

VA MULTIPLE SCLEROSIS CENTERS OF EXCELLENCE

MS VETERAN

SERVING THE HEALTH CARE NEEDS OF VETERANS WITH MS

MY ANGER WITH MS

I was diagnosed with MS in 1965. My MS had been relatively benign for more than 35 years, with only occasional minor exacerbations. The disease was easy to ignore or deny. During those years I had very interesting jobs and traveled worldwide.

In 2001, I began to experience new symptoms. I was told by my neurologist that I had developed secondary progressive MS. A depression followed and I became very angry. That anger still haunts me as I try to deal with it. Along with the anger, I was and am still afraid of the future.

I learned from a therapist who does Reiki that I am still the same person; still have the same values and principles. With this experience I learned that in order to get rid of the anger, I would need to accept the reality of my new physical limitations and get on with living. Sounds easy, but it is not. Intermittent catheterization, injecting interferon-beta-1a, falling, overwhelming fatigue, having maneuverability issues with my wheelchair, and short term memory issues all anger me.

This brings me to another point. I firmly believe that each MS person needs to work with a team of specialists including a neurologist, nurse, physical therapist, social worker, psychologist, and perhaps

others. The disease is complicated at many levels and the MS person may need to turn to one or more of these individuals for help at various stages of the disease process.

Another important point is that the individual MS person needs to become more proactive because it is their life. Let me list some options here. Previously, I had done yoga very seriously, but stopped when I became secondary progressive. It was a big mistake to have given it up. I am now getting back to yoga and other exercise, which makes me feel better physically and psychologically. All that stretching, pulling, and pushing is so beneficial for MS.

Another thing I do is volunteer as a teacher of English as a Second Language. On my class days I have to rise rather early to get a start on the day. This is not easy, but I hope that I will never give it up because it is so exciting, energizing, productive, gives me a feeling of being useful, and I



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learn so much from my students about different cultures. Other teachers and I have about 150 adult students for two twelve week terms each year. Basically, the point here is that those of us with this disease cannot stop doing the things we love. These things have been a part of your life and have been good for you. Do not stop.

I like very much what my nurse practitioner at the VAMC in Washington, DC once said to me, “Do not let this disease become you.” I was letting that happen! Another big mistake on my part, and it is easy for that to happen, but each MS person must do their very best to avoid letting this occur.

It is important for those of us with MS to have a support team including friends and family members. In my own case, I have some great friends

who understand my situation and offer tremendous physical and emotional support. My brother, John, who is seven years my junior, has secondary progressive MS. John is my best support when it comes to understanding the disease. The two of us talk every week. He and I provide tremendous support for each other. When he is down, I help him get back up and he does the same for me. I thank God for John!

These are my thoughts and feelings. I think that some of you might share some of these. I hope that my being able to verbalize these feelings will help some of you to do the same. A final thought - acknowledge the anger and seek help to deal with it.

Alan Campbell, Alexandria, VA

INTIMACY AND SEXUALITY WITH MS

Everyone is a sexual being. From the moment of birth until the moment of death, our capacity for communication, relatedness, and intimacy unfolds in a natural developmental sequence. As such, it is natural for everyone to desire affection and intimacy. Whether you are newly diagnosed, young, mature, single or in a committed relationship, chronic illnesses and disability do not diminish these needs and desires. With MS, symptoms can occur that may present obstacles in your capacity for emotional relatedness and sexual intimacy. By approaching these obstacles as challenges rather than burdens, you can empower yourself to explore the variety of possible solutions in relating intimately. Educate yourself. Overcome your embarrassment and ask questions of yourself, your health care team, and your partner. Experiment, and even challenge yourself to



change some of your ideas about what intimacy and sexuality really means to you. Thinking about yourself as a sexual being, acknowledging that part of yourself, is the first step.

HOW DOES MS AFFECT SEXUALITY? The ways in which MS can affect sexuality and expressions of intimacy can be divided into *primary*, *secondary*, and *tertiary* sexual dysfunction.

Primary sexual dysfunction stems directly from MS-related changes in the brain and spinal cord that affect the sexual response or the ability to feel sexual pleasure. In both men and women, this can include a decrease or loss of sex drive, decreased or unpleasant genital sensations, and diminished capacity for orgasm. Men may experience difficulty achieving or maintaining an erection and a decrease in or loss of ejaculatory force or frequency. Women may experience decreased vaginal lubrication, loss of vaginal muscle tone, and/or diminished clitoral engorgement.

Secondary sexual dysfunction stems from MS-related symptoms that do not directly involve nerve pathways to the genital system, but nevertheless impair sexual pleasure or the sexual response. Secondary symptoms may include

bladder and bowel problems, fatigue, spasticity, muscle weakness, body or hand tremors, impairments in attention and concentration, and non-genital sensory changes.

Tertiary sexual dysfunction results from disability-related psychosocial and cultural issues that can interfere with one's sexual feelings and experiences. For example, some people find it difficult to reconcile the idea of being disabled with being fully sexually expressive. Changes in self esteem—including the way one feels about one's body - depression, demoralization, or mood swings can all interfere with intimacy and sexuality. The sexual partnership can be severely challenged by changes within a relationship, such as one person becoming the other person's caregiver. Similarly, changes in employment status or role performance within the household are often associated with emotional adjustments that can temporarily interfere with sexual expression. The strain of coping with MS challenges a couple's efforts to communicate openly about their respective experiences and their changing needs for sexual expression and fulfillment.

Communication with an MS health care provider on aggressive symptom management with sexual health in mind can be helpful in restoring sexual function. Although treatment of these

symptoms frequently eases associated sexual complaints, it is necessary for the MS health care provider to know that sexual function is an ongoing concern. For example, some anti-depressant medications have excellent efficacy in treating symptoms of depression, but can also cause impairments in libido and capacity for orgasm. If the person with MS and the health care provider have had an open dialogue about sexual function, appropriate medications and/or dosing strategies can be implemented to minimize or eliminate the sexual side effects.

In coping with sexual dysfunction, it is very important to include the sex partner in the discussion when a long-term relationship is present. This enhances intimacy by allowing both partners to learn and explore together. If partners feel inhibited about talking through these issues, counseling with a mental health professional who is knowledgeable about MS can prove helpful.

Frederick Foley, PhD, Yeshiva University of New York

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YOGA AND MS

There is significant growing interest in complementary and alternative medicine (CAM) as options for treatment in MS. In fact, it is estimated that as many as 65% of patients with MS have used some form of CAM. Among the variety of different CAM therapeutic approaches, interest has particularly emerged in the mind-body medicine approach of yoga. Yoga is an ancient Indian, non-religious approach that focuses on meditation, mindfulness, breathing, and postures. In the practice of yoga, the practitioner places their body in a series of stationary positions. Each position is designed to create particular body alignments that

utilize an important balance of isometric contractions and relaxations. At the same time that there is an essential relaxation component to yoga, there is also an emphasis on controlled positioning and breathing methods to exercise concentration.

While MS research in yoga and other types of mind-body medicine approaches have been mostly exploratory, the results of the studies support their potential benefits. First of all, many with MS have reported satisfaction with the practice of yoga. In a survey of 1,980 people with MS from Oregon and southwest Washington, 30% responded that they had participated in yoga classes. Of that group, 57% reported that the use

of yoga was “very beneficial.” In a 6-month randomized clinical trial of yoga in MS, benefits to fatigue and energy were demonstrated. In this study, 69 people with MS were randomly assigned to one of three groups: weekly yoga class, weekly stationary bicycle exercise, and a waiting list control group. (People in the control group were placed on a waiting list before they enrolled in either the yoga or exercises classes after 6 months.) After the 6 month study period, both of the active groups assigned to either yoga or stationary bicycle exercise demonstrated improvements compared to the control group in the areas of energy and fatigue. As anticipated, there were no adverse events directly related to the practice of yoga in the study.



Mind-body therapies like yoga are also a practical therapeutic approach in MS because of their low risk of physical or emotional stress. In general, the financial cost of yoga therapy is also relatively low. The exercise of yoga also allows people with MS to engage in their treatment in a very active and engaged manner. While the physiologic mechanism of yoga’s symptomatic benefits in MS are not entirely known, there are reasonable theories proposed. First, there appears to be benefit in MS from participation in any regular physical activity like yoga. Multiple studies have suggested that any physical activity alone may be associated with improvements in quality of life, fatigue, and mood. Some hypothesize that yoga may additionally improve cognitive ability by exercising one’s attention on focused breathing and positioning techniques and by generally improving mood and reducing stress.

Despite yoga’s potential symptomatic benefits, it remains important to emphasize here that yoga practice has no evidence for any effect on the underlying MS disease process. Other MS disease

modifying medications should be continued as previously prescribed by the treating physician even while practicing yoga.

Before deciding to participate in yoga or other mind-body medicine approaches, there are important choices to consider. First of all, not all yoga practices are the same. Some types of yoga may even be risky for patients. For example, Bikram yoga is performed in very hot temperatures that may worsen MS symptoms in patients vulnerable to heat sensitivity. Other practices may be too difficult due to their demands on physical strength, balance, and flexibility. Certain practices of yoga that incorporate props or supports may actually be better than others for people with strength, balance, or flexibility limitations. We advise consulting with a yoga instructor before signing up to participate in a class. With the right class and instructor, yoga practices may be further modified to better address the needs of each individual with MS. It may just be right for you!

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**QUESTIONS? COMMENTS?
SUGGESTIONS FOR THE NEXT ISSUE OF
THE MS VETERAN? WE WOULD LOVE TO
HEAR FROM YOU!**

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INFLUENZA VACCINATION AND VETERANS WITH MS

Influenza vaccination season is beginning in the United States and will continue through the winter. The VA provides the influenza vaccine without a co-payment to enrolled veterans. Veterans with Medicare Part B or Medicaid can also receive the vaccine free of charge from healthcare providers outside of the VA. Many local and state health departments also offer free or reduced cost influenza vaccinations.

The United States experiences annual epidemics of influenza (flu) each year beginning in the late fall and continuing through the early spring. The symptoms of influenza are fever, muscle ache, headache, cough, sore throat, and runny nose. If there are no complications, many symptoms will be gone in 3-7 days, although cough and fatigue can continue for two or more weeks.

Influenza can cause many other complications, especially in people over fifty or who have other chronic diseases, such as MS. The other complications can include pneumonia, bronchitis, sinus infections, ear infections, and worsening of chronic diseases. The complications of influenza can be serious. Each year, about 36,000 people die and 225,000 people are hospitalized from these complications.

One way to reduce the chance of contracting influenza is by having an annual influenza vaccination. People need to be vaccinated every year for influenza because the vaccine only gives immunity for about one year and because the strains of virus vary from year to year. The influenza vaccine is not 100% effective, and some people will develop the flu even if they are vaccinated. However, it does reduce the chances of getting the flu and also helps to reduce the severity of flu symptoms if you get the flu.

Currently in the United States, 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 MS. *Since the flu shot is made of inactivated or killed virus, people cannot get the flu from a flu shot.* The flu nasal spray has not been studied for its safety when given to people with MS and may carry more risks. The flu nasal spray is a live (but weakened) virus vaccine. Live vaccines might increase the risk of MS relapses since they cause a mild infection. We recommend that people with MS receive the flu shot rather than the nasal spray.

There is very strong evidence that people with MS who get a flu shot are *not* more likely to have an exacerbation as a result of the flu shot. At the same time, there is also strong evidence that people with MS who



get the flu are more likely to have an exacerbation. ***Bottom line: influenza shots are safe for people with MS and, if appropriate, can lower the risk of influenza infection.***

Who should get a flu shot? The short answer is anyone who would like to reduce their chance of contracting influenza. The longer answer involves specific recommendations from the Centers for Disease Control and Prevention found below:

- ◆ Pregnant women;
- ◆ People 50 years of age and older;
- ◆ Adults who have chronic pulmonary (including asthma), cardiovascular (except hypertension), kidney, liver, blood, or metabolic disorders (including diabetes);
- ◆ Adults who have immunosuppression (including immunosuppression caused by medications or by HIV);
- ◆ Adults who have any condition (cognitive dysfunction, spinal cord injuries, seizure disorders, or other neuromuscular disorders)

that can compromise respiratory function or that can increase the risk for aspiration;

- ◆ People who live in nursing homes and other long-term care facilities;
- ◆ People who live with or care for those at high risk for complications from flu.

Many veterans with MS will fall under one of these seven groups-some due to age, another health condition, or as a result of MS-related treat-

ment or secondary disability. Other veterans may not fall into one of these groups, but may be interested in receiving a flu shot. **MS is not a reason to not be vaccinated.** Healthcare providers can provide more specific information centered on an individual's MS course, medications, and allergies and give specific recommendations about receiving a yearly flu shot.

Amy Poel, MPH, VA Puget Sound HCS

TRIALS OF ORAL DISEASE MODIFYING THERAPIES FOR MS

For many reasons, it would be desirable to have a medication which could be taken orally to modify the course of MS. One of the most common questions we hear in the clinic is "When are you going to have a pill I can take to control my MS?". The currently available disease modifying therapies for MS, medications which prevent relapses or slow progression, are all given by injection.

Injection is a method of administration that has a number of obvious disadvantages compared with oral administration. People with MS don't like injections because they can be painful and some individuals have needle phobia. Doctors don't like injectable treatments because people are more likely to miss doses of injected drugs than oral drugs, reducing the effectiveness of treatment.

There are also more potential complications, such as injection site skin reactions, with injected drugs.

Oral medications have the advantages of ease of administration, portability, and reduced cost of production. Because of these advantages, a number of clinical research studies are currently evalu-



ating new oral disease modifying therapies for MS.

Cladribine is an approved treatment for leukemia and lymphoma. It has shown promising results in previous MS trials when given subcutaneously. Oral cladribine is now being tested in an international Phase III trial and is designated by the Food and Drug Administration (FDA) as a "Fast Track Product", meaning study results will receive expedited review by the FDA.

CDP323 is an oral drug that blocks a white blood cell surface "adhesion molecule" called VLA-4. Blockage of VLA-4 is the same mechanism used by natalizumab (Tysabri), a currently approved monthly infusion for treating MS. A small study suggested that CDP323 can be used safely in MS, and a Phase II study is currently being conducted to see if it is effective.

Fingolimod (FTY 720) is a drug that causes lymphocytes to be trapped in lymph nodes so that they can not enter the brain or spinal cord. A Phase II study of Fingolimod taken orally once daily demonstrated a reduction in MRI and clinical activity without serious side effects, and a larger Phase III study is currently in progress. Fingolimod has a different mechanism of action than all currently marketed MS drugs, modulating a receptor on lymphocytes, called sphingosine 1-phosphate receptor, and preventing lymphocytes from leaving lymph nodes.

Fumarate (BG-12) is an immunomodulating drug used to treat psoriasis which has been tested

in a 24 week Phase II trial that showed a beneficial effect on MRI activity with some reduction in MS clinical disease activity. The drug was well tolerated and a larger Phase III trial is currently being conducted.

Laquinimod is thought to limit inflammatory cells from entering the brain and spinal cord. A Phase II trial of once daily dosing of laquinimod in people with MS showed a reduction in MRI activity and an acceptable safety profile. A Phase III trial is currently in progress.

Teriflunomide is an oral chemotherapeutic agent that modulates T lymphocytes and is chemically related to the drug leflunomide, currently marketed for rheumatoid arthritis. A Phase II study showed a reduction in enhancing MRI lesions in treated subjects and a trend toward reduced clinical disease activity. Treatment was well tolerated, and the drug is now being studied in a larger Phase III trial.

The careful testing of these 6 oral drugs for MS in clinical research trials is yielding very promising results. The drugs have generally been safe and well-tolerated. Encouraging clinical and MRI results have been reported in the smaller Phase II trials, which generally include 100-300 subjects with a placebo control group (A placebo is a “look-alike pill” without active drug in it, used for comparison with active drug in clinical research trials.). The completed Phase II trials are leading to larger Phase III trials, in which up to 1,000 or more MS subjects are taking the drug being tested or placebo for 1-3 years to more definitively determine the drug’s effectiveness, safety, and tolerability. Phase III trials are the key trial phase leading to FDA approval of a drug, and several of these oral drugs for MS will receive speedy review by the FDA as “Fast Track Products”.

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WANT TO LEARN MORE ABOUT MS?

Join the **Monthly Patient Education Conference Call** and learn first hand about MS from MS experts and other health care professionals!

DATE: The 2nd Monday of Every Month

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

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

Participation is free and callers are anonymous. Do you have questions about the call or topic for the month? Contact Angela Young at 1-800-463-6295, ext. 7133 or Angela.Young4@va.gov.

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REDUCE YOUR STRESS

- ◆ Simplify daily routines and expectations
- ◆ Schedule daily, weekly, monthly, and yearly breaks
- ◆ Consider hiring help for routine chores
- ◆ Explore on-line purchasing of groceries and household goods
- ◆ Practice health promoting behaviors - good rest, a balanced diet, and exercise
- ◆ Schedule your own health promotion and follow-up with your health providers
- ◆ Use your health benefits for appropriate emotional support
- ◆ Develop and strengthen your support network
- ◆ Explore the spiritual aspect of your life
- ◆ Connect with community resources
- ◆ Share your experiences with others



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