

# The *MSAA* **MOTIVATOR**

Published by the Multiple Sclerosis  
Association of America

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*The Motivator's* purpose is to inform and educate those with MS and their families. MSAA does not endorse or recommend any specific products, services, therapies, or activities mentioned in articles or advertisements that appear in *The Motivator*.

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**Integrative  
Medicine, p. 7**

**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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**U**pdates on the exciting progress of the **MS Coalition** have been referenced in this column before, but I am very pleased to report that we now have an operational

forum established that promises great things for people with MS. MSAA has been a leading advocate for this type of collective effort. The premise of the MS Coalition is that by working through a collaborative network of independent MS organizations, the opportunities to increase cooperation and leverage more effective use of resources can only benefit the overall MS community.

The founding members (MSAA, the MS Foundation, and the Consortium of MS Centers) organized a number of meetings over the past two years to find ways to bring the MS community together. Last year we received excellent support for this concept from the new leadership of the National MS Society. Working from a “one team with one dream” approach, we are discovering multiple ways we can work together while maintaining our individual identities. Collaborating on service outreach, advocacy issues, mutually funded quality-of-life projects, and general support to the MS community, can all lead to improved efficiencies and minimization of gaps in services across the country. We are all committed to this effort to avoid duplicating efforts and ensure maximum use of all of our

limited resources to help people with MS, wherever and whenever we can.

I am honored to have been elected the first president of this nascent organization and I encourage everyone in the MS world to help us help others by getting involved. The websites of the current members are all listed on [www.multiplesclerosiscoalition.org](http://www.multiplesclerosiscoalition.org). We have an opportunity here to do some great things in our collective efforts to improve the quality of life for everyone affected by MS.

I’m also pleased to announce that I’m leading a social marketing campaign encouraging people with MS who are not on any currently approved FDA drug therapy to consider the American Academy of Neurology recommendations to use these therapies to help improve their quality of life and diminish the frequency of exacerbations. We intend to produce public education materials and public service announcements to help address this issue and help more people make informed decisions.

Finally, I hope that everyone remembered that March is MS Awareness Month. MSAA had several events during the month, and many more are planned throughout the year to educate individuals about multiple sclerosis. This time of year also marks an important outreach by MSAA and other MS organizations in advocating for increased federal funding for MS research. Visit MSAA’s website at [www.msassociation.org](http://www.msassociation.org), or call MSAA’s Helpline at (800) 532-7667 for more information.

TOGETHER WE CAN MAKE GOOD THINGS HAPPEN! ♦

*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 and serves on the Executive Committee of Health First – America’s Charities Board in Washington, DC.*

## ***Meet MSAA Board Member Tom Vassallo***

Tom Vassallo discovered MSAA through his long-standing friendship with former Board chairperson and current Development chair Joe King. He and Joe worked together for the Boy Scouts of America “many” years ago and have been lifelong friends ever since. “In talking with Joe, I expressed to him that I wanted to volunteer in some capacity for MSAA, especially since I have a personal connection to multiple sclerosis,” said Tom. Tom joined MSAA’s Board of Directors in November 2005 and has been fully engaged ever since.



Currently, Tom serves on the Development Committee and chairs the Corporate Advisory Council where his advice from the business world is critical. “I try to help the Board take what MSAA does and bring that alive to the corporate world.”

In his role on the Corporate Advisory Council, Tom reaches out to corporations and business individuals sharing the mission statement as well as the programs and services MSAA offers. One of the programs Tom highlights is the toll-free Helpline. “The Helpline is such a great service. It is the ini-

tial contact that people have with MSAA and in some instances it is the first thing a person does when they are first diagnosed with MS.” Tom adds, “I give the Helpline number to anyone I speak with who has a connection to MS, and I tell them to call. The feedback I get is

amazing. People have such great interaction with MSAA – it makes me so proud to be a part of this organization.”

In the years ahead, Tom sees a bright future for MSAA. “MSAA’s biggest opportunity is for national growth in services and to reach more people in more places. With that being said, it is also important that MSAA is able to grow financially as well, so it can sustain these vital programs,” says Tom.

Personally, Tom is one of the founding partners of Axis Global Systems, a transportation, logistics, and fulfillment company. He resides in Mohegan Lake, New York with his wife and two children. When Tom is not busy managing Axis Global Systems, he enjoys golfing and traveling.

— Amanda Bednar

# Understanding INTEGRATIVE MEDICINE

*Some Physicians Combine  
Conventional Treatment  
Therapies with Complementary  
and Alternative Medicine  
to Provide Optimal Care*

*Written by Susan Wells Courtney*



## WEST MEETS EAST . . .

### **A Western-Trained Doctor Evaluates and Integrates Eastern Therapies and Other Forms of Complementary and Alternative Medicine into MS Treatment Plans**

Dr. Allen C. Bowling is medical director at the Rocky Mountain Multiple Sclerosis Center in Englewood, Colorado, where he focuses on the use of CAM therapies and the treatment of multiple sclerosis (MS). As a student, Dr. Bowling was intrigued by medicine and science. His interest led him to earn an MD in medicine and a PhD in pharmacology from the Yale University School of Medicine. He went on to attend the University of California in San Francisco where he completed his training in neurology, and this was followed by his



*Allen C. Bowling, MD, PhD*

fellowship training at Massachusetts General Hospital and Harvard Medical School.

Seeing a possible connection, Dr. Bowling conducted research in the areas of diet, antioxidants, and neurologic disease. He has spent several years researching complementary and alternative medicine (CAM) therapies and

how they may affect MS. He explains, “A good deal of gray area exists with the CAM therapies, however, some might be helpful, especially in treating neurologic conditions.”

Dr. Bowling continues, “The evidence supporting CAM therapies in the treatment of MS is limited. My driving force has been to get good information out to the patients, so they may make wise decisions when considering their treatment options. I am not trying to promote anything; I have no agenda beyond looking at the therapies available in order to provide a good and fair assessment.”

Given his extensive experience in the area of neurology and CAM therapies, Dr. Bowling speaks regularly and has given numerous educational programs on the topic to patients as well as medical professionals. He observes, “The patients want to know which CAM therapies are helpful, while the doctors want to know which CAM therapies are harmful.”

Dr. Bowling finds this dichotomy to be interesting, as it illustrates the two viewpoints that exist with these therapies. On the one hand, some CAM therapies show potential for treating individuals with MS, but on the other hand, these therapies are often lacking strong clinical evidence to support their effectiveness and safety. Clinical evidence refers to rigorous blinded studies conducted with people affected by the condition for which the therapy is being tested. Many times the evidence for CAM therapies is largely anecdotal (based on someone’s personal experience), which is the most controversial as well as the least reliable type of evidence.

### **The Search for Reliable Information**

Most of the printed information on CAM therapies and MS doesn’t offer much

benefit either. Dr. Bowling conducted a survey of 50 books which discuss the topic of MS and CAM therapies. He found that information in these books was frequently misleading, and in some instances, completely wrong – which could present a danger to individuals with MS looking to assess the potential value of a treatment.

“One common error found in these books,” Dr. Bowling notes, “is the assumption that since MS is an immune-system disease, treatments which activate the immune system would be of help. Since MS is actually a disease with an overly active immune system, increasing this activity could have a negative effect on an individual with MS, and may also have the potential to counteract the medications he or she is taking.”

To help medical professionals as well as the MS community acquire accurate information about CAM therapies and the treatment of MS, Dr. Bowling has authored two editions of his book, the first titled, *Alternative Medicine and Multiple Sclerosis*, and the second titled, *Complementary and Alternative Medicine and Multiple Sclerosis* (Demos Medical Publishing Inc., 2001 and 2007).

In his books, Dr. Bowling gives an overview of MS, providing many of the basic facts about the disease, to be sure that individuals reading about CAM therapies understand the MS disease process. He talks about who is most frequently diagnosed (young women), how MS causes injury to the nervous system (resulting from one’s own immune system attacking

the myelin and nerves), typical symptoms (such as problems with vision, weakness, fatigue, depression, etc.), and conventional therapies (including all of the FDA-approved disease-modifying medications for MS).

### The Placebo Effect and Psychoneuroimmunology

Dr. Bowling's book describes the placebo effect and psychoneuroimmunology. The placebo effect refers to a patient who experiences an improvement from a treatment with no medicinal value. Dr. Bowling points out that a placebo effect may frequently result in a 30-to-40 percent improvement, with some improvement rates as high as 70 percent, in studies of various medical conditions.

Positive results of 60-to-70 percent improvements in early studies of MS (before any FDA-approved drug was available) were caused by the placebo effect, and may be at least partially attributed to the extra time the treating physicians were able to spend with their patients. Today, with doctors spending shorter times with their patients (10-to-20 minutes or less per visit), this placebo effect may be declining in clinical practice.

This is not true of CAM practitioners, who typically spend longer periods of time with their patients. One session of a therapy such as acupuncture, homeopathy, or massage may continue for a full hour or longer. This allows for more interaction and discussion between the doctor and



patient, possibly increasing the success of the therapy through the placebo effect.

Studies of the placebo effect suggest that the mind can have a strong influence on a disease such as MS, affecting the behavior of the immune system. How can the mind affect the immune system? Researchers look to interactions between the nervous system and the immune system, a field of study known as “psychoneuroimmunology.”

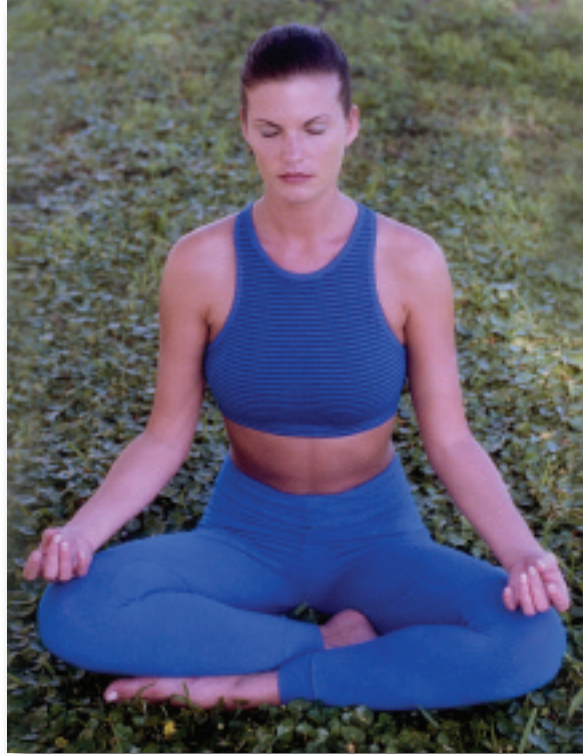
Communications between the nervous system and the immune system occur through different actions. First, the brain affects hormone production, which in turn may affect the immune system; second, nerve fibers have connections with immune organs; and third, chemical messengers are used by both systems and appear to communicate messages and alter each other's activities. This helps to explain

why psychological and emotional issues such as depression, stress, and anxiety can affect one's health and ability to function at his or her best. Conversely, individuals participating in spiritual or other uplifting activities may report improvements in their health and wellbeing.

### Important Precautions and Planning

Important precautions about CAM therapies and MS are also included in Dr. Bowling's books. He stresses that the information he provides is not a recommendation for using these types of therapies, and individuals need to do their own research and make their own decisions about treatment options. He advises that CAM therapies may be best considered when symptoms are mild or conventional therapies are not fully effective – but to only consider those therapies which are at least “possibly effective, probably safe, low-to-moderate cost, and do not require too much effort.”

Dr. Bowling advises individuals interested in using CAM therapies to make a plan, which would consider conventional medicine first; from there they should evaluate the reason to use CAM therapy, obtain accurate information about the therapy (including effectiveness, safety, cost, and effort involved); and finally, discuss this



plan with their doctor. MS patients considering CAM therapies need to use caution and understand that most information about this type of treatment is incomplete, lacking in strong clinical evidence. He also warns not to confuse scientific evidence (from studies using test tubes and/or animals) versus clinical evidence (from studies with people).

Consumers need to recognize “telltale signs” of a CAM therapy that is unreliable. These include a “heavy reliance on testimonies [personal accounts]... strong claims using terms such as ‘amazing’ and ‘miraculous...’ a single therapy claimed effective for many conditions... a therapy’s composition that is ‘secret...’ a therapy with little or no information available... one that involves inpatient treatment, injections, or intravenous medications... or unwillingness of a CAM practitioner to cooperate with a physician.”

For a detailed explanation of how to find and evaluate claims about CAM therapies, MSAA has a monograph available on the topic. Titled, *Thinking about Complementary and Alternative Medicine?*, this booklet was coauthored by Thomas M. Stewart (director of programs & services at the Rocky Mountain Multiple Sclerosis Center) and by Dr. Bowling. To request a copy, please contact MSAA at (800) 532-7667, extension 129.

A copy may also be viewed and downloaded at MSAA's new website address: [www.msassociation.org](http://www.msassociation.org). For more information about the monograph, please see the inside back cover of this issue of *The Motivator*.

In his two book editions, Dr. Bowling provides valuable information on 40 types of CAM therapies – including such topics as acupuncture, chiropractic medicine, diet, exercise, herbs, massage, prayer, and t'ai chi – to name a few. A chapter is dedicated to each of these 40 types of therapies, which includes: a brief history and description of the therapy; the method for treatment; studies with the therapy in MS and other conditions; side effects (with warnings of potential negative effects); practical information (providing specifics about practitioners, costs, and insurance); a conclusion that summarizes the overall assessment of the therapy; and additional readings for recommended books on the topic.

### **The Five-Step Integrated Approach**

Having provided a detailed evaluation of these 40 CAM therapies, Dr. Bowling continues by explaining how he works to integrate certain CAM therapy options with conventional treatments. In the second edition of his book, Dr. Bowling devotes a chapter to talking about the five-step integrated approach that is now being used at the Rocky Mountain MS Center for their clients.

“This approach is the best of both worlds,” states Dr. Bowling, “because it integrates conventional and unconventional types of treatments, using the best-available

evidence to determine benefits. It also allows for each plan to be individualized for the patient's particular personality, orientation, and needs, while treating both the underlying disease process as well as specific MS-related symptoms.

“Step one is to encourage patients to consider using one of the FDA-approved disease-modifying medications for MS. Step two provides a dietary approach, which includes avoiding saturated fats while increasing polyunsaturated fats. Studies suggest that this may have a mild disease-modifying effect in MS.

“Step three is a wellness approach and this is the most individualized of the steps. This considers the mind-body connection, the placebo effect, and who the person is in terms of personality and what they do spiritually. This approach offers hope-generating strategies and encourages personalization, empowerment, and optimism. Some may turn to religion and prayer, while others may turn to exercise for personal fulfillment. Unconventional exercise such as t'ai chi and yoga combine exercise with spirituality. Relaxation methods such as meditation and guided imagery, as well as psychotherapy for individuals with psychological issues, are also a part of this important step.

“Step four promotes exercise. Clinical evidence shows that exercise helps improve some of the symptoms of MS. These include physical benefits such as increasing strength and walking ability, while decreasing fatigue; and emotional benefits such as decreasing depression, anxiety, and anger. Exercise may be conventional, which may



A Sampling of

# POPULAR CAM THERAPIES FOR MS

This listing provides a few of the popular complementary and alternative medicine (CAM) therapies that have been used by some individuals for the treatment of MS symptoms. This list does not include all CAM therapies that might be considered; it is only a sampling of some of the more popular therapies, all of which are deemed to be **(1) possibly effective, (2) probably safe, and (3) low-to-moderate cost**, while **(4) not requiring too much effort**.

Individuals considering CAM therapy are strongly advised to consult their medical professional in advance, to be sure that the therapy selected does not pose any health risks or potential interactions with their medications. Consumers need to know that clinical studies of CAM therapies are extremely limited, particularly studies with MS patients. For this reason, the effectiveness of CAM therapies in the treatment of MS is not fully known. Additional research is needed before all of the benefits and risks associated with the different types of CAM therapies may be identified and evaluated.

Information for this section was taken from Dr. Bowling's books, *Complementary and Alternative Medicine and Multiple Sclerosis* and *Alternative Medicine and Multiple Sclerosis* (Demos Medical Publishing, 2007, 2001).



**Description:** Involves insertion of thin metallic needles into specific points of the body to alter the flow of energy along energy pathways

**Notes:** Generally well tolerated, provided the acupuncturist is well trained; if poorly trained or negligent, serious complications could occur; may produce drowsiness

**Possible effects:** May help with anxiety, depression, dizziness, pain, bladder difficulties, and weakness



**Description:** Uses aromatic substances derived from plants; administered by direct application to the skin, mixing with bath water, or inhalation

**Notes:** Usually well tolerated but not risk-free; some oils may produce a skin rash; approximately five percent of people are allergic to fragrances

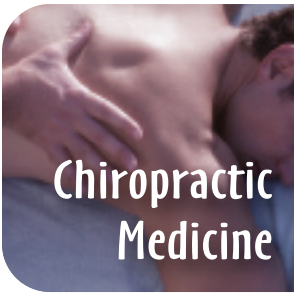
**Possible effects:** Aromatherapy may help anxiety and depression; one large study found it not effective for pain



**Description:** Equipment translates body activity into images (viewed on computer) or sounds, noting muscle tension, skin temperature, perspiration, respiration, pulse, or brainwaves

**Notes:** If electrodermal, people with heart conditions or pacemakers should consult physician; may help several MS symptoms; not known if able to regulate immune system

**Possible effects:** May help with anxiety, insomnia, headaches, pain, incontinence, stiffness, circulation, blood pressure, substance abuse, and posttraumatic stress



## Chiropractic Medicine

**Description:** Misalignment of the spine believed to put pressure on nerves, affecting muscles and organs; chiropractors manipulate bones of spine

**Notes:** Achy muscles common; stroke or bone fractures very rare; people with spinal problems or diabetes, on blood-thinner, or pregnant, should consult physician

**Possible effects:** No strong evidence shows benefit for MS attacks or altering disease; may help low-back pain, and possibly neck pain and headaches

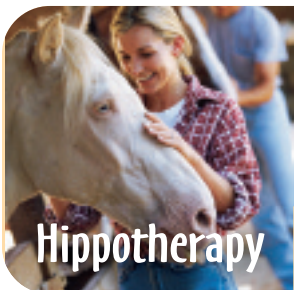


## Cooling Therapy

**Description:** Cool showers or baths, air conditioning, ice pack, or cold drinks; or special clothing for gradual body cooling

**Notes:** Slightly lowering body temperature may temporarily lessen some MS symptoms; well tolerated, except for few whose MS symptoms may temporarily worsen

**Possible effects:** May temporarily improve difficulties with weakness, fatigue, spasticity, walking, bladder, speech, vision, sexual function, coordination, and cognition



## Hippotherapy

**Description:** Therapeutic horseback riding; done in conjunction with physical therapy; therapist controls horse while rider sits, responding to horse's movements

**Notes:** Individuals with severe muscle stiffness, severe fatigue, bone problems, or other serious conditions should consult physician

**Possible effects:** May help with walking difficulties, spasticity, weakness, bladder and bowel problems, as well as depression



## Massage

**Description:** Uses special table in warm, quiet room; soft lighting and relaxing music; techniques include pressing, stroking, rubbing, and tapping

**Notes:** Usually well tolerated, minor effects include headache, muscle pain, and lethargy; rare serious effects include blood in liver from deep-abdominal massage

**Possible effects:** May reduce muscle stiffness and pain, increase self-esteem, improve social functioning, and reduce anxiety and depression

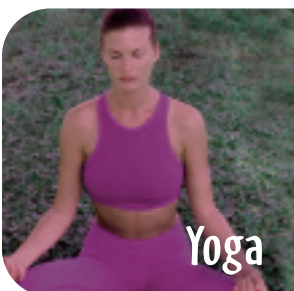


## T'ai Chi

**Description:** Uses slow, rhythmic, body movements and breathing techniques; claimed to balance opposite forces "yin and yang;" and strengthen life force "chi"

**Notes:** Gentle exercise requiring little strength or flexibility; could worsen MS fatigue; walking unsteadiness and/or a sensitivity to overheating may require modifications

**Possible effects:** May increase walking ability; decrease stiffness; improve social and emotional functioning, strength, fatigue, depression, and anxiety



## Yoga

**Description:** Believed to unite the mind, body, and spirit; uses breathing, movement, and posture; may be practiced regardless of physical ability

**Notes:** Consult physician if health conditions limit physical activity; if meditating, individuals with psychiatric disorders should consult doctor

**Possible effects:** Improvements in anxiety, pain, muscle stiffness, depression, cognition, breathing, walking, strength, and wellbeing have been reported



include working with a physical therapist or participating in hydrotherapy (water exercise); or unconventional, such as t'ai chi and yoga.

“Step five is huge. It is also the most complex. This is an integrative approach to symptom management. Treatment of MS symptoms is usually focused on using either conventional therapies or a particular CAM approach to treat the specific symptom. This integrative approach considers all reasonable conventional and unconventional treatments. This approach should be discussed with one’s healthcare provider, particularly when the two types of treatments are used in combination with one another.

“An interesting example is treating MS fatigue. Many conventional and unconventional therapies claim to be helpful. As part of this step, we go through all of the options. On some days, when fatigue is severe, it may make sense to use medica-

tion. A preventative measure is to exercise (as approved by one’s doctor), which has been shown to reduce fatigue. Caffeine in moderation is another reasonable option, as is cooling for individuals who are heat sensitive. Other potential treatments for fatigue may include certain dietary supplements, and uncommon exercise programs such as t'ai chi, and yoga.”

Dr. Bowling lists several other MS symptoms in this chapter, along with several potential conventional and unconventional therapies for each. Many CAM therapies are possi-

sibly effective for several symptoms. For instance, according to this listing, acupuncture may be useful in helping anxiety and stress, bladder problems, depression, pain, sleep problems, and weakness.

### For More Information

Both editions of Dr. Bowling’s books include a summary of the effects of popular supplements, along with several groups of resources, listed under the various types of CAM therapies. Both editions are available for free loan through MSAA’s Lending Library program (please see page 64 for more information). Copies may also be purchased through retail book stores or websites, including Demos Medical Publishing, which may be found at [www.demosmedpub.com](http://www.demosmedpub.com). [Please note that MSAA does not profit in any way from the sales of these books, and does not recommend or endorse any particular product or service.]

Readers may also go to the Rocky Mountain MS Center's website for more information and updates on CAM therapies and MS. This may be found by visiting [www.ms-cam.org](http://www.ms-cam.org). The Rocky Mountain MS Center offers a program to assist individuals with developing their own approach to integrative medicine. Individual 45-minute educational consultations with a trained staff member are available for a fee. For more information, please call (303) 788-4030, extension 103.

### A Look to the Future

In the coming years, Dr. Bowling foresees an increase in research of popular integrative approaches for treating neurological conditions such as MS. Among others, one area

that warrants further research is the study of antioxidants and how they may relate to neurological conditions. (In addition to supplements, antioxidants may be derived from many natural food items, including fruits, vegetables, and green tea.) Antioxidants are thought to act on "free radicals," which are chemicals that can damage cells in the brain and other organs of the body.

According to Bowling, "Antioxidants could play an important role in the treatment of MS and other neurological conditions. Quite a bit of evidence supports a relationship between antioxidants and MS, as well as amyotrophic lateral sclerosis (ALS) and some of the illnesses related to aging, such as Alzheimer's disease and Parkinson's disease.

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“Free radicals might also play a role, especially if the condition is more of a degenerative nature. MS has a degenerative component, but in many cases inflammation is involved.”

Dr. Bowling strongly warns that some antioxidants may activate the immune sys-

tem, which could worsen one’s MS. “More research is needed to see how antioxidants affect MS, and if they may be helpful or harmful to the disease process. This is an active area of research, with a devoted research effort going on now with MS. We should know more in the coming years.”

## EAST MEETS WEST . . .

### An Eastern-Trained Doctor Integrates Western Medicine with the Practice of Eastern Therapies in Treating MS

Dr. Jingduan Yang is the medical director at the Tao Institute of Mind & Body Medicine in Mt. Laurel, New Jersey. He is also a physician at the Jefferson-Myrna Brind Center of Integrative Medicine, which is a division of the Thomas Jefferson University Hospital in Philadelphia, Pennsylvania. Before completing a psychiatry residency at Thomas Jefferson University, Dr. Yang was a neurologist at the Fourth Military Medical University in China. He was also a research fellow in clinical psychopharmacology at Oxford University in England.

Dr. Yang specializes in neurology, integrative psychiatry, and Classic Chinese Medicine. In addition to writing numerous peer-reviewed articles on the topic of integrative medicine, he has been a speaker at many national and international confer-



*Jingduan Yang, MD*

ences as well as academic meetings. At his practices in Pennsylvania and New Jersey, Dr. Yang integrates Chinese herbal medicine, acupuncture, neuro-emotional techniques, and psychotherapy in the care of his patients, while supporting their use of disease-modifying and symptom-management medications.

When asked about his motivation to become a physician, Dr. Yang responds, “I was born to a family that has a tradition of practicing Classic Chinese Medicine for generations. As a child, I observed my father treating patients with neurological conditions and mental illness using acupuncture and herbal medicine. In medical school, I was fascinated by the complexity of the mind, brain, and body interactions and interconnections. These were well emphasized and described in the

Classic Chinese medical textbooks. I have found that my training in neurology, psychiatry, and Classic Chinese Medicine have served my patients very well for their conditions, which almost always require integrative approaches to address health and wellbeing in body, mind, and spirit.”

### The Teachings of Classic Chinese Medicine and Energy Channels

Dr. Yang explains that Classic Chinese Medicine addresses health on an “energetic level,” versus on a “biochemical or physical level.” These latter two levels are the modes for treatment with Western medicine and may be measured through laboratory testing and equipment. For example, identifying health problems on the biochemical or physical levels may be done through blood tests, ultra-sound, and MRI, because the conditions have reached a level where they have measurable changes in the body.

Dr. Yang continues, “Classic Chinese Medicine teaches that health issues do not happen overnight, but rather begin at very deep levels, affecting a patient on an energetic level,” Dr. Yang notes. “This ancient medicine describes the human body as hav-

ing energy channels – also known as meridians – and these channels are connected with specific organs in the body, which serve as energetic centers. For instance, the body has a liver meridian, a gall bladder meridian, and so on. Problems at an energetic level begin with changes that have not yet manifested on a biochemical or phys-

ical level, so they are not measurable by modern equipment or laboratory tests. There are also many different energy levels, in which energy named ‘chi,’ a form of life force, flows.”

Dr. Yang points out that learning about the body’s “energetic level” can be confusing for anyone who is not familiar with the concept, and practitioners of Classic Chinese Medicine

need years of study to understand how the body works on this level. Learning how to evaluate a patient’s energy stages is equally complex, and to a certain extent, is an art. This type of medicine is based on the body as a “whole;” meaning that on an energy level, the mind and body work in unison and cannot be separated.

A doctor who practices Classic Chinese Medicine must know what questions to ask to determine which energy channels are affected. “For instance,” Dr. Yang contin-





ues, “when someone is having headaches, the doctor must find out which part of the head is hurting. Different locations of pain are connected with different energy levels and different energy centers.

“If the pain is temporal, possibly a migraine headache, I look at the gall bladder and liver channels, as there must be other manifestations. So I will ask questions that relate to these channels. I ask if the patient is experiencing depression (an emotional symptom) or having trouble making decisions (a mental symptom). I will also ask if the patient is having physical symptoms such as those of fibromyalgia, chronic fatigue syndrome (CFS), irritable bowel syndrome (IBS), gastroesophageal reflux disease (or GERD), and if he or she is having any dizziness or vertigo. These additional symptoms denote problems

along the energy channels relating to the liver and gall bladder. By asking such questions, I am able to identify the area and nature of the problem.

“Another example is someone with MS who is experiencing problems with bladder control. When I see a patient with this symptom, I ask about his or her memory and ability to concentrate. I also ask if he or she has ringing in the ears, hearing loss, sleep problems, lower back pain, knee pain, or sexual dysfunction. The answers will help me to identify if energy problems are occurring within the kidney and bladder meridians.”

### **The Teachings of Classic Chinese Medicine and Diagnostic Techniques**

During an evaluation, two types of diagnostic techniques are used, and these are unique to Classic Chinese Medicine. The first technique looks at the patient’s tongue. The physical appearance (including the color, shape, thickness, puffiness, and coating) provides details about a patient’s health. By looking at these different features, the doctor can determine the status of blood circulation and energy, digestion and metabolism, and whether someone is sick.

The tongue also carries a message of the whole body. Portions of the tongue refer to different organs. For example, the front-third of the tongue relates to the lung and heart; the middle-third relates to the stomach and spleen; the back-third relates to the bladder and kidneys; and the sides relate to the liver and gall bladder.

The second type of diagnostic technique is performed by reading the patient's pulse. "With Classic Chinese Medicine," explains Dr. Yang, "six pulses are found on each side of the body. The doctor uses three fingers to read these pulses. On each side, the doctor feels three 'superficial' pulses, and detects each one with a different finger. Then by pressing harder and releasing slightly, the doctor can feel three deep pulses. This procedure is performed on both the left and right sides of the body.

"These pulses relate to different organs and energy levels, revealing how well each is functioning. Reading these pulses is not just a case of counting the beats and this technique requires many years of practice. The doctor not only feels how fast and strong each pulse is beating, but also the rhythm, the shape (if 'wide' or 'thin'), and even the tension of the pulse – which may be like the tight strings of an instrument or the loose layers of an onion."

### Integrating Western Medicine with Classic Chinese Medicine

While Dr. Yang practices both acupuncture and Chinese herbal medicine, he also supports the use of disease-modifying and symptom-management medications for individuals with MS and other neurologic conditions. He states, "Many neurological conditions, including MS, have manifested beyond the energetic level to the physical and biochemical levels, where modern medicine can be very helpful.

"Acupuncture and Chinese herbal medicine

are both treatment modalities in Classic Chinese Medicine, a medical system that deals with the human being at an energetic level, in contrast to physical and biochemical levels of modern medicine. Therefore, it complements modern medical treatment very well. MS is one of those conditions that require integrative intervention from both Western and Eastern approaches, addressing physical, social, emotional, and spiritual wellbeing. Acupuncture and



Classic Chinese herbal remedies are major components of the Eastern healing arts." [Western medicine is also commonly referred to in the United States as "traditional," "conventional," or "modern" medicine.]

### Chinese Herbal Medicine

"Chinese herbal medicine uses energetic agents rather than chemical agents; it goes into energetic channels after it is absorbed,"



explains Dr. Yang. “Chinese herbal remedies are medicine rather than food; it should be used based on an evaluation of the energy status of an individual. Frequent re-evaluations should be conducted as the status can change after treatments.

Following each evaluation, the herbal remedies are strategically formulated with individual herbs that fall into one of four categories: treating major problems (disease process), treating accompanying issues (symptoms), minimizing possible side effects, and directing the herbal energy to the targeted parts of the body. So when it is used properly and is based on a good evaluation, it rarely has side effects or interferes with a patient’s medications.”

Dr. Yang notes that herbal formulas are customized for each individual. “They work through a synergy of all the ingredients, each one harmonizing with another. In some instances, a single chemical element may be harmful, but when mixed with numerous others, it becomes detoxified. If used properly, these can be very

safe, but finding the right doctor can be challenging. There is no clear-cut certification for a doctor prescribing herbal formulas.” The success of this type of treatment is dependent on an accurate evaluation of the patient and the combination of ingredients that have been customized for that individual.

Herbal formulas may be taken as pills (that have been prepared in advance according to common energetic patterns), from a concentrated powder made into a soup or tea (which is more potent and individualized, but requires motivation since these herbs have an unpleasant smell and taste), or by cooking with the raw herbs. This latter method is mostly done in China and can give off a strong smell throughout the house.

[Editor’s note: While Eastern medicine relies heavily on the practice of Chinese herbal medicine, Western medicine has yet to thoroughly evaluate its practice in the treatment of MS through rigorous clinical studies. Herbal formulas are very complex and include numerous substances. As with any change to one’s treatment plan or routine, readers are advised to discuss any new medications or therapies with their family doctor or neurologist in advance.]

### Acupuncture, A Tool in Classic Chinese Medicine

Dr. Yang continues, “Acupuncture is also an energetic intervention based on the Classic Chinese medical evaluation of energy status. It taps into very complicated energetic centers and their networks,



producing a powerful modulation that rebalances the energy status responsible for our health and wellbeing.

“Acupuncture is a tool in Classic Chinese Medicine, and the acupuncture I practice is based on all of the theoretic frameworks that are the foundation of the Classic Chinese medical system, including the theories of yin/yang and many others. The selection of the acupuncture points along with the combination of these points is an art of healing. Additionally, the refined technique of manipulating needles is crucial to delivering the desirable results.” Once again, the success depends upon the knowledge and ability of the physician selected.

“In MS patients, case reports and clinical studies show that many areas can be improved through acupuncture and Chinese herbal medicine. These improvements may include: increased motor and sensory function; reduced numbness, tingling and pain; improved bladder control and sexual function; reduced anxiety and depression; increased energy; and better sleep. Overall, such therapies can help improve the quality of life for individuals with MS.”

### **The Future of Integrative Medicine**

“In China, many medical professionals now take advantage of both Western and Classic Chinese Medicine,” Dr. Yang explains. “At times, the treatments in China are much more integrated. For instance, every hospital has a section devoted to traditional Chinese Medicine, while other

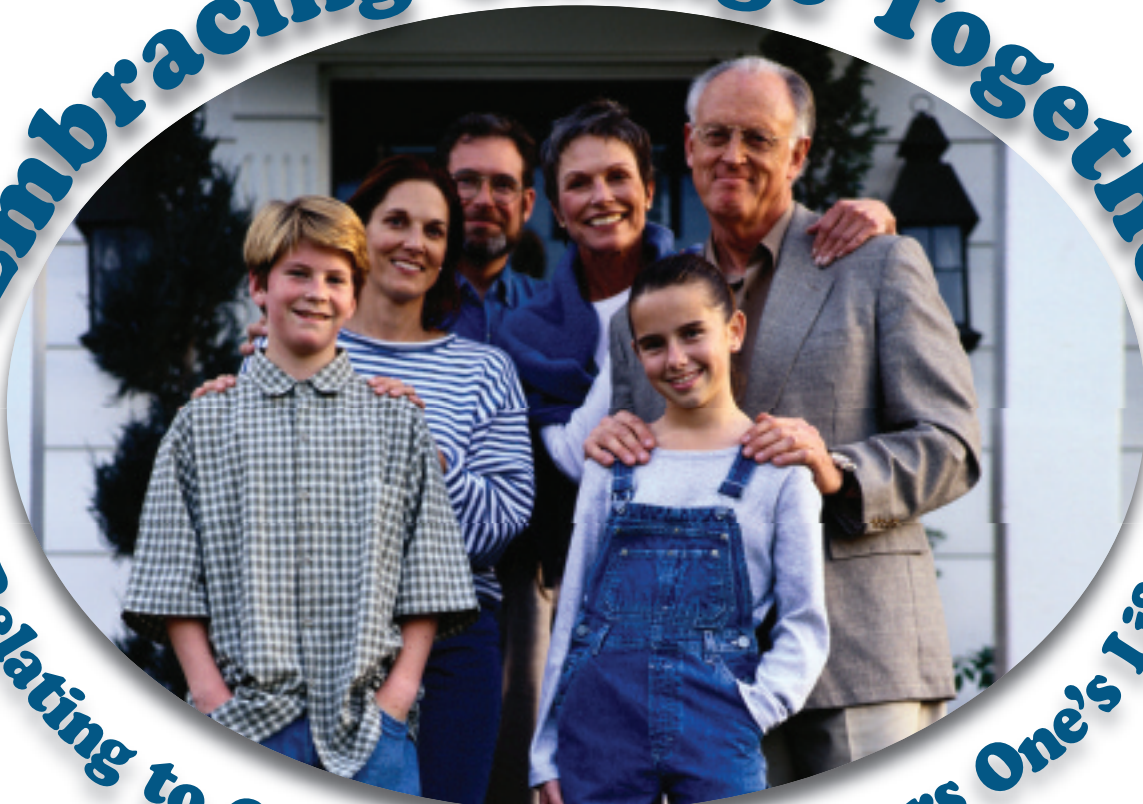


sections offer modern medicine and technology. A patient receiving an IV infusion of antibiotics or steroids may also receive herbal extractions via IV along with these medications.”

Dr. Yang notes that doctors who practice Western medicine now recognize how things like lifestyle and stress can affect one’s health, and how other parts of the body can affect one another. These doctors may now view the mind-body connection as being more valid, and recent studies are starting to look at spiritual types of influences, such as yoga and prayer. As Western medicine continues to evolve, it becomes closer to Eastern medicine, while Eastern doctors become more supportive of Western medicine. Perhaps the day may come when the two schools of thought become one. ♦



# Embracing Change Together



## Relating to Others When MS Enters One's Life



### Written by Christine Norris

**N**o one understands the uncertainty of change more than a person with multiple sclerosis. The course of the disease is often unpredictable, which makes things difficult when thinking about the future. As an individual's self-image changes according to the symptoms that appear, relationships with family, friends, and coworkers also change. With the proper help and guidance from professionals and the fortitude to work through the process of redefining a person's identity, one can enjoy a new lease on life and have hope for the future.

"No one asks to have MS. Yet, in some

*"Don't defy the diagnosis,  
try to defy the verdict."*

– Norman Cousins

ways, because of MS, individuals have to deal with their mortality earlier, and the meaning of life earlier than they might have," says Peggy Walsh, MS, a psychotherapist in private practice in Bala Cynwyd, Pennsylvania. Walsh counsels many newly diagnosed patients referred to her from the University of Pennsylvania MS Center in Philadelphia. "This often means that they have relationships that matter earlier than others. It's almost like a mid-life crisis.

They don't want to waste time. They want to find supportive people who appreciate them for who they are now, not who they used to be."

This self-discovery, however, takes time to achieve. "When I initially see patients who are newly diagnosed, they're usually in some denial. I think that denial is part of the diagnosis. It's both a gift and a curse," Walsh says. "What I mean is that denying some of the possibilities of the disease can actually give them some hope. They don't know what path their life is going to take. The negative part is that if they continue to deny the diagnosis, they don't plan ahead to handle [symptoms such as] the fatigue factor, and they don't get the medications they need to control their condition."

Walsh equates this stage to one of the five stages of grieving developed by Elisabeth Kubler-Ross, a world-renowned psychiatrist, expert on death, and author of *On Death and Dying*. "These stages are also experienced by MS patients and other chronically ill people," says Walsh. The five stages are: **1. Denial and isolation**, a state of shock where the person can't believe it is happening to him or her; **2. Anger**, where the person is mad at the world; **3. Bargaining**, where the person hopes to postpone the inevitable; **4. Depression**, where the person experiences a profound sense of loss, status, and esteem; and **5. Acceptance**, a state in which the person quietly recognizes the inevitable.

"It's also important for people who are newly diagnosed to realize that their



partners are going through the same stages and also may be in a state of denial," says Walsh. "The people close to them don't want to accept that maybe some things are going to change in their relationship. They may be angry with the disease and fearful of the future."

This dynamic can be problematic if it's not discussed, says Kathleen Leahy, MSW, a Licensed Independent Clinical Social Worker (LICSW) in the state of Massachusetts. A social worker for more than three decades, she has held the position of social worker at The Mount Auburn Hospital MS Comprehensive Care Center in Cambridge, Massachusetts, for the past decade. "I have found that everybody is in a crisis mode in the beginning; but usually, the patients are more actively trying to get some answers, while their families are often still in denial," she says. "This can become a serious issue in their relationship." According to Leahy, this denial experienced by family members often comes from the less "visible" symptoms of the disease, such

*“When it is dark enough,  
you can see the stars.”*

– Charles A. Beard

as fatigue. “Even though patients may not have trouble walking or other highly visible symptoms, they may be fatigued. Their spouses, therefore, may not perceive that the disease is impacting them in a major way,” she explains. “On one hand, patients don’t want anyone to view them differently; on the other hand, they want their spouses and other family members to have some empathy for what they’re going through.”

## **Getting the Support One Needs**

Generally, most people with MS need to get through these stages before they are ready to reach out to others. Many men and women with MS find that joining a support group can help them cope with the uncertainties of the disease. The idea behind a support group is a basic one – give people who share a common interest, trait, or problem, a place to meet and to discuss relevant issues and experiences. MS support groups give members the opportunity to learn more about the disease, to exchange feelings and ideas, to make new friends, and to get out of the house and socialize. “Because these are young people I usually see, MS support groups can initially be depressing and overwhelming, because some of the people are often sharing how sick they are,” says Walsh. “I tell my

patients to keep trying to find a support group with people who are going through similar experiences to their own. I advise them not to give up. There’s something energizing, valuable, and supportive about being with other people who have the same illness.”

Leahy also sees the value in sharing feelings and experiences with others through support networks, but she says that these networks don’t always have to be the classic “support groups,” especially for the newly diagnosed. “Often individuals who are newly diagnosed don’t want to attend a support group with MS patients who are severely disabled. This is because they’re afraid of seeing something scary that may be in their future,” she explains.

Instead, Leahy recommends that these patients get the support they need in other “less threatening” ways, such as attending a lecture on MS at a local hospital or other venue. “These lectures always have a social aspect to them, and offer an informal way to meet others with the disease,” she says.

“At our center, we also have MS patients who volunteer to sit in our waiting area to talk to families and patients while they’re waiting to see different members of our staff,” says Leahy. “This can be a really positive experience for the newly diagnosed, to meet someone who has lived with MS for awhile, and who has lived well with the disease.”

Leahy has found over the years that “most MS patients and their families cope better than they think they will. An MS diagnosis doesn’t happen in a vacuum,”

she says. "Patients and their families bring what they have been going through in their lives to it. That's why I try to encourage families to draw upon what has worked in the past to deal with new challenges or situations. Sometimes just sitting down and working things out together gives them the strength to cope. They build on these past inner resources."

Another hurdle families must face is the decision of keep-

ing the MS a secret. While Leahy understands why some patients may want to keep their diagnosis from co-workers or neighbors initially, she usually encourages them to share the news with others as soon as they're ready. "Keeping the MS secret adds

stress to your life, but it's a process that people must go through on their own terms. I try to help them by discussing their concerns and what makes sense to them," she says. "What I have found is that when patients are ready to share their MS diagnosis, it can help with their feelings of helplessness and uncertainty. People often will find that they get more support, even though they long feared that others would treat them differently. Most people are willing to help out and are very understanding."



Keeping MS a secret from one's children can especially be isolating not only to the parent with the disease, but also to his or her child, who senses that something is different at home. This can be frightening for a child. "It's important to remember that parents are the very first and most vital teachers in the lives of their growing children. Parents teach their children from the very beginning that life is indeed a journey,

marked with change and transition," says Cindy Richman, MSAA senior director of services. "By helping children understand multiple sclerosis, parents can help to reduce any fear or anxiety while showing them the importance of loving and caring for one another."

Walsh agrees: "Most children are pretty good about accepting changes in their parents. The more direct that a parent can be about the disease, what it is as well as what it can and cannot do, the better. Because kids have a lot of curiosity, they'll take in the information and move on."

Leahy stresses that understanding the developmental stages all children go through, especially those stages during the adolescent and teen years, is crucial. "These years are never easy. Sometimes a patient

will complain to me about her teenage daughter's room being a mess and the fact that she doesn't help out around the house. She perceives this as her daughter either reacting to her MS or being insensitive to her needs. I try to help the mother understand that it may not be for that reason; it may be because it's a stage her daughter is going through."

MSAA's Richman agrees. "A teenager might be more horrified over the kind of car the parent drives or the fact that the parent might say 'the wrong thing' in front of a peer, or worse, show affection in front of his or her peer group," she says. "It's important for the MS patient to note that it doesn't always matter to a teenager if his or her parent is in a wheelchair or using a device; the problem is the fact that the parent is involved at all, and the same is true for parents without MS." (Individuals with MS and their families can learn more through educational seminars held throughout the country by MSAA. For more information, please call MSAA's Helpline at 800-532-7667, or visit MSAA's website at [www.msassociation.org](http://www.msassociation.org).)

Walsh emphasizes that while it's impor-



tant to have everyone in the family pitch in to help with daily chores, it's important to know their limits. "Parents don't want to put too much pressure on their kids and make them act as the parents, such as having a daughter care for a toddler every day after school," she says. "People have to know when to investigate resources and support. Parents shouldn't depend too much on their children."

### **Dealing With Depression**

"MS and depression is a huge problem that doesn't get the attention it deserves, and it has devastating consequences, so it shouldn't be ignored," says Adam Kaplin, MD, PhD, assistant professor of psychiatry in the Departments of Psychiatry and Neurology at the Johns Hopkins School of Medicine in Baltimore, and the chief psychiatric consultant to the MS Center at Johns Hopkins. "The impact of depression should not be underestimated; not by patients, not by their loved ones, not by their care providers. Depression is treatable, and the goal should be to treat the depression into remission."

According to Dr. Kaplin, clinical depression is extremely common in MS patients,



including physical disability, fatigue, and cognitive impairment. He cites these studies in his contribution to a new book on MS entitled, *Multiple Sclerosis Therapeutics*, third edition, which was recently published by Informa Press. Other studies cited in the book associate clinical depression in MS patients with increased time lost from work, disruption of social support, and decreased adherence to disease-modifying treatment regimens for MS.

with 40-to-60 percent of patients experiencing depression in their lifetimes, a rate three-to-10 times that of the general population. If left untreated, severe depression can sometimes lead to suicide. Dr. Kaplin cites a study that has found the suicide rate in MS patients to be seven-and-a-half times that for the age-matched general population.

“Clinical depression is more common in MS than in other chronic illnesses, including other neurologic disorders,” he notes. “It not only causes great personal suffering, but it can dramatically affect a patient’s function, quality of life, and longevity.” According to Dr. Kaplin, multiple studies have suggested that depression is the primary determining factor in a patient’s self-reported quality of life, with a greater impact than other variables investigated,

In this book, Dr. Kaplin also cites studies showing that, in many cases, clinical depression in MS patients may be caused by changes in the brain as a result of the disease process. Until these studies proved otherwise, says Dr. Kaplin, experts believed that clinical depression developed in MS patients due to the unpredictability of the disease and how difficult and exhausting it can be to live with a chronic disease. It’s important for MS patients and their families to understand that depression is caused by their MS and not by a personal weakness or failure to cope.

Due to these new findings, Dr. Kaplin urges MS patients and their families to receive a correct diagnosis and the proper treatment. He emphasizes that unlike depression in the general population that resolves spontaneously in roughly



75 percent of patients over an average of six-to-12 months, MS depression is unremitting and tends to worsen without therapeutic intervention.

The good news is that depression is one of the most treatable symptoms of MS, with the expectation that individuals who receive adequate treatment will enjoy a complete recovery. Dr. Kaplin wants the “same level of aggressive management for treating depression as MS patients routinely invest in managing other symptoms of their disease. Many individuals are prescribed physical therapy and rehabilitation to enhance ambulation, or urologic consultation for bladder management, and the same degree of care should be given to treat depression.”

### **Criteria for Major Depression**

Dr. Kaplin recommends that physicians use The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV), the primary diagnostic reference of mental health professionals in the United States, to diagnose clinical depression in MS patients. The DSM-IV criteria for “Major Depression” requires the presence of five or more of the following symptoms during the same two-week period, accompanied by functional impairment. Additionally, at least one of the five or more symptoms that are present must either be depressed mood (listing #1) or loss of interest/pleasure (listing #2).

1. depressed mood
2. loss of interest or pleasure (anhedonia)

3. feelings of worthlessness or inappropriate/excessive guilt
4. fatigue or loss of energy
5. insomnia or hypersomnia
6. diminished ability to think or concentrate, or indecisiveness
7. significant weight loss when not dieting or weight gain, or decrease or increase in appetite
8. psychomotor agitation or retardation
9. recurrent thoughts of death or suicide.

Moreover, according to Dr. Kaplin, to correctly diagnose Major Depression in MS patients, the physician must take into consideration the effects of medications prescribed to manage symptoms or the course of the disease; worsening fatigue in the latter half of the day (a sign of depression); and the failure of the person to not move on after a reasonable period of time to accept the disease. “A failure to progress beyond the acute shock of being afflicted with MS after many months or years should raise a question about whether or not a clinical depression has begun,” he explains.

(More information about the symptoms and treatment of depression with MS may be found in the cover story of the Winter 2003 issue of *The Motivator*. To view a copy of this article, readers may visit MSA’s website at [www.msassociation.org](http://www.msassociation.org), select “publications,” “*The Motivator*,” and then scroll down to the Winter 2003 issue. Readers may also call MSA’s Helpline at 800-532-7667 to request a copy.)

## The Love Connection

Whether married, cohabitating, or searching for that special someone, a person with MS may have difficulty feeling desirable or worthy of another's love and attention. "The idea of romance often doesn't seem possible since their body image and self-image changes very quickly after the diagnosis," says Walsh. "I try to help them see that how they may see themselves – possibly as an unattractive disabled person – is not necessarily how they appear to others. They need to share those feelings with their partner or future partner so they may see that others do find them attractive."

Dating can be especially daunting until the person with MS can accept that the disease does not define them. It's only a small part of them.

Walsh explains,

"When MS is thrown into the mix of the usual trauma of dating, two different struggles come into play; they may ask, 'who would want me, and how do I pick a partner?' In a way, MS helps them find better partners because they weed out the lousy dates and start to find people who are more accepting and caring."

Walsh also says that her patients have found that their friendships also improve

and deepen after their MS diagnosis, but it can be a painful period of rediscovery.

"Often they find that their former friends were more of the fair-weather variety. After a few years they find people who are less selfish and more responsive. Many of my patients tell me that they now have better friends because of their MS. Their relationships are deeper because they're not afraid to talk about the harder issues."



Walsh equates these relationship changes as "little deaths," or losses that one must work through and grieve before being able to move on. "The person with MS may not be able to go hiking with a certain group of friends any more but maybe can do water aerobics with another group. The person with MS may not be able to or even want to go out to a club and party all night, but will be able to enjoy a quiet night at

home with a few close friends," she says.

It's also important for the newly diagnosed MS patient to grieve the "little death" that may be experienced from no longer being able to work in the same field or to participate in a particular activity, says Dr. Kaplin. "Once the person with MS stops asking 'why me?,' he or she can begin asking, 'what can I do to make my life better?'"

Dr. Kaplin gives the example of a workaholic father who found a new job less demanding than his old one once he was diagnosed with MS. "With more time at home, he has discovered the joy in raising his kids," he says. Another patient whom Dr. Kaplin treated felt that he had to stop coaching his daughter's softball team after he had to start using a cane from the effects of MS. "He felt that he had to stop because he could no longer show the girls how to throw, catch, and bat. When I suggested that he find an assistant coach to help him, he did, and the team won first place that year," he recalls. "These examples show that those with MS can rise to the occasion in the face of adversity, often better than individuals who have never had to overcome similar hurdles."

The effects of MS can be particularly demoralizing for those who enjoy certain athletic activities, such as long-distance running. "The person has to work through the loss and grieve it in order to move on to examine what else is out there, such as bicycling or swimming," says Walsh. "It's also important to grieve the loss of the image of the individual as a runner."

## Care Partners Need Support Too

John Lennon's famous lyric, "Life is what happens to you while you're busy making other plans," hits home for most care partners of MS patients. Since MS usually strikes men and women at the prime of their lives, often without warning, their spouses or other loved ones take on the role of care partners without support systems in place to help them cope.

Because most wives, husbands, or other family members do not consider what they're doing as "caregiving," they often don't seek the help they desperately need to fulfill this new role. Instead, they often sacrifice their own needs day in and day out to offer care. Unfortunately, this selfless devotion often makes care partners neglect their health and emotional well-being, says Dr. Kaplin. "The vast majority of care partners that I see have no social life. They're with their loved ones 24/7. This is not a healthy situation for them or for their care recipients," he explains. "Care partners are no good to their care recipients if they are 'burnt out.' I tell my patients that their loved ones are not abandoning them if they go out for an hour or two to a movie or to a coffee shop with a friend. They need to give themselves permission to recharge their batteries. If they don't take care of themselves, they are going to be depressed and resent the situation more. When they come back recharged, they'll be better able to handle the demands of being care partners."

Moreover, says Dr. Kaplin, if care part-



ners continue with this personal neglect, they will no longer be able to provide proper care to their patients. To be at their best, care partners must address their own needs and feelings. Caregiving can be physically and emotionally stressful. With a growing list of new demands and less time to complete them, it's only natural to experience a wide range of negative emotions.

### **The most common negative emotions associated with caregiving are:**

**Resentment.** It's difficult not to feel resentment when other family members aren't pitching in to help or if the care recipient is making inordinate demands, such as three-course meals when the care partner is lucky to have enough time to pick up a pizza, according to Leahy. To cope, care partners must learn to delegate certain tasks to other family members in

order to give them some free time. They also need to set limits on the time and effort they put into caregiving. "For example, with neighbors offering to help, care partners must be specific in ways that can lessen their load, such as driving the kids to school and picking them up, or calling before going to the store for a list of items to pick up," she suggests.

With this newfound time, care partners should do something they enjoy. Ideas include joining an exercise class, taking in a movie on a regular basis, or gardening – the possibilities are endless. "The important thing is not to feel guilty and to find something that was once pleasurable and to start doing it again," says Dr. Kaplin.

**Guilt.** According to Dr. Kaplin, there are two major themes to caregiving – depletion and guilt. The depletion is emotional, it's physical, and it's financial. Oftentimes that's where the guilt comes in. Many individuals feel that it's their duty to provide "selfless care" but that's not humanly possible without support from others.

**Anger, sadness, depression, feeling overwhelmed.** Care partners also experience Kubler-Ross' five stages of grief. While these feelings are normal, care partners should seek medical help after six months if they are still depressed, says Dr. Kaplin. If not comfortable talking to a psychologist or doctor about their problems, care partners should reach out to a close friend, spouse, clergy person, or support group member. Ignoring these signs of caregiver stress will only make matters worse.

Leahy points out that joining an MS

caregiver support group also can help relieve the stress of having too much on your plate and feeling overwhelmed. She also notes that most MS centers also offer support groups for other family members, including children, adolescents, and teens, to help them cope. (Readers may find a listing of centers belonging to the Consortium of MS Centers [CMSC] by visiting their website at [www.msca.org](http://www.msca.org) and selecting the "MS Centers Directory" listed on the left side of the screen. Individuals without access to the internet may contact MSA's Helpline at 800-532-7667 to speak with a Helpline consultant, who would be happy to assist in finding the closest MS center.)

Talking with others who are going through similar experiences can help care partners develop strategies for problem solving and communication. Leahy adds that these contacts are also invaluable in providing resources and tips to obtain the specific help needed.

Another good way to better handle the stresses of being a care partner is to take an educational course on caregiving. These courses are offered through local senior centers, community colleges, churches, and other civic groups. By learning more about their new roles, families can establish a new level of normalcy and regain control of their lives.

*For answers to questions about MS in general, or to discuss specific issues relating to MS, relationships, and the family, please call MSA's Helpline at (800) 532-7667. Trained consultants are happy to help by providing information, support, and assistance.*

## Resources

Consortium of Multiple Sclerosis Centers (CMSC) at [www.msca.org](http://www.msca.org)

Hill, BA, *Multiple Sclerosis Q & A: Reassuring Answers to Frequently Asked Questions*, Avery Publishing, New York, 2003.

Kalb, RC, PhD, *Multiple Sclerosis: A Guide for Families*, Third Edition, Demos Medical Publishing, LLC, New York, 2006.

Kraft, GH, MD and Catanzaro, M, RN, PhD, *Living With Multiple Sclerosis: A Wellness Approach*, Second Edition, Demos Publications Inc., New York, 2000.

Courtney, SW, *Mommy's Story: An introduction for younger children to learn about a parent's MS*, Multiple Sclerosis Association of America, Cherry Hill, NJ, 2006. (This book is available free from MSAA. To obtain a copy, please call 800-532-7667, ext. 129.)

**Additional note:** For more resources on relationships and MS, as well as books on several other topics relating to MS, readers may take advantage of MSAA's free Lending Library. For more information, please refer to the "Spread the Word" column on page 64 of this issue. ♦

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## About the Author

A former editor of *The Motivator*, Christine Norris is now a freelance writer specializing in health and wellness.

## IVIg Treatment

The FDA has approved intravenous immune globulin (IVIg) treatment for pregnant and post-partum women. While this therapy is still considered experimental in the treatment of MS, interested individuals who may have difficulty affording this therapy are advised to speak with a representative at their local infusion center. He or she may be able to work with the insurance companies. If additional help is needed, one's doctor may need to write a letter of medical necessity to the insurance company.

## IN APPRECIATION

MCAA would like to acknowledge and thank the following foundations for their current generous support of new program initiatives:

**The Chatlos Foundation**

**The Horizon Blue Cross and Blue Shield Foundation of New Jersey**

**The Medtronic Foundation**

## ¿Habla Usted Español?

### MCAA'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 **MCAA 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. MCAA 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 MCAA's Helpline at (800) 532-7667, extension 108.**

This Helpline service is another way MCAA 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 MCAA marcando el (800) 532-7667, extensión 108.

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

# Ask the Doctor

By Dr. Jack Burks  
Chief Medical Officer for MSAA



*Dr. Jack Burks*

**Q:** What is your opinion, in regards to taking a test for antibodies, to see if one's medication is still working? My doctor feels this test doesn't mean anything.

**A:** This is a very controversial area. The American Academy of Neurology (AAN) reviewed this subject scientifically a few years ago. This panel of experts concluded that the utility of even measuring antibodies with interferons was uncertain, due to the fact that study results have been conflicting and confusing. Some studies show an association between the presence of antibodies in patients who are not responding fully to a treatment. Other studies indicate the opposite trend, i.e., antibodies, especially early in the treatment, are associated with a better response to therapy. The most recent study indicates that patients who are not responding well to an interferon, may be less likely to have high levels of antibodies compared to an overall population of treated patients. You can see why I am not yet certain as to the role of antibodies, if any, in interferon treatment. Except for one study, antibodies to Copaxone® (glatiramer acetate) have not been linked to suboptimal treatment response.

Therefore, I do not order antibody tests to determine the effectiveness of a patient's

medication. In my opinion, if a patient is doing well on his or her medication, I would not switch therapies, even if antibodies were present. On the other hand, if a patient is not doing well on a therapy, I change treatments even if antibody tests were negative. Other experts order antibody tests routinely. The controversy will continue until the scientific data are more complete.

In summary, I make clinical decisions based on a patient's response to a drug, and not on any one test. The AAN is presently reviewing the subject for a second time and I await their additional recommendations, if any.

**Q:** I am a 59-year-old man with primary-progressive MS (PPMS). I have had MS for more than 30 years, I am not on any MS drugs (just those for symptom management), and I am no longer ambulatory. Unlike most people with MS, I am cold most of the time and wear sweat suits throughout the year. I haven't had an MRI of the brain since 1990. Do you have any suggestions as to what I should do next?

**A:** Unfortunately, there is no proven treatment for PPMS, which is diagnosed in 10 percent of the MS population. Future treatments may be helpful, but at this time we need a better understanding of the underlying cause of this form of MS. In a recent clinical trial, Copaxone was studied in PPMS but the trial was stopped early due

to lack of benefit. The potentially good news is that a clinical trial of Rituxan® (rituximab), by Genentech and Biogen Idec, is underway for people with PPMS. This drug is aimed at “B” lymphocytes (makers of antibodies), which are different from “T” lymphocytes (involved with inflammation), which are the targets in many relapsing-remitting MS (RRMS) trials.

There is reason for hope. We know that PPMS is more of a degenerative disease, while the more common relapsing-remitting (RR) type of MS is primarily an inflammatory disease. While current MS treatments focus on inflammation, future treatments will also be aimed at reversing the damage to the myelin (protective covering of the nerve) and the nerve fibers. These types of repair are referred to as remyelination and regeneration. Developing such treatments is an urgent goal in MS research, but we are not there yet. Stem cells may also prove to be of benefit in these areas of remyelination and regeneration of nerve fibers.

Your symptom of feeling cold is not that uncommon in MS. Some people actually feel they function better when they feel cooler than warmer. Some use cooling devices to feel better. However, I would look for other causes of feeling cold, such as low thyroid. If wearing a sweat suit relieves the cold sensation, I would not pursue other treatments.

As for an MRI, ask your neurologist if he or she thinks that an MRI of the brain and possibly the spinal cord could be helpful. I might consider another MRI after 17 years

on the unlikely chance that I might find something additional that may be adding to your disability (such as spinal-canal narrowing or a disc problem).

**Q:** I am having a favorable experience on Novantrone. I have not had any cardiac-related issues, and I attribute this to receiving Zinecard (intravenously) prior to the Novantrone infusion. I understand that Zinecard is a cardiac protector. Can you tell me any more about this drug, and are others using this in conjunction with Novantrone?

**A:** Novantrone® (mitoxantrone) is an anti-cancer drug that has been used successfully to help many MS patients with worsening MS who have not responded adequately to treatment with the other current immunomodulating therapies (Avonex® [interferon beta-1a], Betaseron® [interferon beta-1b], Rebif® [interferon beta-1a], or Copaxone). The decision to use Novantrone therapy is highly individualized and certain patients seem to respond better than others.

Since Novantrone is an anti-cancer drug, concerns of side effects weigh in the decision-making process. The major side effects are potential loss of menstrual periods (amenorrhea), heart toxicity (which may be irreversible), and the rare chance of getting leukemia. The risk of heart toxicity may possibly be lessened by Zinecard® (dexrazoxane), which has been used to protect cancer patients from heart toxicity from drugs similar to Novantrone.



In 2006, a study at the University of Michigan using Zinecard plus Novantrone in MS patients was published. After one year of therapy, in which Novantrone (with or without Zinecard) was given on a quarterly basis, patients also receiving Zinecard with Novantrone had a less severe decline in their heart function, although both groups had some minimal decline in heart function. None of the patients in either group had symptoms of heart disease in this study. The average heart-function reduction in both groups was less than 10 percent. None of the 28 patients treated with Zinecard had a heart-function decrease greater than 10 percent, whereas seven of 19 patients who did not get Zinecard with their Novantrone had a heart-function decrease greater than 10 percent.

Therefore, in this series, patients demonstrated some heart protective effect of Zinecard in conjunction with Novantrone. Nonetheless, Zinecard is not yet used routinely with Novantrone by many neurologists, since it is not FDA approved for this purpose. In addition, Zinecard has its own independent immunosuppressive effect, which must be evaluated with the immunosuppressive effects of Novantrone. Patients with concomitant kidney disease must be especially careful when using Zinecard. Its safety and effectiveness has not been established in pediatric or geriatric patients.

In summary, Zinecard may be helpful in reducing heart toxicity of Novantrone. The additional immunosuppressive effect of Zinecard could potentially add to the effectiveness of Novantrone or it may cause

unwanted additional immunosuppression. I will quote the last sentence of the 2006 paper, “A larger randomized, prospective clinical trial of Novantrone with and without Zinecard seems warranted before considering Zinecard for general use.”<sup>1</sup>

As a reminder, the updated FDA recommendation is that heart testing should be done in all patients treated with Novantrone prior to taking each dose irrespective of whether the patient has signs of heart failure.

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<sup>1</sup> Bernitsas E, Wei W, Mikol D, “Suppression of Mitoxantrone Cardio-toxicity in Multiple Sclerosis Patients by Dexrazoxane,” *Ann Neurol.* 2006;59:206-209.

**Q:** After more than 10 years of vague symptoms, I had a severe attack and was diagnosed with MS. That severe attack left me with permanent disability. I began Copaxone, had one exacerbation about a year later, and since then just some very slight flare-ups, which over time have led to some additional disability. My MRIs have been pretty stable.

When I inquired about Tysabri, my present neurologist said that she did not think it was appropriate as I have the secondary-progressive type of MS. I have already scheduled an appointment for a second opinion with a TOUCH neurologist, but I'd like an objective opinion. First, what is an honest assessment of where I am; and second, is Tysabri appropriate for someone in this stage?

**A:** Tysabri® (natalizumab) has not been tested in secondary-progressive MS (SPMS).

This form of MS is primarily a disease of degeneration and not inflammation (as seen in relapsing-remitting MS, or RRMS). Theoretically, Tysabri may not be helpful in SPMS since it is designed to treat inflammation specifically. However, if you are still having considerable inflammation in the brain (as seen on an MRI) or still having relapses (which indicate inflammation), Tysabri may be helpful, although it has not yet been proven effective in progressive disease. This concern likely explains your neurologist's reluctance to recommend Tysabri, in addition to its rare but potential fatal toxicity. If your doctor feels you are not responding well to Copaxone, interferon therapy or Novantrone are other options.

In summary, Tysabri is designed to treat

inflammation while SPMS tends to be more a degenerative than an inflammatory disease. We do not know yet if Tysabri will benefit patients with secondary-progressive disease. Interferons and Novantrone have both been tested; some studies have shown a beneficial effect, especially in early secondary-progressive disease. A comparison of the risks as well as potential benefits of these three potential therapies (Tysabri, interferons, and Novantrone) should also be part of the discussion with your neurologist.

**Q:** I have had MS for 30 years and was told that it is now (and has been for 20 years) the secondary-progressive type of MS. I am in a wheelchair and had to retire two years ago. I was taking interferons 12

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years ago. The neurologist that I see now wants to put me back on an interferon. What are your thoughts on this?

**A:** I would refer you to the previous question that involves a patient with secondary-progressive MS (SPMS). If your neurologist wants to put you back on an interferon, I assume that he or she has reason to believe you have a chance to respond to this therapy again. Interferons are a reasonable option, if you are having evidence of inflammation in addition to the degeneration. Evidence of inflammation may be apparent on the MRI or if you are still having relapses. Other treatment options include Novantrone and Copaxone, since they are different classes of therapy than the interferons. However, like Tysabri, no clinical trial evidence is available on the effectiveness of Copaxone in SPMS. Again, weigh the risks versus the benefits of all potential medications.

**Q:** I have had MS for five years and I take an interferon. I have tried many pain, anti-depressant, and sleep medications, but I am still experiencing a lot of pain throughout my body as well as my worst symptom, which is extreme nervousness. So far, no medication has helped. I feel like something is racing through my body and I can't stop it. Is there any way you can advise me? I seriously need your help.

**A:** Pain throughout the body, extreme nervousness, and a racing sensation through the body are very disconcerting and drastically affect the quality of life for

anyone, including someone with MS. I do not know if you have tried all types of pain and “nervousness” medications yet. If “stuck,” your doctor may refer you to an expert in these fields. Did you have any of these symptoms before your MS began or before starting interferon treatment? Has your doctor considered having you take a “drug holiday” from the interferon, to see if these symptoms improve? Have you tried alternative treatments such as biofeedback, self-hypnosis, visual imagery, yoga, massage, meditation, and other non-traditional therapies? If your symptoms are related to your interferon therapy, Copaxone® is another option.

I can refer you to the “Symptom Awareness” columns in the Fall 2004, Winter 2005, and Spring 2005 issues of *The Motivator*, for a comprehensive discussion on pain relief – including information on traditional as well as complementary and alternative strategies. Several additional resources are also listed. To view or download these past issues of *The Motivator*, please visit [www.msassociation.org](http://www.msassociation.org), select “publications,” then select “*The Motivator*,” and scroll down to the desired issues. You may also contact MSAA’s Helpline at (800) 532-7667 for article copies.

Some comprehensive MS centers have multidisciplinary expertise in these areas. You may find a listing of centers belonging to the Consortium of MS Centers (CMSC) by visiting their website at [www.mscares.org](http://www.mscares.org) and selecting the “MS Centers Directory” listed on the left side of the screen. If you do not have access to the internet, please

contact MSAA's Helpline at (800) 532-7667 to speak with a Helpline consultant, who would be happy to assist you in locating an MS center in your area.

**Q:** I was diagnosed with MS in 1993. Recently I had a bone-density test done and my doctor has recommended I increase my consumption of milk and other dairy products. I am also taking Didrocal® [a medication used to treat osteoporosis]. Since I have increased my consumption of dairy products, my MS symptoms have worsened. Could this worsening of my symptoms be related to the dairy products, and are there other means to increase my calcium intake that would be as beneficial as eating dairy products?

**A:** I cannot determine if your consumption of dairy products has caused a worsening of your MS symptoms. Some independent researchers have looked into a possible connection between dairy products and MS, (see the Fall 2004 issue of *The Motivator*), but dairy-product consumption has not been linked to worsening MS in any double-blinded, placebo-controlled clinical trials with MS patients.

Nonetheless, I would ask your doctor about other means of increasing your calcium intake. He or she may refer you to a specialist in this area for a more definitive opinion. As you know, calcium supplements are available in all supermarkets and health-food stores. However, your situation may call for advice that is more specific.

Unfortunately, your worsening may be due to the natural course of your MS. Therefore, I would ask your neurologist to evaluate your current MS treatment. It might be time to consider changing your therapy or at least getting another MRI to document the degree of worsening of your MS. ♦

*Jack Burks, MD, is a neurologist who specializes in MS. He is chief medical officer for MSAA, as well as president of the Multiple Sclerosis Alliance. Additionally, Dr. Burks is a clinical professor of medicine in neurology at the University of Nevada School of Medicine in Reno, Nevada, and a member of the Medical Advisory Board of the National MS Society. He has edited two textbooks on MS, and in the 1970s, Dr. Burks established the Rocky Mountain MS Center.*

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### 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  
Attn: Andrea Borkowski  
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](mailto:aborkowski@msassociation.org). Please be sure to write "Ask the Doctor" in the subject line.

# Research News

## Primary-Progressive Multiple Sclerosis: The Less Talked-about Form of MS

Historically, primary-progressive multiple sclerosis (PPMS) has seemingly taken a back seat to other types of multiple sclerosis (MS). By far, the largest amount of information published about research and treatments for multiple sclerosis (MS) has been in reference to relapsing-remitting and secondary-progressive forms of MS (RRMS and SPMS respectively).

The emphasis has been on RRMS and SPMS for a number of reasons. First, 85 percent of individuals diagnosed with MS begin with the RRMS form, and after many years, RRMS usually advances to SPMS – so clearly the vast majority of patients fall under these categories. Second, RRMS, with its trademark flare-ups and remissions, is the easiest to identify, measure, and observe changes – both in terms of symptoms and diagnostic/evaluative testing. And third, unlike PPMS (and eventually SPMS), constant flare-ups of inflammation play a vital role in RRMS.

This inflammation in RRMS occurs within the brain and spinal cord (components of the central nervous system [CNS]), and gives researchers a specific target for potential drug and treatment therapies. Disease flare-ups as well as ongoing subclinical disease activity (referring to changes occurring inside the body without any new or worsening symptoms) are frequently observed and measured through the use of magnetic resonance imaging (MRI) technology.

In contrast to RRMS, only 10 percent of

individuals with MS are diagnosed with PPMS, and only five percent have a form known as progressive-relapsing MS (PRMS). These types of MS often begin (or “present” to the doctor) with a very gradual accumulation of walking difficulties. At the same time, PPMS (and early PRMS) patients do not experience any type of exacerbation, or “flare-up” of symptoms.

Equally confounding for the treating physician is the fact that little or no abnormalities will be visible on the gadolinium-enhanced MRI scan – which is a standard diagnostic tool for identifying lesions (areas of inflammation) in RRMS. Gadolinium is a chemical agent used to highlight areas of inflammation. It is administered to a patient prior to having an MRI scan performed. Since PPMS patients have little or no known inflammation, these types of scans can often appear “normal,” with little or no evidence of active MS.

The reason for a normal-appearing MRI of the brain as well as the presenting symptom of gradual walking difficulties, is the fact that most of the disease’s effects are thought to take place in the spinal cord for individuals with PPMS. An MRI of the spinal cord shows a slowly worsening spinal cord syndrome, also known as “progressive myelopathy,” in at least 60 percent of those diagnosed with this type of MS. Atrophy (cell death) is often apparent in the spinal cord, along with loss of tissue, largely caused by the degeneration of nerve fibers.

Two features are necessary for a doctor to diagnose PPMS. First, the patient must be experiencing a slow and gradual worsening in his or her symptom(s), and second, she or he must have never had a flare-up of symptoms (also known as a “clinical relapse,” “exacerbation,” or “attack”). Some individuals who are initially diagnosed with PPMS, unexpectedly begin experiencing acute flare-ups of their symptoms. This is what distinguishes a person as having PRMS, and the diagnosis at that time is changed from PPMS to PRMS. As mentioned earlier, approximately five percent of individuals with MS are eventually diagnosed with PRMS – but these patients always begin as having PPMS.

Not everyone with PPMS experiences walking difficulties and has disease activity largely limited to the spinal cord. A portion of individuals with PPMS are found to have “progressive cerebellar syndrome.” People who are diagnosed with this type of PPMS show significant changes on their brain MRI, often similar to someone with SPMS. And rather than presenting with problems walking (in terms of strength), someone with progressive cerebellar syndrome will typically have difficulties with balance as well as a disabling tremor.

### **Do the Various Forms of MS Differ Biologically?**

Obvious differences exist in the demographics of who is initially diagnosed. Twice as many women are diagnosed with RRMS than men, whereas PPMS is divided equally between the genders, and some sources report a slight tendency toward more men than women being diagnosed with this form

of MS. Individuals are typically diagnosed or experience initial symptoms of RRMS as a young adult, often in one’s teens or 20s. The onset of PPMS is generally after age 35, with many people being diagnosed in their 40s or 50s.

For several years, experts in the field of MS have suggested that at least two different types of disease pathologies are involved with MS. One mode of action is **inflammation**, as seen as gadolinium-enhanced active lesions on an MRI scan and as a flare-up of symptoms. This is believed to occur as myelin (protective nerve covering) and axons (nerve fibers) are attacked by one’s own immune-system.

Certain types of immune-system cells and chemical responses promote inflammation and damage to the CNS, with resultant flare-ups of symptoms. To a certain extent the myelin may be repaired (remyelination) and function returned (remission). Over time, however, eventual accumulation of deficits usually occurs. The flare-ups and remissions are the defining disease behaviors for RRMS. Inflammation is thought to also be involved to a certain extent with the other types of MS that may exhibit flare-ups and remissions (PRMS and SPMS).

The second mode of action is **degeneration**, which may be defined as the deterioration of specific cells. As with inflammation, degeneration is thought to be caused by one’s own immune system. This process does not promote extensive inflammation, but rather is thought to pre-program healthy cells for an early death. And as the myelin and axons die off, deficits relating to these

areas of damage slowly progress. This appears to be the type of disease activity with PPMS, PRMS, and SPMS, although the latter two may have more inflammatory component because PRMS patients and some SPMS patients experience flare-ups.

These two modes of action – inflammation and degeneration – help to differentiate RRMS from PPMS. Finding treatments for these different types of MS may well involve different approaches.

So far, inflammation has been the easier mode of action to treat. All six of the FDA-approved disease-modifying therapies (Avonex® [interferon beta-1a], Betaseron® [interferon beta-1b], Copaxone® [glatiramer acetate], Novantrone® [mitoxantrone], Rebif® [interferon beta-1a], and Tysabri® [natalizumab]) take action using various methods to reduce the inflammation caused by the immune system's attack on the CNS. They are most effective for individuals with RRMS, with limited effectiveness for some individuals with SPMS. Since the primary mode of action in PPMS is degeneration, these drugs that treat inflammation do not appear to have much effect on this type of MS – although studies are still being conducted with PPMS and some of these drugs.

### **PPMS Research Is Ongoing around the World**

Simply because more people have the RRMS form of MS, which has proven to be easier to study, evaluate, and treat, does not mean that progress is not being made with research into PPMS and other progressive types of the disease. In fact, research is ongoing around the world to discover better diagnosis criteria, more specific evaluation

methods, and possible treatment options.

To follow are a few examples of PPMS research around the world. Researchers are dedicated to learning more about PPMS and possible treatments.

**Internationally**, a trial was conducted with PPMS patients using Copaxone, showing no effectiveness other than a possible effect for men with quickly progressing disease.

**In the United States (Texas)**, another study looked at the cellular changes in PPMS patients when treated with Rituxan® (rituximab), a drug presently in clinical trials for PPMS.

**In the United States (Ohio)**, researchers suggest that a subset of PPMS patients (with active lesions) may potentially respond to Novantrone, although an improved understanding of the drug and disease activity is needed.

**In Canada**, researchers looked to better understand patient characteristics, disease progression, and associated risk factors with PPMS.

**In London**, researchers used magnetization transfer imaging (MTI) to identify abnormalities in the brain (not seen on conventional MRI) occurring in patients with early PPMS. Another study (using triple-dose gadolinium) found that gadolinium-enhancing lesions were on MRI scans of the brain in almost half of the individuals with very early clinical stages of PPMS, suggesting an early inflammatory phase in PPMS (this was also associated with a greater disease impact).

**In the Netherlands**, a course of high-dose corticosteroids showed an initial improvement in progressive MS patients, followed by a subsequent deterioration within days after

the treatment was stopped, resulting in more disability than before treatment began.

**In Italy**, MRI techniques are being researched for more reliable prognostic markers of PPMS, which may help to select and evaluate PPMS patients in future studies.

Another trial found stem-cell transplantation (from bone marrow) to be a promising procedure to slow down progression in a subset of patients affected by “severe, progressive MS.”

**In France**, a study found that a monthly IV pulse of cyclophosphamide with methylprednisolone led to significant improvement in cognition in progressive MS patients (10 with PPMS and 18 with SPMS), although the mechanisms of action remain unclear.

**In Spain**, researchers discuss new findings in MRI studies that demonstrate damage in

normal-appearing brain tissue of patients with PPMS, noting that the findings indicate that disease activity in PPMS patients may now be better evaluated and suggest that this patient population should no longer be excluded from therapeutic trials.

**In Australia**, researchers explain how PPMS differs from the more common types of MS, noting that lesions in PPMS tend to be more diffuse (more scattered and/or less defined), less inflammatory, and less likely to remyelinate; they also recognize rituximab as a potential new therapy for PPMS.

Examples of drugs and therapies that have been studied in recent years or are presently in clinical trials with PPMS include: all of the FDA-approved disease-modifying drugs for

*continued on page 63*

## Financial Assistance Available for Follow-Up MRIs

- A follow-up MRI exam can help you and your neurologist keep pace with the ever-changing course of MS
- New information can assist in evaluating disease progression and help find the best treatment options to meet your needs

The MSAA MRI Institute provides financial assistance in securing MRI scans of the cranium and cervical spine for uninsured, under-insured, or financially challenged MS clients.

To learn more about the MRI Institute, please contact MSAA at (800) 532-7667, ext. 120 or [mriinstitute@msassociation.org](mailto:mriinstitute@msassociation.org).

The MSAA MRI Institute is supported by a charitable contribution from Serono, Inc. and Pfizer Inc.





# Program Notes

## Coming Soon: MS Videos and More on MSAA's Website

It's almost hard to believe that we celebrated the beginning of the new millennium more than seven years ago. Also just as amazing has been the rapid and continuous advances of technology, especially with regard to how we communicate and share information electronically.

As a way to boldly embrace this new era of electronic communication and reach out and deliver service to more clients than ever imagined, MSAA proudly announces the creation of a new program initiative known as MSi, or Multiple Sclerosis Information. Through the portal of our enhanced website, [www.msassociation.org](http://www.msassociation.org), MSi will offer an extensive library of on-demand video programming, webcasts, professionally monitored chat rooms, and additional interactive communication features that bring knowledge and empowerment right into the privacy and comfort of a person's home.

In addition to providing high-quality and up-to-date information about successfully managing MS, MSi video programs will incorporate problem-solving techniques into each piece, giving viewers an extensive resource guide to help clients acquire the support they need. Also, as a way to personalize this somewhat distant form of communication, viewers will be encouraged to submit individual questions electronically to our highly trained Helpline staff, complete online evaluation surveys, and join periodically scheduled live chat discussions with

the nation's top healthcare professionals. All video programs will feature search capabilities, printable transcripts, and the built-in technology to recognize a computer's compatibility to operate with dial-up, DSL, and broad-band connections.

The development and implementation of this exciting new program is made possible through the funding support of: Serono, Inc. and Pfizer Inc; Berlex, Inc.; Avanir Pharmaceuticals; The Medtronic Foundation; and Horizon Blue Cross/Blue Shield of New Jersey. The first web video currently under development is a 60-minute presentation which will provide insight and advice on effectively managing MS symptoms. This video will shine the light on the lesser known conditions of depression, spasticity, and involuntary emotional expression disorder (IEED).

As the MSi program expands, MSAA will produce and release a host of informative half-hour to one-hour web videos covering such topics as the value of MRIs, the need for early treatment, stress management, and many other real-life issues important to the MS community. We welcome everyone to visit our soon-to-be upgraded website and to access these informational videos as they become available online throughout 2007.

## Staying Cool

As summer approaches, the heat and humidity can often cause adverse effects for individuals with MS. Recognizing this,

MSAA provides special cooling apparel at no charge through its national Cooling Distribution Program. This program features five different cooling kits which include a vest, collar, and set of wrist bands. These three products address the primary cooling points on the body (torso, neck, and wrists).

Clients eligible for the program will be able to choose one of the five cooling kits that best fits their needs along with two accessories. MSAA encourages interested clients to contact MSAA before the busy summer season is quickly upon us. Readers may call (800) 532-7667 or download the application forms at [www.msassociation.org](http://www.msassociation.org).

### Staying Safe and Comfortable

A recent letter from a client's occupational therapist (OT) was faxed to MSAA and it stated, in part, "As her OT, I have made several recommendations to her and her family about proper adaptive equipment that would both aid her safety and independence, but her family was not able to afford these items. That is when I found your website and this wonderful program you have established for people living with MS. She would greatly benefit from these items we have selected from your list and would be able to use these pieces of equipment for a long period of time whether her MS is in remission or if she has a relapse."

This letter is referencing MSAA's Equipment Distribution Program. Clients who apply to the program may be eligible to receive a wide array of medical-safety

products such as grab bars, shower chairs, and bed rails, as well as daily living aids ranging from "reachers" to special wide-grip utensils. Other equipment programs offered by MSAA include the use of portable ramps and the provision of walkers, wheelchairs, and scooters to assist with mobility needs. Clients interested in any of the above equipment items may contact MSAA at (800) 532-7667 or download the application forms at [www.msassociation.org](http://www.msassociation.org). ♦

— Peter Damiri

## MSAA Needs Volunteers!

### Volunteering assignments include:

- Fundraising: Events such as bake sales, trivia evenings, and charity dinner parties have all benefited MSAA. Will you organize something similar to benefit MSAA?
- Resource Detectives: Research and report on local resources that help individuals with MS.
- Ambassador Support: Facilitate speaking engagements to community groups and hospitals for our Ambassadors.

Please contact Malcolm Friend at MSAA  
Phone: (800) 532-7667, extension 8  
Email: [volunteering@msassociation.org](mailto:volunteering@msassociation.org)  
Web: [www.msassociation.org/volunteer.html](http://www.msassociation.org/volunteer.html)

(When sending an email, please include areas of interest for volunteer work and any contact information.)

# Symptom Awareness

## Bladder Dysfunction and Treatments

Bladder symptoms in MS are often a result of demyelination, either in an area within the spinal cord which controls bladder function, or along axons (nerves) which carry messages to and from the brain concerning bladder function. The location of the demyelination will determine the type of bladder dysfunction along with the specific symptoms experienced.

The most common symptoms for individuals with MS are frequency (the urge to urinate often) and urgency (the urge to urinate immediately and the difficulty in holding the urine once the urge is felt). Some patients find that they cannot urinate (hesitancy, retention) despite the urge being felt. Others may experience dribbling (small amounts of leaking urine) or a full loss of control resulting in an unexpected emptying of the bladder (incontinence).

### Types of Bladder Dysfunction

A **spastic bladder** occurs when the bladder fills too quickly and urinating becomes an automatic reflex. Also called a “failure-to-store” or “small” bladder, this condition eventually causes the bladder muscles to become thick and spastic (with tight muscles). It can cause dribbling, frequency, and/or incontinence.

Known as “failure-to-empty” or “big” bladder, a **flaccid bladder** occurs when messages of bladder fullness are no longer perceived and the bladder overfills. The walls of the bladder become weak, stretched, and

unable to empty upon command. Symptoms include frequency, urgency, dribbling, hesitancy, or overflow incontinence.

The third condition is called a **dyssynergic bladder** (also referred to as a “conflicting” bladder). With this condition, movements and functions of the bladder wall muscles and sphincter (a muscle that controls the release of urine) no longer work in conjunction with one another. The bladder may contract to empty while the sphincter contracts, causing urine to be retained. This situation can also reverse, with the bladder not forcing the urine out when the sphincter is relaxed and prepared to allow urine to flow.

### Treating Bladder Dysfunction

The treatment of bladder dysfunction differs depending upon the type of bladder problem diagnosed. An up-to-date listing of treatments appears in Dr. Randall T. Schapiro’s fifth edition of his book, *Managing the Symptoms of Multiple Sclerosis* (Demos Medical Publishing, 2007).

The spastic bladder is often treated with medications. According to Dr. Schapiro’s book, common options include: oxybutynin (Ditropan<sup>®</sup>, Ditropan XL<sup>®</sup>), hyoscyamine (Levsinex<sup>®</sup>, Levbid<sup>®</sup>, Bystospaz<sup>®</sup>), flavoxate hydrochloride (Urispas<sup>®</sup>), imipramine (Tofranil<sup>®</sup>), solifenacin (Vesicare<sup>®</sup>), tolterodine tartrate LA (Detrol LA<sup>®</sup>), trospium CL (Sanctura<sup>®</sup>), darifenacin (Enablex<sup>®</sup>), and several cold medications.

A relatively new treatment option uses Botox® injections (botulinum toxin type A) for urinary incontinence with MS. The *Journal of Urology* published an article titled, “Botulinum toxin type A is a safe and effective treatment for neurogenic urinary incontinence: results of a single treatment, randomized, placebo controlled 6-month study” (2005 Jul;174[1]:196-200). Patients with spinal-cord injury or MS received localized, intramuscular injections (two doses) of either Botox or a placebo. This study concludes that “...[Botox] can provide rapid, well tolerated, and clinically significant decreases in the signs and symptoms of urinary incontinence caused by neurogenic detrusor [muscle] overactivity during a 24-week study period.” No safety issues were experienced with this treatment.

In his book, Dr. Shapiro comments about using Botox injections for treating spastic bladder, “This treatment is becoming more popular but remains somewhat experimental. It needs to be repeated about every three months as it wears off.” He also notes that specific exercises developed by physical therapists for overactive bladder, as well as biofeedback techniques, may help decrease the stimulation of the bladder.

The other two types of bladder dysfunction mentioned have fewer treatment options. For the flaccid bladder, an “intermittent” catheter is frequently prescribed. This is an effective and safe method which involves inserting a narrow tube through the urethra and into the bladder, often several times daily.

For the treatment of dyssynergic bladder, an alpha blocker drug is sometimes prescribed. While this medication is commonly used to treat high-blood pressure, it may help to increase coordination and control within the bladder. Alpha blockers prescribed for this latter purpose include phenoxybenzamine (Dibenzylamine®), clonidine, and terazosin (Hytrin®).

### For More Information

Other types of bladder issues may occur for individuals with MS, and other types of treatment are available. For more information, readers may visit MSAA’s website at [www.msassociation.org](http://www.msassociation.org), click on publications, and click on MSAA’s booklet, *Multiple Sclerosis – Managing Symptoms*. Those without internet access may call MSAA’s Helpline at (800) 532-7667 to request a copy of the chapter devoted to “Bladder Problems.” A brief overview of bladder problems may also be found in the Symptom Awareness column of the Fall 2003 issue of *The Motivator*, which may be accessed through MSAA’s website or Helpline phone number, as listed above. In addition to those mentioned, references include the Multiple Sclerosis Council for Clinical Practice Guidelines’ report entitled, “Urinary Dysfunction and Multiple Sclerosis.” ♦

Thanks go to MSAA Healthcare Advisory Council Member Amy Perrin Ross, APRN, MSN, CNRN, MSCN for her assistance.

*Written by Susan Wells Courtney  
Reviewed by Dr. Jack Burks*

# Health and Wellness

## BREAKING UP Is Hard To Do

*When Your Job Gets the Better of You*

**Written by Shelley Peterman Schwarz**

**Edited by Susan Wells Courtney**

You love your job. In addition to much needed income, it gives you a sense of pride and accomplishment, perhaps even a level of status in the community. Our work is an integral part of who we are.

In our culture, we are defined by what we do. If you don't believe that, just think, when you meet people for the first time, what's the first question they ask? Isn't it, "So tell me, what do you do?" When what we do is so much a part of who we are, how do we know when it is time to give up that part of us, and when we do, how do we deal with the psychological, emotional, and social toll surrounding such a major life change?

With a chronic illness like MS, the time may come when the effort it takes to continue working becomes so draining that your health and family life begin to suffer. At first, you may cope by giving up time with friends, and recreational activities are put aside so you can rest up to continue working. At the job, you take short cuts, cut back on extra duties, and find creative ways to have others do the things that are hard for you. But no matter how hard you try, you may not be able to keep up the pace, and you have to face the fact that something has to give. When the symptoms of MS affect your ability to continue working, this may trigger feelings of anger, frus-

tration, and perhaps even embarrassment.

Should you need to leave your job because of the symptoms of MS, I hope that my experience can help to bridge the gap between how things were and how things are now. I also hope that my experience may inspire you to find a new sense of purpose and accomplishment in your life.

### **Shelley's Story**

Perhaps like me, you knew at an early age what you wanted to be when you grew up. I was just 15, when helping several hearing-impaired girls in gym class sparked my desire to become a teacher of the Deaf. I loved my career as a teacher of the Deaf. It was such a part of me that I continued teaching after my children were born; even returning to work from maternity leave early because I was so passionate about my work, and I missed the students terribly.

Being so passionate about my career, imagine my dismay when I began to have trouble finger spelling and signing! It was not long after that I was diagnosed with multiple sclerosis (MS).

For two years after my diagnosis, I continued working, determined not to let this "MS thing" change my life. Fortunately, I was working part time and was no longer teaching in the classroom; I had citywide responsibilities working with teachers, and I could arrange (or rearrange) my schedule and pace myself so I would have the energy I needed to do my job.

I made minor modifications. For example, I'd spend part of the day in my quiet office and part of it in the schools. I

started dictating reports instead of typing or writing them. (This was years before personal computers and voice-recognition software.) I cut back on my committee participation. When I needed to get involved, I chose jobs that were more sedentary and time limited. I tried very hard to pass as "normal," not letting the effects of my illness become apparent. I went so far as to stretch the truth -- one day, when I felt particularly shaky on my feet, I wore an "ACE" bandage around one ankle to give it support, and when a colleague asked me about it, I said that an old sports injury was acting up.

### **How Symptoms Can Affect Work**

MS can affect all aspects of your workday, from getting to and from the office, to communicating with fellow employees. Energy levels ebb and wane, while cognitive abilities may be affected, making it difficult to find the right word or remember important facts. At some point you may be faced with a crisis situation where suddenly your whole body refuses to cooperate. What do you do?

### **To Tell or Not to Tell**

You may be hesitant to tell your employer about your disability, for fear that you might lose your job. This can be an issue, however, the Americans with Disabilities Act<sup>1</sup> (ADA) is designed to offer protection for workers with disabilities; you cannot lose your job simply because of a disability. [To ask questions or receive free printed information on the ADA, readers

may call the toll-free information line at (800) 514-0301 (TTY 800-514-0383).] The key to a successful transition is knowing when to speak up and how to do so in a way that inspires cooperation and offers solutions.

Timing is a key consideration. One option is to approach your employer before the symptoms of MS affect your job performance. Be prepared to briefly explain your illness, how it might affect your job performance, and suggest inexpensive adjustments (accommodations) that will help you to continue to be a productive and valuable employee. Most employers are willing to accommodate your needs if they value the work that you do.

### **Making Accommodations**

Inexpensive accommodations might be as simple as providing an adjustable keyboard tray, relocating your workspace closer to the door, or providing a chair or stool on wheels. If you require a wheelchair, raising your desktop or exchanging your vertical file cabinet for a lateral file are changes that can be easily made.

Perhaps you need to adjust your duties – exchanging job functions that are difficult

for you to perform (such as lifting, reaching into a high file cabinet, or collating papers) with a coworker, while taking over other areas of their job that don't require as much mobility or dexterity. Another option is to take advantage of adaptive computer programs to make your job easier, like Dragon™ NaturallySpeaking® voice-recognition software<sup>ii</sup> to eliminate keyboarding.



You might need to ask for more time to accomplish tasks, to spend part of your workweek telecommuting, or to be retrained to do a less strenuous job. It is the responsibility of each of us to ask for what we need in order to accomplish our job duties in a way that is positive and solution oriented.

### **Resources to Help You and Your Employer**

Each state and United States territory has a vocational rehabilitation (VR) program that can help you assess your work skills, determine your needs, and suggest simple accommodations to help you continue working. They can also help you and your employer to communicate and problem solve in the workplace to accommodate your disability. Other VR programs assist with physical accommodations to your

workplace or retraining for other work, even paying for all or part of the accommodation. For a list of VR programs in your area, readers may visit the Social Security Administration<sup>iii</sup> website at [www.ssa.gov/work/ServiceProviders/rehabproviders.html](http://www.ssa.gov/work/ServiceProviders/rehabproviders.html) or call (800) 772-1213 (TTY 800-325-0778) Monday through Friday, 7:00 am to 7:00 pm.

I was honest with my boss, school principals, teachers, students, and parents, right from the beginning about my diagnosis and how MS might affect my job performance. I was lucky that my honesty was met with understanding and a willingness to work with me as I tried to continue to be a valued employee. I had to learn to be my own advocate and ask for the accommodations I needed. For example, since my dominant right hand was giving me the most trouble, I asked people to share their meeting notes with me so that I wouldn't have to take notes at meetings. My colleagues offered their help as well. To save me steps and energy, they'd bring me a cup of coffee from the break room, get my lunch out of the refrigerator, or run something down to the mail room for me.

I parked as close to the door as I could to avoid walking in the parking lots, and eventually obtained a disabled parking hang tag for my car so that I could park in the handicapped parking spaces. If the school had an elevator, I used it. To recharge at lunchtime, I'd lie down in the nurse's office for a half-hour. I started wearing loafers instead of heels because I felt my balance was off and I had fallen a cou-

ple of times; wearing loafers to work was a very emotional decision for me especially because people in my position were dressed in suits and business-casual clothing. Intellectually I knew it was a small accommodation, but it was a sad reminder that the disease was progressing.

I switched cars with my husband, David, because his car was an automatic and mine was a stick shift. Then I had trouble turning the key in the ignition. Even if I could start my car, once I arrived at the location, walking even short distances was exhausting. I had dropped everything but essential activities, no more volunteering, no more book or craft club, no more dinners with friends. Whatever energy I had, I saved for work and my family – David and our two young children, Jamie (six years

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old) and Andrew (four years old).

I don't think anybody realized all the modifications I was making just to continue doing my job. Looking back, I realize that denial was a powerful coping mechanism. I kept trying to prove that I was stronger than MS; whatever it had in store for me, I was determined to find a way to have the upper hand.

However, every day I felt that I was losing physical abilities. I began to question my ability to find solutions. When I asked my neurologist when the decline would stop, he said it might not. It was a cruel reality that I was unprepared to hear.

### **Giving In, Not Giving Up**

A year-and-a-half after my diagnosis, thoughts of retiring crept into my head on a regular basis. It was terribly depressing to think of my life without Deaf education – it had been so much a part of who I was; I couldn't imagine my life without it. But, MS was a strong adversary and I could no longer ignore my limitations.

Deciding it is time to give up one's job is hard. Feelings of anger, depression, and despair fill your mind. Those old fears of loss of income and the consequences on our family come racing back, along with our own loss of identity and self-worth. Who are we when we are no longer identified by

the job we did? How can we feel like productive members of society when we don't go to work? What do I "DO" now?

But it is more than just the loss of a job, there is the social loss as well. The daily interaction with coworkers and friends is gone. We may be isolated at home, alone with our fear, anger, and other negative thoughts and feelings. Or we may have reversed roles, now our spouse goes to work and we are home with the children.

Major life changes are very stressful. Everyone in the family needs to accept the changes and find their new role. Don't

expect to be able to do this on your own.

If your employer offers an Employee Assistance Program (EAP), use it long before the day comes when you are no longer working. Basic EAP services include free, voluntary, short-term counseling and referral for various issues affecting employ-

ee mental and emotional well-being, such as alcohol and other substance abuse, stress, grief, family problems, and psychological disorders. EAP counselors also work in a consultative role with managers and supervisors to help address employee and organizational challenges and needs. If an EAP is not available to you, ask your doctor for a mental health referral so you and your family can make the transitions more smoothly. The Mental Health Association of Colorado offers



some good tips for overcoming job loss at <http://www.mhacolorado.org/pdf/LifeIssues/Job%20Loss.pdf>.

## Leaving Work

By the time I turned in my letter of resignation, I had already grieved for the loss of my job. However, for months after I retired, just thinking about my job brought tears to my eyes. For the next few years, I was included in department social activities; I loved seeing my colleagues and hearing about former students.

I remember when our neighborhood association was putting out its first directory; there was a space to indicate your profession and I cried because I had nothing to put in that space. At social events, I began to notice that no one ever asked me, “What do you do?” Maybe it was because I was in a wheelchair and they thought that people in wheelchairs didn’t “do anything.” I just sat there feeling like I had nothing to contribute. I applied for Social Security Disability Insurance (SSDI) benefits; when I received notification that I would begin receiving benefits because I was “totally and permanently disabled,” I went into a deep depression. Even the federal government thought I was completely and totally worthless!

## Reinventing Oneself

Try to see this time as an “opportunity;” a time to choose what you want to do for the rest of your life. Consider doing something you enjoy or always wanted to do. Go back to school; there are VR and other programs to fund tuition for people



with disabilities. Teach English as a second language or if you are a professional, share your expertise in your field as an adjunct professor at your local community college.

Another option is to start a home-based business. Professionals can become consultants (accounting, marketing, sales,

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IT) or chairman of the Board. You can turn something you do well into a business like Mrs. Fields® (maker of cookies and other baked goods) or combine the things you can still do to create a new job for yourself.

The internet has opened up a whole new way to work without leaving the house. For home-based business ideas, consult helpful magazines like *Inc.* and *Entrepreneur*, as well as books at your local library. You may also contact your area Small Business Development Center<sup>iv</sup>, Job Accommodation Network (JAN)<sup>v</sup>, Disability Biz<sup>vi</sup>, or ask about VR telecommuting programs.

As for me, about a year and a half after I retired from teaching, I wrote about being a mom with MS. Having no confidence in my writing ability and zero self-esteem, that story sat in my desk drawer for another six months before I had the courage to show it

to my closest friend. She thought the story was good and felt that it should be published. With her help and “holding my hand,” that story was published.

I’ve come a long way since then – I never thought I would be a professional writer nor did I think I would ever be a teacher again. But I’ve become both through my seven books, self-syndicated “Tips for Making Life Easier” columns, as well as articles, personal essays, and teleclasses (taught over the telephone).

I never had lofty goals for a future career after my diagnosis, and I wonder today if I would continue to write if I weren’t in a wheelchair with my dominant right hand “tied behind my back.” All I know is that I feel good about myself today after many years of traveling a difficult MS journey, where I have met and learned from people I would never have discovered otherwise.

### **Help Yourself by Helping Others**

Another great option with many rewards is to volunteer. Maybe you would like to become an MS peer counselor, mentor a child, or offer your services to organizations such as MSAA. Doing something for someone else helps to combat those feelings of being “totally and completely worthless.”

Surround yourself with people who build you up and give you the positive reinforcement you need to try something new. You may enjoy attending a support group, joining a garden or other hobby club, or taking a class just for fun.

When life hands you a page with some empty spaces, remember that you have the ability to fill those in with new ideas of your own. Take advantage of the abilities you have and find the things in life that you enjoy to do. Good luck. You can do it! ♦

## Resources

<sup>i</sup> **Americans with Disabilities Act (ADA) Information Line:** offers information to businesses, state and local governments, or others who call to ask questions and obtain free materials about ADA requirements, including questions about the ADA Standards for Accessible Design. Call (800) 514-0301 (voice) or (800) 514-0383 (TTY) weekdays 9:30 am to 5:30 pm Eastern time (Thursdays 12:30 pm to 5:30 pm), or visit the ADA website at [www.usdoj.gov/crt/ada/adahom1.htm](http://www.usdoj.gov/crt/ada/adahom1.htm); also US Dept. of Labor Disability Resources at <http://www.dol.gov/dol/topic/disability/index.htm>.

<sup>ii</sup> **Voice Recognition Software:** Dragon NaturallySpeaking at [www.nuance.com](http://www.nuance.com)

<sup>iii</sup> **Vocational Rehabilitation Programs** at [www.ssa.gov/work/ServiceProviders/rehabproviders.html](http://www.ssa.gov/work/ServiceProviders/rehabproviders.html)

<sup>iv</sup> **Small Business Development Centers** at <http://www.sba.gov/SBDC/sbdcnear.html>

<sup>v</sup> **Job Accommodation Network** at <http://www.jan.wvu.edu/>

<sup>vi</sup> **DisabilityBiz** at [www.disabilitybiz.org](http://www.disabilitybiz.org)



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# Stories to Inspire

## Baby Steps...

### One Goal at a Time

Written by Lauren Grossman

I'd love to be able to say, in an upbeat, perky way, that "I have MS, but it doesn't have me-e-e-e." But, I'd be lying. Multiple sclerosis has a firm grasp on my family and me. In some imposing ways, and in other almost imperceptible ways, MS has fingered itself into our lives. Lest you, the reader, after having read the first paragraph, think, "Oh no, not another depressing MS story," I want to share with you a heartening story.

I was not diagnosed after my first exacerbation 14 years ago. It was only one incident and I refused a lumbar puncture. Of course, 14 years ago, the ABC drugs were just emerging, so no treatment was encouraged.

Seven years later, my second exacerbation left me with a definitive diagnosis, a somewhat weakened body, aches, pains, a slight depression, and a great excuse for a part-time maid.

Working alongside my husband as his office manager, I was responsible for all the bookkeeping, which of course, included the reconciliation of bank statements. I was also responsible for bank statements at home, and I was treasurer of two different investment clubs. I counted up all the bank statements I was reconciling and found the number to be over twelve.



*Lauren and her husband Michael, who she refers to as her "hero."*

I was a busy woman. Immediately, my concerned husband of 15 years mobilized and removed the most unnecessary stresses in my life. He took over all of our finances at home, leaving me with only the office and investment clubs with which to deal. Very do-able.

Laundry became his domain. He even began doing the major food shopping once a week. After a long day at work, I would come home and col-

lapse, yet he would come home and cook dinner. Slowly, my husband...my hero...lifted away the extra and often unnecessary burdens I once shouldered.

Which is not to say that I am helpless. I still do plenty of my share of the housework; getting children ready for school, carpooling, planning parties, running an office, etc. After all, you still have to live your life.

They say, "The less you do, the less you can do." As I found myself doing less and less, I found myself being less involved in my two children's lives. No more hikes, no more throwing the ball around, no more school chaperoning trips, and no more kite flying. As I said, MS fingered its way into all of our lives.

If the less you do, the less you can do, then it only serves to prove the opposite is also true. The more you do, the more you can do. With that in mind, I began a care-

***“...each time I was on the treadmill, and a size-six woman in leotards would pass me, I noticed I walked just a little faster and sweated just a little harder. I would never look like her, but I would, at the very least, look like a better me.”***

---

fully worked out exercise plan to slowly and painlessly get my legs and body back into reasonable shape. But, please understand, for most of my adult life, the “e-word” (exercise) was not a part of my vocabulary. In fact, if I ever spoke that word it was always in a whisper. The thought of following a regimen of any sort was something I found, frankly, nauseating.

After one year I would be facing an event, which I decided to use as a focus to achieve a new goal. I wanted to be able to dance at my children’s B’nai Mitzvah. My daughter and son were to celebrate their combined Bar and Bat Mitzvahs. It was to be a weekend-long event for family and friends. Beginning with the service, a major party for 150 guests, and a Sunday brunch at our house, I knew I would not last if I did not start this workout regimen.

For nearly one year, I exercised

two times a week. No, it wasn’t easy. But, each time I was on the treadmill, and a size-six woman in leotards would pass me, I noticed I walked just a little faster and sweated just a little harder. I would never look like her, but I would, at the very least, look like a better me.

I began to notice a change in my body. My stomach was getting flatter, and my arms and legs were becoming stronger. I was actually capable of shopping again. The long walk from the overcrowded parking lot to the mall was no longer something I dreaded. My legs were becoming stronger. On the downside, if I did not work out, I found my legs began to hurt.

When the big day arrived, I DID dance continually at the party. I DID last on my feet the entire weekend. Of course, there is a lot to be said for adrenaline.



*Lauren, with the support of her family, achieved her goal of attending their children’s B’nai Mitzvah and participating in all of the activities.*

When the last guest departed, I put my feet up and they stayed up for two days. I expected that. I even prepared for that.

But I made it through one of my family's most important events in our lives. And happily, I was not sitting on the sidelines watching everyone else having fun. I was having a blast and bursting with pride in my family.

That was over three years ago. Over time, my visits to the gym became less and less. I was falling into the same old pattern. So, I have now set another goal. I plan on celebrating my 50th birthday in Hawaii with my wonderful husband. Every other morning, you will see me out for a brief walk to get my legs in shape. I understand there are a lot of nice shops in Hawaii.

Goal-setting has become my standard way of staying healthy. If I can just make it

to the next goal, I feel proud and strong. Baby steps... one goal at a time.

Yes, I have MS and it really does have me-e-e-e. But that's okay, because my family and I have proven that we can handle it together. ♦



*As the picture confirms, Lauren went on to achieve her second goal of celebrating her 50th birthday in Hawaii with her husband, Michael.*

### MSAA News

MSAA has a new website address! Please visit [www.msassociation.org](http://www.msassociation.org) for program information (including applications), important news, publications, and details about educational events scheduled throughout the year.

We want you to be the first to benefit from the enhanced functionality and information available through MSAA online. Please send your name and primary email address to [newsdesk@msassociation.org](mailto:newsdesk@msassociation.org) so we can advise you of information that is important to the MS community. Names and email addresses sent to MSAA are kept confidential.



March is MS Awareness Month. We hope that during the month you attended an MS educational program, volunteered to help someone you know with MS, or made a contribution of time or money to MSAA's mission. Of course, these things are urgently needed throughout the year to provide vital support and assistance to individuals affected by MS. For more information on how you can support MSAA, please call (800) 532-7667 or visit [www.msassociation.org](http://www.msassociation.org). ♦

*continued from page 47*

MS (listed earlier); riluzole (an oral medication used to slow the progression of ALS), Imuran® (azathioprine), methotrexate, cladribine, intravenous immunoglobulin (IVIg) and cyclophosphamide, stem-cell transplantation (also referred to as bone-marrow transplant), total lymphoid irradiation (TLI), pirfenidone (unapproved drug tested in idiopathic pulmonary fibrosis), and Rituxan® (rituximab), among others.

### Future Research with PPMS

As noted earlier, one of the drugs showing potential for the treatment of PPMS is Rituxan® (rituximab), which is currently in phase II/III clinical trials for this type of MS. It is presently approved for the treatment of certain cancers and rheumatoid arthritis, and is in trials for other conditions, including lupus. Rituxan is a monoclonal antibody which binds to the surface of antibody-producing B-cells in the immune system.

Looking to future treatments, researchers point out that the next line of MS drugs and therapies may be aimed at repairing and regenerating lost myelin and nerve fibers (axons). This would have the potential for a return of function, which is a vital goal in MS research. Some agents are showing this type of action in animal studies, but making the leap from animal studies to human trials can be a long and difficult transition.

Neuroprotection is another area of great interest for the treatment of all types of MS. If successful, this type of treatment would potentially protect the central nervous system from damage caused by an attack from the

body's immune-system cells. Theoretically, nerves and myelin would remain more intact, and patients would have fewer symptoms.

While scientists may need several years to accomplish such mighty goals, today's approved drugs for MS are effective in slowing down disease activity for individuals with relapsing forms of the disease. This has been a dramatic step toward a cure, and with studies now being directed to PPMS as well, researchers believe it will only be a matter of time before individuals with PPMS may also have access to several effective disease-modifying treatments.

For a complete list of references used for this article, please call MSAA at (800) 532-7667. ♦

*Written by Susan Wells Courtney*

*Reviewed by Dr. Jack Burks*

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# Spread the Word



## **MS and Your Feelings**

Written by  
Allison Shadday, LCSW  
Published by  
Hunter House Publishing  
MSAA Book #62

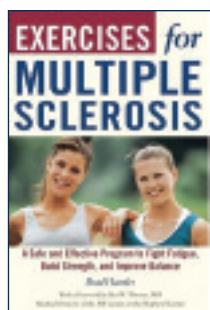
The author is not only a medical/clinical social worker, but was also diagnosed with MS in 1994. Combining her training, professional experience, and personal understanding of the disease, Allison Shadday is able to provide an “insider’s guide” to dealing with the emotional ups and downs that accompany MS. This book offers coping strategies and patient stories to address numerous topics including fatigue, cognitive challenges, depression, self-esteem, relationships, and more.



## **Complementary and Alternative Medicine and Multiple Sclerosis**

Written by  
Allen C. Bowling, MD, PhD  
Published by Demos  
Medical Publishing  
MSAA Book #91

Dr. Allen Bowling has spent many years focusing specifically on complementary and alternative medicine (CAM) and how some of these therapies may provide symptomatic relief for individuals with MS. In this book, Dr. Bowling gives an overview of the many types of popular CAM therapies, along with their potential benefits and/or risks.



## **Exercises for Multiple Sclerosis**

Written by Brad Hamler  
Published by Hatherleigh Press  
(A “Healthy Living Book”)  
MSAA Book #43

Brad Hamler is a fitness professional and licensed postrehabilitation specialist who has worked extensively with MS patients. This book is filled with useful photographs illustrating how to perform each exercise safely and effectively. In addition to information on MS, exercise, gait analysis, and different types of training, the author shows you how exercise can reduce fatigue, increase strength, decrease spasticity, improve balance, and provide other benefits.

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