

## VA MULTIPLE SCLEROSIS CENTERS OF EXCELLENCE

## MS VETERAN

## SERVING THE HEALTH CARE NEEDS OF VETERANS WITH MS

## A VETERAN'S JOURNEY WITH MS

I joined the military right out of high school and quickly decided that I wanted to make the military a lifelong career. After about 12 years in the military, while on night patrol in the infantry, I noticed that my night vision was getting bad. I went to the doctor to see if he could help, but the doctor couldn't find anything wrong with me. He said I was just getting older. I walked away from that appointment thinking, I'm only 30 years old, this doesn't make sense. Yet, I realized that the infantry average age was 18 years old, dismissed my concerns and accepted the ailments of age.

I continued to have issues, but they were never consistent. Some days my legs would tingle or I'd feel a little dizzy, other days I'd feel fine. It was difficult to get a full understanding of what was going on since I was never in one place long enough. I was soon led down a path of medical procedures which ruled out what I didn't have, but failed to tell me what I did have. In 1987, a neurologist noticed a pattern in my symptoms and sent me to Seattle, WA for an MRI. The MRI showed that I had MS, something that was never mentioned in any of



my previous medical procedures.

After I was diagnosed, it seemed like my problems got worse. I began to blame everything that was going wrong in my body on MS. There were days that I would feel good, but never 100%, never like I used to feel before it all happened. One day I woke up with no feeling in my legs. This strange feeling kept rising inch by inch up my body and as the sensation got closer to my heart, a thought crossed my mind that this might be the end. After being given several medications the condition stabilized. I was placed in a wheelchair to prevent injury to myself and I went back to work in a desk job. In 1989, I was retired from the military.

After retirement, I did a lot of work in physical therapy and was put on interferon treatments. Through everything, I kept pushing myself, reminding myself that I wasn't going to let this take me over. After 16 months of being in a

## WHAT'S INSIDE

- ▶ A Veteran's Journey with MS 1
- ▶ What Are My VA Benefits for MS 2
- ▶ Vitamin D and MS 4
- ▶ Monoclonal Antibody Treatment in MS 5
- ▶ MS and Pain 6
- ▶ My HealthVet 8
- ▶ Smoking Cessation 8



## VISIT OUR WEBSITE!

Please visit the VA MS Centers of Excellence website for additional information at [www.va.gov/ms](http://www.va.gov/ms).

wheelchair, I was back on my feet.

After being out of the military for about a year, I decided that I wanted to go back to school. I had an associate degree, but I wanted more. I wanted a degree in public policy. A lot of people told me to reconsider, this would be too much for me, a waste of money, as the program was just too difficult. I talked to my neurologist about what I wanted to do and he told me that if this is what I wanted and I thought I could do it, then I should go for it. Two years later, I graduated with a bachelor's degree from the University of Oregon.

I had always been involved in community de-

velopment and while finishing my degree, I ran for city counselor, which I won. My path quickly led me to being elected mayor of Winston, Oregon, a position which allows me to give back to my community. I've been mayor for 8 years now and I couldn't be happier. I keep very active and I'm always looking to take on more because I know that I can do it. My progression of MS varies, but I always keep in mind that **MS will not set the pattern of my life. I have the disease, but the disease does not have me.** I'm very proud of what I've been able to accomplish and I'm happy with the way my life turned out.

Rex Stevens - Mayor, City of Winston, Oregon

## WHAT ARE MY VA BENEFITS FOR MS?

Veterans may be eligible for a broad range of programs and services provided by the Department of Veterans Affairs (VA). These programs are based upon honorable discharge from active military service. Benefits include service-connected benefits *for veterans who are disabled by an injury or disease that was incurred or aggravated during active military service* and non-service-connected benefits.

### SERVICE-CONNECTED (SC)

MS is a presumptive condition and benefits are based on the presumption that the disability is SC. Veterans with symptoms of MS while in the military or within seven years after honorable discharge, may be eligible for SC disability.

### NONSERVICE-CONNECTED (NONSC)

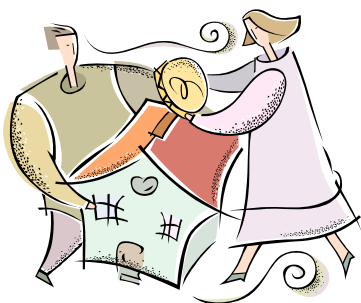
Veterans diagnosed with MS after the presumptive period of seven years could be eligible for VA benefits under nonSC status. NonSC pension is an income-based benefit that is dependent on dates of service and type of disability.

### PROSTHETIC AND SENSORY AIDS SERVICE:

Veterans with MS are eligible for many services from the Prosthetic and Sensory Aids Service (PSAS) program ([www.prosthetics.va.gov](http://www.prosthetics.va.gov)). The basic eligibility for prosthetic items is enrollment in the VA system and proper medical justification. *Service connection does not have a role in eligibility except for certain programs.* PSAS is an integrated delivery system designed to provide to eligible veterans medically prescribed devices such as hearing aids, eyeglasses, speech and communication devices, home dialysis supplies, orthopedic braces, supports and footwear, wheelchairs, home respiratory aids, hospital beds, and other daily-living aids.

**HOME IMPROVEMENT GRANTS:** There are several types of grants available to make medically necessary home improvements like roll-in showers and widening of doorways. The Home Improvements and Structural Alterations program will pay a lifetime benefit up to \$4,100 for home alterations for a SC disability and a lifetime benefit up to \$1,200 for other veterans. The Specially Adaptive Housing (SAH) grant is generally used to make a home wheelchair accessible and has a maximum benefit of \$50,000. The Special Housing Adaptations (SHA) grant is limited to \$10,000 and is related to specific

losses of hand mobility and blindness. The Temporary Residence Adaptation (TRA) grant is also available. The TRA grant is designed to fund adaptations to make the home more accessible for veterans living in a temporary environment or with a family member. Veterans eligible under the SAH program would be permitted to use up to \$14,000 and those eligible under the SHA program would be allowed to use up to \$2,000 of the maximum grant amounts.



**MOBILITY BENEFITS:** It is common for individuals who have MS to experience changes in their mobility, requiring different accommodations to help maintain mobility. A consult should be sent to Physical Medicine and Rehabilitation Services or another appropriate interdisciplinary Mobility Clinic to reevaluate changes in mobility needs.

**DRIVER REHABILITATION:** Maintaining independence is important and the VA assists in getting veterans with disabilities back on the road again. Services include driving assessments and training.

**MODIFICATIONS:** SC veterans qualify for an automobile adaptive equipment benefit up to \$11,000 towards the purchase of an automobile or other conveyance. SC and nonSC veterans can apply for other vehicle modifications.

**CLOTHING ALLOWANCE:** SC veterans may receive an annual monetary allowance for clothing that has been damaged by prosthetic or orthopedic appliances up to \$677.

**AID AND ATTENDANCE:** Upon approval, SC veterans in need of regular aid and attendance from another person can receive compensation for this benefit.

**MENTAL HEALTH SERVICES:** Eligible veterans can receive a variety of mental health ser-

VICES including medications, cognitive testing, and other therapies.

**RESPIRE CARE:** The VA recognizes the importance of supporting caregivers and provides a temporary relief benefit for unpaid caregivers. The benefit includes respite care for up to 30 days in a calendar year. It is important to review these benefits with your local social work department.

**SUMMARY:** The VA offers a variety of medical and support services and programs for people with MS. It is important to contact your local VA medical center social work department and review your eligibility for the benefits discussed. The VA provides Patient Advocates to help with this process and you can always contact one of the veteran service organizations like Paralyzed Veterans of America, United Spinal, and Disabled American Veterans for additional support. The VA is committed to working with veterans and their families toward a better quality of life.

Robert Baum, VA Central Office Prosthetics  
Marsha Tarver, PhD, Puget Sound HCS

*Would you like more information on benefits? Go to **Life Issues** at [www.va.gov/ms](http://www.va.gov/ms).*

### **WANT TO LEARN MORE ABOUT MS?**

Join the **Monthly Patient Education Conference Call** and learn first hand about MS from MS experts and other health care professionals!

**DATE:** The 2nd Monday of Every Month  
**TIME:** 8-9pm ET, 7-8pm CT, 6-7pm MT, 5-6pm PT

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

Participation is free, callers are anonymous, and 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 [Angela.Young4@va.gov](mailto:Angela.Young4@va.gov).

# VITAMIN D AND MS

Correcting vitamin D deficiency may be important to the health of people with MS. Research studies have found that low vitamin D intake and low blood levels of vitamin D may increase the risk of developing MS. Although it is unclear whether vitamin D levels in people with MS are lower than those of people without MS, one small research study found low levels of vitamin D correlated with increased disability in people with MS. It has also been reported that vitamin D levels are lower in people having MS relapses compared with those in remission. Given these findings, it is important to consider vitamin D for MS wellness.

Vitamin D is a fat soluble vitamin that is found in food and can also be made in your body after exposure to ultraviolet (UV) rays from the sun. Sunshine is a significant source of the active form of vitamin D because sunlight triggers vitamin D synthesis in the skin.

Vitamin D exists in several forms. Ergocalciferol (vitamin D2) is the inactive form found in food and cholecalciferol (vitamin D3) is the active form of vitamin D. The liver and kidney help convert vitamin D2 to its active hormone form, vitamin D3. The major function of vitamin D is to maintain normal blood levels of calcium and phosphorus for bone formation and for maintaining bone strength.

Vitamin D3 also can help control the immune system and in one MS study was found to increase the levels of protective anti-inflammatory proteins. Blood levels of vitamin D2 (serum 25-hydroxyvitamin D) are used to determine 'sufficient' or 'deficient' levels of vitamin D. This can be done with a simple blood test. Results are given as nanograms per milliliter or ng/ml:

- > 30 ng/ml indicate sufficient levels
- 21-29 ng/ml indicate borderline deficient levels

- 9-20 ng/ml indicate deficient levels
- ≤ 8 ng/ml indicate severely deficient levels

For adults the recommended daily intake of vitamin D is 400 IU/day. Taking more than 2000 IU/day may be harmful. High blood levels of vitamin D can cause toxicity and raise blood calcium levels. Side effects include headaches, nausea, vomiting, poor appetite, excessive thirst, weight loss, and heart rhythm abnormalities. One can obtain vitamin D from a number of dietary sources.

DIETARY SOURCES	IU/SERV.
Cod Liver Oil (1 tablespoon)	1,360
Salmon (3.5 ounces cooked)	360
Tuna Fish (3 ounces canned in oil)	200
Nonfat Milk (1 cup, vit. D fortified)	98
Cereal (1 cup, vit. D fortified)	40
Egg (one)	20
Swiss cheese (1 ounce)	12

Sunshine is the best source of active vitamin D. Although lack of sun during winter months and using sunscreen with SPF > 8 can significantly affect vitamin D levels, it only takes 10 to 15 minutes of sun exposure twice a week to maintain adequate levels of the vitamin. During the dark winter months, cod liver oil or vitamin D3 supplementation can help maintain adequate vitamin D levels.

People with MS should discuss with their health care provider the need to have their blood vitamin D level checked and if low correct it with supplementation. People with MS who are not receiving adequate sun exposure should consider taking vitamin D supplementation after consulting with their health care providers.

Lynne Shinto, ND, MPH, MS Center of Oregon  
Dennis Bourdette, MD, Portland VAMC

*Would you like more information on vitamin D? Go to <http://dietary-supplements.info.nih.gov/factsheets/vitamind.asp>.*

# MONOCLONAL ANTIBODY TREATMENT IN MS

Monoclonal antibodies are an important class of drugs which have a highly specific ability to bind onto selected targets. Typically, these antibodies are used in the treatment of inflammatory conditions such as MS, rheumatoid arthritis, or malignant diseases such as leukemia and lymphoma. Monoclonal antibodies are produced by modern culture of antibody producing cells that make only one specific antibody. Traditionally, these antibodies were developed in mice or rats, but are now highly engineered by use of newer biochemical techniques. At present, these antibodies have the majority of their structure similar to normal human antibodies. Still, many have some foreign portions in their structure that can raise a reaction to the medication.

MS is an inflammatory disease of the central nervous system. The illness involves a class of circulating blood cells called lymphocytes that are normally part of our defense system against infections and cancer. However, these lymphocytes can be inappropriately activated against normal parts of the body and produce a reaction that is termed autoimmunity. In autoimmune diseases such as MS, two classes of lymphocytes can be activated with the result being onset or relapse of the illness. These two classes of activated lymphocytes are termed T cells and B cells. Both seem to have a role in mediating the damage in MS that results in loss of myelin and axonal injury in the brain and spinal cord.

People with MS are often well controlled on simpler therapies that have far fewer risks than presently available monoclonal antibodies. The immunomodulatory treatments that are FDA approved for MS include glatiramer acetate (Copaxone®) and interferons (Betaseron®, Avonex®, and Rebif®). People with disease well controlled by immunomodulatory treatment

should not advance to monoclonal antibody treatment.

However, if a person continues to have significant disease activity, resulting in relapses or acute changes on MRI, consistent with active disease, while on an immunomodulatory treatment, then he or she may be an excellent candidate for monoclonal antibody treatment. It is usually a good idea to try two or more of these immunomodulatory therapies before considering monoclonal antibody treatment. In this setting, people with very active disease failing other therapies have a very good chance of responding well to monoclonal antibody treatment.

**AVAILABLE TREATMENTS:** *Natalizumab* (Tysabri®) is FDA re-approved for use in MS. Relapsing-remitting and secondary progressive MS with continued relapses are treated with this agent. Efficacy was demonstrated in two multicenter trials. A risk of progressive multifocal leukoencephalopathy was found in these trials.

The Touch Program™ for natalizumab requires multiple certifications and persistent monitoring of patients throughout the treatment.



Logistics of handling the medication and the cost are substantial. The medication is administered every four

weeks by intravenous infusion (by vein). People are screened for problems at the time of each infusion and must sign a document acknowledging the risks of therapy prior to each treatment. Thousands of people are now enrolled in the Touch Program™ which is the only way to receive natalizumab treatment.

**DEVELOPING TREATMENTS:** At present, several additional monoclonal antibodies are being studied as investigational treatments for MS.

They are not currently available for routine use in the treatment of MS.

**Rituximab** (Rituxan®) is reported recently to be efficacious in treatment of relapsing-remitting MS and is in study for primary progressive MS. This drug is FDA approved for treatment of malignancies and has just been reported to be efficacious for MS in a recent study of 69 patients with relapsing MS. **Alemtuzumab** (Campath®) is another monoclonal antibody directed at lymphocytes which is under continued investigation for treatment in MS. Both rituximab and alemtuzumab are associated with longer-term immunosuppression (6 to 12 months). Serious immunological and infectious complications have occurred with these agents.

**Daclizumab** (Zenapax®) is FDA approved for the treatment of kidney transplant rejection. It is off-label for MS and people with relapsing-remitting and transitional MS are treated with this agent. Most often these people have failed

several other treatments. Efficacy was demonstrated in off-label experience, two small phase II studies, and a larger multi-center phase II study. Currently, a longer duration multi-center phase II trial is in progress in Europe. Rash, fever, and occasional overgrowth of lymph nodes have been observed in people on long-term therapy with this drug.

**SUMMARY:** Overall, monoclonal antibodies are important medications with substantial specificity. They have substantial potential to control disease in people with MS failing other therapies. At present, natalizumab (Tysabri®) is the only FDA approved monoclonal antibody specifically approved for treatment of MS. Risks and benefits need to be carefully weighed in each decision to treat. Careful assessment can identify people that are likely to respond to these therapies and result in very rewarding clinical outcomes for responding individuals.

John Rose, MD, Salt Lake City VA

## MS AND PAIN

Approximately two thirds of people with MS experience pain at some time during the course of the disease. MS pain experts understand that MS pain is difficult to manage, and associated with depression, anxiety, and fatigue. Pain should never be ignored and should always be addressed.

**CAUSES OF MS PAIN:** Pain is a sensory symptom directly related to two events – the disruption of central nervous system myelin and the effects of disability. When pain is a symptom of an MS lesion or plaque it is termed neurogenic pain. The disability that is a result of MS causes a different type of pain originating in muscles, bones, and joints.

Neurogenic pain can be continuous and steady or spontaneous and intermittent, and is reported in varying degrees of severity. Intermit-

tent, spontaneous pain is described as shooting, stabbing, electric shock-like, or searing and is often caused by sensations that normally do not cause pain.

Tightness or band-like sensations, nagging, numbness, tingling in legs or arms, burning, ach-



ing, and throbbing pain is categorized as continuous or steady neurogenic pain.

Steady pain is often worse at night, worse during temperature change and worsened by exercise. The most common pain syndromes experienced by people with MS include: headache, continuous burning pain in the extremities, back pain, and painful tonic spasms.

**TREATMENT OF MS PAIN:** The sensation of

pain is difficult to measure, and it is what the experiencing person says it is. Pain impacts sleep, mood, and the ability to work, play and enjoy life. Pain management is approached medically, behaviorally, physically and in some cases, surgically. A good pain history of the onset, location, duration, characteristics, aggravating factors, relieving factors, and treatments helps providers adequately treat pain. Keeping a pain diary helps patients explain their pain and receive the best care.

**Medication:** Treatment of neurogenic pain is aimed at down regulating excitatory neurotransmitters and enhancing inhibitory transmitters of pain with topical agents, antiepileptics, antidepressants, antiarrhythmics, NMDA-receptor antagonists, and non-narcotic and narcotic opioids. The use of opioids for MS neurogenic pain remains controversial. Opioids are considered when other agents become ineffective or not well tolerated. Opioids are constipating. A good bowel regimen including fiber, stool softeners, and laxatives is always considered in MS pain managed with opioids.

VA providers and patients are being warned of a recent Food and Drug Administration bulletin reporting an increased rate of suicide in patients receiving antiepileptic drugs (AEDs). AEDs are commonly prescribed to manage MS pain. There is no need to discontinue these medications. Awareness of any behavior changes or depressed mood should be reported to your providers.

**Behavioral:** Tolerance to pain is decreased with repeated exposure to pain, with stress, fatigue, anger, boredom, and sleep deprivation. Pain tolerance is increased with hypnosis, warmth, distracting activities, and strong beliefs or faith. Competing stimuli such as distraction, socialization, and recreation may act to increase pain tolerance. Relaxation, meditation, imagery, hypnosis, distraction, and biofeedback are strategies that increase the tolerance to pain. Getting involved in work or social activities, joining a

## QUESTIONS? COMMENTS? WE WOULD LOVE TO HEAR FROM YOU!

### MSCoE EAST - VISN 1 TO 11

Baltimore VA Medical Center  
Attn: Jane Stolte, Administrative Officer  
10 N Greene St, Neurology Service 127  
Baltimore, MD 20201  
E-mail: jane.stolte@va.gov

### MSCoE WEST - VISN 12 TO 23

VA Puget Sound Health Care System  
Attn: Drew Blazey, Administrative Officer  
1660 S Columbia Way, S-117-RCS  
Seattle, WA 98108  
E-mail: drew.blazey@va.gov

support group or even having a good laugh are techniques that can minimize pain. Interesting to note, higher pain severity is reported by people with MS who are unemployed or homebound.

**Physical:** Physical agents work to enhance or limit pain transmitters and include the application of heat, cold or pressure, physical therapy, exercise, massage, acupuncture, yoga, tai chi, and Transcutaneous Electrical Nerve Stimulation. Use of physical agents can minimize doses of medication.

**Surgical:** Surgical pain management interventions are sought when medical, physical, and behavioral options fail. Procedures such as regional nerve blocks are reversible and safe. Neurosurgical options, rhizotomy, cordotomy, and Gamma Knife radiosurgery are known to offer relief, but carry risks.

**SUMMARY:** Pain is a symptom that demands serious attention, as it has such pervasive impact on role, mood, capacity to work and rest, and interpersonal relationships. MS pain management is an achievable goal. The management of pain in MS is based on the mechanisms of the pain experienced. The goal of pain management is to optimize mood, sleep, and quality of life.

Heidi Maloni, PhD, NP, Washington DC VAMC

## SMOKING CESSATION

Most people know that smoking is the leading cause of preventable death in the US, and that it is associated with numerous health problems including cancer, stroke, and heart disease. The good news is, it's never too late to quit.

Quitting works best when you are prepared. Here are some tips to **START**.

**S** = **Set** a quit date

**T** = **Tell** family and friends

**A** = **Anticipate** and plan for challenges

**R** = **Remove** cigarettes and other tobacco from your environment

**T** = **Talk** to your doctor about getting help

All VA facilities offer some assistance with smoking cessation. Help and support are also available from the National Quitline at 1-800-QUIT NOW.



**My Health\_Vet** is the gateway to veteran health

benefits and services, available right on your home computer. It provides access to

- trusted health information
- links to Federal and VA benefits and resources
- the Personal Health Journal
- online VA prescription refill

In the future, **My Health\_Vet** registrants will be able to view appointments, co-pay balances, portions of their VA medical records online, and much more! **My**

**Health\_Vet** is a powerful tool to help you better understand and manage your health. Register today at [www.myhealth.va.gov](http://www.myhealth.va.gov).



Portland VA Medical Center  
3710 SW US Veterans Hospital Road  
Mail Code: P3COE  
Portland, OR 97239