with baclofen.

This is a short-acting drug. Because it reaches maximum effectiveness in 1 to 2 hours, and lasts for a maximum of 6 hours, its dosing schedule needs to be carefully monitored. Clinical trials have demonstrated safety and efficacy. A preliminary study suggests that 12 mg tizanidine taken sublingually (under the tongue, for rapid absorption) just before bedtime, results in a statistically and clinically significant reduction in next-day spasticity (this type of administration has not yet been approved).

Side effects may include sedation, low blood pressure, weakness, constipation, and dry mouth.

Valium® (diazepam)

This is an oral medication in tablet form, with initial doses of 2 to 5 mg that may be increased as needed. The sedative effects of diazepam and other anti-anxiety medications make it especially helpful for nighttime use; it is not recommended for daytime use because of its sedative properties.

Side effects include drowsiness, dizziness, lightheadedness, low blood pressure, and shortness of breath.

Klonopin® (clonazepam)

This is an oral medication in tablet form, whose usual dose is 0.5 to 1 mg. Clonazepam is chemically related to diazepam, and is used in MS to treat tremor and pain as well as spasticity. Because it is sedating, it is most commonly used at night.

Side effects include dizziness, lightheadedness, constipation or diarrhea, mouth dryness, and rapid heartbeat.

SPASTICITY (continued)

Dantrium® (dantrolene sodium)
This is an oral medication with a usual dose of 10 to 20 mg. Dantrolene acts directly on muscles to relieve cramping, and may be helpful in some situations. However, its use is limited because it can induce weakness, even at low levels.

Side effects most commonly seen are weakness, unusual tiredness, drowsiness, nausea, diarrhea or constipation, sleep difficulties, and headache. Periodic blood tests to evaluate liver function are recommended.

Neurontin® (gabapentin)
This is an oral medication available in tablet form. The dose may vary widely, from 100 to 1,600 mg per day. Gabapentin and other chemically-related anti-seizure medications have anti-spasticity properties and are effective in some people. They are frequently used as "add-on" drugs to enhance the effects of other medications such as baclofen.

Additionally, gabapentin may be a useful treatment for dysesthesia (a burning sensation along the nerve) and other painful conditions that may be associated with MS.

Side effects include fatigue, sleepiness, dizziness, and balance problems.

Tegretol® (carbamazepine)
This is an oral medication in tablet form. The dose normally ranges from 400 to 1,000 mg per day. Carbamazepine was also originally developed as an anti-seizure medication. It is especially useful for flexor spasms of the extremities. (Flexor spasms usually affect the lower limbs, often worsening at night, and may be very painful.)

This medication is also used to manage trigeminal neuralgia (sudden and brief periods of severe facial pain, occurring on one side of the face), as well as other dysesthesias.

Side effects include dizziness, drowsiness, nausea, and balance problems.

Keppra® (levetiracetam)
This is another oral anti-seizure medication that has been found useful for some of the symptoms of MS. A 2003 study of 12 patients at the University of Texas showed a significant improvement in spasticity following treatment with levetiracetam. Three of the 12 also reported improvement in neuropathic pain. The drug was well tolerated; large, well-controlled trials are needed to confirm these findings. Until then, this will not be considered a routine treatment.

Side effects may include sleepiness and dizziness.

Requip® (ropinirole)

This is an oral medication in tablet form. Ropinirole was developed for use in Parkinson's disease, and is also effective for restless legs syndrome. This may explain its usefulness as a treatment for painful nighttime spasticity.

Side effects include nausea, dizziness, drowsiness or trouble sleeping, constipation, and headache.

PHARMACEUTICAL THROUGH PHYSICAL INTERVENTIONS

Botox® and Myobloc® (botulinum toxin)

Botulinum toxin is administered by injection into a muscle (or muscles) that is involved in severe spasticity, and has almost completely replaced the phenol blocks used earlier for spasticity. It temporarily blocks the nerves that lead to specific muscles, for a period of months. The drug should only be administered by an experienced physician or other healthcare provider.

Side effects may include unexpected weakness.

Baclofen Pump (Intrathecal Baclofen)

When spasticity is severe and does not respond to oral medications, administration of baclofen directly to the spinal cord is often effective. This involves the placement of a tube into the spinal canal that is connected to a pump implanted under the skin. It decreases spasticity with a much lower dose of baclofen than would be needed orally, and with a much lower incidence of side effects. The most frequent complications of this therapy are catheter malfunction and infections, with a higher incidence of malfunction in people who are ambulatory.

Side effects are the same as those for oral baclofen (details given on page 11), although they are less common because the dose is significantly lower.

SURGICAL PROCEDURES

In rare instances, when spasticity cannot be resolved through standard pharmacologic management strategies, irreversible surgical procedures may be considered. This involves cutting nerves to specific muscles that do not respond to the procedures discussed above.

Phone Number Change for Women's Resource

In our Fall 2008 issue of *The Motivator*, our cover story on Women with MS highlighted some helpful resources on page 20. The fifth listing, **Ethel Louise Armstrong Foundation**, has a new phone number. This foundation may now be reached by calling **(805) 252-7983**.

SECTION 3: WEAKNESS

Weakness is a common symptom in MS, resulting from the demyelination of neurons in the brain and spinal cord that control the muscles. It most commonly affects those muscles involved in walking.

NON-PHARMACOLOGIC MANAGEMENT

Exercise
An exercise program that involves extensive work with weights is not generally effective in reducing weakness, although a general exercise program prescribed by a physical therapist or other healthcare provider can lessen weakness by improving your overall level of conditioning. It should incorporate passive exercises that include range of motion and stretching, as well as active exercises tailored to the individual. These often include progressive-resistance exercises and aerobic exercises to whatever extent safely and comfortably possible for the individual patient.

PHARMACOLOGIC MANAGEMENT

Drugs that reduce spasticity and fatigue may also help to reduce weakness.

Fampridine SR® (long-acting fampridine, 4-aminopyridine)
When and if it is approved by the FDA, this oral medication has been studied at a dose of 10 mg, once to twice daily.

This drug may improve communication between damaged neurons to increase neurologic function, as indicated by an improvement in walking speed and strength.

A 14-week, Phase III, multi-center trial in people with MS found that approximately 35 percent of the treated group showed consistent improvement in walking speed, versus just over 8 percent of the placebo group. The treated group also experienced an increase in strength. Patients who responded to the drug also reported feeling less disabled in activities that required mobility.

The favorable results of a second phase III study (sponsored by Acorda Therapeutics), which evaluated the safety, tolerability, and activity in individuals who participated in the original trial, were presented in the fall of 2008. An FDA application was submitted in January 2009, and is now being reviewed for possible approval.

Side effects included dizziness, falls, back pain, insomnia, fatigue, nausea, and balance problems.

SECTION 4: BALANCE

Balance difficulties are common in MS, and can result from a combination of: MS lesions in various areas of the brain that are involved in the control of movement; the presence of weakness, tremor, and fatigue in the muscles involved in walking; and by symptoms such as visual problems and numbness.

COMPENSATORY STRATEGIES

Treating other symptoms that affect balance, such as spasticity, weakness, and tremor, can be of help. Balance can also worsen from being "out of condition," and a physical therapist with experience in MS can design an exercise program and teach helpful techniques. Hippotherapy (therapeutic horseback riding) may improve balance as well. Some individuals may benefit from Ritalin® (methylphenidate), which is a medication developed for attention deficit disorder. The usual dose for this oral medication is 10 to 60 mg daily, normally 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.

SECTION 5: DIZZINESS AND VERTIGO

Vertigo, or the sensation of "spinning," may occur as the result of lesions in the brain areas that coordinate balance.

NON-PHARMACOLOGIC MANAGEMENT

Physical Therapy
If changes in head position are a component of vertigo, a physical therapist can develop an exercise program that will help to reduce the effects of these positional changes.

PHARMACOLOGIC MANAGEMENT

Antihistamines
including Benadryl® (diphenhydramine), Antivert® (meclizine), and Dramamine® (dimenhydrinate)
Mild vertigo may be controlled with these agents, originally used to treat vertigo associated with motion sickness. Dose is usually 25-50 mg every 8 hours.

Side effects include drowsiness, blurred vision, constipation, and dryness of the mouth.

Scopolamine Transdermal Patch
This is an anticholinergic agent, meaning that it acts on neurons that use acetylcholine as their transmitter. One of its main uses is the treatment of motion sickness and its associated vertigo.

Side effects are similar to the antihistamines, listed above.

Benzodiazepines
including Valium® (diazepam), Klonopin® (clonazepam), and Serax® (oxazepam)
These medications decrease activity in the areas of the nervous system that control the inner ear.

Please refer to the *Spasticity and Anxiety* sections (pages 11, 26) for details on these drugs.

SECTION 6: TREMOR

Tremor is an involuntary, rhythmic shaking movement of the muscles. It is most commonly due to the loss of myelin on axons in the central nervous system pathways that coordinate muscle movement and balance. It can affect many parts of the body, and is one of the most frustrating symptoms of MS.

REHABILITATION STRATEGIES

Physical or occupational therapists may be able to reduce the effects of tremor by teaching specific positions for some activities or by balance and coordination exercises. These might include patterning, which involves repeating a series of movements related to an activity such as eating, until those movements essentially become automatic and can be performed without accompanying tremor. Rehabilitation therapists may also teach exercises that focus on stimulating the balance centers of the brain.

Weighting involves using utensils and other devices that are modified so that the extra weight helps to stabilize arm tremors.

PHARMACOLOGIC MANAGEMENT

Atarax®, Vistaril® (hydroxyzine)
These oral antihistamines may be useful for minor tremors that are made worse by stress.

Klonopin® (clonazepam) and Buspar® (buspirone)
These are oral medications originally developed as anti-anxiety agents. Clonazepam may help tremor by causing sedation. Buspirone primarily is not a sedating or habit-forming drug. At a dose of 5 to 10 mg, three to four times daily, buspirone may help with tremor and is well tolerated. Please refer to pages 11 and 26 for details on clonazepam.

Side effects include oversedation (with clonazepam).

Neurontin® (gabapentin)
Please refer to the Spasticity section (page 12) for details on this oral medication.

Inderal® (propranolol)
This oral medication is a beta-blocker, originally developed as a medication to regulate heart rate. The initial dose is 80 mg, and it is increased slowly until an effective dose is reached.

TREMOR (continued)

It provides modest relief for some tremor.

Side effects include abnormal heartbeats, lightheadedness, gastrointestinal symptoms, and confusion.

Zofran® (ondansetron)
This is an oral medication originally developed as an anti-nausea drug for use with cancer chemotherapy. The usual dose is 4 to 8 mg, taken 3 to 4 times per day, and may produce a decrease in tremor in some patients. This medication has few side effects.

Keppra® (levetiracetam)
This is an oral medication in tablet form. It was originally developed as an anti-seizure medication. Small Italian and British pilot studies were encouraging, but more research is needed. For more information, please see the *Spasticity* section (page 12).

Side effects include sedation, weakness, and dizziness.

Mysoline® (primidone)
This oral medication was developed as an anti-seizure drug. It has some anti-tremor effects when used in lower doses than those prescribed for epilepsy. The initial dose is 50 mg, which is increased gradually.

Side effects include significant sedation.

Laniazid®, Nydrazid® (isoniazid)
This oral medication was developed to treat or prevent tuberculosis. It is effective for certain types of tremor; its mechanism of action is unknown.

Side effects may include nervousness, sleep difficulties, headache, and nausea.

SURGICAL MANAGEMENT

Thalamotomy and Deep Brain Stimulation
Because tremor results from damage to axons in an area of the brain called the "thalamus," it is sometimes treated surgically. One technique, known as a thalamotomy, destroys a section of the thalamus. Another technique, deep brain stimulation, was originally developed to treat the tremor associated with Parkinson's disease. Instead of destroying the area of the thalamus that causes tremor, an electrode is implanted in the region, and connects a wire lead to a control device implanted under the skin. Activating the device sends impulses into the thalamus, disrupting the signals that cause tremor.

SECTION 7: PAIN

MS may be associated with a variety of symptoms characterized as "pain." In addition to the types of pain experienced by everyone – with or without MS – some types of pain are directly related to the MS process itself. Other pain may be the result of the physical effects of MS, such as the stress on joints produced by problems such as imbalances associated with walking difficulties. More than 50 percent of all people with MS will experience pain in one form or another during the course of their disease. A recent Canadian study indicated that pain is the second most common symptom of MS, with fatigue being the most common.

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 Neurontin® (gabapentin), Tegretol® (carbamazepam), and Keppra® (levetiracetam)
Please refer to the *Spasticity* section (page 12) for details on these oral medications.

Anti-Anxiety Agents
including Cymbalta ® (duloxetine hydrochloride), Valium® (diazepam), and Klonopin® (clonazepam)
Please refer to the *Spasticity, Depression,* and *Anxiety* sections (pages 11, 25, 26) for details on these oral medications.

T*ricyclic Antidepressants*
including Elavil® (amitriptyline), Pamelor® (nortriptyline), and others
Please refer to the *Depression* section (page 25) for details on these oral medications.

Dilantin® (phenytoin)
This is an oral medication in tablet form. The dose normally ranges from 100 to 400 mg per day. Dilantin is an anti-seizure medication that is commonly used to manage the pain of trigeminal neuralgia, but it may be helpful for other pain conditions as well.

Side effects include dizziness, drowsiness, and balance problems.

Lyrica® (pregabalin)
This is an oral medication in tablet form. The dose normally ranges from 150 to 600 mg per day.

This agent was approved by the FDA in 2004 for the treatment of neuropathic pain associated with diabetes, fibromyalgia, and certain types of seizures. It has not specifically been approved for MS, but has proven effective for many people.

Side effects include drowsiness, constipation, and balance problems.

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.

PHARMACOLOGIC MANAGEMENT

Trigeminal neuralgia can usually be treated with medications such as anti-seizure agents.

Neurontin® (gabapentin), Tegretol® (carbamazepine), and Dilantin® (phenytoin)
Please refer to the *Spasticity* and *Pain* sections (pages 12, 20) for details on these anti-seizure medications.

SURGICAL MANAGEMENT

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

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

PHARMACOLOGIC MANAGEMENT

Medications such as anti-seizure drugs may help to prevent the pain. Pharmacalogic treatment is usually accompanied by physical therapy.

PAIN (continued)

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. 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, physical therapy, and treatment for spasticity. A variety of relaxation techniques have proved helpful, as have acupressure and acupuncture.

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 be sure to follow prescribing instructions. Too much of these medications can cause serious side effects, including liver damage.

COMPLEMENTARY AND ALERNATIVE MEDICINE THERAPIES

Acupuncture

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

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

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

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.

Yoga and Tai Chi

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.

Cannabis

The use of cannabis (marijuana) is illegal in the United States and cannot be recommended. Additionally, there have been reports of adverse cognitive effects on people with MS.

SECTION 8: DEPRESSION

Depression is common in MS. It can be the result of difficult life situations or stresses, but may also occur from the MS disease process, because of damage to areas of the brain that are involved in emotional expression and control. Additionally, depression can also be a side effect of various medications used in the management of other MS symptoms.

NON-PHARMACOLOGIC MANAGEMENT

Because of the wide-ranging issues that affect people with MS and can also contribute to depression, the effective results are usually obtained with a combination of "talk therapy," (through some type of counseling or therapy), pharmacologic agents, and exercise.

PHARMACOLOGIC MANAGEMENT

A wide variety of antidepressant medications are useful in managing depression associated with MS. Most of them appear to work by slowing the removal of specific neurotransmitters, thus increasing their activity because they stay in the system longer. This means that the chemicals that make us feel good remain in the body longer, and this positively affects mood. The two main neurotransmitters affected by antidepressant medications are serotonin and norepinephrine. These medications belong to a variety of subcategories, depending on the neurotransmitter they affect.

SSRI antidepressants (Selective Serotonin Reuptake Inhibitors)
including Prozac® (fluoxetine), Zoloft® (sertraline), Paxil® (paroxetine), Celexa® (citalopram), and Lexapro® (escitalopram)
This group of antidepressants was developed to treat general mental depression and panic disorders, and has proved effective in treating depression and anxiety, as well as several other symptoms of MS. SSRIs inhibit the reuptake of serotonin (a chemical produced within the body, which is known to elevate mood), allowing it to remain in the body's system longer.

Side effects of this class of drugs include decreased sexual drive or ability, drowsiness, dry mouth, headache, and weakness, as well as psychological symptoms that may include agitation and nervousness.

SRNI antidepressants (selective Serotonin and Norepinephrine Reuptake Inhibitors)
including Cymbalta® (duloxetine hydrochloride), Serzone® (nefazodone), Wellbutrin® (bupropion), and Remeron® (mirtazapine)
These are oral medications in tablet form. With side effects similar to the SSRIs, SSRNIs are a newer type of antidepressant and provide additional treatment options.

Side effects vary with the specific drug, but may include gastrointestinal problems, fatigue, sleepiness, drowsiness, and dizziness. Contact your healthcare provider if you experience any sudden emotional or behavioral changes while taking this medication.

Tricyclic Antidepressants
including Elavil® (amitriptyline), Tofranil® (imipramine), Pamelor (nortriptyline)
These are oral medications in tablet form. The dose normally ranges from 10 to 150 mg per day (amitriptyline), 75 to 150 mg per day (imipramine), and 10 to 175 mg per day (nortriptyline).

Side effects include dry mouth, constipation, sexual problems, dizziness, and drowsiness.

SECTION 9: ANXIETY

Anxiety is common in MS, and may be related to depression. In many cases, medications used to treat depression will also alleviate symptoms of anxiety. A recent study at the University of Washington indicated that about one-quarter of all people with MS experience anxiety, and most of them also experience depression.

NON-PHARMACOLOGIC MANAGEMENT

As with depression, and because of the wide range of issues that can contribute to depression, the most effective results are usually obtained with a combination of "talk therapy" (counseling) and pharmacologic agents.

A number of relaxation and therapeutic therapies can also be very helpful in reducing anxiety. Among others, these include exercise, biofeedback, guided imagery, self hypnosis, yoga, tai chi, and massage.

PHARMACOLOGIC MANAGEMENT

Benzodiazepines
including Valium® (diazepam), Serax® (oxazepam), Ativan® (lorazepam), Klonopin® (clonazepam), and Xanax® (alprazolam)
Valium was the first benzodiazepine approved by the FDA for the treatment of anxiety, and most of the agents used to manage this symptom in MS are derivatives of this drug.

Doses vary depending on the specific molecular structure of the diazepam derivatives. All are useful in treating anxiety and panic disorders, as well as the anxiety that is directly related to depression; these conditions are normally treated as a single entity. These drugs must be carefully monitored as they may cause dependence.

Side effects include confusion, depression, drowsiness, insomnia, light-headedness or dizziness, headache, urinary difficulties, and tremor. Habituation – a decrease in response after repeated use – is a concern.

SECTION 10: SLEEP DISTURBANCES

Sleep problems are common in MS, and may be the result of a variety of symptoms such as spasms, urinary frequency, depression, or anxiety, as well as medications used to manage a variety of symptoms associated with the disease. This can lead to the proverbial "vicious cycle," in which symptoms disturb sleep, and the lack of needed sleep in turns worsens a variety of symptoms, such as fatigue.

A variety of strategies can help manage sleep problems.

NON-PHARMACOLOGIC MANAGEMENT

Develop Good Sleep Habits
Some fairly simple changes can help enormously to ensure a good night's sleep. They include:

- Keep a regular schedule; go to bed and get up at the same time every day, including weekends. This will help your body adjust to a normal sleep pattern.
- To minimize nighttime trips to the bathroom, don't drink a lot of fluids in the evening.
- Don't exercise in the evening; whatever your exercise program, do it earlier in the day.

Manage Other Symptoms that May be Contributing to Sleep Problems
Many symptoms of MS can affect sleep, including spasticity, pain, depression or anxiety, and bladder and bowel issues. Addressing these problems can go a long way to improving your sleep.

Relaxation Techniques
There are many meditation tapes and other relaxation-oriented approaches to improving the amount and quality of your sleep. Your nurse or other healthcare professional may be able to guide you to strategies that may be effective.

Pharmacologic Management
Although the occasional use of sleep medications may be helpful, routine use of "sleeping pills" should be avoided, as they lose their effectiveness quickly, are potentially addictive, and do not provide a normal night's sleep. Over-the-counter Benadryl and Benadryl-containing products may be helpful, but should not be used on a regular basis. If sleep aids are needed, consult your doctor for an optimal treatment plan. This will ensure the best rest possible using the least amount of medication.

SECTION 11: COGNITIVE FUNCTION

The term "cognition" refers to a group of mental processes that include functions such as memory, decision making, and concentration, which is the ability to focus on specific tasks and planning. Since other symptoms of MS can affect concentration, and drugs used to treat some symptoms can affect how quickly thoughts may be processed, it is important that any cognitive symptoms be evaluated carefully in the overall context of your MS management. The relationship between fatigue and cognition is significant, and there is a clear association between feelings of tiredness, difficulty concentrating, and memory issues. For this reason, symptoms of cognitive difficulties are often improved by the strategies discussed in the *Fatigue* section, beginning on page 6.

COGNITIVE TESTING AND REHABILITATION

A baseline cognitive evaluation is important and can serve as the basis for a comprehensive management strategy by identifying the areas of difficulty. This testing procedure is generally administered by a neuropsychologist or other specialist.

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.

Disease Modifying Therapies

A number of studies suggest that the disease-modifying therapies (DMTs) delay or improve cognitive problems. The approved DMTs for MS include: Avonex® (interferon beta 1-a); Betaseron® (interferon beta 1-b); Rebif® (interferon beta 1-a); Copaxone® (glatiramer acetate); Novantrone® (mitoxantrone); and Tysabri® (natalizumab).

PHARMACOLOGIC MANAGEMENT

Several drugs may be effective in reducing the cognitive symptoms of MS.

Anti-Fatigue Agents
including Provigil® (modafinil) and amantadine

Separating the effects of fatigue and cognition can often be difficult, but there is ample evidence that fatigue worsens the effect of cognitive difficulties, and that fatigue-management strategies are often effective in decreasing cognitive symptoms. Please see page 7 for details.

Aricept® (donepezil)

This is an oral medication in tablet form. The dose normally ranges from 5 to 10 mg per day.

Aricept® is one of a group of cholinesterase inhibitors that were originally developed for use in Alzheimer's disease. It prevents the breakdown of one of the main neurotransmitters in the brain, acetylcholine, thus increasing its levels in the brain and improving the function of those neurons that are dependent on this substance for normal functioning. Preliminary studies suggest that they may improve learning and memory.

MS trials using drugs for Alzheimer's disease need more rigorous results before they can gain wider acceptance and are FDA-approved for the cognitive symptoms sometimes experienced with MS. Several small clinical trials have shown a modest improvement in memory as measured by test scores, and up to two-thirds of the participants reported improvement.

Side effects may include gastrointestinal problems, painful or difficult urination, seizures, fatigue, or sleep difficulties.

Other Alzheimer's disease treatments

Other pharmacologic agents approved for treating Alzheimer's disease are used in some patients. The effects are usually not dramatic.

SECTION 12: BLADDER

Bladder problems are common in MS, and result from demyelination in the nervous system pathways that control the muscles of the bladder and the *sphincters* of the urinary tract. The three categories of bladder problems are usually referred to as “failure to store,” “failure to empty,” and a “combination” of the two. They can usually be managed successfully, once the cause is identified.

A. FAILURE TO STORE

This problem results from a hyperactive or spastic bladder, and is the most common type of bladder dysfunction in MS. Symptoms include increased urgency and frequency of urination, incontinence, and the need to urinate during the night (nocturia).

NON-PHARMACOLOGIC MANAGEMENT

Dietary and Fluid Management
Changes in your diet combined with timing urination – rather than waiting to feel the urge – may be effective. Your nurse or other healthcare provider can help you to develop an effective management plan. Meanwhile, don’t restrict your water intake! Dehydration and constipation will only add to your problems.

PHARMACOLOGIC MANAGEMENT

Ditropan® and Ditropan XL® (oxybutynin)
This medication may be taken orally, and it is also available through a patch, which is replaced every 3 to 4 days. The dose for regular release is 5 mg two times per day; XL is 5 to 10 mg once daily; and a new patch is usually applied two times per week. This medication decreases the spasms associated with failure-to-store bladder problems, reducing urge and frequency of urination.

A study now recruiting participants, sponsored by Astellas Pharma Inc., will compare the effects of oxybutynin against solifenacin (brand name: Vesicare®; please see individual listing on next page for more information about this drug).

Side effects include dry mouth, constipation, headache, and blurred vision.

Detrol® and Detrol LA® (tolterodine tartrate)
This is an oral medication in tablet form. The dose ranges from 2 to 4 mg per day. It reduces the frequency and severity of the bladder spasms that result in many of the symptoms associated with failure-to-store problems.

Side effects include dry mouth, headache, and gastrointestinal symptoms.

Vesicare® (solifenacin)
This is an oral medication in tablet form. The dose ranges from 5 to 10 mg per day.

As mentioned earlier, a study now recruiting participants, sponsored by Astellas Pharma Inc., will compare the effects of oxybutynin against solifenacin in MS.

Side effects include dry mouth, constipation, and blurred vision.

Enablex® (darifenacin)
This is an oral medication in tablet form. The dose ranges from 7.5 to 15 mg per day. Its actions are similar to those of Detrol® and Ditropan®.

Side effects include dry mouth, constipation, and blurred vision.

Levsinex® (hyoscyamine)
This is an oral medication in tablet form. The dose ranges from 1 to 2 mg per day.

Side effects include dry mouth and difficulty swallowing.

Flomax® (tamsulosin) and Other Antihistamines
This is an oral medication in capsule form. The dose ranges from 0.4 to 0.8 mg per day. Flomax® was originally developed to treat enlargement of the prostate. It acts by relaxing the muscles of the bladder.

Side effects include low blood pressure, dizziness, and sleepiness.

Hytrin® (terazosin); Minipress® (prozosin)
These are oral medications in tablet form. The dose for either drug is 1 mg once to twice daily. These medications were developed to treat high blood pressure. They are also effective in relaxing the muscles of the bladder.

Side effects include dizziness, weakness, and nausea.

DDAVP (desmopressin)
This drug is administered as a nasal spray, as directed, and is also available as an oral formulation. The nasal spray is usually taken once in the evening, as a treatment for nocturia (nighttime urgency). The dose is one squirt (spray) or 0.2 mg (oral), both given at bedtime. Desmopressin is a hormone that controls frequent urination by its action on the kidneys.

Side effects include runny or stuffy nose and headache.

BLADDER (continued)

Botulinum Toxin (Botox®)
Botox injections into the bladder wall and sphincters decreases spasticity and may permit increased retention of urine. However, this technique is still somewhat experimental.

B. FAILURE TO EMPTY

This condition is the result of the muscles of the bladder being flaccid due to a loss of ability for the bladder muscles to adequately contract. Symptoms include urgency followed by difficulty in starting the stream of urine, incomplete emptying, and increased frequency of urination – often the result of incomplete emptying.

NON-PHARMACOLOGIC MANAGEMENT

Catheterization
The most common management strategy is intermittent catheterization, usually done every few hours. In some cases, an indwelling catheter that remains in place for a period of time is needed, especially in people with significant disability.

Pharmacologic Management
Medications are generally not effective for this type of bladder dysfunction. Urecholine has been used by some doctors. The dose is usually 50 mg twice daily.

C. COMBINATION BLADDER DYSFUNCTION

As its name suggests, this problem results from a failure of the muscles of the urinary tract system to act together in a normal pattern, so that bladder contraction and the release of urine occur together.

NON-PHARMACOLOGIC MANAGEMENT

Catheterization
As with the failure-to-empty situation, intermittent catheterization or an indwelling catheter is often effective.

BLADDER (continued)

PHARMACOLOGIC MANAGEMENT

The medications noted earlier for use with failure-to-store difficulties, in combination with catheterization, is often effective. Baclofen may also be of help to some patients; please refer to the *Spasticity* section (page 11) for details on this drug.

D. BLADDER INFECTIONS

Bladder infections are relatively common in people with MS. They are treated with antibiotics, the most common of which are listed below. The specific antibiotic depends on the type of bacteria causing the infection. Increasing the urine's acidity may reduce the risk of infection. Cranberry juice in moderation is commonly used for this purpose.

PHARMACOLOGIC MANAGEMENT (THROUGH ANTIBIOTICS)

Bactrim® (sulfamethoxazole/trimethoprim) and Septra® (sulfamethoxazole/trimethoprim)

These are oral medications in tablet form. The usual doses are 80 mg of trimethoprim and 400 mg of sulfamethoxazole. These medications are used in combination, administered either as a single dose twice a day or a double dose once a day.

Side effects include dizziness, headache, and gastrointestinal symptoms.

Cipro® (ciprofloxacin)

This is an oral medication in tablet form. The dose ranges from 500 to 1000 mg per day.

Side effects include dizziness and sleepiness.

SECTION 13: BOWEL

A significant percentage of people with MS develop bowel problems at some time in the course of their MS. Constipation is fairly common for individuals with MS, and this problem may be ongoing or periodic in nature. Incontinence or diarrhea is far less common with MS and is often temporary. Medications are sometimes a cause of bowel incontinence, and these can include antibiotics and even treatments used to relieve constipation.

A. CONSTIPATION

Constipation is the most common bowel problem in MS, and results from lesions in the nervous system that control the rate at which stool is passed through the bowel. This slowed movement results in more water being absorbed, causing hard, dry stools. It can also occur in people who limit their intake of fluids to minimize bladder problems, as the result of a lower activity level, and in some cases by medications taken to control other MS symptoms.

OVERALL MANAGEMENT

The management of constipation has three main components: diet – including at least 24 ounces a day of water and 20-30 grams of fiber; a consistent bowel program; and the use of stool softeners or other substances that stimulate more rapid passage of stool through the bowels and increase its bulk.

STOOL SOFTENERS

Stool softeners help to retain liquid in the stool to allow easier passage through the bowel.

Colace® (docusate)
This is an oral medication in softgel or tablet form. The usual dose is 1 to 2 softgels or tablets each day, taken morning and/or evening.

Surfak®
This is an oral medication in pill form. The usual dose is 1 pill a day, most commonly taken in the morning.

Chronulac®
This is an oral medication in syrup form. The usual dose is once or twice a day, in the morning and/or evening. It is usually taken after meals, as its taste may be unpleasant.

BOWEL (continued)

BULK FORMERS

Bulk formers absorb liquid and swell to form soft, bulky stools. They increase both the bulk and fluid content of stool, stimulating faster and easier passage. They should be taken with 1 to 2 glasses of water.

Metamucil® (psyllium hydrophilic mucilloid)

This is an oral medication in either gel capsule form taken with water or juice, or as a powder mixed with water or juice, usually at bedtime.

Fibercon®

This is an oral medication in tablet form. The usual dose is 2 tablets, taken 2 to 4 times per day with 8 ounces of liquid.

Citrucel®

This is an oral medication in powder form. The usual dose is 1 tablespoon, 2 to 3 times daily, mixed into 8 ounces of water.

Fiberall®

This is an oral medication in chewable tablets, wafers, or powder. The usual dose is 1 to 3 times daily with 8 ounces of water.

LAXATIVES; ORAL MEDICATIONS

This group includes over-the-counter laxatives taken orally. Only mild laxatives are recommended.

Miralax®

This is an oral medication in powder form. The usual dose is 1 capful dissolved in 4 to 8 ounces of water or juice, 1 to 2 times per day.

Pericolace®

This is an oral medication in capsule form. The usual dose is 1 to 2 capsules at bedtime, which may be increased to twice a day if needed.

Milk of Magnesia® (magnesium hydroxide)

Magnesium hydroxide acts by stimulating the movement of fluid into the bowel, causing a bowel movement within a short time. This fairly harsh laxative should not be used on an ongoing basis. The dose is 30 cc at bedtime.

Mineral Oil

Mineral oil coats the bowel and stool, helping to retain moisture in the stool. It is normally taken at bedtime so that a normal bowel movement will occur the next morning.

Laxatives; Rectal Stimulants

Traditional enemas should be avoided, as they are too harsh for routine use. The following gentler stimulants should be used only as needed, as extended use may result in dependence.

Glycerin Suppositories

These mild suppositories contain no medication and are often used when establishing a regular bowel program. They draw water into the bowel, helping to soften stool.

Dulcolax® (bisacodyl) Suppositories

This suppository contains a medication that stimulates movement of the rectal muscles to facilitate a bowel movement.

Enemeez® Mini Enema (docusate)

This is an enema-type medication in an easy-to-use, single-dose squeeze container. A bowel movement usually occurs within several minutes.

Fleet® (sodium phosphate) Enema

This is a rectal enema that usually produces a bowel movement within 2 to 5 minutes.

B. DIARRHEA

Diarrhea and fecal incontinence are less common than constipation, but can be debilitating. Management primarily consists of making the stool firm and bulky, yet soft and easy to move through the bowel.

OVERALL MANAGEMENT

Metamucil®

This is an oral medication in powder or capsule form. Although used to treat constipation, when used to prevent diarrhea, the bulk former is taken no more than once a day and without any additional water.

Imodium® and Related Medications

These are oral medications in tablet form. These work by slowing the passage of stool through the bowel. These medications should not be taken on a regular basis, as dependence may result.

SECTION 14: SPEECH AND SWALLOWING

A wide variety of speech and swallowing difficulties may occur with MS, depending on the areas in the brain where demyelination occurs. These problems are usually considered together, because they tend to result from the same problems in the muscles of the throat used for speech production and for swallowing. These include spasticity, tremor, or weakness in the muscles involved in producing speech or controlling swallowing, or from a lack of muscle coordination. Speech and language therapists are trained to manage both types of problems.

A. SPEECH

The most common speech problems seen in MS are dysarthria and dysphonia. Dysarthria involves speech that is slurred or poorly articulated; it can involve a loss of volume control, unnatural emphasis on words or sentences, and a slower rate of speaking. Dysphonia results in changes in the quality of speech, such as a breathless quality to the voice, or speech that sounds harsh.

A speech therapist can help with exercises and adaptive equipment, depending on the type of problem you are experiencing.

NON-PHARMACOLOGIC MANAGEMENT

Exercise
Some exercises can strengthen and improve the muscles involved in the production of speech, or improve breathing through relaxation of the affected muscles.

Modifying Speech Patterns
A speech language therapist can teach techniques to help slow speech so that it is more understandable, as well as techniques such as improving the way words are articulated and correctly pausing between words. One technique that is particularly helpful is to listen to your own voice using a tape recorder.

Alternative Speech Production
When speech difficulties are severe and cannot be corrected with exercise or speech modification, alternative means of speech production can restore the ability to communicate. These range from technology that amplifies the voice, to alternative communication systems such as computer boards.

PHARMACOLOGIC MANAGEMENT

No medications can specifically improve speech difficulties. However, medications that relieve symptoms such as spasticity may provide some improvement.

B. SWALLOWING

Swallowing is a complex process that involves chewing, then moving food to the back of the mouth, the pharynx, and through the esophagus into the stomach. Depending on lesion pattern, one or more of these processes may be affected. A speech/swallowing pathologist will evaluate the source of the problem and determine how best to manage the problem. The goal of therapy is to ensure that swallowing is safe, to prevent food from entering the airway and lungs, where it can cause aspiration pneumonia. It will also focus on ensuring that food and fluid intake is sufficient for optimal health.

NON-PHARMACOLOGIC MANAGEMENT

Safe Swallowing Techniques

Techniques designed to promote safe swallowing are individually designed based on an evaluation of an individual's swallowing pattern. To ensure safe swallowing, a medical professional or therapist can provide detailed instructions concerning the kinds of foods that should be eaten, the best way to manage liquids, avoiding foods and liquids that may cause problems, and adjusting posture and head angle when swallowing.

Feeding Tube

If safe swallowing techniques are not sufficient, in rare instances a feeding tube may need to be used.

SECTION 15: VISION

Visual difficulties are common in MS. The most common problems are decreased or blurred vision (*optic neuritis*), double vision (*diplopia*) and what is termed, "involuntary movements of the eyes" (*nystagmus*). All are the result of MS lesions in areas of the brain that control and coordinate vision.

Optic neuritis is an inflammation of the optic nerve, which – unlike the nerves that innervate most of the body, which are part of the peripheral nervous system – is actually a part of the central nervous system and is myelinated in the same way as axons in the brain and spinal cord. Many individuals experience optic neuritis as their first symptom of MS.

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.

Because these conditions are all the result of MS inflammation and myelin damage, treatment is generally the same for all three.

NON-PHARMACOLOGIC MANAGEMENT

Like other MS exacerbations, it is often sufficient to take a "wait and see" attitude; these problems often resolve on their own, after the attack or relapse has subsided. With certain visual problems, prisms in eye glasses may help some patients.

PHARMACOLOGIC MANAGEMENT

Very High-Dose Steroids
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 IV for a few days, but steroids may also be given orally. An example of a "very" high dose of steroids would be 1,000 mg of Solu-Medrol® (IV methylprednisolone).

MS Disease-Modifying Therapies
Mentioned earlier, six disease-modifying therapies favorably reorganize the immune system and are currently 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.

Low-Vision Management
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.

SECTION 16: SEXUALITY

Both men and women may experience sexual difficulties as the result of MS, which can include a loss of libido, altered genital sensation, and decreased frequency and intensity of orgasms. Men may experience difficulties with erection and ejaculation, and women may have reduced vaginal lubrication and pain during intercourse. Other symptoms of MS may also affect the ability to enjoy the sexual experience. Depending upon the cause of sexual dysfunction, a variety of pharmacologic and psychosocial approaches may be helpful.

TREATMENT OF MS SYMPTOMS THAT CAUSE SEXUAL DIFFICULTIES

A number of symptoms associated with MS may affect sexual function and enjoyment. Identifying and treating these symptoms may also relieve what are termed secondary dysfunctions such as those that affect sexual function. These may include fatigue, depression, spasticity, pain, and bladder or bowel issues.

SEXUALITY (continued)

COUNSELING AND SUPPORT

Open communication between partners is essential to managing sexual dysfunction. Both partners need to understand both the medical and psychological issues that can affect sexuality, and work toward open communication and the possibility of alternative approaches to sexual satisfaction.

A. ERECTILE DYSFUNCTION

PHARMACOLOGIC MANAGEMENT

Phosphodiesterase Inhibitors
including Viagra® (sildenafil), Levitra® (vardenafil), and Cialis® (tadalafil)
These are oral medications in tablet form. Dosages are 50 to 100 mg per day (Viagra), and 5 to 20 mg per day (Levitra, Cialis). These agents were developed to manage erectile function due to many causes, but they have proved effective for many men with MS. They are chemically similar, and all delay the actions that interfere with developing and maintaining an erection.

Side effects may include headache, nasal congestion, and gastrointestinal symptoms.

Injectible Agents and Vacuum Pumps
Medications that are directly injected into the penis, including vasodilators and papaverine, are less frequently used.

Vacuum pumps are another alternative if medications are not feasible.

B. VAGINAL DRYNESS

PHARMACOLOGIC MANAGEMENT

Lubrication agents, Estrogen-containing vaginal preparations, and topical creams
These may be prescribed for women experiencing vaginal dryness and/or genital sensitivity. Cold packs before intercourse can reduce sensitivity and muscle spasms.

MORE INFORMATION: Managing MS Symptoms

BOOKS:

Managing the Symptoms of Multiple Sclerosis, 5th Edition, by Randall T. Schapiro, MD; Demos Medical Publishing, 2007

Complementary and Alternative Medicine and Multiple Sclerosis, 2nd Edition, by Allen C. Bowling, MD, PhD; Demos Medical Publishing, 2007

These books and many others are available through MSAA's free Lending Library. Please see page 64 of this issue for ordering information.

VIDEOS:

MSAA's MSi (Multiple Sclerosis information) online video program offers a variety of subjects through its *A Closer Look* series. Among others, topics include: managing various symptoms; MS fatigue; emotions; stress; intimacy; complementary and alternative medicine; and exercise.

Videos may be viewed for free by visiting **msassociation.org** and selecting "MSi" video programs. Some of these videos are available on DVD through MSAA's free Lending Library. Please see page 64 of this issue for ordering information.

MSAA PUBLISHED ARTICLES from *The Motivator* (listed by symptom):

Fatigue: Summer 2005, page 50; Spring 2004, page 31

Spasticity: Winter 2008, page 36; Winter 2004, page 32

Weakness: Fall 2006, page 44; Fall 2006, page 47

Pain: Spring 2005, page 53; Winter 2005, page 48; Fall 2004, page 38

Depression: Winter 2006, page 47; Fall 2005, page 36

[MSAA also has a separate publication, *Understanding and Treating Depression in Multiple Sclerosis*]

Anxiety: Winter 2008 (Cover Story), page 8

Sleep difficulties: Fall 2003, page 32* (call for copy)

Cognitive changes: Spring 2006, page 42

Bladder problems: Winter/Spring 2007, page 50

Bowel dysfunction: Winter 2006, page 38

Speech problems: Fall 2003, page 19* (call for copy); Spring 2003, page 40* (call for copy)

Swallowing issues: Fall 2007, page 38; Fall 2007, page 40

Visual changes: Summer 2004, page 32

Sexual dysfunction: Fall 2004 (Cover Story), page 8

Heat sensitivity: Summer 2007, page 36; Summer 2005, page 44

Mobility, exercise, and weight management: Fall 2008, page 40; Spring 2008, page 34; Winter 2008, page 40; Winter 2004 (Cover Story), page 7

Involuntary Emotional Expression Disorder [IEED]: Summer 2006, page 36

All MSAA articles and publications beginning from 2004 may be viewed, downloaded, and printed by going to **www.msassociation.org** and clicking on "publications." For earlier articles (marked by an asterisk*), and for individuals without internet access, please call MSAA at **(800) 532-7667** to request a copy.

Ask the Doctor

By Dr. Jack Burks
Chief Medical Officer for MSAA

Dr. Jack Burks

Q: I have heard of an MS treatment used in Europe that is having amazing results and I know there are a few physicians in this country who are using this non-FDA-approved treatment. It involves amino acid injections. Do you have any information on this treatment and how I might locate a physician using it?

Also, in addition to MS, I have been diagnosed with fibromyalgia and it seems that whatever helps the MS (i.e., cooling vest) exacerbates the fibromyalgia, which responds well to a heating pad. Can you give any suggestions as to how to balance the two conditions?

A: Your first question on amino acid injections for MS is not specific, and the names of the amino acids are needed before I can comment. Peptides and amino acids are the building blocks of proteins. Vast numbers of amino acids are used to treat a variety of medical conditions. For example, all four of the current first-line MS therapies involve peptides, amino acids, and/or proteins.

Your second question is difficult because every patient responds uniquely. The positive effects of cooling to help MS, and heat to help your fibromyalgia, need to be balanced with their negative effects for each condition. Individual patient responses vary with these different types of therapies. Trial and error may be the best solution. A physical therapist may serve as a good "coach" for you, and may offer additional strategies to help reduce your symptoms. Additionally, Lyrica® (pregabalin) has been approved by the United States' Food and Drug Administration (FDA) for treating pain associated with fibromyalgia. This might be another option to discuss with your doctor.

Q: I've been taking Copaxone for my MS. My neurologist says I don't have any new lesions. I'm 51 and I also have epilepsy, fibromyalgia, rosacea, arthritis, and I've had extensive orthopedic work done, including implanted rods and screws.

I take lots of medicine and see lots of doctors, but I don't have answers for the following question. For years, both of my legs feel like they are full of bees, and they vibrate and shake – sometimes so hard, I get sick to my stomach. No one sees the moving because it is happening on the inside. Now the shaking has also moved to my arms and hands. It's very difficult to deal with. Please, can you tell me what it is, and how to stop it?

A: Your symptoms must be very distressing. While it is most likely related to your MS, some epilepsy patients have similar intermittent symptoms. In MS, damage to the specific areas of the spinal cord and brain pathways which control sensation, can cause these symptoms.

The treatment of these types of MS symptoms usually begins with anti-seizure medications. Are you already taking epilepsy medication? Examples of medications used to treat such MS symptoms include Neurontin® (gabapentin), Tegretol® (carbamazepine), Lyrica® (pregabalin), Cymbalta® (duloxetine), Topamax® (topiramate), Dilantin® (phenytoin), and tricyclic antidepressant medications. If your doctor believes that the sensations are related to an acute MS attack, steroids might be helpful.

In addition, immunomodulating MS treatments are designed to reduce further damage which may otherwise cause an increase in symptoms. The six FDA-approved disease-modifying therapies (DMTs) for MS are: Avonex® (interferon beta 1-a); Betaseron® (interferon beta 1-b); Rebif® (interferon beta 1-a); Copaxone® (glatiramer acetate); Novantrone® (mitoxantrone); and Tysabri® (natalizumab). The first four therapies listed are given via injection at home, while the latter two are given via IV infusion at a medical facility. For more information about these therapies, please see the Summer 2008 issue of *The Motivator*. This may be viewed, downloaded, or ordered through MSAA's website at **www.msassociation.org** and selecting “publications.” You may also call MSAA at (800) 532-7667 to request a copy or to speak with a Helpline consultant.

Q: I am 28 years old and I live in Ireland. I am a social worker and I work with people with physical and intellectual disabilities. I was diagnosed with MS this past summer, so everything is still very new. I am taking Rebif three times a week and feeling okay on it. Do you think that the MS treatment is better in the United States, or is it the same all over the world, as my doctor has told me? I've always felt that America is so much more advanced in many things, especially in terms of medical treatment.

A: Treatments for MS care are similar in Ireland and in the United States. In fact, the standard treatments for MS are available worldwide. These are helping to control the disease, treat the symptoms, increase functions such as mobility, increase employability, and provide support to family and friends. New MS treatments are being developed in many countries, with scientists and physicians working together internationally toward a common goal. You have access to the best available treatments in Ireland, and the neurologists in your country are very well trained. I wish you all the best.

Q: I am 61 years old. I was diagnosed with MS in 1981 and right now I can't stand or walk. Sometimes my body gets too hot while sleeping with just a sheet at a room temperature of 60 degrees. I become so hot, I must remove the sheet and turn on my two table fans using remote controls. Also, I can't sweat at all. Is this a common symptom of MS? I have been on Copaxone for one year and I can feel significant improvement. I'm hoping that one day I will be able to walk again.

A: It is good to know that you feel better on Copaxone. Your feeling of being too hot may

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Research News

Written by Susan Wells Courtney
Reviewed by Dr. Jack Burks

Oral Cladribine Meets Primary Endpoint in Phase III Trial

In January 2009, Merck Serono (Geneva Switzerland) announced results of their Phase III CLARITY trial. According to the release, cladribine tablets met the two-year endpoint of reducing the relapse rate in patients with relapsing-remitting MS (RRMS). More than 1300 patients with RRMS participated in the CLARITY study, which was a 96-week, randomized, double-blind, placebo-controlled, international trial.

Two different dose regimens were compared to placebo, and those taking the lower total dose had a 58-percent relative reduction in annualized relapse rate (ARR) versus those given a placebo. Patients given the higher dose experienced a 55-percent decrease in ARR versus placebo. Secondary endpoints included reductions in lesion activity, proportion of patients who were relapse-free, and progression of disability. All of these secondary endpoints were met as well.

Study participants received low-dose or high-dose active drug, or placebo. These were given in two or four treatment courses during the first year, followed by two treatment courses during the second year. A treatment course consisted of one oral tablet taken daily for four to five consecutive days. Lymphopenia, which is a decrease in the number of lymphocytes (white blood cells) in the blood, occurred more often in the treated group. This was expected given cladribine's presumed mechanism of action. Both the treated and the placebo groups reported headaches and nasopharyngitis (nose and throat irritation) as the most frequent adverse events.

Oral cladribine is the first oral therapy for MS to have Phase III trial data reported to the FDA. This drug reduces the number of certain T-lymphocytes, which are believed to be involved with the inflammation and damage that occurs in MS. Merck Serono plans to submit an application for the approval of oral cladribine to the FDA in mid-2009. ◆

Results Announced from Study of Dirucotide (MBP8298) in RRMS Patients

Dirucotide, previously known as MBP8298, has been in clinical trials primarily for the treatment of secondary-progressive multiple sclerosis (SPMS), but also for relapsing-remitting multiple sclerosis (RRMS). On January 30, 2009, dirucotide's developer (BioMS Medical Corp.), announced the results of MINDSET-01, an exploratory phase II clinical trial designed to evaluate the effectiveness and safety of dirucotide in patients with RRMS.

MINDSET-01 enrolled 218 patients with RRMS at 24 sites in Europe. While the treatment did not meet its primary endpoint of reducing annualized relapse rates or reducing associated secondary MRI endpoints, it did meet certain secondary endpoints relating to the progression of MS. Changes in progression were measured using the Expanded Disability Status Scale (EDSS) and the Multiple Sclerosis Functional Composite (MSFC) score.

In this 15-month study, dirucotide (or placebo) was given via three single intravenous injections

Oral BG-12 Reduces Brain Lesions in Patients with MS

According to the data from a Phase IIb study, Biogen Idec's oral compound BG-12 (BG00012, dimethyl fumarate) reduced the number of new gadolinium enhancing (Gd+) lesions by 69 percent in patients with RRMS, compared to placebo. This data was published in the October 25, 2008 issue of The Lancet. Data also showed a 53-percent reduction in the mean number of T1-hypointense lesions and a 44-percent reduction in cumulative new Gd+ lesions in patients taking BG-12 versus those on placebo.

The presence of Gd+ lesions is thought to indicate continuing inflammatory activity within the central nervous system (CNS), while T1-hypointense lesions (also known as "black holes") are associated with significant damage and loss of brain tissue. According to Biogen Idec, an ad hoc analysis conducted during the study showed that Gd+ lesions were less likely to evolve into T1-hypointense lesions in patients taking BG-12 versus placebo.

These data suggest that BG-12 may have neuroprotective as well as anti-inflammatory effects. Inflammation and damage to the myelin and nerves within the CNS play an important role in the MS process, particularly for those with the relapsing-remitting form of the disease. BG-12 has also been shown to activate the "Nrf2 transcriptional pathway." This pathway helps defend against the destruction of nerves, protects the blood-brain barrier, and supports the integrity of myelin within the CNS.

In the Phase IIb study, the treatment arms included two dose levels of BG-12 given one to three times daily, or placebo. The drug was administered orally (by mouth) for 24 weeks. BG-12 met all of the study endpoints when given at the higher (240 mg) dose level, three times daily. Adverse events in the group receiving active treatment included flushing, headache, nausea, diarrhea, upper abdominal pain, hot flush, and [lower] abdominal pain. Many of these side effects decreased over

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at zero, three, and nine months. Dirucotide was generally well tolerated and no patients withdrew from the study due to side effects – the most common of which were redness and burning sensation at the injection site.

Measuring progression according to the EDSS and MSFC scores are the primary and secondary outcomes in the ongoing SPMS trials, all of which are fully enrolled. These include the MAESTRO-01 (a pivotal phase III study taking place in Canada and Europe with 611 patients), the MASESTRO-02 (an open-label follow-up study with patients who have successfully completed the MAESTRO-01 trial), and the MAESTRO-03 (a pivotal phase III study taking place in the United States with 510 patients).

Dirucotide (a peptide) is a synthetic fragment of myelin basic protein (MBP). It replicates the site on the MBP molecule that is believed to be a target of attack by cells of the immune system – in 65 to 75 percent of all people with MS. This treatment is believed to induce or restore immunologic tolerance to attack. ◆

"… It's Good to Know – You've Got a Friend."
MSAA's Networking Program

You may recognize this as a lyric from the famous James Taylor song, but it also reflects the feelings of many clients who participate in the MSAA Networking Program. One such person is Michelle from Maine; she is married, a mother of four young children, and living with MS since 2007.

"It's nice to correspond with people who have MS and truly understand what you're going though," says Michelle. "When I joined the Networking Program, I wasn't sure what to expect. But, I was happy that people emailed me back and we 'talked' about medicines, symptoms, diet, exercise, how to stay at my job… really all kinds of things."

Revised last year to operate from the MSAA website, **www.msassociation.org**, the Networking Program is an online community of individuals with multiple sclerosis and their care partners, who are interested in finding peer support and corresponding through email exchange. Clients have the opportunity to post information about them in the directory and email other members through a number of searchable categories. Access to the directory is password protected and made available once registration is approved.

As described by Michelle and expressed to MSAA by many, participants in the program find it very helpful and reassuring to link up with others who are affected by MS and face similar challenges. Additionally, this online format allows people to participate from their home around a schedule that best fits their lifestyle. Using email correspondence is especially helpful for those who are unable to attend traditional support group meetings but still want to stay connected to the MS community.

"Living in rural Maine, I find it very convenient to sit at home and stay in touch without traveling long distances," notes Michelle. "Plus, you don't have to worry about how you look when you're in front of the computer."

Recently Michelle made a decision to suspend her return to school, understanding that something had to give between work and her family. With this slight break in her schedule, she plans to spend more time "networking" with her friends in the program.

"So far, the feedback has been positive," said Michelle. "Whether it's the Networking Program or other websites, there's helpful information out there. I encourage everyone to go out and get it."

MSAA welcomes new members to the Networking Program. To learn more or register, log onto **www.msassociation.org/programs** or contact Peter Damiri at **(800) 532-7667**, **extension 109**.

Two MSAA Programs Now Available as a Free DVD Set

Among the 16 videos now posted on MSAA's website, **www.msassociation.org**, two programs have been made available as a free, two-DVD set. *An Introduction to Multiple Sclerosis* and *Talking with Your Children about Multiple Sclerosis: A Place to Begin* are ideal resources for newly diagnosed clients or parents ready to have this important conversation with family members.

An Introduction to Multiple Sclerosis is a four-part video featuring comprehensive explanations of the disease, treatments, and management techniques through graphic animations and interviews with neurologist Dr. Joanna Cooper; MS certified nurse Lynn Jehle; and several MS patients who recall their physical and emotional adjustments to their diagnosis. *Talking with Your Children about Multiple Sclerosis: A Place to Begin* features three families who have a parent with MS, with touching interviews from both the children and the parents on how they talk about, adjust to, and live with MS on a daily basis.

Both videos include Spanish translations. To receive your free DVD set, please go to **www.msassociation.org/programs/videos/** and select the order form below either program. If you're unable to order online, please call **(800) 532-7667, extension 129** and leave your complete name and mailing address.

This program is made possible through the generous support of Teva Neuroscience and produced by Direct Health Media. ◆

MSAA's Life Coaching Program

Coping with the Challenges of Multiple Sclerosis

MSAA's Life Coaching Program teaches strategies to help people cope with multiple sclerosis. Developed with direct input from more than 800 individuals diagnosed with MS, this program will offer toll-free teleconferences throughout the nation. These will focus on a variety of topics such as:

- Finding joy and cultivating happiness
- Resilience ("how to keep going")
- Employment issues
- Managing emotions
- Big questions, "Why me, why now, what next?"

If interested, please visit support.msassociation.org/lifecoaching and complete the survey. Doing so allows us to send you announcements about upcoming programs. In Life Coaching, you will participate in group telephone sessions, respond to questionnaires, and complete a variety of coaching exercises between sessions to develop skills and insights. Get ready to learn about yourself and new ways to meet life's challenges through the support of peers and Life Coaching!

Thoughts about Giving

By Bruce Makous
Vice President of Development

The Shade of Trees: Leaving a Legacy for People Living with MS

Bruce Makous

As the ancient saying goes, "We enjoy the shade of trees planted by those who have gone before us." This is accompanied by the traditional sense that we should replace the legacy we have inherited, so that those who follow us may reap the benefits.

Leaving a charitable legacy is a wonderful way to help future generations. This can simply mean remembering MSAA in your will with a portion of your estate to help people living with MS. There are also a number of other ways that people support MSAA through legacy giving.

A generous man in Wyoming made MSAA the beneficiary of the portion of his retirement plan that may remain upon his death. A woman in Florida designated a specific amount for MSAA from a marital trust. Another individual in New York gave a portion of real assets remaining after he passes.

Contribution of life insurance benefits is another method for providing support for generations who will come after you. Bobby Soileau of Minnesota, an MSAA Board member and supporter of many years, decided to name MSAA as the beneficiary of a portion of the proceeds of his life insurance policies.

"I've been on the TransMontana Snowmobile Ride for MS for the past six years," said Bobby Soileau at a recent MSAA donor recognition event. "That's where I met MSAA President Doug Franklin, several Board chairs, and many other folks from MSAA headquarters. I found that they are good people, very dedicated to the great cause of helping those who live every day with this very difficult condition. I decided that I wanted to leave something to this worthy organization from my estate, so I named MSAA as a beneficiary of proceeds from my life insurance policies."

Legacy giving such as this, supplements the hundreds of thousands of annual gifts contributed by generous donors across the country. I have the pleasure of traveling all around the country on behalf of MSAA and meeting many of our donors. In November, I traveled to meet generous donors in the Denver area, as well as Maryland. In December, it was Tennessee, and in February, Florida.

At an MSAA President's Circle reception held in Tampa, Florida in February, President and CEO Doug Franklin, and our Board members, met many Florida supporters.

MSAA's recently released 2007-08 Annual Report features the theme, "Impact Through Quality," and shows how our many supporters nationwide have enriched the quality of life for people living with MS through our high-quality programs. It is gratifying to see that our President's Circle supporters, those who generously provide $500 or more annually, have

Left: *At the recent Tampa, Florida, President's Circle reception, Board Member Bobby Soileau of Minnesota, was inducted by MSAA Board Chair Eric Simons and President and CEO Douglas Franklin, into the John Robison Circle, MSAA's recognition group for those who have made provisions for MSAA in a will, trust, or other means of leaving a charitable legacy.*

Right: *Also at the Tampa President's Circle reception, Ann Murray and Anne Donlin, Past Chief Daughters of the White Heather Lodge #259 of the Grand Lodge of the Daughters of Scotia, received appreciation from MSAA for their many years of support. The Daughters of Scotia have contributed $100,000 over the past 10 years.*

grown by more than 45 percent this past year.

Thank you, Bobby Soileau and many others who have planted trees for future generations, creating charitable legacies by remembering MSAA in their estate plans. Thanks, too, to everyone throughout our country who provides thoughtful support for MSAA, enriching the quality of life for everyone affected by multiple sclerosis.

Ways You Can Leave a Charitable Legacy

Donors frequently ask how they should go about leaving a legacy to MSAA. Here are a few thoughts about ways to give wisely:

A Charitable Bequest: Your attorney can help you make a provision in your will. Sample language would be:

I give to the Multiple Sclerosis Association of America, Inc., a nonprofit 501(c)(3) Corporation (IRS ID# 22-1912812), headquartered in Cherry Hill, New Jersey, ____ percent [spelled out] (___%) of my estate to go to MSAA's [Equipment Distribution Program, for example.]. This contribution is provided to establish the ***[e.g., John and Jane Doe Fund for Equipment for People Living with MS.]***

Charitable Gift Annuity: Make a contribution of $10,000 or more and receive a fixed income each year for life. Income rates vary from 5 percent to 11 percent, and increase with age. (Please see the annuity table which appears on the back cover of this publication.)

Charitable Remainder Trust: This also provides income for life. Appropriate for contributions of $100,000 or more. You may be able to reduce associated taxes.

Gift of Retirement Plan Assets: Any pension plan, IRA, 401(k), 403(b), or other plan has a provision for designating the beneficiary of the portion of the assets remaining at death. Naming MSAA will create a fund that will benefit people living with MS.

Gift of Life Insurance: Donors may make MSAA the beneficiary of all or part of the death proceeds from life insurance. You may also contribute ownership of the entire policy to MSAA. The proceeds will create a fund that will benefit people living with MS.

Any of these legacy-giving methods may provide funding for a specific program, a permanent endowment, or for general operations. The fund name may be designated to honor the donor or another person.

It is best to discuss your intentions with MSAA staff today to make sure that your fund is established as you wish. You are welcome to visit MSAA headquarters near Philadelphia to meet us, or a senior staff person will be pleased to stop by your home to discuss your goals.

In making your designation, please remember that the Multiple Sclerosis Association of America is a nonprofit 501(c)(3) corporation headquartered in Cherry Hill, New Jersey (IRS tax ID number 22-1912812). ◆

If you have thoughts about giving, please feel free to contact Bruce Makous at ***(800) 532-7667, ext. 148****, or email* ***bmakous@msassociation.org****.*

THE PHILANTHROPY CIRCLE

The following thoughtful corporations and foundations have contributed generously to MSAA to help improve the quality of life for people living with multiple sclerosis. Organizations providing gifts of $10,000 or more are shown in this listing.

CHAMPIONS *($100,000 and up)*
Bayer HealthCare Pharmaceuticals
Bayer USA Foundation
EMD Serono, Inc. and Pfizer Inc
Genentech Foundation
Genentech, Inc.
Novartis Pharmaceuticals Corporation
Teva Neuroscience

VISIONARIES *($50,000 to $99,999)*
Acorda Therapeutics

INNOVATORS *($25,000 to $49,999)*
IBM
Medtronic Foundation

ADVOCATES *($10,000 to $24,999)*
Avanir Pharmaceuticals
Biogen Idec
The Chatlos Foundation
Grand Lodge Daughters of Scotia
The Horizon Foundation for New Jersey
The Wal-Mart Foundation

Ask the Doctor

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be related to your reduced ability to sweat, since sweating is one of the body's ways to reduce body heat. A cool bath before bedtime or a cooling vest or other device may be helpful.

MSAA has a Cooling Equipment Distribution Program for individuals with MS who are sensitive to heat. Various types of cooling apparel (such as vests, neck wraps, and wrist bands) are available at no charge to individuals who qualify. Please visit **www.msassociation.org/programs/cooling** or call MSAA at **(800) 532-7667** for details. These same items may also be purchased through companies which specialize in this type of technology.

Sweating is controlled by the autonomic nervous system, which can be affected in MS, although less commonly than other parts of the nervous system. On the other hand, some MS patients complain of excessive sweating. Everyone is different. I would recommend that you check with your doctor to make certain you are not having any other problems associated with feeling hot. A fluctuating fever can make you feel either excessively cold or hot, so taking your temperature is another good idea. Report any fever to your physician, as this could mean that you may have an infection or other health issue. ◆

Jack Burks, MD, is a neurologist, chief medical officer for MSAA, clinical professor of neurology at the University of Nevada in Reno, Nevada, and member of the Clinical Advisory Committee of the NMSS. He has edited two MS textbooks. Previously, Dr. Burks established the Rocky Mountain MS Center and has served on several Boards of Directors, including the American Society of Neurorehabilitation (past president), the Colorado Neurological Institute, the American Academy of Neurology, and the Consortium of MS Centers. In recent years, he has lectured in more than 30 countries.

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 **agriese@msassociation.org.** Please be sure to write "Ask the Doctor" in the subject line.

Research News

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time. Frequency of infection was low and did not differ between the active-treatment and placebo groups.

The United States' Food and Drug Administration (FDA) granted Fast Track designation for BG-12 in 2008. "DEFINE" and "CONFIRM" are two Phase III studies for BG-12, which will include more than 2,000 patients in North America, Europe, and worldwide. Individuals with relapsing-remitting MS who are interested in enrolling may visit **www.clinicaltrials.gov** and search for "BG-12" for more information. ◆

Mobility Independence and Safety

Written by Patricia G. Provance, PT, MSCS

Part II: Improving Functional Mobility with Exercise

(Please note that Part III will appear in a future issue of The Motivator.)

In Part I of this series on mobility independence and safety, appearing in the Fall 2008 issue of *The Motivator*, we emphasized the need for a baseline evaluation by a physical therapist (PT). We also discussed the downside of inactivity; fatigue and energy management; cooling tips; and some issues and equipment related to ambulation. In this article – Part II of the series – the focus will be on an extremely important, and often overlooked, component of wellness: exercise!

In the past, many physicians recommended rest instead of activity because of fatigue issues and the fact that MS was a "progressive" neurological disease. However, research in the past 10 years has shown that well-paced exercise and activity can, indeed, result in positive outcomes relating to improved functional strength, endurance and quality of life.

As a PT, I have many times heard the refrain, "Why exercise? I have MS!" Burdened by sometimes overwhelming fatigue and frustration, many individuals with MS feel that exercise will just make their situation worse. In fact, that could be true – especially if the exercise or activity is not appropriate or is "overdone." Unfortunately, some therapists and trainers who are not familiar with MS (especially the symptom fluctuations, fatigue issues, and heat sensitivity) will unknowingly push you to failure and more frustration.

My desire in writing this article is to help you become an informed advocate in developing your own, customized, exercise and activity program. The guidance of a PT *with experience in MS care can be helpful* – but there are many things you can do on your own. However, before starting, some planning is necessary. Here are some questions to ask:

- What positions, movements, or activities are difficult for you right now?
- How much time and energy (if any) do you have to devote to exercise?
- Are you doing considerably less than you did a year or two ago?
- Are your goals realistic?
- Are you motivated to go into low-level "training?"
- Do you have support at home for this new change in behavior?
- Can you be flexible if circumstances, weather, energy, or other factors require changes to your routine?

Helpful Advice for Planning an Exercise and Activity Program

1. **Activities** This refers to "Activities of Daily Living" (ADLs) that are the cornerstone of functional independence. For ex-

ample, if you have trouble standing up without using your arms to push off (or a grab-bar to pull up) – that is where you need to start. If you use a wheelchair and have trouble sitting unsupported or doing a chair push-up with good trunk control to assist in transfers – that is where you need to start. Simple exercises or activities that are focused on function can be extremely helpful in the effort to improve strength, safety, and independence.

> ***Research in the past 10 years has shown that well-paced exercise and activity can result in positive outcomes relating to improved functional strength, endurance and quality of life.***

2. <u>Time and Energy</u>
Remember the four "Ps" – Planning, Pacing, Positioning, and Prioritization. This will allow you to incorporate some of the exercises throughout the day instead of trying to do them in a single session. A good rule of thumb is to try to do *something* (such as isometrics, balance exercises, chair push-ups, walking practice, etc.) at brief intervals throughout the day, with a focus on *quality* and *control* instead of quantity.

3. <u>De-conditioning</u> This is a common problem when activity declines, and it usually is a slow, steady process of muscles weakening from disuse, resulting in less endurance. The "primary" weakness caused by MS plaques in the central nervous system will require some compensatory measures (such as a foot-drop brace or cane). However, the "secondary" weakness due to de-conditioning is reversible! "Use it, or lose it!"

4. <u>Realistic Goal Setting</u> If you haven't done much activity in years, it's important to realize that progress will be slow. Patience and persistence are the keys to success as you begin the process of "attitude adjustment" and "behavior modification." Setting realistic and attainable short-term goals will ease frustration – and seeing slow, steady progress will motivate you to continue.

5. <u>"Training"</u> In this case, we are not referring to the grueling workouts of athletes in the gym, but a commitment to improving both strength and health by starting a regular wellness routine. This concept of "going into training" includes healthful eating, good sleep habits, and regular, *appropriate* low-level exercise and/or activity.

6. <u>Support</u> I have had the opportunity for many years to work with thousands of patients with MS. In spite of the wide variation in symptoms and abilities, my observation has been that those with the highest quality of life had two things: SPUNK and SUPPORT. Those attributes will greatly improve the chances of a positive outcome as one begins an exercise program. Having the spunk and desire to do something is important – but having support of family and friends (as cheerleaders and assistants) will help to get it done!

7. Flexibility This does not refer to stretching (which is important for tight muscles), but the need to "flex" your exercises and activities depending on many factors, such as how you're feeling, a busy schedule, transportation or weather challenges, etc. Having a basic home program that can be done at any time (or many brief times) in the day will allow you to continue on the road to functional strengthening, balance, and mobility.

Where to Start!?...

The developmental model requires one to have stability before you can achieve independent mobility. Therefore, the first goals should be attaining good balance and control in many positions – holding still (or *static*) at first, and then moving (or *dynamic*). This will vary greatly, depending on your strength and abilities, but it's always good to review the basics.

The list below can be a starting point for simple exercises in different positions – but please take caution not to try any exercise or position that may be too difficult or unsafe for you. If you are extremely weak, a PT evaluation is strongly advised, and you should have a care partner present to assist with your home program.

Editor's note: Please consult your physician before making any changes to your exercise and activity programs.

Position # 1: LYING DOWN WITH HIPS AND KNEES STRAIGHT

1. Isometric Gluteals, or "Glut Sets:" squeeze buttocks together – hold and breathe – relax and repeat.
2. Isometric Quads: tighten thigh muscles that hold knee straight.
3. "Foot Pumps:" pull toes toward your nose until you feel a stretch in the back of your calf – hold – relax – then alternate with other foot; repeat several times.
4. "Tummy Tucks:" pull lower belly up and in – hold for several breaths – relax and repeat.
5. "Bent-Knee Leg Lifts:" bend both knees with feet on bed or floor – then alternately lift legs like you're marching; this is much less strenuous than straight leg raises!
6. Overhead Reach: clasp hands together or put hands on opposite elbows and try to raise both arms completely overhead until they touch the bed.
7. Roll to and from front to back and vice versa; repeat.
8. Roll to each side and press up to raise shoulders off the bed.
9. Roll to each side and slide legs off the bed and come to a sitting position.

Position # 2: SITTING IN A STURDY ARMCHAIR WITH FEET ON THE FLOOR

1. Sit away from the back of the chair and correct posture: knees forward (like "headlights"), belly up and in, shoulder blades down and back, chin level and eyes forward (this is "static balance").
2. "Trunk Clocks:" pretending that you're sitting in the middle of a clock and lean from side to side, forward and back, and diagonally, as if aiming toward the "numbers" on a clock (this is "dynamic balance").
3. "Chair Push-Ups:" sit tall, put hands on chair arms beside hips, and press up so

that your hips raise up from the seat of the chair; hold, then slowly return to a sitting position.

4. Knee Flexion and Extension: sit tall and *slowly* straighten, then bend each knee.
5. Low Back Stretch: clasp hands behind knees and pull your chest to your thighs; hold, breathe, and relax.
6. "Arm Ballet:" sit tall and raise both arms overhead and out to the side in different patterns such as "a ballet dancer," "V for victory," "airplane wings," etc.
7. Go from sitting to standing: work for smooth control without using your arms, if possible (but do not risk falling or losing your balance).

Position # 3: ON HANDS AND KNEES

1. "Rocking:" balance on hands and knees and rock slowly forward and backward.
2. Arm/Leg Lifts: from hands and knees position, slowly lift one arm and then return to starting position; then lift the other arm and return. Next, try lifting one leg out straight behind you – return to starting position – then lift the other leg. If this is not a challenge, you can try to lift the *opposite* arm and leg at the same time.
3. Crawling forward and backward.
4. Static Kneeling: support with your hands on a firm, soft chair or ottoman (or bed headboard) and tighten belly and buttocks. If this is not a challenge, try to maintain balance without hand support. If you can balance for several minutes, then you are ready to attempt dynamic kneeling, by bowing and twisting slowly to work your trunk and buttock muscles.

Position # 4: STANDING
(with light hand support, as needed)

1. Practice good standing posture: feet comfortably apart, knees forward (but *not* locked), hips straight, belly up and in, shoulder blades down and back, chin level, and eyes forward.
2. "Mini-Squats:" do small, slow knee bends; then return, relax, and repeat.
3. Single-Leg Stand: slowly lift one foot (forward, backward, or out to the side) and balance on the other leg – relax – then do the same with the other foot.
4. Marching: slowly lift one knee after the other while keeping good posture.

Other Exercise Options

Numerous other exercises and activities can provide both variety and fun when the "basics" have been conquered. Many individuals with MS have found low-level exercise, yoga, tai chi, or pilates instruction on DVDs to be a convenient way to exercise at home (alone or with a friend), and many programs can be done from a chair if supported standing is not possible.

Others report more motivation and socialization from joining an exercise class. Aqua-exercises in a cool pool (at no more than 85 degrees) can have wonderful benefits because the water provides support for balance, mild resistance for exercise, and minimal interference by gravity. Hippotherapy (or therapeutic horseback riding) is another popular activity that works on balance and strength. If you choose to exercise in a gym or fitness center (or if you have equipment at home), it's important to take plenty of rest breaks, to have an oscillating fan keeping you cool, and to have an appropriate, effective and well-paced program. Aerobic conditioning is an option when exercise tolerance improves, but fatigue must be respected and rest breaks taken as needed.

Regardless of the exercises or activities you choose, there are some rules to remember:

- WHEN IN DOUBT – DON'T!
- IF IT HURTS – STOP!
- MORE IS *NOT* BETTER!
- FASTER IS *NOT* BETTER!
- YOUR ACTIVITY SHOULD BE A CHALLENGE, *BUT NEVER A STRUGGLE*!

Transient Symptoms brought on by Exercise or Heat

Maureen Shanahan is a nurse with MS and client of Pat Provance (the author of this article). Maureen notes the impact of "Uhthoff's symptom," which is a temporary worsening of vision resulting from exercise or an increase in body temperature. Exercise (which naturally increases body temperature) and other factors contributing to feeling warmer – such as one's surrounding temperature or taking a hot bath – can also cause a transient worsening of other (non-visual) symptoms, including weakness and numbness or tingling sensations.

Maureen explains, "Once the internal temperature is raised in most persons with multiple sclerosis, performance begins to slip. It is barely perceptible in some of us, but a seriously inhibiting factor for exercise in many of us. One can feel sloppy, clumsy, dizzy, and less coordinated. One may also have visual problems and be less able to concentrate or communicate. For example, I have difficulty expressing myself in words, during and immediately after I have been exercising. I cannot write or push buttons, and I also have difficulty lifting a glass to my lips to drink. Using a straw helps me reach the glass, and drinking very cold water can help improve how I feel.

"Individuals with MS need to be reassured that any symptoms brought on by exercise and overheating are temporary and resolve completely, once you have rested and cooled down. They also need to know that getting to this point, does not damage them in some way, though it certainly feels that it would. Experiencing heat-related symptoms isn't an ominous sign, but it should be taken as a warning to be cautious. People with MS who may experience this symptom need to protect themselves from falls and other accidents. They also should consider this when setting realistic goals, and have someone check on them while exercising. The good news is that it has been my experience that the tolerance for heat and exercise is improved over time, and seems to correlate with endurance."

As noted in Part I of this article series, individuals who are heat-sensitive may use cooling techniques to help avoid overheating and reduce the effects of heat-related worsening of symptoms. Among others, strategies include taking a cool bath, sucking on ice chips, or using cooling devices such as collars or vests.

Editor's note: Individuals with MS are advised to stop, rest, and cool down if they begin to feel such symptoms as weakness, tingling, visual issues, lack of concentration, or other neurologic changes during exercise.

Exercise Equipment Considerations

"Try before you buy!" Many tempting advertisements lure us into purchasing that piece of "miracle" exercise equipment. If you are seriously considering making a major purchase, an evaluation by a PT is advised so that you can be assessed and trained by a professional. A treadmill, for example, needs to be both safe and user-friendly, with features such as side hand supports, a wide belt, low ramp-up speed, easy controls, etc. Additionally, it does not need to go faster than four mph if you will just be walking. An exercise bike can help with overall leg strength and conditioning – but it won't improve your "wobbly walking," because you are exercising while sitting! Hand weights are popular, but can be exhausting. A "Theraband," which is a specially designed, large elastic band, is cheaper, more portable, and you can adjust the resistance for each exercise.

Summary

In a recent MSAA survey, more than one-third of the respondents reported that they rarely or never exercised! Hopefully this article will help broaden your horizons to understand that exercise does not have to be an exhausting workout, but instead, can be easily done at home with a focus on carefully paced, functional strengthening activities. Just call it "Back to the Basics!" Then when you're stronger, you might want to supplement your exercise program by joining a program in your community, to enhance the fun and fitness. Good luck! ◆

This article is one of a series of three that have been written and generously provided to MSAA by Patricia G. Provance, PT, MSCS. Pat is an esteemed member of MSAA's Healthcare Advisory Council.

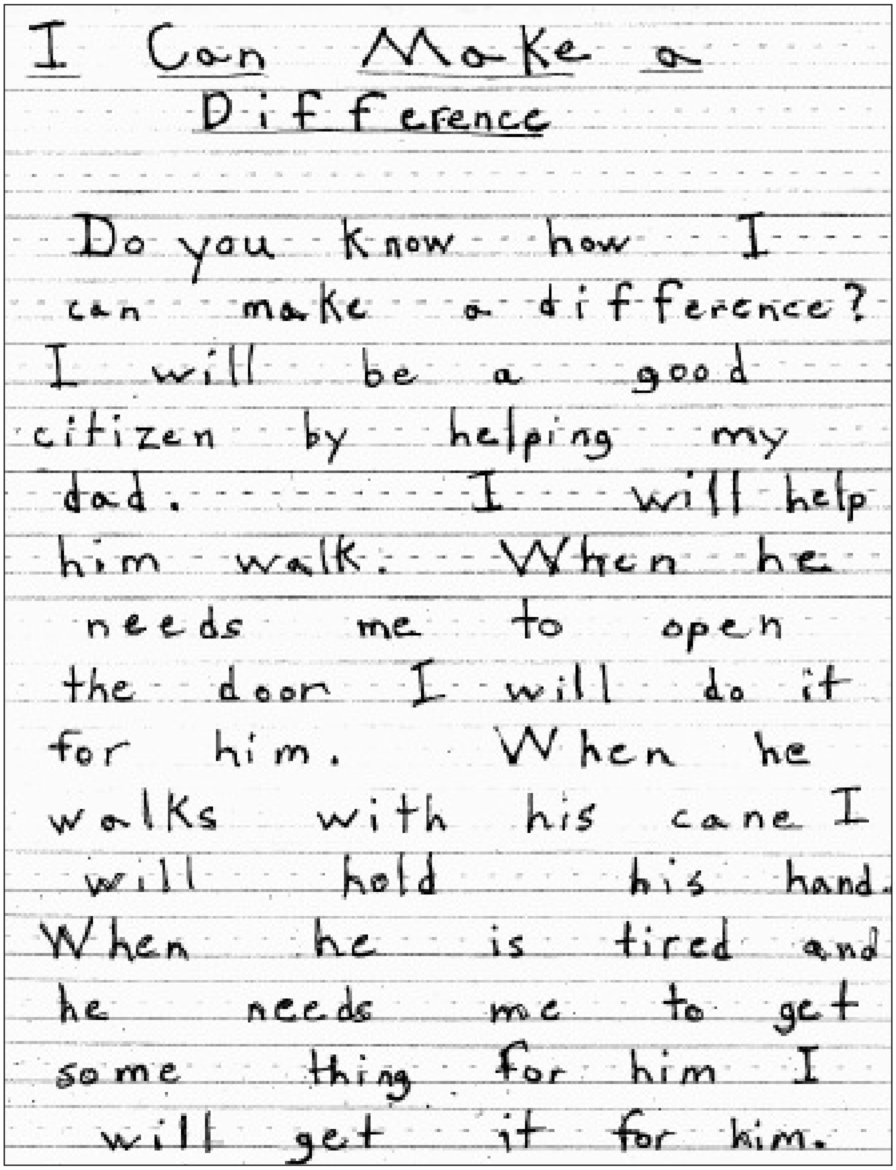
Pat has 37 years of experience in physical rehabilitation, having been in clinical practice since 1971. In 1982, she started the first MS Rehabilitation Program in Maryland at The Union Memorial Hospital, in addition to her orthopedic caseload. In 2000, Pat joined the University of Maryland Medical System at Kernan Hospital to dedicate her practice to MS, and continued as a clinical consultant with the Maryland Center for MS until her "semi-retirement" in December 2006. She became an MS Certified Specialist in 2005 and continues as a clinical consultant with the National Multiple Sclerosis Society. Pat is also an active member of The Consortium of Multiple Sclerosis Centers. She currently is teaching and consulting on MS care to patients and professionals throughout the country. Publications include the clinical bulletin, "Physical Therapy in Multiple Sclerosis Rehabilitation," and co-authorship of the textbook, Muscles, Testing and Function with Posture and Pain, 4th and 5th editions.

Making a Difference By Helping Her Dad

Michael Crisomia (left) and daughter Sophia, whose school paper (below and opposite) about helping her father deal with his MS earned her three awards – and touched her father and others deeply.

In a letter sent to MSAA, proud father Michael Crisomia talks about his daughter Sophia, who submitted a paper on "I can make a difference by…" for a contest at her school. She wrote about how she would make a difference and be a good citizen by helping her dad. Michael has MS, and to follow are excerpts from his letter to MSAA.

"When I found out about Sophia's paper, I was amazed and inspired that my little girl, 7 years old at the time, would even think of writing about me and my MS. I was so touched by her words and how she understands the ways in which this disease affects me, that I cried with happiness as I read her paper. Sophia is one of my two little angels, with the other being my younger daughter,



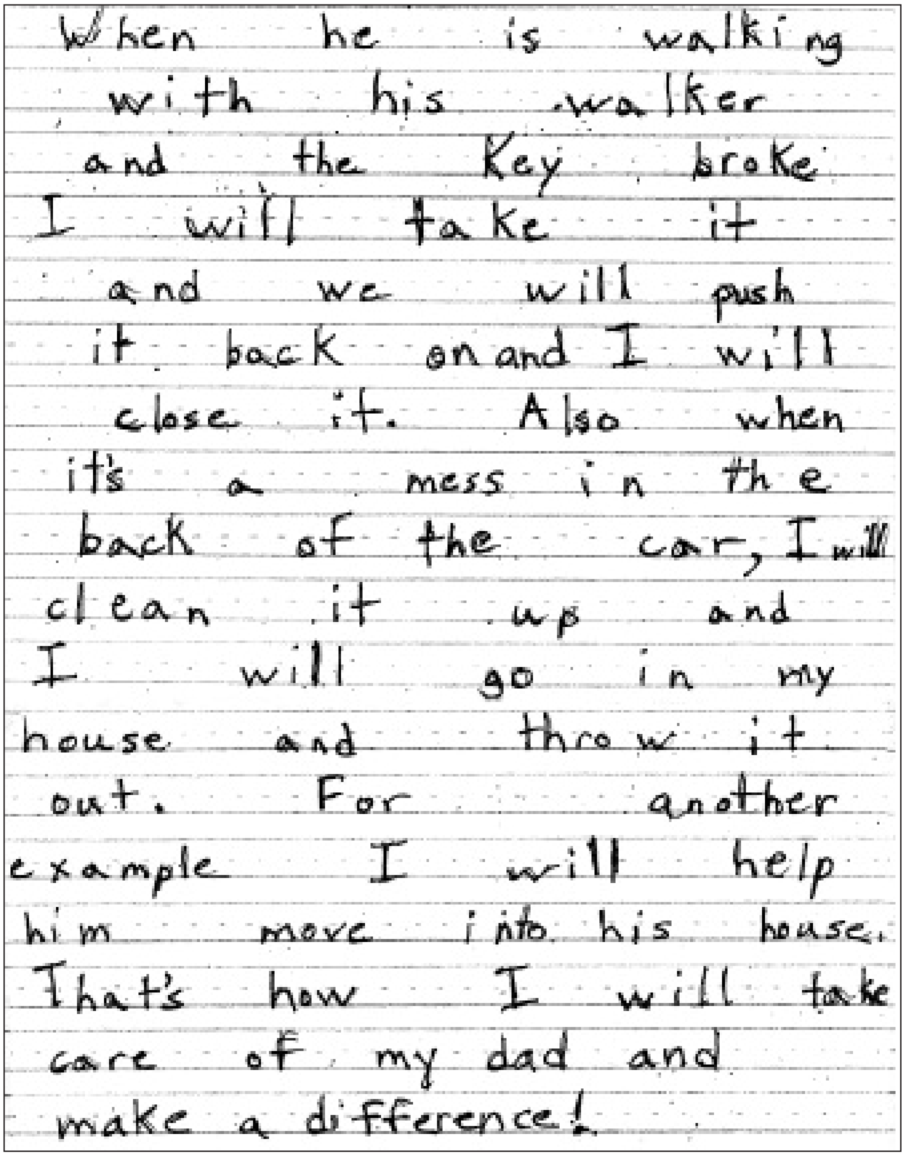
I Can Make a Difference

Do you know how I can make a difference? I will be a good citizen by helping my dad. I will help him walk. When he needs me to open the door I will do it for him. When he walks with his cane I will hold his hand. When he is tired and he needs me to get some thing for him I will get it for kim.

Joanna – who is just as helpful, understanding, and loving.

"Sophia's paper won First Prize in the contest at her school. Her paper was then entered in a contest held by the Delaware PTA, where she won First Prize again, and received an Award of Excellence in Literature along with a medal.

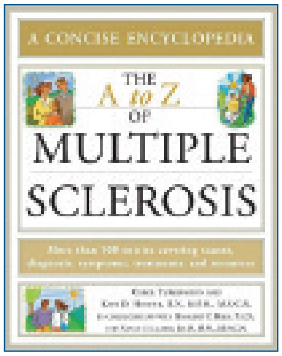
"I can't express just how happy this made me feel! I read her letter often, but it's not just the words that she wrote; she acts this way all of the time. She is a blessing to me, and if she can inspire others… this would be awesome!" ◆



When he is walking
with his walker
and the Key broke
I will take it
and we will push
it back on and I will
close it. Also when
it's a mess in the
back of the car, I will
clean it up and
I will go in my
house and throw it
out. For another
example I will help
him move into his house.
That's how I will take
care of my dad and
make a difference!

> *"Do you know how I can make a difference? I will be a good citizen by helping my dad. I will help him walk."*
>
> – Sophia Crisomia

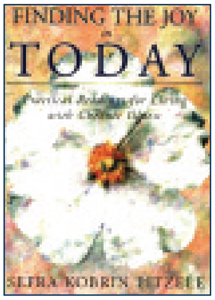
Spread the Word



The A to Z of Multiple Sclerosis

Written by Carol Turkington and Kaye D. Hooper, RN, MPH, MSCN; in collaboration with Rosalind C. Kalb, PhD, and Nancy Holland, EdD, RN, MSCN
Published by Checkmark Books
MSAA Book #157

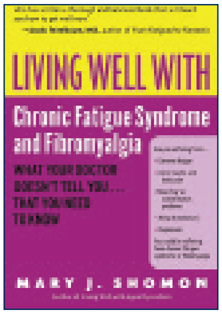
This encyclopedia-style guide is an excellent resource that features more than 500 entries relating to such topics as MS research, the immune system and MS, possible causes and environmental triggers, as well as treatments, symptoms, and therapies. The appendices include organizations and MS centers for assistance, treatment, and research.



Finding the Joy in Today: Practical Readings for Living with Chronic Illness

Written by Sefra Kobrin Pitzele
Published by Hazelden
MSAA Book #42

This uplifting publication provides daily readings to offer inspiration and hope, using consecutive dates of the year in place of page numbers. Its author, Sefra Kobrin Pitzele, holds positions on two national health associations, co-founded a magazine for people with chronic health conditions, and speaks at conferences as well as on radio and TV shows.



Living Well with Chronic Fatigue Syndrome and Fibromyalgia: What Your Doctor Doesn't Tell You… That You Need to Know

Written by Mary J. Shomon
Published by Collins Living
MSAA Book #1

The symptoms of chronic fatigue syndrome and fibromyalgia often overlap with those of MS – and some individuals have been diagnosed with these conditions concurrently. This book helps people who are suffering from pain, fatigue, cognitive issues, and sleep problems by offering treatment options and tips for developing a recovery plan.

MSAA Lending Library

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