

VA MULTIPLE SCLEROSIS CENTERS OF EXCELLENCE

MS VETERAN

SERVING THE HEALTH CARE NEEDS OF VETERANS WITH MS

SEEING THE SILVER LINING

I was in the Coast Guard during much of the eighties and early nineties. Physical fitness, balance, and agility were important. In my late twenties, I began to experience coordination and sensory problems, which, at the time, I thought must be age related as I neared the big three-zero. I received a real shock in early 1994 when my doctor ordered neurological tests following a series of ankle sprains. After anxiously waiting a couple weeks, I was diagnosed with MS. It was somewhat of a relief to know. Subsequently, I experienced some of the five stages of grief - denial, anger and bargaining, depression, and acceptance. The Coast Guard began proceedings to medically retire me. I was newly married. My first child was born two months after my diagnosis and my job was demanding. I was medically retired in 1996 and returned home.

My MS has worsened steadily, most active in the spinal cord. I have tried interferon beta-1b, mitoxantrone, glatiramer acetate, mycophenolate, low dose naltrexone, as well as many vitamins and alternatives. Probably the most beneficial medical help has been a Medtronic Baclofen Pump, which greatly reduces spasticity. Most



important though, is the closeness to family and friends, which has developed because I have needed much more help from others than I ever thought I would at this point in life. Depending on others reveals so much human goodness that might otherwise never be seen. My parents and brother, my daughter Madeline, my sweetheart Lauren, as well as many friends and helpers show me this lesson every day.

I gave up driving in 2001 and started using a wheelchair full-time in 2004. Both were tough on the pride but good risk management decisions. I have seen many elderly people stubbornly insist on driving past when it became unsafe. I quit when I was forty and initially it was depressing. Ultimately, I was proud of myself for making a responsible decision. My first wheelchair outing occurred when my daughter and I went to a museum. She was about six years old and a lot of help. I used

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



forearm crutches to get from the parking lot to the admission desk. She spied wheelchairs and insisted I use one. With her as a little motor, we had a lot of fun although I can't say the people we bumped into did. After that, I quit fighting the notion of using a wheelchair.

My activities have adapted as the MS has progressed. Early on, I was physically active and involved in a lot of community activities. I served on local committees and boards and even was Mayor of my hometown. Besides MS, the weather in Alaska encourages me to stay indoors. I do a lot on my computer. I find it liberating to pursue my own projects and truly think independently.

Here are some observations: Several people I know who were healthy when I was diagnosed have died from various causes since then. We absolutely do not know what is next in life so we

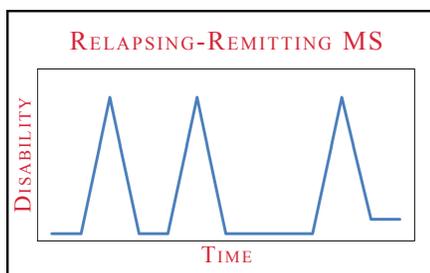
need to make the most of our abilities and time. There is no secret or miraculous cure just around the corner. Early on, I thought there had to be. I studied everything I could get my hands on and volunteered for and followed clinical trials. Most of these are lengthy and inconclusive. Information from the media or promoters of products tends to be overly optimistic at best.

My prescription for MS is to spend a lot of time with kids and animals and get plenty of sleep, fresh air, and sun. Avoid stress and stressful people. Actively manage your medications by eliminating those that don't help. Look out for the people you love by not expecting too much of them or letting them expect too much of themselves. You can always find a helper but family and friends come in a limited supply.

Ivan Nance - Juneau, AK

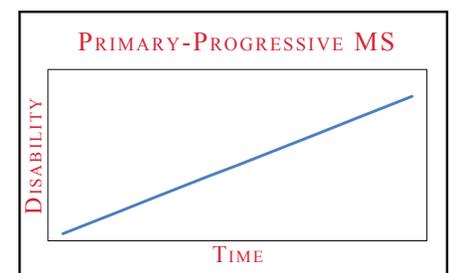
THE CLINICAL SUBTYPES OF MS

Julie has had MS for three years. Her first symptom was blurred vision in her right eye. After a month, her vision returned to normal and she was normal for nearly a year until she developed weakness in her right leg. She received treatment and after a few weeks, the strength in her leg returned to normal. She then remained normal until six months ago when she developed numbness in her legs that lasted for several months. She is now nearly normal. A graph of Julie's disease course over the past three years is shown above.



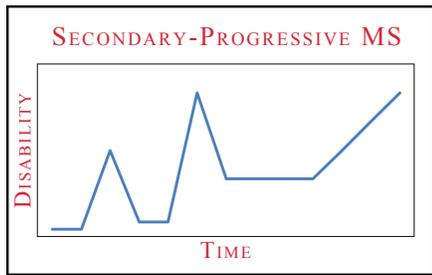
John has also had MS for three years but his experience has been very different. His vision has never been affected and he can't pinpoint

the onset of his illness. He had weakness and stiffness in his legs and difficulty walking that came on gradually over many months. In addition, his symptoms have progressively gotten worse without improvement at any time. A graph of John's disease course is shown above.

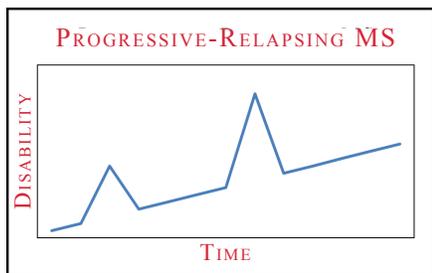


Julie and John both have MS, but their experiences, what doctors call their disease course, have been very different. Julie has had periods of worsening symptoms, which are called relapses or exacerbations, followed by periods of improving symptoms, which are called remissions. Julie has the subtype of MS called relapsing-remitting disease. John has had progression of his symptoms with no periods of remission. John has the subtype of MS called primary-progressive disease.

Disease course studies of large numbers of people with MS have shown four different basic patterns of disease. All of the forms of MS other than relapsing-remitting MS and primary-progressive MS are combinations of relapsing and remitting symptoms and progressive symptoms. People



who start with relapsing disease and then develop progressive symptoms are said to have secondary-progressive disease. People who start with progressive disease and later have relapses are said to have progressive-relapsing disease.



The different forms of MS are not all equally common. The most common form of MS is the type of MS that Julie has, relapsing-remitting. About 85% of people start out with relapsing-remitting MS. About 50% of these people will later develop secondary-progressive MS, during which they may still have an occasional relapse or may stop having relapses altogether. Primary-progressive MS affects about 10% of people with MS and 5% have progressive-relapsing MS.

Relapses and progression are thought to reflect the two disease processes that occur in MS: inflammation and neurodegeneration. Inflammation is a normal part of our body's defenses involved in protecting us from bacteria and other organisms that invade our bodies. In MS, inflammation appears to be misdirected, causing damage to normal tissues. Neurodegeneration is an abnormal process in which nerve cells and nerve fibers in the brain and spinal cord degenerate and die. Relapses appear to reflect episodes of brain and spinal

cord inflammation. Progression appears to reflect the degeneration and death of neurons and axons. Why some people have relapses at onset while others have progression at onset is not known.

MS subtype is important because responses to the medications used to treat MS are different in different MS subtypes. The standard disease modifying therapies, beta-interferon and glatiramer acetate, and the newer agent natalizumab, have all been shown to reduce the frequency and severity of relapses. They are useful treatments in people with relapsing forms of MS: relapsing-remitting MS, secondary-progressive MS with relapses and progressive-relapsing MS. The same medications have not been shown to slow progression. Therefore, the standard disease modifying therapies are generally not used in people with progressive MS: primary-progressive or secondary-progressive disease without relapses.

Mitchell Wallin, MD, MPH - Washington DC VAMC
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LEARN MORE ABOUT MS!

MSCoE produced and recorded DVD's from our live educational programs. They are a great way to learn more about MS issues that affect you or the ones you care for.

- ▶ **ADVANCES IN TREATING MS: AN UPDATE ON DMT'S**
- ▶ **FATIGUE & COGNITIVE EFFECTS OF MS**
- ▶ **MOBILITY FOR PEOPLE WITH MS**
- ▶ **MRI GUIDELINES FOR DIAGNOSING & MANAGING MS**
- ▶ **PAIN & PALLIATIVE CARE IN MS**
- ▶ **SEXUAL INTIMACY & MS**
- ▶ **WHEELED MOBILITY & MS**

Interested in receiving some free DVD's? Contact Jaimie Henry at (800) 949-1004, ext. 53296 or e-mail your full name and mailing address to Jaimie.Henry@va.gov.

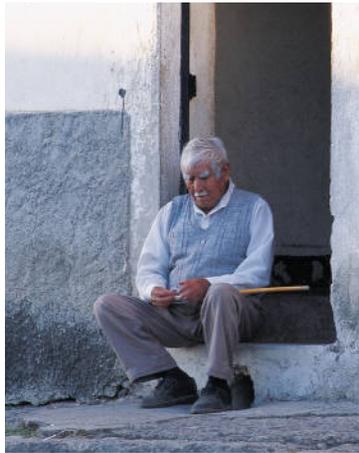
QUESTIONS AND ANSWERS ABOUT DEPRESSION

Depression is a common medical disorder in the general population, but even more so among people with MS. *Approximately 50% of people with MS will experience an episode of Major Depression; a clinical diagnosis made after at least two weeks with five or more depressive symptoms.* This is higher than the rate in the general population and higher than what is seen in other chronic diseases. While Major Depression is a serious condition, it is important to remember that it is very treatable.

WHY IS MAJOR DEPRESSION SO COMMONLY SEEN IN THOSE WHO HAVE MS?

While it is not clear why so many people with MS experience depression, it is clear that people with depression do respond to medical treatment.

Major Depression is a separate disorder from MS and is the result of a chemical imbalance in the brain. It is important to understand that this disorder is not sadness or grief and it should not be “expected” because a person has a chronic disease. In



fact, studies show that there is no correlation between the degree of a person’s disability and the diagnosis of Major Depression.

WHY SHOULD SOMEONE BE CONCERNED IF THEY ARE DEPRESSED?

Depression is a serious condition, and if left untreated, can lead to a Major Depressive episode. Depression is a medical disorder that can be mild, severe, or even life threatening. Not only can it affect a person’s quality of life, it can interfere with relationships, jobs, and a person’s overall health. People with depression are at higher risk

for suicide, and the suicide rate is even higher for those with both MS and Major Depression. Depression is not something to ignore, you can’t “just get over it.” It is a disorder that requires close monitoring and treatment.

HOW CAN YOU TELL IF YOU HAVE MAJOR DEPRESSION?

The two main symptoms that may indicate Major Depression are persistent sadness and loss of interest in usually enjoyable activities. Also, a person may sleep too much or too little, eat too much or too little, feel excessively guilty, have decreased concentration, or decreased energy. Some might be irritable, angry, have feelings of hopelessness, or have thoughts of hurting themselves or others. Often, signs and symptoms of depression can mimic MS symptoms, like fatigue or difficulty with concentration. Everyone feels down or overwhelmed every once in a while; however, when a person feels this way for more than two weeks or is starting to have difficulty enjoying life, it is time for a more complete evaluation by a health care provider.

WHAT SHOULD YOU DO IF YOU THINK YOU ARE DEPRESSED?

A person who suspects depression should talk to a health care provider. These providers might include a person’s primary care team, neurologist, or rehabilitation doctor. They can help with diagnosing and treating depression or they may make a referral to a behavioral health specialist like a psychiatrist or psychologist for further assessment and treatment. If a person is having thoughts of suicide, immediate attention is required. A person can call 911 for help. Another resource available 24 hours a day 7 days a week is The National Suicide Prevention Hotline at (800) 273-TALK (8255).

HOW IS MAJOR DEPRESSION TREATED?

Treatment options for Major Depression include a combination of antidepressant

medication, counseling, life-style modifications, and support networks, as well as complementary and alternative medicine. Effective treatment plans often use a combination of these therapies. For some people, treating their depression reduces some of their MS symptoms like fatigue, decreased cognition, and memory difficulties.

Major Depression often requires the use of antidepressant medication for treatment. There are many antidepressants available and some have the added benefit of treating pain, insomnia, or fatigue. Although each person responds to medications uniquely, overall, antidepressants are well tolerated with occasional mild side effects such as weight gain, constipation, dizziness, and

decreased sexual libido. Other substances can interfere with the effectiveness of antidepressants, and a health care provider should be informed about all medications including vitamin and herbal supplements, as well as alcohol and drug use before starting an antidepressant. Antidepressants can take as long as six weeks to see results, so a person should not become discouraged if results are not seen immediately.

In addition to medication, health care providers often recommend counseling and life-style modifications to help manage depression. It is important to know about and understand depression in order to receive effective treatment.

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GET WHAT YOU WANT FROM THE INTERNET!

The Internet, a magical world at your finger tips... or not. Numb fingers, poor vision, a little tremor, cognitive problems, to name a few, can all interfere with your joy of the World Wide Web. Living with MS can be a challenge when using the Internet. This article is aimed at giving you tips on how to easily, quickly, and reliably get the information you want from the World Wide Web.

To begin, let's clear the air on some Internet language. Your PC or personal computer will have access to the Internet through a web browser. Some examples of web browsers are Firefox, Internet Explorer, Opera, Safari, and Chrome. The World Wide Web (www or Web) is a specific place on the Internet, for computer files. A URL or Uniformed Resource Locator is a web address and is reached through a Hyper Text Transfer Protocol (http). So, your search will have an address that looks like this:
<http://www.msinformation.com>.

A search engine is a program or application that helps you locate a website when you type in a few key words. Search engines, such as Google,

Yahoo, AltaVista, and Search.com work through key words that are located in documents and websites on the Web. Key words are words or phrases related to information you are trying to locate. Specifying key words will narrow your search. If you want your search to match your key words exactly, put quotes around them ("CAM MS"). A plus sign placed between key words can direct your information search (MS +CAM). The space placed just before the + indicates you want to emphasize CAM information.

Now that you know something about the basics of getting information, you will want to customize your PC to adapt to your specific needs, to minimize the frustration and maximize the fun of crawling around the Web. Computer software and hardware is available that can magnify your PC screen well beyond your PC settings.

Text-to-speech software converts talk into type. Programs are available that interpret the



meaning of information. This can be helpful when cognitive problems are an issue. Equipment such as alternative keyboard and mouse, voice recognition systems, touch screens, and motion sensing equipment can enhance your computing ability. Adaptive and assistive technology can be found at www.disability.gov.

The Internet is an endless source of information, with emphasis on endless. Separating the jewels from the junk is the challenge. Wrong information can send you down a path that could be harmful to your health. Acting on information based on quackery can keep you from effective treatment. But how can you trust what you read on-line? Remember, anyone can create a website and call themselves “doctor” on-line. Internet sites are primarily sponsored by commercial (.com), organizational (.org), educational (.edu), government (.gov), and military (.mil) institutions.

The MS Centers of Excellence have a website that offers dependable information on MS as well as information specific to the needs of Veterans with MS at www.va.gov/ms. Health websites sponsored by the Federal government are reliable sources of health information. You can reach all Federal websites by clicking on “Health and Nutrition” at www.usa.gov. MS organizations offer reliable information on MS research, treatments, and services, as well as offer support chat rooms.

Commercial sites (.com) should be approached with caution. Often their main intention is to sell you something. Make certain that any commercial site contains reliable information. Here are some simple questions to ask which will help you recognize sites you can trust.

SITE PROVIDER AND FUNDING

Who is in charge of the site? Who is the sponsor? The site sponsors establish the site as respected and dependable. Is the site trying to sell you something? What do they want from you?

CONTENT AND QUALITY

Are there experts who review the site content? Does the site make claims that seem too good to be true? Is the content current? Health information that is over five years old is outdated.

PRIVACY

Is your privacy protected? Will the site share your personal information with others? Are you comfortable giving out your personal information? Read site privacy policies to learn how personal information is collected and used.

The Internet is a rich and valuable source of information. Reliable Internet health information is convenient, cost-effective, offers in-depth understanding, and allows for autonomy and anonymity. However, information found on-line is not a substitute for medical advice. Discuss on-line advice with your health care provider. Your best MS health rests in a trusted patient-provider partnership, so share what you find with your doc and have fun surfing!

Heidi Maloni, PhD, NP - Washington DC VAMC

PATIENT EDUCATION CONFERENCE CALL

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

DATE: 2ND MONDAY OF EVERY MONTH

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

TOPIC: DIFFERENT TOPIC EVERY MONTH

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

Participation is free. Questions can be asked as time permits. Callers are anonymous. Do you have questions about the call or topic of the month? Contact Angela Young at (800) 463-6295, ext. 7133 or send an e-mail to Angela.Young4@va.gov.

CCSVI AND THE “LIBERATION TREATMENT”

Could MS be caused by narrowing of veins that drain blood from the brain and spinal cord? This novel but unproven idea has gained much attention over the past two years via news reports and multiple website postings. The blood vessel abnormalities are reported to lead to a condition called chronic cerebrospinal venous insufficiency or CCSVI. It has also been suggested that MS could be treated by correcting the blood vessel narrowing by dilating the veins and inserting small, expandable tubes called stents to keep them open. This proposed treatment has been referred to as the “liberation treatment.”

IS CCSVI A REAL BREAKTHROUGH AND SHOULD PEOPLE WITH MS BE UNDERGOING THE “LIBERATION TREATMENT”?

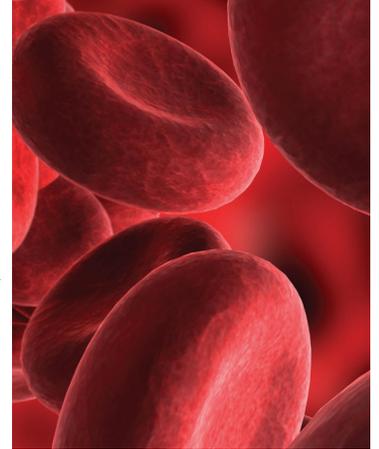
The excitement about CCSVI has largely arisen by reports coming from Dr. Paulo Zamboni and colleagues at the University of Ferrara in Italy. Using sound waves (doppler ultrasound) to assess blood flow through veins, Dr. Zamboni studied 65 people with MS and compared them with 235 people who did not have MS. They found that 100% of the people with MS had blood vessel flow abnormalities while none of the people without MS had this pattern of abnormalities.

Dr. Zamboni dilated the blood vessels of the 65 people with MS using angioplasty, a procedure that opens blocked or narrowed blood vessels. Some of the people seemed to improve while others did not. Subsequently, Dr. Robert Zivadinov and colleagues at the University of Buffalo have claimed in news releases to have replicated Dr. Zamboni’s findings, although they report only 50% of people with MS have abnormalities compared with 25% of people without MS. Other physicians have begun

treating people with MS with dilatation of blood vessels.

While there is understandable excitement about CCSVI, much more research needs to be done. First, Dr. Zamboni’s observations need to be repeated by other researchers. If

CCSVI is associated with MS, then other researchers should be able to find the same abnormalities. Second, if there are blood vessel abnormalities associated with MS, this does not prove that they cause MS. It could be the



other way around. The inflammation seen in the brain and spinal cord of people with MS could be causing the blood vessel abnormalities. If so, treating the blood vessels may have no effect on MS. Third, the “liberation treatment” carries significant risks; there has already been one person with MS who underwent blood vessel dilatation who died as a complication of the procedure. No one should be treating people with MS with this procedure outside the setting of an approved research study.

This is an exciting, intriguing notion that has not yet gone through the usual steps that a pharmaceutical agent does before being implemented in practice. There are legitimate concerns that people could be harmed undergoing testing and procedures while we wait for answers. The United States and Canadian MS Societies will start funding research on CCSVI this year. Several research groups are trying to repeat the findings of Dr. Zamboni. We will know within a couple of years whether CCSVI is really a breakthrough. Until then, unless enrolled in an approved research study, people with MS should not be undergoing the “liberation treatment.”

Dennis Bourdette, MD - Portland VAMC



My HealthVet offers Veterans, active duty service members, their dependents and caregivers Internet access to VA health care information and services. My **HealthVet** is a free, online personal health record that empowers Veterans to become informed partners in their health care.

With **My HealthVet**, America's Veterans can access trusted, secure, and current health and benefits information as well as record, track, and store important health and military history information at their convenience. Veterans who are enrolled in a VA facility can refill their VA prescriptions and more, so register today at www.myhealth.va.gov.

To be removed from this mailing list, please send an e-mail to Jaimie.Henry@va.gov or call (800) 949-1004, ext. 53296.

WHAT IS RESEARCH?

Research allows us to collect and analyze information and increase our understanding of how things work. In a clinical setting, it allows us to learn more about disease and what methods are efficient and effective in the treatment of disease. It also helps us understand how and why our bodies behave the way they do.

Research isn't for everyone and you must be willing to accept some level of "risk" that a new therapy might cause side-effects. You may gain access to a new medication or a placebo may be received. Many people find that participating in a research study is very rewarding, whether it's to be able to help others or to be a part of a team. To learn about research studies in your area and to find out if being involved in a research study is right for you, visit www.clinicaltrials.gov.



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