

VA MULTIPLE SCLEROSIS CENTERS OF EXCELLENCE

# MS VETERAN

SERVING THE HEALTH CARE NEEDS OF VETERANS WITH MS

## COMPETITION BRINGS OUT THE BEST IN ME!

I retired from the US Air Force after 20 years of service and sometimes I miss it. I enjoyed meeting new people, learning new things, seeing exciting places, and being challenged to be the best I could be. I left the military to spend more time with my young daughter and husband, but I never forgot the camaraderie I felt when I was surrounded by my fellow Veterans.

I experienced my first MS symptoms while in the military, but I wasn't officially diagnosed until after my retirement. I had horrible pain in my feet and doctors removed several nerves from my feet to help alleviate the pain. Unfortunately, the surgery didn't help and the pain persisted. I went back to the hospital a few times, but they couldn't find anything wrong and told me it was in my head. I knew the pain wasn't in my head, but there was nothing I could do or say to convince them otherwise.

After my military retirement, I went to a civilian doctor to discuss the pain as it wasn't getting better and I had a few other health issues that didn't seem right. The doctor performed a spinal tap and magnetic resonance imaging (MRI) to see if he could find out what was wrong. The results from the procedures showed that I had MS. Although it was difficult to learn that I had MS, it was also a relief to know that what I was feeling and experiencing was not in my head. I didn't like what was happening to my body, but to be able to put a name to it was a relief.

I was retired when I discovered I had MS so life didn't really change much. I had been experiencing symptoms for years and was making adjustments as needed. I started attending an MS support group about three months after my diagnosis, which

allowed me to meet people who were going through the same things I was. To be able to talk to someone that could relate to what I was going through was very therapeutic. One of the support group attendees told me about the National Veterans Wheelchair Games and the more I learned about the Games the

more I wanted to get involved. Sports have always been an important part of my life and to be able to continue with that part of my life was very exciting.

I'm a member of the SE Paralyzed Veterans of America (PVA) team "Wheels of Fire" and the first Games I competed in were in Spokane, WA in 2009. I also competed in the Games in Denver, CO, Pittsburgh, PA, and Tampa, FL and plan to participate in all future

Games. I've competed in a variety of events and try to compete in something new each year. I love stick bowling, but golf is great too since you get to use an accessible golf cart and an accessible club allows you to remain in a sitting position. One year I competed in the kayaking event and it was amazing. There was no wind and the lake was like glass, allowing me to paddle the whole event myself. For the 2013 Games, I competed in bocce ball and won a bronze medal which was exciting. I also tried waterskiing on an



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accessible ski for the first time and had so much fun going around the lake I couldn't stop smiling.

I get so much from participating in the Games, but I'm also able to give back which makes the experience even better. There are always attendees and volunteers at the Games who are newly diagnosed with MS. Sometimes it's hard for people to talk about their disease and being around others who share the same symptoms and experiences is beneficial. As we spend the week together, I'm often able to help them better understand MS and realize that a diagnosis of MS doesn't mean they have to change who they are or what they want to accomplish in life.

The Games are not about winning or even being good at sports; they are about coming together and being your best. I have MS, but I'm still able to do a lot of things and many of my limitations can be overcome with a little help and hard work. There are days that I don't think I'm capable of something, but that's just human nature. We often create our own limitations before we even try something. Being part of the Games is an amazing experience that I hope to continue with for a very long time. I look forward to seeing my teammates every year and I hope that more Veterans with MS get involved.

*Judy Overholt - Myrtle Beach, SC*

## NATIONAL VETERANS WHEELCHAIR GAMES

We want you to know that no matter your disability or skill level, an adaptive sports opportunity exists for you. Besides the fun, friendships, and exercise, why should you make adaptive sports a part of your life? Studies show that adaptive sports provide clear benefits for disabled Veterans including less stress, reduced dependency on pain and depression medications, fewer secondary medical conditions (diabetes, hypertension, etc.), higher achievement in education and employment, and more independence. What does that mean for you? It means getting out there, taking life by the reigns, and having a blast every day. What could be more important? No one is minimizing the fact that adjusting to a disability is challenging. However, through adaptive sports, you can redefine yourself and live an active, healthy, and fun lifestyle.

Over the past 33 years, the National Veterans Wheelchair Games (NVWG) have introduced thousands of Veterans with spinal cord injuries (SCI), amputations, MS, and other neurological injuries to wheelchair sports. Co-presented by the Department of Veterans Affairs and the Paralyzed Veterans of America (PVA), the NVWG is the largest annual wheelchair sports event in the world and represents a unique and significant commitment to the rehabilitation of our nations Veterans. We firmly

believe that teaching and providing opportunities that challenge and show newly-disabled Veterans what they can do through sports, sets the stage for success throughout their life.

Competitive events at the Games include air guns, archery, basketball, bowling, field events, handcycling, a motorized wheelchair rally, nine-ball, power soccer, quad rugby, slalom, softball, swimming, table tennis, track, trapshooting, and weightlifting. Athletes compete in all events against others with similar athletic ability, competitive experience, and age. While the sport and recreation

### 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 will be discussed.

**DATE:** 4<sup>TH</sup> 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  
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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

competitions bring out the best in everyone, the Games are much more. The NVWG is a community that welcomes and engages each other to succeed during the week and beyond.

As a coach for years with the NW PVA Team and a recreation therapist at the VA SCI Unit in Seattle, WA, words can't accurately express the power and amazement of the Opening Ceremonies where teams from across the country enter the arena to a cheering crowd. The validation and discovery that is expressed in the faces of new participants lets me know that they feel part of a fraternity of their peers. Participants who before the Games sought encouragement and assistance are now saying, "Don't worry, I got this!" Conversations explode around you as people who have experienced the frustration and daily challenges of a disability realize they are not alone and they are able-bodied. The experiences, lessons, and relationships acquired during the week are life changing for many.

The 2013 NVWG recently closed in Tampa, FL after a fantastic week of sports and recreation competition. Hosted in July by the James A. Haley Veterans' Hospital, 567 Veterans competed in 18 events including a new medal sport and Paralympic event, Bocce Ball. This year, 55 of the Veterans who competed have MS. The 2014 Games are being planned for Philadelphia, PA next August and the theme is "Where Heroes Make History."

If you are interested in participating in the Games, talk with a recreation therapist at your local VA

medical facility or your PVA Chapter Sports Director. Think about what you would like to compete in and don't limit yourself to the possibilities. You are still the same person with the same preferences for fun; don't try to change who you are, but be open to discover new possibilities. Find out about adaptive sports opportunities near your home and how you can get involved. Look into setting up practices and how you can get the sports equipment that you may need for training and maintaining a healthy, active life. Remember, it's not about one week of the year, it's about every day.



Information about registration for the NVWG and finding local sports clubs in your area can be found at [www.wheelchairgames.va.gov](http://www.wheelchairgames.va.gov). Registration for the Games opens at the end of January 2014 and is due by April 15, 2014. The NVWG averages 550 Veterans each year and many of the events have participant limits. Priorities for assigning athletes to events are made based on the applications we receive first so don't delay. To be successful, learn the rules, acquire the right equipment, and practice. Preparing for your event is the key to a successful and enjoyable experience. See you in Philadelphia next year!

*David Tostenrude - Director NVWG*

## COMPLEMENTARY AND ALTERNATIVE MEDICINE

Most people with MS, between 50 and 84 percent, have used non-traditional products or therapies either along with their prescribed medical regimen, considered complementary, or instead of traditional medicine, known as alternative. Called Complementary and Alternative Medicine (CAM), these products and therapies can include herbs, nutritional supplements, acupuncture, massage, diet, mindfulness, yoga, tai chi, and visits to naturopaths,

homeopaths, and chiropractors. The attraction to CAM is supported by the personal belief that traditional medicine has failed to relieve suffering or prevent disease, CAM is "natural", CAM is less expensive and safer than traditional medicines, or the user feels more control over what is put into the body.

But STOP - what about the science? What is the evidence that a CAM treatment will have the desired effect and is safe? US adults spend \$33.9 billion annually out-of-pocket on CAM, yet many CAM products and therapies are supported by very little, if any, scientific evidence. Before plunking down your

hard earned dollars, ask these questions: What does the treatment involve? How effective is it? Is it safe? How does it work? How much does it cost? And most importantly, could it impact my MS? This article will review some common CAM treatments and discuss the benefits and possible harm to those with MS.

Herbs are plants that may improve and maintain health. Certain herbs can have a stimulating effect on the immune system. Experts suggest that immune stimulation may be detrimental in MS and can lead to disease activation or progression. The immune system may be activated by herbs such as echinacea, Asian ginseng, garlic, alfalfa, and astragalus. Herbs that may help MS symptoms include psyllium for constipation; coffee for improved fatigue and attention; cranberry to prevent urinary tract infections; valerian for improved sleep and calm as well as reduced anxiety and spasticity; and St. John's wort for mild depression.

Diet in MS has received a great deal of attention and several low fat diets have been studied for their effect on MS. A well-balanced, low fat diet can be beneficial for maintaining wellness, but scientists agree that there is currently no convincing evidence that diet changes the course of MS. Although there isn't a cure-all-diet for MS, some vitamins, minerals, and fats may be beneficial. A diet rich in omega-3 fatty acids (found in the oil of fish, soybeans, canolas, walnuts, and flaxseeds) and omega-6 fatty acids (found in the oil of safflower, sunflower, and sesame seeds) may decrease the severity and duration of a MS relapse. Vitamin C may help with urinary tract infections while vitamin B1 may reduce fatigue.

Antioxidant vitamins (A, E, and C) while advertised as good for the body are anti-inflammatory. Antioxidant vitamins should be obtained mostly from fruits and vegetables in the diet and supplements should be used in moderation.

Supplements may be needed when food cannot supply needed vitamins and minerals. Vitamin D is often low in people with MS and scientists are trying



## 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. The DVD's are a great way to learn about MS in the comfort of your home.

- ▶ BOWEL AND BLADDER ISSUES 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

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to understand why this is the case. What is known through recent studies is that insufficient vitamin D contributes to the risk of getting MS and worsening MS. Vitamin D can be obtained from exposure to the sun, fortified milk products, and fatty fish. Vitamin D may reduce risk of attacks and slow MS disease progression. Calcium and Vitamin D are needed for strong bones. Some CAM that have shown no benefit for MS include increased intake of aspirin, sodium salicylate, colchicine, myelin basic protein, coral calcium, prokarin, and hydrogen peroxide.

Body-mind therapies such as acupuncture, massage, tai chi, and yoga may have a beneficial effect on MS symptoms including pain, spasticity, bladder, and insomnia. Some alternative therapies that have shown no benefit for MS include hyperbaric oxygen therapy (breath pure oxygen in a pressurized room); thymectomy (remove thymus); mercury-amalgam

(remove tooth fillings); chelation therapy (receive metal-binding chemicals through IV); supersonic wave energy programs (energy interacts with body); bee sting therapy (live bees sting body); and molecular magnetic energizers (magnets interact with body).

CAM products and therapies have the potential for enhancing quality of life, managing MS symptoms

## ORAL THERAPIES FOR MS: A PROMISE DELIVERED

This is an exciting time in the treatment of MS! There are now 10 disease modifying therapies (DMTs) that have been approved by the Food and Drug Administration (FDA). The three most recently approved drugs are oral agents, delivering on the promise that MS providers have been making for years to people with MS who are anxious for an alternative to injectable therapies. Dimethyl fumarate (Tecfidera®) was approved in March 2013, following closely on the heels of teriflunomide (Aubagio®), which was approved in September 2012. The first oral DMT, fingolimod (Gilenya®), has been in use since September 2010. These three oral DMTs are available through the VA Pharmacy Benefits Management (PBM) Program.

All three oral DMTs are approved for relapsing forms of MS, which include relapsing-remitting MS, progressive-relapsing MS, and secondary-progressive MS in those people who continue to have relapses. Large phase III clinical trials showed that each of the three oral DMTs reduced MS relapse rate, disability progression, and brain magnetic resonance imaging (MRI) measures of MS activity, compared to placebo (a pill or capsule without active medication in it).

**Dimethyl fumarate (Tecfidera®)**, formerly known as BG-12 in clinical trials, is an agent that changes the immune system. While we don't know precisely how it works, we do know that the medication activates anti-oxidant pathways that may protect nerve cells from oxidative damage. Dimethyl fumarate (DMF) may also have anti-inflammatory properties. A similar drug has been used in Europe for many years to treat psoriasis. DMF is taken twice daily as a

and disease, and contributing to overall health. Embracing all things natural to forgo proven disease treatments puts a person with MS at risk and there should be a balance. Knowledge of the safety and efficacy of CAM specific to MS is essential and continued research in this area is needed.

*Heidi Maloni, PhD, NP - Washington DC VAMC*

240 mg capsule, after a short dose titration period (usually one week) of a lower dose 120 mg capsule twice daily. The titration period, where a smaller dose of the medication is taken to build up to the maximum dose, can help to reduce side effects. Common side effects of DMF include skin flushing reactions and gastrointestinal disturbances such as nausea, vomiting, abdominal pain, or diarrhea. These side effects are usually most common and most bothersome during the first 1-2 months of treatment and then may improve or disappear. More serious side effects such as liver damage and low white blood cell counts have been reported with DMF, and periodic monitoring for these with blood tests is recommended. Because this is a new drug, there may be side effects or risks that are not yet known.

**Teriflunomide (Aubagio®)** is the active metabolite (a compound produced when the body breaks down

### GET YOUR VACCINATIONS!

**INFLUENZA:** The VA provides a free influenza vaccine to enrolled Veterans. There are two forms of the vaccine: 1) a flu shot and 2) a flu nasal spray. Research has shown that the flu shot is safe when given to people with MS and does not worsen or trigger MS symptoms. The flu nasal spray has not been studied for its safety with MS and may carry more risks. It is recommended that people with MS receive a flu shot rather than the nasal spray.

**PERTUSSIS (WHOOPIING COUGH):** Booster doses of tetanus-diphtheria are needed at 10-year intervals. People age 19-64, and those 65 and older who are in contact with infants, should get a one-time dose of tetanus-diphtheria-pertussis to also protect against whooping cough.

a parent drug) of leflunomide, a drug approved for treatment of rheumatoid arthritis. Teriflunomide interferes with DNA synthesis in rapidly dividing cells such as lymphocytes (type of white blood cell), which may inhibit lymphocyte activation and reduce inflammation in MS. Teriflunomide is taken as a 7 mg or 14 mg tablet once daily. Both doses were approved by the FDA and both doses were effective in a phase III clinical trial, although the 14 mg dose was slightly more effective for some measures, and the 7 mg dose had slightly fewer side effects.



This drug carries two FDA “black box warnings”, which means there are two potentially very serious side effects with this medication. The first is the possibility of serious liver damage, usually during the first six months of therapy and requiring regular blood tests for monitoring. The second is that this drug should not be taken by a woman who is pregnant or by a man who plans to father a child while on the drug, due to risks of fetal harm. Other possible side effects include hair thinning, infection including reactivation of tuberculosis, skin reactions, increase in blood pressure, and lung problems. A special elimination protocol is needed to rapidly clear teriflunomide if it is discontinued because of side effects, due to the long persistence of the drug in the body (up to two years) without the elimination protocol.

**Fingolimod (Gilenya®)** binds to sphingosine-1-phosphate receptors, proteins on the surface of white blood cells, and is thought to work in MS by trapping white blood cells in the lymph nodes and preventing their migration to the brain and spinal cord. Fingolimod is taken as a 0.5 mg capsule once daily, with careful cardiac monitoring for at least six hours after the first dose, due to a risk for serious heart rate slowing. Fingolimod can have a number of side effects, including infection, especially herpes infections, and effects on the retina. Individuals considering fingolimod must be carefully screened

for cardiac and other safety issues that might prevent its use.

For many people with MS, these long-awaited oral DMTs are appealing because of the convenience of an oral agent compared to an agent requiring intravenous infusions every four weeks (natalizumab (Tysabri®)), or self-injections on a regular basis with interferon beta preparations (Avonex®, Betaseron®, Extavia®, or Rebif®), or the non-interferon injectable glatiramer (Copaxone®). People who have injected a DMT for many years may have “needle fatigue” or injection site fibrosis or atrophy, and people with newly diagnosed MS are often more enthusiastic about an oral treatment than an injectable therapy.

However, there is as yet no clear demonstration of the relative effectiveness of the available DMTs for MS; in other words, MS experts cannot say for sure which DMTs are the most effective. In addition, MS providers and seasoned people with MS often have a comfort level with the general safety of the self-injectable DMTs (interferon beta’s and glatiramer) because they have been in widespread use for 10 to 20 years. The safety of the oral DMTs over the long term has not been established. Decision-making about DMTs and assessing the potential risks and benefits for each individual with MS is more important than ever and requires a careful and complete discussion between the person with MS and a knowledgeable MS provider.

We can be very optimistic about the future for people with MS, as laboratory research and clinical trials provide more treatment choices. Staying informed and asking lots of questions are important ways for people with MS to advocate for themselves and navigate some of the complex treatment issues and decisions. More information about oral DMTs for MS can be found at the Emerging Therapies Collaborative website at [www.ms-coalition.org/emergingtherapies](http://www.ms-coalition.org/emergingtherapies) as well as the National MS Society website [www.nationalmssociety.org](http://www.nationalmssociety.org). Information on the history of oral DMT research and FDA approval can be found in the Fall 2008 and Fall 2010 issues of the MS Veteran newsletter, which can be found in the “Veterans with MS” section of the VA MS Centers of Excellence website at [www.va.gov/MS](http://www.va.gov/MS).

*Ruth Whitham, MD - Portland VAMC*

# UNDERSTANDING COGNITIVE DYSFUNCTION

Cognition refers to a person's ability to perform high-level brain functions and includes things like thinking, learning, remembering, and understanding. Approximately 50% of individuals with MS will develop cognitive dysfunction over the course of their disease. For some people, cognitive dysfunction can be very mild and not easily noticed by those around them. For others, it can be significant and make it difficult to work or take care of things at home. When a person has cognitive dysfunction, there may be feelings of depression, anxiety, or insecurity. Three areas that are commonly affected by cognitive dysfunction in MS are information processing, learning and memory, and executive functioning.

**Information processing** includes working memory and processing speed. We use *working memory* when we need to remember something but cannot write it down, such as remembering a phone number for a few moments before dialing it. While this can be difficult for most people, those with working memory problems find it even more challenging. *Processing speed* refers to how quickly we can

deal with information that we see or hear. A person with slowed processing speed might have difficulty keeping up with conversations and feel like others are talking too quickly. If processing speed is particularly slow, it is important that an individual not be placed in danger, such as driving a

vehicle. Problems with information processing can also make other cognitive functions difficult, such as problem solving or memory.

People with MS can have problems with certain aspects of **learning and memory**. Remembering the name of your third grade teacher or what you ate for breakfast are two examples of what is called episodic memory. People with MS can usually remember



## 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:** 2<sup>ND</sup> 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  
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If you have questions about the call or topic of the month, please call (800) 463-6295, ext. 6623, send an email to [MSCentersofExcellence@va.gov](mailto:MSCentersofExcellence@va.gov), or visit our website at [www.va.gov/ms](http://www.va.gov/ms).

things from their childhood, but may have difficulty remembering things that happened yesterday. Studies have shown that people with memory problems because of MS tend to remember more when information is repeated or when they have reminders.

**Executive functioning** is a broad term that refers to things like organizing an event, being able to do more than one thing at a time, and problem solving. An individual with such problems might find it difficult to plan a party for a large group of friends or “let go” of a topic in a conversation and move on to a new one. This can be even more noticeable if the person also has slowed processing speed and these tasks have to happen quickly.

Although there is no cure for cognitive dysfunction because of MS, there are things that people can do to try to lessen the effects.

**WORKING MEMORY TOOLS:** It can be helpful to write down phone numbers, addresses, directions, shopping needs, etc. as soon as you learn them. A calendar, organizer, or application on a computer or smartphone are good for tracking appointments and activities for you and your family. These can also be used to remember names as well as conversations. If you tend to lose things, pick a designated place for objects. Using visual reminders is a great way to keep on track. For example, place the laundry basket upside down in an obvious location when laundry is being washed.



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**PROCESSING SPEED TOOLS:** If you find that you can't keep up with a conversation, ask people to slow down when talking to you or ask them to repeat themselves. Allow yourself extra time to complete tasks and plan your most challenging tasks at a time of day when you feel at your best. If you feel like something is taking too long to complete, take a short breather and come back to it with a fresh mind.

**EXECUTIVE FUNCTIONING TOOLS:** Give your full attention to the task at hand and reduce the noise and distractions around you. Trying to do too many things at once can be difficult and overwhelming. Get organized, or have someone help you get organized. Reducing clutter can improve focus. If you run into a problem you just can't solve, ask for some advice or find someone that can help.

Getting enough sleep, maintaining adequate nutrition, and taking care of your physical and emotional

needs can also be useful. While it can take time and practice to get used to doing these things, many people find them helpful and studies have shown that using such strategies can make someone feel less depressed or anxious.

If there are concerns about cognitive dysfunction, talk to a medical provider. Early assessment and treatment are important as cognitive dysfunction may affect quality of life. In some cases, it might be helpful to see a neuropsychologist who is a doctor with specialized training in cognitive problems. This type of doctor can do specific testing to see if there are problems and, if so, how severe they are. Once a person knows if he/she is having cognitive problems and what type, the individual can work with a doctor or therapist to come up with strategies to help manage the cognitive challenges.

*Brett Parmenter, PhD - American Lake VAMC*

VISIT THE VA MS CENTERS OF EXCELLENCE WEBSITE AT [WWW.VA.GOV/MS](http://WWW.VA.GOV/MS).