

VA MULTIPLE SCLEROSIS CENTERS OF EXCELLENCE

MS VETERAN

SERVING THE HEALTH CARE NEEDS OF VETERANS WITH MS

MS IN THE COMPANY OF OTHERS

I joined the Army right after I graduated from high school in 1965. Everyone in Basic Training called me “Sport” and I made friends who I continue to keep in touch with. I learned skydiving with the Special Forces and trained as an x-ray technician. After leaving the Army, I pursued my license as an x-ray technician and worked in the field as a civilian.

In 1988, I was diagnosed with MS. For years I knew something was wrong, but it was too difficult to think about and much easier to ignore. It started with severe headaches that knocked me off my feet and progressed to a clumsiness that I couldn’t quite explain. I could barely hit the button on an elevator and it became a challenge to throw a ball for my dogs. Even as more medical issues surfaced, I continued on with my life as if all was well.

I guess you could say I was in denial that I had a serious, chronic problem. I probably would have stayed in denial if it hadn’t been for one of the physicians I worked with. He noticed there was something “off” with my coordination and was concerned. He recommended I get an MRI which helped diagnose the MS. I began

treatment and found a physician at the Seattle VA who listened to my MS needs. She helped me better understand the disease and how it was affecting me.

In 2007, I faced another serious health problem. I was diagnosed with breast cancer. I ended up having a bilateral mastectomy, where both breasts were removed, and received chemotherapy once a week for six months. Ironically, the chemotherapy for the cancer improved my MS symptoms. When the chemotherapy ended, all of my MS symptoms returned.

Like others, I’ve faced hardships in my life. I’ve had days with my MS where the pain was intense or it was difficult to get around. I’ve had severe headaches, double vision, and even broke my back skydiving in the Army. Yet, I continue to live my life to the fullest. When times feel bleak, I remind myself that there is another day and that things will get better. I may have MS, but it



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doesn't define who I am or what I can do.

In 2005, my husband and I started our own ice cream business, The Whidbey Island Ice Cream Company. We make ice cream in our certified facility year round - four times a week in the summer and once a week in the winter. The ice cream is sold throughout Whidbey Island and neighboring communities.

I teach knitting to female inmates at the Whidbey Island county jail once a week and I'm a member of the North Puget Sound Dragon Boat Team. The Team is made up of cancer survivors and their support network. We get together from spring to late fall for camaraderie and fun competition. Last summer, we won the 2008 Gold Medal and Cancer Cup in a race held on Lake

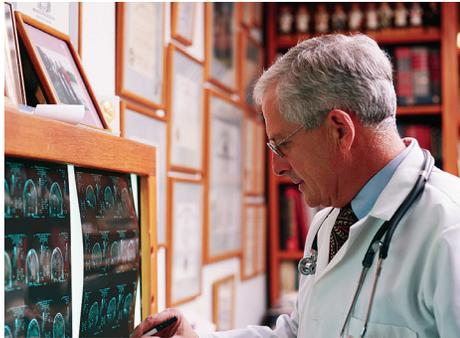
Washington in Seattle. I am also the caregiver for my mother who is 93 years old. When I'm not together with friends and family, I enjoy riding my horse and taking walks in the country.

I've had MS for over 20 years and if there is anything that MS has taught me, it's this, "Enjoy life, don't let your disease set limitations for you, and make sure you surround yourself with wonderful, supportive people." I'm 61 years old. I've been married for over 25 years to a man who always makes life interesting. My family and friends are amazing. I've accomplished so many things in my life and there is still so much more that I want to accomplish. I truly count my blessings for all that I have.

Mary Stoll - Whidbey Island, WA

UNDERSTANDING YOUR MRI REPORT

Magnetic resonance (MR) imaging is used along with the neurological examination and laboratory tests as a tool for the diagnosis of MS and also to follow the course of disease after diagnosis. An important strength of the MR exam is its ability to detect disease that is called "subclinical." Subclinical disease includes existing or new injury to the brain or spinal cord from MS that does not result in definite symptoms evident to you, the person with MS, or to your doctor, even after a careful physical examination.



Despite the wide use of MR imaging, for many people understanding an MR and what the report means is not always so clear. Don't feel bad, as even medical professionals don't have a full understanding of the MR, and we all are learning

more each day. Sometimes we have to correct our prior incorrect ideas as we learn more.

Here I would like to very briefly highlight some important aspects of the MR interpretation to help you better understand your MRI report.

YOUR MR IMAGING REPORT

The report or "interpretation" generally includes the following components, although not always, and not always in this order: (i) a technical description of the procedure, for example, was an intravenous contrast injection included, and what types of MR pulse sequences were used; (ii) a comment as to whether a prior study was available and compared to your current MR study; (iii) the findings in detail; (iv) an impression, highlighting important points.

Regarding ii, prior studies are important, but not always available, and not always comparable, as different techniques may have been used. That is why the MS Centers of Excellence encourage the use of a standardized MR exam for MS. The findings (iii) usually include a description of the major abnormalities of MS that are apparent on an MR image.

FINDINGS INCLUDE: Enhancing lesions, also called **gadolinium** or **contrast enhancing lesions**, are areas of new injury, where there is inflammation, that is areas where special types of white blood cells are contributing or responding to injury. Enhancing lesions always disappear in MS, usually by about 12 weeks or less.

Another finding on MR imaging might be the **T2-lesion** (pronounced *tea-two*). These spots or larger areas all look alike, but some are caused by only very mild injury, while others may be from severe injury. So although we may count up these areas as if they were all equal, in fact they are not equal in the same person or in different people. Your report may indicate the number and location of these T2-lesions. This is most important on the first or an early MR to help us make a proper diagnosis (for example possible MS, or MS). The report may indicate if there is a mild, moderate, or severe amount of these (sometimes called the T2 burden of disease). But a person with mild amounts may have very troublesome MS, while another person with high T2 burden of disease may be doing very well.

T1 black holes, or **T1-holes**, are areas that may be discussed in the report because these usually small areas are more likely to be locations where there is more severe injury. It is important to understand, however, that most injuries in MS, even if severe, such as the T1 black holes, may occur in parts of the brain or spinal cord that may not cause obvious symptoms or problems. So like T2-lesions, it is not just the number, or size, or extent that is important, but the whole picture that is important.

The report may comment on **atrophy**, also called **volume loss**. We know that the more severe injuries we talked about can result in loss of the neuronal tissues (axons and myelin). So the report might include comments about a structure being smaller, or water spaces (ventricles or sulci) being larger as a sign that the brain size

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- ▶ **SEXUAL INTIMACY AND MS**
- ▶ **TREATING MS: MAKING A DIFFERENCE IN VETERANS' LIVES**
- ▶ **FATIGUE AND COGNITIVE EFFECTS OF MS**

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has decreased. Just like the other findings we discussed, in any one person, the atrophy may not be closely related to the amount of apparent injury or disability - this is one of the mysteries that remain. But like the other findings, descriptions of these findings in your report helps your team follow your disease course and helps them in their treatment decisions.

Finally, your report's impression sums it all up. You may see medical terms like active disease (new T2-lesions or enhancing areas), or the word stable (no new areas). All this information together is helpful for your care. Sometimes the information is only useful when looked at over longer periods of time.

In conclusion, the MR report contains important information, but is only part of the full picture. Remember - If you have questions about your report, always ask your health care provider for more information. Both you and your health care provider will learn from the question.

Jack Simon, MD, PhD - Portland VAMC

FAMPRIDINE AND MS

The current disease-modifying therapies for MS act on the immune system to prevent relapses and delay disease progression. These treatments tend to work optimally in the early phase of MS. In both relapsing and progressive forms of MS, a broader array of tools is needed to improve function. Loss of the myelin insulation (demyelination) of nerve fibers is the cause of many of the symptoms of MS. Medications that could improve function of these demyelinated nerves may offer therapeutic benefits. The “potassium-channel blockers” are a class of drugs that may improve conduction in damaged nerve fibers. The potassium-channel blockers have shown the potential to improve neurologic function in people with MS in studies published over the past 25 years.

Fampridine (also known by its chemical name 4-aminopyridine) is a selective blocker of potassium channels in excitable tissues such as nerves. In healthy individuals, potassium channels within nerve fibers (axons) are wrapped with myelin and play a minimal role in the generation of nerve impulses (action potentials). When myelin is attacked and destroyed, as occurs in MS, the potassium channels become exposed and local electrical currents become disrupted, impairing the ability of the nerve fiber to produce electrical impulses. Fampridine preferentially acts on potassium channels and blocks them, with more complete blockage of the channels as the dose of fampridine is increased. By blocking exposed potassium channels, fampridine restores nerve fiber conduction and allows electrical impulses to be conducted along the nerve.

A number of clinical trials testing fampridine in subjects with MS have shown that fampridine improves visual function, motor power, ambulation, spasticity (muscle stiffness), and fatigue in people with MS. However, immediate release forms of fampridine have the potential to produce

high peak doses and rapid changes in dose, which may lead to side effects. Major side effects of fampridine can include tingling, dizziness, nausea, confusional states, balance problems, and occasionally seizures. Side effects appear to be related to high blood levels of fampridine. These observations prompted Acorda Therapeutics to create a sustained-release tablet form (Fampridine-SR) which provides a more stable and predictable blood level of fampridine.

Two recent controlled trials have been published that investigated the benefits of Fampridine-SR in people with MS. Both trials demonstrated an improvement in leg strength in people with MS taking Fampridine-SR compared to people with MS in the trial taking placebo (a look-alike pill that contains no active drug). A re-analysis of the trial after study completion also suggested that approximately one-third of the MS subjects in the study had improvements in their walking abilities, as measured by the time it took them to walk 25 feet. Regarding safety, Fampridine-SR was generally well-tolerated with most side effects related to higher doses. Of note, two

PATIENT EDUCATION CONFERENCE CALL

Learn first hand about MS from MS experts and other health care professionals.

DATE: 2nd Monday of Every Month

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

TOPIC: Different Topic Every Month

TO PARTICIPATE: Dial 1-800-767-1750,
Access Code 43157#

Participation is free. Callers are anonymous. Questions can be asked as time permits. Do you have questions about the call or topic for the month? Contact Angela Young at 1-800-463-6295, ext. 7133 or send an e-mail to Angela.Young4@va.gov.

seizures occurred in people taking high doses of Fampridine-SR in both of the trials. Therefore, people with MS who have a history of seizures or who have risk factors for the development of seizures may not be able to take Fampridine-SR.

Overall, Fampridine-SR is an innovative drug that has the potential to improve neurologic function in people with both relapsing and progressive forms of MS. It offers a therapeutic strategy which differs from the currently available dis-

ease-modifying medications by targeting potassium channels rather than the immune system. Acorda Therapeutics has completed the final round of phase-3 trials (placebo controlled trials which include large numbers of people with MS) for Fampridine-SR and has recently submitted an application to the Food and Drug Administration (FDA) for approval to market this drug.

[Mitch Wallin, MD, MPH - Washington DC VAMC](#)
[Christopher Bever, MD, MBA - Baltimore VAMC](#)

SPOTLIGHT ON LOW DOSE NALTREXONE (LDN)

LDN. People with MS are talking about it. The web is filled with information and testimonials about it. There is even a book devoted to it. But what is LDN and what do we know about it?

Nalrexone is a drug that is FDA approved to treat opiate and alcohol addiction. It is available in 50 mg tablets and, when it is used to treat addiction, it is given at that dose. Low-dose naltrexone (LDN) refers to taking not 50 mg but 1.5-4.5 mg a day of naltrexone. Many claims are being made about the ability of LDN to treat not just MS but a variety of diseases, including AIDS, lupus, Crohn's disease and cancer.

The theory behind LDN is that it stimulates the body to produce endorphins (the body's natural opiate-like peptides), which then help regulate the immune system, make people feel better, and reduce pain, spasticity, fatigue and a variety of other symptoms. There are many testimonials from people who have taken LDN and feel that it has helped them. There is even a pharmacist in Florida who claims he knows of over 10,000 people with MS who have taken LDN and almost all of them supposedly have been helped. However, there have been very few scientific studies done on LDN.

An Italian group published in the journal

Multiple Sclerosis the results of treating 40 people with primary progressive MS for over six months. There was no control group as the purpose was to determine the safety of taking LDN. The people in the study did not experience any significant side-effects from the LDN. There was minor improvement in symptoms in some people, but no dramatic improvements were noted.

A group of scientists at the University of California at San Francisco (UCSF) completed an eight week double blind placebo controlled trial of LDN in 80 people with MS. (Double blind means that during the trial neither the subject nor the doctor knew whether the subject was receiving the LDN or a placebo look-alike pill without active drug.) Again there were no significant side-effects in the people taking LDN, aside from vivid dreaming in some people. The people taking LDN had some improvement in their sense of well-being but did not improve in how they physically functioned. Again no dramatic improvements occurred in any of the people taking LDN.

These two scientific studies are somewhat encouraging. LDN appears safe and some people experience some improvement in some of their symptoms. However, the results are not nearly as dramatic as one might have expected based on reading website testimonials. Much more research needs to be done on LDN before we understand what symptoms it might help and

who might benefit from it. At this time it is premature to believe claims that it “stops MS” or that it is a “cure.”

Based on the research so far, it appears that LDN is safe. It is also relatively inexpensive; one website advertises 90 capsules, which would be enough for 30-90 days, for \$38. To obtain LDN, one needs to have a prescription from a physician and the prescription has to be filled, not at a regular pharmacy, but at a “compounding pharmacy.” At the compounding pharmacy, a pharmacist prepares capsules with the low doses of naltrexone. The recommended dose is 1.5-4.5 mg at bedtime.

If you have MS and want to try LDN, what should you do? First, you should realize that it is an unproven treatment and, based on the first scientific reports, does not look like it is a “wonder drug.” Second, LDN should not be used in place

of proven, FDA approved therapies. Some websites about LDN claim that interferons should not be taken with LDN and that the interferon should be stopped in order to take LDN; there is no basis for this claim and people with MS should continue to take the FDA approved MS therapies that they are already taking, whether or not they choose to go on LDN. Third, if you want to try LDN, you should discuss it with your physician. Finally, you should expect that you will have to pay for the LDN out-of-pocket because no insurance company or health care organization is currently covering LDN.

Whether LDN will be shown to be beneficial for MS or not remains to be determined. More research is being done and we should have a better understanding of where it fits in the treatment of MS within a few years.

[Dennis Bourdette, MD - Portland VAMC](#)

HEALTHY LIVING WITH MS: SMOKING AND ALCOHOL

Living with MS requires patience and flexibility to deal with chronic and often unexpected life changes. Despite the challenges, there are many opportunities for people to take charge of their health and become active managers of their disease. Research on healthy living with chronic illness has consistently shown that people who engage in intentional and systematic self-management of their disease report a higher quality of life and better health outcomes. This can be done by identifying personal goals for health and well being, monitoring and pursuing those goals, reflecting on whether their actions were successful,



and making changes when needed. Health habits such as smoking and alcohol use represent areas where people with MS can make important health changes that contribute to long term health.

SMOKING AND MS

Most people are aware that smoking is the leading cause of preventable death in the United States. Smoking worsens many chronic illnesses, decreases sexual functioning, and shortens the life span of the average smoker by 8 to 13 years. Fewer people know that smoking may also be linked to MS. Several studies have shown that smokers have a higher risk of developing MS, and that smoking is linked to a more aggressive disease course. Smoking may also complicate other challenges people face with MS, like decreasing lung functioning, making wounds or ulcers heal more slowly, and increasing fatigue.

The good news is it’s never too late to quit, and the benefits are numerous. Some benefits can be felt almost immediately; many last for

years to come. Within 24 hours of quitting the risk of heart attack decreases. Within 3 months lung capacity increases up to 30%. At one year, many people report increased energy and decreased coughing and shortness of breath. By year five, the risk of heart attack, stroke, and many cancers is cut in half.

It's Never Too Late to Quit. Many people have smoked for years and just thinking about quitting is stressful and overwhelming, but it can be done. People have many reasons for stopping their smoking. Not all are related to health. Smoking is also expensive and time consuming. Think about why you want to quit. Helpful strategies include writing down the reasons you want to quit and keeping the list where you can see it, setting a quit date, and telling people about it.

All VA facilities offer some assistance with smoking cessation. Often people start by talking to their doctor or another provider who can put you in touch with a VA smoking cessation program that may include medications and counseling. Both have been shown to be helpful to assist quitting. Help and support are also available from the National Quitline 1-800-QUIT NOW. You can call this number any time, or in conjunction with the plan you establish with your doctor.

ALCOHOL AND MS

There is increasing evidence that moderate alcohol consumption may bring some health benefits, but it is far clearer that alcohol misuse is linked to a host of medical problems including cardiovascular disease, obesity, diabetes, high blood pressure, stroke, and cirrhosis, as well as oral, gastrointestinal, and breast cancer. As a result it is still considered one of the leading causes of preventable death.

How much alcohol use is too much? Drinking more than 14 drinks a week for men or more than 7 drinks a week for women is associated with an increased risk of health consequences, as is

**SEND US YOUR COMMENTS AND QUESTIONS.
WE WOULD LOVE TO HEAR FROM YOU!**

MSCoE EAST - VISN 1 TO 11

Baltimore VA Medical Center
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Baltimore, MD 20201
E-mail: Jane.Stolte@va.gov

MSCoE WEST - VISN 12 TO 23

VA Puget Sound Health Care System
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drinking more than 4 (women) or 5 (men) drinks per occasion. Alcohol consumption is only one piece of the equation, however. Not everyone who drinks has a drinking problem, and not everyone who has a drinking problem drinks every day. Try asking yourself the following questions:

- ▶ Have I failed to do what was expected of me because of my drinking?
- ▶ Have I ever felt guilty or concerned about my drinking?
- ▶ Has drinking impacted my relationships with family and friends?
- ▶ Has anyone in my life been worried about my drinking or asked me to cut down?

If you answered yes to any of these questions you might want to think about the impact drinking has on your life and whether making a change would improve your health and quality of life. Most people who make changes in their alcohol use do this on their own. If you have additional questions, or would like some assistance, talk with your doctor who can help you formulate a plan, or refer you for additional assistance.

Aaron Turner, PhD - Puget Sound HCS



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KEEPING COOL WHEN IT'S HOT OUTSIDE

- ▶ Increase your intake of fluids
- ▶ Wear cotton clothing that is light in color
- ▶ Exercise in a cool environment and try an aspirin before exercising - aspirin has been found to slightly lower body temperature
- ▶ Try cooling garments or other products
- ▶ Keep your head covered when in the sun
- ▶ Keep a hand-held mini fan in your bag
- ▶ Moisten your skin and clothing using a water sprayer
- ▶ Get an air conditioner or air cooler
- ▶ Cool your legs gradually to cool the rest of your body



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