

VA Multiple Sclerosis Centers of Excellence

MS VETERAN

Serving the Health Care Needs of Veterans with Multiple Sclerosis

Do It Yourself!

By Kevin Byrne - Portland, OR

“Hey, Eleanor! Can you come here and help me for a moment, please? I needed help buttoning my pants, my 34” jeans. You know, the ones with the regular tab closure.” The reality is my arms just don’t work anymore. My left has complete sensation, but it’s quickly losing mobility. My right arm has complete mobility, I just can’t feel anything. This combination makes everyday tasks difficult. Buttoning a button is my Kilimanjaro. Normally, I wear 36” waist pants and jeans. This way, I can take them on and off without unbuttoning them.



My other option with pants is to buy ones with a hook and clasp closure, bypassing the need for a button. They don’t make them in jeans, and I really wanted to feel normal for a bit. I’m not willing to consider wearing elastic waistbands all the time, not yet. Clothes which will fit me, and don’t merely compensate for my disability, help me feel a bit more normal. Just for a moment, I feel normal again.

For my self-confidence, I wanted to wear my 34’s. I just couldn’t get the button to work. Ellie gave it a halfhearted effort before jabbing me with, “If you can’t put them on yourself then don’t wear them.”

Barking orders like I was a Captain in the Air Cavalry again wouldn’t work. First, she’s my seven-year-old daughter. Second, she was right.

I struggled for the next 25 minutes, cursing everything under the sun except for Ellie. She was right. Do it myself. I ended the battle with a successfully buttoned pair of jeans and a newfound skill in this strange world in which I’m living. Today, I buttoned and unbuttoned my pants 10 times in a row, just to see if I could. My body learned a whole new set of motions. They’re childish tasks mastered a long time ago; learning them

again when you’re 46 is humbling.

I retired from the Army with MS in 2003. For a long time, my symptoms were manageable. My MS has worsened significantly over the past few years; it’s a battle so many of us face every day. Things I used to love doing, others I never thought twice about, are beyond my physical capability now. Caretaker assistance, incredible support from friends and loved

Inside This Issue

- 2 Military Cohorts & Big Data
- 3 Depression & Anxiety
- 5 Social Security Disability
- 6 Managing Pain

ones, is always needed and valued. On occasion, however, I still demand to fight for my independence.

So, I say if you can care for yourself, then do it. As long as you're safe, don't worry about how silly you look or how others may react. If you can do yourself, do it. If you can't do something, you won't get the rewards.

I am confident those close to me will help me in any capacity I need. Still, I go in with the mindset of 'do it yourself or it won't get done.' Force your mind into the urge to find your new normal. If you lose

independence for a specific task, at least you put up one heck of a fight! If my MS is going to worsen, it'll have to take my abilities battle by battle, fight by fight.

My time in uniform taught me a surprising number of ways to fight back - to push, learn, and adapt. Take advantage of everything your body still wants to do and can do. And, for the sake of everything you value, ***Never Stop... Never Quit... The fight is not over and it won't be over until a cure is found. It will never stop...nor will we. It will never quit... nor will we. This is why we fight! Never Stop... Never Quit...[®]*** (neverstopneverquit.com)

Research: Military Cohorts & Big Data

By Mitchell Wallin, MD, MPH & Joel Culpepper, PhD - Washington, DC VAMC

The rates of MS in the US have been increasing over the last fifty years. Recently, there have been relatively few epidemiology studies that have looked at MS disease prevalence (total number of people with MS in a given area) and incidence (the number of new cases of MS in a given area). Researchers look at prevalence and incidence to understand the frequency of a disease over a large population of people in a given period of time and to understand the disease "burden."

This information helps to describe trends and patterns of disease in order to understand possible factors that might contribute to the development of disease. These trends and patterns may also help with the development of preventive interventions and treatments. The study of disease patterns, trends, risk factors, and overall health within a population is called epidemiology. Epidemiologic studies also investigate how disease interventions influence health outcomes.

The US military population has provided a rich resource for epidemiological studies on MS. These studies date back to World War I when Dr. Fred Davenport, a distinguished epidemiologist and associate member of the US Armed Forces Epidemiological Board, presented the first

nationwide study of military draftees that were discharged for MS.

These MS studies progressed to the next generation, Veterans who served in World War II and the Korean Conflict, and then to a third cohort of Veterans



who served in the Vietnam War and later up to 1994. Most of these studies examined risk factors for MS at the onset of the disease and through the progression of the disease until death. Dr. John Kurtzke, an early leader of MS epidemiology, authored virtually all of these studies using large military populations.

Along with Dr. Kurtzke, our Washington, DC-based group characterized a new nationwide incident cohort of MS from the US military population. A total of 2,691 Veterans who (1) served in the military between 1990, the start of the Gulf War era, to 2007 and (2) were service-connected for MS by the VA, were included in the epidemiological study. Our goal is to review this population and look for trends and MS risk factors within this cohort. While this project is still ongoing, I will share some of our early results.

This Gulf War era MS population had an average age of MS onset of 31 years. While the range of MS diagnosis was between 17 and 50 years, 31 years is the average age for men and women, which was similar across racial groups. We found that women of all races now have incidence rates for MS that are about three times higher than those in men. This finding correlates with the trend found for most countries throughout the world, where MS incidence and prevalence rates for women are increasing.

An interesting pattern was found in looking at rates of MS by Service branch. We found that Air Force Veterans had the highest rate of MS, next was the Army, then Navy, Coast Guard, and the last group was the Marines. In fact, the rate of MS for Marines was about half that of the Air Force. Additionally, racial and ethnic minority populations (African American, Asian/Pacific Islanders, Native American/Alaska Natives, and Hispanics) in the US had rates for MS that were higher than previously reported.

We recently explored disability at the time of the diagnostic evaluation among 1,919 cases of clinically definite MS. A total of 94% had a relapsing-remitting course and 6% were primary progressive at diagnosis. More males of all races and blacks of both sexes were progressive. In this incident cohort,

males and blacks had significantly higher proportions of primary progressive MS. MS disability at diagnosis was significantly more severe in blacks and significantly less so in whites and in women vs. men. The MS Severity Score, a disability measure that accounts for time with MS, was marginally greater in black males and other males compared to the other sex-race groups. This morbidity assessment early in the course of MS provides population-based data for diagnosis, management, and prognosis. More details about this study can be found in the article “The Gulf War era multiple sclerosis cohort: 3. Early clinical features” in the journal *Acta Neurologica Scandinavica*; 2018 Jan;137(1):76-84.

We do know that in general, environmental risk factors, such as smoking and vitamin D insufficiency, as well as genetic risk factors, contribute to the onset of MS. What we will be exploring in more detail is this relationship to minority populations and branch of Service. This Gulf War era military MS cohort, like prior cohorts, provides a unique resource for further study that can lead to better understanding and hopefully improved treatments. Our VA MSCoE epidemiology group is contributing to the National MS Society’s MS Prevalence Project along with several other investigators to assess the MS prevalence in the US.

Psychosocial Aspects of Depression & Anxiety

By Jason C. Steward, PhD, LP - Portland, OR VAMC

MS is often experienced as a debilitating illness that creates many hardships for the millions of people with this disease. MS causes a wide range of symptoms, including physical and sometimes psychological problems. MS can affect the person’s self-image and identity: how they look, behave, think, feel, and how others see them.

Since MS has no clear cause or cure, people with MS often wonder, “Why me?” and struggle with existential questions after receiving this diagnosis. Questions such as: “What does my life mean now?” and “Is there any hope?” are common. The difficulty

with not knowing how this occurred and how they will deal with it can trigger a sense of hopelessness, unfairness, and even victimization – as if life itself has done them “dirty.” Some people experience MS as trauma in their lives. This is especially true given that the attack of symptoms themselves are unpredictable. Dealing with disability associated with MS can trigger strong feelings of anxiety and depression. In addition, MS can cause depression directly, likely because of lesions in the brain and the inflammation associated with the disease.

Depression and anxiety in people with MS can

go less noticed than the physical symptoms. But depression and anxiety are common with MS and can have more impact on the person's daily functioning than physical symptoms. They can linger in the shadows, influencing the person to see themselves in a negative fashion. And, by the time the person recognizes the depression and anxiety, it may already have a significant amount of power and influence in their lives, shaping almost every decision they make on a day-to-day basis.



MS can cause a profound sense of fear that can shake a person's most fundamental beliefs (e.g., belief in a "just world"). And at the root of this fear is an internalized feeling of helplessness which can lead the person to feel like they always need to "be on guard" from future MS attacks and increased disability. This "on guard" behavior can lead people to develop coping mechanisms rooted in avoidance.

To cope, people with MS will often avoid going out in public, being in crowds, or being around others (including family and friends) – preferring to isolate. Isolation can have devastating impacts on a person's life and is one of the main symptoms of both depression and anxiety. Isolation cuts people off from things they used to do for fun, people they love, and those who support them. Isolation stops people from participating in things that make life feel good to them. Over time, isolation also magnifies feelings of anger as life may begin to feel more and more unfair. Trust and intimacy problems are also common, as the person is likely to see himself/herself as a "burden" and feel as if others cannot understand what they are going through.

There are several tell-tale signs of depression and anxiety. Depression is referred to as "the absence or decrease of positive emotionality." The hallmark sign of depression is a pronounced decrease in the amount of positive emotions the person experiences (e.g., pride, joy, happiness, satisfaction). Depression

is the absence of the "spark" in the person's life and may be a byproduct of the isolation and the physical limitations imposed by MS. With depression, as the person loses their "spark" they may begin to feel as if their life has no meaning or is not worth living.

Anxiety, on the other hand, is an increase of negative emotions. Unlike depression, with anxiety everything "ramps up too fast" - the heart beats faster, thoughts "race", you sweat more, etc. ***People with MS often experience both depression and anxiety and in general, it will impact their sleep, interest, guilt, energy, concentration, appetite, psychomotor (i.e., "how fast they move/think"), and degree of suicidal ideation.*** If you or your loved one is experiencing changes in these areas, it is possible that they have depression and/or anxiety.

In addition to antidepressant and anti-anxiety medications, there are things you can do to help with depression and anxiety associated with MS. ***There are four main protective factors, grounded in solid research, that can help with depression and anxiety: diet, exercise, social support, and an emphasis on post-traumatic growth.*** Specific to diet, eating a balanced, healthy diet can promote healthy brain function. Although exercise may be difficult, it's important to stay as active as you can for as long as you can. Sometimes I tell my patients, "Give the depression a moving target and you'll be harder to hit." Social support is also key as it lessens the feelings of "aloneness" you or your loved one might be feeling. Try to set a target to find five really solid people you can learn to trust with what you are going through. Having a few good people in your life can greatly impact your mood.

Lastly, remember that "growth is possible." Many people report positive changes in their lives after traumas, even a diagnosis of MS. Find out what others did, how they approached redefining meaning in their lives, and what their secrets to success were. Therapy or counselling that focuses on these factors can be a "gamechanger" in a person's experience of depression and anxiety related to MS. Don't be afraid to reach out to improve the quality of you or your loved one's life.

Social Security Disability

By Rosalind Kalb, PhD & Kathleen Costello, CRNP, MSCN - National MS Society

You may qualify for disability benefits under the Social Security Administration (SSA) criteria if you are **unable to work eight hours a day, five days a week due to MS-related impairments or other conditions**. Benefits may be Social Security Disability Insurance (SSDI), for individuals who have worked sufficient time and paid Social Security taxes, or Supplemental Security Income (SSI), for those who have not worked or paid Social Security taxes or who are elderly, blind, or disabled with very limited means.

Applying for Social Security Disability is often a long and complex process. The National MS Society Guidebook is available to assist people applying for disability and their healthcare providers. In addition, the Society's MS Navigators (800-344-4867) can help individuals and providers understand and complete the application process. Following the timeline of steps outlined in the Guidebook can make the process less daunting and ensure that the information provided to SSA is sufficient for a fair decision.

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

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.

SSA recognizes MS as a chronic illness or “impairment” that could cause disability severe enough to prevent a person from working. Any of the following (or other) MS symptoms may become severe enough to interfere with a person’s ability to remain in the workforce:

- ▶ Difficulty walking, maintaining balance, or engaging in other physical activities
- ▶ Difficulty using your arms, hands, and fingers to carry out tasks
- ▶ Difficulty with cognitive tasks such as information processing, memory, attention, multi-tasking, planning, and prioritizing
- ▶ Inability to function physically or cognitively for long periods of time because of severe fatigue
- ▶ Problems with seeing, speaking, swallowing, or breathing
- ▶ Severe and persistent depression or other changes in mood
- ▶ Severe and persistent pain

As part of the application review process, the SSA considers input from the healthcare provider(s), the person with MS, and family members, friends, and colleagues who may be able to supply valuable information to help in the disability determination. The challenge for both people with MS and their healthcare providers lies in understanding the specific criteria established by law and in making sure that the information and evidence provided in the application directly address those criteria. Too many applications are denied simply because the applicant and healthcare providers have not provided the right information in the right way.

If you believe that you can no longer work due to physical or cognitive challenges related to MS, discuss the issues with your healthcare provider

and determine whether this is the time to apply for benefits. ***You and your healthcare provider(s) need to be able to prove, through accurate and complete documentation, that your MS-related symptoms have worsened significantly and are now severe enough to prevent you from being able to perform the physical and/or mental demands of your past job(s) or of other jobs in the US economy.***

The Guidebook provides a Glossary in Appendix A and forms in Appendices B-D to help with this documentation.

Your role is to gather information about (1) your work history, (2) your medical history, (3) the impact of your symptoms on your ability to function at work, and (4) supporting information from other healthcare professionals who have treated you over a period of time, as well as family members, friends, or colleagues. ***Your healthcare provider's role*** is to (1) be familiar with the Social Security disability criteria listed in the Guidebook and (2) document in your medical record (a) your disease progression, (b) any impairments that interfere with your work, and (c) the dates and results of all relevant tests and evaluations you have had.

The Guidebook also explains:

- ▶ the information needed for your application
- ▶ how to get assistance with your application from

SSA (800-772-1213 [TTY 800-325-0778] or visit www.ssa.gov/disability) and the Society (800-344-4867 or ContactUSNMSS.org)

- ▶ how to prepare for your SSA interview
- ▶ when/how to access a disability attorney to assist you with your application or if your application is denied

If your application is accepted, you will receive a letter telling you when you can expect to receive your benefits, as well as any back benefits that SSA owes you. You will also become eligible for Medicare if you applied for SSDI or for Medicaid (in most states) if you applied for SSI. Medicare coverage will not begin until two years after your SSDI benefits begin (29 months after you stop working). An SSA representative can tell you about other types of publicly-financed healthcare coverage if you lose your employer-based insurance before Medicare begins.

In summary, it is important to discuss any work performance difficulties that you are having with your MS healthcare provider. Accommodations may be possible to help you continue working. However, if you are unable to continue your employment due to MS, you and your healthcare provider must be prepared with relevant and accurate documentation to complete an application for Social Security benefits.

Successfully Managing Pain in MS

By Heidi Maloni, PhD, APRN, BC-ANP, CNRN, MSCN - Washington, DC VAMC

Pain is a common MS symptom that can occur at any time in the disease course. Studies show that 60% of people with MS have experienced pain associated with their MS at some time. Pain is important to understand because, if left untreated, it can affect relationships, mood, sleep, work, and the ability to have fun and generally enjoy life. Fortunately, there are many ways to successfully manage pain.

People with MS can experience many kinds of pain. MS tends to cause neuropathic (nerve) pain and/or

musculoskeletal (muscle/bone) pain. ***Neuropathic pain is directly caused by MS. A lesion in the brain or spinal cord can cause nerves to fire inappropriately.*** This can interfere with smooth nerve transmissions that carry sensations.

Neuropathic pain is often either steady and constant or intermittent and spontaneous. Steady pain is described as burning, tight, tingling, nagging, aching, throbbing, or even icy. Steady pain is more common than intermittent pain. Intermittent pain is described

as shooting, stabbing, or lightning bolt-like. Other unpleasant sensations, like the feeling of crawling bugs, water running down an arm or leg, or tingling, pins and needles sensations can also be caused by abnormal nerve firing and can become so bothersome these are described and treated as pain.

Musculoskeletal pain in MS may result from living with physical impairments. Muscles, bones, or joints can become painful when stressed due to decreased mobility, prolonged sitting, spasms, and improper use and disuse. For example, if you are using your back muscles to compensate for weak or lost leg muscles, you may overuse those muscles and experience back pain. Sitting or lying in one spot limits blood supply to tissues and increases pressure on bones near the surface. Being immobile may contribute to aches, infections, wounds, numbness, and spasms.

The most common pains in people with MS are burning pain in the legs or arms, back pain, painful spasms, trigeminal neuralgia (stabbing, intermittent facial pain), and Lhermitte's sign (shock-like sensation down the back and into the arms when dipping your chin to your chest). People with MS are also more prone to migraines than people without MS.

If you have a new onset of these sensations, report this to your healthcare provider. These symptoms may reflect a new MS lesion or an exacerbation.

Treating Pain

The kind of pain experienced guides the selection of treatment. Treating pain often requires a multipronged approach.

Medications are just one approach. Anti-seizure medications are frequently used for neuropathic pain.

They work by calming inappropriate nerve firing and help make nerve cells more stable. Anti-depressant medications are also used for neuropathic pain. They can stabilize chemicals in the nerve cells and increase the “feel good” neurotransmitters in your brain which



soften the perception of pain. Any of these medications may take a while to be effective and can cause side effects. A slow increase in dose over time (as much as a month) can often be

needed to get over the side effects so you have the chance to experience the benefit. Muscle relaxants can help control painful spasms. The use of opioids or narcotics remains controversial in MS pain management and are only considered when other agents are ineffective or not well tolerated. Narcotics may help you escape pain in the short-term but can take away choice and true control over pain and function in the long-term.

Physical agents work to limit pain transmission and include the application of heat, cold, or pressure. Physical therapy, exercise, massage, acupuncture, yoga, tai chi, and transcutaneous electrical nerve stimulation (use of electric current to stimulate nerves for therapeutic purposes) may also be helpful.

Pain ***psychology*** is becoming a common, well accepted, and important approach to pain management. This approach looks at mental and emotional factors, as well as attitudes, that may affect pain and a person's pain experience and behaviors. Feelings like anger, fear, boredom, depression, and anxiety, and situations such as loss of sleep, loneliness, and fatigue make a difference in the severity of the pain you feel. It's important to

Contact us to receive this biannual newsletter by e-mail.

If you would like to be removed from this mailing list or know someone who would like to receive this newsletter, call (800) 949-1004, x 53296 or send an e-mail to MSCentersofExcellence@va.gov.



VA
HEALTH
CARE

Defining
EXCELLENCE
in the 21st Century

VA Maryland HCS
10 N Greene St, NEU 127
Baltimore, MD 21201

VA Puget Sound HCS
1660 S Columbian Way, S-117-MSCoE
Seattle, WA 98108

VA Portland HCS
3710 SW US Veterans Hospital Rd, P3MSCoE
Portland, OR 97239

recognize that how you feel, how you cope, and how you interact with the world greatly influences the severity and intensity of pain. Relaxation, meditation, imagery, strong beliefs or faith, mindfulness, hypnosis, and distraction are strategies that can increase the tolerance to pain. Getting involved in work or social activities, joining a support group, or even having a good laugh are techniques that can minimize pain. Managing pain by learning to improve coping is more complicated and effortful than taking a pill but can be much more rewarding. Pain may not disappear but its intensity, frequency, and impact on your life can be reduced by managing emotions and influences in your life.

Your Action Plan

Managing your pain means developing an action plan. Make your plan important to you, be specific, be flexible, be positive, and write it down. Part

of your personal pain prescription begins with mastering emotions and reducing stress and environmental pain triggers. You may not be able to do this alone. Seek the help of the pain team at your VA facility or ask for a referral to the mental health team. A mental health professional will be able to fully assess your mood and can offer individual or group counseling. Assess your social situation and your general activity. Make an effort to get out of the house, call a friend to go to the movies or get a bite to eat. Is it time to join a gentle yoga class?

Pain is manageable and can be tackled with an integration of medications, physical agents, interventions to relieve mental and emotional factors, and strategies to enhance social support and help you become more active. Successful management will not happen overnight or with one pill. Set your mind on a positive course. You have the capacity to effect MS pain and your VA healthcare team is here to help.