

# VA MULTIPLE SCLEROSIS CENTERS OF EXCELLENCE

# MS VETERAN

## SERVING THE HEALTH CARE NEEDS OF VETERANS WITH MS

### MS CHANGED MY LIFE

I enlisted in the US Army in 1987. After completing Basic Combat Training, I went into Advanced Individual Training (AIT) as a Field Medic. I went to AIT again in 1990 for Transportation. While in AIT the 2<sup>nd</sup> time, our reserve unit was activated and sent to Kuwait. We were overseas for 184 days before being sent home.

Life went back to normal once I was home, until April 2009 when my vision became a little strange. I wasn't sure what was going on so I made an appointment to see an eye doctor. The optometrist ran a series of tests on my eyes and found that my eye exam suggested a possibility of MS. She recommended I see a neurologist. I made an appointment and had a MRI scan and then a spinal tap completed. Following my tests, an MS Specialist confirmed that I had MS. At first I was in denial that I had MS. This denial stayed with me even as I administered my daily disease modifying therapy injections. In time, I accepted my diagnosis and realized that MS was not going to prevent me from living my life to its fullest every single day.

My journey with MS has not always been an easy one. I've had my ups and downs, but through it all, I've come through all right. I exercise every day; push-ups, sit-ups, turn, and bounce. I like to bicycle, take walks, and enjoy swimming at the Young Men's Christian Association (YMCA). I really enjoy being



in the water and think I must have been a fish in a previous life. I've found that doggy paddle is a good stroke for me as it prevents water from getting in my mouth. Every year I participate in the National MS Society Bike MS and Walk MS fundraising events. Last year I participated in the Society MuckFest fundraising event which was a lot of fun.

The MuckFest is a 5K course that has 15+ outrageous obstacles along the course route. The course I participated in was in a forested area with 18 obstacles laid out in clearings along the route. Each of the obstacles varied, some spinning and swinging you in the air while others took you over, under, and through various elements. I completed all of the obstacles, although that wasn't required to complete the course. Some folks didn't want to get muddy so they avoided the obstacles that got them too dirty.

The MuckFest was a challenge, made me laugh, and was a great opportunity to meet new people. There was an obstacle early on where I couldn't get my leg over a barrier and a couple came and helped me. They were there to have fun just like me, and they kind of stayed with me throughout the remaining course. I enjoyed talking with them and was touched that these people, who were once

### WHAT'S INSIDE

- ▶ Managing Spasticity 2
- ▶ Peginterferon: A New Treatment for MS 3
- ▶ Vaccines and MS: A Practical Guide 4
- ▶ Creating a Support Network 7

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strangers to me, stayed with me, providing emotional support and a little physical support when needed. Being surrounded by so many people who have been touched by MS in some way was amazing. The sense of community was all around me and I hope to be able to compete again next year.

I've had MS for over five years now and although I've had to make adjustments to accommodate some of my symptoms, life is good. I like keeping my body healthy, active, and fit. I enjoy watching sports of all

kinds, playing keyboard, writing poems, and collecting baseball cards. I like being involved in fundraisers and would like to find additional ways that I can raise money to benefit Veterans as well as MS organizations working to find a cure. I enjoy life and every new day gives me an opportunity to get out there, meet new people, have new experiences, and raise awareness for MS. I'm just one person, but I am going to make a difference in the fight to find a cure for MS.

*Jeff Jensen - LaPorte, Indiana*

## MANAGING SPASTICITY

Spasticity is a common symptom affecting many people with MS. Although the stiffness associated with spasticity can sometimes be helpful for performing daily activities such as getting in and out of a wheelchair or walking, it can also be a nuisance and lead to serious health concerns such as pain, wounds, or loss of function. The good news is that there are a growing number of treatments available to help ease the burden of troublesome spasticity. To prevent good spasticity from turning into bad spasticity, all people with MS, their caregivers, and/or loved ones should have a basic understanding of the signs of spasticity, as well as understand the various options to keep spasticity in check.

### *Is this spasticity?*

Generally, spasticity shows up as increased tightness or resistance to movement of a body part or involuntary movements. For some, spasticity means one or both legs make uncontrolled bouncing or jumping motions. For others, spasticity may be a tight arm that makes it difficult to wash the underarm area during showers or a feeling of tightness that makes a stretching program painful or difficult. When in doubt, it's helpful to ask a therapist, neurologist, or rehabilitation provider to evaluate suspicious symptoms and tease out spasticity from other conditions.



***Why is spasticity acting up now?*** Many issues can actually trigger a sudden increase in spasticity. Therefore, it's important to consider whether any of these causes are behind a sudden change in symptoms before “covering up” the symptoms with medication or other treatment. Common triggers for increased spasticity include bladder or urinary tract infection, skin wound, or kidney/bladder stones. Before starting treatment for spasticity, your health care provider might recommend a physical exam, blood or urine tests, or imaging studies to look for one of these “spasticity triggers.”

***Are there treatment options for spasticity?*** A wide variety of possible treatments for spasticity exist. These allow the health care provider to match the treatment to the severity of the symptoms and the preferences of the person with MS.

**STRETCHING AND THERAPIES:** In all cases, overactive muscles causing tightness or spasticity should be regularly stretched multiple times per day to maintain range of motion and minimize the symptoms of spasticity. Prolonged stretches (at least 20-30 seconds at a time) are the most effective to treat spasticity. When needed, physical or occupational therapists can help set up a stretching program, evaluate for and provide splints to provide a longer lasting stretch (over hours rather than minutes), and also provide useful “tricks” to quiet spasticity and permit more stretching. Many of these tricks or “modalities”- such as using ice, vibration, or electrical stimulation- have been used for over a half century to treat spasticity and are still commonly used today. While the results from these treatments might not last a long time (less than an hour), the positive side

is that most of these treatments can be done at home, can be controlled by the person with MS or caregiver, and have little to no side effects.

**MEDICATIONS:** Medications to relax overactive muscles provide another means to address spasticity that is out of control. These medications- such as baclofen, tizanidine, diazepam, gabapentin, and others- can provide longer-lasting relief of spasticity (for hours). Side effects, such as drowsiness or weakness, may be experienced with these medications. Most of these medications are taken several times per day, every day, in order to prevent or suppress spasticity.

**INJECTIONS:** Overactive muscles from spasticity can also be treated with local injections with medications such as botulinum toxin, phenol, or alcohol. These medications are injected directly into the overactive muscles and block the communication between the overactive muscle and the nerve controlling it. These injections can be a good option for individuals with spasticity affecting a few individual muscles (rather than the whole body). The advantage to this treatment is that one round of injections can have effects lasting several months. One possible disadvantage is that these treatments work by weakening muscle, so the risk of too much weakness needs to be considered before the injections are performed.

**INTRATHECAL BACLOFEN PUMP:** When spasticity affects a larger region of the body, particularly in the legs, an intrathecal baclofen pump is another possible option for treatment. This device delivers small amounts of an antispasticity medication directly to the spinal canal. The benefit of this intervention is

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

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that the medication is delivered directly to the place it needs to go to (without having to take pills), and the treatment is adjustable to meet an individual's needs over time. The drawback of this treatment is that it involves a surgery to implant the pump, and routine clinic visits to adjust and refill the pump as needed.

*In summary*, many individuals with MS will experience spasticity, and a significant proportion of those individuals will have undesirable side effects as a result. Troublesome spasticity can usually be managed effectively when it is recognized and addressed early. The best outcomes result when patients and health care providers work together to identify and manage spasticity symptoms.

*Ileana Howard, MD - Seattle VA*

## PEGINTERFERON: A NEW TREATMENT FOR MS

The first drug to reduce relapses in MS was approved by the Food and Drug Administration (FDA) over 20 years ago. That drug (Betaseron<sup>®</sup>) was a form of beta interferon, a naturally occurring chemical that normally helps us fight viral infections. Many Veterans have been treated with that form of beta interferon and the other beta interferons (Avonex<sup>®</sup>, Rebif<sup>®</sup>, and Extavia<sup>®</sup>) that have been

approved since then. Beta interferons are effective in treating MS, but they do have some limitations. They have to be injected once a week or more frequently, and some beta interferons stimulate the immune system to make antibodies (proteins in the body that identify and neutralize foreign objects) that block the drug's beneficial effects. Peginterferon (Plegridy<sup>™</sup>) is a chemically modified beta interferon that was developed to address those limitations. Peginterferon only has to be injected every two weeks and it is less likely to cause the production of neutralizing antibodies than some other beta interferons.

**How effective is peginterferon?** Peginterferon was tested in a study of 1,512 people with relapsing remitting MS who were randomly assigned to either placebo injections, injections of peginterferon 125 micrograms every two weeks, or injections of 125 micrograms every four weeks. After one year, those subjects treated with peginterferon had fewer relapses and fewer new white spots on their brain MRI scans than the subjects who received placebo injections. Every two week injections were more effective than every four week injections; therefore, every two week injections were approved by the FDA.



It is not known whether peginterferon is as effective as other interferons already on the market as it has not been tested against other beta interferons. It appears to be similar in effectiveness to other beta interferon treatments, but head to head comparative studies would be needed to determine whether it is more or less effective.

**What are the side effects of peginterferon?** The side effects of peginterferon appear to be similar to the side effects of other forms of beta interferon. Common side effects include flu-like symptoms after injections (fever, chills, headache, muscle pains, and joint pains) and local skin reactions at the site of injections. The flu-like side effects can be reduced by taking aspirin, acetaminophen, or non-steroidal anti-inflammatory medications (such as ibuprofen or naproxen). To avoid severe skin reactions, injection sites should be rotated with each injection.

### **Are there safety concerns with peginterferon?**

Available evidence suggests that the safety profile for peginterferon is similar to that seen with other forms of beta interferon. Negative effects of beta interferon include liver damage, depression, seizures, severe allergic reactions, injection site skin necrosis, heart damage, decreased production of blood cells, and autoimmune disorders. Peginterferon, like other interferons, is not generally recommended in women who are pregnant or breast feeding.

**Who should consider taking peginterferon?** Any individual with a relapsing form of MS who was considering treatment with beta interferon could consider taking peginterferon. Individuals who are already on beta interferon treatment might consider switching to peginterferon because it only has to be injected once every other week or because it has a low likelihood of causing the production of neutralizing antibodies. Individuals who do not tolerate other forms of beta interferon or who have developed neutralizing antibodies to beta interferon should not consider peginterferon.

**In summary,** beta interferons have been used for over 20 years as a safe and effective treatment for MS. Peginterferon is a chemically modified form of beta interferon. The benefits of peginterferon include less frequent injections (every two weeks) and a low likelihood of causing antibodies that block the drug's effectiveness. If you would like to learn more about peginterferon, please visit the Emerging Therapies Collaborative website at [www.ms-coalition.org/emergingtherapies/](http://www.ms-coalition.org/emergingtherapies/).

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*Ruth Whitham, MD - Portland VA*

*Karen Nater-Pineiro, MD - Baltimore VA*

## **VACCINES AND MS: A PRACTICAL GUIDE**

Vaccines are important for preventing other illnesses. Preventive care is also an important part of MS management. You may wonder about links between MS and vaccines. Are vaccines safe to use in people with MS? Do vaccines cause MS? Are they

safe for me? Should I have them? This article clarifies that vaccines do not cause MS and guides you in how vaccines are used safely by people with MS.

**Do vaccines cause MS?** After mass vaccination programs for hepatitis B were begun, some people developed MS. This led to an investigation into a possible connection between the hepatitis B vaccine and MS. The Food and Drug Administration (FDA)

reviewed the results of clinical studies used for approval of the hepatitis B vaccine and did not find any increase in MS. The World Health Organization Global Advisory Committee on Vaccine Safety states that “multiple studies and review panels have concluded that there is no link between MS and hepatitis B vaccination”. The US Centers for Disease Control and Prevention (CDC) and the National Network for Immunization Information also support the safety of the hepatitis B vaccine.

**Why are vaccines important?** Vaccines are an important way to protect everyone from serious infectious diseases. Today’s vaccines are among the most successful and cost-effective public health tools available for preventing diseases. Thanks to vaccines, serious and often fatal diseases like polio are now distant memories for most Americans. In almost all cases, getting a vaccine is much safer than getting the disease itself. Currently, vaccines to protect children and adults from at least 17 diseases are available. Travelers to foreign countries, where uncommon diseases such as typhoid and yellow fever may be encountered, may need additional vaccines before their trips. Guidelines on vaccinations for people with MS have been established by the MS Council for Clinical Practice and by the CDC.

**TYPES OF VACCINES:** Several types of vaccines are available. Live, attenuated vaccines contain a version of the living microbe that has been weakened so it does not cause disease. Although live, attenuated vaccines are generally very effective, because they contain live microbes, they should not be given to people with damaged or weakened immune systems, such as those with HIV. Since there may be an increased risk with live, attenuated vaccines in people taking certain MS disease modifying medications, including natalizumab (Tysabri<sup>®</sup>), fingolimod (Gilenya<sup>®</sup>), teriflunomide (Aubagio<sup>®</sup>), and possibly dimethyl fumarate (Tecfidera<sup>®</sup>), people taking these medications should avoid live, attenuated vaccines when an alternative is available.

Vaccines that are not live are inactivated (contain microbes killed by chemicals, heat, or radiation), subunits (contain only part of the microbe), toxoids (inactivated toxins), or conjugate (a subunit linked to

### CAREGIVER AND FAMILY TELEPHONE CALL

Join the free, monthly conference call to connect with caregivers and family members supporting people with MS. A variety of educational topics and resources are discussed.

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

**MONDAY - FRIDAY:** 8 AM - 11 PM ET

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a toxoid) vaccines. These non-live vaccines cannot cause disease and are therefore generally safe for use in people with MS.

In addition to the active component of the vaccine (the part that induces disease protection), vaccines contain other substances. Anyone with a severe, life-threatening allergy to any component of a vaccine should not get that vaccine.

**FLU VACCINE:** One of the most commonly used vaccines is influenza (flu) vaccine. Flu vaccines are one of the most important ones we should all be sure to get, because flu can be unpleasant and even fatal. There are several types of flu vaccine. The most familiar and commonly used one is the standard flu shot. The standard flu shot is an inactivated vaccine containing only killed flu viruses. The injectable flu vaccine is recommended for everyone over six months of age. It has been studied extensively in people with MS and is very safe. A high-dose, injected flu vaccine is available for people over age 65. This high-dose vaccine is also an inactivated vaccine. It has not been studied in people with MS and, at present, the CDC is not recommending the high-dose vaccine over the seasonal flu vaccine for the general population.

In contrast to the flu shot, the intranasal spray flu vaccine (FluMist<sup>®</sup> Quadrivalent) is a live, attenuated

vaccine. Because a safe, alternative, non-live flu vaccine is available, FluMist<sup>®</sup> is generally not recommended for people with MS. It is important to know that if other family members receive this intranasal vaccine, the attenuated virus can be in their urine or feces for up to one week after the vaccination and could thus be transmitted to others.

**CHICKENPOX (VARICELLA) VACCINE:** The varicella vaccine (Varivax<sup>®</sup>) protects against the varicella zoster virus that causes chickenpox. This vaccine is different than the shingles vaccine. The Varicella vaccine is a live, attenuated virus. Most adults had chickenpox as children so they are immune. However, there are some people who have never had chickenpox or the chickenpox vaccine. Because fingolimod can increase the risk of chickenpox in people with MS, if you are going to use fingolimod and have not had chickenpox or the vaccine, the CDC recommends that you receive the varicella vaccination. The varicella vaccine is given in two doses four weeks apart. People with MS should not start fingolimod until at least one month after the last dose of the varicella vaccine.

**SHINGLES (ZOSTER) VACCINE:** The shingles vaccine (Zostavax<sup>®</sup>) protects people from shingles which is a reactivation of varicella zoster virus if you had chickenpox earlier in life. The CDC recommends adults 60 years or older receive the shingles vaccine. The shingles vaccine is a live vaccine; however, because most people have had chickenpox earlier in their lives and therefore already have the virus in their bodies, the risk of getting disease from the vaccine is much lower. If a person has had chickenpox or tests positive for the antibodies, the shingles vaccine would generally be safe and beneficial.

**PNEUMONIA VACCINE:** The pneumonia vaccine (Pneumovax<sup>®</sup>) protects people from pneumonia caused by the pneumococcus bacteria. This is a non-live, subunit vaccine. The pneumonia vaccine is recommended for people with compromised breathing or lung function, such as those who are wheelchair-dependent or bedbound, because they are more prone to pneumonia. This vaccine is generally safe for people with MS.

**OTHER VACCINES:** Both hepatitis A and hepatitis B vaccines are not live and are safe for people with MS. If you have not had these vaccines during childhood or as a condition of employment, discuss it with your health care provider to see if you need them. The measles, mumps, and rubella (MMR) vaccine is a live, attenuated vaccine generally given during infancy, after 1 year of age, and is recommended by CDC for the general population. Tetanus vaccine, which is often given as a combined vaccination with diphtheria (Td) or with both diphtheria and pertussis (Tdap), is not a live vaccine.

NON-LIVE VACCINES	LIVE VACCINES
Influenza Injectable (shot, including high dose)	Influenza Nasal Spray (FluMist <sup>®</sup> )
Pneumonia	Chickenpox
Hepatitis A	Shingles
Hepatitis B	Measles, Mumps, Rubella
Tetanus	
Diphtheria	
Pertussis	

**Overall,** vaccines are safe and effective for people with MS and are important disease prevention tools. **There are no concerns for use of non-live vaccines in people with MS.** Live, attenuated vaccines should usually be avoided in people with MS when an effective, safe alternative is available. The use of live, attenuated vaccines should be avoided during and for two months after treatment with fingolimod because of the risk of infection. The risk of live, attenuated vaccines for people taking natalizumab, teriflunomide, and possibly dimethyl fumarate is uncertain; people on these medications should discuss the potential risk and benefits of live, attenuated vaccines, such as Zostavax<sup>®</sup>, with their health care provider. Vaccines should not be received during or within 4-6 weeks of an MS relapse. If you have any questions or concerns, please talk with your health care provider.

**Kathy Tortorice, Pharm D, BCPS - VA National Pharmacy Benefits Management Service**  
**Michelle Cameron, MD, PT - Portland VA**

# CREATING A SUPPORT NETWORK

Living with a chronic illness like MS can be stressful and challenging. Uncertainty and the constant need to adapt to change can have you feeling like you are on a roller coaster ride. Many people feel they no longer have control of their life. It's common to feel you are alone, believing no one can possibly understand what you are going through. You are not alone. There are thousands of people living with MS that are struggling with many of the same issues you are. Many of these people have found that creating a supportive network of family and friends has helped them through difficult days as well as provided the day-to-day support they may need.

**What is a support network?** A support network is made of family members and friends who are willing to support you. This is something you create yourself, for you. These are people that you can turn to in times of crisis as well as for simple things like talking about your day, going out to lunch, or getting a ride to a medical appointment. These people “get it,” they understand your needs and offer help when you need it.

**How do I set up a support network?** Cultivating and maintaining a network of support can take effort and it's important you establish a support network that works best for you. Some people find that a small support network of family and friends is sufficient, while others enjoy a large, diverse support network. Asking for or accepting help can be difficult. Try to remember that friends and family care about you and want to help. Allowing them to help gives them an opportunity to express their love for you.

MS affects everyone differently. It's up to you to let family and friends know what you need. Be specific on what you would find most helpful; no one is a mind reader. Start by making a list of everyday chores and activities. From this list,



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check off those things you either still enjoy doing or those things you don't feel comfortable asking others to do for you. Enlist a family member or trusted friend to 'supervise' the list and recruit members on your support team to volunteer for the remaining tasks. People will likely choose activities they enjoy or feel expertise in, assuring they're a good fit for the task. Set realistic expectations for these tasks to avoid disappointment if things don't go exactly the way you had hoped.

If you would like to expand your social network, get involved in activities where there are people with interests similar to yours or take some time to reconnect with old friends or colleagues. Volunteer with an organization that you find interesting or join a cause that is important to you. Many community centers have classes you can join as well as planned excursions that you can participate in. Having a variety of interests and activities in your life will open up opportunities to make new friends.

**What is a support group?** Support groups bring together people facing similar issues, allowing attendees to share experiences and advice, as well



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as offer emotional and moral support. While not everyone needs support beyond their family and friends, support groups may lessen feelings of isolation as attendees make connections with people experiencing similar challenges. Attendees can also gain a sense of empowerment by better understanding their disease through the eyes of others.

Support groups come in a variety of formats including in-person, through the internet, or over the phone. Some groups are structured, moderated groups while others are more informal. If you are interested in a support group, plan to attend a few meetings to see if it's a good fit. If you're not comfortable with the group or don't find it beneficial, try a different one. It's important to find a group that works for you. Support group options may be available through your local VA facility; talk to your health care provider. If you need help finding a support group, nonprofits, service organizations, churches, and community centers may be able to help.

Taking the time to build a network of support or participate in a support group is an investment not only in your mental well-being, but also in your overall physical health. Spending time with people you consider friends contributes to a feeling of belonging, helps ward off loneliness, and increases feelings of self-worth. Remember that the goal of building a support network is to provide support for you and to reduce your stress. Prioritize your social commitments and watch for signs of stress and fatigue. Control your environment by choosing to surround yourself with positive people. This is not the time to keep company with people who are constantly critical or negative.

Keep in mind that relationships are give and take. Be willing to support those willing to support you. Make the effort to stay in touch with people and be a good listener when they need you. Show appreciation to your friends and family and don't forget to say thank you for all they do.

*Janet Spencer, MSW, LCSW - Portland VA*