

# VA MULTIPLE SCLEROSIS CENTERS OF EXCELLENCE MS VETERAN

SERVING THE HEALTH CARE NEEDS OF VETERANS WITH MS

## LIVING WITH MS

MS came into my life in 1981 when my left side suddenly went numb. Two days later, the feeling returned and I continued with my life unaware of what this numbness might mean. My next, and most severe symptom, was optic neuritis in 1990 when I suddenly lost the vision in my left eye. Thankfully, steroids allowed my sight to return. My eye doctor mentioned that my loss of vision could possibly be an indication of MS, which I chose to ignore. All was quiet again until 1996, when I experienced entirely new symptoms. This led me to a neurologist who confirmed the diagnosis of Relapsing-Remitting MS.



My reaction to this diagnosis, I would learn, was common. My emotions went full spectrum and were mostly negative. I felt that my future had been snatched away, just when I was at the peak of my career in computers and the Internet. It was a tough road and it took me a couple of years before I saw that life with MS could be “okay” – not great – but “okay”. The rock solid support of my wife, Marian, was key in making this possible for me.

Soon after my diagnosis, Marian and I went to the National MS Society (NMSS) office in

Minneapolis where we met a wonderful woman, Jeannie, who guided us through the realities of living with MS. I have taken advantage of the many NMSS resources available, including self-help groups, seminars, weekend retreats, and much more. I highly recommend using the services of the NMSS as they can offer valuable support and information.

Being involved in the Internet at work, I naturally sought out information on the web. I was looking for a way to talk to others who were newly diagnosed to see what they were doing to manage their MS. I was fortunate to find MSWorld.org and became a frequent visitor to this site.

Over the 11 years I’ve been using MSWorld, I became a volunteer and now serve as Vice President. It is an amazing group of 30+ volunteers with MS who manage the website. There are more than 30,000 registered members from around the world. MSWorld is a free service

## WHAT’S INSIDE

▶ Living With MS	1
▶ Low Fat Diet: Does it Help MS?	2
▶ Flu and H1NI (Swine Flu) Vaccine	3
▶ Let’s Talk About Fatigue in MS	5
▶ Epstein-Barr Virus and MS	6
▶ My Health_eVet	8
▶ VA Fisher House	8

### VISIT OUR WEBSITE!

Please visit the VA MS Centers of Excellence website for additional information at [www.va.gov/ms](http://www.va.gov/ms).



that is there to help people with MS, and their loved ones, when the need is most urgent.

I receive outstanding care for my MS at the Minneapolis VAMC. I have also been fortunate to be able to volunteer for a number of programs, including training sessions on using the web-based program MyHealthVet and facilitating a 6-week course for people with chronic health conditions to help them better manage their illness.

It is my belief that our attitude has an effect on our health. Once I decided to learn how to take charge of my MS, I knew it was up to me to stay as healthy as possible, albeit not perfect, so I am able to do the things that matter in my life. I know the medication I take for my MS works for me and I take it faithfully, as prescribed. We all hope for a better quality of life. I found that taking charge of my health has helped me live that hope.

David Anderson - Minnetonka, MN

## LOW FAT DIET: DOES IT HELP MS?

Many people with MS want to know if a low fat diet is beneficial for MS. This interest largely originated from Dr. Roy Swank's advocacy of a low fat diet for the treatment of MS for over 60 years. Dr. Swank wrote many scientific articles on the subject and authored a series of books on what came to be known as the "Swank MS Diet." Others have advocated similar dietary approaches based on eating a very low fat diet.

Despite interest among patients, most physicians do not recommend that their MS patients follow a low fat diet and do not think it is a "treatment" for MS. This is because there is no scientifically compelling evidence to support recommending a low fat diet as a treatment for MS. However, there is indirect evidence to suggest that a low fat diet might be beneficial for MS.

Dr. Swank's idea to use a low fat diet originated in research he conducted after World War II. He and others showed that MS was more common in Norway in the inland regions where the diet was rich in saturated fats (fat in dairy and animal products, tropical oils, and processed foods) than on the coastal regions where the diet was enriched in unsaturated fats (fat in nuts, fish, and vegetable oils). Subsequent studies have also suggested that diets high in saturated fats may increase the risk of developing MS and diets low in saturated fats may

reduce the risk of getting MS.

Because there were no treatments for MS in 1948, Dr. Swank started treating a group of over 200 people with MS in Montreal with a low fat diet. His follow-up on the original Montreal patients after 30 years suggested that those who followed the diet lived longer and became less disabled from MS than those who did not follow the diet.

Dr. Swank's diet contains 10-15 gm of total saturated fat a day, fish and chicken as primary protein sources, and only dairy products containing 1% or less fat. He also supplemented

**DEDICATED TO INCREASING THE QUALITY OF LIFE FOR VETERANS WITH MS!**

**MSCoE EAST - VISN 1 TO 11**

Baltimore VA Medical Center  
Attn: Jane Stolte, Administrative Officer  
10 N Greene Street, Neurology 127  
Baltimore, MD 20201

*E-mail:* Jane.Stolte@va.gov

*Phone:* 1-800-463-6295, ext. 7480

**MSCoE WEST - VISN 12 TO 23**

VA Puget Sound Health Care System  
Attn: Drew Blazey, Administrative Officer  
1660 S Columbia Way, S-117-MSCoE  
Seattle, WA 98108

*E-mail:* Drew.Blazey@va.gov

*Phone:* 1-800-329-8387, ext. 64688

the diet with cod liver oil, which is enriched in omega-3 fatty acids.

While a low fat diet has not been proven to be effective in treating MS, there is a growing body of scientific literature that diets enriched in omega-3 fatty acids are “anti-inflammatory.” The omega-3 fatty acids modulate the immune system and may be neuroprotective. Both effects could be beneficial in controlling MS. In addition, following a low fat diet helps to prevent and reverse obesity, which in turn reduces the risk of diabetes, hypertension, and high cholesterol. There is some evidence that MS patients who have these other health problems are more likely to become disabled than those who do not.

So what is a person with MS to do? First, there is no evidence that following a low fat diet is a “cure” for MS and it should not be used in place of appropriate use of disease modifying therapies, like interferon beta or glatiramer acetate. Second, it is reasonable to follow a healthy, low fat diet,

such as that recommended by the American Heart Association. Third, for those who are motivated to adhere to a more stringent, well-balanced low fat diet, following the Swank Diet or a well-balanced vegan diet, such as the McDougall Diet, is safe and may be beneficial.



More research needs to be done to determine whether a low fat diet is actually a partial treatment for MS. Until then using common sense is prudent.

#### RECOMMENDED RESOURCES:

- ▶ *The MS Diet Book: Low-Fat Diet for the Treatment of MS* by RL Swank and BB Dugan
- ▶ [www.americanheart.org](http://www.americanheart.org)
- ▶ [www.drmcDougall.com](http://www.drmcDougall.com)

Dennis Bourdette, MD - Portland VAMC

## FLU AND H1N1 VACCINE

As in previous years, the National MS Society (NMSS) recommends a regular flu shot as a safe and effective vaccination for people with MS. The flu shot - which is a de-activated or “killed” vaccine - can safely be taken by individuals who are on any of the disease-modifying medications (Avonex<sup>®</sup>, Betaseron<sup>®</sup>, Copaxone<sup>®</sup>, Rebif<sup>®</sup>, Novantrone<sup>®</sup>, or Tysabri<sup>®</sup>).

In 2003, the FDA approved a flu vaccine nasal spray “for healthy children and adolescents, ages 5-17, and healthy adults, ages 18-49.” According to Dr. Aaron Miller, the Society’s Chief Medical Officer, FluMist - which is a live, weakened vaccine - is not recommended for use by people with MS, and should specifically be avoided by any person with MS who is on an immunosuppressive medication such as mitoxantrone (Novantrone<sup>®</sup>), cyclophosphamide (Cytosan<sup>®</sup>), azathioprine

(Imuran<sup>®</sup>), or methotrexate.

Live-virus vaccines are more likely than de-activated-virus vaccines to cause an increase in disease activity in people with MS. A person taking an immunosuppressive medication is more susceptible to developing an infection with the vaccine strain of the virus - an infection that may be particularly severe because the person’s immune system is suppressed. The interactions between live vaccines and the disease-modifying medications are not known.

**H1N1 (Swine Flu) Vaccine:** On September 15, the U.S. Food and Drug Administration (FDA) approved four vaccines for the H1N1 flu virus. The vaccines are manufactured using similar processes by four different companies. A person being vaccinated against H1N1 influenza will receive one dose of one of these vaccines. It is anticipated that these vaccines will be available in early to mid-October.

Three of the H1N1 vaccines are de-activated or “killed” vaccines that are administered by injection. These de-activated vaccines are considered safe for people with MS. One is a live, attenuated vaccine that is administered by nasal spray. This live, nasal spray vaccine should be avoided by individuals with MS.

The initial supply of H1N1 vaccine will not be adequate to vaccinate everyone. The Centers for Disease Control (CDC) have indicated that five groups will initially be targeted for vaccination:

- ▶ Pregnant women
- ▶ Persons who live with or provide care for infants under 6 months of age
- ▶ Healthcare and emergency services personnel
- ▶ Children and young adults aged 6 months to 24 years of age
- ▶ Persons aged 25-64 who have medical conditions that put them at higher risk for influenza-related complications.

It is important to note that people with disabilities (including people with MS) are not necessarily considered part of this high-priority group. *However*, the flu virus can precipitate MS exacerbations *and* a person with advanced MS or someone with less severe disease (Kurtzke 6.0) who has reduced pulmonary function or has any difficulty with breathing is considered at risk for complications and a good candidate for the H1N1 vaccine. The NMSS recommends that people talk with their MS doctor to determine if they are a good candidate for the H1N1 vaccine.

The NMSS will update their website when new information is forthcoming. You can read information from the CDC about the regular flu vaccine and the H1N1 vaccine at [www.cdc.gov](http://www.cdc.gov). Comprehensive information is also available at [www.flu.gov](http://www.flu.gov).

This information has been provided by the NMSS.

For additional information about MS or the work of the Society, please call 1-800-344-4867 or visit [www.nationalMSSociety.org](http://www.nationalMSSociety.org).

According to the CDC, H1N1 is anticipated to infect 25-50% of the U.S. population over the next 1-5 months.

### WHAT ARE THE SYMPTOMS OF H1N1 FLU?

- ▶ High fever (101 or higher)
- ▶ Muscle and joint pain
- ▶ Coughing or sore throat
- ▶ Runny or stuffy nose
- ▶ No energy
- ▶ Lack of appetite or nausea
- ▶ Vomiting or diarrhea

### HOW CAN I PROTECT MYSELF?

- ▶ Avoid close contact with people who are sick, keeping a minimum distance of 3 feet
- ▶ Wash your hands often or use hand sanitizer
- ▶ Wear a mask in public if you have a low immune system
- ▶ Cover your mouth and nose with a tissue when coughing or sneezing
- ▶ Avoid touching your eyes, nose, or mouth
- ▶ Wipe down surfaces with antibacterial soaked cloths whenever possible

### WHAT TO DO IF YOU GET H1N1 FLU?

- ▶ Stay home and take care of yourself
- ▶ Get lots of rest and drink plenty of liquids
- ▶ Keep your germs to yourself and contain the virus in one room so that others don't get sick

### WHEN SHOULD YOU SEEK MEDICAL CARE?

- ▶ Find it difficult to breathe or breath much faster than usual
- ▶ Hear a high pitched sound on exhale (wheezing)
- ▶ Sound like a seal “whoop” when taking in a breath during severe coughing
- ▶ Have a cough that lasts longer than three weeks

This information has been provided by  
Veteran Affairs Infection Control

# LET'S TALK ABOUT FATIGUE IN MS

Symptoms of MS are varied and numerous. Among them, fatigue is one of the most common and important problems. It is associated with a reduced quality of life and interferes with the ability to function both at home and at work. It is one of the most important reasons why many people with MS have to leave the workforce early.

People with MS who struggle with fatigue are far from alone. About 75-95% of people with MS report fatigue as a problem, and half of these people say that fatigue is their single worst problem. There is a need to better understand the causes for fatigue in MS and to better develop strategies for coping with this problem.

## WHAT IS FATIGUE IN MS?

Fatigue in MS is defined as an overwhelming sense of tiredness, lack of energy, or a feeling of exhaustion. It is distinct from weakness, and it's different than depression. Fatigue alone, even in the apparent absence of other physical symptoms, may significantly slow people with MS who otherwise have no physical impairments or disabilities simply by limiting their ability to participate. For those without MS, it can be described as the feeling of fatigue we feel when we get the flu and we're just sort of "wiped out."

## WHAT CAUSES FATIGUE IN MS?

The causes for fatigue in MS are not fully understood. We have not identified a specific affected location of the brain to explain the fatigue in MS. Imaging studies have not shown a significant association between lesion size or number with the severity of fatigue in MS. Depression may contribute to fatigue and should be evaluated and treated if it is a problem. However, depression alone cannot fully explain the extent of fatigue experienced by so many, particularly those who do not experience any depression.

Some hypothesize that the fatigue in MS may result from the direct effects of inflammatory enzymes released in the blood and nervous tissue of people with MS. These chemicals may be released as a part of the chronic inflammation that occurs in MS. Another hallmark of MS is the injury to the myelin covering around nerves. Without this myelin covering, signals are not transmitted as efficiently down nerves. Increased energy demand of conducting signals down these injured, demyelinated axons may also contribute to fatigue. Possible abnormalities in hormonal regulation have also been linked to fatigue in MS. The control of certain hormonal responses to physical stress may contribute to how fatigue affects people. In the end, it is likely that there are different contributions from multiple causes of fatigue in MS.

## HOW CAN FATIGUE IN MS BE TREATED?

Goals of treatment are to reduce fatigue severity, to improve quality of life, and to help people reach their goals. This is first done by addressing contributing factors to fatigue, such

### 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.

- ▶ **ADVANCES IN TREATING MS: AN UPDATE ON DMTs**
- ▶ **FATIGUE & COGNITIVE EFFECTS OF MS**
- ▶ **MOBILITY FOR PEOPLE WITH MS**
- ▶ **MRI GUIDELINES FOR DIAGNOSING & MANAGING MS**
- ▶ **PAIN & PALLIATIVE CARE IN MS**
- ▶ **SEXUAL INTIMACY & MS**
- ▶ **TREATING MS: MAKING A DIFFERENCE IN VETERANS' LIVES**

Interested in receiving a free set of DVD's? Contact Jaimie Henry at 1-800-949-1004, ext. 53296 or e-mail [Jaimie.Henry@va.gov](mailto:Jaimie.Henry@va.gov) with a name and mailing address.

as depression. If someone is depressed, that must be treated first. No progress will be made toward reducing MS fatigue while significant depression is present. If someone has impaired sleep, this should also be evaluated and treated. If someone is inactive, deconditioned, or taking medications that are responsible for fatigue, each must be addressed to reduce fatigue. These factors should be evaluated by a healthcare provider.

Keep in mind that physical therapy and exercise can be beneficial for someone trying to battle fatigue. For example, yoga and aerobic exercise have been shown to positively impact fatigue in clinical trials. Keeping cool, sometimes by using a cooling vest, can be helpful since fatigue is made worse by heat. Other good strategies include taking rest periods, doing endurance training, and getting a better handle on sleep. It is also important to reassure people that this fatigue is a part of MS. Fatigue in MS is not a product of “being lazy.” It is a part of MS, and it can improve.

There are a number of different medications that have been used successfully for fatigue in MS. One of the first was amantadine, which is actually an antifu agent. Its benefit was discovered by

accident. A physician in Canada (who happened to have MS) was taking amantadine for the flu and noticed that, while he was taking the medication, his fatigue was less. This led to several research studies that showed it was an effective treatment for many people with MS.

Another frequently used medication that may be helpful for fatigue in MS is modafinil. Although it is not universally effective for all people with MS, many people have derived some benefit. In some cases, a stimulant called methylphenidate has also been tried. However, it has not been studied in an MS clinical trial, and in some circumstances it can be addicting. The VA also recently completed a clinical trial of ginseng for fatigue in MS. Although the study did not show a significant benefit overall, many people in the study reported some improvement in their fatigue while on ginseng.

In the end, fatigue can be treated. Please share your concerns with your health care provider. There are a variety of medications and rehabilitation strategies that are available to address fatigue and other MS symptoms.

Edward Kim, MD - Portland VAMC

## EPSTEIN-BARR VIRUS

MS appears to result from a number of environmental and genetic factors. Among the various elements that are present in the environment, viruses have been considered a prime candidate as a potential cause for the disease. This is because viruses can cause symptoms that appear many years after infection. Also, proteins produced by some viruses can be similar to those present in myelin or other nervous system components, thereby triggering an immune response against nervous system tissue via a process referred to as “molecular mimicry”.

Of the many viruses that have been considered as a cause for MS, the most convincing evidence

has been generated in favor of Epstein-Barr virus which is also referred to as EBV. EBV belongs to a family of virus called the herpesviruses. Following initial infection, the herpesviruses go into a dormant state and can be reactivated at a later time. Such reactivation frequently occurs in people who are otherwise healthy and have no sign of illness or immune abnormalities.

About 90% of all people worldwide have been infected with EBV. The risk of EBV infection begins in early childhood with infection occurring in about 50% of children by the age of 5 years. Among children, the infection tends to occur without causing any symptoms, but in adults EBV infection is the cause of infectious

mononucleosis (sometimes called “mono” or the “kissing disease”). In the vast majority of people, reactivation of EBV does not cause clinical symptoms. However, about 10% of adults who develop infectious mononucleosis may later have recurrent symptoms of fatigue, mild discomfort, or weakness which in some cases can be shown to occur with reactivation of the virus.

Persons with a history of infectious mononucleosis are at greater risk for future development of MS. Information obtained from studies performed over a number of decades has provided additional evidence in support of prior EBV infection being associated with an increased risk of MS. These studies have tended to show that EBV infection occurs at a higher frequency among persons with MS than in healthy individuals. The immune response that is directed against the virus is more prominent in the central nervous system than outside of the nervous system.

An association between EBV infection and MS was provided in a very large study, published six years ago. In the study, an analysis of blood samples that had been collected from over 3 million military personnel showed that high levels of antibodies against specific EBV proteins was indeed associated with a significant risk of subsequently developing MS. In other studies it was shown that not only are antibodies detectable, but that there are also immune cells that target the virus infiltrated within MS lesions.

In 2007, researchers demonstrated that the virus can actually be present in MS lesions in brain white matter and in areas along the surface of the brain. In this study there was evidence of EBV infection of B cells (type of white blood cell), and such infection was associated with increased immune activation by B cells and the presence of T cells (type of white blood cells) targeting the virus. In addition, all of these findings correlated with the intensity of the MS-related immune activity that was present in the tissue that was studied. Therefore, this study

showed for the first time a direct link between actual EBV infection and MS-related tissue damage. To date, however, efforts by other researchers that have been aimed at replicating these findings have not been successful. In addition, there has been no clear demonstration of an association between reactivation of EBV and the occurrence of MS exacerbations.

On the other hand, several studies show that healthy people with risk factors for MS, such as female gender, a history of tobacco smoking, and the presence of an appropriate genetic background, are likely to produce high levels of antibodies against EBV. For persons with the genetic risk factor, the risk of developing MS is even higher if they are shown to also produce these antibodies. Therefore, there remains strong evidence in support of a link between EBV infection and MS.

Further research is required to understand how this information can be used to modify a person’s risk for developing MS and for developing treatments for the disease.

Walter Royal, III, MD - Baltimore VAMC

### **PATIENT EDUCATION CONFERENCE CALL**

Join the monthly Conference Call and learn first hand about MS from MS experts and other health care professionals.

**DATE:** 2nd Monday of Every Month

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

**TOPIC:** Different Topic Every Month

**TO PARTICIPATE:** Dial 1-800-767-1750,  
Access Code 43157#

Participation is free and callers are anonymous. Questions can be asked as time permits. Do you have questions about the call or topic for the month? Contact Angela Young at 1-800-463-6295, ext. 7133 or send an e-mail to [Angela.Young4@va.gov](mailto:Angela.Young4@va.gov).



**My HealthVet** is the gateway to Veteran health benefits and services, available right on your home computer. It provides access to:

- ▶ **TRUSTED HEALTH INFORMATION**
- ▶ **LINKS TO FEDERAL AND VA BENEFITS AND RESOURCES**
- ▶ **PERSONAL HEALTH JOURNAL**
- ▶ **ONLINE VA PRESCRIPTION REFILL**

In the future, **My HealthVet** registrants will be able to view appointments, co-pay balances, key portions of their VA medical records online, and much more! **My HealthVet** is a powerful tool to help you better understand and manage your health. Register today at [www.myhealth.va.gov](http://www.myhealth.va.gov).

## VA FISHER HOUSE

A Fisher House is “a home away from home” for families of Veterans receiving medical care at some VA medical centers and major military centers. These homes enable family members to be close to a loved one during hospitalization for an unexpected illness, disease, or injury. The Fisher House is a temporary, no cost residence and is not a treatment facility, hospice, or counseling center.

The 43 Fisher Houses are designed to offer all the amenities of home, including a common kitchen, laundry facilities, spacious dining room, living room with library, and toys for children. Since 1991, these homes have served over 120,000 families nationwide. For more information about the Fisher House services contact 1-888-294-8560 or visit their website at [www.fisherhouse.org](http://www.fisherhouse.org).



Portland VA Medical Center  
3710 SW US Veterans Hospital Road  
Mailcode: P3CoE  
Portland, OR 97239