

VA MULTIPLE SCLEROSIS CENTERS OF EXCELLENCE

MS VETERAN

SERVING THE HEALTH CARE NEEDS OF VETERANS WITH MS

THE BRIGHTER SIDE OF LIFE

I've had MS for over 34 years, experiencing my first MS exacerbation when I was 18 years old. My MS is unpredictable, but so is life. Some days are good, while other days are a little less good. Over the years, I've learned that I can't control everything that happens in life, but I can control how I react to life's unexpected changes and challenges. I can choose to find the good instead of focusing on the bad.

I was 20 years old when I joined the Army in April 1984. I was deployed to Frankfurt, Germany, which was West Germany at the time. I worked in transportation as a 64' Charlie. In November 1985 I was seen by a neurologist at the University of Erlangen-Nürnberg, where I was diagnosed with MS. While no one wants to receive the bad news that they have a disease, I felt relief knowing what was causing me to feel so poorly. When my MS flared up, people thought I was acting out. The neurologist who examined me when I was 18 told my parents it was all in my head. Knowing that I had MS gave me some control in a situation where I felt I had none, and I soon learned there were ways to manage the disease.

In May 1987 I received an honorable, medical discharge from the Army. The discharge followed a debilitating exacerbation at my base in Fort Carson, CO where I became paralyzed from the neck down and my lungs started to shut down. I was paralyzed for almost 6 months. My doctor told me that I may

never walk again. I spent several days lying in bed, wondering what the future would hold. I knew MS symptoms could come and go and one day I made the decision that I was not going to let MS dictate my life. I started physical therapy and found that with time and hard work, I was able to regain my mobility and even start running again. Building myself back up from something that knocked me so low showed me that I could tackle any challenge.



Following the Army, civilian life kept me on my toes. I soon met my life partner who happened to be a dairy farmer; we've had 24 wonderful years together. I work the farm full-time with my husband, tending to the animals and finding creative ways to increase milk production, expand the herd size, and improve the efficiency of the farm. Farming challenges me mentally as well as physically. I have to listen to my body and decide when to push through the MS, when to slow down, and when to rest. My husband supports my needs and we've found our hard work on the farm has strengthened our communication and support for each other. We work together, not against each other.

My husband and I have raised four beautiful children. Two of my children are autistic, and while that has its own set of challenges, I've found that I'm

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able to meet those challenges head on. I volunteer for a special needs class at my church, using what I've learned in taking care of my own children for other children with developmental disabilities. I've learned the value of patience and perseverance as I see my children meet life's daily challenges. The perseverance I see in them helps me get through those days that seem a little tougher than others.

My life has had its fair share of challenges, but with those challenges I've found new opportunities and

experiences. I've learned to make adjustments so that I can keep doing the things I love. I don't compare myself to others and I never think that something I do is not good enough. I do my best and that's all anybody can ask of me. When I wake up every morning I see all the wonderful people and things I have in my life and I'm not worried about what I don't have. It's all about perspective and I've decided to look at the brighter side of life.

Dawn Rittmeyer - Winnebago, IL

INTEGRATIVE HEALTH AND WELLNESS

No longer secret practices hidden from your health care provider, people are talking about complementary and alternative medicine (CAM). CAM practices, which can include dietary supplements, food and diet modifications, and mind-body therapies, are increasingly accepted by patients, providers, health care systems, and insurance payers as important aspects of comprehensive care and wellness. In the US, 38% of adults use CAM, while 80% of people with MS report using CAM.

What exactly is complementary and alternative medicine? When the US Food and Drug Administration (FDA) reviews and approves the safety and effectiveness of a drug or device, it becomes a part of conventional medicine.

Complementary means using a non-mainstream practice together with conventional medicine.

Alternative means using non-mainstream practices in place of conventional medicine. For instance, using an herb to manage your MS alone would be alternative. Using an herb together with an MS disease-modifying drug would be complementary. Bringing conventional and complementary approaches together in a coordinated way is known as "integrative" health care. Integrative health is gaining recognition and is an acknowledgment of your preferences.

Evidence of the increased recognition is a change in the name of the National Institutes of Health, National Center for Complementary and Alternative Medicine to the National Center for Complementary

and Integrative Health (NCCIH). NCCIH has studied complementary medicine practices since 1998. Their aim is to study the safety and effectiveness of CAM to help you make the right decisions about your health.

Driving the increased recognition of CAM is you. The National MS Society did some "social listening". They looked at what was being said by people affected by MS on the internet from blogs, message boards, social networks like Facebook, video sites like YouTube, and their own website. The most frequent postings related to wanting emotional support and wellness. In the past few years the interest in wellness strategies for symptom management has been high, exceeding the interest in medications.



Wellness for you may mean changing your lifestyle to adopt health-promoting behaviors like diet and exercise. It may mean taking a yoga class, increasing your circle of friends, or adding supplements to your diet. Wellness is about physical, emotional, spiritual, and psychological well-being. Wellness is important. According to the National MS Society's recent survey, wellness is the most important priority for people living with MS. The wellness strategies survey respondents were most interested in were diet, cannabis, exercise, vitamins, supplements, and mindfulness. Many said they use complementary approaches to help manage their MS symptoms.

While the survey respondents were very interested in using wellness strategies and complementary

approaches, very little is known about the effect of these methods on MS symptoms and disease management. The American Academy of Neurology CAM Guideline Development Subcommittee recently reviewed studies of CAM therapies for treating MS. The Subcommittee found little evidence, from the few studies that met criteria for good science, that CAM is effective at treating either MS symptoms or the disease. They were concerned about the lack of FDA approval to assure the safety and effectiveness of CAM therapies, the lack of information to know if CAM therapies interfered with MS prescription drugs, and noted that CAM therapies are generally not covered by insurance. The following is a summary of highlights from the Subcommittee:

- Ginkgo biloba does not improve thinking ability, although it may help reduce tiredness. It is well tolerated, but may increase bleeding; watch if you take a blood thinning drug.
- Low-fat diet and fish oil probably do not help decrease MS symptoms or relapses.
- Reflexology (pressure on areas of the feet, hands, or ears) might help reduce numbness and tingling.
- Bee sting therapy might not help MS symptoms, and can cause an allergic reaction and possible death, itching, tenderness and swelling at the sting site, and flu-like symptoms.
- Cari Loder regimen (a combination of amino acids, vitamin B12, and antidepressants) might not help improve MS symptoms, and can cause constipation, dry mouth, nausea, and insomnia.
- Magnet therapy (putting magnets in contact with the body) probably helps reduce tiredness, but does not help depression.
- Oral cannabis extract may reduce symptoms of spasticity and nerve pain. A derivative of tetrahydrocannabinol (THC), called dronabinol (trade name, Marinol) also may reduce spasticity and help lessen frequent urination. Dronabinol does not reduce tremor and has not been shown to improve sleep, anxiety, tiredness, thinking, overall bladder problems, or quality of life. There is no good evidence that smoking marijuana is safe or helpful for treating MS. Cannabis extracts

do have side effects, including difficulty with attention and concentration, drowsiness, and possible long-term memory impairment, which could worsen cognitive problems and fatigue caused by MS. (VA providers cannot prescribe or recommend marijuana and cannabis as Federal law prohibits their use. It also is VHA policy to prohibit VA providers from completing forms regarding a Veteran's participation in a State marijuana program. State laws authorizing the use of marijuana, even when characterized as medicine, are contrary to Federal law.)

INTEGRATIVE HEALTH AND WELLNESS

The VA has established 13 Integrative Health and Wellness (IHW) clinics and 80% of VA Medical Centers incorporate health and wellness into medical practice, referring Veterans when facilities lack programs. IHW programs include acupuncture, nutrition workshops, massage, yoga, meditation, chiropractic services, and many other specialized options. Talk to your provider about your wellness goals and referrals to IHW programs.

Heidi Maloni, PhD, APRN, ANP, MSCN - DC VA

LEARN MORE ABOUT MS

MSCoE produced free DVD's from our live education programs. They are a great way to learn more about MS in the comfort of your home.

- 1 BOWEL AND BLADDER MANAGEMENT IN MS
- 2 MS AND EMOTIONAL DISORDERS: APPROACH TO MANAGEMENT
- 3 MS, COGNITION, AND BRAIN IMAGING: UNDERSTANDING COGNITIVE DYSFUNCTION
- 4 MS MODIFIABLE RISK FACTORS
- 5 PAIN AND PALLIATIVE CARE IN MS
- 6 SEXUAL INTIMACY AND MS
- 7 STAYING MOBILE WITH MS PART I AND II: MOBILITY FOR PEOPLE WITH MS AND WHEELED MOBILITY AND MS

If you are interested in receiving our free DVD's, call (800) 463-6295, ext. 7133 or send an email to MSCentersofExcellence@va.gov

ESTRIOL FOR MS?

Recently you may have heard some excitement about research on hormone therapy to treat MS. Results from the study “Estriol combined with glatiramer acetate for women with relapsing-remitting multiple sclerosis: a randomized, placebo-controlled, phase 2 trial” by Dr. Rhonda Voskuhl (UCLA) and colleagues was published online November 29, 2015 and in print January 2016 by *Lancet Neurology*. Let’s take a closer look at this interesting study.

Where did the idea for hormone use come from?

Many women with MS have fewer relapses when pregnant, especially in the 2nd and 3rd trimesters (months 4 to 9). Since estriol, a type of estrogen, increases during pregnancy researchers wondered if estriol might be the key to this improvement. If so, we’d expect to see a benefit if we gave estriol to women with MS. Low-dose estriol can be used to manage some menopausal symptoms and it is relatively inexpensive. If estriol helps women with MS, it might then be used as another alternative disease-modifying therapy (DMT).

Why was this study done? An earlier small study of six women with MS taking estriol suggested possible benefit. Other preliminary work in animals also suggested a possibility of benefit. This two year study was the next logical step to determine if there might

be benefits in terms of relapses, magnetic resonance imaging (MRI), and symptoms.

Who paid for this study? Funds came from the National Institutes of Health (specifically, the National Institute of Neurological Disorders and Stroke), the National MS Society, and various foundations. The pharmaceutical company Synthetic Biologics donated the estriol. Participants received their own glatiramer acetate (Copaxone) through their regular health care provider.

Who participated in this study? 164 women aged 18 to 50 with relapsing-remitting MS enrolled in the study. 158 of these women completed at least one study visit while 113 participants completed the two year follow-up.

What medication did participants receive? The women enrolled in this study were randomly assigned to take either 8 mg of estriol or a similar looking placebo pill each day for 2 years. All of the women also took a daily injection of glatiramer acetate. Of the 113 women who completed the 2 year study, 57 were on estriol and 56 were on placebo.

What was measured to see if estriol helped? The study focused on the number of relapses per year that occurred during the 2 years of the study. To count, relapses had to involve new or worsening neurological symptoms, last at least 48 hours, and be confirmed by medical examiners who did not know whether the subjects were taking estriol or placebo. Researchers also looked at whether there were changes in MRIs - for example, if the women in either group lost more brain volume - and whether they experienced some changes in MS symptoms.

Was the relapse rate better with estriol and glatiramer acetate than with placebo and glatiramer acetate? At 2 years, the women in the estriol group had an annualized relapse rate of 0.25% (comparable to an average of one relapse in about 4 years) while the women on placebo had an annualized relapse rate of 0.37% (comparable to an average of one relapse in about 3 years). However, there was so much variability within the groups that statistically it was not clear if this apparent difference was significant or was just due to chance.

PATIENT EDUCATION TELEPHONE CALL

Join MSCoE's free, monthly conference call and learn firsthand about MS from MS experts and other health care professionals.

DATE: 2ND MONDAY OF EVERY MONTH

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

TOPIC: DIFFERENT TOPIC EVERY MONTH

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

If you have questions about the call or topic of the month, call (800) 463-6295, ext. 7133, send an email to MSCentersofExcellence@va.gov, or visit our website at www.va.gov/ms.

Were there differences on MRI? Somewhat surprisingly, the estriol group did not show improvement on MRI scans compared with the placebo group.

What about side effects, or risks, from estriol? As expected, the estriol group was more likely to have irregular menstrual periods or spotting. The study was too small and too short to show risk for conditions such as uterine or breast cancer.

What can we learn about estriol and MS from this study?

- We don't have strong evidence that estriol decreases relapses or MRI changes in women with MS.
- The key to the reduced relapse rate we see in many women during pregnancy is still unknown.
- We still need information on the long-term effects of estriol on risks of endometrial cancer, breast cancer, or other serious problems.

MS & ME: VETERAN YOUTUBE VIDEOS

View the MSCoE produced videos, featuring Veterans telling their MS stories with explanation and commentary by VA medical providers, at www.va.gov/MS/products/videos.

- The short-term side effects of estriol were irregular periods.
- We don't know how estriol may affect men.
- Additional research is needed to determine if estriol helps decrease MS changes in women.

This study provides information to guide additional larger scale clinical trials of estriol while also suggesting that we should consider whether there are factors in pregnancy other than high estriol levels that lower MS relapse rate. Watch for other medium-sized and possibly larger research studies in the future.

Lynda Hillman, DNP, ARNP, MSCN - Seattle VA

LIVING YOUR BEST LIFE WITH MS

People with MS want to know what they can do today to feel their best, and if lifestyle interventions such as diet, stress-management, and physical activity, have any benefits in reducing the impact of the disease. Over the years the concept of health has evolved to include a dynamic sense of well-being across multiple dimensions of life, and not just the absence of disease.

Wellness is attainable for everyone, even when living with a chronic illness. Achieving health and wellness is a lifelong process in which people make intentional choices, set personal priorities, and engage in health-promoting activities. Intentional choices include choosing the foods you eat, choosing whether to smoke, choosing to spend time with friends and family, choosing to engage in physical activity, devoting time to intellectual stimulation, and more.

Making healthy choices that promote satisfaction in the various dimensions of wellness can help you attain a sense of well-being and life satisfaction. Here is what we mean by the '*dimensions of wellness*':

Physical: Making positive lifestyle choices about regular physical activity/exercise (such as walking, swimming, and yoga) geared to one's abilities, healthy eating, MS care and primary care, and preventive health behaviors (including smoking cessation, limited alcohol use, and attention to personal safety).



Social: Developing positive, healthy relationships that nurture interconnectedness with family, friends, and community.

Emotional: Developing coping strategies to enhance problem solving, manage stress, foster a positive outlook, and develop resilience in the face of unpredictable changes, while paying attention to

mood changes, including depression and anxiety, that may require treatment.

Occupational: Engaging in meaningful and rewarding activities that promote a sense of purpose and accomplishment, including opportunities to contribute one's unique skills, talents, and knowledge to others at home, at work, or in the community.

Spiritual: Developing a world view that provides a sense of peace and harmony, and enables one to cope and adapt throughout life - with the ultimate goal of finding meaning and purpose in the face of one's personal challenges.

Intellectual: Engaging in mentally stimulating and challenging activities that lead to personal growth, enhanced creativity, and new learning.

As people manage their MS, they want to understand the role of conventional medicine, including disease-modifying therapies and symptom management medications, as well as how they can integrate lifestyle interventions and complementary approaches to maximize their well-being. They may wonder about the impact of a specific diet or exercise regime on MS or about the potential benefit (or harm) of other approaches like vitamin supplements, probiotics, or acupuncture. Many have felt frustrated by a lack of support from health care professionals, who say there is not sufficient scientific evidence to provide guidance, or who may not have the time or expertise to discuss it with their patients.

To address these questions the National MS Society has created a discussion guide for people with MS and their health care providers for use to help facilitate conversations about how to integrate lifestyle and complementary approaches with conventional health care to yield optimal health and wellness. This guide can be found at www.nationalMSSociety.org/wellnessguide. Other resources about wellness and MS including information about diets that have been proposed for MS, exercise and physical activity, mindfulness, and other strategies can be found at www.nationalmssociety.org/Living-Well-With-MS.

While many things may feel beyond one's control when living with an unpredictable and chronic disease like MS, exerting control over your personal lifestyle

behaviors can help alleviate feelings of helplessness. Setting your own personal wellness objectives and discussing them with your health care providers are the first steps to maximizing your well-being, even in the context of MS. Some tips for incorporating wellness behaviors into everyday life include:

- Make time to relax every day, even if only for 10-15 minutes - listen to music, meditate, listen to a guided relaxation on CD
- Consider making a small healthy change to your diet - replace dessert with a piece of fruit twice per week, use whole grain flour when baking
- Explore how yoga, tai chi, or another physical activity can be modified for your level of ability and interest
- Make a plan to enjoy time with friends or family at least once per month - watch a movie together, enjoy a meal together, take a walk together
- Listen to a book on tape, attend a lecture, take an online course, visit the museum - stimulate your curiosity and enhance your intellectual well-being

For additional information about MS, please contact the National MS Society at (800) FIGHT-MS.

Debra Frankel, MS, OTR - National MS Society
Deborah Hertz, MPH - National MS Society

CAREGIVER AND FAMILY TELEPHONE CALL

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

DATE: 4TH MONDAY OF EVERY MONTH

TIME: 2 PM - 3 PM ET, 1 PM - 2 PM CT,
12 PM - 1 PM MT, 11 AM - 12 PM PT

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

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

SATURDAY: 10:30 AM - 6 PM ET

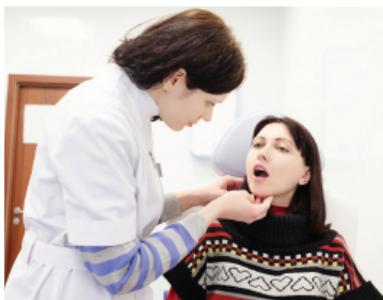
SWALLOWING, SPEAKING, AND THINKING

Individuals with MS experience a wide variety of symptoms, which may impact swallowing, speech, or cognition. Speech-language pathologists, often called SLPs, can evaluate and provide treatment options should difficulties in these areas become problematic.

SWALLOWING

Swallowing difficulty, called *dysphagia*, can be characterized by fatigue during meals, difficulty chewing or swallowing, coughing and choking on foods and liquids, sensations of something “stuck” in the throat, increase in reflux (sometimes called heartburn or gastroesophageal reflux disease), or unexplained chest infections. If there are concerns about swallowing, a speech-language pathologist may evaluate swallow function and provide additional strategies such as dietary texture changes, postural movements, or possibly exercises to help support safe and efficient swallowing. In rare cases, alternative means of nutrition may be considered. General safe and comfortable swallow strategies include:

- Reducing distractions during meal times
- Eating smaller meals more frequently throughout the day
- Sitting as upright as possible while eating and for 2+ hours after
- Small bites and sips at a slowed rate
- Alternating bites of food with sips of liquid
- Keeping foods soft and moist, using sauces



SPEAKING

Just as the muscles involved in swallowing can be impacted by MS, the muscles involved in speaking can, too. Speech difficulties, called *dysarthria*, are relatively common for people with MS, with about 40-50% of individuals reporting changes in their communication. Speech difficulties might include

slurred-sounding speech, increased fatigue with conversation, or reduced vocal loudness. This is often mild and may not impact overall intelligibility or successful communication, but can be of concern to the individual. Some general strategies to support effective communication include:

- Breath support and diaphragmatic or “belly” breathing
- Increased speaking loudness
- Reduced speech rate
- Exaggerated articulation of each sound

In more severe case of MS, speech supplementation or speech-generating devices might be necessary. When dysarthria interferes with safety, functional communication of daily needs/desires, or general quality of life, both low-tech and high-tech devices may be useful. Low-tech devices include alphabet and eye gaze boards, pictures, notebooks, or whiteboards, bells and buzzers, and simple yes/no systems. High-tech alternatives include voice amplifiers, text-to-speech devices, and applications (“apps”) that can be found on smartphones and tablets. Some apps to assist with communication include Proloquo2Go, LAMP, Speak for Yourself, and SmallTalk.

If recommended, there are more complex, computer-based devices available, called speech-generating devices. These devices have a variety of modes of access dependent upon physical abilities that may include via joystick, mouse, or eye gaze technology. Tobii, Dynavox, GoTalk, and Tango might be familiar brand names. It is important to work with a knowledgeable professional to determine the best-suited complex, computer-based device, as indicated.

THINKING

Cognition is a fancy word to refer to thinking processes, such as attention, memory and learning, or executive functions (think planning, organizing, goal setting, and time management). Some individuals with MS report changes in cognition which may include:

- Increased reliance on organizational systems such as dayplanners, smartphones, or alarms
- More difficulty making decisions



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- Reduced ease of remembering names, places, conversations, or recent events
- More difficulty “multitasking,” tuning out distractions, or focusing for a long period of time
- Problems with word-finding
- Slowed information processing

Typically, these changes do not impact an individual’s overall ability to function independently, but may require more support and strategies including use of sticky notes, maps or GPS devices, dayplanners or smartphones, or requests for repetition or for written information. General recommendations to support cognition include:

- Focus on one task at a time
- Reduce distractions
- Write it down
- Actively listen: request slower speed, repetition, and clarification as needed

- Use calendars, dayplanners, computers/tablets, or smartphones to keep track of appointments, and for planning/prioritization
- Use word-finding strategies: describe the word, think of the first letter or sound of the word, use a similar word, or use gestures
- Keep your mind active and engaged with work, games, social activities, reading, playing music, or physical exercise
- Eat well, get enough sleep, and practice basic healthy habits

If an individual with MS experiences difficulty or concern about issues related to speaking, eating and drinking, or thinking, consider a visit to a speech-language pathologist who may assist you with providing more information, strategies, or possibly therapy to support cognitive, communication, and swallowing issues.

Joanna Close, MS, CCC-SLP - Portland VA