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VA Multiple Sclerosis Centers of Excellence

MS VETERAN

Serving the Health Care Needs of Veterans with Multiple Sclerosis

Activity Keeps My Mind & Body Fluid

By Tina Messmer - Lakewood, WA

Growing up, I didn't have the most supportive parents. When I turned 18, my parents kicked me out. With nowhere to go, I found myself living on the streets for close to a year. One day, I walked by an Army recruiting office and went inside. I believe that decision saved my life. I was with the U.S. Army for 10 years. They trained me to be a medical specialist, an area that I thrived in. I loved my time in the military and even met my husband while serving my country.

Following my departure from the Army, I used my training and found employment as a medical assistant. I worked in family planning and then urology. I was a clinical consultant in my last job, a position which allowed me to travel all over the U.S. I spent my days meeting new people, teaching them how to use medical equipment on their patients, and I loved it. Unfortunately, I had to leave due to my MS. I was having a lot of exacerbations about that time, and the traveling became too hard on me. Following my early retirement, I applied for social security disability.

I enjoy being active, and with a little research I found lots of ways to stay active and meet new people. I started volunteering at the American Lake VA in Washington. There I'm able to socialize with fellow Veterans, exchanging our life experiences and helping them however I can, even if it's just to lend an ear. There are so many people and service animals that I look forward to seeing. Through volunteering, I learned that I could get medical benefits for my years of service and applied for VA health care which has been wonderful. The other volunteers and Veterans have become a family for me, something that I haven't always had.

I also volunteer and advocate with the National MS Society (NMSS). They do so much for people effected by MS, including supporting MS research. With everything we are learning about MS and the new medications, I'm optimistic there will be a cure in my lifetime. While at a VA support group, someone from the NMSS spoke about their resources and how they can help people with MS. I contacted a NMSS Navigator and

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

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the NMSS is now helping me by paying my VA MS support group co-pay for a year. While there are other MS support groups I can attend at no cost, I'm more comfortable going to the VA Veteran support group, and the NMSS is helping make that happen for me.

I also do a lot with my grandchildren, including volunteering at the elementary school my youngest grandchild attends. During this last summer, my oldest grandson volunteered with me at the American Lake VA which was a real treat. I go to the gym seven days a week and have two rescue dogs that keep me busy. I find that keeping active keeps my mind and body fluid.

I was diagnosed with MS about 10 years ago, though I believe I've had the disease for a lot longer. I experience the symptoms of MS every day, but it's not what I want to focus on. There are days that I feel down and frantic, but doesn't everyone at some time? When I feel this way, I think of my husband and family, and how supportive they are. I think of everything I have and don't focus on what I don't have. I treat every day like a new beginning, doing my best to stay positive. I find ways to help others. It's fulfilling and hopefully it helps those I'm helping.

New Drug For Possible Treatment of MS

By Arthur A. Vandenbark, PhD, Roberto Meza-Remero, BSc, MSc, PhD, Ashley Headrick, & Halina Offner, Dr Med - Portland, OR VAMC

MS is a harmful and sometimes disabling disease of the brain and spinal cord that afflicts almost 1 million people in the U.S. and about 2.3 million people worldwide; typically between the ages of 20 and 40. I became acutely aware of the challenges MS can impose because of my sister, Louise, who developed MS in her first year of medical school at Stanford. She could not finish medical school but, being very determined, she completed a Master's Degree. Her struggle was a huge motivation for me. In graduate school I did my PhD thesis on factors in blood that might lessen the severity of an MS-like disease in rodents. Meanwhile, Halina Offner was earning her Doctor of Medicine degree in Copenhagen, Denmark, studying changes in the blood of people with MS. Ten years later Halina and I met at the 25th Anniversary Meeting of the Danish MS Society hosted by their Queen Margarita. We married and soon became an MS research team at the Portland VA, dedicated to developing new therapies for MS.

With our backgrounds in immunology, we studied how the immune system attacks nerve cells in the brain and spinal cord. Misdirected "bad" white cells from the blood (T-cells) migrate into the central nervous system (CNS) and mount an attack that strips off a protective coating around the nerves. This disrupts the way information is processed within the brain, interfering with the flow of information between the brain, spinal cord, and body. This can lead to a wide range of symptoms, including numbness, pain, and impaired coordination or more severe symptoms like paralysis, the loss of the ability to move.

Over several decades, our laboratory has focused on creating new treatment options for MS. Almost 20 years ago, we designed a promising new drug that we call "DRQ". In a mouse model of MS, DRQ can block the migration of the "bad" T-cells from blood to the CNS to prevent their destructive effects and also promote nerve regeneration in the brain and spinal cord. Our research team showed

that injections of DRQ after onset of symptoms can reverse the course of both mild and more severe chronic disease in mice and we are hoping that it will also be helpful for treating relapsing and especially progressive MS for which there are few effective drugs.

Currently, we are focusing our efforts to translate our drug into a treatment for people with MS. This process takes many steps. We need positive results in the mice, a good method for manufacturing the drug to make it safe for human use, approval by the U.S. Food and Drug Administration for use in clinical trials with people, and, eventually, licensing the drug to a company for public distribution.

In spring 2019, we teamed up with Dr. Michelle Cameron, Co-Director of the MS Center of Excellence West, who has a long history of MS clinical trial experience, to host a VA sponsored "Roadmap" meeting to help plan these steps. The meeting included over 20 MS experts from the U.S. and abroad to chart the course of our drug development. This will include both smaller and larger clinical trials in MS, some of which we hope to carry out at our local VA, so please stay tuned.

We are very excited at the prospect of contributing a new and possibly very effective drug to help Veterans and other people with MS like my sister Louise.

Steroids For MS Relapses: Pills or IV?

By Alexis A. Lizarraga, MD, MS - Buffalo, NY VAMC

Relapses are new or worsening symptoms caused by MS. They can lead to a temporary or permanent increase in disability. Until recently, high doses of intravenous methylprednisolone, a type of steroid, were the standard treatment for relapses in MS. Steroids are thought to work in MS relapse due to their ability to change the immune system. Steroids may help to reduce the active inflammation seen in MS attacks by preventing movement of immune cells from the body's circulation to the brain and spinal cord areas.

Intravenous (IV) steroids, or steroids administered via a needle placed in the vein, were found to hasten recovery after an MS attack in several placebo-controlled studies. The largest of these clinical trials was the Optic Neuritis Treatment Trial (ONTT) in 1994 which evaluated people with a first episode of optic neuritis, or inflammation of the optic nerve, a typical relapse in people with MS. In the ONTT, subjects were treated with either 3 days of IV methylprednisolone at a dose of 1 gram per day or low-dose oral steroids at a dose of 1 mg of prednisone per kg of body weight for 14 days. This study suggested that subjects receiving this low dose of oral steroids recovered more slowly than those treated with the high dose of IV steroids. Moreover, the study indicated that frequency of relapse was higher in the low dose oral steroid-treated group than those treated with high dose IV steroids.

The ONTT had its limitations, however. The doses of oral steroids were much lower than the doses of

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IV steroids. Also, subjects with optic neuritis, but not necessarily a diagnosis of MS, were included in the study. Other studies comparing oral and IV steroids had similar problems in design. Nevertheless, these studies provided a rationale for the preference of treatment of MS relapse with high-dose IV steroids rather than oral steroids for the next 20 years.

In 2012, an expert evaluation of several studies concluded that there was not enough evidence to decide whether or not oral steroids are effective for MS relapses, particularly if high-dose oral steroids are used. In 2015, the landmark French COPOUSEP trial "cleared the air". This study of 200 people with relapsing remitting MS was designed specifically to decide if oral steroids were as effective as IV steroids. In contrast to the ONTT, a similar dose of steroids was administered either orally or intravenously within 2 weeks of onset of relapse symptoms. Both the subjects and examiners did not know which treatment participants received, and subjects were randomly chosen for each group.

The primary outcome studied was to see if disability scores 1 month after treatment were different between subjects treated with equivalent doses of IV versus oral steroids. Results of the trial showed that 81% of people in the oral group and 80% of people in the IV group improved at least one point in their disability score. The results confirmed that oral methylprednisolone at a dose of 1 gram/day for 3 days was not inferior to treatment with the same dose of IV methylprednisolone. Other outcomes examined include recovery at 6 months after treatment and frequency of new relapses for up to 6 months after treatment, which were also similar between the oral group and the IV group. Side effects for each treatment were also compared via questionnaire and were essentially the same, except for a slightly higher risk for insomnia for the oral regimen. The authors recommend taking oral steroids in the morning to avoid insomnia.

These results are very important for MS management. We now have solid evidence that the appropriate dose of steroid pills is just as effective for MS relapse as IV steroids. Advantages of pills include ease of dosing, ability to take the medication in the comfort of home, and excellent and quick availability in pharmacies of oral steroids.

It is important to remember that steroids, either IV or pills, have the potential for side effects. Side effects of steroids include allergic reactions, depression, and mood changes which can include psychosis, insomnia, swelling, headache, increased appetite, increased blood sugar levels, increased blood pressure, lower resistance to infection, stomach irritation or, even rarely, changes in the rhythm of the heart. Treatment with steroids should only be undertaken under the care of a medical professional with expertise in treating MS to ensure that the benefits of steroids outweigh the risks in your particular case. If you are receiving IV steroids and are interested in receiving the medication orally, talk to your provider.

MS-Related Fatigue: Swimming In a Fur Coat

By Christopher Hollen, MD - Portland, OR VAMC

"Like swimming in a fur coat", "wading through quicksand", and "being under a lead blanket" are ways people with MS have tried to describe their fatigue. Fatigue can be a tremendous burden in people with MS. It is not only the most common symptom of MS but also one of the single biggest causes of disability and decreased quality of life. To make matters worse, fatigue is one of the most difficult symptoms to communicate to others. Fatigue is a feeling, a lack of energy and motivation, an invisible symptom that can't be detected on a brain scan, blood test, or physical exam.

The specific cause of fatigue in MS is not entirely clear but likely comes from multiple sources. The inflammation that causes lesions in MS can also cause chemicals to be released in the brain (cytokines) that may cause fatigue. Damage to the brain's neurons likely also contributes. Neurons transmit information to the body. When damage builds up over time, this can cause impaired connections, interrupting the flow of information. Often fatigue from MS is worsened by warm weather or vigorous exercise that raise the body temperature.

It's important to remember that there are also secondary causes of fatigue that are very common, results of having MS. Many symptoms of MS negatively affect sleep that in turn makes fatigue worse. Anxiety, spasticity, pain, and urination problems can reduce the amount and quality of sleep in a person with MS. These symptoms may be modifiable with treatment. If experiencing fatigue, your provider may check for other health problems that can cause fatigue such as low thyroid hormone, sleep apnea, diabetes, anemia, and depression. Sometimes a sleep study may be helpful to make sure that you are maximizing the benefits of sleep.

There are medications that may help with fatigue for some people MS. These should be considered, along with controlling the secondary causes of fatigue. However, the evidence that these medications work is relatively weak and the benefit can be fairly modest. You may want to discuss with your provider whether these medications are right for you, based on consideration of potential benefits and side effects.

For many, a combination of medications and other methods of treatment such as physical therapy, exercise, and diet changes can make a big difference. Fortunately, many VA hospitals have specialized providers and therapists who have access to cutting-edge techniques that may be able to help.

Effective communication between the physician and patient is required to develop an individualized plan for managing a person's fatigue and overall health. Sometimes there may be difficulty expressing the significance of fatigue a person is experiencing in the setting of a brief visit with their provider when other issues may take precedence. If experiencing fatigue, here are a few things you can consider before talking to your provider about your fatigue.

- Write down the most important issues you want to discuss with your provider to help guide your visit.
- Journal your fatigue. When do you have the most energy? When do you feel really drained? What activities are absolutely necessary for you to handle? Which of your activities could be delegated to others?
- Think about your diet habits and if fatigue has impacted your eating habits. Start with simple substitutions – like replacing packaged snacks with nuts, seeds, or whole fruits or using beans and lentils which provide protein without saturated fats. Aim to make your plate more

colorful with fruits and vegetables that provide antioxidants.

- A brief amount of regular exercise can make a big difference. Skilled therapists can help guide you on creating a reasonable plan and goal.
- Discuss with your provider whether any of your medications could be causing or contributing to your fatigue. Some medications that can cause sedation are baclofen, tizanidine, or gabapentin. Your provider may consider changing a dose or stopping a medicine if it doesn't seem to be helping.
- Maximize quality of sleep through sleep hygiene. Avoid drinking water just before bed and schedule a trip to the bathroom prior to sleeping. Avoid computer or TV screens before or while you sleep. If you smoke you should try to quit but until you do, avoid cigarettes and alcohol in the 6 hours prior to bed.

Fatigue is a complex issue with no one-size-fits-all approach to solving it, but sometimes simple changes can have a big impact. The first step in getting better is taking an honest and thorough personal inventory on lifestyle changes that are feasible. The weight and challenge of swimming in the fur coat of MS-related fatigue can improve but it often requires a multi-pronged treatment approach and should be coordinated with help from your primary care and MS providers.

Adaptive Movement for Improved Wellbeing

By Sarah S. Brindle, PhD, RYT 200 & Janice Kim, OTRL, ATP, ROT - Long Beach, CA VAMC

Many people with MS struggle with negative feelings about their bodies and experience a decrease in the mind-body connection. This can be related to physical weakness, numbness, fatigue, and the general physical unpredictability that often comes with MS. A lack of connection to the body can also occur when people come in contact with multiple health care providers and end up feeling like their bodies are no longer their own, but are subject to constant scrutiny, even if that scrutiny is well-intentioned.

Activities that promote mind-body integration can help people regain a sense of wholeness and wellbeing--and can also promote awareness of body sensation that can help with management of MS. If people are more aware of their bodies, they can potentially manage their symptoms better. Adaptive yoga and dance are two movement activities that can help you achieve this goal.

Adaptive Yoga

Yoga is an ancient practice that originated in India several thousand years ago. The general overarching goal of yoga is alleviating suffering. In our Western culture, the emphasis in yoga practice has been mainly on physical movements (called "asana"), but the traditional practice of yoga actually has three integrated components that incorporate yoga concepts: breathing exercises, meditation, and physical movement.

In recent years, medical researchers have found that practicing yoga can be associated with improvements in blood glucose, cholesterol, fatigue, anxiety, depression, overall stress, chronic pain, and general quality of life. Yoga is therefore now being incorporated in many VA settings as part of the VA's Whole Health Initiative, focused on self-healing mechanisms within the whole person.

Adaptive yoga was created to accommodate people who might not feel comfortable in a traditional yoga class, including people with physical, cognitive, or psychological issues that might make a traditional class more challenging. Adaptive yoga teachers use many strategies to make yoga accessible, including teaching the inner experience of a pose (rather than just how it looks on the outside), using various props (like chairs, blankets, yoga blocks, or sandbags) to make poses comfortable or more stable, and using "disability-friendly" meditations. Teachers providing instructions for a home yoga routine may also suggest poses that can be done in bed, rather than on a mat on the floor.

Most adaptive yoga classes also focus on incorporating the whole body, rather than just parts of the body that have full sensation or movement. This allows for more mind-body integration and a focus on increasing body awareness. Participating in an adaptive yoga class can also provide a beneficial social component in learning yoga concepts along with other people who experience similar challenges with their mobility.

Dance as a Whole Body Workout

Dance can also be used as a rehabilitation therapy. Research shows that dance may help people with physical, cognitive, or psychological impairments. Specific benefits of dance include improvements in quality of life, self-esteem, coping with disease, balance, and mobility.

Dancing at its most basic level is a whole body exercise to the rhythm of music, which means that any movement to any type of music may be beneficial. Dance as part of rehabilitation therapy usually includes exercises that are modified to meet each individual's needs (for instance, dancing in a chair vs. standing), encourages active participation, and challenges the physical body as well as the mind (for instance, following a series of dance moves). A therapeutic dance class may involve structured dance exercises in time to music or may be less structured, with "freestyle" periods where people can find their own enjoyable movement. The music adds to the experience as it can be motivational and inspire an upbeat mood. For many people, music itself is very stimulating, so with the right music, they are more interested in trying a challenging dance exercise or moving their bodies for a longer period of time. This also makes dance therapy enjoyable and a fun social experience if shared with fellow Veterans in a group class.

Some forms of dancing are better than others for preserving and improving mental sharpness, as in partner dancing. Studies have shown that it requires a lot of quick decision-making, as the dance partners must continuously interpret the signals of each

Veteran YouTube: MS & Me

Our videos are 6-13 minutes long, providing information from the viewpoints of Veterans with MS and VA health care providers.

Our current videos discuss **bladder**, **cognition**, **community reintegration**, **diagnosis**, **exercise**, **fatigue**, **mobility**, **VA services**, and **sleep**.

To view the videos, go to the VA MSCoE website, www.va.gov/MS. They can be found on the homepage banner, or you can go to the *Programs and Product* column, select *Veterans*, and then select *YouTube*.

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other. Partner dancing also enhances relationships, social connectedness, and a sense of belonging. The inclusion of accessible dance-related activity into one's daily life through classes or parties means having a fun way to connect with people that is not only healthful physically, but meaningful mentally.

Finding Adaptive Yoga & Dance

1. Talk to your treatment team! There may be existing adaptive yoga or dance offered at your VA. Yoga is often offered through the Primary Care Service in the VA. If your treatment team isn't sure of local options, they can contact their VA Whole Health coordinator. Talk with your rehab therapists about incorporating music and dance into your existing therapies.

2. Find ways to incorporate music and dance into your daily life. Moving your body along with enjoyable music - even sitting at the kitchen table with your morning coffee - can improve your wellbeing.

3. Explore the Whole Health website for other resources for Veterans on yoga and meditation at: www.va.gov/WHOLEHEALTH/veteran-resources/MobileApps-OnlineTools.asp.

4. Find local adaptive yoga teachers outside the VA through www.mindbodysolutions.org or by contacting local yoga studios about instructors who have experience working with people with MS or other physical disabilities. Don't be afraid to ask!

The bottom line is that enjoyable movement of your body can be beneficial psychologically and physically. Find your own way to reconnect with your body!