

VA MULTIPLE SCLEROSIS CENTERS OF EXCELLENCE MS VETERAN

SERVING THE HEALTH CARE NEEDS OF VETERANS WITH MS

NEVER GIVE UP!

NEVER GIVE UP! These are the words spoken to me by my mother, family, friends, and the staff at the Caribbean VAMC in San Juan, Puerto Rico, where I was diagnosed with MS in 2007. I am Alberto Manfredi and I was born in Manhattan, NY. I moved to Ponce, PR at the age of 28 and later went into the US Army. I was stationed in Ft. Hood, TX with many assignments that included a tour in Germany, where I served in the infantry from 1980 to 1988.

After leaving the Army, in 2000 I accepted a job in Florida, working at the Tampa VAMC. This is when I first began experiencing numbing in my hands and legs. In 2005, I had my first attack and was admitted to the hospital because I was seeing double, the left side of my body went completely numb, and I could not walk. The physicians thought I had a stroke and they began treating me for the stroke symptoms.

For years, the numbing symptoms continued until I needed to resign my position at the Tampa VAMC due to health reasons. After being seen by several physicians and specialists, a spinal tap and MRI were done and an MS diagnosis was confirmed. This diagnosis was a devastating blow.

I had already left my job and since I had no family in Tampa, FL, I returned home to Ponce, PR.

I received preliminary treatment from the Ponce Outpatient Center and was later referred to a neurologist at the Caribbean VAMC for further treatment by the MS and SCI Team. I was admitted for 46 days and, I must say, I got to know the staff pretty well and they got to know me too. The staff attended not only to my health care needs, but to my emotional, spiritual, and psychological needs. After the 46 days, I was released from the hospital and sent home with the necessary adaptive equipment to assist with daily living activities.



I would not be where I am today were it not for the encouragement and care of Ms. Millie Velez, the MS/SCI Nurse, and the Caribbean VAMC staff. They told me to NEVER GIVE UP! I was determined that while I have MS, MS does not have me. A short time later, I was introduced to the Multiple Sclerosis Foundation (MSF) as a way to get connected with community support

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VISIT OUR WEBSITE!

Please visit the VA MS Centers of Excellence website for additional information at www.va.gov/ms.



and network with others who have MS. I am truly grateful for the connections that I gained from the MSF because I met Lilliam, the woman who would become my lovely wife in 2009. Lilliam also has MS and she has been a blessing to my life.



I had been isolated, overweight, and alone. I prayed every day about my situation. I thought I was going to die. After some time, my state of mind changed and I was uplifted with the continued support of my wife, loved ones, and the VA MS/SCI caregivers, Psychiatrist, and Chaplain. They all encouraged me to NEVER GIVE UP and to have faith.

I thank God for bringing people into my life to help me on my MS journey. My wife and I

are a support for one another. I receive assistance from the Caribbean VAMC MS and SCI team, who trained me to use a motorized wheelchair and assistive devices so that I can stay mobile. I faithfully do my exercises as I am determined not to let MS keep me down. I am grateful to be happily married, have a great support system, and a love for life that is more powerful than this disease.

My future goals are to compete in the VA National Wheelchair games, travel with my wife, and continue staying involved with the MSF. My advice to Veterans with MS is to set goals, exercise, follow your health care provider's instructions, stay involved in social and family activities, keep the faith, and NEVER GIVE UP because God hears your prayers. I am grateful for the opportunity I had to serve my country and if asked, I would gladly serve again.

Alberto Manfredi - Ponce, PR

AN UPDATE ON CCSVI AND "LIBERATION THERAPY"

In 2009, an Italian radiologist, Dr. Paolo Zamboni, reported on his research assessing the veins that drain blood from the brain and spinal cord in a group of people with MS. His research suggested that 100% of people with MS had abnormal veins compared with 0% of healthy controls. These abnormalities were called "chronic cerebrospinal venous insufficiency" or CCSVI. Dr. Zamboni subsequently reported on the results of dilating the veins, a treatment later referred to as "Liberation Therapy." Dr. Zamboni's research stirred much excitement because it seemed to offer the hope of a cure for MS by dilating veins and inserting small, expandable tubes called stents to keep them open, as is done for coronary artery disease.

Since 2009 multiple research groups at

academic institutions in the US, Canada, and Europe have attempted to replicate Dr. Zamboni's findings. None of these research groups have been able to find abnormal veins in people with MS. Despite this, some radiologists in North America

PATIENT EDUCATION CONFERENCE CALL

Join the free monthly conference call and learn firsthand about MS from MS experts and other health care professionals.

DATE: 2ND MONDAY OF EVERY MONTH

TIME: 8 P.M. - 9 P.M. ET, 7 P.M. - 8 P.M. CT,
6 P.M. - 7 P.M. MT, 5 P.M. - 6 P.M. PT

TOPIC: DIFFERENT TOPIC EVERY MONTH

TO PARTICIPATE: CALL (800) 767-1750
ACCESS CODE 43157#

Do you have questions about the call or topic of the month? Contact Angela Young at (800) 463-6295, ext. 7133 or send an email to Angela.Young4@va.gov.

and Europe are offering vein dilation to people with MS without adequate research to support doing this. Sadly, there have been at least two people with MS who have died as a consequence of this treatment and several others have suffered significant complications from the procedure.

One can find testimonials to the therapy on the web from people with MS saying how much they have benefited from “Liberation Therapy.” Doesn’t this mean it must help? Unfortunately, these testimonials do not prove the treatment works. There is a long history of people with MS claiming dramatic improvement in their symptoms with a large number of treatments, such as bee stings, Procarin gel, hyperbaric oxygen, and replacement of amalgam dental fillings with gold. Over time, none of these therapies have proven to be beneficial. There is a big placebo effect from these therapies and the more dramatic

the treatment the bigger the placebo effect. Undergoing vein dilation is certainly a dramatic treatment that we would expect to have a strong placebo effect.

The inability of multiple research groups to replicate Dr. Zamboni’s findings raises serious questions about whether there are blood vessel abnormalities in people with MS. Because of these questions, there is no basis at this time for people with MS to expect balloon dilation and stent placement to provide them with any lasting benefit. In addition, this unproven treatment carries serious risks that should be avoided. Veterans with MS should seek the care and advice of a VA MS health care provider to discuss the many well-studied and Food and Drug Administration (FDA) approved therapies for MS that are available through the VA.

Dennis Bourdette, MD - Portland VAMC

SOCIAL MEDIA: CONNECTING VIRTUALLY

Social media, or social networking, is the 21st Century approach to connecting with others via the Internet. We have come a long way from sending messages by wire with dots and dashes over the telegraph, to currently sending wireless messages with binary codes of zeros and ones. However, the purpose is still the same - social connection.

Since social media will continue to grow as a means of sharing information, it is important to be informed about this type of social connection.

WHAT’S CURRENTLY AVAILABLE?

There are numerous opportunities for Veterans to be socially connected on the Internet. All one has to do is use any search engine and type in “social connection websites” and a multitude of links become available. Social networking sites include personal sites like Facebook and

Friendster, professional sites like LinkedIn and Academia.edu, and many special interest sites for health concerns, new moms, dating, and connecting with old high school friends.

The VA also provides opportunities to socially connect. The Secretary of Veterans Affairs Eric Shinseki stated, “Veterans should have consistent and convenient access to reliable VA information [in] real time using social media - whether on a smartphone or a computer.” A VA News Release announced that the VA has over 100 Facebook pages, more than 50 Twitter feeds, 2 blogs, a YouTube channel, and a Flickr page. And, the nation is clicking on these links (over 1.1 million times) to watch videos, read stories, and make their comments. Recently, the VA created a new Social Media Policy establishing a VA philosophy



FAMILY AND CAREGIVER CONFERENCE CALL

Join the free monthly conference call to connect with people supporting those with MS. A variety of educational topics and resources will also be presented!

DATE: 4TH MONDAY OF EVERY MONTH

TIME: 8 P.M. - 9 P.M. ET, 7 P.M. - 8 P.M. CT,
6 P.M. - 7 P.M. MT, 5 P.M. - 6 P.M. PT

TO PARTICIPATE: CALL (800) 767-1750
ACCESS CODE 43157#

The VA has a National VA Caregiver Support Hotline for family members dealing with chronic illness. The Hotline toll-free number is (855) 260-3274. It is open

MONDAY - FRIDAY: 8 A.M. - 11 P.M. ET

SATURDAY: 10:30 A.M. - 6 P.M. ET

about communication. Brandon Friedman, Director of Online Communication, states, “This policy sets us on a path toward changing how we talk - and listen - to Vets.”

HOW DO WE USE SOCIAL NETWORKING?

Most people think of social media as a way to stay in touch with family and friends. Yet, research shows that people are also making connections with complete strangers on common interest sites. People share their search for jobs, ask others about health information, and can give a thumbs up or down for messages they receive. Other studies show that people use this type of communication to get first-hand knowledge about specific national events whether they are political races or natural disasters.

WHAT IS A MODERATED PAGE?

The VA follows the protocol of moderating their social networking pages. This means that all comments are reviewed for appropriate content. Any content that does not relate to the VA, or any abusive or vulgar language, hate speech, or personal attacks are not allowed on the site. This

is not the case with all social media sites. It is up to individuals to review each site’s disclaimers and publishing protocols and make an informed decision on whether to participate on each site.

WHY USE SOCIAL NETWORKING?

There are several advantages to using social media, but first on the list is increasing the opportunity to connect with other people. Additional reasons might include:

- ▶ It’s convenient, instant, and anonymous,
- ▶ Offers less threatening approaches to floating ideas and getting instant feedback,
- ▶ Provides rural-based connections,
- ▶ Allows sharing of health resources or beneficial web links, and
- ▶ Creates a forum to offer and receive help with less judgment from others when comments or ideas are shared.

WHAT CAUTIONS SHOULD BE CONSIDERED?

The most important message around this type of communication is to understand that these sites do not provide medical advice and should not be used for this purpose. Most sites include this message in their disclaimer; however, it is easy to forget when you are searching for an answer to a specific health need not to take what you see on the Internet as medical advice for you. In general, most sites including the VA, recognize that this is a public forum, and by the nature of privacy policies, responses from commentators are more general.

Other cautions you should consider when engaging in social networking include:

- ▶ Decide what you consider to be “private” before you post personal information,
- ▶ Set up privacy settings on each site to increase personal control over connections,
- ▶ Be aware that you can increase your circle of “friends” but not all of these “friends” will have friendly intentions, and

- ▶ Remember that whatever you post - you can't take back - and posts are available to the general public. While the VA will not collect or retain these comments, some sites do.

The future holds more access to social networking as newer technology is developed

HIGHLIGHTING RESEARCH: SMOKING CESSATION

Cigarette smoking has long been known to cause a multitude of health problems, both in smokers as well as in non-smokers who are exposed to second hand smoke. In the general US population, the number of new people starting to smoke has decreased over the past 40 to 50 years; however, the global number of people who smoke has increased.

Specifically among Veterans, the number of people smoking has increased to some of the highest levels seen in over four decades. This increase is believed to reflect a high number of younger Veterans who are returning from the recent wars in Iraq and Afghanistan and from other current Middle East conflicts. Some of these Veterans begin smoking while on active duty while others start smoking upon their return from duty. For individuals who develop post-traumatic stress disorder (PTSD), approximately half are cigarette smokers.

In recent years an increasing amount of evidence has accumulated which suggests that exposure to cigarette smoke can increase the risk of developing MS. Convincing studies performed by researchers have shown that not only are adults who are exposed to cigarette smoke more likely to develop MS, but so are the children of cigarette smokers, implicating second hand smoke as a risk factor in children. Also, people with MS who are exposed to cigarette smoke are more likely to experience worsening of their MS symptoms and to have more progressive disease. This can

and used to interact with others. New devices to communicate will continue to be part of our everyday lives. It is up to each individual to decide how they will engage in this innovative approach to connecting with others.

Marsha Tarver, PhD - Seattle VAMC

result not only in the development of more severe disability, but such individuals are also more likely to respond poorly to MS treatments.

The underlying cause for why exposure to cigarette smoke can have such effects is currently a focus of research by investigators at the MS Center of Excellence East. They have found that cigarette smoke itself can induce the development of inflammation in the brains of rodents that are exposed to cigarette smoke. How such inflammation might either trigger new autoimmune responses against the nervous system or worsen immune activity that might already be present is currently under investigation.

It is important to pursue such studies, as information that can be obtained from them could result in the identification of treatments that can specifically prevent these effects. However, the obvious way to eliminate smoking as a potential factor in MS is to quit smoking. It has been shown that nearly three quarters of Veterans wish to stop smoking, and smoking cessation has been a top priority of the VA.

Screening for the use of tobacco is provided at the time of primary care clinic visits. Smoking cessation programs are available to Veterans and consist of counseling and either nicotine replacement therapy and/or other medications to help reduce smoking. The use of nicotine gum, patch or lozenge as well as the drug



bupropion (brand name Wellbutrin® or Zyban®) can reduce the craving for nicotine. The drug varenicline (brand name Chantix®) was approved to specifically reduce the pleasurable effects that result from smoking.

In studies performed in people with PTSD, varenicline was found to be effective and, after initial concerns that treatment was associated with an increased incidence of suicidal thoughts, it was concluded that treatment with the drug is safe. These and other programs have been shown to help Veterans stop smoking. There is currently

other research being conducted by the VA, and Veterans who smoke are encouraged to consider participating in such programs.

It is difficult to quit smoking but programs and resources are available to help. If you would like information on how to quit smoking, please visit www.myhealth.va.gov or www.cdc.gov/tobacco. If you are interested in being part of a research team and would like to learn about research studies in your area, including those on smoking cessation, please visit www.clinicaltrials.gov.

Walter Royal III, MD - Baltimore VAMC

BLADDER CHANGES IN MS

Changes in bladder function are common after developing MS and they often occur early in the disease process. Between 50 to 90% of people with MS will develop bladder problems at some point. The big question is - why does this occur?

The symptoms of bladder problems are wide ranging, and can include:

- ▶ Urgency - barely getting to the bathroom in a timely manner,
- ▶ Frequency - feeling the need to urinate more than every 2 to 3 hours,
- ▶ Hesitancy - being unable to easily start a flow of urine,
- ▶ Incontinence - a loss of control of urine,
- ▶ Nocturia - being awakened from a restful state by a need to urinate, and
- ▶ Double voiding - needing to urinate again a few minutes after voiding.

Other symptoms can be: feeling like the bladder isn't empty after urinating, involuntary leaking of urine, difficult or painful discharge of urine, and urinary tract infections (UTI's).

Bladder symptoms are broken down into three basic types of problems: emptying problems (hypoactive bladder), storage problems

(hyperactive bladder), and a mixture of these two types of problems (Combined Dysfunction). Each of these types of problems has a different treatment approach.

HYPOACTIVE BLADDER

Approximately 20% of people with MS have a hypoactive bladder. A hypoactive bladder overfills and stretches the bladder wall, causing the sensors that trigger bladder contractions to stop working. Additionally, often the sphincter that allows urine to leave the bladder doesn't release and the urge to urinate doesn't occur until after a large volume of urine has collected (and sometimes not at all!). The danger with this type of bladder is that when it becomes overfilled, urine can back up into the kidneys, causing kidney damage or infection.

GET YOUR INFLUENZA VACCINATION!

The VA provides a free influenza vaccine to enrolled Veterans. There are two forms of the vaccine; 1) a flu shot and 2) a flu nasal spray. Research has shown that the flu shot is safe when given to people with MS and does not worsen or trigger MS symptoms. The flu nasal spray has not been studied for its safety with MS and may carry more risks. It is recommended that people with MS receive a flu shot rather than the nasal spray.

The methods used to treat this condition are abdominal tapping (tapping on your lower abdomen to trigger a urination reflex), double voiding, adequate fluid intake, good bowel management, catheterization (intermittent catheterization or indwelling Foley/suprapubic urinary catheter) and, for males, good prostate care. Medications, such as bethanechol, to stimulate bladder contractions or reducing prostate swelling with prostate or anti-hypertension medications have been successfully used.

HYPERACTIVE BLADDER

The majority of people with MS (60%) have the opposite type of bladder - a hyperactive bladder. A hyperactive bladder doesn't hold the normal amount of urine before the urge to urinate occurs. Instead of triggering urination when it fills to 350-400 ml (normal), the urge occurs at 150-200 ml (or less), making it important to always know where every bathroom is located.

Treatments for this type of problem include decreasing irritants that trigger bladder spasms (caffeine, artificial sweeteners, alcohol, tobacco, spicy foods), reducing excessive weight, practicing good bowel care (to reduce the amount of abdominal pressure on the bladder), pelvic muscle exercises (especially with women), and learning to manage when and where urination occurs.

Managing urine output can involve a number of strategies: wearing easily and quickly opened/removed lower garments, the use of external urinary drainage devices or protective pads/garments, and determining what the best time and amount of fluid intake should be. Changing the volume or time fluids are consumed will help make sure the need to urinate doesn't occur at inopportune times.

The last common treatment strategy is the use of medications. Common medications used include antispasmodics (such as baclofen), bladder relaxing medications (such as oxybutynin and

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- ▶ **MS THERAPIES: STRATEGIES FOR OPTIMIZING DISEASE MANAGEMENT**
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Interested in receiving a set of free DVDs? Contact Jaimie Henry at (800) 949-1004, ext. 53296 or Jaimie.Henry@va.gov.

tolterodine), or botulinum toxin (botox) injections into the bladder sphincter.

COMBINED DYSFUNCTION

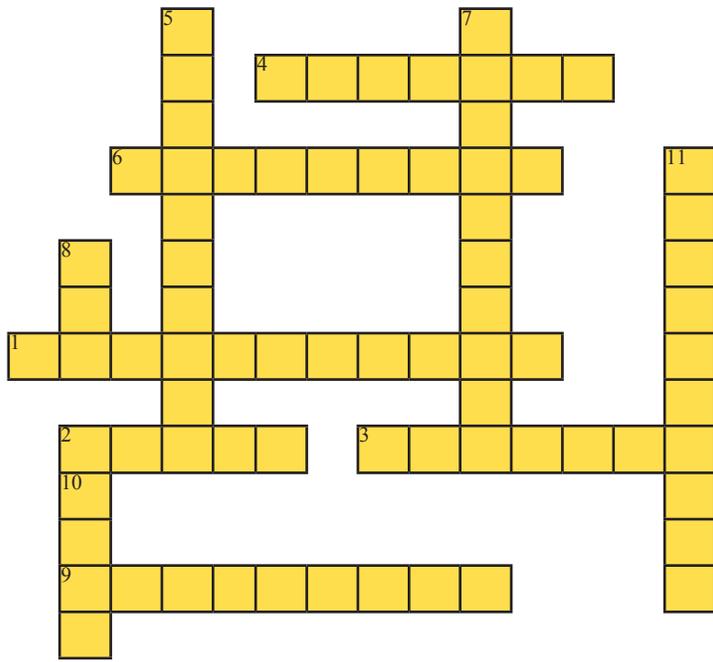
The third type of problem is a mixture of these first two problems and may be more difficult to treat. With this type of bladder dysfunction, the bladder wall spasms, but the sphincter releasing urine won't relax and open. Finding the correct balance of the above treatments that work best can be a trial-and-error process. Most people are able to find a combination of treatment strategies that work well for them by working with their health care provider.

Hopefully, this description of bladder function has helped you understand the bladder better. If you feel that you are experiencing bladder difficulties, please talk to your VA health care provider.

James Hunziker, MSN, ARNP - Seattle VAMC

CROSSWORD ANSWERS: 1. Social Media, 2. Stent, 3. Monthly, 4. Smoking, 5. Hypoactive, 6. Moderated, 7. Liberation, 8. Two, 9. Cessation, 10. Spicy, 11. Oxybutynin

CROSSWORD PUZZLE



1. A way to stay in touch on the Internet
2. Expandable tubes used to keep veins open
3. Frequency of Patient Education Calls
4. Voluntary act that causes a multitude of health problems
5. A condition where the bladder overfills and stretches the bladder wall, causing the bladder to stop working
6. A type of page on the Internet that is reviewed for appropriate content
7. An unproven therapy that is based on the results of dilating the veins
8. Number of VA blogs on the Internet
9. Word that means to stop doing something
10. Type of food that triggers a hyperactive bladder
11. Name of common bladder relaxing medication

To be removed from or added to this mailing list, email Jaimie.Henry@va.gov or call (800) 949-1004, ext. 53296.



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