

VA Multiple Sclerosis Centers of Excellence

MS VETERAN

Serving the Health Care Needs of Veterans with Multiple Sclerosis

Life is What You Make It!

By Matthew McCullor - Bellevue, NE

I was diagnosed with MS in the year 2000, in my 14th year of service in the Air Force. I was medically retired in 2004, after 18 years, 2 months and 17 days of military service. When I was first diagnosed, I wasn't sure what that meant to me. I was aware of MS; I had been doing the National MS Society MS Walk since the late 1980's. I wasn't sure if I should be mad, scared, worried... I honestly didn't know what I needed to be. MS affects everyone so differently, how was it going to affect me?

I do know that in the first three months, I didn't want to bring anybody down. I withheld the diagnosis from my wife and kids for 3 months. I did this because I knew that they would be sad and worried, all those emotions and there was nothing that I or they could do about curing MS. I found myself worrying about my future a lot, not concerned with what may happen to me, but what I might miss out on in life. I came to the conclusion that I needed to accomplish some stuff that I'd been dreaming about my whole life.

In 2002, I graduated with my Bachelor's Degree in Anthropology. I was finally on the road to be an archaeologist. In 2011, I got my Master's Degree

in Anthropology, focused on Archaeology. I worked in the federal service as an archaeologist until 2017. Short-term memory troubles, attention disorders and not being able to walk long enough to do archaeology fieldwork or through tall grass and downed trees, caused me to retire.



Following my retirement, I again started to think about what was important to me, focusing on what I needed to accomplish before I was physically and/or mentally unable to do so. Travel was a big interest and concern for me. I needed to get to see my son and daughter, on the opposite sides of the country, on a regular

basis. They are an important part of my life, and my grandchildren were growing up very quickly and I was missing it. Traveling to see my family turned into a way for me to accomplish some of my dreams.

Traveling to different cities, checking out new museums, touring Civil War sites and other historic features of the country became very important to

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

me. Since I no longer work, I have traveled what I consider extensively. I have driven from one side of the country to the other, watching baseball games, visiting gravesites of US presidents, touring historical sites and attending archaeological conferences. While I travel, I need to constantly keep aware of handicap accessible rooms in hotels, access to museums, baseball fields and you know, just about everywhere I want to visit. I use a wheelchair, so this became just one of the many steps I need to take when I plan a trip.

Throughout my life and travels, I've learned that I need to enjoy life and I want to make a difference in the lives of others. I'm not important enough to have a big statue made for me, so I am trying to leave my legacy in the idea that I brought a smile to everyone

that I've come across, making their day a little better. I try to break large goals into smaller goals, making them more manageable. I take advantage of what has been given to me and find joy in the daily tasks of living. If I see something interesting in my travels, I don't pass it up thinking I'll get another chance. I take advantage of every opportunity that crosses my path. I recently got certified as an adaptive SCUBA diver, not wanting to miss out on what might be in the water on my travels.

Having a good attitude helps my mental state stay pretty even, relaxed and fun. We should all look on the bright side. I have MS but it hasn't stopped me from doing so many of the things that are important to me. I've toured dinosaurs with my grandsons and seen waterfalls with my granddaughter. Life is good.

Vascular Disease Risk Factors & MS

By Vijayshree Yadav, MD, MCRP - Portland, OR VAMC

Recent research involving thousands of people with MS suggests that vascular disease risk factors (VDRF) such as obesity, hypertension (high blood pressure), hyperlipidemia (high cholesterol) and diabetes can contribute to the worsening of disability in MS. According to one survey involving more than 8,000 people with MS, nearly 50% of people with MS have at least one VDRF at the time of their MS diagnosis. This article reviews current literature on the relationship between these potentially changeable factors that can affect MS activity and progression.

Among Veterans, VDRF are highly prevalent. Studies suggest that more than 80% of Veterans have at least two VDRF. A current pilot study at the VA in Portland, OR evaluated the prevalence of VDRF in Veterans with MS. The study found that among the 45 enrolled Veterans, 44% had hypertension, 33% had hyperlipidemia and 11% had diabetes.

Obesity is commonly defined as having a body mass index (BMI) above 30 kg/m² and overweight

individuals as having a BMI between 25 - 29.9 kg/m². Several studies have suggested higher BMI is associated with greater disability. Importantly, being overweight or obese has been associated with an increase in other comorbidities, with an individual being almost five-times more likely to develop diabetes or hypertension and two-times more likely to develop depression. More comorbidities are also related to decreased quality of life and increased odds of disability.

Hypertension also has a relationship with MS disability. The North American Research Committee on MS (NARCOMS) registry showed increased levels of disability among people with MS with hypertension. People with hypertension had 29% higher risk of early gait disability, 25% higher risk of requiring unilateral assistance (example: cane) and 17% higher risk of requiring bilateral assistance (example: walker) compared to those without hypertension. This registry also showed that people with MS who developed hypertension had a 32% higher risk of developing mild visual disability,

31% higher risk of moderate visual disability and 16% higher risk of severe visual disability.

Hyperlipidemia has also been associated with MS-related disability and brain imaging (MRI) outcomes. One study looking at blood fat (lipid) levels found that higher low-density lipoprotein (LDL), or “bad” cholesterol, and total cholesterol levels were associated with higher MS disability. Higher high-density lipoprotein (HDL), or “good” cholesterol, was associated with lower inflammatory disease activity on the brain MRI.

It is estimated that 3-8% of people with MS have diabetes mellitus II (DMII), with the highest percentage in North America at 4.1%. In the NARCOMS registry, those with DMII had a 29% higher risk of early gait disability, 28% higher risk of requiring unilateral assistance and 56% higher risk of requiring bilateral assistance compared to those without DMII, as well as a 35% higher risk of developing mild visual disability, 41% higher risk of moderate visual disability and 54% higher risk of severe visual disability.

Portland VA and Oregon Health & Science University MS doctors and scientists are currently conducting a 3-year observational study looking at the progression of MS disability in relation to VDRF. Sixty subjects have been grouped into VDRF positive and VDRF negative. All subjects will have a total of seven study visits consisting of four annual MRI scans. Each study visit will include

a neurological exam, physical exam, cognitive tests and quality of life, nutrition, fatigue and depression questionnaires. The researchers believe that VDRF may increase disability in MS by slowing blood flow through the gray matter (brain and spinal cord tissue that predominantly contains the nerve cell bodies), decreasing the ability of nerve cells to produce the energy needed for healthy functioning. Using one of the most advanced brain MRI techniques available in the world today, this study will explore abnormalities in vascular function, including blood flow and volume and energy metabolism in the gray matter of brain. This study may help us develop novel interventions targeting VDRF to slow MS disease progression. The study plans to finish in 2020.



Early identification and management of VDRFs, including lifestyle modification and targeted medical management, may potentially improve outcomes for people with MS by slowing disease activity and disability progression and reducing the risk of other comorbidities that can affect quality of life. While optimizing the management of VDRF will not cure MS, it may provide an additional promising avenue for improving overall health and quality of life.

Staying Well with MS

By Rebecca Spain, MD, MSPH - Portland, OR VAMC

Staying well with MS means not just keeping on top of your MS, but also taking charge of your general health. Because people with MS can still develop medical conditions like high blood pressure, high cholesterol, heart disease, diabetes and cancers, it is important to have a yearly primary care evaluation. During these visits, your primary care provider can

manage your existing health problems, screen for new health conditions and make sure you get your routine health screenings.

To successfully manage your MS, it is also important to be seen at least once a year by an MS specialist. An MS specialist is generally someone

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in the neurology, rehabilitation or spinal cord injury department with additional training in MS. MS specialists are able to help figure out if what you are experiencing is due to your MS, or due to other medical problems. This specialty clinic evaluation may include a comprehensive neurological history review and neurological examination. Your MS evaluation is a great opportunity to find out what is new in the management of MS and to find ways to stay active with your family and friends. If you don't know your MS specialist, or don't have an upcoming appointment, ask your primary care provider for a referral.

Your primary care provider and MS specialist work closely together to care for you. You can help prepare for efficient and productive primary care and specialty care visits. Bring all of your medications, including the ones prescribed by a non-VA provider, a naturopath and those purchased over the counter. Also, bring any medical records and test results that are not VA documents. Write a list of your most important questions and identify which are priorities ahead of time. Tell all of your concerns to both your primary care provider and MS specialist, and let them decide who should best

address each concern. Similarly, your primary care provider and MS specialist may ask you similar questions such as:

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

Taking charge of your general health means more than just seeing your primary health care provider. It means taking care of the day to day activities that prevent and treat diseases. Did you know that taking care of your general health also helps your MS? Dr. Ruth Ann Marrie and colleagues reviewed a large North American database and found that people with MS who also had even one vascular risk factor - high blood pressure, high cholesterol, heart disease, peripheral vascular disease or diabetes - had MS walking problems an average of 6 years sooner than those without those conditions!



Vascular risk factors are all preventable and all treatable with a healthy diet, regular exercise and positive mindset. Diet, exercise and strong mental health are absolutely necessary to staying well with MS. The VA has many resources to help achieve these goals.

Staying well with MS means taking charge of your general health and taking the time to care for your primary and specialty needs. Doing so is a great way to maximize your life potential.

That Part of You That is Sexual

By Heidi Maloni, PhD, NP, MSCN - Washington, DC VAMC

Sexual arousal begins in the brain. The brain sends messages to the sexual organs along the nerve pathway in the spinal cord. MS-related damage to these nerve pathways can directly or indirectly impair sexual functioning. Nerve damage can contribute to diminished sexual response and feelings. MS symptoms can get in the way of sexual initiation or satisfaction. Symptoms of fatigue can be the biggest culprit or spasms that seem to be worse at night or when lying down. Weakness contributes to exhaustion and may be a limiting factor in initiating sexual activity.

Sexual dysfunction is a common symptom that affects more than 75% of people living with MS, more often than in people with other chronic diseases. Sexual dysfunction can present in many ways, limiting your ability to be sexual with your partner, to behave as a sexual being and benefit from this way of expressing love and intimacy. The ability to be a sexual person is not lost because you live with MS, although you may need to learn new ways to be sexual and accept things that are not in your control. Intimacy is a feeling of belonging to another, involves trust and is both an emotional and physical sharing of one's most personal nature. Your MS does not need to interfere with your ability to be intimate.

Recognition of sexual dysfunction can help people with MS understand the problem, find treatment, build healthier relationships, enhance self-esteem, reduce depression and improve quality of life.

Ladies First

For women, low desire or no desire is usually the first and foremost problem. Physical changes include lack of lubrication (dryness), genital numbness, decreased vaginal tone and pain during intercourse. Body image is important to women as are acceptance and personal security. Women rate affection and emotional communication as

more important than orgasm. For women, a sexual partner who is tender and romantic, with touching, kissing, caressing and extended foreplay is often ideal. Communication, honesty, warmth and understanding are important for women.

Gentlemen

For men, sexual problems may occur with erections and ejaculation. Men often desire sexual partners who do not make demands and appreciate partners who are reassuring and supportive, without pressure regarding erections or performance. Men also want to feel secure in the relationship and share affection.

The first step in managing sexual dysfunction in MS is accepting that it is a common symptom that should, and can, be addressed. Sexual dysfunction not only impacts quality of life but can contribute to relationship conflict, depression, isolation, performance anxiety and fear of intimate relationships and sexual encounters. Talk to your provider about your symptoms and what can be done to help. Physical and occupational therapists can help with positioning, techniques and “tools” while a mental health professional can help you address emotional issues that may be hindering intimacy.

Men who experience erectile dysfunction should talk to their provider about the many medications in both pill and injectable form that can help. Before buying “Men’s Performance Supplements” you should discuss the ingredients with your provider so they can advise you if they are safe with your other medicines and any other medical conditions you may have. For example, yohimbine, a herbal supplement advertised to promote sexual function,



may be dangerous to your liver, especially when taking some MS disease modifying treatments.

Manage other MS symptoms that might get in the way of sexual satisfaction. If spasticity is a problem, time sexual activity between one and four hours after taking baclofen. If fatigue is a problem, take advantage of morning sex, which may be your time of peak energy. If you experience weakness, consider different positions to conserve energy and consider using supports (wedge, pillow, support chair) to reduce strain or pressure on your body. Lack of bladder or bowel control can be addressed by using the lavatory immediately before sex. Genital stimulators can help compensate for decreased sensitivity. Know that alcohol, nicotine,

some medications and even some foods may diminish your sexual response.

Intimacy and closeness is important to your life satisfaction. Intimacy can be scary, even more so with fears around performance, rejection, failing to satisfy and fear that MS symptoms will spoil a sexual encounter. Having an open and honest conversation with your partner about your fears is a good start to fueling greater intimacy. Have realistic expectations. Focus on the process rather than the goal. Plan a date night. Enjoy intimate times, such as holding hands and making eye contact. Create romance. Light candles, play music from your most romantic days, bring out that scent you wore in high school and touch yourself and

VA MISSION ACT OF 2018

The “VA Mission Act” was passed by both houses of congress and signed into law by the President on June 6, 2018. This \$52 billion legislative package, formally called the VA Maintaining Systems and Strengthening Integrated Outside Networks Act, has some short term provisions and several long term requirements to maintain health care and services for Veterans. Key features of the bill include:

- ▶ Maintains VA Choice (non-VA health care) funding and consolidates community care programs
- ▶ Requires VA to contract with private networks to ensure timely access to community providers
- ▶ Expands the VA Veteran Caregiver Program
- ▶ Provides hiring incentives for health professionals
- ▶ Creates a commission to assess how best to modernizing VA facilities.

Having a coherent, modern system of care that allows for easy access outside the VA is a laudable goal. How this bill impacts core VA services has yet to be determined. Additionally, federal funding for the VA Mission Act has not been reserved so there will be debate on how the financing of the bill is ultimately achieved.

Regardless of where health care is received, either in the community or in the VA health care system, Veterans living with MS recognize that managing the disease and its symptoms requires education and access to a team of knowledgeable providers including neurologists, nurses, physical and occupational therapists, urologists and mental health providers to name a few. Access to MS disease modifying therapies, symptomatic therapies as well as prosthetic items is important. Monitoring for safety and navigating within a health care system should be clear with common pathways for communication between patients and providers. Veterans with MS deserve excellent, comprehensive health care to live their life to the fullest. For more information, visit the VA Community Care website at www.va.gov/communitycare/.

your partner all over to discover what body mapping is all about. Engage in activities that have nothing to do with MS.

You are a sexual being. Having love and intimacy is a basic human need. Sex is an important aspect

of love and intimacy. Be open to making changes to improve your sexual functioning. Talk to your provider and MS team about your sexual concerns. They can refer you to resources that will help. For more information on relationships and intimacy, visit the National MS Society website.

MS DMT Generics & Biosimilars

By Wei Zeng, MD - Baltimore, MD VAMC & Kathy Tortorice, PharmD, BCPS - National Program Manager, VA Pharmacy Benefits Management

Disease modifying therapies (DMTs) have been shown to decrease the frequency of MS relapses and slow the short-term course of MS. Fifteen DMTs are currently approved by the U.S. Food and Drug Administration (FDA). Fourteen are approved for relapsing MS and one is approved for primary progressive MS.

As with all medications, DMTs are protected by patents. A patent is given to the first company to submit a medication for approval to the FDA. Once approved, the patent is in place for a set period of time, excluding other companies from making, using or selling the medication. When the patent expires, other companies can make the medication.

Essentially, generic medications are copies of prescription medications. Generic medications are just as safe and effective as their brand-name counterparts, and they often cost less. The FDA ensures a generic medication provides the same clinical benefit and is as safe and effective as the brand-name medicine that it duplicates. A generic medication must have the same active ingredients, safety, effectiveness, strength, quality and benefits as the brand-name medication it copies. Companies

that make generic medications do not have to repeat animal or human studies that led to the initial FDA approval of the medication. This is in part why generic medications usually cost substantially less than the original brand-name medication. Because generic medicines have the same benefits and safety profile as the brand-name, but lower cost, there is no reason not to use a generic medication if it is available. It is therefore VA's policy to dispense generically equivalent medications when they are available.



For example, in 2014, the patent for the brand-name DMT Copaxone® (glatiramer) expired, allowing other companies to develop generic versions of this medication. Glatiramer is used for the treatment of relapsing forms of MS. The FDA has now approved generic glatiramer; made by two companies, Mylan and Sandoz. Both generic glatiramer's are available in 20 mg/mL and 40 mg/mL doses. This has allowed VA to negotiate a sole source contract for glatiramer. This means the VA

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ensures Veterans will receive the same medication from a single company, typically for 5 years, minimizing potential practical challenges with transitions. As more patents for MS DMT's expire, more generics will become available. VA will continue to work to ensure smooth transitions from brand-name to generics.

Some of the other MS DMTs, such as natalizumab (Tysabri®) are considered “biologics”. These medications are made in living cells. When the patent for these medications expire, biosimilars may be developed. Biosimilars are not generics because they are not an exact copy of the branded drug. The cell lines used to make biologics can cause there to be tiny differences between batches of the medicine each time it is made. This means that the biologic medicine someone takes may not be exactly the same every time they take it. But biosimilars go through many tests to check that they act in a

similar way in the body to the original medication. The FDA requires that biosimilars prove they are similar to brand-name medications in these ways: structure, function, clinical effectiveness and tolerability. However, unlike generics, biosimilars must be tested in human clinical trials before they are approved.

The decision to take an MS DMT is based on several factors including a person's current MS disease course, lifestyle and the medication's expected benefits and side effects. Although generics and biosimilars for most people have the same benefits and risks as the brand name medication, in some cases, changing to another company's medication may impact absorption and delivery. Some people may also develop side effects with a given generic medication. It is important to monitor these issues with your health care provider as you initiate a generic medication.