

VA Multiple Sclerosis Centers of Excellence

MS VETERAN

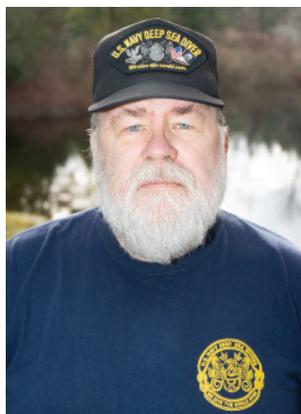
Serving the Health Care Needs of Veterans with Multiple Sclerosis

Life is a Journey... Savor the Moments

By Dave Peterson - State of Washington

As a kid, one of my favorite television shows was Sea Hunt, which followed the underwater adventures of a Navy diver. I was fascinated by the sea rescues and adventures and knew that was what I wanted to be when I grew up. I delayed enlistment into the Navy when I was a sophomore in high school and joined right after my graduation in 1975. Unfortunately, I only served for 5 years. I became medically disqualified for diving after a chemical exposure incident, and without diving, my heart just wasn't in it.

It was many years before I was diagnosed with MS. I was 48 and I went blind in my right eye. At the time, I thought I had a stroke, or worse. When I received the diagnosis of MS, I thought to myself, well this isn't so bad. I dove into learning more about the disease and started volunteering at my VAMC in Seattle, WA, talking to other Veterans with MS. I developed relationships with a lot of the Veterans in the MS clinic. I found these interactions to be a great way for me to learn, heal myself and help others. I've always enjoyed meeting new people and being around my friends. Following my diagnosis, I made sure this important part of my life didn't change.



I've been volunteering at the Fort Nisqually History Museum in Tacoma, WA since 1992. One day I had a life changing moment. Someone approached me about watching their pets while they were gone and

I said "yes, I was happy to help". Now, that doesn't seem like a life changing moment, but it was for me. Soon others, who learned about me through word of mouth, were asking me to watch their homes and pets while they were gone. In time, I had to start a Facebook housesitting page so people could find me and know when I was available.

Now, my house-sitting services are a little different from others because I do it for free. I get a place to plug in my remodeled RV, my primary residence, free Wi-fi, critters to keep me company and interactions with new and old friends. They get someone to watch their place and take care of their animal family. I've housesat for chickens, pigs, dogs, cats, birds and

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Visit our website www.va.gov/ms for information on MS, VA services and benefits and MS resources.

even a llama. I have lots of pets, even though they don't live with me all the time, and I have made many friends.

While some people like to stay in one place, I've learned that I like something a little different. I'm someone that is willing to work but I also enjoy the journey from one destination to the next.

Through my volunteer work with the Snoqualmie Train Museum, I discovered that I was living the hobo lifestyle. They asked me to portray a hobo in a living history reenactment. To do so, I had to research what a hobo was. I was pleasantly surprised when I learned I was a hobo and became fascinated with the concept. I have a lot of admiration for hobos who are survivors, adapting to their surroundings.

Before I was diagnosed with MS, I had no patience. I wanted everything immediately. MS made me take a step back and let things happen as they were meant to. I've learned to adapt and accept that life changes you. I'm not the same man that I was 20 years ago and that's okay. I don't have the same lifestyle as most people and that's okay too. I've found something that works well for me and so should you.

Living in various places gives me the opportunity to participate in local activities. I research activities in the areas around me, making sure I visit local events, finding things that give me opportunities to look forward to during the week. I've found that having a list of things to look forward to, plans for my day, can be a light that gets me out of bed.

Having MS can be hard at times but I'm a fighter and I'm going to do what is needed to survive. I've learned to adapt to my surroundings. I've also learned to accept help when needed, whether from friends or the great providers at the Seattle VAMC. Without the Seattle VAMC, I wouldn't be as healthy and active as I am now. I am so thankful to them.

MS is not what it was 20 years ago. There are more medications and things that can be done to keep MS symptoms at bay. A diagnosis of MS is not a lifetime sentence to sit on the couch. People with MS can do many, if not all, of the things they enjoy. Make an effort to find joy and activities around you. Get a calendar set up with things to look forward to for the month. If something isn't the same, be willing to adapt and enjoy life a little differently. And most importantly, surround yourself with people who care about you, it can be life changing.

National MS Society & VA Alliance

By Coleen Friedman, MSW - National MS Society

On March 6, 2019 the National MS Society and VA signed a four-year Memorandum of Agreement (MoA) to work together to benefit Veterans with MS.

How will Veterans with MS benefit from this agreement?

First proposed in 2012, discussions about the creation of a formal MoA was led by Donald Higgins, Jr, MD, National Director of Neurology, VA Specialty Care Services. Leaders of both organizations realized that their resources and expertise could be employed to their fullest impact for Veterans and others affected by MS, and their

providers, by working together. The signing of the MoA was attended by Laurence Meyer, MD, PhD, Chief Consultant, VA Specialty Care Services, and Cyndi Zagieboylo, MS Society President and CEO.

While the VA has been associated with the MS Society for many years through the VA MS Centers of Excellence (MSCoE), this MoA is a key strategic partnership. The mission of the MS Society is for people with MS to live their best lives as we stop MS in its tracks, restore what has been lost and end MS forever. To that end, one of our core strategies is to ensure comprehensive high-quality healthcare

to the almost one-million people with MS in the United States. Of those, it is estimated that up to 60,000 are Veterans diagnosed with MS. The MSCoE were established in 2003 to develop a national network of healthcare professionals and standards of care for Veterans with MS. Now, with a formal agreement, Veterans can continue to receive MS care through the VA and take advantage of the many other opportunities for support, education and connection through the MS Society.



The MS Society provides a wide range of programs and support for people living with MS.

Programs: There are in-person programs and support groups throughout the country in addition to the MS Society’s vast array of online educational and support programs. For example, *Pathways to a Cure* is an in-person program which provides updates on the latest research, information about community resources and opportunities to connect with others living with MS. *Relationship Matters* is a couples’ communication program, which will be offered in one or two-day formats. Or Veterans can access online programs, such as *Everyday Matters*,

to build emotional well-being and resilience in the face of MS. MS Society programs can be found through a direct link on the MSCoE website www.va.gov/MS under “Products” and then “Partner”.

Support: The MS Society’s signature *MS Navigator* program is available to Veterans to access additional resources to live their lives with MS. MS Navigators serve as supportive partners to find sustainable solutions to the challenges of MS. Compassionate professionals will assess for, and provide access to personalized and intensive case management services through the Edward M. Dowd Personal Advocate Program when the scope of need is complex and support systems are lacking. Call (800) 344-4867 or e-mail CONTACTUSNMSS@nmss.org to reach a MS Navigator. Last year 50,000 people connected with a MS Society Service Navigator; 87% of those who responded to the satisfaction survey reported that they were better equipped to manage challenges and/or take specific action in their current situation.

Veterans will also benefit through the collaborative efforts of MSCoE and the MS Society to offer professional education for healthcare providers caring for our nation’s Veterans. Hundreds of VA and non-VA healthcare providers across the country have participated in our free programs to learn the latest information about MS. Together, we will strive to ensure people with MS have the information and resources to live their best life.

New DMTs for MS in the Pipeline

By Kathy Tortorice, PharmD, BCPS - VA Pharmacy Benefits Management

When it comes to Disease Modifying Therapies (DMTs) for the treatment of MS, the new year is off to a rapid start for drug approvals. The US Federal Drug Administration (FDA) currently has two therapies being reviewed; cladribine (Mavenclad®) and siponimod (Mayzent®). The first of these DMTs out of the FDA approval gates will likely be cladribine.

Cladribine is used as an anti-cancer medication and is now being developed as a possible treatment for relapsing forms of MS. It was reviewed by the FDA in 2011 for treatment of MS but was not approved at that time because they wanted a better understanding of how safe the medication was for people with MS, as well as how the medication’s overall risks compared to its overall benefits.

Specifically, the FDA had concerns about a possible increased risk of cancer. Now, additional clinical trials and data analysis have been conducted to address these concerns.



Cladribine has a robust amount of clinical trial experience both in short term and long term trials. The data now being reviewed by the FDA represents more than 10,000 patient-

years of data with over 2,700 people with MS from several clinical trials. The data from these combined trials show cladribine to be effective in relapsing forms of MS, and the long-term safety data have not raised concerns.

Several large-scale clinical trials have been conducted on cladribine, including the Phase 3 trials CLARITY, CLARITY Extension and ORACLE MS. Phase 3 trials are large scale trials conducted to confirm and expand the understanding of safety and efficacy results from earlier Phase 1 safety trials and Phase 2 smaller efficacy trials. In the CLARITY trial, cladribine reduced the annualized relapse rate by 67%. (The annualized relapse rate is the average number of relapses a group of people in a clinical study have in one year.) Cladribine also reduced the risk of six-month disability progression by 82% compared to placebo (sugar pill). In addition, follow-up analysis of CLARITY and CLARITY Extension found that up to 90% of those who received cladribine had no new lesions on MRI and up to 81% remained relapse-free after 4 years.

The dosing for cladribine is based on a person's weight. It is given as an oral tablet during two treatment courses, 12 months apart: in the first course cladribine is given for up to five consecutive days in the first month and for up to five consecutive days in the second month. The second treatment course is given 12 months later with the same dosing schedule.

Common side effects of cladribine include a reduced white blood cell count (WBC), herpes infections (oral herpes and shingles), rash and hair loss. MS providers will monitor the WBC of people who receive the medication, checking this with a blood test when the medication is initially administered and at 3 and 7 months of the first year of therapy. This monitoring will be repeated in year two of therapy. At the end of the second year, no further WBC monitoring is required. MS providers should check that people who receive cladribine don't have active infections, such as tuberculosis, before they start treatment with cladribine.

Cladribine should not be used by men or women while they are trying to have a child, or in pregnant women. In men it could affect the development and quality of sperm for up to six months after treatment, and in women it could seriously harm the developing fetus. Both men and women should use effective contraception while taking cladribine and for six months after stopping cladribine.

There are now over 15 DMTs approved for the treatment of MS. More are being approved each year, giving people with MS a variety of medications to help them manage their MS. If you think cladribine may be a good choice for you, talk to your MS provider.

CAN DO MS WEBINAR

Join Can Do MS live from the convenience of your home for free, in-depth discussions that cover a variety of topics.

Date: 2nd Tuesday of Every Month

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

Go to www.cando-ms.org for information about topics, speakers and registration.

Learn about their free **JUMPSTART** programs occurring across the US as well.

Number of People in the US with MS

By Mitchell Wallin, MD, MPH - Washington, DC VAMC

We don't know exactly how many people in the US have MS, but we are getting better and better estimates. In 2000, researchers estimated there were 400,000 people in the US with MS. We now believe MS is much more common, with 2017 estimates showing there are closer to 900,000 people in the US with MS. This information was published, in collaboration with the VA in March 2019.¹

How did we learn how many people have MS in the US?

The National MS Society funded a workgroup to study how many people currently have MS. This recent study estimated the number of people with MS from health claims datasets from 2008-2010. These datasets were from the Veterans Affairs as well as two private health insurance companies and Medicare and Medicaid. Together, these datasets provided information on 125 million adult US residents. Researchers identified people with MS using an algorithm; a process or set of rules to be followed for calculating information. For a person to be counted as having MS they had to have three or more MS-related hospitalizations, clinic visits or MS medication fillings within a year. The researchers combined these estimates with 2010 US census data to estimate how many people have MS across the entire US.

This study estimated that, in 2010, about three in every 1,000 adults in the US had MS, which means there were closer to 725,000 people with MS, not 400,000 as previously thought. MS was about three times more common in women than in men. This means that about 4.5 in every 1,000 women, and only 1.5 in every 1,000 men, have MS. MS is also more common in Northern parts of the US than in Southern parts. Based on the increases in numbers of people with MS in the VA and private health insurance datasets since 2010, the researchers estimated that in 2017 the number of people with MS was likely between 852,000 and 914,000.

Researchers in the workgroup believe the new estimates are much higher than older estimates because many people were not counted in the past. In addition, the numbers are higher now because people with MS live longer and because MS is now detected and diagnosed earlier. These new estimates are consistent with recently reported estimates from Nova Scotia, Manitoba and British Columbia in Canada that were calculated using similar methods. This study is a start to better understanding the needs of Veterans with MS and people with MS throughout the US and around the world.

¹ Wallin MT, Culpepper WJ, et al. *Neurology*. 2019 Mar 5;92(10):e1029-d1040.

Whole Health Comes to VA

By David Greaves, PhD - Portland, OR VAMC

The VA Healthcare System has begun a journey to transform the way healthcare is delivered to Veterans, and it's called Whole Health. If you think about a typical appointment with your health care provider, it usually involves a meeting where the doctor asks, "tell me what's the matter with you today?" The provider then proceeds to make treatment recommendations and the encounter is

over. However, the idea behind Whole Health is different. When you sit down with your doctor, the question he or she asks is "what matters the most to you today?"

The Whole Health approach is designed to consider what is important to the Veteran, not merely what the provider thinks is most important. Responsibility

for success is shared between provider and Veteran. They partner together to create a personal health plan that will address all aspects of a person's life - in other words, helps the Veteran achieve Whole Health.

The Whole Health approach considers how the Veteran defines wellness, and supports the Veteran's goals as they relate to physical wellness, desired life activities, emotional well-being, relationships, diet, exercise level and so forth. We now realize that being healthy and well is much more than making the symptoms go away.

Whole Health also considers new and complimentary methods of treatment, including such things as Yoga, Tai-Chi, chiropractic care, acupuncture or other modalities that Veterans want to use in their care. These types of care are more and more available to Veterans within the VA system.

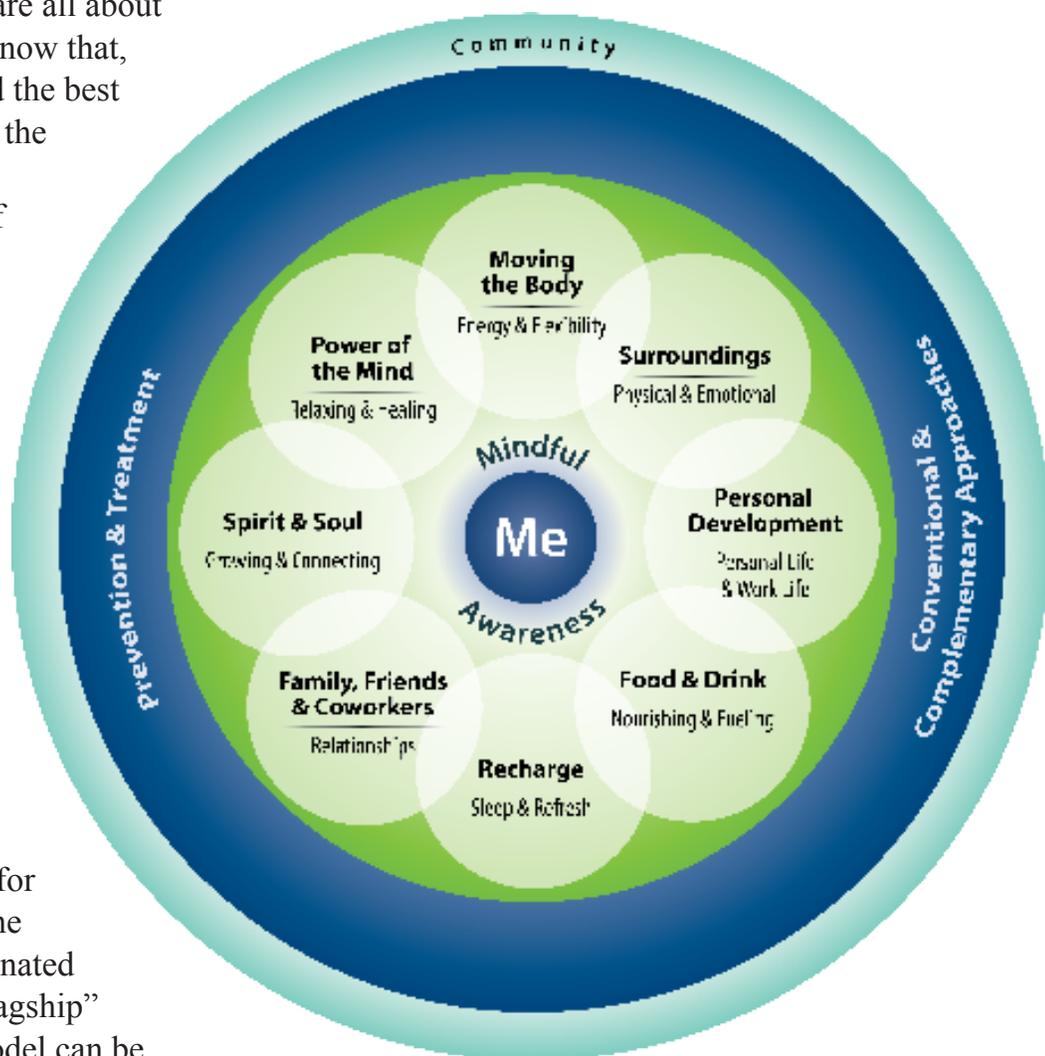
The principles of Whole Health are all about quality of life. People with MS know that, despite their own best efforts and the best efforts of experienced providers, the disease can impact their lives in significant ways. Management of current MS symptoms can be interrupted with unexpected relapses, lasting for short or long periods of time, which can be discouraging. Whole Health teaches us that there are many ways to feel well, and it's important to remember all the options available; everything from social support to meditation to learning a new hobby. Wellness and health come from many sources.

Whole Health is still a new idea for many providers and Veterans. The VA Healthcare System has designated certain medical centers to be "Flagship" sites where the Whole Health model can be

developed and perfected. In the coming months even more sites will be rolling out this new model of care. Even if your site of care is not using Whole Health widely, the diagram below can show you how to think about your healthcare in a Whole Health-fashion.

It starts with you in the middle, being mindful of what you need and what is important to you. The eight light green circles represent ways you can improve your wellness, from exercise and diet to family support, meditation or even your surroundings. Please consider the many resources you have to feel good!

If you would like to learn more about Whole Health, there are many online resources. Check out the VA site www.va.gov/patientcenteredcare/explore/about-whole-health.asp.



How To Handle the Heat

By Lynda Hillman, DNP - Seattle, WA VAMC

If your MS symptoms are worse when it's hot, you have plenty of company. Approximately 75% of people with MS have heat sensitivity. You may have heard heat sensitivity or heat intolerance referred to by its medical term, "Uhthoff's phenomenon." Regardless of what name you use, heat intolerance is unpleasant and can interfere with your usual activities. Why does heat intolerance happen? And what can be done to stay more comfortable?

Hot temperatures affect nerve functioning by slowing or blocking transmission of nerve impulse conduction. Another way to look at it is that the electrical messages sent to and from your brain and the rest of your body are garbled or never arrive. Nerve conduction is already impaired due to axonal demyelination and degeneration from MS -- heat makes this far worse and symptoms flare up.

Hot weather, vigorous exercise, a hot bath or a fever are just a few examples of circumstances where heat can exacerbate MS symptoms. A rise in your body's core temperature by as little as 0.25°F can produce symptoms. Even if only skin and not body core temperature is increased – for example, with direct sunshine or being in a hot room – that may be enough to trigger worsening of your symptoms.

While fatigue is the most common reaction to heat, any symptom of MS may occur, including cognitive dulling, increased spasticity, weakness or visual disturbances. In hot environments, people with MS may therefore also find it harder to balance when standing, walking or transferring which can increase the risk for falling. Heat can also affect the nervous system's ability to regulate internal temperature.

This results in a decreased sweating response, so you have less evaporative cooling.

You'll have an easier and safer time coping with the heat when you're prepared. Let's take a look at some ways to do that.

The best strategy is to avoid heat if possible.

- ▶ Stay out of direct sun or wear wide-brimmed hats and use sun umbrellas.
- ▶ Recreational swimming or pool therapy water should be less than 85°F.
- ▶ Avoid saunas, hot tubs and activities such as "hot" yoga.
- ▶ Avoid exercising during hot weather, particularly the hotter parts of the day, or have a shorter workout.

It's not always possible to avoid the heat. What about summer when you want to enjoy the backyard with your grandkids, or stay reasonably comfortable in places without air conditioning?

Or, think of the MS Veterans competing in the annual National Veterans Wheelchair Games (NVWG).

How are they able to perform during events such as cycling, wheelchair basketball, power lifting, archery and obstacle-course racing? Practical cooling strategies can help, and will work even better in lower-intensity situations.



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Educational newsletter for Veterans!

- ▶ Use wet wraps – top your head with a cloth hat soaked in cool water, or drape an iced or cold wet towel over your shoulders. This is a frequently-used technique at the NVWG, where they keep a constant supply of towels and buckets of icy water.
- ▶ Pre-cool by wearing a cooling vest for 30 to 60 minutes prior to being active. Vests, neck wraps and other garments which use ice packs to cool you are available in many different sizes and styles. Talk with your MS provider or therapist about which ones would work best for you.
- ▶ Take frequent sips of cool drinks. A recent study found that persons with MS doing vigorous exercise who drank about 9 ounces of 34°F water every 15 minutes increased the time they could exercise by about 30%!

Smaller volumes of icy water should work well if you're doing lighter exercise or are sedentary.

- ▶ Minimize caffeine intake. Caffeine increases urination and causes risk of dehydration.
- ▶ Take a cool shower before and after exposure to heat.
- ▶ Wear loose, breathable clothing in light colors.
- ▶ Keep a spray bottle filled with cold water nearby for refreshing spritzes.
- ▶ Use fans and air conditioning in your home and vehicles. Talk with your MS provider about air conditioning units which may be covered under your VA benefits.

These cooling strategies are low-tech and simple yet can make a world of difference in helping you enjoy the upcoming warmer weather and longer days.