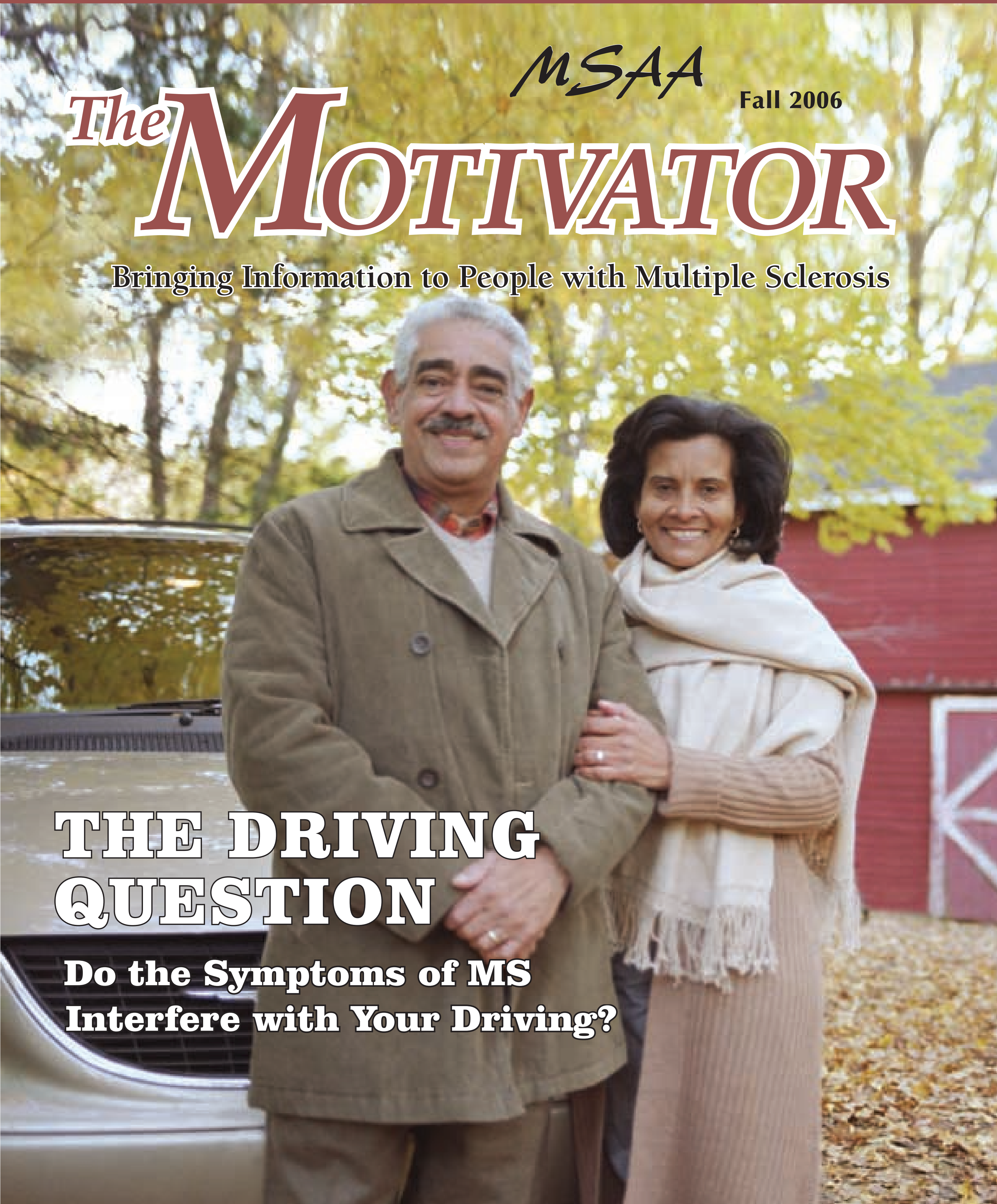
MS Nurses Wear Many Hats • Strategies for Treating Weakness



MSAA

Fall 2006

The MOTIVATOR

Bringing Information to People with Multiple Sclerosis

THE DRIVING QUESTION

Do the Symptoms of MS Interfere with Your Driving?

The MSAA Motivator

Published by the Multiple Sclerosis Association of America

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By Shelley Peterman Schwartz
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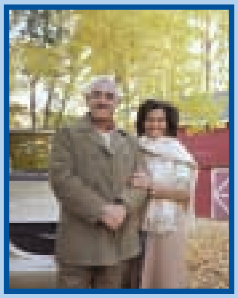

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The Multiple Sclerosis Association of America's mission is to enrich the quality of life for everyone affected by multiple sclerosis.

Up Front

By Douglas G. Franklin
MSAA President and CEO

MSAA has experienced explosive growth in the delivery of our programs and services. When I first started with MSAA in 1999, the charity had distributed 100 pieces of equipment the previous year. During the last fiscal year (July 2005 – June 2006) we distributed more than 10,000 pieces of equipment. Our toll-free Helpline is averaging 1,200 calls per month – that's over 14,000 calls for the year! We performed 149 home modifications in 36 states last year. We are doing all that we can to help more people with MS in more places in meaningful, sustainable ways. The quality of our services is second to none and we are very proud of that.

Like any charity, MSAA depends on the kindness and support of its contributors. We are very fortunate to have many individual and corporate supporters believe in what we do and give generously to help us fulfill our mission. We cannot, however continue to grow without significant increases in the number of donors and the amount of support.

We are pleased to provide our services for free, but we can only do this if everyone reaches out to their own networks of friends, family, coworkers, and community members to help MSAA help others. Donations make our work possible. All donations are important and every dollar counts. We simply can't do it without your support.

To follow are just a few quotes taken from actual letters received by MSAA:

"I wanted to send you a note of thanks for the cooling equipment you sent to me this summer at no charge. It really made a difference in the way I felt when I attended outdoor events. This program of yours is truly appreciated so a big THANK YOU to you!!"
— L.C. from Pawleys Island, North Carolina

"I just want to thank you for all of the equipment I received from your wonderful program. I just want you to know that the items have allowed me to do things I have not been able to do on my own in a long time. Thank you just doesn't seem like enough."
— R.W. from Westminster, Colorado

"Thank you for assisting me with funds for modifying my bathroom, cooling equipment, and all of the educational articles in *The Motivator*. My quality of life has intensified. I feel empowered and in control of myself and adversities I may encounter. I can't thank you enough."
— N.M. from Erie, Pennsylvania

Please help MSAA "enrich the quality of life for everyone affected by multiple sclerosis." Help us be a "lifeline for a lifetime!" To make a donation to MSAA or to inquire about volunteering or fundraising, please contact MSAA at **(800) 532-7667, extension 159**, or visit our website at **www.msaa.com**. ◆

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 Annette M. Howard

Annette M. Howard, MD, is the most recent addition to MSAA's Board of Directors. Prior to her election to the Board this past May, Dr. Howard became involved with MSAA through Dr. Jack Burks, MSAA's vice president and chief medical officer. "I first joined MSAA as a member of MSAA's Healthcare Advisory Council (H.A.C.). Dr. Burks came to me and asked if I would be a member," says Dr. Howard. "From there, I was able to see first-hand the wonderful programs and services my patients have been talking about."

After medical school, Dr. Howard found neurology to be very interesting. She explains, "With neurology, there were a lot of questions and not a lot of answers. I always thought I would be learning if I stayed in this field." Following her residency at Baylor College of Medicine, Dr. Howard took over the practice of a neurologist who specialized in MS. "My patients were the ones who were teaching me that MS is more than just a person experiencing symptoms – there is a heart and soul inside that body," says Dr. Howard. "My patients taught me compassion and understanding, helping me to figure out that MS is my niche."

In 2001, Dr. Howard opened her clinic, the Multiple Sclerosis Institute of Texas, with the idea of treating the whole patient and taking care of the patient over his or her entire lifespan. She recognized that MSAA is a good fit for this type of care. "I see MSAA as an organization that provides services to patients for their lifetime," says Dr. Howard. "MSAA provides the bridge that gets the person from being newly diagnosed, to living and excelling in their daily lives with MS."

Dr. Howard is originally from Houston, Texas and still resides there today. She enjoys spending her time doing service-oriented activities and reading. Dr. Howard is a self-proclaimed "news junkie," as she is always tuning in to see what is happening on CNN, MSNBC, and Fox news shows.

— *Amanda Bednar*

THE DRIVING QUESTION

Do the Symptoms of MS Interfere with Your Driving?

By Shelley Peterman Schwartz

Edited and portions written by Susan Wells Courtney

My Own Story: The Last Time I Drove a Car

September of 1985 was the last time I drove a car. I vividly remember following my husband Dave to the Chevy dealership to have some work done on our Impala. He drove "my car," the Ford Pinto with a stick shift that required more strength and energy to drive than the automatic.

For months leading up to that day and the days following, I was severely depressed about losing my ability to drive and the independence that driving represented. Our children were ages 11 and nine; I was 39… and knew that I would never drive again.

Today, 21 years after that emotionally painful day, I can look back without the pain and sadness. I understand why I began grieving the loss long before I gave up driving, and why I found excuses not to drive. It took months and months to come to terms with how my MS was affecting all aspects of my life, and as my MS worsened, I began to feel unsafe behind the wheel. That day in September, I knew it was time to hang up my keys.

I can honestly report that my life did not end when I gave up driving; it just changed. As time went on, I found ways to manage. Perhaps some of the lessons I've learned will help you to drive longer and with greater safety than I was able to – given the technology and adaptive devices that are available today.

Are You Able to Drive Safely?

This is a scary question, but one you MUST answer honestly. Do symptoms such as fatigue, tremors in your legs, hand strength or coordination, vision problems, or cognitive function affect

your driving? Talk openly and honestly with your family and/or your doctor. You don't want to put yourself, your family members, or anyone else at risk because your skills, thought processes, or reaction times are not up to par.

For me, leg tremors, strength to turn the key in the ignition, and fatigue were the symptoms that got my attention. As much as I wanted to continue driving, I was terrified of being involved in an accident because I might hurt someone else, and I certainly didn't want the adverse effects an accident might have on my MS.

In an effort to hold onto our freedom to come and go as we please, we may initially be in denial about our driving abilities, ignoring the signs that may tell us it is time to restrict or even give up our driving privileges. For instance, many individuals with MS have visual problems, which might limit their side (or peripheral) views, while others may experience blind spots. Maybe signs and traffic signals have become difficult to distinguish, and judging distances and the rate of speed that other drivers are going has become challenging.

Other MS symptoms may include weakness, reduced coordination, and slower reaction time. Being able to quickly move your foot between the gas and brake peddles at appropriate times, as well as precise steering and signaling, are crucial when driving. Following signs and the rules of the road, making snap decisions while speeding along the roadway, interacting with other drivers, and knowing where to turn and when to stop… can all be affected by reduced cognitive functioning.

If you or someone you are close to has MS and can see that the symptoms are interfering with the ability to drive safely, then you must view the situation objectively. Identify exactly what symptoms are having an effect on driving and investigate to see if any solutions are available. The first place to look would be with your medical professional, to see if any symptom-management strategies or medications may be of help.

If nothing new may be done medically, you can look to other possible solutions. Perhaps these symptoms are not as pronounced earlier in the day – in which case driving could be limited to the morning hours. Maybe fatigue is the issue and keeping the drive time down to shorter distances may resolve the danger of becoming tired and weak. If fatigue or other symptoms are a result of heat sensitivity, then staying inside during warmer times, and possibly using a cooling device, may be helpful. Adaptive devices (listed later in this article) are also available to assist with specific limitations.

When no solutions may be found and the symptoms of MS are compromising the safety of the driver and anyone else on the road, the time has come to stop driving. This freedom is not worth risking your own safety or that of others. Even if you work or have a family, options are available, and life will go on!

Wondering How You Could Survive Without Driving?

I admit that it's difficult to get your mind around all the things we do that require driving, but I found ways to manage and it helped make me stronger. I asked people who were going to the same meeting, event, or activity to pick me up. For people who frequently drove me (or the kids), I gave them gas money. I didn't feel as guilty asking for a ride and they appreciated my monetary “thank you.” Today, with inflated gas prices, it makes sense to carpool.

When people said, "Let me know how I can help," I did. My friends have picked up a few things for me at the grocery store, taken my books back to the library, and dropped off prescriptions from the pharmacy, among other errands. Even a trip to the doctor’s office or hairdresser’s can be managed when arranged in advance. These small favors usually require little time and trouble for others to do – often they can tie them in with their own errands – and people feel good when they can help.

When family or friends are not available, other resources for transportation may often be found. These might include religious organizations, charitable groups, and government social services. Some resources may be listed in the phone book under “transportation,” and readers may also contact their State Office of Disabilities or their area’s Agency on Aging for additional sources of transportation. Anyone in need of further assistance may speak with an MSAA Helpline consultant at (800) 532-7667.

Using Adaptive Devices for Assistance

If you, your family, and your doctor have determined that with some modifications, it would still be safe for you to continue driving, there are a number of energy-conserving and adaptive products that could make driving a little easier for you. A few of these products are described in the following sections.*

Getting in and out of the car

The CarCaddie™ is a portable handle that offers you stability when getting in or out of a car, van, or truck. Easy to install, it straps around the top of the window frame providing a cushion grip to hold on to. Because it is adjustable and not permanently installed, it can be moved to other vehicles (although not suitable for convertibles or other vehicles without an enclosed window frame). The cost is about $20.

The Handybar™ is a forged-steel-shaft support handle with a soft, non-slip grip that helps you get in or out of the car with ease. Capable of safely supporting up to 350 lbs, the removable bar inserts into a "U-shaped" plate installed on your vehicle door frame. It can be used on both driver and passenger side doors and the price is about $35.

If you use a wheelchair or scooter and are able to transfer, Bruno Independent Living Aids Inc., offers several Turning Automotive Seats that use or match existing

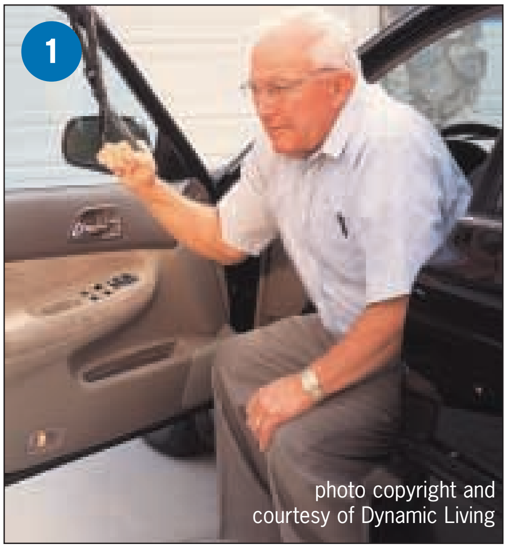

photo copyright and courtesy of Dynamic Living

(1) The CarCaddie™ by Dynamic Living® offers stability and ease when getting in and out of your vehicle. (2) The Blind-Spot Mirror by Driving Comfort provides a panoramic view that is up to two-and-a-half times wider than the standard side mirror. (3) The Bruno Carony Automotive Seating System offers a no-lift solution that integrates a seat and convertible wheelchair combination. (4) The Remote Key Pocket Extension by Mobility Products & Design fits a remote key and gives better leverage when starting your vehicle.

photo copyright and courtesy of Driving Comfort

photo copyright and courtesy of Bruno Independent Living Aids, Inc.

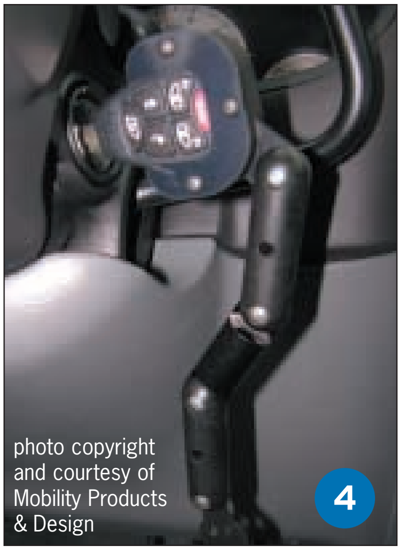

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photo copyright and courtesy of Bruno Independent Living Aids, Inc.

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(5) The Tri Pin Grip by Mobility Products & Design uses Push/Pull Control movement to engage the accelerator and brake. (6) Extension Controls by Mobility Products & Design give extra leverage when operating your gear selector (as shown) and turn signals. (7) Bruno™ offers a complete line of Turning Automotive Seating™ products that allow you to effortlessly enter and exit your vehicle. (8) The Handybar™ by Dynamic Living® provides extra support for getting in and out of your vehicle.

seating. Some seats just swivel, while other models have power controls that allow you to pivot and lower the seat to your level making transferring easier. Check with Bruno's application experts to confirm compatibility with your vehicle (including sedans, SUVs, wagons, crossovers, minivans, pickup trucks, and full-size vans).

Bruno also offers special lifts to pick up your wheelchair and load it in and out of your vehicle. One model (The "Carony Turning Automotive Seating" system) even converts from a fully cushioned car seat into a wheelchair, making a separate lift unnecessary.

Most seats range in price from $1,000 to $7,000. Many automobile manufacturers provide a discount for these special seats when installed in new vehicles. If you use your vehicle to provide transportation to work, your local Department of Vocational Rehabilitation (or state agency that helps people with disabilities receive work-related accommodations) may pay for part or all of the cost.

Other adaptive devices to make driving easier

Adaptive Key Devices fit on your regular key and give better leverage to make turning keys easier. Hardware stores and home healthcare stores have different styles from which to choose. Be sure to try them first to see which works best for you.

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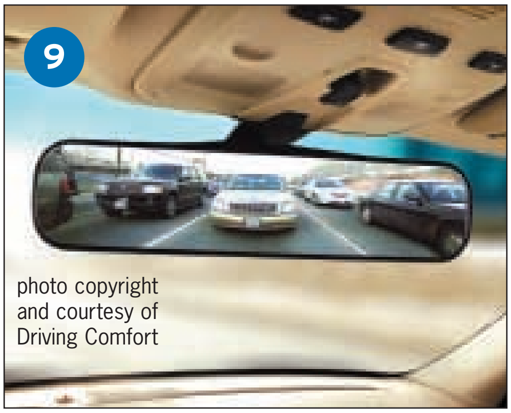

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(9) The Panoramic Rear View Mirror widens your field of vision to make changing lanes and merging easier and safer. (10) The easy-to-install Backup Alert lets others know you are backing up. (11) The ScopeOut® SUV Backup Mirrors increase the field of view when backing up or changing lanes. All three products on this page are from Driving Comfort, a division of International Auto Parts.

One device, the “Key Holder,” is a large ergonomically-designed handle which holds a key in position to offer maximum leverage. It holds up to two straight metal keys (for house or auto), which fold away into the curved handle when not in use. The price is $8.

An Automatic Car Starter/Keyless Entry System might be helpful if you have difficulty using keys. Install on any automatic transmission, fuel-injected vehicle and you can lock, unlock, or start your car from up to 2500 feet away. This is priced at $65 and up.

If the turn signal is on the wrong side for you to operate, the extension control, right-hand turn signal extension is a lightweight, crossover lever that operates your turn signals easily. This is installed using bands, not screws, so your vehicle's interior remains in its original condition. It meets or exceeds VA (Veterans Affairs) specifications.

Do you have trouble turning your head or problems with your peripheral vision? You can install panoramic or wide-angle rear and side-view mirrors to widen your view. By using the regular and wide-angle mirrors together, you’ll have greater visibility and won’t have to turn your neck as much. Some mirrors have double sided tape on the back of them so they're easy to install; others attach with screws. These range in cost from $20 to $30.

For added safety when backing up, you can install a Back-Up Alert warning alarm and light. Just replace one of the backup lights in your light truck, RV, car, or van with this combination beeper and tail light. Whenever your vehicle is in reverse, it will automatically emit a continuous beeping sound. Installation is as easy as changing a light bulb and the device is guaranteed for as long as you own your car. The cost ranges from $30 to $40.

Trouble managing your seatbelt? You could use a seatbelt extender, which is a piece of seatbelt material about eight inches long with a buckle on the end that clicks into the existing seat belt. Originally designed to provide extra room for larger drivers and passengers (over 215 pounds), it makes the seatbelt easier to grasp, pull, and buckle for people with arm, shoulder, or strength limitations. Unfortunately, seatbelt extenders are not a universal fit and some car models do not even offer the device. Some dealers will include the extender when you purchase a new car. If interested, you may contact your car dealership to see if there is a seatbelt extender for the car you drive.

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(12) Drivease by Driving Comfort is a molded rubber insert that minimizes leg pain while supporting the sciatic nerve and lower back. (13) The Parking Brake Extender by Mobility Products & Design makes setting your parking brake an easy task. (14) The Original Sticky Pad by Driving Comfort is a "grippy" surface to hold cell phones, sunglasses, and other necessities on your dashboard.

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photo copyright and courtesy of Driving Comfort

Take Advantage of Services for Drivers with Special Needs

All states offer temporary and permanent disabled parking permits and license plates for people who are unable to walk or have difficulty walking. In most cases, the permit must be authorized by your physician. The disabled parking permit allows holders to park in designated handicapped parking spots, as well as metered street or municipal parking spots of one-half hour or more, without time restrictions (unless otherwise posted). For more information about disabled parking permits, contact your state Department of Transportation (DOT) about the requirements and application procedures where you live.

Every car needs gas. However, how do you obtain your gas if you have strength or mobility limitations? The federal Americans with Disabilities Act (ADA) requires that gas stations, including self-service, provide refueling assistance at the same price as self serve to disabled patrons. Please note that patrons must ask for the discounted price. For more information contact the United States' Department of Justice ADA Information Line at **(800) 514-0301** (voice) or **(800) 514-0383** (TDD) or look for more information online at **www.ada.gov/gasserve.htm**.

If You Get Pulled Over While Driving

Most law enforcement officers are trained on techniques and procedures for interacting with people with disabilities. However, if your speech, coordination, or walking abilities are impaired, being stopped by a police officer could lead to miscommunication and misunderstandings. As a safety precaution, keep an informational card handy.

The Rocky Mountain MS Center offers identification cards for individuals with MS. The card includes your name, address, physician's name and address, as well as emergency contact on the one side; common symptoms of MS (such as problems with balance, walking, speech, and vision) are listed on the other side. When submitting the application for the card, the diagnosis of MS will need to be confirmed by your physician.

The center recommends that you keep

this card in a convenient place, such as in your wallet near your license. For more information, readers may visit their website at **www.mscenter.org** and select "Get Your MS ID Card" on the right side of the page. Individuals without access to the internet may call the center's toll-free number at **(866) 557-7030**, or locally at **(303) 788-4030**.

If you are pulled over, safety tips to follow include:

- Pull over to the shoulder or other open area on the right
- Turn on the car's interior light
- Place both hands on the steering wheel
- Wait until the officer arrives, then provide the informational card along with your license
- People with speech or hearing problems may want to communicate by writing. Drivers and law enforcement officers can request an interpreter, especially if communication is complicated or the charge is serious.

Law enforcement officers may initiate a medical review either from personal observation or if a number of complaints have been received from citizens.

If Concerned about a Driver's Ability to Drive

If you're concerned about a family member or friend who you feel should have his or her driving skills re-evaluated, contact your state Department of Motor Vehicles (DMV) or Department of Transportation (DOT) for the rules and regulations regarding drivers with a disability.

You might also want to mention your concerns to the driver's physician. For privacy reasons, the doctor may not be able to discuss his or her examination results. The physician can, however, fax a simple letter regarding his or her concerns to your state DMV. They will act on the doctor's recommendation and suspend the driver's license. In most states, if doctors have reason to believe an individual's driving is impaired, they must report it.

A private citizen or family member may also report an unsafe driver to the state DMV or DOT. They will need to obtain a medical review form from the state and have a second party witness to begin the review process. The specific details of this process may differ from state to state.

Drivers can appeal the decision. Licenses can be restricted; for example, driving may be limited to staying within five miles from home, no highway driving, or no driving at night. Please note that if the person gets better and can prove his or her ability to drive, driving privileges may be reinstated.

Drive or Ride Safely

Dr. Jack Burks, MSAA's vice president and chief medical officer, explains, "An often-overlooked medical issue is the effect of medication on driving. Certain medications cause fatigue, inattention, drowsiness, and cognitive problems. Individuals need to ask their doctor about the effects of their treatment before getting in the driver's seat."

Dr. Burks continues, "Independence is an honored value. As disability occurs, some people fight as hard for the right to drive as any sixteen-year old. For teenagers, it is paramount in their minds – as witnessed by their zeal for driving. The issue is the same, control and independence.

"Alternatively, the issue is safety in both groups. Many people with MS cope more readily with a cane, scooter, or wheelchair than giving up driving. The struggle between independence versus safety (theirs and others) is not easy – and the answer is not always obvious. Soul searching, counseling, and a driving evaluation may all be needed.

"Once the decision has been made to stop or restrict driving (for example, limiting one's driving to daylight hours within the local neighborhood), the adjustment may actually reduce anxiety and stress. Family members and friends often become more involved and relationships can grow closer. Figuring out bus schedules and handicap transportation options stimulate people's creativity, although one must be prepared for frustration at times. With thoughtful trip planning, such efforts can also increase efficiency when several trips to the store are avoided."

Dr. Burks concludes by noting, "As the famous ski racer, Jimmie Heuga tells the participants at the Heuga MS Wellness Center, 'It is not the cards you're dealt in life that matters, as much as the way you play those cards.' Adjusting to changes in their driving status, whether limiting or discontinuing their operation of a motor vehicle, can be a blessing to some MS patients -- especially if they no longer feel safe behind the wheel." ◆

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*Please note that MSAA does not endorse or recommend any specific product or service. The products in this article are used only as examples. Interested readers will need to determine on their own the value of any product or service listed. MSAA cannot be held responsible for the use of these items and any possible issues that may result. This article is for informational use only; decisions to drive and to use specialized equipment may only be made by the individual with MS, family members, and medical professionals.

Assistive Devices to Help with Driving

For more information on the assistive devices mentioned in this article, readers may contact the businesses shown below.* In addition to the products listed, many of these companies offer other assistive products for the car and home.

Dynamic Living
428 Hayden Station Road
Windsor, Connecticut 06095-1302
Phone: (888) 940-0605
Website: **www.dynamic-living.com**

- The Car Caddie™
- The Handybar™
- Key Holder

Bruno Independent Living Aids, Inc.
1780 Executive Drive, PO Box 84
Oconomowoc, Wisconsin 53066
Phone: (800) 882-8183
or (262) 567-4990
Website: **www.bruno.com**

- Turning Automotive Seating system
- Turning seat and convertible wheelchair combination

GNU Industries, Inc.
1919 NW 19th Street Building 1A
Ft. Lauderdale, Florida 33311
Phone: (800) 780-1409
Website: **www.commandoalarms.com**

- Automatic Car Starter
- Keyless Entry System
- Back-up alert

DesignTech International, LLC.
1 Viper Way
Vista, California 92081
Phone: (800) 274-0200 for retailer
Website: **www.designtech-intl.com**

- Automatic Car Starter
- Keyless Entry System
- Back-up alert

Mobility Products & Design
PO Box 306, 144 South 100 West
Winamac, Indiana 46996
Phone: (800) 488-7688
Website: **www.mobilityproductsdesign.com**

- Hand, foot, and steering controls
- Key, turn, gear, and parking brake extensions

Driving Comfort.com
PO Box 9036
Charlottesville, Virginia 22906
Phone: (800) 675-5411
Website: **www.drivingcomfort.com**

- Panoramic rear view mirror
- Wide-angle side mirrors
- Back-up alert

For information on driver rehabilitation specialists, you may visit The Association for Driver Rehabilitation Specialists at **www.driver-ed.org.**

*Please note that MSAA does not recommend or endorse any specific product or service; readers are responsible for the evaluation and use of any items they select.

PUTTING PATIENTS FIRST

MS Nurses Wear Many Hats to Deliver Superior Care

By Christine Norris

MS Nurses and Nursing Certifications

Nurses who specialize in multiple sclerosis perform many roles to establish care, continue care, and sustain care. They not only help diagnose and treat the disease, but also support a wellness-oriented quality of life through education and advocacy. These experts also help families cope with the often difficult byproducts of MS, such as job loss or reduction in hours worked, depression, changing family roles, and sexual dysfunction.

"MS Nurses must leap tall buildings in a single bound, incorporating the qualities of teacher, leader, advocate, caregiver, social worker, Florence Nightingale, and cheerleader," says June Halper, an MS Certified Nurse (MSCN), Adult Nurse Practitioner (ANP) and Fellow of the American Academy of Nursing (FAAN). Halper holds the positions of executive director of the Consortium of Multiple Sclerosis Centers and executive director of The MS Center at Holy Name Hospital in Teaneck, New Jersey. Approximately 2,500 clients are seen yearly at her center. June Halper is also a member of MSAA's Healthcare Advisory Council (H.A.C.).

Another member of MSAA's H.A.C. is Advanced Practice Nurse (APN) Amy Perrin Ross, MSCN, who works as the neuroscience program coordinator for the MS Center at the Loyola University Health System in Maywood, Illinois. With 25 years of experience as an MS Nurse, Perrin Ross agrees that the role of MS Nurse has expanded. “It’s much better now than when I started. Before there was a great need for case management. Now my role is more to help patients understand the importance of remaining adherent to disease modifying therapies and to assist them with symptom management,” she says. “But the biggest issue is helping them negotiate the healthcare system in this country. It’s incredibly cumbersome.”

Halper stresses that it’s important to know that all nurses working with MS patients cannot be grouped together generically. They have different levels of education and preparation. Specific certifications include: LPN (Licensed Practical Nurse), RN (Registered Nurse), BSN (an RN with a Bachelor of Science degree in Nursing), and MSN (Master of Science degree in Nursing).

“The MS Nurse comes in a variety of packages, and nursing services for individuals with MS can be provided by a wide variety of nurses. Their level of preparation determines how much care they can give patients. For example, some of my colleagues can only renew prescriptions, while I can prescribe them,” says Halper. “Nurse practitioners and advanced practice nurses are more knowledgeable with helping patients manage specific MS problems than a non-specialized nurse. For instance, they can identify the high-risk factors for mental illness, such as depression, and can find different models of intervention to help.”

To earn the designation MSCN (MS Certified Nurse) from the Multiple Sclerosis Nursing International Certification Board (MSNICB), nurses should have experience in caring for MS patients over the course of at least two years and pass a comprehensive exam. The MSNICB has more than 600 MS-certified nurses around the world.

Besides helping nurses obtain their MSCN certification, the International Organization of Multiple Sclerosis Nurses (IOMSN) provides networking opportunities and support services to help members achieve their goal “to positively impact the care of people who are affected by MS." To become an APN (Advanced Practice Nurse), a candidate must have a certain amount of clinical experience, pass national licensing exams in order to practice, and maintain the licenses through ongoing educational activities and testing.

To receive the ANP (Adult Nurse Practitioner) designation, candidates must have a master's degree in healthcare and complete a number of post-master's courses in their specialty. The Consortium of MS Centers (CMSC) also provides education and support to its growing roster of MS Nurses.

Although Halper says that patients prefer working with a nurse who is knowledgeable about MS, she points out that doing so is not always realistic. "In certain parts of the country, there may be only one nurse with that kind of experience."

To close that gap, the IOMSN is helping experienced RNs gain valuable experience in the specifics of MS through two-day, onsite apprenticeships with an advanced practice MS Nurse. Perrin Ross recently hosted a nurse at Loyola for the program. "It's an invaluable experience for the person visiting. By watching what I do, the nurse sees how much care an MS Nurse gives," she explains. "The practice of medicine has changed. We [MS Nurses] fulfill a big part of the role that doctors and social workers used to fill. MS patients really need someone now to coordinate their care. They need someone to look at the overall picture and to access the resources that they need."

> **"Individuals with MS really need someone right from the start to coordinate their care. They need someone to look at the overall picture and to access the resources that they need."**
>
> —Amy Perrin Ross, APN, MSN, MSCN

All the pharmaceutical companies that produce disease-modifying medications for MS also offer nursing services to patients (see "Helpful Nursing Resources" on p. 31). These may include such services as toll-free hotlines staffed with registered nurses and in-home visits to train patients in the safe administration of medication and management of side effects. These nursing services were developed to assist the client and healthcare team in reducing side effects and increasing adherence to therapy.

The IOMSN has established certain criteria for its members to follow. It is a three-pronged approach that includes establishing care, continuing care, and sustaining care. All three are crucial in helping individuals with MS live well with the often unpredictable course of the disease.

Creating a Treatment Plan

The MS Nurse works side-by-side with the neurologist to create a treatment plan. "It's our job to recognize symptoms. The

nurse should ask the patient: 'How are you doing? Are you better, worse, or the same as your last visit? How are you walking? Are you finding it difficult to climb the stairs?' By helping to identify these potential problems, nurses fulfill one of the most important roles in the care of the MS patient," says Halper. "By doing so they also acknowledge the patient as a person who has to deal with the disease."

MS Nurses are taught to ask the necessary questions and to order the necessary tests for common primary symptoms, including fatigue, depression, focal muscle weakness, ocular changes, bowel and bladder problems, sexual dysfunction, gait problems, spasticity, and paresthesias (numbness and tingling). Additionally, MS Nurses are knowledgeable about detecting less common symptoms, such as dysarthria (slurred or otherwise impaired speech), Lhermitte's sign (electric-like sensations caused by flexing the neck), neuritic (nerve) pain, vertigo, cognitive dysfunction, tremor, and loss of coordination. They must also be aware of rare symptoms, which include decreased hearing, convulsions, tinnitus (ringing in the ears), mental disturbance, and paralysis.

MS Nurses must know the different classifications of MS, how each type behaves, and how to best treat them. The different types of MS are: relapsing-remitting (RRMS); secondary-progressive (SPMS); primary-progressive (PPMS); and progressive-relapsing (PRMS). The goals of current therapies are to control relapses, delay disability, alleviate or modify symptoms, and to enhance quality of life. Current therapies at their disposal include anti-inflammatory agents, immunosuppressants, immunomodulators, symptom-management medications, rehabilitative services (such as physical therapy), counseling, and education.

Perrin Ross says that it can be very difficult for individuals who are newly-diagnosed to even consider taking disease-modifying or preventive medications. "They don't want to take medications that will possibly make them feel worse. They also hear all of these horror stories about the side effects of medications and aren't willing to consider injections, especially if they're young. They don't want to have red spots on their arms and legs which are visible reminders of the disease. They don't want them to be seen," she explains. "It's our job to help them understand the 'silent' aspects of the disease, such as lesions that develop during the time they're not on a preventive medicine."

Managing Symptoms and Side Effects

"Even when patients do agree to go on disease-modifying therapies," Perrin Ross adds, "it's difficult to get them to remain on the therapy, especially when they have the relapsing-remitting form of the disease. If their MS is in remission, they don't see the need to take the medication."

To reduce side effects from medication and to increase long-term adherence, Perrin Ross uses "dose titration," which is the practice of starting off with a one-quarter dose and slowly increasing to a full dose. This strategy was developed through the network of IOMSN nurses. "I often give non-steroidal anti-inflammatory medications (such as ibuprofen) or acetaminophen to reduce the flu-like symptoms associated with the interferons," says Perrin Ross. "I also stress the idea of injection-site rotation. If the injection site is moved, tenderness and swelling are less likely to occur."

MS Nurses regularly provide telephone support to patients concerning medication side effects or injection-site problems, but only to a certain extent. "Telephone support is very important, but if the patient calls more than twice about a particular problem, then they have to come into the office for treatment," says Halper. "It's very inappropriate to treat patients over the phone. For example, if a person has suicidal thoughts, how would you know that if you don't see the person?"

According to Halper, telephone support can best be given by nurses at an MS clinic or neurological practice for MS to clarify points discussed at a visit or to screen

continued on page 28

patients before a visit. "Additional telephone support should come from established organizations, such as the Multiple Sclerosis Association of America (MSAA) or the National Multiple Sclerosis Society (NMSS). There are also nurses from pharmaceutical companies that can answer questions or even visit patients when necessary," explains Halper.

To educate clients and their families about MS and its effect on their lives, MS Nurses distribute information from organizations such as MSAA and NMSS. They also encourage patients and their families to attend support groups. "For young people just diagnosed with MS, we also help counsel them about what it will be like to live with MS, especially if they are planning on having children and a career," says Perrin Ross. "It's so important to help families understand what patients are going through, especially if they're in remission. Although their loved one may be doing fine, they still have to understand that heat and fatigue management is key."

The MS Nurse must also be sure that the client is following the instructions for taking medications, exercising, reducing stress, getting enough sleep, and visiting his or her primary-care provider regularly. Moreover, it's the nurse's job to recognize if any outside factors, unrelated to MS, may be worsening symptoms – such as poor sleep causing fatigue, or caffeine and artificial sweeteners irritating the urinary tract.

The role of the MS Nurse also involves helping the severely disabled manage the disease. "They must have a primary-care physician to keep on top of their overall physical health. It's important to manage respiratory infections and to ensure that patients are having their PAP smears, mammograms, and other tests. This shouldn't be left up to the MS physician," says Perrin Ross. "Many patients blame everything on MS, but it's often their overall health that's problematic."

It's also important to encourage clients to continue their physical therapy or other rehabilitative therapy even when formal visits have stopped. "No insurance company pays for maintenance rehabilitative therapy with MS. Patients have to know the types of gains they are receiving from the therapy and to keep doing the exercises after the physical therapy ends," says Perrin Ross.

Complementary therapies, such as

hippotherapy (therapy through horseback-riding), yoga, and aqua therapy (water exercises), have also been found to be beneficial to MS patients regardless of their level of disability. "Exercise helps physically but also mentally," says Perrin Ross. "Aqua therapy is especially good because it allows patients to move their muscles without the weight of gravity. They don't get too fatigued, so they get a good workout."

Advocating for the Patient

To ensure that the patient receives the support services needed, the MS Nurse must act as an advocate. "Our biggest role, and the role that takes the most time, is advocacy," stresses Halper. "Sometimes we're the voice for the patient when he or she doesn't realize that certain symptoms, such as loss of bladder control, are NOT acceptable. We explain that while a symptom is a part of MS, we can make it go away, or at least greatly help to reduce its effects."

In this role, MS Nurses spend a lot of time pre-certifying clients through insurance companies for care. "We spend a lot of time advocating for patients, helping to get approval from insurance companies for medications and to pay for another MRI," says Perrin Ross. "We also advocate for patients in the community and in the workplace. For example, getting the provisions of the Family and Medical Leave Act (FMLA) to apply for a patient's specific needs and making workplace accommodations."

Perrin Ross adds that at her center, if a patient needs to see a neuropsychologist, physical therapist, occupational therapist, speech therapist, nutritionist, or home-care aide, it's easy to arrange because they're on her staff. "It's more difficult in cases where patients are not treated at an MS center, but it can be done. It just takes more time to accomplish," she emphasizes.

Keeping a Positive Outlook

To promote optimism and hope, the IOMSN encourages MS Nurses to help patients find and define "MS-free zones" in their lives. An MS-free zone includes activities where MS does not need to play a role – such as socializing with friends and family; enjoying a good book, a movie, or attending a show; participating in gardening and other hobbies; and any other enjoyable activity where MS may be left behind. MS Nurses are also encouraged to: acknowledge the grief and loss accompanying MS; accentuate the positive; and tap into their spiritual side. To accomplish this, MS Nurses must establish a creative partnership with patients, one with an emphasis on positive outcomes by setting realistic goals.

"The uncertainty of MS is difficult. That is one reason why the rate of depression is so high with patients. We are striving to make the uncertainty more manageable for patients, but that's the toughest part of education," says Halper. "Often after their first relapse, patients feel hopeless and sad, wanting to give up. It's our challenge to continue advocating for them and to keep them hopeful." ◆

About the Author

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

For Additional Information

Helpful Nursing Resources

Created and managed by the pharmaceutical companies that develop and market medications for MS, these support programs not only help patients learn how to properly administer therapy, but how to manage other issues related to the disease. All are staffed with nurses specially trained to deal with the uncertainties and unique aspects of MS. Their services include: information on financial reimbursement; on-line patient mentoring; nursing support, both on the phone and in the home; educational information; networking opportunities; and research news.

MS ActiveSource (Avonex®)
Phone: (800) 456-2255
Website: www.avonex.com,
www.msactivesource.com

MS Pathways (Betaseron®)
Phone: (800) 788-1467
Website: www.mspathways.com
(You must register first to take
part in the 24-hour support service)

Shared Solutions (Copaxone®)
Phone: (800) 887-8100
Website: www.sharedsolutions.com

MS LifeLines (Novantrone®)
Phone: (877) 447-3243
Website: www.novantrone.com

MS LifeLines (Rebif®)
Phone: (877) 447-3243
Website: www.MSLifeLines.com

MS ActiveSource (Tysabri®)
Phone: (800) 456-2255
Website: www.tysabri.com

Other Helpful Sources

Multiple Sclerosis Association of America (MSAA)
Phone: (800) 532-7667
Website: www.msaa.com

Consortium of Multiple Sclerosis Centers (CMSC)
Phone: (201) 837-0727
Website: www.mscare.org

International Organization of Multiple Sclerosis Nurses (IOMSN)
Phone: (210) 837-0727, ext. 123
Website: www.IOMSN.org
E-mail: info@iomsn.org

Multiple Sclerosis Foundation
Phone: (888) 673-6287
Website: www.msfacts.org

National Multiple Sclerosis Society
Phone: (800) 344-4867
Website: www.nmss.org

Ask the Doctor

By Dr. Jack Burks
Vice President &
Chief Medical Officer for MSAA


Dr. Jack Burks

Q: I began taking interferon beta-1a (Avonex®) in 2002, and began hormone replacement therapy (HRT) in 2003, stopping after a little more than a year and a half. In 2005 I was diagnosed with breast cancer, even though I was not at any increased risk for cancer. I wondered if the HRT might have started the cancer at a time when Avonex was suppressing my immune system. I reported it to Biogen, who said they were required to report it to the Centers for Disease Control and Prevention (CDC). These may well be two excellent drugs, but perhaps they should not be taken together. What are your thoughts on this, and do you think a survey should be taken among women taking immunosuppressive drugs to see if others have also been diagnosed with breast cancer?

A: To begin, I want to clarify that the interferons do not "suppress" the immune system, as anti-cancer drugs do, so they are not considered immunosuppressants. Instead, they are referred to as immunomodulators, which indicates that they "modulate" the immune system. This means that some of the processes and/or components of the immune system are altered, causing them to behave differently. The same is true for glatiramer acetate (Copaxone®).

No data has been found to implicate the combination of interferon with HRT in increasing the risk of cancer. Recent data is reassuring in that interferon beta-1b (Betaseron®), after 16 years, did not show an increased risk of cancer when taken alone or in combination with any other medication. All three of the interferons as well as Copaxone have several years of data behind them. This type of data reduces the need for additional surveys.

Many of the cancer-fighting drugs do suppress the immune system, and those used to treat MS include mitoxantrone (Novantrone®), methotrexate (Rheumatrex®, Trexall®), azathioprine (Imuran®), and cyclophosphamide (Cytoxan®). With these types of drugs, there could be an increased risk for some cancer-type complications, but efforts are made to minimize this risk.

Q: My wife has had MS for 14 years. Over the years she has developed paralysis and complains of intense "burning pain" in the leg, shoulder, and arm. We have brought this to the attention of her neurologist, family doctor, and the physician who installed and services her Medtronic® pump (for the Baclofen® she needs to control spasms). No one can find a drug that will give my wife any relief... except for perhaps morphine... which makes her into a "zombie." At this time she is not taking any drug to control the pain. Do you have any suggestions?

A: You mention that your wife is receiving Baclofen, which works to reduce spasticity (stiffness) and spasms. Since spasticity and spasms cause pain, taking Baclofen can help to reduce the pain associated with these symptoms, and hopefully your wife is experiencing some relief through this treatment. When this drug is administered by an implanted pump, it is infused directly into the spinal fluid (intrathecally), and the benefits include greatly reduced dosing, increased effectiveness, and significantly fewer side effects. So it sounds as though your wife's physician made a good treatment choice.

In addition to Baclofen and other anti-spasticity drugs such as tizanidine (Zanaflex®), different types of medications may be used to treat MS pain. These include anti-seizure medications, such as gabapentin (Neurontin®), carbamazepine (Tegretol®), and phenytoin (Dilantin®). Tricyclic antidepressants such as imipramine (Tofranil®) can sometimes be helpful as well. In severe cases, some doctors might prescribe a narcotic-type of drug using an intrathecal pump similar to the Baclofen pump, providing the same benefits as listed in the previous paragraph.

For more information on pain management, you may refer to previous issues of *The Motivator*. In the Fall 2004, Winter 2005, and Spring 2005 issues, a three-part pain management series was given in the Symptom Awareness column. These articles provide information on the different types of MS pain, different medications that may be prescribed, the benefits of keeping a pain diary, and CAM therapies (such as acupuncture, acupressure, massage, and others) that may be of help in managing pain.

Please visit MSAA's website at **www.msaa.com** and click on "publications," then select *The Motivator*, to view these previous issues. If you do not have access to the internet, you may call MSAA at **(800) 532-7667** to request free copies to be mailed to you.

You may also seek a second opinion from another MS professional by visiting an MS center. You may find a listing of centers belonging to the Consortium of MS Centers (CMSC) by visiting their website at **www.mscare.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.

Please note that depression often accompanies chronic pain and I would advise that you be aware of the warning signs. Among others, these can include: depressed mood, lost interest in activities, change in appetite, negative feelings and thoughts, difficulty sleeping or excessive sleeping, restlessness or fatigue, and diminished ability to concentrate and make decisions. The Symptom Awareness column in the Fall 2005 issue of *The Motivator* discusses symptoms and treatments. Please follow the instructions mentioned earlier to view a copy of this article.

Q: I'm a 64-year-old man who would be in good health minus the progressive form of MS. I recently heard that people with progressive MS do better after they discontinue using interferons. Is there any truth to this? I've been taking Betaseron for 10 years and still have some mild side effects. Am I wasting my money?

A: Betaseron, along with the other disease-modifying treatments for MS, are indicated for individuals who are still experiencing inflammation in the brain and disease flare-ups with their MS. If you have the progressive form of MS and are not experiencing flare-ups, then you would not meet the established criteria for this treatment group. If your MS symptoms have remained basically stable during the 10 years while taking Betaseron, however, the possibility exists that the Betaseron continues to help you. Your doctor would be the best judge of your situation.

No evidence supports the idea that people with progressive MS do better after they discontinue the use of interferons. As noted above, immunomodulatory therapies are not indicated for progressive types of MS, specifically those types of MS which are non-inflammatory. This means that in clinical trials, no evidence has been found that such drugs would be beneficial to these forms of MS. Of course, if you were to discontinue the drug, you would no longer have the expense or experience the mild side effects. I advise that you discuss your situation with your doctor.

You may also seek a second opinion from another MS professional by visiting an MS center. Please refer to the answer from the previous question for information on locating an MS center in your area. ◆

Jack Burks, MD, is a neurologist who specializes in MS. He is vice president & 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.

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@msaa.com**. Please be sure to write "Ask the Doctor" in the subject line.

Visit MSAA's website at
www.msaa.com
for resources, program information, news updates, and much more!

Research News

News Briefs from the ECTRIMS Meeting

The 22nd Congress of the European Committee for Treatment and Research in Multiple Sclerosis (ECTRIMS) was recently held in Madrid, Spain. Taking place from September 27th through September 30th, this annual meeting provides the latest in MS information to neurologists and other medical professionals from around the world. MSAA's Vice President and Chief Medical Officer Dr. Jack Burks was in attendance. He returned to MSAA with much news about currently approved MS medications, as well as investigative drugs showing potential in clinical studies. To follow is a brief overview of a few topics that were presented at the meeting.

News Regarding Some of the Currently Approved MS Medications

Betaseron: Berlex's 16-year follow-up study, which is the longest follow-up study for any disease-modifying therapy in MS, continues to show positive results for individuals taking Betaseron® over the course of several years. Data shows long-term effectiveness, safety, and tolerability in MS.

Results of the 16-year follow-up study show that individuals with relapsing forms of MS experience an average of up to 40 percent fewer relapses per year (than those not taking the drug) over a 16-year time period. Individuals who remain on Betaseron also have slower disease progression as compared to those not taking the drug, nearly doubling the time (from seven years to 13 years) before reaching an EDSS level of 6.0 (at which time one needs assistance with walking). Additionally, no new or unexpected adverse events were observed.

Since the ECTRIMS meeting, Berlex announced that the United States Food and Drug Administration (FDA) had expanded the indication for Betaseron. As of October 2006, Betaseron may now be prescribed for individuals experiencing a first event suggestive of MS (and prior to the diagnosis of MS). A two-year study named BENEFIT (Betaseron in Newly Emerging MS for Initial Treatment) showed that early treatment with Betaseron delayed the time to a second clinical event by one year when compared to those taking a placebo.

Rebif: One-year data from an ongoing two-year study show that a new formulation of Rebif® (interferon beta-1a) is better tolerated than the presently approved formulation. When compared to an earlier trial (known as the EVIDENCE study), the percentage of those who were positive for neutralizing antibodies (NAbs) at 48 weeks was reduced by nearly half, going from 24.4 percent during the first study, to 13.9 percent at the same time with the second study using the new formulation. Persistent NAbs were observed in 14.3 percent of the participants in the first study at 48 weeks, but only 2.5 percent of the study participants taking the new formulation were found to have persistent NAbs.

Additionally, injection-site reactions were reduced by nearly two-thirds, going from 83.8 percent during the first study to 29.6 percent during the second study with the new formulation of Rebif. More information will become available as the two-year study is completed.

Copaxone: A new study shows that while antibodies to Copaxone® (glatiramer acetate injection) develop in all patients treated with the drug, these antibodies do not interfere with Copaxone's effectiveness. Over a mean period of more than six years, patients in this study who were continuously treated with Copaxone experienced only a minimal increase in their EDSS score, indicating that the long-term efficacy of the drug was not compromised by treatment-related antibodies.

Another new study showed that patients with very active MS may benefit from a combination therapy of Novantrone® (mitoxantrone) followed by Copaxone therapy alone. Those who first received short-term induction treatment with Novantrone® (mitoxantrone), and then followed-up with Copaxone therapy alone, experienced an 89 percent reduction in disease activity as measured by Magnetic Resonance Imaging (MRI), compared to patients taking only Copaxone from the start. This initial benefit was achieved early on and was maintained throughout the 15-month study period. No adverse events outside of those associated with either treatment (when either is used as a monotherapy) were observed.

A third study showed significant and sustained efficacy of Copaxone alone, following the short-term combination therapy with intravenous (IV) steroids for individuals with highly active MS disease activity (as shown by baseline MRI scans). Participants who first received combination therapy for six months with IV steroids and Copaxone injections, followed by treatment with Copaxone alone, experienced a 65-percent reduction in lesions. This reduction was observed during the first six months of the study, and was sustained for an additional six-month period while patients received Copaxone treatment alone. This was an open-label, one-arm study, however, which did not include a placebo (or "control") group.

News Regarding Some of the Investigational Drugs Still in Clinical Trials

FTY720: The investigational drug known as "FTY720" (fingolimod) is a once-daily oral therapy being studied for the treatment of relapsing forms of MS. Data from a Phase II study show that up to 77 percent of patients taking the drug remained free of relapses for more than two years. They also maintained a low rate of inflammatory disease as measured by MRI. FTY720 showed minimal toxicity (adverse events) in this study.

New data suggest that FTY720 may work through more than one mode of action. First, this drug reversibly traps a portion of circulating lymphocytes in the lymph nodes. These cells, also known as T-cells, are believed to attack the myelin and nerves of the central nervous system (CNS), causing the symptoms of MS. FTY720 lowers the number of T-cells circulating in the bloodstream and the CNS. Second, this drug reduces the permeability of the blood-brain barrier, allowing fewer damaging cells to cross from the bloodstream and into the CNS. Third, FTY720 may also have the potential to reduce neurodegeneration, enhancing nerve repair (this effect was observed in animal studies).

A large-scale program of Phase III clinical trials to study FTY720 began earlier this year. This includes a Phase III clinical trial program known as FREEDOMS (FTY720 Research Evaluating Effects of Daily Oral therapy in Multiple Sclerosis). This two-year study is designed to include more than 2,000 patients worldwide between the ages of 18 and 55, with the relapsing-remitting form of MS. For more information about the study, including eligibility criteria and study locations, readers may call **(866) 788-3930**, or visit **www.msclinicaltrials.com**.

MBP8298: Results from the completed Phase II trial, long-term follow-up treatment and current status of the ongoing pivotal Phase II/III clinical trial, as well as future clinical development plans, were presented at the ECTRIMS meeting. According to BioMS (developers of the drug), MBP8298 safely delayed disease progression for five years in progressive MS patients who had certain immune-response gene types. Approximately 75 percent of the total MS population has these gene types.

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@msaa.com.

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

Treatment and follow-up demonstrated that patients in the gene-responder group had a median time to disease progression of 78 months (six-and-a-half years) compared to 18 months (one-and-a-half years) for patients who received a placebo. MBP8298 is typically administered intravenously every six months. The current Phase II/III clinical trial is being conducted with secondary-progressive patients at study locations throughout Canada and Europe. For more information, readers may visit the BioMS website at **www.biomsmedical.com**, or call MSAA's Helpline at **(800) 532-7667** for assistance.

Oral Cladribine: A few days before the ECTRIMS meeting was held, Serono announced that oral cladribine had been designated as a "Fast Track" product by the FDA, for patients with relapsing forms of MS. Fast Track programs are designed to facilitate the development and expedite the review of new drugs that are intended to treat serious conditions. They must also demonstrate the potential to address unmet medical needs.

This oral formulation of cladribine is currently being evaluated in a multi-center, multi-national Phase III study, known as CLARITY (CLAdRIbine Tablets Treating MS OrallY). Patient enrollment for this two-year, double-blind, placebo-controlled study is planned to be completed by the end of the year. Currently, recruitment is taking place in 15 cities across the United States. Further clinical trial site information is available at **www.TheCLARITYStudy.com**, or the U.S.

National Institutes of Health clinical trial information website at **www.clinicaltrials.gov**. Readers without internet access may contact MSAA's Helpline at **(800) 532-7667** for assistance.

Campath: Two-year interim results from its three-year Phase II trial have been presented for Campath® (alemtuzumab), which compares the effectiveness and safety of Campath to Rebif. Dosing of Campath in the study was suspended in September 2005 after three patients developed immune thrombocytopenic purpura (ITP). This is a treatable but serious condition in which patients experience a low platelet count from an immune response against the platelets, which can cause excessive bleeding. The first patient to present with ITP died. The other two patients, along with three more who have since been diagnosed with ITP, all underwent treatment for ITP and responded well.

At that time, most patients had received two cycles of Campath (one cycle/year). Treatment with Rebif continued without interruption. Analysis showed that patients taking either a high or low dose of Campath experienced at least a 75-percent reduction in the risk for relapse after at least two years when compared to the Rebif-treated group. Participants in the Campath group also experienced at least a 65-percent reduction in the risk for progression of clinically significant disability compared to the Rebif-treated group.

Additionally, previous studies with Campath and MS have shown a connection between Campath and thyroid problems, including Graves' disease. Campath works by destroying the body's T-cells, which are believed to be responsible for the damage to the myelin and nerves with MS.

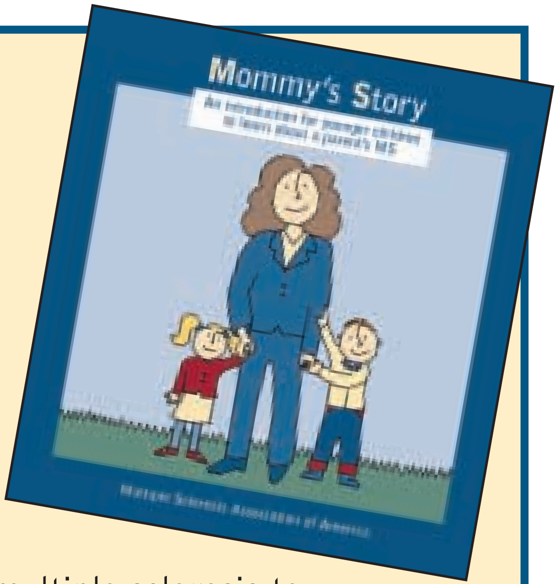
BG00012: BG00012 is an oral drug that is an effective treatment for chronic plaque psoriasis. A preliminary study indicated that BG00012 may also be effective in patients with relapsing-remitting MS. This drug has an immunomodulatory mechanism of action.

This randomized, double-blinded, placebo-controlled Phase 2b study was conducted with patients who had relapsing-remitting MS. The study compared a placebo group and three groups taking different doses of BG00012 to see which dose level was the most effective with the least side effects. Compared to placebo, treatment with the highest dose experienced a 69-percent reduction in the total number of gadolinium-enhanced lesions and a reduction in the number of new and enlarging, T1 and T2-hyperintense lesions over a 24-week period. A 32-percent reduction in relapse rate was also observed, but since this endpoint was not included in the study design, it could not be considered significant. ◆

By Susan Wells Courtney
Reviewed by Dr. Jack Burks

Please note: The information given in this article was obtained through MSAA resources, ECTRIMS news releases, as well as statements from the drug companies whose approved medications or investigational drugs were highlighted.

MSAA has recently published a book
to help young children understand MS:



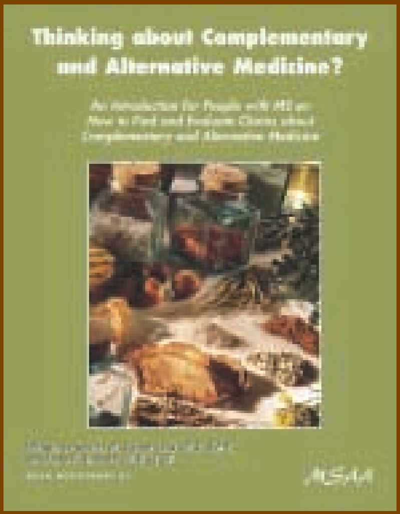
Mommy's Story

An introduction for younger children to learn about a parent's MS

This publication was written to encourage parents with multiple sclerosis to begin the conversation about the diagnosis and ongoing implications of MS with young children. This book is suitable for children ages three to seven.

You may request a copy of **Mommy's Story** by contacting MSAA at **(800) 532-7667**, **extension 129**. You may also visit MSAA's website at **www.msaa.com**, select "Publications," and complete the order form. In addition, MSAA publications can be viewed and downloaded from **www.msaa.com**.

COMING SOON:



Thinking about Complementary and Alternative Medicine?

An Introduction for People with MS on How to Find and Evaluate Claims about Complementary and Alternative Medicine

Written by Thomas M. Stewart, JD, MS, PA-C and Allen C. Bowling, MD, PhD.
Both authors are from the Rocky Mountain MS Center in Englewood, Colorado.

This monograph has been created in honor of MSAA's Vice President and Chief Medical Officer Jack Burks, MD, in recognition of his personal dedication to the MS community, as well as his long-standing commitment to MSAA.

You may request a copy of Thinking about Complementary and Alternative Medicine by contacting MSAA at (800) 532-7667, extension 129.

This monograph has been made possible through a grant from Berlex.

Program Notes

Charity CD Project Inspires Listeners and Benefits MSAA

This holiday season, join the Multiple Sclerosis Association of America (MSAA) in supporting Jilladair Carlson, a music producer from Seattle, Washington, and Erik Kjelland, a singer and songwriter from Madison, Wisconsin, in a unique fundraising opportunity benefiting MSAA. Kjelland and Carlson have joined forces to write, sing, and produce *Everybody Falls*, a CD compiled to inspire not only individuals in the MS community, but all who listen.

The *Everybody Falls* charity CD project is the brainchild of Carlson, who came to MSAA through a listing on the website, "Volunteer Match" (at **www.volunteermatch.org**), where she applied to be a public education ambassador for MSAA. The public education ambassador program is a national volunteer program that assigns volunteers to speaking engagements where they talk about MSAA and its programs and services for the MS community.

After speaking with Malcolm Friend, MSAA's director of volunteer services, Carlson decided she wanted to do more than just go out and speak on behalf of MSAA. "Once Malcolm started to talk to me about MSAA and its mission, it was as though a light bulb went on in my head," says Carlson. "This is the charity I have been looking for. I like how MSAA helps to restore the quality of life for individuals who have MS."

"We are all stars,
everybody falls sometimes

How you stand up,
and get there

Makes you stronger
and brighter..."

In addition to wanting to help MSAA, Carlson also has a personal interest in MS, as she was diagnosed 20 years ago with the disorder. As a way to express her feelings about living with MS, she helped to write "Brighter," the title track to the CD. "I wrote the lyrics to 'Brighter' because I believe them. I believe that each person who has MS is a star and we are all special," states Carlson. "And yes, we do fall, but it is how we pick ourselves up – that is what makes us stronger."

Picking herself up is something Carlson should know about; during this project she has been putting in 18-hour days and even battling through some exacerbations, but this is a project she believes in. "This CD is a message of hope," explains Carlson. "I believe in this project and particularly the title track 'Brighter.' This is about never giving up and realizing it's okay to fall; there is a place to go and people there to help you along the way."

Carlson, a recording industry veteran of 26 years, used many of her industry connections to get *Everybody Falls* launched. "I have called in some favors," states Carlson. "But everyone I asked was more than happy to help, especially since everyone involved has some type of connection to the world of MS."

She even found a way to arrange a CD launch party, scheduled for March 2007, at the Guest House in New York City. Along with the launch party, Carlson put together a celebrity auction and was able to get some of Hollywood's stars to donate items. Guests at the launch party will have the opportunity to bid on items donated from George Clooney, Mary Tyler Moore, and Maria Sharapova, just to name a few.

Carlson has set some ambitious goals for "Brighter" and the *Everybody Falls* CD. "One is to raise awareness of MS and MSAA," says Carlson. "The second is to bring in two million dollars to MSAA through CD sales." In order to facilitate this, Carlson herself will serve as the distributor – which means that the CD will only be available online at **www.everybodyfalls.com**. To help fulfill orders and meet her goals, Carlson has a team of volunteers waiting to help, along with the equipment needed to ship the orders from her office.

"It was important for me that as much of the funds as possible go directly to MSAA. So other than the fees that go to Eric for his rights to the songs, there is no big cost," Carlson continues. "If we had gone to one of the large stores, they would have charged us a fee to have the CD in their stores. That extra cost is what I wanted to avoid. That is why it is so important that people who go to the website (**www.everybodyfalls.com**) to purchase a CD, also tell their friends and family about it."

The success of *Everybody Falls* will allow Carlson to embark on a second CD. "If *Everybody Falls* has the success that I think it will, there will be a second CD. This will be a compilation CD of some of the music industry's top artists," says Carlson.

For more information about the *Everybody Falls* CD, or to place an order, please go to **www.everybodyfalls.com**. Anyone without internet access may call **(877) 783-7516** for more information. *Everybody Falls* costs $10 plus shipping and handling. ◆

— Amanda Bednar

Symptom Awareness

Weakness

Weakness is a common symptom associated with MS. When caused by MS, weakness is a result of damage to the nerves of the Central Nervous System (CNS), which includes the brain and spinal cord. As the protective covering (known as myelin) of these nerves becomes inflamed and eventually damaged, the swift flow of nerve impulses is interrupted, preventing instructions from adequately reaching the extremities. This type of weakness in MS is often caused by demyelination within the spinal cord, although demyelination within the brain can also be at fault.

Weakness may also arise as a complication of other factors. For example, a number of other MS symptoms, such as fatigue, spasticity, and balance problems, can lead to weakness. Additional issues, such as stress, overexertion, and inactivity, may result in weakness as well.

The symptom of weakness is frequently perceived as one leg feeling heavy and being difficult to lift, especially at the end of the day. This may be particularly evident when stepping up onto a stair or curb. Although less common, some may experience similar sensations of heaviness or clumsiness in one or both of their arms and hands. Losing the ability to grip, push, or lift can be very frustrating.

Physical Therapist Brian Hutchinson, MS, PT explains, "The amount of weakness is not necessarily associated with the duration of one's MS. In fact, weakness can be a 'presenting,' or initial symptom. A common presentation is that one will experience weakness in one extremity, and at a later time, a second extremity could become affected."

Treating Weakness

Weakness, as with any MS symptom, may be temporary, subsiding as inflammation from an exacerbation decreases. Treatment for weakness in this type of situation may involve steroids to reduce inflammation, in an attempt to lessen the intensity of the flare-up and accelerate recovery.

"Getting plenty of rest is important while recovering from an exacerbation," Hutchinson points out, "but resting the muscles too much may have a negative impact. Specific exercises should be prescribed by a physical or occupational therapist, or a physician who specializes in neurological conditions, to keep muscles moving. This helps to reduce muscle stiffness, decrease atrophy, and maximize function."

Hutchinson warns, "When weakness continues beyond an exacerbation, the patient should be re-evaluated by a professional. Strategies should be developed to avoid overuse of the affected limb, while keeping the muscle active."

He goes on to explain, "No medications are available at this time to specifically treat weakness. Treating related symptoms – such as using an anti-spasticity medication to reduce muscle tightness and spasms, will have a secondary effect of reducing weakness. A new drug is on the horizon, however, but is not yet approved. Fampridine-SR may help individuals with both relapsing as well as progressive forms of MS to walk faster and to have an increase in leg strength."

Acorda Therapeutics' Fampridine-SR works by blocking areas where damaged myelin has exposed portions of the nerve membrane. The drug helps to keep nerve impulses on track so they may pass through areas of damage. Following the announcement in September 2006 of positive results from its phase III clinical trial, Acorda plans to meet with the United States Food and Drug Administration (FDA) to discuss the next steps toward approval of the drug.

Fampridine-SR is a sustained-release tablet formulation of the investigational drug fampridine (4-aminopyridine, or 4-AP). Adverse events include an increased risk of seizures that appears to be dose related (meaning that the risk increases as the dose increases).
For more information on Fampridine-SR, readers may visit Acorda Therapeutics' website at **www.acorda.com**. Readers may also call Acorda Therapeutics' patient information line at **(877) 223-5212**.

Sometimes assistive devices, such as a cane or brace, are used to remove some of the pressure on a weak limb. People who are moderately to severely weak are often reluctant to use a wheelchair or scooter, but using these devices can be very helpful. By conserving energy, a wheelchair or scooter enables an individual to be more active over a longer period of time.

If desired, the use of assistive devices may be reserved just for times of extra activity. Using a cane will not make someone more dependent on others, but rather increases independence by providing added support, so he or she may have the strength to continue with activities longer.

Individuals using or planning to use any assistive device should always do so under the direction of a physical or occupational therapist, or a physician who specializes in neurological conditions. These professionals can make sure that the device is properly fitted, and a professional will also provide specific instruction for correct use of the device.

An assistant therapist demonstrates how to improve balance with a physioball. By improving balance, less strength is required to sit or stand upright, and this can help reduce weakness. (All photos on pages 44-51 are reprinted from the Winter 2004 issue of The Motivator, "The Benefits of Rehabilitation" article.)

Parallel bars are used to help regain strength and balance.

Planning ahead is particularly valuable for dealing with weakness. When traveling or involved in a prolonged activity, arranging for a wheelchair in advance to cover long distances can save time and energy. Being aware of limitations while organizing one's schedule may help to avoid late-day weakness. Taking care of more difficult tasks early on is also a good strategy; it allows for easier tasks to be done later, when one might have less strength. ◆

By Susan Wells Courtney
Reviewed by Jack Burks, MD
Contributions by Brian Hutchinson, MS, PT
and Valerie W. Gibson, PT

Many thanks go to Brian Hutchinson and Valerie Gibson for their assistance with this article. Hutchinson works as a physical therapist for The Heuga Center, located in Edwards, Colorado, which specializes in education and wellness for individuals with MS. Readers may visit The Heuga Center's website at **www.heuga.org**; the center may also be contacted by calling **(800) 367-3101**.

Gibson is a physical therapist and founder of Advanced Physical Therapy and Rehabilitation Center, LLC in Vienna, Virginia, specializing in neurorehabilitation. Readers may visit the center's website by going to **www.aptrehab.com**; the center may also be contacted by calling **(703) 749-0223**.

For more information and resources on weakness, assistive devices, or physical therapy, readers may contact MSAA's Helpline at **(800) 532-7667**.

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Exercise for Individuals Experiencing Weakness

Weakness may result from one or more of a number of factors. When weakness is caused directly by MS, it is caused by damage to the nerves and an interruption in the flow of nerve impulses, going from the brain or spinal cord to the affected extremity. Additionally, weakness may result from other impairments of MS, such as fatigue, spasticity, or balance problems. “Disuse” can cause weakness as well, and this is when the symptoms of MS reduce one’s level of activity and movement of an extremity.

Some people with MS will attempt to overcome a weakness problem by trying to aggressively strengthen muscles on their own through exercise and lifting weights. Unfortunately, this may further fatigue the muscles. On the other hand, lack of exercise can cause a muscle to become weaker from disuse. Although this sounds like a no-win situation, a physical therapist can design a program aimed at keeping the affected muscles healthy while avoiding further weakness.

According to Physical Therapist Brian Hutchinson, MS, PT, “Different types of exercise therapies may be used to help strengthen muscles. These include weights, elastic tubing, gravity, and manual resistance through skilled intervention by a physical or occupational therapist. In this latter type of therapy, the therapist provides controlled resistance against the limb being strengthened, while the patient pushes against the therapist.

“When treating MS through exercise, the key is ‘quality of movement,’ versus ‘quantity.’ In other words, <u>how you do</u> the movement is far more important than <u>how many times</u> you do the movement. Individuals with MS need a thorough assessment with a physical or occupational therapist to prescribe the appropriate exercises for strengthening as well as overall conditioning.”

Instruction on how to properly perform the exercises is vital. When exercises are prescribed by an experienced therapist, he or she will include: type of exercise, how long to exercise, how often to exercise, and to what degree of intensity. All of these factors promote safety and success.

Hutchinson continues, “Exercising with symptoms of MS is much more complex than just going to the gym. For instance, without the proper instruction, individuals exercising on their own can easily create an imbalance between opposing

Exercise can provide many benefits, including flexibility, strength, and improved health, which all play a role in improving weakness.

muscles. One example is when the muscles that surround the ankle are stronger in turning the foot 'in' versus turning the foot 'out.' This may create movement of the foot 'inward' when swinging your leg through while walking. This movement could cause one to 'land' on the outside of the foot – increasing the risk to twist the ankle and fall. The same is true when working other muscle groups and this can create a greater risk of injury.

"For patients whose insurance does not cover physical therapy and are unable to afford a professional assessment, other avenues for basic instruction are available. Information on exercising with MS may be found through written pieces and websites, although individuals need to make sure that the source is reliable. Specific educational clinics and one-day programs held by organizations such as MSAA can also provide opportunities to learn and practice successful and safe exercises.

Arm/leg bicycles may be switched to hand pedals for upper body exercise.

"Regardless of level of ability or disability, everyone should do some type of exercise, preferably at least three to four times weekly. Any exercise program, however, should only be done under the supervision of a medical professional. Those unable to be assessed by a physical or occupational therapist should consult their physician for guidance," states Hutchinson.

Physical Therapist Valerie W. Gibson, PT, is in full agreement with Hutchinson. Gibson comments, "I want to stress the importance of consulting with a medical professional for an evaluation before beginning an exercise regimen. This may be a physical therapist, occupational therapist, or a physician, but these professionals must also have a background in treating MS."

Gibson continues, "It is important to have an individualized exercise program. Many patients will have different combinations and degrees of symptoms, each requiring a different exercise prescription. Some may have leg weakness while others may have hand and finger problems; some individuals will be ambulatory while others are not; and additional symptoms, including balance, fatigue, and spasticity, contribute to weakness and will need to be addressed as well."

According to Gibson, the most important exercises are stretching, strengthening, and aerobic conditioning. Stretching exercises should be performed prior to strengthening exercises, and offer several benefits. Stretching decreases the effects of spasticity, increases range of motion (helping joints remain mobile), increases flexibility, and increases blood flow to the muscles and surrounding tissues.

Strengthening exercises will not alter the disease process, but strengthening of the non-affected muscle groups to help compensate for the affected ones, will prevent weakness resulting from disuse. Gradually, strengthening exercises can improve energy and decrease fatigue – and by doing so, can reduce weakness. Muscle groups that have not been affected by damaged nerves should be strengthened as much as possible, but this needs to be done slowly over time. All exercises for individuals with MS need to be minimal to moderate in terms of intensity.

Examples of aerobic exercises for ambulatory individuals include working out on a stationary bike, treadmill, or walking. Water exercise, also known as hydrotherapy, offers the benefits of buoyancy. By reducing the pull of gravity, a person with weakness is able to have greater range of motion while exerting less energy to move the limb. The cooling effect of water on core body temperature may also reduce exercise-induced fatigue. Individuals who are non-ambulatory may be prescribed repetitive upper extremity exercises, Theraband® (elastic) exercises, transfers, and bed mobility.

A thorough evaluation is absolutely essential in creating a prescribed exercise program for an individual with MS. During an evaluation, the following areas need to be assessed:

- Range of motion and flexibility in joints
- Strength
- Tone (muscle tightness or degree of spasticity)
- Fatigue and endurance
- Sensory impairment (sense of touch and other sensations, such as numbness or tingling)
- Visual status
- Balance
- Coordination
- Ambulation and assistive devices being used
- Cardiovascular and respiratory status
- Activities of daily living and independence
- Bed mobility and ability to transfer
- Cognition and perception
- Swallowing and speech impairment
- Employment status

Special stairways help individuals learn to negotiate different-height steps, sometimes with an assistive device. They may also be used for stretching (as shown).

- Psychosocial status (including how the family is adjusting to changes with MS)
- Physical environment, accessibility, community resources

Many of the categories above involve weakness. For example, reduced range of motion, lack of strength, spasticity, and fatigue, all contribute to weakness, as extra effort is required for each movement. When vision, balance, and/or coordination are affected, extra energy is needed to remain upright, so these too can increase weakness. Stress – whether related to home, work, social issues, depression, and accessibility – can deplete available energy and result in weakness.

Developing a treatment plan to treat weakness with MS can be quite complex. In addition to medications which may be used to treat the individual symptoms, many other strategies come into play. Among others, this may include planning, energy conservation, and the proper fit and use of assistive devices; different types of exercises, including those to improve balance and coordination; relaxation exercises to reduce stress; counseling to address depression; and possibly modifications to the home to improve accessibility.

Gibson explains, "Most insurance plans will cover physical therapy provided a specific plan is developed and the participant is making progress. For individuals whose insurance does not cover physical therapy, exercise is still very important. The first step is to have any exercise approved by their medical doctor."

To follow are some general tips for exercise which Gibson provides for individuals with MS. Please note that before beginning any exercise program, individuals should consult their physician.

- Different types of exercises may be done to improve function in weak muscles. These include "active" exercises (performed independently by the patient), "active-assistive" exercises (patient is assisted either by another person, or patient assists him/herself, such as when using the stronger arm to support the weak one to perform an exercise), and/or "resistive" exercises (using items to provide resistance, such as weights, elastic band, etc.).
- Stretching exercises may be done several times throughout the day to keep muscles limber.
- For non-ambulatory patients, programs may include partial weight-bearing exercises, movement with the help of special standing equipment, and repeating the moves needed to transfer from one spot to another.
- Keep in mind that with exercise and MS, quality is important, not quantity.
- Overexertion can cause a rise in core body temperature, which can temporarily worsen symptoms.
- Following exercise, some muscle fatigue or general fatigue may be expected, but if exercise-induced fatigue continues beyond 30 minutes, the exercise was too rigorous.
- If extremities are difficult to lift, do not add weights.

- If using weights, begin with the smallest weight available, then progress very slowly.

Gibson concludes, "The key to being successful with an exercise program is to make it more enjoyable; this will encourage greater compliance. Even in the general population where MS is not a factor, only one-third of those in an exercise program continue to exercise beyond one year.

"Finding a fitness partner can help to make workouts more fun. Participants need to schedule workouts and make them non-negotiable. Keeping an exercise log or journal to chart progress – noting any new achievements – is a good motivational tool. Progress is typically slow, however, and those working out should be aware of this and not become discouraged." ◆

This specially designed treadmill has extended bars and lower speeds.

By Susan Wells Courtney
Reviewed by Jack Burks, MD
Contributions by Brian Hutchinson, MS, PT and Valerie W. Gibson, PT

Many thanks go to Valerie Gibson and Brian Hutchinson for their assistance with this article. Gibson is a physical therapist and founder of Advanced Physical Therapy and Rehabilitation Center, LLC in Vienna, Virginia, specializing in neurorehabilitation. Readers may visit the center's website by going to **www.aptrehab.com**; the center may also be contacted by calling **(703) 749-0223**.

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As with all of MSAA's articles, the information provided is for patient education only. Readers are strongly advised to consult their treating physician or other medical professional before making any changes to their treatment, diet, and exercise regimens, as well as to their activities and/or lifestyle.

Stories to Inspire

Valerie's Story

In 1975, when Valerie was five and her brothers nine and 13, my husband was diagnosed with MS. It was a diagnosis that he could not accept. From the first day, he stopped being a father and a husband and completely gave up on life. He died 14 years later.

The children grew up with a father in the house, but he was never really there for them. The boys were active in sports, but he never saw them play. He missed seeing Valerie, who had become an accomplished dancer at age 10 and was performing with a local ballet company professionally.

Michael went on to college and later married; John graduated and started a good job. At 16, Valerie traveled to Great Britain on a dance tour. She was a finalist in the Miss Teenage Philadelphia Pageant, a member of the school orchestra and student government, and kept her grades up while keeping a part-time job. She went on to attend college with scholarships and grants. As an intern majoring in therapeutic recreation, Valerie worked part time with ventilator-dependent children.

Right before Christmas during her senior year she complained of vertigo. The doctor gave her some pills and after a few weeks she felt better. Then in February she lost the vision in one eye and was admitted to the hospital.

The first things she asked me to bring were her school books so she could continue her schoolwork while she was there. That night the doctor called our family into the hall and told us that Valerie had multiple sclerosis.

Valerie Gelovich with daughters Alyssa and Kayla

Valerie was my beautiful, intelligent, talented daughter; I could not believe this was happening again. When we went back into the room she insisted that we tell her what the doctor said. All I could think of was that she would picture herself like her father and completely give up.

Unknown to us, being in the medical field, Valerie was pretty sure that she had MS and was holding it from us. When we confirmed her thoughts she said, "Don't worry about me, I'll be fine. I'm not going to be like my father. I'm going to do everything I planned to do with my life."

The first thing she asked her doctor was if she could have children. He told her she could, but that she may need help to care for them. She went back to school on Monday, to her internship and then her part-time job at night. Several weeks later she had another exacerbation and was admitted to the hospital again. She told the doctors that she had to be out in three days because she had an interview for a scholarship.

In May she graduated with honors with a degree in therapeutic recreation as a therapeutic recreation specialist and received the only two scholarships given by her department. With her scholarship money, she attended nursing school during the day and worked at Children's Seashore House with ventilator-dependent children at night.

Never once did she feel sorry for herself or shed a tear. Her best friends tell me that she never dwells on her illness and people never believe it when told because she is so vibrant and full of life. Although she does not hide the fact that she has MS, it is not something that rules her life.

In May of 1995, Valerie graduated from the Thomas Jefferson University School of Nursing, passed her boards, and started working full time with her beloved ventilator-dependent children.

On June l, 1996 Valerie-Lynn Valle, certified therapeutic recreation specialist/registered pediatric nurse and Stephen Paul Gelovich, MD were married. Through his tears his vows to her were that he had seen the sun, but never felt its warmth, he had seen the birds, but never heard their song until he had met her. He told her that he hoped that he could make her life as happy and complete as she had made his.

She told him that she knew that her father was her guardian angel and had sent him to her when she had given up on love, that she loved him for many reasons, some

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, ext. 8
Email: volunteering@msaa.com
Website: www.msaa.com/volunteer.html

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

being his compassion and sincerity and for how he held her and took care of her when she was sick.

They realize that the future can be uncertain, and Stephen, being a doctor, knows what can happen. They love each other very much and say that they will handle whatever the future has in store for them. I thank God every day for giving her the courage and determination to accept her fate and for sending her Stephen. While we never know what life has in store for us, my daughter has taught me that we must live for today and never to let anything prevent us from achieving our dreams. With her attitude and faith, Valerie is succeeding and realizing her dreams.

She continued to work at Children's Seashore House in Philadelphia; her devotion to these severely handicapped children was so great. The children she took care of were long-term care patients who were born with underdeveloped lungs. They arrive as infants, and for some, the only parents they know are the nurses. Sometimes they stay at Children's Seashore House until they can be placed in a long-term care facility for life, which is usually when they are about six or seven. The nurses become very attached to them and treat them as if they were their own. When one of Valerie's "kids" left, if they are placed in a facility close by, she would visit them on her day off.

Before her pregnancy, once a week after work she taught dance to children with Downs Syndrome and hearing impairments. She had to stop because her dream to become a mother had come true.

Valerie had a wonderful pregnancy. She was not due until June 20th, but while at work almost two weeks earlier, she went into labor. Valerie drove herself home and called her husband. On June 8, 1999, Valerie and Stephen had a beautiful baby girl, Alyssa Ann. Afterward, Valerie said labor was a "piece of cake" and was already talking about having another baby.

Valerie is determined to live as normal a life as possible and so far that is happening. Valerie, Steve and Alyssa moved to Florida in October of 2001. On March 28, 2004, she gave birth to Kayla. Valerie now works two nights a week in a group home for ventilator-dependent babies.

Valerie was chosen to carry the Olympic torch in the Philadelphia run on December 23, 2002 and was one of five winners in the Redbook/Chevrolet Women of Uncompromising Strength Awards. She also has a Pedal Partner who rides in her name at the MS Annual Bike Ride, raising money for MS.

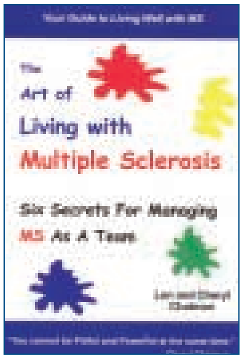
Valerie is a courageous, dedicated young woman who is always there to help someone in need. She has received glowing praises from her professors, employers, and peers. She is determined to not let MS take over her life. In the meantime, she devotes her time to helping others.

No matter what a person has, an illness, a loss, a disappointment, etc., he or she must realize attitude is one of the most important things that will help conquer his or her problems. With faith and determination, miracles happen. Just ask Valerie. ◆

— By Kathleen Valle

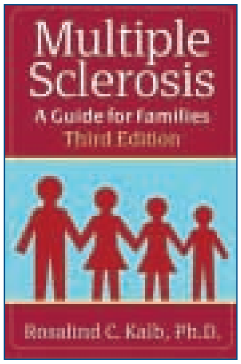
Spread the Word

The Art of Living with Multiple Sclerosis
Written by Len and Cheryl Chatman
Published by Two Hearts Publishing, Inc.
MSAA Book #271



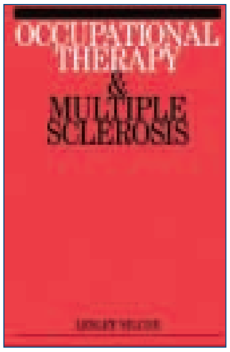
The six secrets outlined in this book are aimed at helping families, couples, and care partners cope with the "life challenges" of living with multiple sclerosis. The authors take a motivational approach to helping others to experience a more fulfilling life and to find greater happiness.

Multiple Sclerosis: A Guide for Families (Third Edition)
Written by Rosalind C. Kalb, PhD
Published by Demos Medical Publishing
MSAA Book #99



This unique guide provides the information and advice needed to help relatives cope with shifting roles, heightened emotions, and other changes that MS brings. Now in its third edition, new chapters have been included on parenting a child with MS and planning wisely for possible care needs.

Occupational Therapy and Multiple Sclerosis
Written by Lesley Silcox
Published by Whurr Publishers Ltd
MSAA Book #249



This book describes the assessment and treatment techniques used by occupational therapists to help people who are experiencing the symptoms of MS. Issues surrounding work, fatigue, leisure, mobility, and the home are discussed in detail. Insight into the impact of MS is provided by individuals with MS.

MSAA Lending Library

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

MSAA Lending Library
Attn: Woody Dyer
706 Haddonfield Road
Cherry Hill, NJ 08002
(Please reference book number)

MSAA Publications Receive Four Awards in National Health Information Awards Competition

2006 NATIONAL
Health
INFORMATION
AWARDS
WINNER

The Multiple Sclerosis Association of America (MSAA) recently received four awards in four different categories in the 13th annual National Health Information Awards competition. This program recognizes the nation's best consumer health information programs and materials.

MSAA's quarterly magazine, *The Motivator*, earned three awards for the following articles:

- "Employment Strategies," featured in the Spring 2005 issue of *The Motivator*, received a Gold Award for Patient Education in a Magazine/Newspaper/ Newsletter Article
- "Planning for the Future - The Importance of Advance Directives," featured in the Fall 2005 issue of *The Motivator*, received a Gold Award for Consumer Decision Making Information in a Magazine/ Newspaper/Newsletter Article
- "Healthcare Beyond MS," featured in the Winter 2005 issue of *The Motivator*, received a Silver Award for Health Promotion/Disease and Injury Prevention in a Magazine/Newspaper/ Newsletter Article

The fourth award MSAA received was for the booklet, "All About Multiple Sclerosis," which won a Silver Award for Patient Education Information in the category of Booklet/Brochure/Pamphlet.

"We have always been very proud of our publications and this was the first year we submitted samples for judging," states MSAA President and CEO Doug Franklin. "To be awarded such honors is a tribute to our communications staff, which has always produced high-quality educational materials for the MS community."

Copies of the award-winning articles and MSAA's award-winning booklet, "All About Multiple Sclerosis," as well as all of MSAA's publications, are currently available by contacting MSAA at (800) 532-7667, or by logging onto MSAA's website (www.msaa.com) and clicking on the "publications" section. Copies of *The Motivator* and all other MSAA publications may be ordered free of charge.

The National Health Information Awards Program is coordinated by the Health Information Resource Center, a national clearinghouse for consumer health information programs and materials. The Center, which houses a large collection of such public and private sector materials, promotes the distribution of accurate and timely consumer health information materials to professionals and managers in the field. A national panel of health information experts reviewed nearly 1,000 entries from across the country for this year's program. ◆