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MSAA

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The MOTIVATOR

Bringing Information to People with Multiple Sclerosis

Imagine the Possibilities

An Introduction to Guided Imagery and Its Potential Benefits for Individuals with MS

The MSAA Motivator

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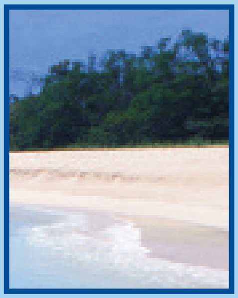
By Susan Wells Courtney
Guided imagery may offer several health benefits; among others, these include lowering blood pressure, improving mood, lessening pain and fatigue, as well as potentially reducing injection anxiety.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The Multiple Sclerosis Association of America's mission is to enrich the quality of life for everyone affected by multiple sclerosis.

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2007 National Health Information Awards Winner

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Up Front

By Douglas G. Franklin
MSAA President and CEO


Douglas G. Franklin

The upcoming months will be a busy time at MSAA. Among the many events is MS Awareness Month in March – a time when the needs of the MS community, along with the services and programs available, receive national attention. In April and May (respectively), MSAA will participate in the annual meetings of the American Academy of Neurology (AAN) and the Consortium of Multiple Sclerosis Centers (CMSC). MSAA is both an exhibitor and attendee of these important conferences. Additionally, a number of educational programs and events are planned throughout MSAA's six regions nationwide.

I am also excited about the work we are doing right now toward reaching more people with our educational information. MSAA has taken the opportunity in this issue of *The Motivator* to solicit your feedback in this vital area of service. A survey is featured in "Program Notes" (on page 29), asking how you would like to receive information from MSAA, and what topics are of greatest interest to you. Technology today affords us so many ways to provide information, and we are sincere in our efforts to be as flexible as possible. This includes our aim to have more publications available electronically, as well as to provide you with more online programming. I look forward to hearing from everyone who would like to take part in this important survey.

MSAA's second Board meeting of the fiscal year was held in January, and this meeting focused on technology as well. The Board members spent time "behind the scenes" of MSAA's virtual programming, to see firsthand the highlights of the MSi video educational program, as well as the many new interactive features of MSAA's website. The Board members showed much enthusiasm for this new technology and how these advances are helping MSAA bring more services to more people.

Also in January, a teleconference was held for the members of the MS Coalition. This presented an opportunity to look at gaps in services, see who is helping where, and allow us to coordinate services more effectively. Our goal is to avoid duplication of services, while making sure that no one is missed. We are still going through the process of developing a better degree of coordination, aiming toward the MS Coalition's theme of "One Team, One Dream." Members of the Coalition are actively planning a workshop for the CMSC conference scheduled for May in Denver, Colorado. The workshop will focus on advocacy, which ties in with the presidential election year.

MS Awareness Month in March was another area of discussion during the MS Coalition's teleconference, noting the activities that we each have planned and how we should promote them together. Recognizing those with MS is important at all times, but March is the month to unite in working with the media to highlight activities and bring as much attention as possible to the urgent needs of individuals with MS. As always, please be sure to check MSAA's website (**support.msassociation.org/calendar**) for a listing of planned educational events and activities for the MS community, not only in March, but throughout the year.

On the topic of collaboration, MSAA and the National Multiple Sclerosis Society (NMSS) are co-hosting a conference on primary-progressive multiple sclerosis (PPMS), sponsored by a grant from Genentech. Scheduled for Dallas, Texas in early February (during the printing of this publication), the conference features seasoned experts in the field of MS and aims to gain a better understanding of the experiences and needs of those affected by PPMS, including patients, families, and healthcare providers. Individuals with PPMS are often referred to as the "neglected population;" however, hope is on the horizon for new research and treatments in the coming years.

In other news, MSAA's public education program on MS drug therapies is moving right along as two TV public service announcements (PSAs) have been distributed and viewed in five major United States' cities, many of which being aired in prime time. A plan is in place to expand this program to other cities as well as include radio PSAs and billboard placements. A new MSAA brochure, *Taking Steps to Feel Your Best,* explains the importance of beginning and maintaining an MS treatment with one of the six, FDA-approved drug therapies. The brochure will be circulated through doctors' offices and MS centers. Along with the AAN, MSAA supports the idea that people with the most common forms of MS should be on a disease-modifying therapy to slow disease activity and to minimize exacerbations. As a neutral charity, we are free of bias – as we are not selling any drug – but we are dealing with people's inhibitions. These are good therapies, and they work, but only if taken. Please take the time to visit MSAA's website (**www.msassociation.org**) to view the PSAs and read the brochure.

On a special note, MSAA's Board meeting in September was the first Board meeting in six years without former Board member Francisco Ramirez. During his time with the Board, "Pancho" shared his Board experience with the Maryland Society for Nonprofits and helped MSAA become a charity second to none in proper governance procedures. He had no connection to MS – just a biding interest in helping others – and during his tenure, he became what other Board members referred to as "the conscience of the organization!" Thank you Pancho! We will miss you! ◆

Doug Franklin joined MSAA as President & CEO in 1999. He has a distinguished career in association leadership and is a former national trainer in strategic planning for the Peter Drucker Foundation. A published international expert in the field of social marketing, 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.

Imagine the Possibilities

An Introduction to Guided Imagery and Its Potential Benefits for Individuals with MS

Written by
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Reviewed and Contributions by
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Reviewed by
Jack Burks, MD

We often hear about the mind-body connection in regard to our health and wellbeing. Many Western-trained physicians and researchers are discovering that the mind appears to have a powerful influence over one's physical and emotional health, a concept long held by those who practice Eastern Medicine. In recent years, a technique known as guided imagery has been gaining much recognition by individuals, families, care partners, and health professionals. This is an exciting area of complementary and alternative medicine, offering benefits to almost anyone who practices this therapeutic exercise.

Dr. Miriam Franco is an experienced psychologist and social worker who is also certified to practice Integrative Guided Imagery. According to Dr. Franco, "Guided imagery may be described as specific mind-body techniques that first teach people to become deeply relaxed, and then to use sensory images to focus attention on positive and intuitive images. These images are from their own experience or their imagination, and are healing as well as helpful. In so doing, processes change in their body. By relaxing the body first, this promotes mental relaxation and allows worrisome thoughts to become less prominent.

"With practice, guided imagery can produce radical shifts in attitude, coping, and problem solving… which, in turn, can increase positive coping skills. Unlike some forms of meditation or hypnosis, guided imagery does not involve focusing your mind on a single word or image. Instead, guided imagery takes you on a journey through your own sensory experience in a relaxed state. It is based on the assumption that the mind can influence certain functions of the body."

A well-known resource on this topic is the book, *Staying Well with Guided Imagery*, written by Belleruth Naparstek (Warner Books, 1994). While the copyright date is not recent, the information and guided imagery "scripts" are still considered to be an excellent foundation for learning about and practicing guided imagery. Belleruth (as she is referred to in all of her work) has since written and recorded a huge collection of books and CDs, while continuing to provide extensive information online at **www.healthjourneys.com**, all on the subject of improving emotional, mental, and physical wellbeing. These publications and recordings frequently appear under the series entitled, "Health Journeys."

In her book, *Staying Well with Guided Imagery*, Belleruth refers to imagery as "any perception that comes through any of the senses." She emphasizes that imagery is not strictly limited to visual images, but also to "images" that may be sensed through sounds, smells, tastes, or touch, as well. She defines guided imagery as "a kind of directed daydreaming, a way of using the imagination very specifically to help mind and body heal, stay strong, and even perform as needed."

While guided imagery is more involved and more meaningful than simply daydreaming, for individuals who have no experience with any type of imagery – talking about daydreaming may be a good place to start. We are all familiar with daydreaming, which is a time when we are very relaxed and less focused on what is going on around us. We drift off into our imagination, often becoming totally immersed for a matter of seconds or possibly a few minutes, tapping into the creative and emotional right side of the brain. This is a shift from the left side of the brain, which uses logical reasoning and linear thinking to help us problem-solve throughout the day.

While daydreaming, we may lose ourselves in a pleasant, far-away time or place that may well cause us to smile or feel some other kind of emotion, almost as though we are actually experiencing

Pictured in photo at left: Miriam Franco, MSW, PsyD, is a psychologist, social worker, and esteemed member of MSAA's Healthcare Advisory Council. She is certified in Integrative Guided Imagery by Beyond Ordinary Nursing organization. Dr. Franco provides stress reduction and guided imagery interventions to MS patients in her psychology practice, and has conducted stress reduction and wellness workshops for the National Kidney Foundation, The Philadelphia Wellness Community, and Philadelphia Corporation for Aging. She is chair of the Sociology Department at Immaculata University and is a member of the Consortium of Multiple Sclerosis Centers.

whatever is going on in our mind. Sometimes we don't even hear a person speaking to us when in this "altered state." Mentally returning to the immediate surroundings can almost feel abrupt, and we may need a moment to collect our thoughts and return to the matter at hand.

Becoming fully immersed in something we imagine while in a very relaxed state, and feeling as though we are actually experiencing it, are the keys to imagery. The mind responds to an imagined situation in the same way as it would respond to a real experience, causing the mind to send the same signals through the body, prompting the same physiological changes.

For instance, imagining your favorite food – seeing its appearance, noting the steaminess of its warm recipe, smelling the aroma it gives off, hearing it sizzle in the pan, and of course, its delicious flavor – might cause you to feel hungry and your mouth to water. This is how your body responds to the messages sent by your brain, which is reacting to an imagined experience versus a real experience. While the brain's response would have been more intense in a real situation, it still mimics the same behavior when imagining the same scenario.

Research is showing that through guided imagery, the mind can promote far more changes than just feeling hungry or having your mouth water. Biophysical and biochemical changes may take place within the body through the use of guided imagery, bringing about physical, emotional, and mental benefits. In general, these types of changes include:

With guided imagery, once relaxed, you may be given a topic to imagine, such as a favorite place to visit or a loved one you would like to see. One example is to remember when you were a child and the happiness of visiting your grandparents' home.

- Mood may be improved, by calming, relaxing, inspiring, and motivating
- Depression and anxiety may be reduced
- Intuition, creativity, and performance may be increased
- Blood pressure may be lowered
- Blood sugar may be reduced
- Immune functioning may be improved
- Surgical wounds may heal more quickly
- Pain and headaches may be lessened
- Negative reactions to medications or treatments such as chemotherapy may be reduced
- Pre-surgery fears may be lessened

Guided imagery requires a state of deep relaxation, and adds the component of a gentle direction for your sensory images. A healthcare professional trained in the area of guided imagery may use a script to first help you to relax, and then he or she may give you a topic to imagine – such as a favorite place to visit, a loved one you would like to see, or possibly envisioning yourself accomplishing an important goal. In more advanced sessions of guided imagery, patients may learn to imagine specific cellular changes going on in their body to help fight disease, or they may return to a specific traumatic event to recall details and find closure.

Seeing a healthcare professional to participate in guided imagery is just one option; guided imagery dialogues are also available on CD, as well as in books. When using a book, individuals may record themselves reading a written script for their own guided imagery sessions. Some therapists may give guided imagery sessions over the phone or record an individualized CD for a client. Group sessions or workshops for guided imagery are additional options.

Guided imagery practitioners may obtain certification from two major training organizations in the United States. The Academy for Guided Imagery was founded by several psychiatrists and was initially the only center where healthcare professionals could obtain comprehensive training in Interactive Guided Imagery, a specific method in which the individual's own imagery is solicited and scripts are not used. For more information about the Academy for Guided Imagery, visit their website at **www.academyforguidedimagery.com**.

Beyond Ordinary Nursing (online at **www.integrativeimagery.com**) is an organization founded in 1996 by two nurses who graduated from the Academy for Guided Imagery. Its mission is to provide registered nurses and licensed healthcare professionals with comprehensive, high quality training in relaxation and imagery skills. According to the organization’s website, “Guided imagery refers to using the power of the imagination to evoke positive mind/body responses… Guided imagery techniques are commonly scripted and directed by the practitioner or recorded on tape/CD. Typically, the recipient is guided to a peaceful scene or to concentrate on a theme in a guided visualization. And the widening field of therapeutic imagery is rapidly being accepted as an evidence-based holistic modality in many conventional healthcare settings.”

Different Conditions and Different Types of Guided Imagery

In her book, Belleruth notes that individuals seek help from a mental-health professional for different reasons. Some are suffering as a result of a traumatic event they have experienced or the heartbreaking losses they have had to endure. Others may have trouble with excessive worrying, loneliness, dysfunction in their relationships, or patterns of behavior that repeatedly cause problems.

Additionally, individuals who are chronically ill or suffer from a debilitating or possibly life-threatening medical condition may consult a mental-health professional. Such individuals may be looking for ways to get help with accepting their diagnosis and cope with any upcoming medical procedures. They may be seeking strategies for improving quality of life, reducing symptoms, and fighting their illness.

A tool for gaining more courage when facing difficult procedures and treatments (such as surgery, chemotherapy, dialysis, and frequent injections) can be of much help. People dealing with chronic illness or life-threatening conditions often feel helpless in their situation and would benefit greatly by becoming more proactive in the treatment of their condition. They are looking for something to help them gain more control, or a sense of mastery, over what is happening… providing new hope for the future.

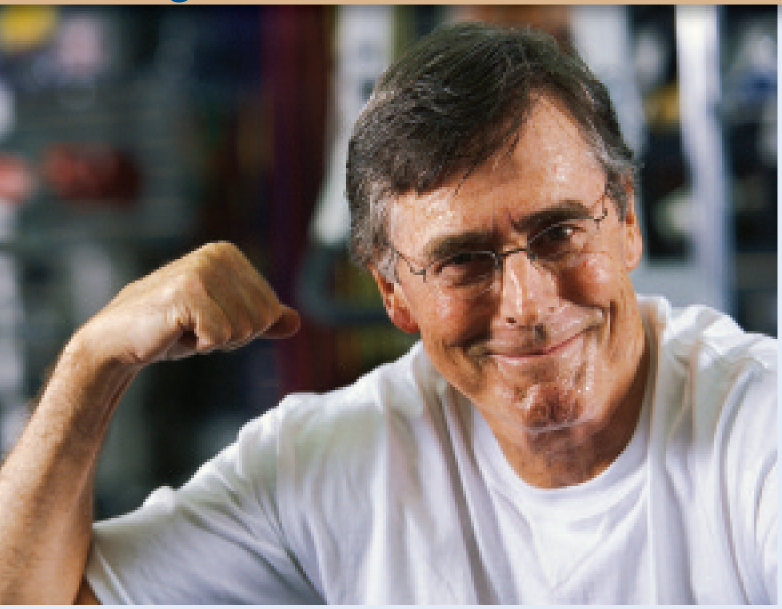
A psychotherapist gives people the opportunity to speak with someone who is unbiased and outside of their group of family and friends. This enables patients to look at themselves in a more caring way, disconnected from their own suffering. The psychotherapist may give his or her clients the encouragement, input, and strategies they need to feel better and work toward their desired goals.

Fortunately, guided imagery can also help with all of the different types of physical and emotional conditions mentioned. While it is not a substitute for other treatment of these urgent issues – including psychotherapy, counseling, and possibly medication or other therapy as prescribed by one's medical and mental-health professionals – guided imagery is a useful "therapeutic intervention" that can be of great help as an add-on to these other treatment plans.

EDITOR'S NOTE: *Anyone experiencing excessive anxiety, depression, worry, or other types of mental or emotional issues noted in this section, is strongly advised to seek professional help. Treatments are available and no one should suffer needlessly.*

Different types of guided imagery may be used for different outcomes. Examples include: "Feeling-State Imagery," aimed at improving your mood; "Final" or "End-State Imagery," used to imagine yourself in an ideal condition or situation in your future; and "Physiological Imagery" or "Cellular Imagery," which refer to imagining specific physical processes or cellular changes to fight disease and promote good health.

Belleruth's book gives sample scripts for these and other types of guided imagery. She also offers several imagery exercises for general health, emotional resiliency, and common complaints, such as headaches, allergies, insomnia, and pain.



"Final" or "End-State Imagery" is used to imagine oneself in an ideal condition in the future. Someone with weakness or other physical limitations might imagine a return of strength and function.

Dr. Franco explains that people can use guided imagery to imagine the healing properties of their bodies and/or their medicines or treatments. Noted earlier, these are referred to as Physiologic or Cellular Imagery. Once deeply relaxed, patients can picture and feel healing on a microscopic level.

For example, a person with cancer can picture how their body is increasing its number of white blood cells and imagine through their senses particular mechanisms in which they are destroying cancer cells in the body with elaborate detail. Or they may imagine the reduced swelling of a tumor or a boil on the skin many times a day.

This is a very empowering process and one that has been found to increase a person's adherence to treatment.

EDITOR'S NOTE: *Guided imagery is not a cure for these types of conditions, but by practicing imagery, some individuals may feel more in control, and more actively involved in the treatment process. Researchers continue to look at the possible effects this type of guided imagery may have on different illnesses.*

To practice this type of imagery, using anatomically-correct information is important. People have been found to connect more personally to their illness and healing process when engaged in this type of imagery work, and often love to practice imagining it throughout the day.

This is a particularly helpful technique to engage with medicine, medical treatments, or injections, enabling patients to embrace their treatments as healing allies. They can imagine, picture, and feel how these medicines or treatments are actually helping them to heal with specific sensory details.

Patients soon discover that the medicine is not some 'outside force or property,' but rather one they can direct into their imagery and personal healing experience. This is a very empowering process and one that has been found to increase a person's adherence to treatment – as treatment becomes unified with their own natural abilities to engage in their healing process and respond to it.

How Guided Imagery May Help Individuals with MS

Dr. Franco has conducted several workshops and has provided many guided imagery interventions to MS patients. Dr. Franco uses guided imagery to help individuals with MS to experience the following benefits:

- Become deeply relaxed, reducing stiffness and lowering muscle tension
- Reduce fatigue, renewing one's energy and drive
- Lower anxiety, promoting adaptive and positive coping skills
- Cope more effectively with specific stresses associated with MS

Several studies have shown the effectiveness of relaxation and guided imagery in lowering blood pressure (Agras,1983; Henry & Sancore, 1987; Kaushik, Mahajan, & Rajes, 2006; Young, 2000; Yung, French, & Leung, 2001). Another study found that use of these [intervention] techniques, designed to enhance the coping process, were seen to improve adherence to therapies, including drug therapies (Mohr et al, 1997).

Studies have also been conducted with imagery and MS patients specifically. One study showed that the use of relaxation and Autogenic Imagery (using diaphragmatic breathing) led to significant reductions in state anxiety for individuals with MS (Maguire, 1996). Another study with MS patients found improvement in quality of life in regards to a significant increase in vigor and energy as compared to the control group (Sutherland, Andersen, Morris, 2005). The study also noted that since imagery does not require active effort, it is a suitable method for individuals across the range of physical disability, including individuals with significant mobility issues.

Lowering Injection Anxiety for Individuals with MS

Dr. Franco is especially enthusiastic about her most recent MS endeavor. She has created a guided imagery intervention to help reduce injection anxiety for individuals on an MS disease-modifying therapy (DMT). She will be conducting workshops for members of the MS community, and has produced a CD for MS patients to use at home.

As many of you already know, MSAA supports the American Academy of Neurology's position that individuals with the most common types of MS (relapsing-remitting and other relapsing forms of MS) should be on a DMT. This helps to slow disease activity (as shown on magnetic resonance imaging) and reduces the severity and frequency of disease flare-ups.

Since the first lines of MS treatments are administered via self-injections at home, anxiety over these injections can play a major role in not adhering to the therapy. The frequency of these injections ranges from once daily to once weekly, depending on the specific medication prescribed, but these must be taken consistently to derive any benefit. This is the message that MSAA is advocating through its public education program, and Dr. Franco's work toward reducing injection anxiety can do much to help MS patients to sustain treatment.

As part of her introduction to her CD, *Relaxation and Guided Imagery for MS: Lowering Anxiety with MS and MS Injections,* Dr. Franco states:

"Know that it is natural to be anxious or stressed about having MS and to learn how to

use injected medications. As you learn to become deeply relaxed – a very healthy state of being – you can develop confidence in your ability to stay calm and focused while administering or receiving injections and you can learn to enhance the positive healing effects of the medicine as you create deeply restful, healing experiences… Your MS symptoms improve when you are less stressed. With practice, you can learn to be deeply relaxed, promote deep states of rest and healing and can even picture your healing process with your senses… This is a wonderful way to tune into your body's intuitive healing mechanisms and to use state of the art medicine to reduce the frequency and severity of relapse symptoms, to forestall the development of new lesions, to alleviate stress, restore vitality and energy and to calm your inner world and body… to bring back the balance to your immune system and to your life." (*Excerpt from: Relaxation and Guided Imagery for MS: Lowering Anxiety with MS and MS Injections, copyright Franco, 2007.)*

Dr. Franco is conducting educational workshops to determine the effectiveness of guided imagery in reducing anxiety associated with MS injections. MSAA is interested in the results of this project and was recently awarded a Bayer HealthCare Pharmaceuticals educational grant to fund the workshops. Dr. Franco will be teaching relaxation and guided imagery techniques to patients with relapsing-remitting MS, as well as to nurses and healthcare professionals. These workshops will help determine the potential of guided imagery to offer self-empowering skills for individuals with MS… to gain relief from anxiety and improve their ability to cope with MS and the disease-modifying therapies.

Initial feedback from participants in a similar workshop has been very positive. The six individuals who took part in the demonstration commented on how relaxed they have become while taking their injections. Many were surprised at the effectiveness of the guided imagery.

Practicing Guided Imagery

According to Dr. Franco, guided imagery is a specific mind-body intervention in which a person is guided to a deep state of relaxation by means of diaphragmatic breathing and images that invite stress reduction. Lower arousal in the body is first achieved before sensory images are introduced, related to a specific goal or end result the person wishes to experience and practice.

When relaxed, you might imagine an ideal place of relaxation to be the beach. You may picture the blue sky, hear the sea gulls, feel the warm rays of the sun, and feel the sand beneath your toes.

Under the right conditions of being deeply relaxed in a conscious state, our bodies don't discriminate between sensory images in the mind and what we call reality. When we call upon a sensory image in our imaginations in a relaxed state, the emotions, mood, and physiological state associated with it appear very vivid, very immediate; and the imagined place, image, or event reverberates in the body.

Images in the mind are real events to the body, especially multi-sensory ones. So, for example, if when relaxed you are invited to an ideal place of relaxation, which may be the beach, you may picture the blue sky, hear the sea gulls, feel the warm rays of the sun on your back, or feel the sand beneath your toes, all sensory images of the beach. You may imagine a beach you know or have never visited, it does not matter – as in either event, your body starts to respond as if you are there, allowing you to experience the positive, soothing, or healing effects of being at the beach.

In this relaxed state, research demonstrates that your body is reliving this scene in a sensory way and is increasing the transmission of the restful properties of your parasympathetic nervous system. This system restores energy, rebuilds, relaxes, and opens one up to receptive processes.

Guided imagery is a method that allows us to deliberately introduce healthful images, even allow people to practice being relaxed during difficult medical procedures, and the body will respond positively. If you practice this, you can empower yourself to become more attuned to your natural healing abilities, more attuned to your body, and can use your deep states of relaxation and imagery to cope more effectively.

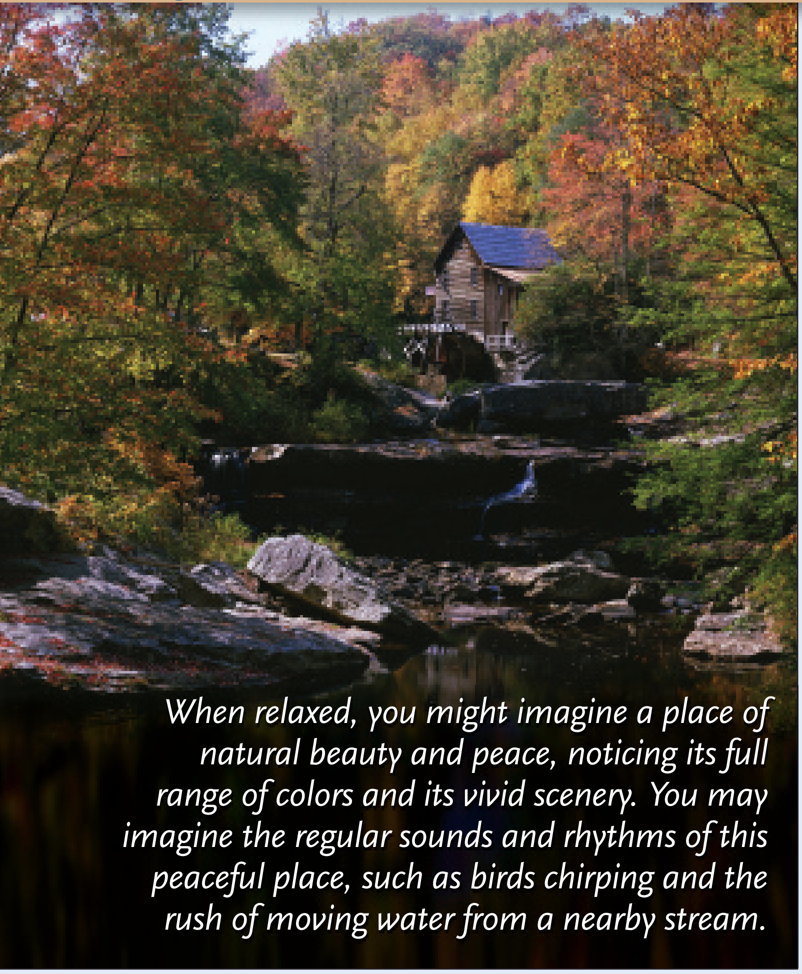
It also creates a locus of control within us – a way of letting go and relaxing that allows us to learn to feel better about ourselves because we can learn a sense of mastery in responding to what is happening to us. This provides positive ways in which we can rehearse and prepare for emotionally difficult or physically painful events. This lowers a sense of helplessness and increases our responsiveness. With relaxation and guided imagery, we have at our disposal a technique that gives us a sense of control, and this helps us to feel better and do better.

As you practice relaxation and guided imagery, you can learn to develop a relaxed focus, a kind of calm yet energized alertness – what athletes sometimes call “being in the zone” or “flow.” We're in and out of these states all day long, we just don't think about them nor use them in a specific, practiced, and directed way to increase healing, lower reactivity, and promote growth and change.

Historically, guided imagery was referred to as visualization techniques, but this term is no longer used, as guided imagery involves the use of multiple senses and is a whole-body experience. It is a well established form of complimentary medicine practiced by nurses who can use guided imagery to quickly and effectively teach patients to “befriend” a breathing tube, or lower anxiety associated with surgery, or reduce the nauseous effects of chemotherapy.

To follow is a brief description of a “safe place.” This is a very basic guided imagery intervention that is used right after one has become deeply relaxed, to center and anchor the self before he or she engages in a problem-solving or challenging task. It is an excerpt from Dr. Franco’s new CD: *Relaxation and Guided Imagery to Relieve Caregiver Stress*. This CD is customized to fit caregivers’ needs “to lower your stress, renew your energy and spirit, as well as restore the balance and meaning in your life, while actively responding to the needs of those you cherish.” (Please note that dashes and dots indicate pauses and changes in inflection.)

“As your body remains relaxed and comfortable, imagine yourself in a special, safe place - - - - maybe some place you've visited or have never been…..some place you always wanted to see or perhaps some place most suited for you now.....a place of natural beauty and peace.....slowly survey this wonderful place with all of your senses -- allowing it to become more vibrant and alive with all of its special properties.........as you glance around you, notice its full range of colors and its vivid scenery.....your ears become fully attuned to its unique sounds: waves lapping the shore, logs crackling in the fire, perhaps birds chirping.......as you accustom your ears to the regular sounds and rhythms of this peaceful place, you settle yourself down, to take a fuller moment to capture its beauty and safety.......as you commit this vision to memory, you start to feel whatever you are sitting upon: the soft, freshly mowed grass...a sandy embankment.....or a stone wall you can dangle your feet over........you can even feel the imprint of this site on your skin...a cool breeze that caresses your cheek, the refreshing mist of a waterfall that sprinkles your hair, sprinkles your face, or the warm glow of the sun on your back......the corners of your mouth may even curl into a smile as you recognize that this special place is always there, for you to return to at anytime you need it.....your blueprint for relaxation...a wellspring of hope to restore healing and coping...know that this is just the beginning, at any time, you can return to your special place and become secure, relaxed, and receptive to your next caregiver experience....or



When relaxed, you might imagine a place of natural beauty and peace, noticing its full range of colors and its vivid scenery. You may imagine the regular sounds and rhythms of this peaceful place, such as birds chirping and the rush of moving water from a nearby stream.

challenge….." (copyright Franco, 2008)

Tips for practicing guided imagery include:

- Finding a comfortable, quiet place to practice
- Practice the same program once or twice daily; listening to a guided imagery script while waking or falling asleep is a good time
- Guided imagery becomes easier and stronger with practice
- Don't force yourself to relax and imagine certain imagery; allowing the mind to wander in and out is normal
- Guided imagery can help, even if you don't believe it will work
- If you find that you become emotional, this just means that the imagery is working for you in a deep way; exhale slowly while breathing to stay responsive
- You can use your hands as a natural cue; holding them the same way each time you listen to a CD will eventually allow you to become more deeply relaxed through the position of your hands

Please note that certain types of music can also be of therapeutic value. Listening to music (with a slower beat) while practicing to relax with guided imagery can enhance your experience. Music with a quicker beat may be used when practicing guided imagery for motivational purposes. Children may also benefit from guided imagery. As always, consult a physician before starting any type of change to your lifestyle or medical care.

For More Information

Readers interested in purchasing guided imagery CDs, including those for reducing MS-injection anxiety and for relieving caregiver stress, may visit Dr. Franco's website at **www.imagerywork.com**. For more information on these CDs or for weekend workshops in the Philadelphia area, readers may call Dr. Franco at **(610) 935-8330**.

To find local therapists who are certified as guided imagery practitioners, readers may visit Imagery International's website at **www.imageryinternational.com**. Readers without internet access may call Imagery International at **(707) 592-7667**.

A great number of books, CDs, and other references on guided imagery are available through local and online suppliers, including **www.healthjourneys.com** and

Ask the Doctor

By Dr. Jack Burks
Chief Medical Officer for MSAA


Dr. Jack Burks

IMPORTANT NOTE: *While Dr. Burks is able to provide helpful information in response to the various medical questions sent in by readers, he is not able to give specific medical advice or offer any type of diagnosis. This may only be done through one's own physician, and this is often stated within the answers.*

Q: Six years ago I developed trigeminal neuralgia (causing facial pain). Since that time, I have had ringing in my ears, dizzy spells (lasting from seconds to hours), and I have an electric shock-like pop in my head. I also have a strange visual syndrome, where over the course of an hour, I lose my center vision, followed by my vision becoming blurry and shaky, before clearing up from the center out. Then I am left with pressure and a small headache. I have come to think that these things may not be caused by my neuralgia. Could you please advise me?

A: You are right. The other symptoms described are not typical of trigeminal neuralgia. Therefore, I suggest seeking other possible diagnoses from your doctor. For example, temporomandibular (TM) disorders (also known as TMJ or TMD) refer to problems in the joints of the jaw and its movement, causing pain and other symptoms. TM disorders and migraine/vascular headaches are examples of diagnoses that the doctor may consider. As you know, I am not able to make diagnoses in this column. Please talk to your doctor about other possibilities. If you have MS, which is one cause of trigeminal neuralgia, an MRI might show other MS lesions to explain some of the symptoms.

Q: I have seen several neurologists and have had extensive testing, but have yet to receive a diagnosis. My symptoms include: heat sensitivity; intention tremors; balance problems; double vision; voice problems; and cognitive issues. Some symptoms come and go. Brain and spinal MRIs have been negative; a spinal-fluid analysis showed two oligoclonal bands (with a slight amount of blood). The last neurologist suggested that even if I had lesions, my symptoms are too symmetrical to be MS. Could this be true, and do you have any thoughts on my situation?

A: The diagnosis of MS is usually dependent on the history of certain characteristics of neurological symptoms and specific findings during a neurologic examination. The MRI and spinal-fluid analysis are tests used to help confirm such suspicions. For example, the MRI shows MS-type lesions in more than 90 percent of MS patients after a few years. Your negative MRIs makes it less likely, but not impossible, for you to have MS. The fact that your spinal fluid was contaminated with blood makes the interpretation of that test more difficult.

Time will tell if you have MS. However, your symptoms are troubling, and these can certainly be investigated and treated now, without a definite diagnosis. For example, cognitive issues can be evaluated by neuropsychological testing, and may be addressed through different types of cognitive intervention. Similarly, balance problems can be evaluated and addressed by a balance expert. Voice problems can be evaluated and treated by a speech and language therapist. Double vision can be evaluated by an eye doctor, who may be able to offer some strategies to help you cope with this symptom. Last, MS symptoms are usually not completely symmetrical, since MS brain and spinal-cord damage is not symmetrical. Your doctor's neurological examination may have led him or her to this conclusion. Another MRI and spinal tap may be warranted in the future, if your doctor recommends them.

Q: **I broke my arm, wrist, and both legs a few years ago. My left leg now has a plate with screws in it. How can I get an MRI of my spine? Can it be done at all?**

A: This is a specific question for your orthopedic surgeon and your MRI center. The feasibility of being able to perform an MRI depends on the material in the plates and screws. Some materials have magnetic properties, but most do not.

Q: **During an exacerbation, I have times when my heart rate has slowed down to fewer than 50 beats per minute. Conversely, I have also experienced a racing heartbeat of about 120 beats per minute; this typically occurs in the evening, after my last dose of Ritalin. I tend to have these changes in heart rate when I've done too much and am worn out. Can heart rate be affected by MS, or might this be a side effect of certain medications?**

A: Heart rate is not usually directly affected by MS. However, I have seen some MS patients with rapid heart rates that needed investigation. Your rapid heart rate after Ritalin® (methylphenidate) may be related to your medication. Fatigue, stress, and other stimulants (including caffeine and nicotine) can also affect heart rate. I would ask your doctor about other possibilities. Certain cardiac conditions such as superventricular tachycardia (SVT) should also be considered.

Q: *The following two letters were received by Dr. Burks in regards to itching (as a symptom of MS) and its treatment. Dr. Burks' response to these letters is shown below.*

1) I was diagnosed with MS in February of 1999 at the age of 31. I have had itching since I was nine years old. No one could find a reason, but the drug Atarax was prescribed. Whenever I had an itch attack, I would take a pill. I never went anywhere without this medication. My itching would disappear for months and then start again. There was no pattern, no tests, no reason... just the itches. I have not had

itching since I was placed on Copaxone. I do not know if one is related to the other. I can tell you that relief comes within 22 minutes from taking one Atarax pill.

2) In the Fall 2007 Issue of *The Motivator*, a person with MS was experiencing attacks of severely itchy skin. My mother has MS, and one of her doctors prescribed 20 mg of Geodon for this symptom. The medication eliminated her itching problem.

A: For itching, I evaluate for a drug or other allergic reaction. Then, I use moisturizing cream and make certain that fingernails are kept short to avoid more skin irritation from scratching. Also, antihistamines such as Benadryl® (diphenhydramine) or Atarax® (hydroxyzine) can be used at bedtime if the itching keeps people awake. However, they make many people drowsy. Some non-drowsy products are also available, and I advise readers who experience itching to consult their doctor or pharmacist to learn more about these products.

I am happy to hear that the Atarax pill has provided consistent relief for the individual who wrote the first letter. Copaxone® (glatiramer acetate) is an effective drug for MS, but its role in treating itching, which has been present for this person since age nine, is an unknown to me.

Regarding the second letter, I do not use Geodon® (ziprasidone) for itching, so I cannot discuss it specifically. Geodon is a drug that is usually prescribed for psychiatric conditions and has its own side effects, including an allergic reaction with itching as a symptom. In any event, I am pleased that the writer's mother has been able to eliminate her itching by using this medication.

Q: **I would like to know if there is a form of MS that causes tumors. I have relapsing-remitting MS and I was told by someone that this happens sometimes. Is this true?**

A: Can MS patients also have tumors? Yes. However, they may not be specifically related. MS is a disease affecting more than a million people worldwide. With this many people, they get many other medical conditions as well. The occurrence of MS and tumors in the same patient is unusual. Therefore, I would not be overly concerned that you will get a tumor as well as MS. However, science and symptoms of a tumor, such as rectal bleeding, the increasing size of a mole, and unexplained weight loss, should not be ignored.

Q: **Does anyone in the medical MS community have experience with the specific area of oral cancer in patients who also have MS? What are some special concerns that a person with MS undergoing cancer treatment needs to be aware of? I've read that in some instances, chemotherapy has been used to treat MS. Also, are you aware of any experimental/non-traditional therapies for treating oral cancers in patients with MS?**

A: As mentioned earlier, any tumor can occur with MS as well as for the general population. The symptoms of oral cancer can overlap with some MS symptoms. For example, trouble with swallowing, speech, and salivation can be seen in both conditions. A speech and language therapist who is knowledgeable with both conditions can be helpful.

If radiation is necessary near the throat, care will be taken to reduce radiation damage to the nearby nervous system. Radiation oncologists are aware of these issues.

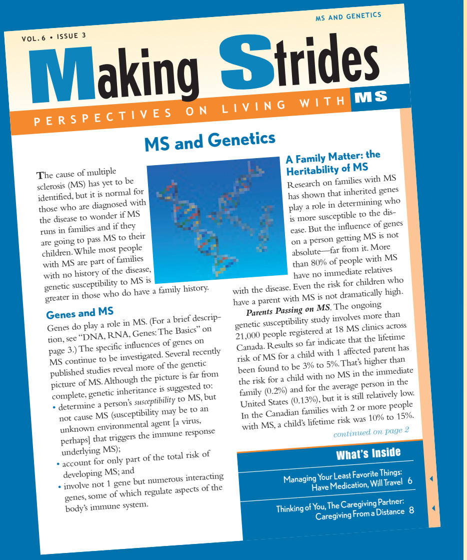
Cancer chemotherapies, such as Novantrone® (mitoxantrone), Imuran® (azathioprine), and methotrexate, are used for MS treatments, when other MS therapies have shown suboptimal responses. Other cancer drugs may also help MS patients, but have not been tested adequately. Your oncologist may have more specific insights into your specific cancer drug and its potential effects on MS. Since the combination of oral cancer drugs and MS is so unusual, your doctors may wish to consult with a major cancer center and/or MS center for more specific advice in your situation.

I am not aware of any experimental or nontraditional therapies that are being used specifically for oral cancer and MS.

Q: Are viruses involved with MS?

A: A number of viruses and other infectious agents (such as chlamydia) have been incriminated as possible causes of MS. These are still viable theories. The current leading candidate is the Epstein-Barr virus, which is associated with mononucleosis. More than one virus may be involved,

continued on page 35



VOL. 6 • ISSUE 3

MS AND GENETICS

Making Strides

PERSPECTIVES ON LIVING WITH MS

MS and Genetics

The cause of multiple sclerosis (MS) has yet to be identified, but it is normal for those who are diagnosed with the disease to wonder if MS runs in families and if they are going to pass MS to their children. While most people with MS are part of families with no history of the disease, genetic susceptibility to MS is greater in those who do have a family history.

Genes and MS

Genes do play a role in MS. (For a brief description, see "DNA, RNA, Genes: The Basics" on page 3.) The specific influences of genes on MS continue to be investigated. Several recently published studies reveal more of the genetic picture of MS. Although the picture is far from complete, genetic inheritance is suggested to:

- determine a person's *susceptibility* to MS, but not cause MS (susceptibility may be to an unknown environmental agent [a virus, perhaps] that triggers the immune response underlying MS);
- account for only part of the total risk of developing MS; and
- involve not 1 gene but numerous interacting genes, some of which regulate aspects of the body's immune system.

A Family Matter: the Heritability of MS

Research on families with MS has shown that inherited genes play a role in determining who is more susceptible to the disease. But the influence of genes on a person getting MS is not absolute—far from it. More than 80% of people with MS have no immediate relatives with the disease. Even the risk for children who have a parent with MS is not dramatically high.

Parents Passing on MS. The ongoing genetic susceptibility study involves more than 21,000 people registered at 18 MS clinics across Canada. Results so far indicate that the lifetime risk of MS for a child with 1 affected parent has been found to be 3% to 5%. That's higher than the risk for a child with no MS in the immediate family (0.2%) and for the average person in the United States (0.13%), but it is still relatively low. In the Canadian families with 2 or more people with MS, a child's lifetime risk was 10% to 15%.

continued on page 2

What's Inside

Managing Your Least Favorite Things: Have Medication, Will Travel 6

Thinking of You, The Caregiving Partner: Caregiving From a Distance 8

WELCOME

Making Strides: Perspectives on Living With MS is a quarterly newsletter written especially for people living with MS (patients, family members, and care partners). It is chock-full of up-to-date information about MS and practical tips for dealing with it. Much can be done to manage MS—*Making Strides* can show you how!

SIGN UP NOW

Enroll today for your FREE SUBSCRIPTION to *Making Strides: Perspectives on Living With MS*

MANAGING YOUR LEAST FAVORITE THINGS

Have Medication, Will Travel
As an air traveler living with multiple sclerosis (MS), your travel experience will be less exasperating if you leave behind inconvenience and unpredictability.
(Vol. 6, Issue 3)

Heat-Related Pseudoattacks
Overheating can cause the nervous system to work more slowly than usual for some people with MS.
(Vol. 6, Issue 2)

Q&A: YOUR QUESTIONS ANSWERED

Getting the Most From Your Office Visits
Visits to a doctor are a regular occurrence for people with MS, but sometimes the visits are too quick, and a person can leave with important questions unanswered.
(Vol. 6, Issue 2)

Your Questions Answered
The editors of Making Strides offer their expert responses to questions from readers on oral MS therapies and a trial that investigated testosterone treatment in men with MS.
(Vol. 6, Issue 1)

THINKING OF YOU, THE CAREGIVING PARTNER

Caregiving From a Distance
Personal circumstances such as jobs and marriage, can often make families and friends live far apart. It is possible that distance will be a factor if a loved one with MS needs assistance
(Vol. 6, Issue 3)

When A Child Has MS
When the person with MS is your child, regardless of his or her age, the challenges may be overwhelming.
(Vol. 6, Issue 2)

Making Strides and Making-Strides.net are supported by an educational grant from Teva Neuroscience and published by

Research News

Evidence of Epstein-Barr Virus Found in MS Patients

Using postmortem brain tissue from 21 individuals who had multiple sclerosis (MS), researchers in Italy found evidence of Epstein-Barr virus (EBV) infection in 20 of 21 samples. No evidence of the virus was found in the brain tissue they tested from individuals with other inflammatory neurological diseases.

Evidence of EBV infection was discovered in a large portion of brain-infiltrating B cells (immune-system cells that cross the blood-brain barrier and cause damage to the brain) as well as plasma cells (antibody-producing cells). Certain areas were found to be major sites of EBV presence in the samples from individuals with secondary-progressive MS (SPMS).

While expression of inactive viral proteins was commonly seen in the MS brain tissue, viral reactivation appeared only in B-cell clustering in the meninges (covering of the brain) and acute MS lesions. Researchers do not know if EPV plays a role in the development of MS, or if it is a consequence of the disease process, but these findings suggest that EBV is involved in the damage caused by MS.

(Serafini B, et al, "Dysregulated Epstein-Barr virus infection in the multiple sclerosis brain," *J Exp Med*, 2007 Nov 26; 204(12): 2899-912.)

Botox Injections Improve Bladder Function and Quality of Life

Researchers in London collected data to demonstrate the effectiveness of botulinum neurotoxin type A (Botox®) detrusor (bladder muscle) injections for the treatment of bladder dysfunction in MS patients. The researchers also wanted to measure the impact of this treatment on quality of life.

Forty-three MS patients who were experiencing severe urgency incontinence participated. Measurement of bladder function, diaries recording urination, quality-of-life questionnaires, and medication usage for bladder incontinence, were all collected before treatment and at four as well as 16 weeks after the injection was given. The same information was collected after repeated treatments.

Researchers found that the participants experienced "highly significant" improvements in: episodes of incontinence; urinary urgency; daytime frequency; and nocturia (the urge to urinate, or the leakage of urine, at night during sleep). While nearly all of the patients needed to perform self-catheterization following this treatment, all quality-of-life scores improved. The positive effects of the botulinum neurotoxin type A injection continued for a mean average of almost 10 months, and similar benefits were experienced with subsequent treatments.

The authors of this report conclude that the minimally invasive botulinum neurotoxin type A injections are exceptionally effective for treating bladder dysfunction in patients with MS.

(Kalsi V, et al, "Botulinum injections for the treatment of bladder symptoms of multiple sclerosis," *Ann Neurol*, 2007 Nov;62(5):452-7.)

Mitoxantrone May Provide Delayed Benefit

Italian researchers conducted a five-year, open-label, prospective study to evaluate the effectiveness and safety of mitoxantrone (Novantrone®) treatment. Fifty individuals with SPMS or rapidly worsening relapsing-remitting MS (RRMS) were given intravenous infusion treatments with mitoxantrone every two months for two years. Clinical assessments and magnetic resonance imaging (MRI) scans of the brain were performed prior to treatment, at the end of treatment, and then annually for the three-year follow-up period.

Approximately one-third of the participants experienced disease progression (as measured by the Expanded Disability Status Scale [EDSS]) during treatment, and only one-fifth of the participants experienced disease progression during the three-year follow-up. In addition, while approximately 35 percent of the participants had active MRI lesions prior to treatment, this dropped to 18 percent during treatment, and to zero (i.e., none of the participants had active lesions) at the end of the three-year follow-up period. These findings suggest a delayed beneficial effect after mitoxantrone treatment is completed.

(Buttinelli C, et al, “Mitoxantrone treatment in multiple sclerosis: a 5-year clinical and MRI follow-up,” *Eur J Neurol*, 2007 Nov;14(11):1281-7.)

— Summarized by Susan Wells Courtney; Reviewed by Dr. Jack Burks

MSAA Needs Volunteers!

Act on your resolution to volunteer in 2008!

Don't wait until National Volunteer Week (April 15–21) to offer your service. MSAA needs volunteers year-round, so please start today.

How can you volunteer to help MSAA? Please reply directly by email to **volunteering@msassociation.org**

Looking for ideas? Please go online and visit **support.msassociation.org/volunteer** to learn more about:

- ***Resource Detectives*** *(conduct local research on resources that help individuals with MS)*
- ***Fundraising tips*** *and ideas for all ages*

Your help is needed and valued!

For more information about volunteering with MSAA, please contact the Director of National Volunteer Services by calling **(800) 532-7667, extension 8**, or write to:

Director of National Volunteer Services
Multiple Sclerosis Association of America
706 Haddonfield Road
Cherry Hill, NJ 08002

RESOURCE DETECTIVES℠ NEEDED

MSAA needs you "on the case" as a **Resource Detective℠** to help identify valuable resources for the MS community. Through MSAA's Resource Detectives Program, volunteers use skills to research and report to MSAA information about local agencies and organizations that offer assistance for the MS community.

For more information, please contact Bonnie Yares at **(800) 532-7667, extension 132** or visit **support.msassociation.org/detectives**

You may also email Bonnie Yares at **byares@msassociation.org**

The Resource Detectives Program is supported through a grant from Novartis Pharmaceuticals Corporation.

Program Notes

Calling All Readers of *The Motivator*: We Want to Hear from You!

MSAA strives to provide the MS community with the most up-to-date and accurate information as possible. We know how important information is to meet the challenges that living with MS poses, not only to the individual, but to his or her support system of family, friends, and care partners, as well.

Based on the "Needs Assessment Survey" MSAA conducted in 2005, educational information on such topics as new medications, treatments, and research were the greatest perceived needs from our clients and their care partners. Some of the other areas of information that were ranked highly in the survey included exercise, fatigue management, better problem-solving and coping skills, along with complementary and alternative medicine.

With this in mind, MSAA has focused its educational programming and events on these issues, as well as covering them in *The Motivator*. MSAA has a series of its own publications which are available in print and electronically through MSAA's website **www.msassociation.org**.

MSAA has also begun a movement to incorporate new ways of communicating with our clients. One way has been through enhancements made to the website (**www.msassociation.org**) and MSAA's MSi program, which features, *A Closer Look*, MSAA's educational on-demand video programming, as a way to bring knowledge and empowerment right into the privacy and comfort of a person's home.

But information is not limited to MSAA's publications and online programming. Information can also come from your local support group leader, MSAA's regional directors, MSAA's Helpline (telephone) consultants, or through local, public-education events. Information is everywhere and MSAA would like to learn more about your thoughts and preferences on how to share our vast resources and knowledge.

This is why MSAA is looking for your help! We have developed a five-question survey inquiring about the type of information you would like to receive from MSAA and how this can be best delivered, whether through mailed publications, electronic newsletters, videos, educational events, etc. Your answers and feedback will play a vital role as we work to develop new publications, cover more topics, and look for new ways to better understand your informational needs.

To participate in the survey online, visit **support.msassociation.org/survey**. For those who prefer to mail or fax a written copy to MSAA, we have included the survey on the following two pages. Please complete this brief questionnaire and mail or fax it to MSAA. Our address and fax number are listed at the end of the survey. Thank you so much for your participation and assistance in delivering urgent information to the MS community. ◆

— Amanda Bednar

MSAA
MULTIPLE SCLEROSIS
ASSOCIATION OF AMERICA

Client Information Survey

Please help MSAA communicate more effectively with the MS community by completing this survey. If you prefer, an electronic version is available online at **support.msassociation.org/survey.** See reverse for instructions on returning this completed survey to MSAA. Thank you!

1. **Which best describes yourself?**
   - ☐ An individual with MS
   - ☐ A care partner for someone with MS
   - ☐ A relative of someone with MS
   - ☐ A friend/associate of someone with MS

2. **Please circle your level of interest for each topic.**
   I am interested in receiving information about:

Topic:	*Level of Interest (circle only one for each):*				
	lowest				**highest**
MS research, medications, treatments	1	2	3	4	5
MS symptom management	1	2	3	4	5
Health insurance/disability issues	1	2	3	4	5
Personal relationship issues	1	2	3	4	5
Exercise, nutrition, therapy	1	2	3	4	5
Organizations or groups who might assist with MS-related problems	1	2	3	4	5
Problem-solving/skill building techniques	1	2	3	4	5

Other topics of interest: ______________________________

3. **Within the past 12 months, please select all of the ways you have received information on multiple sclerosis (from all sources, not just MSAA).**
   - ☐ Attending educational events/seminars
   - ☐ Support group meetings
   - ☐ Printed publications (i.e., magazines, books, brochures)
   - ☐ Telephone Helpline
   - ☐ VHS tapes/DVDs/CDs
   - ☐ Websites/internet
   - ☐ Live webcasts
   - ☐ On-demand web videos/programs
   - ☐ Email updates/e-newsletters
   - ☐ Online chat rooms/blogs

MSAA™ Client Information Survey

4. **What is your preferred method(s) of receiving the types of information listed in question number 2? Please check no more than three options.**

   ☐ Attending educational events/seminars
   ☐ Support group meetings
   ☐ Printed publications (i.e., magazines, books, brochures)
   ☐ Telephone Helpline
   ☐ VHS tapes/DVDs/CDs
   ☐ Websites/internet
   ☐ Live webcasts
   ☐ On-demand web videos/programs
   ☐ Email updates/e-newsletters
   ☐ Online chat rooms/blogs

5. **How can MSAA best meet your informational needs in terms of topics and methods of delivering the information?**

____

____

____

____

MSAA appreciates your willingness to complete this survey which will help us communicate more effectively with the MS community. You do not need to include your name or any other personal information on the questionnaire. If you do provide personal information, it will remain confidential.You may complete the survey online at **support.msassociation.org/survey**. You may also fax or mail your completed survey to MSAA using the following contact information:

Via Fax:
Attention: Programs and Services Department
(856) 488-8257

Via Mail:
MSAA
Attention: Programs and Services Department
706 Haddonfield Road
Cherry Hill, New Jersey 08002

Thoughts about Giving

People Helping People

Bruce Makous

I frequently have an opportunity to meet our donors. It's always a great pleasure to become acquainted with the generous people who provide the financial support that allows us to enrich the quality of life for people living with MS.

In November I met many supporters in the Dallas area at a President's Circle reception, and I was impressed to see their enthusiasm and support for MSAA. I also recently visited with one of our key donors, Dr. Aida Chohayeb, at her home in Rockville, Maryland. She told me the story of her distinguished career in dentistry and dental research. She explained that she has a very close friend with progressive MS and this is why she has such strong feelings about supporting MSAA.

My duties also afford me the special opportunity to become acquainted with MSAA clients, which is another great pleasure. Our 2006-2007 Annual Report features a number of our clients. Mary Lynch recently spent the morning at our national headquarters. A retired nurse, Mary shared her enthusiasm about our Helpline and Equipment Distribution Programs – particularly our cooling equipment – which reduces reactions to heat, which Mary doesn't tolerate well because of her multiple sclerosis.

I also became acquainted with Joyce Jackson, a retired medical administrator. Joyce expressed her appreciation for all of the items MSAA has provided to her, including a wheelchair, a bathtub seat, and a walker. Diane Wassy received a ramp that provides

"When I was first diagnosed, I called MSAA every day, especially when I had new symptoms. MSAA was a ready resource. When I called, I received information and comfort."

– Mary Lynch,
Pennsauken, NJ
pictured with MSAA Helpline
Consultant Sue Offenberg

photo by Joy Moody

access to her home in her wheelchair and she too expressed how grateful she was to MSAA and the donors who made this possible.

Meeting both the people who give and those who receive is a wonderful part of my work. It reminds me everyday that MSAA is a special vehicle through which many good people (our generous donors) can help another group of good people (those living with multiple sclerosis) by supporting programs that help enrich their lives everyday.

Thank you, Mary, Joyce, Diane, and all the other people like you who have expressed your warm goodwill towards MSAA. And thank you, Aida, and all of our generous donors, for helping so much in the lives of people living with multiple sclerosis.

— Bruce Makous
Vice President of Development

President's Circle Reception in Dallas

MSAA was pleased to hold a special reception for its supporters at the Baron House in Dallas, Texas. Attendees were given tours of the house, and MSAA representatives expressed appreciation for their vital support.

MSAA President and CEO Douglas Franklin, along with several members of MSAA's Board of Directors, had the opportunity to personally thank MSAA's donors and volunteers in the Dallas area. MSAA's President's Circle program provides special appreciation and recognition for loyal and generous donors. More than 350 individuals from across the country are currently recognized as President's Circle donors.

MSAA donor Jane Yates receives special recognition at the Dallas President's Circle reception in November. From left, MSAA Board member Joe King; MSAA Board member Annette Howard, MD; Jane Yates; and President's Circle Chairman Eric Simons.

Charitable Planning to Reduce Taxes

As we head into the 2008 tax season, strategies for reducing taxes are always a popular subject. Consider tax-advantaged methods of contributing to MSAA, such as a gift of appreciated assets or a gift annuity.

A Gift of Stocks, Bonds, or Mutual Funds

A gift of appreciated assets such as stocks or mutual funds, has several advantages. First, you receive an income tax deduction for the full fair-market value of the assets. Second, a charitable contribution eliminates the need to pay the capital gains taxes that you would pay if you sold the assets.

Finally, MSAA will be able to use the full value of the transferred funds to help people with MS. It's a win-win situation.

For example, let's assume a donor in the 33-percent income tax bracket owns stock that originally cost $20 a share, and today is worth $100 a share. If she contributes 10 shares, or a $1,000 stock value, to MSAA, she saves $333 in taxes. And she avoids paying $120 in capital gains taxes, required if she sold the shares. Finally, the gift will allow MSAA to help more people through its programs.

A Gift Annuity

Creating a gift annuity is an excellent way to establish a legacy fund with MSAA, while also receiving additional income for yourself and your spouse. A gift annuity provides income to the donor or couple for a lifetime, at a rate based on age at the time the annuity is created. (Please refer to the gift annuity rate chart on the back cover.) Gift annuities also provide funding for MSAA from the residual value.

For example, if both members of a couple are age 72 and give MSAA a gift annuity worth $10,000, they will receive 6 percent, or $600 per year, for life. And they will qualify for a federal income tax deduction of approximately $3,496, which will save them $1,154 in taxes, assuming they are in the 33-percent tax bracket. In addition, $346 of each year's payments will be tax-free for the first 18 years. Finally, the residuary of the gift provides generous support for their favorite charity: MSAA.

Please note that after the tax savings from the income tax deduction, their initial contribution is actually only $8,846, so the $600 annual payment to them actually represents an after-tax rate of return of 6.8 percent. Also, $346 of the annuity payment is tax-free, making the $600 annuity equivalent to $771 of taxable income for a beneficiary in the 33-percent income tax bracket. Based on the $8,846 initial contribution, this is an equivalent rate of return of 8.7 percent. It's hard to find an investment that is guaranteed for life and will provide you with rates this high… and also one that will give funding to a charity you want to support.

GIFT ANNUITY ILLUSTRATION

Annuitants:	Couple both age 72
Principal Donated:	$10,000.00
Annuity Rate:	6%
Annuity, paid quarterly:	$600.00
Charitable Deduction:	$3,496.30
Tax Savings at 33%:	$1,153.78
Net Donation after Savings:	$8,846.22
Tax-free Portion of $600:	$346.20
Ordinary Income Portion:	$253.80
Effective Return Rate:	8.7%

After 18.8 years, the entire annuity becomes ordinary income.

"I had been supporting MSAA through annual contributions, and decided I wanted to establish a legacy gift, too," said Herbert Weisz of Deerfield Beach, Florida. In April, Herb and his wife created a gift annuity with MSAA and will receive income from this gift throughout their lifetime. The balance will provide general support for MSAA to help people with MS.

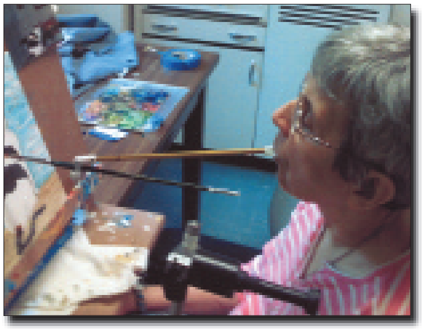
If you have thoughts about giving, please feel free to contact Bruce Makous at **(800) 532-7667, extension 148**, or email **bmakous@msassociation.org**. ◆

Meet the winning artists in MSAA's inaugural

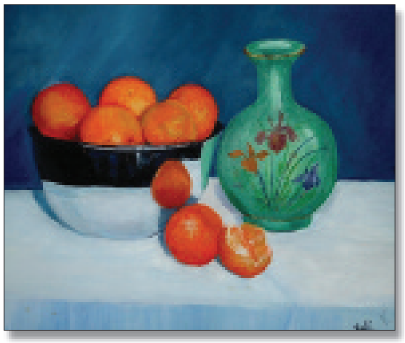
Art Contest

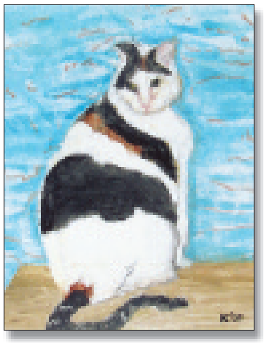
Kali Valencia studies fine arts, anatomy, and painting. She has lived with MS for 23 years. Now a resident of Florida, Ms. Valencia was born in Manhattan, raised in New Jersey, and lived in Colombia. She says she appreciates MSAA's programs and services, especially information and support she receives from the Helpline.

Cynthia Hinchey says she has "always made art." Since she has been unable to work outside her home, Cynthia says art is her "friend, refuge, and therapy." A resident of Texas where she has studied at VS Arts in Houston, Ms. Hinchey participates in an ongoing fine arts program for people with disabilities. She has painted a series of trees, which she says she explores physically and metaphorically. Ms. Hinchey was diagnosed with MS in 1997.



In 1992, at age 50, after living with MS for 22 years, **Sister Kathy Cairone** began painting. Because of her MS, she holds her brush in her mouth. Working weekly with art teachers, Sister Kathy has mastered her craft and completed numerous mouth paintings. She says she finds paintings rewarding and therapeutic. In the order of the Sisters of Mercy, Sister Kathy lives in New Jersey.





WINNING ENTRIES (from left):

Still Life with Oranges (first prize) by Kali Valencia; *Unexpected Seasons* (second prize) by Cynthia Hinchey; and *Trudy* (third prize) by Sister Kathy Cairone

continued from page 21

and the cause of MS is likely multi-factorial. Regardless, MS is not a contagious disease. Could a virus-related vaccine be developed for MS? Possibly, but more research needs to be conducted. ◆

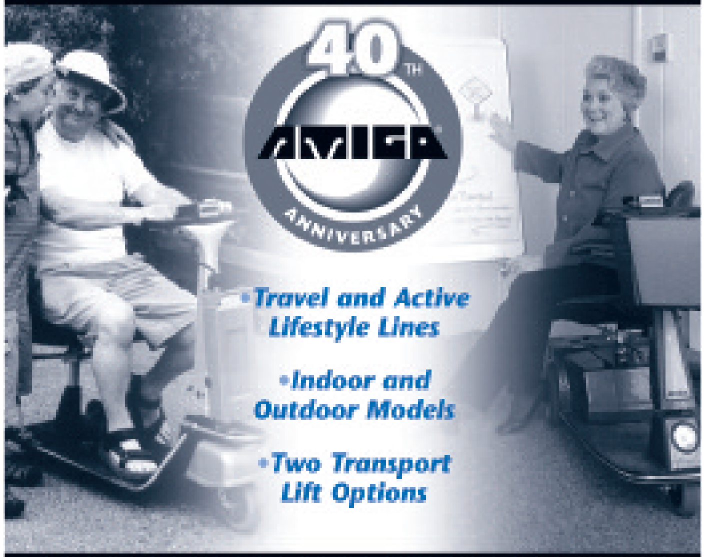
To Submit Questions to Ask the Doctor…

If you have a question that you would like to ask, please submit your question 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 **aborkowski@msassociation.org.** Please be sure to write "Ask the Doctor" in the subject line.

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.



Treatment Options for Spasticity

Written by Susan Wells Courtney

Reviewed and edited by: Jack Burks, MD; Donald A. Barone, DO; Annette M. Howard, MD; and Amy Perrin Ross, APN, MSN, CNRN, MSCN

Causes and Effects

With normal muscle function, opposite muscles work in opposite directions. This means that when one muscle pulls or contracts, the other relaxes. Spasticity is a condition which occurs when muscles opposite each other both contract or relax at the same time.

Spasticity is a common symptom of MS. Resulting from demyelination along the nerves that control muscle tone, spasticity causes a tightening of the muscles. With MS, spasticity most frequently affects the different muscles of the legs, buttocks, back, and arms.

For some, spasticity can be mild, causing no real discomfort or inconvenience. Mild spasticity even provides some benefits, such as improving circulation, helping to prevent blood clots, maintaining muscle tone, and decreasing leg weakness. Muscle stiffness can provide added support while an individual is standing, walking, or transferring from one spot to another.

Unfortunately, many individuals with MS experience moderate to severe spasticity. This can be a debilitating symptom, which can greatly limit movement, use up valuable energy, and become quite painful. Another form of spasticity occurs in episodes, often at night. These are unexpected, involuntary movements of the leg (or sometimes the arm) where the limb suddenly draws up into a clenched position, or kicks out into an extended position.

Spasticity, when combined with weakness, can lead to contractures as well. This is when the tendons are tight and the joint is difficult to move; it can even become locked in one position. In addition to pain and immobility, complications of contractures include an increased risk of pressure sores, pneumonia, urinary tract infections, and generalized debilitation.

When spasticity is successfully treated, tight muscles relax, restoring movement and reducing pain. While many treatment options are available for spasticity, physicians continue to look to new drug and therapy combinations for optimal treatment plans.

Therapies and Devices

Treatment begins by regularly seeking help for any other health conditions that may aggravate or intensify spasticity and its painful effects. Such conditions can include infections, as well as anything worn that doesn't fit properly, such as a brace, cast, or tight clothing.

The next lines of treatment are stretching exercises and physical therapy. Stretching exercises can be very effective in relieving symptoms of spasticity, and these are typically performed while sitting or lying down, allowing gravity to assist with the stretching. A physical therapist can create a customized exercise program for an individual to perform daily at his or her home.

Devices or mechanical aids are another type of treatment to relieve spasticity and reduce the risk of contractures. The physical therapist can design a custom brace, splint, toe or finger spreaders, or other device to hold an affected area in position. Contractures are sometimes treated through a series of casts which progressively stretch the tendons around a joint to promote greater movement.

Medications and Other Options

The most commonly prescribed drug for spasticity in MS is oral baclofen. This drug works well for a number of people, but dose must be carefully monitored. Too little of this drug can prove to be ineffective, while too much causes muscle weakness, fatigue, and confusion. Drowsiness and nausea are other side effects of this medication. Baclofen may not be abruptly discontinued as serious problems such as seizures may result.

Tizanidine (Zanaflex®) is another drug frequently prescribed for spasticity. Dose titration (building gradually to a full dose) is important to reduce sedation. The combination of baclofen and tizanidine is feasible if done cautiously to avoid side effects.

If baclofen or tizanidine is not successful or well tolerated, other types of drugs may be used to treat spasticity and spasms in MS. These include muscle relaxants, anti-epileptic medications, and certain sedatives. Many cause drowsiness, so some may be more appropriate at nighttime. These medications include: sodium dantrolene (Dantrium®); clonazepam (Klonopin®); diazepam (Valium®); gabapentin (Neurontin®); carbamazepine (Tegretol®); cyclobenzaprine HCl (Flexeril®); methocarbamol (Robaxin®); L-dopa (Sinemet®); and selegiline (Eldepryl®).

Another option for treating spasticity is botulinum toxin A (Botox®) injections. While initially used for treating small areas such as the face or eye, Botox has since been shown to be very useful for localized areas of spasticity in the limbs. Bladder spasticity is sometimes treated with Botox as well. Please note that Botox, as well as other treatments for spasticity, may have potential adverse side effects. Individuals are advised to consult a physician about any potential risks before starting a new treatment.

More severe procedures, such as blocking the nerve permanently (through injecting phenol into a muscle or by surgically cutting the nerve) can result in flaccidity, which is a significantly loose muscle. While these procedures reduce or eliminate spasticity, spasms, and pain, they do not increase mobility and also carry risks.

Intrathecal Baclofen Therapy

Often referred to as the baclofen pump, Intrathecal Baclofen Therapy (ITB™ Therapy) is a successful treatment option for many individuals with severe spasticity who are either not responding well to other therapies or having side effects. This therapy uses a surgically implanted pump and a thin flexible tube to automatically deliver small doses

Intrathecal Baclofen Therapy (baclofen pump). Photos provided by Medtronic, Inc.

of liquid baclofen into the spinal fluid. It has a powerful effect on spasticity, particularly reducing severe muscle tone.

One advantage to using this system is that it brings the medication directly to where it will be the most effective, into the spinal fluid that bathes the affected nerves. With oral baclofen, the medicine goes into the blood system, requiring larger doses and causing more side effects.

This is another benefit to ITB Therapy; a much smaller amount of medication is needed to produce results. The average dose is about 1/100th (one percent) of the oral dose. Additionally, most of the medication bypasses the blood system, so individuals do not normally experience side effects like muscle weakness, drowsiness, confusion, nausea, and vomiting, as some do with oral medications. Anyone allergic to baclofen or prone to infection is not a candidate for the baclofen pump.

The pump is implanted just under the skin of the abdomen, and the thin tube called a catheter is threaded back to the spine and into the spinal-cord fluid. The pump is computer programmed according to the individual's activities and symptoms, so various doses may be given throughout the day and/or night.

Individuals with MS who are suffering from severe spasticity will often experience a significant improvement after receiving a baclofen pump. While an individual will not gain back lost function resulting from demyelination, he or she will get back any ability that was prevented due to spasticity. Moving, walking, transferring, activities of daily living, sleeping, and personal care can all be dramatically improved if spasticity has been the problem.

ITB™ Therapy is available through Medtronic®, Inc. As with any surgical procedure, some risks are involved that need to be considered before making a decision. For more information, individuals are advised to consult their physician. Readers may also go to **www.spasticity.com**, or contact Medtronic by calling **(800) 328-0810**.

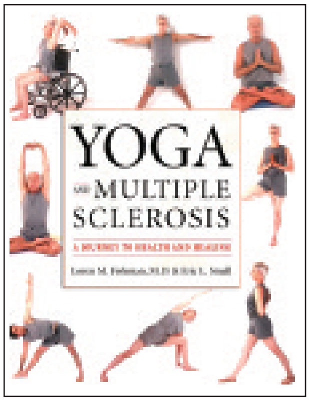
Please note that MSAA does not endorse or recommend any specific product, medication, or procedure. All details given are for informational purposes only; all decisions regarding changes in treatment should be made under the guidance of a qualified physician. For more information about spasticity, please visit **msassociation.org/programs/videos** for an online MSi video presentation on spasticity, given by Dr. Donald Barone. Readers may also speak with an MSAA Helpline consultant by calling **(800) 532-7667**. ◆

An earlier version of this article appeared in the Winter 2004 Issue of The Motivator.

Enjoying the Benefits of Yoga

Highlights from *Yoga and Multiple Sclerosis: A Journey to Health and Healing*

Written by Maryann B. Hunsberger



My introduction to yoga came at age 14 when a pen pal sent me the book, *Be Young with Yoga*, by Richard L. Hittleman. For twenty-one years, I practiced the Hatha yoga poses shown in the book every day. After becoming disabled, I began doing the poses in bed, as the floor was no longer accessible to me. With each exacerbation of my disability and the resultant weight gain, I did less yoga, so I became less flexible and eventually stopped exercising altogether.

The book, *Yoga and Multiple Sclerosis: A Journey to Health and Healing* (Demos Medical Publishing, 2007) by Loren M. Fishman, MD and Eric L. Small, couldn't have come across my desk at a better time. After a 126-pound weight loss, I had gingerly resumed exercising, but no longer had my book of yoga postures. I leafed through the pages of Fishman and Small's book, eager to attempt some basic poses.

Fishman and Small derived the yoga program described in the book from the teachings of B.K.S. Iyengar, one of the world's most renowned yoga instructors, who practices therapeutic Hatha yoga in Poona, India. Small has spent the past 40 years as an internationally recognized Iyengar yoga instructor. He has also had MS for more than 50 years. He has further developed Iyengar's work to create a yoga program for MS patients of varying mobility levels. Fishman, an assistant clinical professor in rehabilitation at Columbia University's College of Physicians and Surgeons in New York City, has incorporated yoga in his medical practice for more than 25 years. Both authors have studied with Iyengar in India.

Hatha yoga is one of several different types of yoga and is the most popular form practiced in the United States. Hatha yoga, through its many postures, strengthens and tones the muscles, enhances flexibility, and increases circulation. Many exercises taught by physical therapists are adaptations of Hatha yoga poses.

People with MS – whether they show no outward signs of illness or whether they use a wheelchair – need physical exercise. Yoga is especially beneficial, as it releases muscular tension, improves flexibility and circulation, helps with balance and fatigue, and boosts mental alertness. It reduces the effect of sensory changes by increasing functional abilities to a higher level.

Yoga is a gentle form of exercise, and the authors point out that yoga always gives more energy than it takes, making it ideal

Entry-Level Marichyasana

This is one of a series of positions aimed at reducing the effects of spasticity. The exercise may be performed while sitting either in a wheelchair or in any chair with arms.

During this exercise, the participant turns his or her upper body to the left, grasping the chair's arm and back for support, while breathing calmly and evenly. The same exercise is repeated to the right. Please refer to page 180 of *Yoga and Multiple Sclerosis* for specific instructions and safety recommendations.

for those whose energy is limited from MS. Since yoga involves sustained muscle stretches, it helps with the spasticity that sometimes accompanies MS by promoting muscle relaxation. Holding these postures requires isometric effort that increases strength. Because yoga encourages muscle groups to work together, it helps with impaired coordination and balance.

According to the authors, individuals with relapsing and progressive types of MS may benefit in seven ways from yoga:

1. **Reduction of fatigue**
2. **Improved range of motion**
3. **Reduced spasticity**
4. **Increased strength**
5. **Improved coordination**
6. **Improved balance**
7. **Increased confidence and calmness**

The authors divide *Yoga and Multiple Sclerosis* into two sections: an introduction to gentle yoga poses for people with significant MS involvement, and a functionally oriented segment showing different yoga postures that help specific MS symptoms. Only those who can complete the first part of the book should attempt the second part. Yoga exercise should never hurt, so individuals are advised to only stretch as far as they find comfortable and not exceed the time limits prescribed by the authors for each stretch.

Six series of poses encompass Part I of the book, with pictures showing how to do each pose. Each day's exercise session begins with the restorative series of poses that promote relaxation. These restful poses take place lying on the floor, but I found lying on the bed easier, with my headboard serving as a wall.

According to the authors, these restorative poses soothe the nervous system and oxygenate the liver, heart, and lungs. The poses, like most postures in the book, require props such as blankets, bolsters, straps, sandbags, blocks, yoga mats, eye bags, and armless chairs. The authors recommend household items – including bathrobe ties, phone books, bath mats, hand towels, and couch pillows – to use in place of standard yoga props.

Wheelchair users can attempt the wheelchair series of poses (with a doctor's approval). This group of light stretches is intended to strengthen back muscles, tone the legs and arms, lengthen the hamstrings, and increase range of motion. According to the authors, these poses can boost energy by bringing more oxygen into the body, enhancing blood circulation, and stimulating the nervous system. Wheelchair users might need assistance in setting up the props.

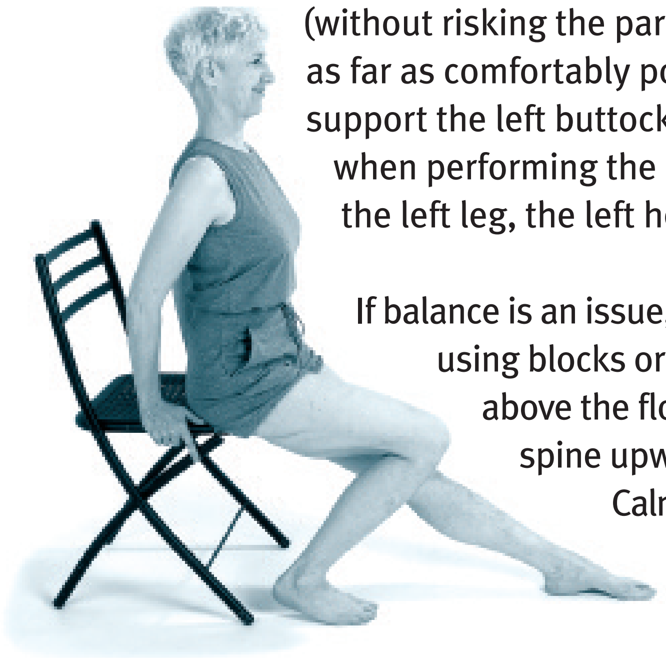
This is followed by a series of stationary chair poses, which are performed using an armless folding chair. These stretches improve posture and extend range of motion, while reducing tension in the shoulders and neck. The chair poses also aim to strengthen leg muscles and relieve leg cramps.

Seated poses, which are believed to stimulate elimination and digestion, while improving flexibility, come next. These poses require three folding chairs without arms. Individuals with MS may be able to gain enhanced flexibility in the hips and legs, experience less neck and shoulder tension, and notice reduced lower back discomfort, from doing these postures.

The seated/floor series of postures require the ability to get down to the floor, and in some instances, using a chair as a prop. The authors recommend this series for people who

Entry-Level Triang Mukhaikapada Paschimottanasana

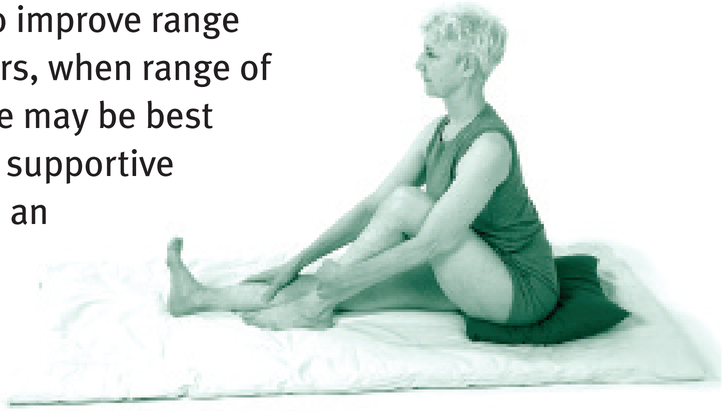
This position is among those designed to improve range of motion. The authors note that nearly everyone has difficulty sitting firmly on the bent-leg side of this pose.



The participant is instructed to move close to the edge of the chair (without risking the participant's safety), and extend the left leg as far as comfortably possible. A small cushion may be used to support the left buttock. (The cushion is switched to the other side when performing the exercise using the right leg.) While extending the left leg, the left heel needs to rest firmly on the floor.

If balance is an issue, the individual may sit further back on the seat, using blocks or pillows to support the straight leg – raising it above the floor. The participant needs to extend his or her spine upward, while grasping onto the chair for balance. Calm breathing, as well as relaxing certain muscles, is involved. Please refer to page 163 of *Yoga and Multiple Sclerosis* (illustration 1) for specific instructions and safety recommendations.

Intermediate Triang Mukhaikapada Paschimottanasana



This position is among those designed to improve range of motion. According to the book's authors, when range of motion is a significant issue, this exercise may be best done in bed. A firmer surface, along with supportive props, is recommended if balance is also an issue. This exercise involves straightening the spine, holding onto one's shins, or holding onto the mattress (if needed for balance). This position also involves leaning forward, while calming one's entire body, and calmly breathing. Please refer to page 164 of *Yoga and Multiple Sclerosis* (illustration 3) for specific instructions and safety recommendations.

can sit on the floor unassisted. I found most of these poses to be difficult to accomplish, as they require more strength, balance, and coordination than I have. However, strengthened quadriceps muscles, reduced hip-joint stiffness, and reduced spasticity can occur in those who can accomplish these poses.

The relaxation series is comprised of simple poses that are designed to help with the absorption of oxygen. These poses were easiest for me to do on the bed, rather than on the floor. Relaxing the body and quieting the mind is central to these postures, which also assist in reducing stress and tension.

Part II of the book is function directed, so the authors group the poses according to their health benefits. Each section contains three types of poses. Entry-level poses are best for wheelchair users and those in bed. Intermediate postures work best for people with some ambulatory and transferring abilities. Classical poses are suitable for people with the least MS involvement. However, the authors caution that even those individuals with mild disability should start with entry-level poses and work up to classical poses.

Before beginning any exercise program, including yoga, people with MS should consult their physician. If possible, a physical therapist can supervise an individual as he or she learns to do the stretches.

Therapeutic yoga's most important role is to limit disability, whether the individual has a relapsing-remitting or progressive form of MS. Therefore, patients, physical therapists, and other health professionals can use these poses to address specific MS symptoms, such as limited range of motion, spasticity, reduced strength, and poor coordination. Although yoga cannot cure MS, embarking on a yoga program can improve strength, coordination, and balance. Even those with significantly limited mobility, such as people who are in bed, can gently stretch to strengthen muscles and increase range of motion.

A 100-minute accompanying video, *Yoga with Eric Small: Adapted for People with Multiple Sclerosis and Other Disabilities*, is available in VHS or DVD form, through the National Multiple Sclerosis Society, Southern California Chapter at **(310) 479-4456**. The video is appropriate for individuals with all levels of ability and experience.

Practicing yoga may help many people to feel better physically, mentally, and emotionally. As mentioned earlier, before beginning any exercise program, individuals with MS should consult their physician. ◆

About the author of this article

Maryann B. Hunsberger is a New Jersey-based freelance writer/editor who specializes in disability issues. Since 1985, she has written for nonprofit and government organizations, newspapers, magazines, corporations, and internet sites.

About the book, *Yoga and Multiple Sclerosis*

The information, photos, and captions used in this article were excerpted with permission from *Yoga and Multiple Sclerosis: A Journey to Health and Healing*. To order online and to view other MS titles, please visit **www.demosmedpub.com** or call **(800) 532-8663**.

Other recent publications from Demos Medical Publishing which may be of interest include:

- *101 Accessible Vacations: Travel Ideas for Wheelers and Slow Walkers*
- *Living with Progressive Multiple Sclerosis: Overcoming the Challenges, 2nd Edition*
- *Multiple Sclerosis: The Questions You Have – The Answers You Need, 4th Edition*
- *Complementary and Alternative Medicine and Multiple Sclerosis, 2nd Edition*
- *Multiple Sclerosis: A Guide for the Newly Diagnosed*

Some of these publications, including *Yoga and Multiple Sclerosis: A Journey to Health and Healing*, may also be borrowed through MSAA's Lending Library. Please see page 48 for ordering information.

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
EMD Serono, Inc. and Pfizer Inc
Genentech Foundation
Novartis Pharmaceuticals Corporation
Teva Neuroscience

VISIONARIES ($50,000 to $99,999)
Medtronic Foundation

INNOVATORS ($25,000 to $49,999)
IBM

ADVOCATES ($10,000 to $24,999)
Acorda Therapeutics
Avanir Pharmaceuticals
The Chatlos Foundation
Genentech, Inc.
Grand Lodge Daughters of Scotia
The Horizon Foundation for New Jersey
The Wal-Mart Foundation

¿Habla Usted Español?

MSAA's Bilingual Helpline Offers Assistance for the Spanish-Speaking MS Community

Helping Spanish-speaking MS clients find access to health care, information, and community resources are just a few examples of the support offered through the **MSAA Bilingual Helpline**.

Helpline Consultant Richard Palacio reports that calls from Spanish-speaking MS clients and a growing network of social workers are steadily increasing as awareness of service expands throughout the United States and Puerto Rico.

MSAA is offering this service in an effort to assist individuals in the Spanish-speaking community receive information, referrals, and reassurance in the fight against this disease.

Individuals requiring assistance may contact MSAA's Helpline at (800) 532-7667, extension 108. This Helpline service is another way MSAA strives to enrich the quality of life for everyone affected by multiple sclerosis.

Call the Helpline for:
- MS Information
- Disability/Insurance Issues
- Reassurance and Support
- Connect to Other MS Resources

La comunidad hispano-hablante puede contactar la línea de ayuda (Helpline) de la MSAA marcando el (800) 532-7667, extensión 108.

This service has been made possible through the support of the Medtronic Foundation.

Stories to Inspire

The Power of Poetry

Written by Helen McManus

My name is Helen McManus. In April 2002, at the age of 51, I was diagnosed with relapsing-remitting multiple sclerosis (RRMS) after a long year filled with many misdiagnoses.

Shortly after the initial symptoms began, I visited my primary-care physician and a series of blood tests were done. Since many of my symptoms were insidious and coincided with the beginning of menopause, "change of life" was the first diagnosis given. But soon after, other symptoms came into play – including vertigo, headaches, numbness, joint pain, and the worst of all, fatigue.

I suspected something far worse. After doing some research online, I found my way to the Multiple Sclerosis Clinic at the University of Pennsylvania and was diagnosed with MS. Since developing MS after the age of 50 is fairly rare, I was certainly surprised. However, when I finally had a name to go with all the symptoms, being diagnosed with MS was a mixed blessing. Like many others in my situation, it was a relief to finally know what was happening and why... yet the aftermath was stressful.

I felt extremely apprehensive about a future so uncertain, but my husband Jim was my rock. He loved me unconditionally and helped so much with his constant support and encouragement. He did the tasks that I could no longer do, since maintaining my full-time job took every bit of energy. Jim made sure all of my prescriptions were filled and helped with housework. He scheduled and drove me to doctors' appointments, tests, and MRIs. He was there for me when I needed his support most and his constant assistance proved invaluable. Jim also worked at MSAA's national headquarters as a volunteer, donating his time so that others with MS would have the Lending Library books and the various types of equipment they requested.

Helen McManus and her late husband, Jim, at the Marine Corps Birthday Ball in November 2001.

Sadly, one day without warning, Jim passed away. He suffered a massive heart attack in September of 2004. It was over in a matter of minutes, the love of my life was gone and I felt so alone.

My daughters were and continue to be Godsends, and with my family's support, I was able to begin picking up the pieces of my shattered life. And what a long road it was! MS compounded every facet of the grieving process. The emotional stress of grieving took its toll on my body and my health suffered. I became unable to sleep through the night, and found myself hard pressed to function with only a few hours rest. I needed to find an outlet for my grief.

He was the man of my dreams, and when he passed away, part of me did as well.

I found a very unlikely yet interesting way to deal with my grief… through poetry. I had never written a poem before Jim's death, but somehow the words started to flow. I began to express myself through prose, which in turn became a source of comfort to others. Every emotion I felt was articulated, freeing my soul and spirit to try to live once more. I have been consoled by the thought that this is Jim's final gift to me, and one that I will treasure forever.

I began to join poetry websites and finally found one called, "Soul Asylum Poetry and Publishing." Its founder, Kenneth Cowle, enjoyed my work and agreed to publish my first book of poetry called, *Widowed Dreams*. This book is an account of my journey through grief, done in poetic format. It begins with the earliest stages and continues all the way to acceptance and healing.

In many ways, my book corresponds to everyone's journey with MS. Similarly, we lose our old way of life, but develop and find new ways to facilitate our healing as well as an acceptance of our diagnosis.

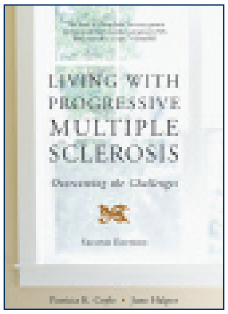
Although there is no way that someone can actually "get over" the loss of a loved one, with time, the heartache lessens. We learn to move forward, accept God's will, and try to live again. Since that time, the exacerbation of my MS symptoms has subsided. I still work full time and try to stay as healthy as possible through diet and exercise.

I asked the publisher to release my book in September, to commemorate the third anniversary of my husband's death – as a way to honor his memory. On September 30, 2007, I visited with Ken (the publisher) in Ontario, along with a few other poets, as part of a kick-off event for the release of my book. The publication is being marketed as a condolence gift for anyone who has suffered the loss of a loved one.

You just never know where circumstances in life will lead. Out of the pain from grief and loss can also come healing and acceptance, along with a brand-new way to move forward. God bless! ◆

Helen's book *Widowed Dreams* may be ordered through online bookstores or directly through the publisher at Soul Asylum's website: www.soulasylumpoetry.com, ISBN: 978-0-9781338-9-4. This book may also be borrowed through MSAA's Lending Library (please see page 48 for ordering information).

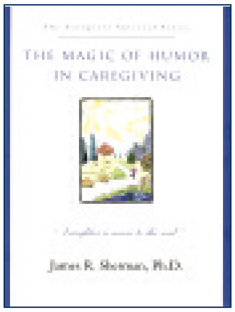
Spread the Word



Living with Progressive Multiple Sclerosis: Overcoming the Challenges, 2nd Edition

Written by
Patricia K. Coyle, MD and
June Halper, MSN, ANP, FAAN
Published by Demos Medical Publishing
MSAA Book #293

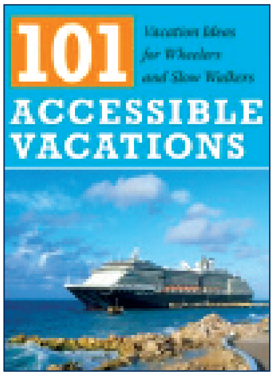
This recently published book focuses on the latest advances in managing worsening symptoms and provides encouragement to individuals with progressive forms of MS. Topics include diagnosis, disease-modifying therapies, managing difficult symptoms, coping strategies, as well as vocational and legal issues.



The Magic of Humor in Caregiving

Written by
James R. Sherman, PhD
Published by
Pathway Books
MSAA Book #196

Endorsed by numerous healthcare professionals and agencies, this writing is designed to be a self-help book aimed at assisting caregivers to feel good again. Among many topics, it looks at laughter as a healer, a stimulator, and a tranquilizer. The author discusses "applying the magic" through lightening up, smiling, finding humor everywhere, and several other strategies.



101 Accessible Vacations: Travel Ideas for Wheelers and Slow Walkers

Written by
Candy B. Harrington
Published by Demos
Medical Publishing
MSAA Book #294

This new travel guidebook offers information on more than 101 cities, lodging options, national parks, tourist attractions, and recreational activities around the country. The author specifically describes the degree of accessibility for each of the attractions and lodging options listed. She also organizes the destinations according to specific interests or travel styles, ranging from "Road Trips" and "The Great Outdoors" to "Historic Haunts."

MSAA Lending Library

If you would like to borrow any of the books featured in this column or any other book in MSAA's Lending Library, please send us your name and address. We will send you an application and a list of books for the Lending Library. MSAA and its clients greatly appreciate any donations made to help build the Lending Library. If you would like to donate a book to the Lending Library you need only send it to us at the address below. Please address all correspondence to:

MSAA Lending Library
706 Haddonfield Road
Cherry Hill, NJ 08002

(Please reference book number)