

VA Multiple Sclerosis Centers of Excellence

MS VETERAN

Serving the Health Care Needs of Veterans with Multiple Sclerosis

I Am Not My MS!

By Lia 'Lisa' Coryell - La Crosse, WI

My journey with MS began 32 years ago. Like most people with MS, it took several years to finally receive a diagnosis; relapsing-remitting MS. Five years ago I was having pain in my legs and feet when walking and was falling daily. I had a surgery on my left knee and have not walked since that surgery. I began my life as a 'wheeler' on that day, going from relapsing-remitting to progressive MS.

I was absolutely terrified when I was told that I now had secondary progressive MS. I was afraid to do anything that would make the disease progress faster than it already was. I was afraid to live because I was afraid of dying. It was a dark and horrible place to be. I was so depressed, I wished I would just die and be done.

In 2013, I attended the VA's National Veterans Summer Sports Clinic in San Diego, CA. That adaptive sports camp both changed and saved my life. The minute we came off that plane we were 'Adaptive Athletes'. I had thought of myself as a patient for many years. I didn't think a person with MS could even be an athlete.

The level of courage, bravery, and tenacity of the other athletes at the Summer Sports Clinic humbled and shamed me. Most of them were young people injured during their enlistments during the wars in Iraq and Afghanistan. Many were missing limbs or paralyzed, yet they laughed, talked smack, and competed with all their heart. It was at this camp that I met Randi Smith, the Paralympic Archery Coach, and I discovered archery. I had never shot a bow and found that I really liked it.



A year later, I was back at the Summer Sports Clinic. I roomed with Air Force Veteran, Samantha Tucker. Sam is a below the elbow amputee. We decided that we were going to make the USA Para Archery Team the following year. On January 1, 2015 we packed up our belongings and met in Colorado Springs, CO to train together. Seven months later, we were named to the USA Para Archery Team and the World Championship Team. I was 50 years old and Sam was 45.

Inside This Issue

- 2 | Improving Fatigue & Depression
- 3 | Ocrelizumab
- 5 | Communication & Self Advocacy
- 7 | Get Out & Play

In 2016, I became the 1st American woman in the W1 class (classification for the most significantly impaired archers) to be named to the USA Paralympic Archery Team. Although I didn't medal, my world ranking rose to #4 in the world. I am #1 in the USA. Sam also made the Paralympic Archery Team as the USA's 1st female compound archer.

My training and competition schedule is carefully structured around my needs and MS triggers. I found that working with a Strength and Conditioning Coach helps my fatigue and spasticity. My bowel/bladder program and wheelchair accessibility needs are carefully considered when traveling, especially internationally. Heat is a huge issue, both in training and competition, but we are learning and adjusting

every day. The disease continues to progress and most recently the dexterity and strength in my hands has diminished. I am very careful with my nutritional planning and have lost 75 pounds in the last 3 years.

This journey has taught me that I am NOT my diagnosis. MS does not get to define me or determine what I will accomplish. I don't dwell on what the future holds for me anymore, it is what it is. MS is going to progress whether I sit around and wait for it or not. I believe that what I am doing is not even about me or archery, it is about stepping up and leading by example. There is no room for apathy in MS. Live life like you mean it. Don't just hand MS the win, fight for yourself! To learn more about me and my team, our Instagram is @USAParaArchery.

Research: Improving Fatigue & Depression

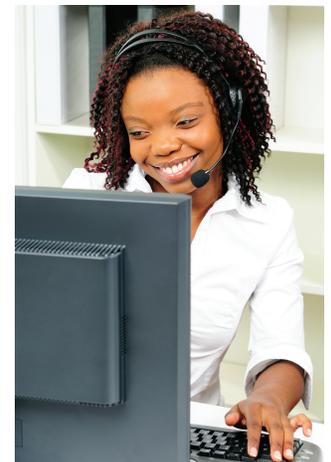
By Aaron Turner, PhD & Alicia Sloan, MPH, MSW, LICSW - Seattle, WA VAMC

Does MS affect your ability or motivation to do physical activity? Do you have fatigue or depression from MS? Physical activity not only increases physical fitness, it decreases fatigue and improves mood, especially in people with MS. Over 90% of people with MS have experienced fatigue. Nearly 50% find fatigue their most disabling symptom. Depression is 2-3 times higher in people with MS than in the general public. Physical activity can be challenging for people with MS, especially if they have fatigue, depression, or mobility issues. But, people with MS who increase their physical activity can have improved fatigue and depression.

Clinical psychologist Aaron Turner, PhD, and his team at the VA Puget Sound Health Care System and MS Center of Excellence - West in Seattle, WA, recently published results from their MS Fit Study. They found that for people with MS, telephone counseling helped increase physical activity and decreased fatigue and depression. In this study, 64 participants enrolled; 31 received education and telephone counseling (active intervention group) and the other 33 received education but no telephone

counseling (control group). Participants were Veterans from the MS clinics at VA Puget Sound Health Care System and non-Veterans with MS from the surrounding area. All participants were given an exercise DVD from the National Center for Health Promotion and Disease Prevention along with health information and home exercise sessions for different ability levels.

The control group was encouraged to use the DVD as a resource to plan their own exercise plan. The active intervention group received six weeks of telephone counseling about setting and achieving physical activity goals, was mailed personalized graphic feedback, and used a home telehealth monitor to communicate information to the study therapist. The telephone counseling was a type of counseling called motivational interviewing. Motivational interviewing has been



shown to facilitate positive lifestyle changes, like increasing physical activity. The counseling was intended to help with motivation, building confidence, and overcoming barriers to achieve exercise goals. The home telehealth monitor was used as a reminder to exercise and asked questions about the exercise goal for that week. Answers from the monitor were transmitted through a 'landline' telephone line to a website accessed by the study therapist. Participants who answered that they did not meet their goal were called by the study therapist and provided with extra telephone counselling 'booster sessions' to look at barriers to exercise and to work some more on goal-setting.

Results of this study were promising. Participants in the active intervention group improved their physical activity and decreased their fatigue and depression more than those in the control group. The active intervention group liked the telephone counseling and telehealth monitor, and found the telehealth monitor easy to use. This study shows us that providers can use telephone counseling to help people with MS to increase their exercise, which can help treat fatigue and depression. Telephone counseling can be especially helpful for Veterans with MS who have difficulty traveling to, or live far away from, VA services.

The bottom line: if you have MS and are physically active, keep being active! It is likely the physical

CAN DO MS WEBINAR

Join Can Do MS live from the convenience of your home for a free, in-depth discussion on topics relating to exercise, nutrition, communication, symptom management, employment, and wellness.

Date: 2nd Tuesday of Every Month

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

Topic: Different Every Month

Go to www.mscando.org for information about the webinars, including topics, speakers, and registration.

activity you are doing is helping your mood and reducing your fatigue. If you don't engage in regular physical activity, talk to your provider about how you can become more physically active. Your provider can help you start a physical activity program designed for your abilities. Physical activity not only keeps you healthy, strong, and mobile, but it can also help decrease depression and fatigue.

If you would like to view the study publication, go to www.ncbi.nlm.nih.gov/pubmed/26913621.

Ocrelizumab

By Gregory Wu, MD, PhD - St. Louis, MO VAMC

Many treatment options are currently available for people with relapsing MS, a testament to the rapidly productive and innovative MS research that has been done. Since 1993, 15 disease-modifying therapies (DMTs) to alter the course of MS have been approved by the Federal Drug Administration (FDA).

The newest disease-modifying therapy for MS is ocrelizumab (Ocrevus™) which was approved by the

FDA on March 28, 2017 for the treatment of both relapsing and primary progressive forms of MS. This article summarizes how ocrelizumab is thought to work and the clinical studies supporting its use.

Ocrelizumab is known as a monoclonal antibody therapy. Monoclonal antibodies are medications that very specifically bind to selected targets.

Ocrelizumab specifically binds to CD20, a molecule

on the surface of a type of immune cell called B cells. This destroys these B cells. Hence, along with a host of other medications under development, ocrelizumab is a B cell depletion therapy. B cells are believed to play a role in the auto-immune damage that MS causes to the brain and spinal cord. Therefore, reducing the number of B cells in the body may reduce the damage MS causes.

Much of what is known about ocrelizumab is based on a very similar medication called rituximab (Rituxan®), another monoclonal antibody that targets CD20 and that is a B cell depletion therapy. While ocrelizumab and rituximab are slightly different (rituximab is a mixture of mouse and human components while ocrelizumab is 'humanized', and rituximab and ocrelizumab bind slightly differently to CD20), their effects are likely similar.

Rituximab was studied before ocrelizumab, based on its use in other diseases where B cell activity is thought to contribute to inflammation, such as lupus and rheumatoid arthritis. In 2008, a small phase II clinical trial using rituximab for people with relapsing-remitting MS (RRMS) suggested that rituximab very effectively reduced disease activity. The following year, results from a separate clinical trial investigating the effect of rituximab for people with primary progressive MS (PPMS) did not find any overall benefit.

Efforts to translate the findings from these rituximab trials into an FDA-approved drug for RRMS gave way to the development of ocrelizumab. Two large phase III studies in people with RRMS showed ocrelizumab to be effective in reducing MS disease activity -- reducing the average number of relapses per year by approximately 45%. Other indicators of ocrelizumab's effectiveness include fewer number of lesions on brain magnetic resonance imaging (MRI) scans and a decrease in disability worsening in comparison to study subjects who were given interferon therapy (interferon β -1a, Rebif®).

A separate clinical trial compared ocrelizumab to placebo for people with PPMS. In this study, fewer people experienced progression of their disability if

they received ocrelizumab instead of placebo. While the difference was small (33% of people treated with ocrelizumab had disability progression compared with 39% of people treated with placebo), it is still encouraging.



This led to FDA approval of ocrelizumab for the treatment of RRMS and PPMS, making ocrelizumab the first DMT

approved for PPMS. Some VA MS providers have already been using rituximab to treat people with RRMS and PPMS. Many of those receiving rituximab have found that their MS has been stabilized on this medication. There are pros and cons to using or switching from rituximab which can be discussed with your MS provider.

Safety of new medications is always a concern. In the major clinical trials, certain side-effects were more common in subjects treated with ocrelizumab than in those taking interferon or placebo. These include reactions during the ocrelizumab infusion (30-40% developed symptoms such as itchiness, flushing, throat irritation, etc.) and infections (commonly an upper respiratory tract infection, swelling of the nasal passages and back of the throat, or urinary tract infection). Additionally, slightly more of those treated with ocrelizumab than those treated with placebo developed cancer. In particular, breast cancer occurred in 6 of the 781 women treated with ocrelizumab and none of the 668 women treated with interferon or placebo. However, because the percentage of ocrelizumab-treated subjects with cancer at the end of the trials appears to match the expected rate of cancer seen in other trials involving MS subjects, we don't really know if ocrelizumab does or does not increase an individual's risk for cancer. A better understanding of whether ocrelizumab increases the risk of cancer will be eagerly anticipated once long-term data becomes available.

It is important for people taking ocrelizumab to use an effective birth control method during treatment

and for six months after the last dose. Ocrelizumab may cause harm to a fetus, so tell your provider right away if you or your partner become pregnant. People with MS should have any vaccines they need at least six weeks before starting ocrelizumab. Do not get any types of immunizations or vaccinations, especially those that are live vaccines, until your provider tells you your immune system has recovered.

Ocrelizumab is a potent option for the treatment of RRMS, stacking up well against other infusion therapies, and is the only option approved by the FDA for PPMS. Remaining to be explored by real-world use are the benefits and risks in a much larger and more varied group of people with MS than those

who were in the clinical trials. Further, it will be important to understand the basis for differences, if any, between ocrelizumab and rituximab.

Ocrelizumab is available for prescription in the VA and is on the VA National Formulary (listing of medications for prescription at all VA facilities). While it's exciting that we now have a FDA-approved DMT for the treatment of PPMS, it is not appropriate for everyone. If you are interested in the medication, talk to your MS provider. Your MS provider will be able to discuss the appropriateness of the medication for you, as well as the possible side effects and monitoring that is needed to ensure that ocrelizumab is used safely and effectively in people with MS.

Communication Matters: Self-Advocacy

By Maggie 'Margaret' Kazmierski, MSW, LCSW-C, CCM - Baltimore, MD VAMC

MS can be a life-changing diagnosis. The unpredictability of the disease may cause self-doubt and uncertainty about the future. The chronic, fluid, and ever changing symptoms can affect the self-esteem and emotional wellness of many individuals living with MS. A sense of control and overall positive self-esteem and wellness can be regained through self-advocacy with ourselves, our loved ones, and the health care community.

Self-advocacy can be translated into understanding your strengths and weaknesses, developing personal goals, being assertive (meaning standing up for yourself), and making decisions that reflect your best interest. An effective self-advocate is someone who lets other people know what he/she is thinking, feeling, and needing. Self-advocacy doesn't mean someone will always get their desired outcome, but practicing the skills to self-advocate when living with a chronic illness can be an empowering, positive, and important step in living your fullest and healthiest life with MS.

Becoming a self-advocate while living with MS can allow others, such as family, friends, and

healthcare providers, to learn more about your unique perspective with managing MS symptoms. It can improve a sense of unity and belonging when advocating with others living with MS. It can increase awareness and educate loved ones, family, and friends about symptoms associated with MS that are not always openly discussed due to social stigma (such as bladder issues, cognitive changes, and depression). It can also empower and install a sense of hope and resiliency which in turn promotes a positive feeling of overall wellness and direction. There are multiple strategies and various resources for becoming an effective self-advocate.



Believe in Yourself: You are valuable, unique, and worth the effort to advocate for your health care needs. Know that your perspective is imperative in managing your MS wellness journey. Repeat the following affirmation each day to

yourself, "I am worth the effort to self-advocate for my needs and be the healthiest person I can be."

Set Goals for Yourself: Clarify what you need and use the SMART system to set goals that are

- S**pecific,
- M**easurable,
- A**chievable,
- R**esults-oriented, and
- T**ime-sensitive.

For example, you may have difficulty remembering all the recommendations your healthcare specialist provides for you during your visit. Or, you may

realize when you get home from a visit, that you are not sure where to start or what was said regarding a strategy for follow-up care. A SMART goal could be to ask your healthcare specialist for a list of the recommendations, to get a print out of the follow up instructions/health strategies, and to outline projected dates to complete any health tasks before your next appointment (e.g. blood work completed a week before returning to the clinic).

Get the Facts: Make sure you are armed with information that is accurate when advocating for yourself. For example, if you feel you need to have a conversation about switching your disease modifying therapy (DMT) with your MS provider, make sure you do your due diligence in finding unbiased information about each DMT option. The VA MS

National MS Society MS Navigator Program

The nationwide NMSS Navigator program helps individuals and families manage the challenges of MS. People can access MS Navigators by phone: (800) 344-4867, through on-line live chat from the NMSS website www.nationalmssociety.org, or via e-mail at ContactUsNMSS@nmss.org.

Highly Skilled MS Navigators:

- Connect people to the information, resources, and support services needed to move their lives forward.
- Provide information about MS, referrals to healthcare professionals, and emotional support for those newly diagnosed to those with progressive challenges.
- Provide referrals for the most complex situations to our case management service through the Edward M. Dowd Personal Advocate Program. The case management service contracts with local case management professionals, overseen by an internal case management team, to provide:
 - Assistance to access services, benefits, community resources,
 - Comprehensive assessment of home environment and individual needs,
 - Development of clear goals based on eight goal areas,
 - Monitoring of progress against goals,
 - Home visits, and
 - 6 week and 3 month follow-up with each participant.



Center of Excellence, National MS Society, and Federal Drug Administration (FDA) websites are good resources for unbiased information on DMT's as well as medications for symptom management.

Gather Support: Nothing helps self-advocacy more than supportive family and friends. Educating family members and friends on MS and rallying the troops when you need support can be a great confidence builder and lessen feelings of isolation. Support can also be found through MS or Veteran self-help groups, MS or disabled Veteran advocacy organizations, community centers (classes and planned excursions), VA Vet Centers, and sometimes local health departments or social service agencies. Contact your local VA facility or the National MS Society to see what options are available in your area and what might make sense for you.

Communicate & Express Your Needs

Clearly: Learning how to communicate effectively takes some practice, but with a SMART plan in place, you can begin to develop good communication skills. If you feel like you may forget a point, or lose your train of thought, write it down or record your thoughts ahead of time. Be firm, but don't lose your temper, if you find you have resistance from family, friends, or community organizations when self-advocating. Listen to what the other person is trying to communicate to you. Be persistent in advocating for what you need while remaining open to a compromise to move forward.

It may take several tries before you feel more confident in expressing yourself in a concise, clear, and direct manner, but practice does make perfect when advocating for yourself.

Get Out & Play!

By David Tostenrude - Director, National Veterans Wheelchair Games

What are you doing today? If the answer is "Going to work", what are you going to do when you are off? If the answers then become "I don't know", "I can't do ... because ...", or "I wish I could ...", you aren't alone! We can help turn those responses to "I don't have time or room for one more hobby!".

As healthcare professionals, we are going to tell you that getting out and exercising is fun, will decrease your stress, reduce weight, improve cardiovascular endurance, decrease depression, and reduce secondary medical conditions such as diabetes, heart disease, stroke, etc., etc. You know all that. However, we all find ourselves, at some point in our lives, in a situation where getting started can be the challenge. The movement from the rut to something different has to start with you, but we are there to back you up.

When confronted with a condition, such as MS, either newly diagnosed or perhaps you are dealing with newly onset challenges, support to move forward can really help. If you relate to this frustration, let us know. Contact your healthcare provider or VA recreation, physical, occupational, or other

rehabilitation therapist. If you don't have one, ask your healthcare provider for a consult to get started

overcoming the barriers you are facing and develop a fitness, sports, or recreation program to get you going. The ultimate goal will be to get you active at



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home throughout the year in meaningful activities that will make a difference in your life and health.

The first step is letting your VA therapist know about your interests. Some VA rehabilitation programs will have sports programs to get you started at the medical center. Others may get you out in your community and introduce you to organizations that you can get involved with right in your own backyard. If your condition is such that adaptive sports equipment will help you get more involved, the VA can help you get the right equipment. Some people avoid wheelchairs or 'adaptive equipment' due to feelings of being more dependent or being viewed as disabled. These are just tools. Recumbent bicycles, handcycles, and sports wheelchairs can improve your mobility and intensity to play sports, allow you more freedom to exercise and explore your community with your family and friends, and expand opportunities in your life.

If your passions are sports, creative arts, skiing, golfing, or even if you have a wild idea of trying surfing, the VA has several National Sports Program and Special Events that can give you a kick start. Each is designed to introduce you to activities that will reinforce what you can do at home and in your life. In each event, you'll also be included in a greater community of Veterans that have faced or are facing the same challenges you may be experiencing. Go to www.va.gov/adaptivesports and follow the links to each of the national opportunities. One of the national programs is the National Veterans Wheelchair Games (www.wheelchairgames.org). The 2018 National Veterans Wheelchair Games is in Orlando, FL from July 30 to August 4, 2018. There are 19 medal sports and it's guaranteed you'll find something to connect with. For more information on the Games or for help to get started, contact Dave Tostenrude, Director of the National Veterans Wheelchair Games, at david.tostenrude@va.gov.