

# VA Multiple Sclerosis Centers of Excellence

# MS VETERAN

Serving the Health Care Needs of Veterans with Multiple Sclerosis

## Accepting Life's Changes

By Michael Whittaker - Long Beach, CA

I joined the military in July 1982 through the delayed entry program. I served in the US Navy for 24 years, 16 active and 8 years in the Ready Reserves. I remember a moment where an enemy was in sight during Operation Iraqi Freedom (OIF) and my fingers became numb. It felt like I had frostbite. I reported what happened to the physician, but he couldn't find anything wrong. When I returned to the US, I had a series of tests and they figured it out. I was diagnosed with MS in 2006.

When I was diagnosed with MS, I knew nothing about the disease. While I was extremely active before I had MS, my activities diminished as MS started to change my body. Before MS, I felt there were no barriers to what I could do. With MS, I found myself having a pity party and I stopped participating in the things I loved. It didn't help that I pushed my family and friends away following my diagnosis. Everyone seemed to have a suggestion on what I should or shouldn't be doing. I didn't want to hear people's home remedies, that they "understood" what I was going through or that I could still do so much even though I had MS.

It wasn't until I became affiliated with the VA's spinal cord injury program that my outlook started to

improve. I joined an MS support group where I could talk about what I was feeling and experiencing. MS symptoms are different for everyone, but members of the group understand and can relate to how I feel. They understood not just about living with MS, but

about serving in the military and dealing with the PTSD I was diagnosed with. Talking with others helped me to look at things as achievable. I found that I didn't have excuses not to do things, I just had to do them differently.

I discovered adaptive sports through the VA; riding a bike, golfing, air gun shooting and sailing were now things that I could do again. I even took some cooking classes at my local VA. In September

2019 I attended the National Disabled Veterans Tee-Tournament in Iowa City, IA with about 400 other Veterans. It was amazing to see so many Veterans together, competing in sports and making the most out of life.

While my diagnosis of MS was difficult to accept,



## Inside This Issue

- 2 | Imaging Neurodegeneration in MS
- 3 | Mindfulness Strategies
- 4 | New Drugs in the Pipeline for MS
- 6 | Bowel Management in MS

Visit our website [www.va.gov/ms](http://www.va.gov/ms) for information on MS, VA services, benefits and MS resources.

I've now educated myself about the disease and feel prepared to take on anything that comes my way. Whenever I tell my providers that I can't do something, they don't accept the excuses. They help me to break down barriers that MS has caused, or that I've created myself. Everyone is dealing with changes and difficulties in life, and I've learned that adapting is the best way to move forward. I've also learned the importance of communicating, not just

with family, friends and my healthcare team, but with others going through the same thing.

MS has changed me. There are days that I miss my military lifestyle, but I've learned that I'm not that guy anymore and that's okay, life changes us. I feel I can lift my head high now because of all the amazing staff, nurses and doctors at the Long Beach, CA VA medical facility who have helped me.

## Imaging Neurodegeneration in MS

By Francesca Bagnato, MD - Nashville, TN VAMC

MS is a complex disease that affects people at all ages. Scientists don't have a full understanding of this disease but we do know that two main components appear to drive physical and cognitive decline in people with MS. One component is called inflammation. Inflammation is temporary and causes MS relapses. There are a lot of medications that can reduce how often relapses occur. The second component is called neurodegeneration. Neurodegeneration is responsible for individuals' slow clinical worsening. Neurodegeneration is due to injury of the axons and their covering, called myelin. Axons are like wires which connect various parts of the brain and the spinal cord to allow people to move, think, sense and perform activities of daily living. Currently there are no medications clearly shown to halt neurodegeneration. Part of why these medications do not exist is because we do not have a good way to detect neurodegeneration on magnetic resonance imaging (MRI).

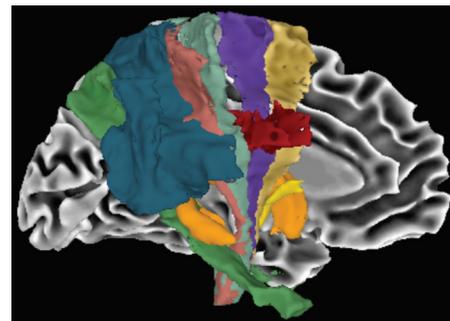
MRI is a picture that can be used to look at the brain. MRI does not use radiation and is therefore very safe although, because it uses an electromagnetic field, you do need to be careful about metal in peoples' bodies. Certain metals can be attracted by the magnetic field around the MRI, which can be dangerous. This is why it is very important to let your doctor know if you think you have any implanted objects, shrapnel or other metal in your body before you have an MRI.

MRI has revolutionized the management of MS. MRI allows doctors to look for lesions and disease activity before these cause new symptoms. This can help guide which medications to use and to start medications early when they are more effective. Usually, people with MS have a brain MRI about once a year. These MRIs show lesions, which are evidence of new or prior inflammation, but today our MRIs are not good at detecting neurodegeneration.

Scientists at the VA in Nashville, TN and Vanderbilt University Medical Center, led by Dr. Bagnato, are studying new MRI techniques to help identify neurodegeneration in MS, including myelin and axonal loss. The figure below shows bundles of axons in different colors. For example, the green bundle is the one that allows people to walk. Within these bundles, one can identify lesions and see neurodegeneration. We are also able to measure the size of the bundle to quantify neurodegeneration.

Dr. Bagnato's team can also indirectly assess the amount of myelin and axons in the brain of people with MS using new MRI techniques. Over

the next four years they will be doing a study with this new MRI technique to monitor changes in myelin



and axon measures over time in over 50 people newly diagnosed with MS. They will also assess how these imaging changes relate to clinical changes in physical and cognitive abilities. This study has the potential to fill the gap of having a way to measure neurodegeneration in MS which is essential for studying potential treatments for progressive MS. Dr.

Bagnato and her team are committed to the success of this research project and to helping find ways to detect subtle MS disease and arrest its progression. They are extremely grateful to all the patients and families who participate in their research studies as without them, scientists would not be able to find treatments for many devastating diseases.

## Mindfulness Strategies for Healthy Living

By Ekaterina A. Davis, LCSW, NBC-HWC - Aurora, CO VAMC

Pandemics like COVID-19 can make you think about your physical health and wellbeing. It is also important to pay attention to your mental health needs as stress on your mind and body can cause depression, anxiety or other mental health conditions. Stress can happen at any time and without warning. A pandemic can add direct and indirect stress into your life.



Contracting an illness such as the novel coronavirus can add direct stress to your body. A few examples of direct stress include developing a fever, difficulty breathing or getting hospitalized. Indirect stress can show up in different shapes or forms. You can experience indirect stress if someone close to you gets ill or you lose your job or experience other financial hardships. You can experience indirect stress if staying away from others makes you feel isolated, withdrawn or sad.

When we experience direct and indirect stress, we can develop unhealthy coping strategies. A common unhealthy coping strategy is heavy drinking of alcohol. For an adult man, drinking too much means drinking 15 or more standard alcoholic drinks per week. For an adult woman, drinking too much means drinking 8 or more standard drinks per week. Other coping strategies may be eating less healthy food or sleeping for longer than usual. The list of unhealthy coping strategies is vast and long.

Taking care of yourself, including your mental health, is essential during this time. Everyone reacts differently to stressful situations. Many people may experience fear, anxiety or feelings of depression. This is normal. There are things you can do to manage these experiences and practice good self-care.

### Strategy #1: Be Present

Being in the present moment means that you are aware or mindful of what is happening in and around you from moment to moment. Start to pay attention to your thoughts. Don't try to change your thoughts or cling to them. Instead, observe your thoughts and allow them to pass by, just like a cloud on a warm sunny day might pass by.

### Strategy #2: Practice Breathing Exercises and/or Meditation

You can download one of VA's many free mental health mobile applications for on-demand support or daily practice reminders. One application designed to help build resilience, manage stress and increase well-being during the crisis is COVID Coach. COVID Coach is for everyone, including Veterans and Servicemembers, to support self-care and overall mental health during the COVID-19 pandemic. Features include: Education about coping during the pandemic; tools for self-care; exercises for emotional well-being; trackers to check your mood and measure your growth toward personal goals; and graphs to visualize your progress over time. The application is free and secure.

The second application is Mood Coach. Mood Coach is a free VA app based on behavioral activation, a non-medication intervention for low mood. You can use the app on its own or in combination with face-to-face or virtual health care. The app can help you identify your values, set goals and participate in exercises associated with each value you identify.

These mobile applications should not be used to substitute conventional mental health treatment including therapy with a licensed professional or prescription medications when necessary. If you are a Veteran in crisis or worried about one, VA responders are standing by to help 24 hours a day, 7 days a week at the Veterans Crisis Hotline, call 1-800-273-8255 and Press 1.

### Strategy #3: Fill Your Cup

“Fill your cup” is a reminder to practice self-care and to understand why self-care is so important. To fill your cup means to refill your mental, physical and emotional energy. “Filling your cup” is like recharging your battery. A car cannot run when the battery

has no energy. People cannot be their best when their personal resources are exhausted. Start filling your cup today by creating a pause in your daily life. Schedule alone time and do something that will make you feel good.

If you have trouble deciding what to do, use the VA Whole Health model to come up with new or creative ideas for self-care. Go to [www.va.gov/WHOLEHEALTH](http://www.va.gov/WHOLEHEALTH) and take the Personal Health Inventory. If you enjoy writing, use the brief Personal Health Inventory as journal prompts.

Direct and indirect stress can show up in your life at any point. Whether you are experiencing stress right now or not, it is important to start practicing self-care today. By exploring and practicing self-care strategies, you are building a mental muscle and forming new neural pathways in the brain. Neural pathways are the building blocks of creating new and automatic responses. The time it takes to build a new neural pathway varies from person to person. It's never too early or too late to start creating healthy coping strategies.

## New Drugs in the Pipeline for MS

By Tyrell J. Simkins, DO, PhD, Patti Yager-Stone, PharmD, BCPS & Rebecca Spain, MD, MSPH - Portland, OR VAMC

In the last decade, the number of treatment options for MS has exploded. Starting with the approval of fingolimod in 2010, there are now 25 US Federal Drug Administration (FDA) approved disease modifying therapies (DMTs) for MS. This burst of new drugs is the result of years of research and a better understanding of MS, leading to therapies that work in unique ways.

Some newly-approved DMTs are completely new. Others are similar to existing DMTs but designed to reduce risks and side effects, while others



are generic or biosimilar (modified) versions of existing therapies. People with MS and MS providers strive for medications that are more effective, easier to administer and have fewer side effects/risks. There is also a growing need for financially affordable options. In this article we present 1) the latest DMTs approved for MS treatment, 2) new generic versions of approved drugs and 3) some of the most promising drugs in the pipeline as new treatments for MS.

### Newly Approved DMTs

**Cladribine** (Mavenclad®) was FDA approved in March 2019 and it is the newest DMT for MS with a unique mechanism of action. Cladribine works by interfering with the ability of immune cells to

copy DNA. This leads to a reduction in T and B lymphocytes, the cells involved in MS attacks on the brain and spinal cord. A unique feature of cladribine is that it is given as a series of pills taken by mouth once per year. The side effects of cladribine include significant and prolonged reduction in white and red blood cells, increased risk of infection and headaches.

**Ofatumumab** (Kesimpta®) is the newest FDA approved DMT for the treatment of MS - approved in August 2020. Ofatumumab is an antibody directed against a molecule called CD20, which is present on B cells of the immune system. B cells serve many functions including antibody production, identifying harmful viruses and bacteria and coordinating immune responses. CD20 is also the target of an older DMT, ocrelizumab (Ocrevus®), but ofatumumab recognizes a different portion of CD20. Ofatumumab is administered as a monthly subcutaneous (under the skin) injection, whereas ocrelizumab is administered by an intravenous infusion every 6 months. The side effects of ofatumumab (similar to ocrelizumab) include infusion reactions, increased risk of infection and flu-like symptoms.

**Monomethyl fumarate** (Bafiertam®) was FDA approved in May 2020. It is a 'cousin' to dimethyl fumarate (DMF; Tecfidera®) and activates the Nrf2 (antioxidant) cellular pathway, which makes the immune system less prone to attack the brain. Monomethyl fumarate is taken by mouth twice daily and side effects (similar to DMF) include flushing, nausea, diarrhea and increased risk of infections.

**Ozanimod** (Zeposia®) was FDA approved in March 2020. Ozanimod is a 'cousin' to fingolimod and acts on cellular receptors for sphingosine-1-phosphate. These drugs prevent lymphocytes, immune cells important in MS, from circulating in the blood to cause MS relapses. Ozanimod is taken once daily by mouth and side effects (similar to fingolimod) include increased infection risk, low lymphocyte count, liver injury and heart rate and blood pressure changes.

**Diroximel fumarate** (Vumerity®) was FDA approved for MS in October 2019. It is also a 'cousin' to DMF. Diroximel fumarate is taken by mouth

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Go to [www.cando-ms.org](http://www.cando-ms.org) for information on topics, speakers and registration. Learn about their free, one-day virtual **JUMPSTART** programs as well.

twice daily and has side effects similar to those of monomethyl fumarate and DMF.

## New Generic DMTs for MS

**Teriflunomide** was among the first oral DMTs for MS, approved in September 2012 (Aubagio®). Teriflunomide works by interfering with the ability of immune cells to copy DNA during cell division. It is still used by many people for effective prevention of MS relapses. Since 2019, the FDA has approved 7 AB rated generics for teriflunomide. As of October 2020, these generic versions of teriflunomide are not yet being distributed for purchase, but it is anticipated they will be available soon.

**Fingolimod** was the first FDA approved oral DMT for MS (Gilenya®) and is still used by many people for the prevention of MS relapses. Fingolimod was the first MS drug targeting sphingosine-1-phosphate receptors and prevents lymphocytes from reaching the brain to cause MS relapses. Currently there are 16 AB rated generics for fingolimod with either FDA approval or tentative approval. As of October 2020, these generic versions of fingolimod are not yet being distributed for purchase, but it is anticipated they will be available soon.

**Dimethyl fumarate** (DMF) was approved as a DMT for MS in 2013 (Tecfidera®) and continues to

be widely used for the prevention of MS relapses. As mentioned above, DMF activates the Nrf2 cellular pathway leading to the immune system being less prone to attack the brain. Currently there are 16 AB rated generics for DMF with either FDA approval or tentative approval. As of October 2020, these generic versions of DMF are not yet being distributed for purchase, but it is anticipated they will be available soon.

**Glatiramer acetate** (GA) was one of the first DMTs approved for the treatment of MS in 1996 (Copaxone®) and is still used by many people for the prevention of MS relapses. GA is a mixture of short protein chains that when injected changes the immune system to be less reactive, particularly to parts of the brain involved in MS. Generic versions of GA have been FDA approved since 2015.

### Promising Drugs in the Pipeline

**Evobrutinib** (Merck) is a drug being developed for the treatment of relapsing MS. Evobrutinib works differently from any other approved MS therapy. It interferes with a protein called Bruton's tyrosine kinase, which plays an important role in the development and function of several immune cell types, most prominently B cells. Evobrutinib is

currently in large Phase 3 human trials as a pill taken twice daily.

**GA Depot** (Mapi Pharma) is a new formulation of GA. Current versions of GA are injected under the skin every day or three times weekly. GA Depot is given as an intramuscular (into the muscle) injection once every four weeks. It is currently in a large Phase 3 human trial for the treatment of relapsing MS and a smaller Phase 2 human trial for progressive MS.

Teriflunomide, fingolimod and dimethyl fumarate are available on the VA formulary and it is expected that their generics will be utilized once they are marketed, similar to GA. A biosimilar for natalizumab developed by Polpharma is currently in phase 3 clinical development for the treatment of MS. Cladribine and diroximel fumarate are not on the VA formulary, but these can be requested by your provider if appropriate through the VA's non-formulary process. Ofatumumab, monomethyl fumarate and ozanimod have not yet been reviewed for the VA formulary, but they can also be requested through the non-formulary process. As the choices for DMTs increase, so do the opportunities for people with MS to receive the medication that is best for them. If you have questions about your medication, talk to your VA provider.

## Bowel Management in MS

By Megan K. Raverty, MD - Minneapolis, MN VAMC

Bowel function is not something most people want to bring up in casual conversation. The topic might be uncomfortable or embarrassing, especially when things aren't working as they should. But having a conversation about bowel function with your MS team is very important in helping you manage your symptoms and improve your function.

Most people with MS who experience bowel problems have constipation, or report feeling "bound up" and have difficulty with regular bowel movements. The reason for this is related to your central nervous system (CNS), which is your brain and

spinal cord. Together, the CNS speeds up or slows down the digestive process in your bowels. When the communication between your CNS and your bowels is disrupted, as it is in MS, the bowels tend to "slow down" and constipation can result.

Fortunately, there are many approaches and medications that can help with MS related constipation. For some people with MS, managing their bowels is as straightforward as making time to have a bowel movement at the same time every day. This is best done after a meal because this is when your gut becomes more active and begins the

digestion process. Sometimes, people need more help with managing constipation, which is called a bowel program.

Simply put, a bowel program is a combination of medications and routines that helps a person with MS related constipation have bowel movements regularly and lessens the chance of incontinence, or accidents. The first part of a successful bowel program is maintaining a regular, healthy diet including consistent amounts of fruits, vegetables and fiber as these can affect how quickly or slowly your bowels move. Consultation with a Registered Dietician, a person who is trained to help people manage their diets to meet their health goals, can be valuable in managing your bowels. They can give you suggestions specific to your needs and situation that can help keep your bowels regular.

When diet changes alone aren't enough, medications can be added to a bowel program. Medications for a bowel program tend to fall into one of two major types: oral or rectal. Oral medications are most commonly used. Oral medications might be in pill form, or as a powder that is mixed with liquid which you drink. Oral medications can be taken by mouth or given through a feeding tube if a person with MS is unable to swallow. The goal of these medicines is to speed up bowels (a "stimulant") or to keep stools from becoming too hard (a "softener"). Some people may only need one type of oral bowel medication, while others may use a combination of several types.

While many people have success with oral medications alone, others might need rectal suppositories or enemas. A suppository is a round or cone-shaped medication that is put into the rectum, or end of your intestine where stool exits. An enema is a liquid that is put into the rectum. The goal of both types of medications is to stimulate or speed up the bowels so that you have a bowel

movement shortly after they are used. If an enema or suppository is needed, the time of day that it is given is important. The bowels are most likely to move after a meal, so most people use an enema or suppository after breakfast or dinner. While which time of day works best for a bowel program can be different for different people, being consistent with the time of day is important. Taking your medications at the same time each day improves your chances of success and makes accidents less likely over time. Think of it as "training" your bowels to move at a certain time each day, and taking your medications as prescribed to match that time.



While constipation is the most common pattern of bowel dysfunction in people with MS, the opposite can also be true and bowel function can actually "speed up", causing loose stools, diarrhea and incontinence. Sometimes, loose stools are caused by foods in your diet. Common foods that can contribute to loose stools are spicy foods, fatty or fried foods, certain fruits high in a type of sugar called fructose and foods or drinks that have caffeine in them, such as chocolate or coffee, and alcohol. In this case, simply avoiding these foods can be helpful. Additionally, fiber can be helpful in making stools less loose.

Loose stools or diarrhea can also be caused by taking too many bowel medications. In that case, it is helpful to talk to your medical team about how to manage your medications to avoid loose stools while still having regular bowel movements and avoiding constipation. If this doesn't help, in some cases, other medications can also be prescribed to help slow down your bowels. However, you should talk to

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VA Maryland HCS  
10 N Greene St, NEU 127  
Baltimore, MD 21201

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VA Puget Sound HCS  
1660 S Columbian Way, S-117-MSCoE  
Seattle, WA 98108

VA Portland HCS  
3710 SW US Veterans Hospital Rd, P3MSCoE  
Portland, OR 97239

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your provider before starting any over-the-counter medications to slow down your bowels, because these can cause constipation if not used correctly.

While both constipation and loose stools can happen in people with MS, it is important to note if you have changes to your particular pattern. That is, if you usually have constipation and are now having loose stools, this can mean something else is causing it or you are not on the right bowel program. Your health care team can help you figure out the cause and make changes if needed.

In summary, while changes in bowel function related to MS may be frustrating or embarrassing to talk about, a conversation with your MS team is an important one to have. There is no “one size fits all” solution to managing bowel function in MS but working closely with your providers can help you find a way to manage these issues in a way that works best with your life.

### Veterans Living with MS

MSCoE's **library of articles** written by Veterans living with MS are filled with information on life's challenges, the value of family and friends and a little bit of hope and inspiration.

Our **YouTube** videos are 6-13 minutes long, providing information from the viewpoints of Veterans living with MS and VA MS health care providers.

We hope you enjoy these stories and in a small way feel connected to other Veterans living with MS. To view the articles and videos, visit the VA MSCoE website, [www.va.gov/MS](http://www.va.gov/MS). They can be found in the homepage banner or in the Veteran Features tab on the homepage.