

VA Multiple Sclerosis Centers of Excellence

MS VETERAN

Serving the Health Care Needs of Veterans with Multiple Sclerosis

Community Matters

By Suzanne O'Connell - Floyd, VA

I served in the US Navy during the Vietnam War. I am a member of our nation's vast military community. I was diagnosed with MS in 1983 and am also a member of the multiple sclerosis community. While I have always been blessed with the support of family and friends, following my diagnosis with MS, I quickly learned the importance of receiving support from people who understand where I've been, what I'm going through, and what might be around the corner. I am a member of an MS support group that has improved my life in ways that I never imagined.



I had my first encounter with MS while at boot camp in Florida. It was late August when the temperatures were at their highest and I found that the heat affected my body in unexpected ways. I had several illnesses, found myself falling out of the blue, and even broke my ankle one day. After a few years of service, I was honorably discharged because of my MS symptoms, although nobody knew it was MS at the time. Almost 10 years passed before I was diagnosed with MS, before I knew the cause of all the crazy things I was experiencing. I've met many people with MS who have had similar experiences; the years of not knowing why they felt so bad. I was not alone.

I've experienced just about every MS symptom there is, with fatigue, cognition, and balance being my most common symptoms. MS symptoms can be unpredictable, and I've learned to take each day as

it comes, make adjustments, and move forward. One of my biggest struggles living with MS is that I don't think people can really understand the disease unless they've lived with it. I sometimes wonder how I can expect anyone to understand MS when I don't always understand it myself. Within my MS support group, I've met people of all ages and stages of MS who understand my struggles. I know that I'm not losing my mind because they

are going through the same things as me.

I didn't start out as an advocate of meeting others with MS. Following my diagnosis with MS, I made a cocoon around myself to feel safe and comfortable. I found reasons not to do new things or push myself too hard. If there was an excuse, I could find it. In time, I learned that life on the couch wasn't really living. I forced myself to branch out, and while it was hard, really hard, I'm so glad I did. That one step out

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the door soon led me to meet amazing people and experience wonderful things.

I started out by attending the local MS support group, and in time was asked to lead the group. While I was reluctant, and a little scared, I said yes. I did marketing for a living before my retirement and decided I would use that talent to advertise the group. Our MS support group started small, but quickly expanded to over 300 members. As the group became larger and more organized, someone recommended starting a non-profit.

In January 2016, the MS Alliance of Virginia (MSAV), a totally volunteer organization, received its 501c3 non-profit status. I am the founder and current president of MSAV. The Board of Trustees is composed of people who have been affected by MS. Our organization provides programs, events, and opportunities for people living with MS in the southwest Virginia area. MSAV contributes to MS awareness in the community and educates, assists, and empowers people with MS, as well as their care partners, friends, and family.

The MSAV has helped start several new support groups in the area and created an outreach program

to visit people who cannot come to meetings; providing information from the last group speaker or program. We have several current projects, including our Annual MS Patient Educational Conference, MS Coloring Parties, Strike Out MS Pool Tournament, Be Anything but MS Halloween Party, and Winter Holiday Gala to name a few. One of the MSAV projects dearest to my heart is Cinderella's Closet, an opportunity for people whose lives have been affected by MS to attend a ball with music and dancing, but only after they've visited the "closet" for a new outfit and some pampering. The ball is one magical night for people who rarely put looking pretty at the top of their list to feel better about themselves and life.

I find such joy in being around others who understand me and am so proud of all the projects I've been able to be a part of. I've found that the secret to living with MS is not just staying active, but getting out of your comfort zone and pushing yourself to do new things and meet new people. If there isn't an MS support group in your area, join the MS community through Facebook or an on-line organization dedicated to MS. Make the choice to make a positive change in your life and then make that change happen, no matter how hard or scary it might seem.

VA Research Study: Lipoic Acid & SPMS

By Rebecca Spain, MD, MSPH - Portland, OR VAMC

Despite all the breakthroughs in MS research, treatments for secondary progressive MS (SPMS) are still lacking. With the help of many colleagues, I (Dr. Rebecca Spain) conducted a pilot trial at the VA Portland Health Care System to see if the over-the-counter supplement, lipoic acid, would help people with SPMS. Lipoic acid is a substance naturally made by our bodies. It has a number of useful actions such as boosting energy production of cells, keeping the immune system from over-reacting, and fighting damaging and aging forces (free radicals) in the body. Although we don't fully understand what happens to cause SPMS, we do know that a loss of energy, altered immune system, and free radicals

may all make SPMS worse. Therefore, it made sense to see if lipoic acid could help slow the worsening of disability in SPMS.

In this 2 year trial, we enrolled 54 volunteers (21 were Veterans) with SPMS. Participants took 1200mg of oral lipoic acid or placebo (sugar pill) daily on a full stomach. The study was double-blinded, meaning that neither the participants nor any of the examiners knew who was on the lipoic acid or placebo. The goal of the study was to see if the participants taking the lipoic acid had less atrophy, or brain shrinkage, than the participants taking the placebo. Why is brain atrophy important? Brain atrophy is a normal part of

aging that happens to all of us, starting in our mid-20's. However, in MS this atrophy can happen faster than the normal pace. The increased brain atrophy goes hand in hand with greater MS disability.

Therefore, we believe that by slowing the rate of atrophy, we may slow the rate of worsening disability from MS.



To understand whether there was a difference between participants taking lipoic acid and those taking placebo, a series of tests were done. These included magnetic resonance imaging (MRI), eye tests, neurological exam, gait and balance tests, memory test, and questionnaires. The results of the study were very exciting. The participants taking the lipoic acid had 66% less brain atrophy than those taking placebo. In fact, the people taking lipoic acid had less brain atrophy than might be expected by aging alone. Because the trial was so small, we didn't expect to find a clinical benefit such as improvement in the neurological exam, cognitive tests, and so forth, and we didn't find any significant changes in these

areas. Yet, we did see a trend that the people taking lipoic acid improved their walking speed while the placebo group did not, although the difference was not statistically significant. Happily, the lipoic acid was safe and overall well tolerated. As expected, there was more stomach upset in the lipoic acid group than placebo, a side effect known from other trials. Unexpectedly, there were half as many falls in the lipoic acid group than in the placebo group.

These are exciting results as lipoic acid is inexpensive and widely available over the counter, and because there are no US Food and Drug Administration (FDA) approved treatments that alter the course of SPMS. However, results of a single pilot study do not in and of themselves prove that lipoic acid is an effective treatment for SPMS. In order to do that, a larger, multi-site trial will have to replicate the results and determine if the slowing of brain atrophy makes a difference in a person's day to day abilities and quality of life. In particular, we will be paying close attention to walking speed and falls. I will be conducting this larger trial as soon as possible to help determine if lipoic acid truly is a disease-altering treatment for SPMS.

Daclizumab: A New Medication for MS

By Samer Saleh, MD & Mitchell Wallin, MD, MPH - Baltimore, MD VAMC

MS continues to be challenging to manage despite advancements in disease modifying therapies. Many people with MS continue to have relapses and progression in disability although they take their MS medications consistently. In the spring of 2016, the US Food and Drug Administration (FDA) approved a new drug for the treatment of relapsing forms of MS called daclizumab (Zinbryta™). This article describes how daclizumab is thought to work and the research examining its benefits and risks.

Daclizumab is a monoclonal antibody. Monoclonal antibodies are made in a laboratory where they are carefully engineered to attach to specific parts of cells. Daclizumab has been engineered to attach to the interleukin-2 (IL-2) receptor; a receptor that

activates the immune system. When daclizumab attaches to the IL-2 receptor, it inactivates it, preventing T-cell activation, increasing natural killer cells, and decreasing lymphoid-tissue inducer cells. All of these actions are thought to help prevent the immune system from attacking the brain and spinal cord.

- ▶ T-cells in people with MS are known to attack the myelin coating around nerves, preventing their activation is therefore likely to be beneficial.
- ▶ Natural killer cells are able to destroy infected or damaged cells while not attacking healthy cells, which may be beneficial for people with MS.

- ▶ Lymphoid-tissue inducer cells are believed to be involved with the regulation of the immune attack in MS, so decreasing their number may be beneficial.

The FDA approved daclizumab for the treatment of MS based primarily on results from two clinical trials, DECIDE and SELECT. DECIDE, led by Dr. Ludwig Kappos at the University Hospital in Basel, Switzerland, was the largest and longest study ever conducted in MS. A total of 1,841 people with relapsing-remitting MS were enrolled for up to 3 years to compare daclizumab 150mg subcutaneous (under the skin) injection every 4 weeks to once a week intramuscular (into the muscle) injection of interferon beta-1a (Avonex®). They found that daclizumab was 45% better for reducing the relapse rate but was no better for reducing MS disability over time compared to interferon beta-1a.



The SELECT trial, led by Dr. Ralf Gold at the Ruhr-University Bochum in Bochum, Germany, compared

two doses of daclizumab, 150mg or 300mg every four weeks, to placebo (sugar pill). A total of 621 people with relapsing-remitting MS participated in the trial. Results from the trial showed that the 150mg dose of daclizumab reduced the relapse rate by 54% compared to the placebo.

Although these studies show that daclizumab can help reduce the relapse rate in people with MS, daclizumab can also cause side effects. The most common side effects found in DECIDE and SELECT included upper airway and urinary tract infections, skin rashes, and increased serum liver enzymes. In some cases, the infections were serious and liver injury was severe. Because of these side effects, daclizumab requires monitoring by a certified prescriber and people who are taking this medication must be enrolled in a risk evaluation program.

In summary, daclizumab is a new MS disease modifying therapy useful in reducing relapses in adults with relapsing forms of MS. It is administered by subcutaneous injection every 4 weeks. But, because of its side effects, daclizumab is generally reserved for those who have failed two or more disease modifying-therapies.

Cognitive Rehabilitation

By Adam Nelson, PhD, ABPP - Portland, OR VAMC

Approximately 40-65% of people with MS experience noticeable changes in cognitive functioning related to their MS. For some, these changes are fairly minor, while for others, the cognitive changes significantly disrupt their daily lives. Declining cognitive functioning is among the top concerns for those with MS because this can affect employment, relationships, driving, health management, and other important areas of daily life.

Cognition refers to a wide range of brain functions involved in thinking, including learning and memory, concentration, problem solving, planning and organization, multi-tasking, language skills, and reasoning. Forgetfulness and taking a little longer

to process information and respond are some of the most commonly reported cognitive complaints of people with MS. Because MS is unpredictable it is difficult to predict in what areas, if any, a particular individual may have cognitive difficulties. For some, an assessment of cognitive functioning by a trained professional can be a helpful part of a treatment plan, allowing them to better understand their cognitive strengths and weaknesses.

Cognitive rehabilitation refers to clinical interventions to improve cognition and, or, help a person develop strategies to help compensate for cognitive difficulties in daily life. While many of the activities included in cognitive

rehabilitation can be practiced without the help of a clinician, some individuals may benefit from cognitive rehabilitation with a professional. Cognitive rehabilitation is often done by speech and occupational therapists, neuropsychologists, and others with appropriate training.

An important part of cognitive rehabilitation is providing information *about why* a person with MS experiences cognitive changes and the factors that might make cognition better or worse. This can help the person feel more in control of their life and their experience. Some examples of helpful questions that may be addressed in cognitive rehabilitation include:

- ▶ Why do I remember some things well, but not others?
- ▶ How does energy level impact my cognitive functioning?
- ▶ Why does it take me twice as long to complete some tasks?
- ▶ How does depression impact my cognitive functioning?
- ▶ What cognitive changes can I expect in the future?

Cognitive rehabilitation can also be *compensatory*; that is, they help an individual compensate, or develop tools and strategies, to help cope with a cognitive problem. Examples of compensatory strategies include:

- ▶ Using a notebook to write down important information during the day
- ▶ Using an appointment calendar for scheduling and setting alarms to prompt
- ▶ Allowing an extra 15 minutes to get to appointments
- ▶ Making "to do" lists for task completion and crossing off when complete
- ▶ Breaking down large goals into smaller tasks, prioritizing the tasks, and scheduling the tasks into an appointment calendar

MS Learning Opportunities

EDUCATIONAL DVDS

- 1 Bowel & Bladder Management
 - 2 Disease Modifying Therapies
 - 3 Emotional Disorders
 - 4 Cognitive Dysfunction
 - 5 Modifiable Risk Factors
 - 6 Mobility for People with MS
 - 7 Pain & Palliative Care
-

VETERAN YOUTUBES

Videos of Veterans, with commentary by VA providers, can be viewed at www.va.gov/MS/products/videos.

PATIENT EDUCATION CALLS

Date: 2nd Monday of Every Month

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

Topic: Different Every Month

Phone: 800-767-1750, 43157#

In January 2017, MSCoE is transitioning to a new date and format for the calls. Information on this change will be available on our website.

If you have questions or are interested in receiving any of our free DVDs, call (800) 949-1004, ext. 53296 or send an email to MSCentersofExcellence@va.gov.

- ▶ Following a structured daily schedule
- ▶ Using imagery, grouping, or other internal memory strategies

Other approaches to cognitive rehabilitation are *restorative*; that is, they aim to restore lost functioning in a particular cognitive skill, and, or, lead to a more general improvement in daily

cognitive skills. Restorative cognitive rehabilitation is conducted in a treatment setting with a provider and usually involves a schedule of cognitive exercises administered by the clinician and or a computer.



RESEARCH SUPPORT

So far, the strongest scientific evidence for the effectiveness of cognitive rehabilitation comes from studies with individuals with traumatic brain injury (TBI) or stroke. To best understand what works and what doesn't work with people with MS, more research needs to be done with people with MS. Even though research on cognitive rehabilitation in MS is in its infancy and is far from conclusive, there are some promising findings suggesting that physical activities, such as walking, Pilates, and yoga, some of which are already frequently used by people with MS, may also help cognition. Relaxation and mindfulness exercises

also show promise for improving attention, in addition to their known benefits for stress reduction.

BRAIN TRAINING COMPUTER PROGRAMS

Many people have heard about computer-based “brain training” software, some of which is available for free, but much of which costs money. While some of these training programs have shown promise for improving certain cognitive skills, it is still unclear whether they lead to lasting and generalized improvement in cognitive abilities. The research in this area is far from conclusive. Individuals who are already mentally and physically active should not necessarily change their routines to engage in computer-based exercises; however, for some individuals who aren't as active, these activities may be a way to get them engaged in some mental stimulation.

In summary, people with MS who have memory or other cognitive difficulties may benefit from cognitive rehabilitation; however, more research is needed to better understand how and why it works. A cognitive evaluation is often a first step, to assess a person's strengths and weaknesses, in order to best guide treatment. For some, cognitive rehabilitation activities may be done in the home, while for others, office visits may be more appropriate. If you have further questions about cognition or cognitive rehabilitation, ask your health care provider!

There's No Place Like My Home

By Jacqueline Hall, MS, OTR/L, ATP - Seattle, WA VAMC

Most Americans close to retirement say they plan to live in their homes for as long as possible, despite less than half having accessible living areas to allow for changes in mobility. Similarly, most people with MS want to live at home, but have also not made plans to make it easier to get around their home. The primary mobility challenges many individuals with MS develop with the disease are fatigue, changes in vision, and less strength and balance for walking. Studies show that 20 years after

diagnosis, 30-50% of individuals with MS will need to use a wheelchair.

Making changes in your home before you have less mobility can help with your safety, managing your fatigue, and keeping your independence. Modifying your home can feel like an overwhelming project but, there are some steps to follow that can make this much easier. If you have information about your home environment and needs, a rehabilitation

specialist, such as an occupational or physical therapist, can help you with your planning.

EVALUATE YOURSELF & YOUR HOME

If an occupational therapist completes an evaluation in your home, they will measure rooms and doorways for wheelchair accessibility and look for safety concerns – tripping hazards, lighting, emergency access, etc. They will also evaluate your ability to complete activities of daily living and help determine what is limiting your independence. You can plan for this home evaluation, as well as your next clinic appointment, by gathering information.

Make a table that lists each room in your home, and write down what difficulties you are having with completing activities of daily living in that room. For example:

Room	I feel unsafe when... I have difficulty with... I need help with...	I am having difficulty because...
Bathroom	getting into the tub getting up from the toilet drying off after I shower	my wheelchair will not fit through the doorway I get too tired

If your home has more than one level, list rooms separately for each level. Remember to include entrances, steps/stairways, parking, and your yard. In each of the rooms you are having trouble, also write down why you think you are having difficulties. Is it the layout of furniture? Are there too many things in the room? Is there good enough lighting?

MAKE A PLAN

Once you have figured out where you are having difficulties in your home, decide what is most important to work on first. Your safety should be

the most important focus, followed by things that affect your symptoms the most, e.g., fatigue. There are many simple changes you can make to make your home more accessible. A major remodel should be the last option.

Follow the “**4 R’s**” to modify your home for safety and accessibility:

- ▶ **Reduce:** Eliminate duplicates – clothing you don’t use or need; extra dishes, utensils, and pans in the kitchen; unused or expired medications in the cabinet. Overfilled storage areas require more work, energy, and time to find what you need and too many items often overflow into living spaces and walkways creating safety hazards.
- ▶ **Reorganize:** Save energy by moving heavier items to lower shelves. Create pathways for safe walker or wheelchair use. Clear areas near light switches for easier reach.
- ▶ **Relocate:** In a multi-level home, consider whether you can rearrange rooms so you spend most of your day on the most accessible level of your home. Can you convert a main floor office to a bedroom, use a dining room as a multi-purpose room by putting your computer there, or move a family member or attendant bedroom to the upper level?
- ▶ **Remodel:** Make home modifications before you actually need them to reduce safety concerns and your stress level. Remodeling may include adding ramps to entries, widening doorways, changing furniture heights, adding safety equipment to your bathroom, or using technology to operate your home with hands-free or voice activated devices.

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Happy Veterans Day - November 11, 2016

HOW VA CAN HELP

The Veterans Health Administration (VHA) and Veterans Benefits Administration (VBA) have many resources available to help modify your home. A rehabilitation specialist can evaluate your home, review your concerns, and make recommendations about making your home more accessible. Recommended equipment can usually be ordered through your local VA Prosthetics Department. Several larger remodeling grants may be available through the VBA to assist with full wheelchair accessibility in your home.

Being proactive in planning for your future mobility and care needs can help you remain at home as long as possible, improve your quality of life, and keep you safe. Contact your primary care provider or MS team with any concerns that you may have about your home.

GET YOUR FREE FLU VACCINATION

The VA provides a free flu vaccine to enrolled Veterans. There are two forms of the vaccine: **1)** a flu shot and **2)** a flu nasal spray. The flu shot is safe when given to people with MS and does not worsen or trigger MS symptoms. The flu nasal spray is ***not recommended*** for people with MS. People being treated with alemtuzumab (Lemtrada®) should receive their flu shot 6 weeks before their infusion.

From August 25, 2016 through March 31, 2017, free flu shots are available to enrolled Veterans at all Walgreens and Duane Reade stores. A valid ID and current VA ID must be presented to ensure vaccination information is transferred to the Veteran's VA health record accurately.