

VA MULTIPLE SCLEROSIS CENTERS OF EXCELLENCE

MS VETERAN

SERVING THE HEALTH CARE NEEDS OF VETERANS WITH MS

BEING THE BEST THAT I CAN BE

I've always been a very active, healthy person. While in the Army I completed the physical fitness test 3 times a week, sometimes running 5 miles a day. Then one day, I lost vision in my left eye and the left side of my body went numb. I had no idea what had happened to me. I went to the hospital and the doctors thought I had a mini-stroke. While at the hospital, a neurologist read my chart and said that I didn't have a mini-stroke, I likely had MS and should be tested. After a series of tests that occurred over a three week period, I was diagnosed with MS.

It was November 1999, I had been in the Army for 22 years, and I was informed that I had MS. At first, I didn't believe it. I was too healthy to have MS. The tests must be wrong. Continuing with my denial, I refused to take any MS medication. I was upset that my body wasn't working like it used to, but that was life and I moved on. Fortunately, my neurologist at the Salt Lake City VAMC continued to try and reach out to me. At one of my visits he asked, "If an MRI shows that you have MS, will you start an MS treatment plan?" I was convinced that the test would show that I didn't have MS, so I agreed. Following the MRI, my MS



diagnosis was confirmed beyond any doubts that I had, and I began an MS treatment plan.

Following my career in the Army, I found things to do that kept my mind occupied and found ways to help others. I opened up my own t-shirt shop. I went back to school and graduated in 2003 with a degree in business. I joined the VA

Women's Clinic Club. The Club is a great way to provide support for other women as well as get the support that I need. I talk to a lot of newly diagnosed Veterans. I try to help them understand that they shouldn't give up just because they've been diagnosed with MS.

They're going to be okay and they need to keep an optimistic outlook on life as their MS diagnosis is not going to change.

I've been an Ambassador for the National MS Society (NMSS) in Salt Lake City since 1999. I'm actively involved in the NMSS MS Walk event in April and NMSS MS Bike event in June. Being involved with these events gives me the opportunity to meet new people with MS each year, as well as their families and friends. It's fun

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VISIT OUR WEBSITE!

Please visit the VA MS Centers of Excellence website for additional information at www.va.gov/ms.



to meet so many people and I'm always surprised by how many people have MS.

I'm a very independent person, but must admit that I've come to rely on the emotional support of those around me. My daughter goes to MS events with me and is there daily should I ever need her. My husband helps whenever he can and never treats me like I'm handicapped. I'm very active in my church and have found God to be a source of strength.

I have a very good doctor. Dr. John Rose is one of the best neurologists in the world. He answers

all of my questions and cares about me as an individual, not just a patient.

Having MS doesn't mean that I can have a pity party for myself and I don't want people to feel sorry for me. I've learned to adjust to my MS. I exercise and do everything the doctors tell me to which has helped. I won't give up on life and I keep an optimistic outlook that things will get better... not worse. Everything happens for a reason and just because I have MS, I will not change who I am and who I want to be.

Tonia Davis - Salt Lake City, UT

DALFAMPRIDINE ROLL-OUT

Dalfampridine (Ampyra) was approved by the US Food and Drug Administration (FDA) in January 2010 to improve walking in people with MS. Dalfampridine was called fampridine prior to its FDA approval. The name change was mandated by FDA to avoid confusion with other marketed products.

Dalfampridine is an extended release formulation of 4-aminopyridine, a potassium channel blocker. It is available in 10 mg tablets that are to be taken every 12 hours. A proportion of people with MS had faster walking speeds while taking dalfampridine compared with people taking placebo. This is the first drug approved by FDA for this purpose. Dalfampridine is considered a symptomatic medication for MS and not a disease modifying agent. It has not been demonstrated to alter the MS disease course.

A Risk Evaluation and Mitigation Strategy (REMS) consisting of a medication guide and communication plan was stipulated by the FDA with the approval of dalfampridine. This was done to ensure safe prescribing of the drug. Currently, dalfampridine is available for Veterans through a specialty pharmacy distribution program. Dalfampridine will be available for distribution within the normal

Veterans Health Administration (VHA) pharmacy system soon.

The VHA has created a Dalfampridine Criteria for Use (CFU) document which provides guidance on the prescribing of this medication. The CFU specifies the medication should be prescribed only in people with a diagnosis of MS made by an MS specialist. Difficulty in walking must be demonstrated by an objective scale such as the timed 25 foot walk or the MS Walking Scale-12.

LEARN MORE ABOUT MS!

MSCoE produced DVDs from our live educational programs. They are a great way to learn more about MS issues.

- ▶ **FATIGUE & COGNITIVE EFFECTS OF MS**
- ▶ **MRI GUIDELINES FOR DIAGNOSING & MANAGING MS**
- ▶ **MS THERAPIES: STRATEGIES FOR OPTIMIZING DISEASE MANAGEMENT**
- ▶ **PAIN & PALLIATIVE CARE IN MS**
- ▶ **SEXUAL INTIMACY & MS**
- ▶ **STAYING MOBILE WITH MS**

Interested in receiving a set of free DVDs? Contact Jaimie Henry at (800) 949-1004, ext. 53296 or Jaimie.Henry@va.gov.

Because fewer than 50% of people respond to therapy, and there are potential side effects, a 2 to 4 week trial of therapy is mandated prior to continuing ongoing therapy. People with MS should be evaluated prior to starting therapy and then after the initial 2 to 4 weeks to determine whether there are objective improvements in walking that justify continued therapy.

Dalfampridine is not recommended for people with moderate to severe kidney impairment or a history of seizures. When given at doses greater

than the recommended 10 mg every 12 hours, dalfampridine can cause seizures. Common side effects (> 2%) included bladder infections, insomnia, dizziness, headache, and nausea.

Overall, dalfampridine is a welcome addition to the list of symptomatic therapies for people with MS. The MS Centers of Excellence staff can offer further guidance and updates regarding use of dalfampridine in the VHA.

Christopher Bever, Jr., MD, MBA - Baltimore VA
Mitchell Wallin, MD, MPH - Washington DC VA

MARCH IS NATIONAL MS AWARENESS MONTH

The MS Centers of Excellence would like to remind you that March 2011 is National Multiple Sclerosis Education and Awareness Month. We would like to encourage Veterans with MS and their families to partner with local health care providers, VA Medical Centers, and their community to plan something special during MS Awareness Month.

The Multiple Sclerosis Foundation (MSF) has developed March Awareness Kits, packed with educational tools in keeping with this year's theme, *The MS Journey of Self-Discovery: Learn How to Manage Your Disease*. Because MS is different for everyone, it is important that people discover the treatments, therapies, and lifestyle adaptations that can help improve their quality of life. The materials in these kits can be copied and distributed at community centers, police and fire departments, libraries, doctor's offices, and places of business. Call (800) 225-6495 or send an e-mail request via the MSF website at www.msfocus.org.

The National Multiple Sclerosis Society (NMSS) is sponsoring March 14th to 20th as MS Awareness Week. The NMSS website has information on this project as well as free

educational materials. Please check with your local and state chapters for additional activities planned for March or go online to www.nmss.org.

The Multiple Sclerosis Association of America (MSAA) has a useful calendar of activities organized by region that may be accessed at their



website www.msaa.com. The MSAA provides educational materials free of charge for distribution to people with MS and their families.

SUGGESTIONS TO GET INVOLVED:

Contact MS organizations: Ask MS organizations for free materials that can be distributed to family, friends, support groups, local businesses, and communities.

Contact the VA: Ask your local VA Medical Center's Public Relations or Education Department for assistance with having this month recognized for MS awareness.

Join a MS support group: MSCoE has monthly conference calls, MS World has an on-line MS support group at www.msworld.com, or connect with your local VA or community center.

Volunteer at the VA: Check with your local VA Medical Center's Voluntary Services Department to see how you can volunteer your

time. There are opportunities available for people of all ability levels, skill sets, and career backgrounds.

Volunteer at your local Veteran Service Organization: There are several VSOs such as the Paralyzed Veterans of America, Disabled American Veterans, American Legion, Veterans of Foreign Wars, and other state and local nonprofit organizations that you can volunteer your time to raise MS awareness.

Register for a MS event: Help raise community awareness of this disease by participating in MS events like walk-a-thons and bike-a-thons.

Include an email tagline: Add to all of your emails “March is MS Awareness Month” to encourage discussion.

Conduct a Facebook campaign: Ask your friends to dedicate their status or profile picture to the cause of MS awareness.

Make some lifestyle changes: Talk to your health care provider about life style habits that could help you manage your MS like joining a smoking cessation program, making healthy diet choices, and participating in an exercise program.

The most important message is to help raise MS awareness by getting involved with your local VA Medical Center and community. As you move through your MS Journey become an active participant in sharing with others about the disease and accessing the variety of resources that will help you take an active role in managing your health and increasing your quality of life.

Marsha Tarver, PhD - Seattle VA

WHAT TO DO IF YOU SUSPECT AN MS RELAPSE

By its very name, multiple sclerosis tells us that there are many (multiple) scars (sclerosis) in the brain, spinal cord, and optic nerves. When these plaques or scars are formed, they can be silent and only detected by MRI or can cause symptoms. New plaque formation accompanied by new symptoms is called a relapse, attack, or exacerbation. The symptoms of plaque formation include vision loss, weakness, sensory changes, balance problems, double vision, slurred speech, or bladder problems.

HOW DOES A RELAPSE CAUSE SYMPTOMS?

The symptoms of a relapse are caused by disruption of an area of the brain, spinal cord, or optic nerves due to immune cells inappropriately entering the brain and attacking the nervous tissue, a process called neuro-inflammation. While inflammation is present, nerve cells cannot successfully transmit signals through the affected area. The blocked impulses do not reach

their muscle targets, causing weakness, or do not allow brain regions to interpret sensory signals, causing reduced vision, diminished sensation, and imbalance.

A typical relapse usually lasts from a few days up to several months. After the inflammation subsides, repair mechanisms naturally present in the nervous system begin to heal the damage. The repair process allows the electrical signals to once again conduct through the area of the plaque, although sometimes not as efficiently as before the relapse. The incomplete repair causes some people to have permanent symptoms after a relapse even though active inflammation is no longer present.



DO ALL PEOPLE WITH MS HAVE RELAPSES?

Not all people with MS experience relapses. About 85% of people start MS with relapses due to neuro-inflammation followed by periods of

stability, called relapsing-remitting MS (RRMS). Many of these people transition to secondary progressive MS (SPMS), during which relapses stop and MS symptoms worsen in the absence of neuro-inflammation. People with SPMS may have sudden worsening of symptoms that seem like a relapse. However, instead of being due to neuro-inflammation, these episodes are probably due to medical or emotional stresses that worsen overall neurological functioning. Finally, people with primary progressive MS (PPMS) do not experience relapses.

Whether your symptoms are due to neuro-inflammation or not is important for determining what treatments will help. In general, only neuro-inflammation will respond to steroid treatments. However, all worsening of MS, due to any cause, will respond to other types of treatments. How your MS health care provider will investigate and treat your worsening MS symptoms will depend on factors specific to you.

WHAT SHOULD I DO IF I SUSPECT I AM HAVING AN MS RELAPSE?

First, pay attention to your symptoms. Typically a relapse causes symptoms you never felt before or are more severe than in the past. Next, determine how long your symptoms are lasting; anything lasting less than 24 hours is probably not a relapse. Take note if you have other medical issues like urinary discomfort, cough or cold symptoms, abdominal pain, skin infections, or any recent immunizations. Finally, take stock of your psychological state including any recent stresses affecting you or those close to you.

HOW WILL MY MS HEALTH CARE PROVIDER DETERMINE IF I AM HAVING A RELAPSE?

Once you've gathered this information and your symptoms have lasted at least 1 to 2 days, call your MS health care provider. Depending on the severity of symptoms and other factors specific to you, your provider may require an office visit.

FAMILY AND CAREGIVER CONFERENCE CALL

Join the free monthly conference call to connect with others supporting those with MS. A variety of educational topics and resources will also be presented!

DATE: 4TH MONDAY OF EVERY MONTH

**TIME: 8 P.M. - 9 P.M. ET, 7 P.M. - 8 P.M. CT,
6 P.M. - 7 P.M. MT, 5 P.M. - 6 P.M. PT**

**TO PARTICIPATE: CALL (800) 767-1750
ACCESS CODE 43157#**

In addition, 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. It is open

MONDAY - FRIDAY: 8 A.M. - 11 P.M. ET

SATURDAY: 10:30 A.M. - 6 P.M. ET

Blood and urine testing may be ordered to ensure you do not have an infection. An MRI may be considered but often is not necessary. If your symptoms are severe and cannot wait for you to contact your MS health care provider, see your primary care provider or visit the emergency room for evaluation. Your MS health care provider will determine if your symptoms are due to neuro-inflammation or not, and make treatment decisions accordingly.

HOW ARE MY MS RELAPSES TREATED?

MS relapses due to neuro-inflammation will respond to intravenous steroids. However, steroids only shorten the duration of symptoms and do not affect the extent of recovery. They can also have unwanted side effects like high blood sugars, insomnia, and agitation. Therefore, they are only prescribed if symptoms are severe or disabling. When prescribed, intravenous steroids are given for 3 to 5 days. If relapse symptoms are mild or non-disabling, treatment may simply be rest and relaxation at home. Regardless of whether neuro-inflammation is present or not, physical therapy,

speech therapy, and other related treatments may also be prescribed to improve worsening neurological symptoms.

In summary, you should suspect an MS relapse if you have RRMS, you have new or more severe neurological symptoms than previously experienced, symptoms last for more than 1

to 2 days, and there are no other medical or psychological stressors present. If you think you are experiencing an MS relapse or have unexplained worsening of your MS symptoms, please call your MS health care provider to discuss your evaluation and treatment.

Rebecca Spain, MD, MSPH - Portland VA

STAY WELL WITH MS

It is important to get your general primary care and specialty care evaluations in 2011. Staying well with MS depends on taking charge of your general health as well as keeping on top of your MS. Because people with MS can still have medical conditions like high blood pressure, high cholesterol, heart disease, diabetes, and cancers, it is important to have a yearly primary care evaluation. This visit should include a comprehensive medical history review and general medical examination.

During these visits, your primary care provider can manage any health problems you may have and also plan for any routine health screenings. Bring all of your medications, including the ones prescribed by a non-VA provider, a naturopath, or those purchased over the counter. Also, bring any medical records and test results that are not VA documents.

Primary care providers work closely with MS specialists to provide comprehensive care for you. To successfully manage your MS, it is important to be seen annually by an MS specialist as well. This is generally someone in the neurology, rehabilitation, or spinal cord injury department with additional training in MS who is capable of performing a full evaluation of your needs. This specialty evaluation should include a comprehensive neurological history review and examination.

The evaluations can be done in a single outpatient visit, multiple outpatient visits, or

in some instances as an inpatient. Your MS evaluation is a great opportunity to find out what is new in the management of MS and to stay ahead of problems that limit your activities or ability to participate in society. A careful determination of whether MS is impacting other aspects of your health, and developing the best management strategy for you, will improve your health and general well-being. If you don't know your MS specialist, or don't have an upcoming appointment, ask your primary care provider for a referral.

You can help prepare for an efficient, productive MS visit. Write a list of your most important questions and identify which are priorities ahead of time. As with your primary care visit, be sure to bring all medications and non-VA medical documentation with you to your appointment.

HAVE YOU TAKEN MITOXANTRONE (NOVANTRONE) IN THE PAST?

Mitoxantrone is a chemotherapy drug which has been used for MS treatment since 2000.

- ▶ Based on an FDA alert in 2008, it is recommended that all people with MS who received mitoxantrone have a follow-up heart (cardiac) imaging study.
- ▶ The cardiac imaging study should be an echocardiogram (cardio echo) or a cardiac MUGA (multiple gated acquisition) scan, to evaluate for the possibility of delayed heart muscle damage from mitoxantrone.

If you have received mitoxantrone, talk to your MS provider about this.

SOME COMMON QUESTIONS YOUR MS SPECIALIST MAY ASK ARE:

- ▶ How active has your MS been over the last year?
- ▶ Are you having any memory, speech, or cognitive difficulties?
- ▶ Are you experiencing fatigue?
- ▶ How are you sleeping?
- ▶ Are you experiencing any depression or anxiety?
- ▶ Are you experiencing any pain?
 - ▶ Where and when?
- ▶ Are you experiencing any spasticity or muscle spasms?
- ▶ Are you having any swallowing or breathing difficulties?
- ▶ Are you experiencing any bladder difficulties such as incontinence, urgency, or difficulty voiding?
 - ▶ How many UTIs have you had this year?
- ▶ Are you experiencing any bowel difficulties such as constipation or accidents?
- ▶ Do you have any sexual or intimacy concerns?
- ▶ Are you experiencing any vision difficulties?
- ▶ How is your mobility?
 - ▶ How often do you fall (or nearly fall) and why?
 - ▶ What type of assistance or equipment do you require?
 - ▶ Have you ever taken dalfampridine (Ampyra)?
- ▶ How often do you exercise?
- ▶ Are you able to take your disease management agent (interferon beta 1a (Avonex, Rebif), interferon beta 1b (Beteseron, Extavia), glatiramer acetate

PATIENT EDUCATION CONFERENCE CALL

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

DATE: 2ND MONDAY OF EVERY MONTH

TIME: 8 P.M. - 9 P.M. ET, 7 P.M. - 8 P.M. CT,
6 P.M. - 7 P.M. MT, 5 P.M. - 6 P.M. PT

TOPIC: DIFFERENT TOPIC EVERY MONTH

TO PARTICIPATE: CALL (800) 767-1750
ACCESS CODE 43157#

Do you have questions about the call or topic of the month? Contact Angela Young at (800) 463-6295, ext. 7133 or send an email to Angela.Young4@va.gov.

(Copaxone), natalizumab (Tysabri), fingolimod (Gilenya), or mitoxantrone (Novantrone)) as prescribed or are you having difficulty?

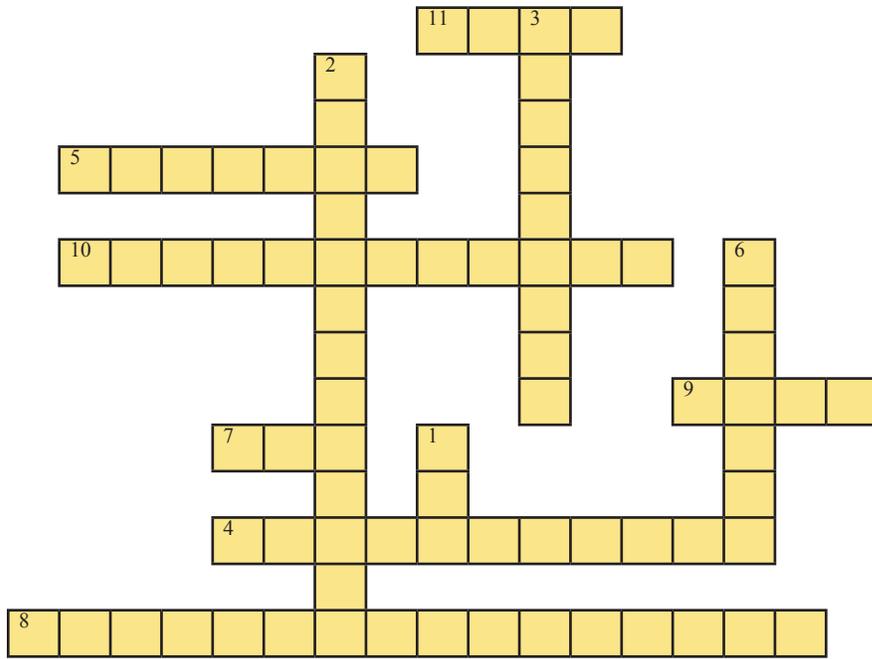
- ▶ How is your ability to perform self care such as bathing, dressing, transfers, eating, meal preparation, and other chores?
- ▶ Are you experiencing any difficulties with work?
- ▶ What type of social support do you have from family, friends, and your community?
- ▶ How much tobacco, alcohol, or other substances do you use?

Attention to these and other details can maximize your independence and quality of life. Taking the time to care for your primary and specialty needs is a great way to minimize difficulties you and your family may experience with MS and your health.

Jodie Haselkorn, MD, MPH - Seattle VA
Christina Hughes, MD - Seattle VA

Crossword answers: 1. FDA, 2. Dalfampridine, 3. Sclerosis, 4. Primary Care, 5. MS World, 6. Relapse, 7. MRI, 8. Disease Modifying, 9. Cane, 10. Mitoxantrone, 11. NMSS

CROSSWORD PUZZLE



1. Abbreviation for US Food and Drug Administration
2. First drug approved by FDA to improve walking
3. Term for scars in the brain
4. An appointment with this provider should be made every year
5. An on-line support group
6. New plaque formation accompanied by new symptoms
7. Medical procedure that detects silent symptoms
8. Type of therapy that affects disease course
9. Provides assistance when walking
10. Chemotherapy drug
11. Veteran is Society Ambassador

To be removed from or added to this mailing list, please send an email to Jaimie.Henry@va.gov or call (800) 949-1004, ext. 53296.



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