Spring 2014

VA Multiple Sclerosis Centers of Excellence

MS VETERAN

Serving the Health Care Needs of Veterans with MS

I Am Not My MS

I was diagnosed with MS on February 25, 2003 while deployed for military duty. I thought my life as I knew it was going to change forever. I was right that my life did change, but not for the reason I thought. I did not know a lot about MS. I did not even realize that I had relatives with MS. For the past 11 years, I have come to the realization that "I am not my MS."

My journey with MS began over a decade ago. I was on deployment in Ft. Benning, GA. My unit had been "called up" to active duty. After being on active duty for a while, I realized that something didn't feel right. I was experiencing numbness and tingling on the left side of my body. My left arm felt paralyzed and I had involuntary movement in my right hand. I had a "high step" which was making my walking a little more difficult. At first I attributed my symptoms to the overwhelming stress that comes with finding out that my unit was being activated, to actually leaving my family and my home in eight days.

Initially I tried to hide my ailment because I thought it would improve with time. But, my condition continued to worsen and the "high step" became more noticeable. For my own peace of mind, I needed to find out what I was dealing with. I had a few visits to the clinic before I was sent to get an MRI. I remember the doctor telling me about five or six different possibilities, "or it could be MS." Those words have resonated with me. About a week later I was diagnosed with MS.

Although I was medically discharged from the Army Reserve, I was able to maintain my position as a law enforcement officer. I have had many exacerbations, but MS has left me with a greater appreciation for life. I give God all the credit for me being the person I am. Every day I reaffirm to myself, "I am not my MS, I don't live with MS, it lives with me." I have accomplished so many things since I was diagnosed. I have obtained a Bachelor of Science degree as well as a Juris Doctorate in law. I was a single parent before my diagnosis and I still am. By far, being the mother of two wonderful children is my single greatest accomplishment.

I cannot pretend like the road has always been easy. Although the path sometimes looks straight, MS has made the road more difficult to navigate. I am often reminded by friends and family of my MS when they feel like I am overdoing it or when I try not to make excuses for not carrying out a task. And frequently my MS reminds me, especially when I cannot feel my feet or I cannot get out of bed because of the weakness in my legs. But, I always remind myself that "I am not my MS."

Sometimes my MS makes me proud. I am so honored to have the support of not only my family and friends but the support of my boss and co-workers who have joined forces to form an MS Walk team. It does not hurt to have a VA neurologist

What's Inside

- Understanding Your MRI Report 2
- Update on Vitamin D 3
- Remyelination: Are We Any Closer? 5
- Driving and MS 6

who attends to my every care and concern whether they have anything to do with my MS or not.

Having MS is a challenge to say the least. Having MS and trying to have a normal life is more challenging. MS is so unpredictable and it affects everyone differently. I look forward to a world free of MS. But until then, I look forward to each day where the effect of MS does not affect my ability to freely function and enjoy life to the fullest.

Kim Harrison - Jackson, MS

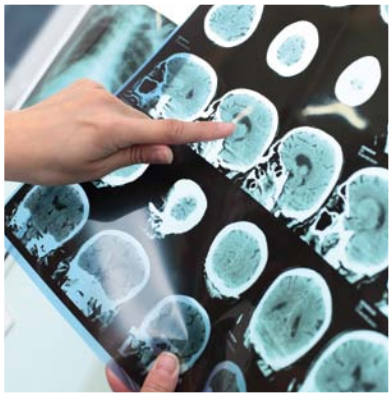
Understanding Your MRI Report

Magnetic resonance imaging, or MRI, is a wonderful tool to help diagnose and follow people with MS. MRI is safe and relatively non-invasive yet can provide very detailed images of the brain and spinal cord that can reveal MS lesions (also known as demyelination, spots or plaques) and changes in MS activity over time.

With advances in information technology, people have increasing access to their own medical records through computerized medical records, meaning that it is now possible for people to read their own MRI reports, sometimes even before discussing them with their health care provider. Reviewing an MRI report is best accomplished face-to-face or over the phone with a health care provider who can explain the language of the report, the significance of any MRI findings and interpret the report in the broader context of your overall condition. If you choose to review your MRI report on your own, you should be prepared to encounter a great deal of radiological jargon.

MRI can show the brain and spinal cord in many different orientations. Commonly the brain is "sliced" into sections in one of three possible ways. ***Axial slices*** are horizontal slices taken from top to bottom or from bottom to top. ***Sagittal slices*** are side-view slices taken from left to right or from right to left. ***Coronal slices*** are face-forward slices taken from front to back or from back to front. Using these different orientations allows MS lesions to be seen from different points of view, giving a better sense of where the lesions are related to other brain or spinal cord structures.

MRI scans are obtained using different physical parameters that create a variety of different types of images, known as "sequences." Each sequence has its advantages and disadvantages. ***T1 sequences*** are used to show the anatomy of the brain and spinal cord. MS lesions may not be very noticeable on T1 sequences unless they are very old. Old lesions which have resulted in atrophy may appear as dark spots or "black holes" on T1 sequences. ***T2 sequences*** highlight MS lesions, areas of demyelination or edema (abnormal accumulation of fluid). T2 sequences may be used to count the total number of MS lesions or "MS lesion burden." MS lesions look like white spots on T2 sequences. ***Fluid attention inversion recovery (FLAIR) sequences*** are special T2 scans in which signals from the fluid surrounding brain tissue (cerebrospinal fluid or CSF) has been removed. This makes MS lesions easier to identify. ***Contrast-enhanced sequences*** (also known as ***T1+ sequences***) are special T1 scans taken after a person has been injected with a gadolinium (naturally occurring rare earth metal) solution. Gadolinium highlights or "enhances" any active MS lesions, which are characterized by inflammation or breakdown of the blood-brain barrier (semi-permeable barrier around brain).



In other words, T2 and FLAIR sequences help show the overall number of MS lesions in the brain or spinal cord ("MS lesion burden"), T1 sequences show any old areas of atrophy ("black holes") and contrast-enhanced sequences show any new and active MS lesions ("enhancing lesions"). Just as looking at MS lesions using different orientations gives you a better sense of the anatomy of the lesions, using multiple MRI sequences gives a more complete picture of the age and activity of the MS

lesions. Sometimes MRI reports describe lesions as hyper-intense, hypo-intense or iso-intense. ***Hyper-intense lesions*** are bright or white. In general, MS lesions are hyper-intense or bright on T2 or FLAIR sequences. ***Hypo-intense lesions*** are dark or black. In general, old MS lesions are hypo-intense or dark on T1 sequences ("black holes"). ***Iso-intense lesions*** are gray, the color of surrounding brain tissue. Some MS lesions that are hyper-intense on T2 or FLAIR may be iso-intense (difficult to see) on T1 sequences.

Is it MS or not?

MRI scans are an important way to help health care providers figure out if a person has MS or not, but MRI scans can not diagnose MS by themselves. While it is true that almost all people with MS will have lesions on MRI, not all people with MRI lesions have MS. This is one of the many challenges that faces a health care provider trying to make a diagnosis of MS. MRI lesions can occur in MS, but can also be seen as a result of strokes and migraines or even rarer conditions such as vasculitis, lupus and sarcoid.

MRI reports are created by radiologists who might know very little about a given person's clinical history and examination. In order to be thorough, radiologists must provide a list of all possible explanations that could be compatible with the MRI appearance. The long list of possibilities or "differential diagnosis" must be evaluated by the person's health care provider and interpreted in the context of the broader picture.

Is my MS getting worse?

By itself, an MRI report cannot tell whether or not a person with MS is doing well. Some people have a lot of MS lesions but are doing very well clinically. Some people with just a few MS lesions can be significantly disabled. In general, though, the fewer MS lesions a person has the better. A single MRI may reveal many T1 hypo-intensities ("black holes") suggesting old damage or multiple contrast-enhancing lesions suggesting active MS. Even more valuable, however, is making a comparison between old and new MRI scans. Comparing a new MRI to an old one can reveal changes over time, which suggest ongoing MS, as opposed to no changes over time (sometimes referred to as "no interval change"), which suggest that the person is stable.

While it is always better to review an MRI report with your health care provider, with a little bit of understanding of terminology it is possible to make some sense of your MRI report even before communicating with your doctor or nurse.

Robert K. Shin, MD - Baltimore VA

Patient Education Telephone Call

Join our free monthly telephone conference call and learn firsthand about MS from MS experts and other health care professionals.

Date: 2nd Monday of Every Month

Time: 8 pm - 9 pm ET, 7 pm - 8 pm CT, 6 pm - 7 pm MT, 5 pm - 6 pm PT

Topic: Different Topic Every Month

To Participate: Call (800) 767-1750 Access Code 43157#

If you have questions about the call or topic of the month, call (800) 949-1004, ext. 53296, send an email to MSCentersofExcellence@va.gov or visit our website at www.va.gov/ms.

Update on Vitamin D

In recent years there has been an accumulation of evidence that suggests vitamin D may have a role in preventing the occurrence of MS and perhaps in the treatment of the disease. The first clinical description of rickets, the clinical syndrome that is now recognized to occur as a result of vitamin D deficiency, was made in the 17th century. However, it was not until almost three hundred years later that vitamin D was identified. Vitamin D is a fat-soluble vitamin. It is ingested in the diet as a precursor form and is normally converted to an active form by a process that involves chemical reactions triggered by ultraviolet light produced by the sun and by enzymes that are primarily produced by liver and kidney cells, but also by immune cells. A product of this reaction is 25-hydroxy vitamin D, which can be measured

in blood to determine whether a person has normal levels or is deficient in vitamin D.

Since its discovery, the primary effects of vitamin D had been ascribed to the maintenance of bone health. However, it is now apparent that the vitamin also has important effects on the function of the immune system. With respect to MS, vitamin D deficiency has been linked with an increased risk of developing the disease. This was initially shown in a study performed in a cohort of nurses in which it was found that an increased intake of vitamin D, either in the diet or in the form of supplements, was associated with a lower risk of MS. The results of this study were supported by the findings of a subsequent study in which analysis of blood samples from military personnel showed that individuals who had the highest levels of vitamin D had the lowest risk of developing the disease, and the risk increased with progressively lower levels of vitamin D.

Subsequently, a large number of studies have provided further information regarding the effects of vitamin D in MS. These include evidence that higher vitamin D levels are associated with lower numbers of new lesions as well as less brain atrophy on MRI. Higher vitamin D levels were not clearly associated with a lower chance of relapses, but people with MS were found to be less likely to develop worse disability. Such information suggests that vitamin D supplementation would likely result in people obtaining such beneficial effects. Unfortunately, so far it has not been demonstrated from clinical trials that taking vitamin D supplements, which can be purchased over the counter, can have a beneficial effect on a person's course of MS. It has been found from such studies, however, that supplementation can have effects of immune function in a manner that can be expected to be beneficial to people with MS.

There are many potential reasons why it has been difficult so far to show a definite benefit from taking vitamin D supplements in MS. These include the fact that there is strong evidence for benefit from vitamin D in MS and with respect to overall health, so it is difficult to ethically justify a clinical trial where one of the study groups is given placebo instead of vitamin D. Also, for people who are in a clinical trial, it is difficult to monitor the amount of vitamin D that is otherwise being ingested in the diet since there are many sources of the vitamin in addition to its availability as a supplement .

Finally, we have learned from studies that involved currently approved MS drugs that clinical trials that are designed to study potential MS therapies require larger numbers of people than what have been enrolled in vitamin D treatment trials to date. It can be difficult to enroll the required number of people for such studies. However, there are randomized, controlled clinical trials that are currently planned or underway that will examine larger numbers of people. These studies will also formally examine specific questions such as the effects of a higher versus a lower dose of vitamin D and whether such doses are safe and well tolerated. Observation studies in which people were not randomized to take a particular treatment, suggest that vitamin D can be effective when it is administered in combination with one of the FDA-approved disease modifying therapies. This will also be studied in a clinical trial in which people will be randomly assigned to take a specific dose of vitamin D with their standard MS drug.

As we await information from these studies, people with MS are advised to take vitamin D supplements and have their vitamin D levels checked at regular intervals. The daily dose of vitamin D that will be optimal for people to take will be learned from clinical trials. It is currently recommended that the average person take up to 2,000 international units (IU) of vitamin D in combination with 1,000-1,200 milligrams (mg) of calcium. Low calcium levels impede the body's normal use of vitamin D and can promote a false increase in vitamin D levels.

However, common recommended doses of vitamin D in people with MS are between 1,000-4,000 IU of vitamin D3 per day, with individuals treated

with doses within this range being very unlikely to develop complications related to toxicity from taking the vitamin. It is possible to check blood levels of 25-hydroxy vitamin D and to use the result as a guide for how much vitamin D should be taken. A normal range for 25-hydroxy vitamin D level in blood is 30-74 nanograms per milliliter (ng/ml). Levels between 20-30 ng/ml are referred to as insufficient, and vitamin D deficiency is defined as levels less than 20 ng/ml.

People with MS should discuss their vitamin D levels with their health care provider, including testing and approaches to ensure adequate levels. Additional information related to vitamin D and MS can be found on the websites of the VA MS Centers of Excellence (www.va.gov/MS), National MS Society (www.nationalmssociety.org) and National Institutes of Health Office of Dietary Supplements (http://ods.od.nih.gov/factsheets/list-all/VitaminD).

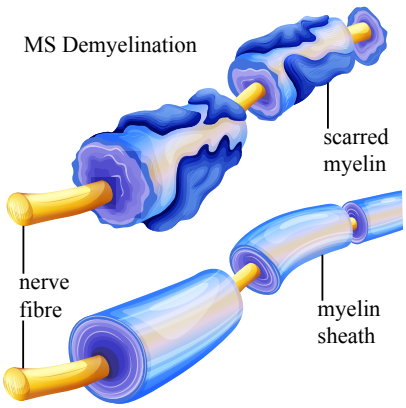
Walter Royal, III, MD - Baltimore VA

Remyelination: Are We Any Closer?

Nerve cells communicate which each other. They receive sensory information from the body and control muscles by sending electrical impulses along long extensions, called axons. Axons function a bit like electrical wires and have an "insulating" material called myelin. In MS, myelin is destroyed in bits and pieces in various parts of the brain and spinal cord. The resulting demyelinated axons do not work well, sometimes not at all and they are prone to slowly die off. Demyelinated axons are responsible for much of the permanent disability that affects people with MS.

Is there anything that can be done to repair these axons that have been stripped of their myelin and thereby reverse disability in MS? Repairing demyelinated axons requires remyelination. A number of research laboratories have been working on ways of stimulating remyelination in animal models of MS. This research is promising and some of these approaches are beginning to enter early clinical trials in people with MS.

Myelin in the brain and spinal cord is made and maintained by a special cell called an oligodendrocyte. For remyelination to occur, immature oligodendrocytes must migrate to areas of demyelination, mature and then form myelin around the demyelinated axons. For a number of years it has been recognized that immature oligodendrocytes are present in areas of demyelination in MS, but for unclear reasons these cells do not mature and make myelin. There are several ideas about why remyelination fails to occur and these ideas form the basis for developing treatments to stimulate remyelination.



One idea is that remyelination fails because the immature oligodendrocytes need stronger stimulation to mature. Scientists at the Mayo Clinic have discovered an antibody that stimulates immature oligodendrocytes and this antibody promotes remyelination in animal models of MS. Plans are in process to begin studying this antibody in

Caregiver and Family Telephone Call

Join the free monthly telephone conference call to connect with caregivers and family members supporting people with MS. A variety of educational topics and resources are discussed.

Date: 4th Monday of Every Month

Time: 2 pm - 3 pm ET, 1 pm - 2 pm CT, 12 pm - 1 pm MT, 11 am - 12 pm PT

To Participate: Call (800) 767-1750 Access Code 43157#

The VA has a National VA Caregiver Support Hotline for family members dealing with chronic illness. The Hotline toll-free number is (855) 260-3274 and it is open:

Monday - Friday: 8 am - 11 pm ET
Saturday: 10:30 am - 6 pm ET

humans. Scientists at the University of California at San Francisco have evidence that an anti-histamine, clemastine, might stimulate the immature oligodendrocytes and they have started a small early trial of clemastine in people with MS. Another idea is that there is a block between the oligodendrocytes and axons that prevents new myelin from being formed. One possible block is a protein called lingo-1, which is increased on the surface of the myelin forming cells. Biogen Idec has created an anti-lingo antibody to inhibit lingo-1 and thereby promote remyelination. This anti-lingo antibody works in animal models and an initial short-term safety study of the anti-lingo antibody in people with MS has been completed. Plans are being made to conduct a larger clinical trial of anti-lingo antibody to see if it stimulates remyelination in MS.

Another block could be the scar that forms in areas of demyelination in MS. A sticky sugar-like substance called hyaluronic acid is part of this scar and digested pieces of hyaluronic acid prevent the immature oligodendrocytes from maturing. Scientists at Oregon Health & Science University have shown in an MS animal model that a drug that blocks the enzyme that digests hyaluronic acid could promote remyelination. These scientists are developing other drugs that can block this enzyme in hopes that this approach can eventually be used in people with MS.

Finally, remyelination might not occur because there are not enough immature oligodendrocytes to get the job done. To overcome this, scientists at the University of Rochester have developed a technique to grow immature oligodendrocytes from stem cells. They then inject these cells into the brains of rodents deficient in myelin. The injected cells spread out, mature and form myelin in these rodents. These scientists are now planning to start an investigation of the effectiveness of injecting human immature oligodendrocytes into the brains of people with MS. It is hoped that this research will begin within the next two years.

There is a lot of exciting research on ways to stimulate remyelination and some of these approaches are beginning to be studied in people with MS. Hopefully one or more of these approaches will be successful. We don't have treatments to stimulate remyelination in people with MS yet but hopefully we will within 5-10 years.

Dennis Bourdette, MD - Portland VA

Driving and MS

MS can affect the ability to perform activities of daily living. Driving is the most complex activity of daily living performed every day. It is important not to minimize the complexities of driving or overestimate one's abilities. Driving requires adequate vision, motor, memory and thinking skills. MS can affect all these areas. As MS evolves, required driving skills may diminish in several domains:

- Blurred vision, poor night-time vision, blind spots, double vision, loss of color vision, impaired visual searching, scanning and attention.
- Short-term memory loss, confusion about vehicle operation or one's location or destination, stress tolerance, impaired motor planning, multi-tasking, reaction time, fatigue and heat intolerance.
- Impaired sensorimotor function may manifest as difficulty with car transfers, muscle weakness or stiffness/spasms/cramps, poor light touch and joint position sensation, pain and impaired coordination, particularly in the arms or right foot.

A cardinal feature of MS is its unpredictability. Symptoms often fluctuate during the course of a day and from day to day. Most people with MS have a relapsing course and during exacerbations (attacks, relapses or flare-ups), driving may be unsafe but may return to normal upon recovery. However, with disease progression, driving can become permanently affected.

If you, your loved ones or your health care provider are concerned about your driving ability a ***driving evaluation*** performed by a ***driver rehabilitation specialist*** can help identify challenges you experience and the need for appropriate adaptive auto equipment to keep you safely on the road. The purpose of a driving evaluation is to assess driving skills, recommend adapted auto equipment

if indicated to meet specific functional needs and train the driver and family in its use, ensuring safety of entering/exiting the vehicle and proper storage of wheelchair and assistive devices.

The VA maintains 48 driver rehabilitation clinics nationwide. An evaluation takes up to two hours and includes a cognitive assessment, vision examination, tests for muscle strength, movement, coordination, sensation and reaction time, as well as a behind-the-wheel evaluation using a VA-owned vehicle. Upon completion of the evaluation the driver rehabilitation specialist makes recommendations on driving safety. Adapted equipment may be recommended. Examples include mechanical hand controls to operate the gas and brake, a spinner knob to help turn the steering wheel, power transfer seats, digital driving rings and hi-tech driving equipment for reduced effort and zero effort steering and braking.

Learn More About MS!

MSCoE produced free DVD's from our live education programs. Each DVD includes 1.5 hours of educational content provided by MS health care professionals. They are a great way to learn about MS in the comfort of your home.

- Bowel and Bladder Management in MS
- MS and Emotional Disorders: Approach to Management
- MS, Cognition and Brain Imaging: Understanding Cognitive Dysfunction
- MS and Pathogenesis: 30 Years of Progress
- Pain and Palliative Care in MS
- Sexual Intimacy and MS
- Staying Mobile with MS Part I and II: Mobility for People with MS and Wheeled Mobility and MS
- Updates on MS Disease Modifying Therapies

If you are interested in receiving free DVD's, call (800) 949-1004, ext. 53296 or send an email to MSCentersofExcellence@va.gov.

Some Service-Connected Veterans are eligible for an Auto Grant from a Regional Office. This is a one-time grant of $19,505 (2014) for vehicle purchase. Information on the grant can be found on the Prosthetic and Sensory Aids Service (PSAS) website at www.prosthetics.va.gov. The Grant also reimburses for medically indicated adapted auto equipment such as platform wheelchair lifts, under vehicle lifts, power door openers, lowered or raised floors, raised doors, hand controls, left foot gas pedals and digital driving systems.

Non-Service-Connected Veterans may seek assistance from local and national service organizations, such as the National MS Society or Paralyzed Veterans of America. If you attend work or school, Vocational Rehabilitation may assist with the cost. For new vehicle purchases, vehicle manufacturers offer rebates for adaptive equipment. It is best to consult a driver rehabilitation specialist ***before*** you buy a vehicle as they can help you decide what vehicle best meets your needs.

Keen awareness of the fluctuating nature of MS symptoms can help you avoid the risk of unsafe driving. ***Here are some tips:***

- Don't drive if you are having a bad day.
- Avoid driving when you have another illness, because MS symptoms are often worse when the "system" is under increased stress.
- Keep trips short if you suffer fatigue and don't drive when fatigue is severe.
- Avoid distractions like cell phone calls/texting, eating, listening to the radio and arguing with passengers.
- If you are heat intolerant, carry a cooling vest.
- Strategically plan out errands and appointments so that you can avert heavy traffic times or areas that get congested.
- Avoid driving in bad weather.

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10 North Greene Street (NEU 127)
Baltimore, MD 21201

VA Puget Sound Health Care System
1660 South Columbian Way (S-117-MSCoE)
Seattle, WA 98108

Portland VA Medical Center
3710 SW US Veterans Hospital Road (P3MSCoE)
Portland, OR 97239

To be removed from or added to this mailing list, email jaimie.henry@va.gov or call (800) 949-1004, ext. 53296.

What if you decide to stop driving or are told it's no longer safe to drive?

Just as you plan for other circumstances associated with your disease (e.g. making your home more accessible), planning for the day when driving becomes impossible can ease the transition from driver to passenger. When transitioning from driver to passenger, explore transportation options in your community.

- Ask a friend, neighbor or family member if they could give you a ride.
- Inquire about volunteer drivers at your local community center, place of worship or Veteran service organization.
- Contact your city and state public transportation agencies about transportation options.
- Talk to your VA social worker or health care provider about transportation options in your area.

Driving can be seen as a sign of independence and it can be scary to think about limiting or giving up that freedom. A professional evaluation and the use of adaptive auto equipment can increase your safety on the road and promote independence for as long as it's safe for you to drive. If you feel like you can no longer safely drive, there are a variety of transportation alternatives and your family members, friends and health care professionals are here to help and support you with this transition.

Change can be hard and if you are having difficulty accepting or adjusting to changes in your ability to drive, you might consider talking with a VA health care provider. Talking about how you feel may help you better understand and address the grief felt over these changes.

Pat Niewoehner, OTR/L, CDRS - St. Louis VA
Florian P. Thomas, MD, MA, PhD - St. Louis VA