

VA Multiple Sclerosis Centers of Excellence

MS VETERAN

Serving the Health Care Needs of Veterans with Multiple Sclerosis

Finding the Strength to Fight Back

By Kenneth Johnson - Los Angeles, CA

I am a US Army disabled Veteran who deployed during Operation Desert Shield/Storm. I was honorably discharged after my 6-year enlistment and later pursued a 17-year career in law enforcement. I was employed by a Sheriff's Department, Police Department, and later, a federal agency as a US Special Agent. I've traveled throughout the US, as well as various overseas locations, and had some of the best experiences of my life. I was satisfied with my accomplishments.

All was going well until I started having difficulty recalling memories, names, appointments, and dates. Sometimes my fatigue was so intense that it felt as if I hadn't slept in over 72 hours.

I experienced indescribable body pain and spasms wildly traveling throughout my body as I lay still in bed. I had blurred/double vision and was seeing things in my peripheral vision that were not there. I felt anxious when planning to attend gatherings because I was unsure how I'd feel that day. The list of symptoms seemed never-ending, and that's when I realized something is happening with my body.

In the summer of 2014, after months of medical testing, my VA neurologist Dr. Robert Baumhefner

delivered the news that I had MS, and there was no cure. Additionally, I was to begin my disease modifying drugs in 30 days. I left my appointment, drove home, and searched the web for information about the disease. I experienced the emotional effects of being diagnosed with a chronic illness - denial, anger, sadness. I rapidly began to lose weight along with muscle mass. It was time to make a decision, fight or fall victim to MS.



The first order of business was to share my diagnosis with family and friends. I quickly learned I could not fight this disease alone and shifted from being an independent Veteran to a Veteran who needs support. Next, I

needed to integrate myself into the MS community by attending self-help group meetings, attending seminars related to different medications, registering with the National MS Society, and connecting with others who have MS. I also needed to construct a healthy diet and exercise plan in an effort to counter/delay disease progression. Lastly, I needed to come

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to terms with my diagnosis in order to move beyond the diagnosis.

Since my diagnosis, I have accomplished these goals, and so much more. I connected with many others in various stages of MS; some mobile like me, some using devices to assist with walking, and others who are wheelchair-bound. These individuals continuously fuel my motivation to fight and to continue to do so. I opened up, sharing my diagnosis with any and everyone in an effort to help raise MS awareness. The more I share about my diagnosis, the more liberated I feel.

I volunteer with the National MS Society in support of the search for a cure through fundraising or donating my time. I eat healthy foods and exercise daily to keep my body and mind in peak condition. I try to consume raw fruits and vegetables daily along with plenty of fluids. My daily exercise routine consists of weight lifting and cardio, which helps with spasticity, muscle atrophy, and fatigue.

I've learned to become patient with myself and to take each day as it comes, make adjustments,

and move forward. One of my biggest struggles living with MS is people's lack of understanding. Then again, how can I expect others to understand when I'm still learning about MS? I've learned that patience and forgiving myself are crucial, and have been very effective as I've put them into practice.

Now, 2½ years since my diagnosis, I am stronger due to my exercise and diet. I feel mentally and physically sound, as much as a person with MS can be. I am more educated about MS and how to identify signs and symptoms of potential exacerbations, and able to fight through my fatigue. There are times when I do all of the above and I'm still symptomatic. This is when I listen to my body and rest.

My hopes are that someday a cure for MS will be found, and we are able to have a life free from the symptoms and disability of MS. In the meantime, MS should know we stand firm in our will to fight, and we are determined to win. *We all possess the ability to fight; it's up to the individual to decide when he or she will surrender.* MS is not the end for me nor should you allow MS to be the end for you.

Are Bladder Problems Tied to Falls in MS?

By Michelle Cameron, MD, PT, MCR - Portland, OR VAMC

Does your MS affect your bladder? Do you fall because of your MS? We know falls and bladder symptoms are common in people with MS. More than 50% of people with MS fall in a 3 to 6 month period, and about 75% or more have problems with their bladder. We now think that in some people these symptoms may be related.

Recently published research by Dr. Michelle Cameron, a neurologist at VA Portland Healthcare System, VA MS Center of Excellence-West, found that in people with MS, urinary urgency (a sudden, compelling urge to urinate) with incontinence (involuntary leakage of urine) was associated with a significantly increased risk of falling multiple times in a 3-month period. In fact, in this study, people

who had both urinary urgency and incontinence had almost a 60 times greater odds of recurrent falls compared to those people who did not have these bladder symptoms.

Interestingly, those people who only had urinary urgency or urinary frequency, but not incontinence, were not at increased risk for multiple falls. And, no bladder symptoms were associated with an increased risk of just falling once.

Participants in this study had to meet certain criteria, including a confirmed diagnosis of MS, mild-to-moderate disability due to MS, no relapse within 30 days of the study start date, and be 18-50 years old to minimize the cause of falls being something other

than MS. In addition, participants were excluded if they had balance or walking issues because of a condition other than MS, or if they could not walk at least 100 meters. In this study, a fall was defined as “any unexpected event that results in ending up on the ground, floor, or any lower surface.” Of the 51 study participants, 32 people fell at least once in 3 months, and 15 people fell at least twice in 3 months.



The findings of this study are important and useful because we really don't know all the reasons why people with MS fall, or how to best help prevent them from falling so much. Many treatments to prevent falls in people with MS have been tried. Most of these consist of a combination of safety education and balance exercises. Although these may be helpful, they certainly don't fix the whole problem. They increase knowledge and improve people's balance, but they don't prevent all falls. Many of the reasons people with MS fall, like weakness or numbness, probably can't be fixed completely or easily. Finding that something like urinary incontinence, which can often

be treated easily and effectively with medications, may help prevent falls is therefore particularly encouraging. This study suggests that improved bladder management may be able to reduce the risk of falls in people with MS.

It is not clear why people with MS who have urinary urgency with incontinence tend to fall more. Although it is possible that they just have worse MS, this is not likely. In Dr. Cameron's study, statistical tests showed that the relationship between bladder symptoms and falls was not affected by how severe the person's MS was. So, we think that bladder problems might cause falls in people with MS because, if you have urinary urgency and incontinence, you are likely to often rush to the bathroom, not paying as much attention to your safety when walking or transferring. It is also possible that people with bladder problems avoid drinking water and become dehydrated, which can then make them dizzy when walking.

How can knowing that bladder problems and falls may be connected help you? If your MS affects your bladder, and you have frequent falls or near falls, tell your provider about it. Treatment for your bladder might not only help resolve or improve your bladder problems, it might also help prevent you falling.

MS Medications: Decisions & Discussions

By Kathy Tortorice, PharmD, BCPS - National VA Pharmacy Benefits Manager

Receiving a diagnosis of MS can be overwhelming. Suddenly you are faced with a multitude of decisions you need to discuss with your healthcare provider and your support system. One of these discussions will be about the medications used to treat MS. Trying to understand and decide on what questions to ask takes some planning. There isn't a list of the “right” questions for everyone. You may have different questions or concerns than someone else does.

One important area to think about when discussing and choosing medications is risk vs. benefit. Asking

questions based on the potential risks and benefits of a medication allows you to consider the effects of a medication on your lifestyle, as well as on the disease course and symptoms. Every person is different, and every person's MS is different. Some people are willing to accept a high level of risk in taking a medication for a potential high level of benefit. Others prefer to keep the risk low. Also, some people's MS is very aggressive so risky treatments may be the only ones that will work. Other's may have a mild form of MS, so a high level of risk isn't necessary to control it.

Many types of medications are used to treat MS and its symptoms. This article focuses on the “disease-modifying” medications, which change the course of the disease by decreasing the number of relapses. By decreasing relapses, these medications also reduce how much damage MS does to your brain over the years. Each person’s body or disease can respond to these medications differently. Some people get certain side effects when other people don’t. One person’s MS may be controlled by one medication, however the same medication may not control someone else’s MS. So, the medication that is the best option for one person may not be the best option for another. Also, people change over time. A medication that works well for you now may not work as well in the future, and you may need to change to a different medication. Fortunately, there are many medications to choose from, and they are coming up with new ones all the time.

The first MS disease-modifying medication, Betaseron, became available in 1993. Betaseron is given by injection. Several other injectable MS disease-modifying medications have also been around since the 1990’s. Providers and many patients now have over 20 years of experience with these medications. The injectable MS medications have proven very safe and quite effective. More recently, oral (pills and capsules) and infusible (given intravenously) MS medications have become available. In general, the oral and infusible MS medications are more effective than the injectables but they also tend to be riskier.

You need to choose a medication you think you can take regularly. Taking your medication as prescribed is key to its effectiveness. If you can’t stand shots or hate needles then one of the oral agents may be the best choice for you. But if you want a medication that’s had more years of demonstrating safety, one of the injectables might be a better choice.

All of the MS disease-modifying medications affect your body’s immune system. Some of them, particularly the newer ones, can make you more likely to develop certain infections. Some of them can be extremely dangerous when taken in combination

MS Learning Opportunities

VA MSCoE DVDS

Each DVD provides 1.5 hours of educational information from MS healthcare professionals, as well as real life stories from Veterans.

- 1 Bowel & Bladder Management
- 2 Disease Modifying Therapies
- 3 Emotional Disorders
- 4 Cognitive Dysfunction
- 5 Modifiable Risk Factors
- 6 Mobility for People with MS

If you would like to receive the free DVD’s, call (800) 329-8387, x 66079 or send an email to MSCentersofExcellence@va.gov.

"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.msando.org for information about the webinars, including topics, speakers, and registration.

with other medications. Also, certain medications are not safe to use in people with other health issues such as heart conditions, breathing problems, or other chronic diseases. None of the MS medications are approved by the US Food and Drug Administration for women who are pregnant, plan to become pregnant, or who are breastfeeding, but some are safer than others. It is important for women to discuss their plans for pregnancy with their provider so that they can decide together the best and safest plan for managing their MS through their pregnancy and beyond.



Discuss your medication options with your provider. Make a list of questions that will help you make a

treatment choice you are comfortable with and can stick with. This will give you the best chance of treatment success. Some potential discussion points:

- ▶ Which medication(s) can be used to treat your MS or help manage your symptoms?
- ▶ How effective are these medications? What are their benefits?
- ▶ What types of side effects are common with these medications? What should you do if you develop side effects?
- ▶ Which type of medication would you prefer, a self-injected shot, pills, or traveling to a clinic once a month for an infusion? How do you feel about follow-up visits and labs for monitoring?
- ▶ If you have other medical problems, which medications will affect your ability to take your other medication(s) safely?
- ▶ If you are hoping to get pregnant, how should this affect your treatment choice?

Resilience: Addressing the Challenges of MS

By Coleen Friedman, MSW - Director NMSS Healthcare Provider Engagement

People with MS may find that the physical, emotional, cognitive, psychological, and spiritual challenges of living with the disease can be overwhelming. Some may feel that the challenges of living with a chronic disease are very hard to face day after day. But many people living with chronic diseases, including MS, have learned that practicing behaviors which promote resilience is the secret to not just coping with the disease, but thriving with it.

What is resilience?

Resilience is commonly described as the ability to bounce back from difficult circumstances - to find happiness and life satisfaction despite challenges. These challenges can be with relationships, finances, health, or any of the myriad stressors that we face in life. It's finding hope and meaning in life, even while confronting obstacles. It's finding the motivation to

take on new challenges and opportunities. It's thriving in the face of whatever life throws at you. Resilience is the ability to maintain or regain well-being and progress toward valued goals in the face of adversity.

Resilience is not about acting happy all the time, or ignoring the very real difficulties in life. Resilience is not even about trying to eliminate negative thoughts or feelings. In fact, it's quite the opposite: A significant part of being resilient involves what researchers call "positive adaptation" or "realistic optimism" - remaining hopeful about the future while making plans that enable us to cope with our actual reality. It requires moving forward despite facing difficult events and emotions. It requires courage and hope.

Results of several studies suggest that people who are resilient report significantly greater satisfaction

with their lives. A study in the *Journal of Health Psychology* evaluated 1,862 people with MS, muscular dystrophy, post-polio syndrome, or spinal cord injuries. The researchers used various tests to assess the participants' resilience, including levels of depression, pain, and fatigue, and overall quality of life. The study team found that people with higher resilience scores also had lower rates of depression and a higher quality of life, even if they had high levels of pain and fatigue.



Other studies suggest that when people engage in activities that boost resilience, for example, stress management, social activities, or exercise, they report greater life satisfaction. Some people may be more naturally resilient than others. Researchers have found that people have a natural “set point” for resilience that is determined partly by genetics and partly by their early environmental circumstances. Together, those factors make up about half of a person's capacity to adapt positively to significant challenges. The other half of resilience comes from learning and using cognitive, behavioral, and interpersonal skills. Even if it doesn't come entirely naturally, you can learn to be more resilient.

Dawn Ehde, PhD, a psychologist at the University of Washington, collaborated with the National MS Society and the MS Society of Canada on the most recent program in their series, *North American Education Programs*, to create a video and workbook about resilience. The workbook describes three steps to building resilience:

1. **Understanding** - Learn as much as you can about MS and how it can change over time. Talk to others living with this chronic disease.
2. **Managing** - Use your knowledge to learn new ways to cope and live your life with MS, with physical, social, and financial adjustments. You may feel more confident and in charge.

3. **Growth** - Begin to shift your priorities and determine what is most important in life.

There are also lifestyle practices which can help people develop resilience:

- ▶ Maintain strong social connections - family, friends, and others who have MS
- ▶ Maximize physical wellness - healthy eating habits, exercise, sleep, and MS therapies
- ▶ Set realistic goals and move towards them - attainable goals result in feelings of competence
- ▶ Practice gratitude - be mindful of positive things in life
- ▶ Nurture positive emotions and savor them when they occur - hope, optimism, and humor
- ▶ Allow negative feelings - recognize, express, and move on
- ▶ Use mindfulness and relaxation approaches - develop techniques to reduce worry
- ▶ Practice forgiveness towards people and situations - release resentment and bitterness
- ▶ Plan for the future - make realistic assessments and practical adjustments
- ▶ Find a sense of meaning and purpose in life - relationships, activities, or other avenues
- ▶ Help others - volunteer
- ▶ Turn to faith or spirituality - seek a larger sense of belonging and meaning in life
- ▶ Learn to tell a different version of your story - reframe it to see both sides
- ▶ Nurture your sense of humor

Rather than making a chore of your resilience-building activities, focus on the ones you really enjoy. Watching a movie with your friends or children builds resilience. So does having a hobby and taking time to enjoy it. Taking time to meditate or engage in mindful breathing can also boost your resilience. “It's within the vast majority of humans to become more resilient - to develop the hope that leads to feeling more happy or content,” says Dr. Ehde.

“People with MS, perhaps more than most, can benefit from building their resilience because of the ongoing, unpredictable changes they face in their health, abilities, and self-image,” notes Dr. Ehde. “People who are resilient have the ability to grow from adversity. They can learn things about themselves, about what they value. They learn that they can get through tough things.”

To find out more about resilience, visit the National MS Society website at www.nationalmssociety.org. In the search engine window, type “resilience” and a wealth of information will be at your fingertips.

(Content in this article was drawn from “Resilience - Addressing the Challenges of MS” created by the National MS Society and MS Society of Canada.)

Volunteer for the Million Veteran Program

By Mitchell Wallin, MD, MPH & W. Joel Culpepper, PhD - Baltimore, MD VAMC

The VA MS Centers of Excellence (MSCoE) want you to know about a great opportunity to contribute to MS research - Volunteer for the Million Veteran Program (MVP). With just a few simple steps you can help researchers collect data to learn more about what causes MS.

What is MVP and how can it help figure out the causes of MS? MVP is a voluntary, nation-wide research program from VA Office of Research & Development. The goal of MVP is to better understand how genes affect health and illness in order to improve health care for Veterans. To do this, MVP will establish one of the largest anonymous databases of genetic, military exposure, lifestyle, and health information. Findings from MVP may lead to new ways to prevent and treat illnesses in Veterans, and may help answer questions like, “Why does a treatment work well for some Veterans but not for others?” and “Why are some Veterans at a greater risk for developing an illness than others?”

Why should Veterans with MS participate in MVP? The short answer is, right now we don’t know what causes MS. There is evidence that environment and genes both play a role, but there are a lot of variables to consider. Most studies so far have not had enough participants to show the effects of both genes and

environment. We need data on a large number of people - people with MS, and people without MS to compare with each other. Collecting that much data for a study just on MS is expensive and difficult. Because MVP shares that cost with other research, this is a “can’t miss” opportunity.

MVP plans to collect data on 1 million Veterans. Over 500,000 volunteers have participated so far. We need enough Veterans with MS to participate so that we can learn more about MS and what might cause MS. That’s why we’re reaching out to you.



The VA recently requested grant proposals for studies using MVP data, listing MS as a priority. Staff from MSCoE-East have submitted a grant to use MVP data to study MS. If awarded, we will be able to use MVP data to improve our understanding of how genetic and environmental factors interact to cause MS, and possibly how they affect responses to treatment. We would also like to look at changes that occur around the time when a person’s MS symptoms

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first appear. The VA is in a great position to do this research because many Veterans are diagnosed with MS during or shortly after they leave the military. This makes it easier to get information about environmental exposures, lifestyle, and health in addition to genetic information from blood samples.

What will the MVP research about MS look like? Over 200 genes have been connected to MS. While most have small effects, the immune genes on chromosome 6 have been consistently found to pose the highest risk. Genes may also influence how people with MS respond to disease modifying medications or predict the long-term course of the disease. On the environment side, studies have shown that MS is more common in parts of the world farther from the equator. There also seems to be a connection to some viruses. Recent studies also found that smoking and obesity increase a person's risk for developing MS. More research needs to be

done to understand what other factors impact MS risk and how all these risk factors interact.

Veterans - and in fact all Americans - stand to benefit greatly from MVP. Learning more about the effects of genes on health will lead to new knowledge about which genes put people at risk for all sorts of diseases, and which genes affect how people respond to treatment. ***Participation in MVP is voluntary and will not in any way affect Veterans' access to health care or benefits.*** Information security and patient confidentiality are top priorities for MVP, and the program has extensive safeguards in place. Through MVP, Veterans today will help transform the health care of tomorrow, for themselves and for generations of Veterans to come. MVP is available at more than 50 VA Medical Centers around the country. To learn more about MVP and to make an appointment go to www.research.va.gov/mvp or call (866) 441-6075.