

VA MULTIPLE SCLEROSIS CENTERS OF EXCELLENCE

MS VETERAN

SERVING THE HEALTH CARE NEEDS OF VETERANS WITH MS

A SECOND GENERATION VETERAN WITH MS

I left the Army in December of 1980 after serving 8 years as a ground support equipment, missile, and computer repairman in Germany. I then served as an instructor at the Field Artillery School in Fort Sill, OK. Following my military career, I joined the Lawton Police Department which is where I learned that I have MS. I went on to serve another 3 years with the Lawton Police Department, completing a 27 year career.

At the time of my diagnosis I was injured on duty as a police officer and after initial testing, I was told I had a brain tumor. The doctor scheduled me for surgery and after further testing I learned the tumor was really a demyelinating lesion. The doctor told me I had MS but I had never heard of it before and asked "Just what is MS?" He looked at me and said, "It is just a slow and painful death". I was crushed. I called a close friend and told her what I had just learned. When I went to see a neurologist it was explained to me that I was going to be okay and I was not going to die from MS. He then clarified that the doctor who did the surgery had no specialty training in MS.

In November of 2007, I relocated to central Oklahoma and transferred my MS care to the VA Medical Center in Oklahoma City (OKC VAMC). I had a new career working for the state of Oklahoma, which prompted my move. I have been able to remain very active and stay working with my MS. I worked as a security officer at

the state capitol, then as an instructor for the Oklahoma State Bureau of Investigations and the Law Enforcement Technology Development Department. I am also a Trustee on the Oklahoma Police Pension and Retirement Board, appointed by the Speaker of the House for the State of Oklahoma.



I am very thankful for the Spinal Cord Injury/MS Disease Team at the OKC VAMC and most of all Kimberly Kreyborg, PA-C, MSCS. Because of her help, I now understand the importance of being compliant with my recommended treatment plan and also how important it is to communicate any

concerning symptoms that I have. I have learned that there is a difference in being treated by a provider who has specialty training in MS.

My life has been very positive because of the people in it caring enough to show me what a bright future I have. I realize how blessed I am to have my loving wife Jeanie and my best friend Butch who was there at my side as I was

WHAT'S INSIDE

- ▶ A Second Generation Veteran with MS 1
- ▶ Home Safety Evaluation 2
- ▶ Understanding Your Medications 3
- ▶ Being Mindful of the Present Moment 5
- ▶ Speech and Swallowing 6

being diagnosed. I am also thankful for my dad who is there when I have any concerns.

Since I learned that I have MS, I have gone sky diving and my wife and I stay busy by traveling. We are also season ticket holders for the University of Oklahoma Sooners football team and tailgate with other fans before home games. I have also enjoyed being very active in helping

other people with MS by encouraging them to stay on track with their MS medications.

I think it is important for Veterans to be aware of the many programs the VA has to offer them. The VA has helped me and my family. I am a second generation Veteran and I have not let MS control my life, instead I am in control of it!

Charles Kerr - Oklahoma City, OK

HOME SAFETY EVALUATION

Our home is the place where we live and it is filled with an abundance of memories. But, what happens when your home presents challenges to your safety and independence? While moving and purchasing another home is not always an option, a home safety evaluation may help.

A home safety evaluation is a process used to identify hazards that may affect your safety in the home. It provides recommendations for eliminating these hazards through the use of assistive devices and home repairs and modifications. The benefits of a home safety

evaluation include increased use of the home as well as safety, security, and independence for you. A home safety evaluation is often helpful for those who have experienced a fall in the home, have balance issues, or have observed a decrease in their physical mobility. It is also useful for those who have noticed changes in their cognition (memory, attention, making decisions) and sensory systems (vision, hearing, taste, smell). If you have experienced any of these issues, notify your provider. Your provider will assess your concerns, request a consultation for an evaluation, and possibly refer you to physical therapy for an assessment of balance and gait issues.

For a home evaluation, an occupational or physical therapist will come to your home to evaluate your needs and identify strengths and weaknesses of your home. The therapist will assess the entrance to your home as well as the hallways, staircases, living room, kitchen, and bathrooms for various hazards. These hazards may include inadequate lighting, lack of or unstable handrails and grab bars, unsafe steps, slippery or uneven flooring, inaccessible cabinets, slippery tubs, and high or low toilet seats. Following the evaluation, the therapist will provide recommendations to improve your safety in the home.

The VA offers various resources and grants to help you cover the costs of the therapist's recommendations. The Prosthetics Department of your local VAMC can help you obtain

FAMILY AND CAREGIVER CONFERENCE CALL

Join the free monthly conference call to connect with people supporting those with MS. A variety of educational topics and resources will also be presented!

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 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

assistive devices and offers a home modification grant through the Home Improvements and Structural Alterations (HISA) program. The HISA grant covers modifications to improve access to the home and essential lavatory and sanitary facilities. It can be used for installing handrails, lowering electrical outlets and switches, improving paths or driveways, and increasing access to kitchen and bathroom counters. The grant is available to service-connected (limited to \$6,800) and non-service-connected (limited to \$2,000) Veterans. Detailed information on the HISA grant is available at www.prosthetics.va.gov/HISA2.asp.



The Special Home Adaptation (SHA) grant (limited to \$63,780) and the Specially Adapted Housing (SAH) grant (limited to \$12,756) are

provided through the VA Benefits Office. These grants are available to Veterans who have a service-connected disability. Both grants allow you to modify an existing home for a barrier-free living environment while the SAH can be used for constructing a new, adapted home. A Temporary Residence Adaptation (TRA) grant (up to \$14,000 from the SHA grant and up to \$2,000 from the SAH grant) may be available for those who are or will reside temporarily in a home owned by a family member. You can access detailed information about these grants at www.benefits.va.gov/homeloans/sah.asp.

The VA has resources that will allow you to maintain your independence and improve your safety in the home with the installation of assistive devices and home modifications. Please contact your provider about any home safety concerns that you may have.

[Lisa Mitchell, RN, BSN, MSCN - Baltimore VA](#)

UNDERSTANDING YOUR MEDICATIONS

Do you look at your prescription bottles and wonder - how did I get to this point? What are all these medications costing me, not only in dollars but in my quality of life? You aren't alone with these questions. Many people take medications for chronic diseases like MS, often as many as 20 different medications a day.

KNOWING YOUR MEDICATIONS

It is important to keep a record of what medications you are currently taking. Be sure to include the name, dose, and directions for each prescription. Remember to include any over-the-counter (OTC) medications like acetaminophen (Tylenol®), herbal supplements, and vitamins that you take on a regular basis. Many of these medications and supplements can interact with your prescription medications, which might

cause side effects or make your medications less effective. When purchasing OTC medications, be sure to look at the list of active ingredients. Many of these products contain more than one ingredient, especially products for cold/flu or allergies. Some of these ingredients may cause undesired reactions when mixed with your prescription medications or with the health conditions for which you are being treated.

Be sure to check before beginning any new products. You may be considering obtaining prescription medications or supplements from other countries which are not available in the US. These medications may pose a health risk. Some imported medicines may have been made using unsafe procedures or may not have been checked for safety or effectiveness. Vendors may make claims or suggest uses for imported medicines that the US Food and Drug Administration (FDA) has not approved. Some products may have been

made using addictive, dangerous, or impure ingredients which might not be listed on the label.

VA PRESCRIBED MEDICATIONS

Veterans may hear that the VA will only cover medications on the formulary. What does formulary mean in the VA? The VA National Formulary (VANF) is a comprehensive list of medications approved by a group of physicians and pharmacists from VA facilities throughout the nation. Formularies promote rational, clinically appropriate, safe, and cost effective drug therapy. This list is carefully developed to include a full-range of medications necessary to treat medical conditions.

When a medication is called non-formulary, your provider will need to request this non-formulary medication by completing a special request form. This form is then reviewed to ensure that the non-formulary drug requested is being used appropriately and for an FDA approved use. This process may take a few days. If the request is denied, there is an appeal process that would allow the request to be reconsidered. You or your provider can get more information on the appeal process from your local VA pharmacy.



You might wonder if you can get prescriptions from non-VA providers filled at your VA pharmacy. In order to receive your medication from the VA, a VA provider needs to see you and prescribe your medication. VA providers will work closely with your private provider to ensure continuity of care and it is important to supply your VA provider with your medical records from your private provider.

Many MS medications are injectables: self-administered syringes and auto-injectors that are prefilled, easy to use syringes. Your provider

can teach you how to safely self-administer medications using a syringe and how to use the auto-injector, which is a spring-loaded syringe. Auto-injectors can improve the safety of injections and make it a little easier to take your medication. They should be replaced yearly and when new models are available. The auto-injectors can be accessed through your provider.

DISPOSING OF PRESCRIPTION MEDICATIONS

You might have questions about the best way to dispose of medications you no longer take. It is not safe to flush drugs down drains. Drugs flushed down drains can harm the water supply that we and the wildlife drink. The first step is to check the label of the drug container to see if guidance has been provided regarding its disposal. If there are no instructions on the label, the information can sometimes be found on the internet or by calling the manufacturer of the drug. If this step is not successful, contact your local VA pharmacy to find out if they can dispose of your medication. Another option is to take advantage of community drug disposal programs. These programs allow the public to bring in their unused or expired medication for proper disposal. Check with your local government to see if this service is offered in your area.

Many drugs can be thrown out with the trash but precautions should be taken before doing this. Medications can be left in their original bottle but you should remove names and prescription numbers on labels for safety. Add some water or soda to pills to start dissolving them. Mix pills or liquid drugs with something that you cannot eat, like cat litter, saw dust, or dirt. Close the bottle lid and secure with duct or packing tape. Place the bottle(s) inside a non-see through container like a coffee can or detergent bottle. Tape that container closed and hide the container in the trash. Do not put the container in the recycle bin.

Many people with MS have questions about disposing of needles which are used for medications. The laws that guide safe disposal of needles vary from state to state. To find out how to dispose of needles in your area go to www.safeneedledisposal.org and search by your state. Many communities offer a drop off site that you can use and you can also check with your local VAMC for information on disposal.

A reminder... make sure that you bring a list of all of your over the counter and prescription medications to each clinic visit. Ask your provider about possible medication interactions and be informed about how and when to take your medications, as well as how to dispose of them properly.

Kathryn Tortorice, Pharm D, BCPS - Hines VA
VA Pharmacy Benefits Management Services

BEING MINDFUL OF THE PRESENT MOMENT

Recently, classes teaching mindfulness have received a great deal of attention in health care. This upsurge in interest has been fueled by multiple studies showing that becoming more mindful (being more aware of what is happening in your life, thoughts, and emotions in the present moment) results in lower stress and a greater sense of wellbeing. What is mindfulness? Mindfulness has been defined in the *Journal of Alternative and Complementary Medicine* as: ***The awareness that emerges, by way of paying attention, on purpose, in the present moment, and nonjudgmentally, to the unfolding of experience moment by moment.*** When this definition is examined, a lot of information can be found about how mindfulness practice reduces feelings of stress.

First phrase... the awareness that emerges suggests that it is indeed possible to develop a greater understanding of ourselves, others, and life circumstances - and that this will occur naturally.

Second phrase... by way of paying attention reminds us that bringing attention to our experience helps us to grow. We begin to realize that our thoughts come and go throughout the day, and that these thoughts may or may not be true. Realizing that thoughts about oneself, others, or the future are not necessarily an

accurate representation of reality can help to reduce feelings of stress. For example, the thought "I won't be able to be happy because of my MS" can be seen as an idea or thought that may or may not be true.

Third phrase... on purpose means that it takes a conscious effort and personal motivation to help bring about a shift in perspective.

Fourth phrase... in the present moment refers to the ability to focus on what is happening in your life at this very instant. Getting distracted by thoughts of events that occurred in the past, or carried away by worries or ideas about the future,

LEARN MORE ABOUT MS!

MSCoE produced DVD's from our live educational programs. They are a great way to learn more about MS issues.

- ▶ **UNDERSTANDING BRAIN IMAGING AND COGNITIVE DYSFUNCTION**
- ▶ **MS THERAPIES: STRATEGIES FOR OPTIMIZING DISEASE MANAGEMENT**
- ▶ **PAIN AND PALLIATIVE CARE IN MS**
- ▶ **SEXUAL INTIMACY AND MS**
- ▶ **STAYING MOBILE WITH MS PART I AND II MOBILITY FOR PEOPLE WITH MS AND WHEELED MOBILITY AND MS**

Interested in receiving a set of free DVD's? Contact Jaimie Henry at (800) 949-1004, ext. 53296 or Jaimie.Henry@va.gov.

can stand in the way of living fully in the present moment. For example, research shows that ruminating (turning things over and over in your mind) is a key factor in the relapse of depression. Learning how to let go of these cycles of rumination is an important part of mindfulness.

Fifth phrase... nonjudgmentally refers to a non-critical, kind attitude toward experience. This nonjudgmental attitude means having openness to all experiences, including experiences we might not choose, such as painful thoughts or feelings. This is not to be confused with being passive. Rather, it is based on the observation that what is here... is here.

For example if we are experiencing feelings of sadness or grief, judging yourself for having those feelings won't help the situation. Although at times we can distract ourselves from unpleasant feelings by doing something else, in the long run personal growth is facilitated by 'staying with' a feeling and having an attitude of openness and nonjudgment. Staying with an experience and having an attitude of kindness and curiosity allows us to have greater insight into our values and motivations. What makes this

process easier is learning to recognize and let go of added layers of self-criticism which promotes acceptance of oneself. When a person learns to regard oneself with less judgment, this often has the effect of spilling over to others, who are then viewed with less judgment.

Sixth phrase... unfolding of experience, moment by moment indicates that our thoughts, emotions, and life experiences are always in a state of flux. Our experiences can change gradually and change may not be so obvious, or change can be quite abrupt and very obvious. Mindfulness practice helps a person to recognize the fact that experiences are changing or "unfolding", and acceptance and recognition of change helps us to adopt a realistic mindset and openness to these new experiences.

Combining the above factors helps to bring about a shift in perspective, allows an increased focus on the moment, and often reduces identification with the inner dialogue we have in our minds. The shift in perspective is one of greeting life's experience with an attitude of openness, friendliness, and with an eye toward gaining added understanding of what is going on. This shift can lead to an enhanced quality of life, decreased stress, better coping mechanisms, improved sleep, diminished risk of depression, and possible reduced need for pain medications.

How is mindfulness taught? Mindfulness is usually taught through classes which teach mindfulness meditation. Meditation is a broad term used to describe exercises that develop skills in paying attention. An increasing number of VA facilities now offer mindfulness meditation programs, including a program called Mindfulness-Based Stress Reduction, which has been shown in studies to increase mindfulness skills, decrease stress, and increase wellbeing. For more information contact your VA provider or visit your local VA education department.

David Kearney, MD - Seattle VA

PATIENT EDUCATION CONFERENCE CALL

Join the 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#**

Do you have questions about the call or topic of the month? Contact Angela Young at (800) 463-6295, ext. 7133 or send an email to Angela.Young4@va.gov.

SPEECH AND SWALLOWING

Approximately 40% of people with MS will experience speech and/or swallowing problems. MS can damage the nerves that aid in speech and swallowing. Depending upon the area that is damaged, MS lesions can impact the lips, tongue, soft palate, vocal cords, and diaphragm muscles that control speech patterns. Damage to the brain can also interfere with the ability to produce or understand words, called aphasia. In addition, since many of the muscles that aid in speech are also part of the swallowing function, MS lesions can impact the ability to swallow. Impairment can impact not only communication but also your interactions with others.

SPEECH

Speech is a highly complex process that depends on finely controlled and coordinated muscles. Speech problems, also called dysarthrias, can include speech that is slurred, slow, very soft, or nasal sounding. Speech that can't seem to keep up with your thoughts, causing long pauses between your thoughts and words (scanned speech), is a common occurrence with people who have MS. For a thorough evaluation of your speech disorder, it is important to see a speech and language pathologist (SLP). They can help you develop skills and techniques to manage your speech impairment such as...

Exercise your speech muscles. Your SLP can provide you with exercises that can be practiced daily to improve function and strengthen muscles that support breath control and speech production. These exercises will also promote relaxation of these muscles.

Practice speech techniques. Your SLP can teach you techniques that can slow down your speech, help with your phrasing and pausing



to help make speech more clear, and can demonstrate how to over-articulate words to make your speech more understandable.

Self-monitor your speech patterns. Use a recording device to capture how you speak. This allows you to correct some of your speech issues by adjusting your volume or phrasing.

Use new devices and current technology to assist with your speech. Devices like voice amplification, electronic aids, and other computer-assisted communication systems are readily available and easy to use. Many programs can be downloaded for free over the Internet.

Practice speech in group settings. Involving supportive friends and family who can provide you with feedback on your speech patterns will be helpful.

Consider medications. Check with your provider about medications that can improve speech by helping affected muscles.

Experiment with food smoothies. Making food smoothies can be nutritious, fulfilling, and easier to swallow. Use a kitchen blender to puree a variety of your favorite foods.

SWALLOWING

As MS progresses, swallowing problems, also called dysphagia, can increase. These problems include difficulty with chewing or starting the swallowing process, a feeling of a sticking sensation, frequent throat clearing, or a choking sensation when you eat or drink. Some people might also experience unintentionally inhaling food or liquid into the airways. This is called aspiration and sometimes referred to as “going down the wrong pipe.”

Difficulty with swallowing interferes with eating and the desire to eat and can lead to poor nutrition and dehydration. The overall goal of treating swallowing problems is to maximize the safety and efficiency of eating. To create a safe



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

To be removed from or added to this mailing list, email Jaimie.Henry@va.gov or call (800) 949-1004, ext. 53296.

eating environment, the swallowing techniques listed below should be routinely practiced.

1. Sit upright when eating or drinking.
2. Take smaller bites of food, eat slowly, and don't speak when food is in your mouth.
3. Sip drinks, don't gulp.
4. Double swallows might be needed. Double swallows refers to swallowing once to send liquids or food down then doing a dry swallow to clear any leftover particles.
5. Add moisture/liquid to foods. Foods with moisture are easier to swallow.
6. Eat smaller portions. If you are experiencing fatigue, which can interfere with swallowing, try to consume smaller meals throughout the day instead of one or two large meals.

It is very important that a multidisciplinary healthcare team be involved in managing speech and swallowing problems. This team should include patients, family members, and caregivers who can provide essential feedback to providers as to what is working in the home environment and when modifications are needed to address these problems.

Improved speech can increase your ability to communicate with others as well as improve relationships. It is important to have a SLP complete a full evaluation so specific treatment recommendations can be made. Check with your provider about VA services that can help improve your speech and swallowing.

Katherine Parsons, MA, CCC-SLP - DC VA
Angela Young, BS - Baltimore VA

VISIT THE VA MS CENTERS OF EXCELLENCE WEBSITE AT [WWW.VA.GOV/MS](http://www.va.gov/ms).