

MS Perspectives™

Volume 13, Issue 1

Practical Insights on
Multiple Sclerosis

In This Issue

- New MS Drug Approvals
- NMOSD and MOG Antibody Disease: Alike and Yet Different from MS
- Tips on Using Telemedicine
- Finding Wellness During the COVID-19 Pandemic



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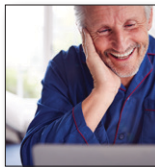
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COVID-19 and MS: Connections and Concerns

C COVID-19 is on everyone's mind, and rightly so: It's a serious, sometimes deadly, highly contagious infection that has spread rapidly throughout the United States since it was first documented in January 2020 in Washington state. But people with chronic diseases like multiple sclerosis (MS) are particularly worried about the risks of COVID-19 on their health. And while we're all excited that there are several vaccine candidates that appear to be highly effective in preventing COVID-19 and likely will be approved by the Food and Drug Administration (FDA) before year's end, most people have questions about whether it will be safe for them to be vaccinated.

We called on *MS Perspectives'* advisors to answer some of MS patients' most pressing questions about COVID-19 and their health, and offer a variety of expert opinions. Here are their answers...

Question: Does having MS or my MS therapy increase my risk of getting COVID-19?

Barbara J. Green, MD: Data regarding MS and susceptibility to COVID-19 is being collected in the US and Canada by a voluntary registry called COViMS. Cases are being reported to the registry by providers caring for people with MS and MS-related diseases such as clinically isolated syndrome, radiologically isolated syndrome, neuromyelitis optica spectrum disorder, and myelin oligodendrocyte glycoprotein (MOG) antibody disease. There are also large registries of patient data from Italy and other European countries that are providing insights into MS and COVID-19 risks.

Thus far, these registries do not suggest that people with MS have an increased risk for contracting this novel coronavirus. In both Europe and the US, however, people with MS who take disease-modifying therapies (DMTs) that deplete certain types of white blood cells (lymphocytes) such as ocrelizumab (Ocrevus®) may have a more severe course if they get infected. Also, people with and without MS who have co-existing risk factors such as age over 65, diabetes, high blood pressure, severe obesity, and heart

and lung diseases are more likely to have a severe course of illness and a higher chance of death.

Barbara S. Bishop, MS, ANP-C, MSCN, CNRN: To date, it is generally believed that having MS does not in and of itself put you at increased risk for getting COVID-19. But you still need to follow the Centers for Disease Control and Prevention's (CDC) guidelines for social distancing, wearing masks in public or in places where you cannot social distance, handwashing, and keeping your hands away from your face.

Some of the DMTs that we use to manage MS can suppress the immune system and this might lead to a higher risk for contracting COVID-19. Having other medical conditions that also weaken your immune response can complicate the picture further. There's no easy answer to this question, which is why you should have a discussion with your MS provider about your personal risks and benefits.

Aliza Ben-Zacharia, PhD, DNP, ANP-BC, FAAN: The data we have on the effects of SARS-CoV-2 (the virus that causes COVID-19) so far reinforce that MS itself doesn't raise the chances of getting COVID-19, but having MS may



make people more susceptible to having a severe case of COVID-19. In addition, people with underlying conditions such as lung and heart disorders, progressive MS with a high level of disability, and those over 65 years of age are more likely to experience complications and become ill if they get COVID-19.

Question: Should I change my therapy or stop taking my medication until the virus is gone?

Barbara J. Green, MD: Based on what we currently know, I am not advising my patients to switch therapies. Breakthrough MS disease becomes a significant risk for MS patients who discontinue highly efficacious therapies such as Ocrevus®, and rebound hyperactivation of MS is a risk for people stopping medications such as Tysabri® and Gilenya®. Keeping MS itself under control is still the primary goal, even in this era of COVID-19.

Aliza Ben-Zacharia, PhD, DNP, ANP-BC, FAAN: It's important not to stop your medication, but instead discuss your concerns with your MS team.

Tracy Walker, FNP-C: No! Don't make any changes to your treatment without discussing it with your provider.

Question: How can I tell if I have a cold, flu, or COVID-19? Are the symptoms different?

Aliza Ben-Zacharia, PhD, DNP, ANP-BC, FAAN: There are common symptoms that both COVID-19 and flu share, including fever, cough, shortness of breath, sore throat, runny nose, headache, tiredness, and muscle aches. Distinct symptoms of COVID-19 are a change in or loss of taste or smell. Some people may have no symptoms, but can still give the infection to others through the air. COVID-19 is spread more easily than the flu and can cause more serious illness.

Since flu and COVID-19 have multiple similar signs and symptoms, it is difficult to diagnose what you have without testing to rule out or confirm the presence of COVID-19.

Barbara J. Green, MD: It is not easy to distinguish coronavirus infection from other viral or even bacterial infections since these diseases can share symptoms of fever, cough, aches and pains, shortness of breath, and diarrhea. Loss of taste and smell without any other symptoms seems to be an identifying characteristic of COVID-19.

Question: What should I do if I think I have COVID-19?

Barbara S. Bishop, MS, ANP-C, MSCN, CNRN: If you think you have COVID-19, follow CDC recommendations to quarantine until you can get tested and get a result. Call your primary care provider for instructions on where and how to get tested.

Aliza Ben-Zacharia, PhD, DNP, ANP-BC, FAAN: Reach out to your medical team by telephone first. Closely monitor your symptoms and if they worsen, seek immediate care at an emergency department. If your symptoms are mild, stay at home and by yourself in isolation until you feel well and your clinician says you can stop your quarantine.

Barbara J. Green, MD: Given the current widespread infectious rate of coronavirus, I advise every patient to assume he or she has COVID-19 if symptoms develop and to be proactive in getting tested. The first step is to call your primary care provider and find out the best procedure for safe testing and quarantining until a definite answer is provided by a test result.

If a patient of mine contracts the virus, we carefully monitor his or her status, but we don't tell the person to stop taking most of the oral or injectable MS medications. We do delay infusions of lymphocyte-depleting medications like Ocrevus® and Lemtrada® until the person is fully recovered from the infection.

Question: Is it safe for me to go into my provider's office or should I be doing medical visits by Zoom or phone?

Barbara S. Bishop, MS, ANP-C, MSCN, CNRN: Depending on your situation, it might be better to do a telemedicine visit versus going to your provider's office. Most offices do multiple levels of screening to make sure you and other patients don't have COVID symptoms, but you should ask your provider if your risk is high and it would be better to do a virtual visit, at least sometimes. (There may be times, for instance if there's been a change in your health status, where a provider may need to see you in person.) You can also let your healthcare provider know that you don't feel comfortable coming into the office and prefer a telemedicine visit.

Tracy Walker, FNP-C: If your provider is offering telemedicine, it may be a good option for you. However, there are times when your provider may need to actually see you in person. If that's the case, you can rest assured

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Barbara J. Green, MD: Blood tests and MRI exams are essential for monitoring MS and for the safe use of DMTs. Those tests should definitely be done as needed and recommended by providers. Delaying or avoiding medical testing and treatment is an additional risk that is causing poor medical outcomes in the general population during this pandemic, and we must avoid allowing that to happen with people with MS.

Aliza Ben-Zacharia, PhD, DNP, ANP-BC, FAAN: Most labs and radiology centers follow specific guidelines and regulations, so it should be safe to have any required blood tests and MRI films. Recently, I had a blood

COVID-19 AND MS (Continued from page 5)

your provider's office is probably one of the safest places you can go. Most MS providers' offices are going above and beyond to keep their facilities clean and safe for their patients in case they do need to be seen in person.

Barbara J. Green, MD: Seeing your provider onsite is probably fairly safe to do since medical facilities are following strict protective procedures with increased cleaning, frequent screening of staff and patients, and use of personal protective equipment (PPE). That said, if you are a high-risk patient who prefers to stay at home, consider the use of telemedicine if available.

Question: What should I do if I need a magnetic resonance imaging (MRI) scan or blood tests?

Tracy Walker, FNP-C: You should get tests as needed, and if you're worried, it is perfectly fine to call ahead to facilities and ask what measures they are taking to reduce your risk of COVID-19 exposure.

Barbara S. Bishop, MS, ANP-C, MSCN, CNRN: Most outpatient facilities are screening to minimize risk and taking appropriate precautions, so it is usually okay to get an MRI scan and bloodwork.

test myself at my hospital and I felt safe throughout the process. Each person needs to address his/her needs with their team and maintain rigorous precautions, such as frequently washing your hands, wearing a mask, and maintaining social distance.

Question: Will it be safe for me to get a COVID-19 vaccine when one becomes available?

Barbara J. Green, MD: We do not yet know if a coronavirus vaccine will be equally effective in everyone. Prior data suggest that people on certain DMTs may have a less robust response to vaccines than healthy individuals. That said, vaccines that don't contain live virus (which can cause infections) are usually safe and often somewhat effective in MS patients on DMTs. The timing of when the vaccine is administered needs to be coordinated with the timing of your DMT, especially if you're on a lymphocyte-depleting therapy like Ocrevus®. We will know better how best to protect you once vaccines are available and better understood.

Barbara S. Bishop, MS, ANP-C, MSCN, CNRN: Vaccines are tricky with MS in general and COVID-19 vaccines will be no different. At this time, we do feel that patients with MS can get COVID-19 vaccines since they don't contain live virus. Your MS provider will need to determine the

best time to get a vaccine depending on the type of DMT you're taking so you have a robust response to the vaccine.

Aliza Ben-Zacharia, PhD, DNP, ANP-BC, FAAN: I recently did a survey in March and April 2020 to learn about coronavirus knowledge, attitudes, and practices among patients with MS, healthcare professionals, and other people. The vast majority (88.4%) of the survey participants reported that they would accept an approved vaccine for coronavirus and 61% said that they would accept an approved vaccine for their children. This is great news, since the more people who get vaccinated, the better we will all be protected from COVID-19.

Question: Should I get a flu shot this year?

Tracy Walker, FNP-C: Getting a flu shot this year is more important than ever. Although a flu shot can't protect you from COVID-19, it can protect you from getting the flu or lessen the severity of the flu if you get it. This is especially important right now because you do not want to be hospitalized or treated in facilities where you might also be exposed to COVID-19. The CDC says it is possible for a person to contract both the flu and COVID-19, which could be very dangerous as both can cause serious respiratory issues. So get your flu shot, if you haven't already!

Barbara J. Green, MD: Annual flu shots are recommended for most adults, including those with MS, and getting a flu shot this season is particularly important to try and avoid other viral illness that may mimic the coronavirus.

Barbara S. Bishop, MS, ANP-C, MSCN, CNRN: It is OK to get your flu shot this year, and a good idea to do so. Getting sick with the flu and COVID-19 would not be a good thing. Most flu shots are okay for people with MS to get; just avoid the nasal mist, which contains live or live attenuated virus, as it might cause infection in people with an altered immune system and can trigger an MS flare-up.

Aliza Ben-Zacharia, PhD, DNP, ANP-BC, FAAN: While you should always discuss any vaccines you plan to get with your primary care provider or MS team, it is safe to get the flu vaccine and highly recommended, too, to minimize flu cases and any complications related to COVID-19. In addition, if you are 65 or older, discuss with your team whether you should get the 'stronger' flu vaccine, called Fluzone® high-dose quadrivalent vaccine. This vaccine contains inactivated influenza (flu) virus and is safe for patients with MS. You should also get a pneumonia vaccine if you are over the age of 65 or otherwise at high risk for this bacterial disease.

Question: Should I take any vitamins, like vitamin D or C, to lower my chances of getting COVID-19?

Tracy Walker, FNP-C: There is some evidence that taking some immune-boosting vitamins and supplements can help prevent COVID-19 or lessen its severity. Vitamins D and C are the most widely recommended, but there is also some evidence that zinc and melatonin may help as well. Before you start taking any supplement, check with your provider to be sure it is safe for you and won't interact with medications you are taking.

Barbara S. Bishop, MS, ANP-C, MSCN, CNRN: In general, we are trying to quiet the immune system so I do not recommend taking any herb or vitamin supplement that can affect the immune system. Vitamins D and C are okay, although the evidence is not strong that they will reduce the risk of getting COVID-19.

Barbara J. Green, MD: For now, the best protection against COVID-19 is to follow safety recommendations to wear a mask, wash your hands frequently, and stay at least 6 feet away from others. There are no vitamins or supplements definitely proven to prevent infection. Also avoid travel and gathering with other people indoors.

CDC COVID-19 GUIDELINES

- Stay 6 feet (two arms' length) away from others.
- Wear a purchased or homemade mask in public that covers your nose and mouth to protect yourself and others.
- Wash your hands frequently for at least 20 seconds with soap and water, and especially after coming in from a public place or after blowing your nose, coughing, or sneezing.
- Avoid touching your eyes, nose, and mouth.
- Stay home as much as possible and do not gather indoors with people who don't live with you.
- If you feel ill but your symptoms are mild, stay at home and avoid contact with others for 14 days. If your symptoms are moderate to severe, contact your healthcare provider to find out about testing and treatment.

Visit <https://www.cdc.gov/coronavirus/2019-ncov/your-health/need-to-know.html> for more information and the latest news from the CDC on COVID-19.

NEW MS DRUG APPROVALS



Good news in the year of COVID-19! The last few months have been filled with more treatment advances for patients with multiple sclerosis (MS). Three new disease-modifying therapies (DMTs) were approved by the Food and Drug Administration (FDA): ozanimod (Zeposia®), diroximel fumarate (Vumerity®), and ofatumumab (Kesimpta®). Other medications are in clinical trials, including a group called BTK inhibitors that have a completely new mechanism of action from other available drugs and attack a different part of the immune reaction seen in MS.

MS Perspectives asked Barbara Green, MD, one of the publication's advisors, to provide some insight into the three drugs approved in 2020. "All three of the drugs are next-generation medications," she says, "meaning they are similar to other DMTs that are available. But they offer some benefits over older drugs that might make them appealing to certain patients, particularly those who are newly diagnosed with MS."

Zeposia®

What is it? Zeposia® is a sphingosine 1-phosphate (S1-P) receptor modulator and is in the same class of drugs as fingolimod (Gilenya®) and siponimod (Mayzent®). Zeposia® is believed to work by preventing white blood cells called lymphocytes from leaving the lymph nodes. This reduces the number of immune cells available in the circulation to enter the central nervous system, where they cause inflammation and damage to nerve cells.

What types of MS does it treat? Clinically isolated syndrome, relapsing-remitting MS, active secondary progressive MS in adults.

How is it taken? As a pill once a day.

What were clinical trial results? Zeposia® was compared to the injectable drug interferon beta-1a (Avonex®) in two large trials, and was found to outperform the older drug in preventing relapses and the development of new or enhancing lesions as seen on magnetic resonance imaging (MRI) scans. The studies did not find a difference between the two drugs in slowing disease progression of MS.

How is it different from Gilenya®?

Although Zeposia® was not compared directly to Gilenya® in clinical trials leading to its approval, it appears to be more targeted in its effects than Gilenya®. And although it may temporarily slow the heart rate like Gilenya®, a gradually increasing dosing schedule over the first 7 days of use reduces the chances of this side effect. For that reason, people don't need to stay in the clinician's office to have their hearts monitored during the first day of use as they do when they start Gilenya®. Also, it doesn't suppress lymphocyte counts as much as Gilenya® does, although there is still a possibility of similar serious side effects like the infection progressive multifocal leukoencephalopathy (PML). Common side effects include upper respiratory infections like colds, other viral infections like shingles, increases in blood pressure, abnormalities in liver function tests, back pain, and headaches. On the upside, it may have some positive effects on cognitive functioning, such as confusion, attention, thinking ability, and memory. "We were hoping for a gentler form of Gilenya®," says Dr. Green, "but we don't yet know if we have a drug that is equally strong in its effects."

Who might be a good candidate for this drug? Patients with relapsing forms of MS who are starting on their first medication or switching from another type of DMT due to breakthrough disease, and people who want the convenience of taking a pill. People who have certain types of heart disorders should not use Zeposia®.

Vumerity®

What is it? Vumerity® is similar to dimethyl fumarate (Tecfidera®). When you take it, Vumerity® converts to the same active ingredient in the body as Tecfidera®. Because it has a different chemical structure, though, it causes fewer gastrointestinal (GI) side effects. It is believed to have an anti-inflammatory effect on the body by stimulating the Nrf-2 pathway.



Barbara J. Green, MD

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What types of MS does it treat? Clinically isolated syndrome, relapsing-remitting MS, active secondary progressive MS in adults.

How is it taken? As a pill twice a day.

What were clinical trial results? Vumerity®'s approval was based primarily on two trials of Tecfidera® that showed it significantly reduced the chance of relapses and new or enhancing lesions seen on MRIs; one trial also showed Tecfidera® slowed the progression of disability.

How is it different from Tecfidera®? Some people have trouble tolerating Tecfidera®. They experience bloating, abdominal pain, constipation, diarrhea, and cramping. A 5-week trial comparing GI side effects between Vumerity® and Tecfidera® found that while both groups of patients experienced side effects like nausea and diarrhea, the former drug caused significantly less. Both drugs can cause flushing (a red, hot, itchy facial rash) within the first hour after taking the pill. Serious side effects are the same between Tecfidera® and Vumerity®, and include the potential for PML, low white blood cell counts, and liver abnormalities.

Who might be a good candidate for this drug?

Similar to those who might want to take Zeposia®, good candidates for Vumerity® are people who want to start with or switch to an oral pill rather than take an injection or infusion, and people who don't need an aggressive DMT.

Kesimpta®

What is it? Kesimpta® is in a class of drugs known as monoclonal antibodies and is similar in its mechanism of action to ocrelizumab (Ocrevus®), but is delivered by a self-administered injection rather than an infusion. Kesimpta® works by binding to a cell surface receptor, thus causing the death of select B-cell lines in the immune system. These cells are believed to regulate damage to the nervous system in people with MS.



MS Medications

Pills	Injections	Infusions
Aubagio®	Avonex®	Lemtrada®
Gilenya®	Betaseron®	Ocrevus®
Mavenclad®	Copaxone®	Tysabri®
Mayzent®	Extavia®	
Tecfidera®	Glatiramer Acetate Injection	
Vumerity®	Glatopa®	
Zeposia®	Kesimpta®	
	Plegridy®	
	Rebif®	

What types of MS does it treat? Clinically isolated syndrome, relapsing-remitting MS, active secondary progressive MS in adults.

How is it taken? By an injection that goes just under the skin (subcutaneous injection). You start with weekly injections for 3 weeks and then go to a once-a-month schedule in the fourth week of treatment.

What were clinical trial results? Kesimpta® was compared to the oral drug teriflunomide (Aubagio®) in two clinical trials and led to a large reduction in annual relapses over the other drug and significantly less disease activity on MRI scans. People taking Kesimpta® also had less disability than those taking Aubagio®.

How is it different from Ocrevus®? It's an injection that you can give to yourself at home rather than an infusion. Side effects are similar to those of Ocrevus®, such as upper respiratory tract infections and a risk of PML. Injection-site reactions and other injection-related side effects such as headache, aches and pains, and fever can occur but lessen as your body becomes used to the drug.

Who might be a good candidate for this drug? People who need aggressive and fast disease control. You should not get Kesimpta® if you have an active infection, nor should you receive vaccines that contain live virus during and immediately after treatment as your body will be less able to fight off infection. Women of reproductive age should use birth control as the drug may harm a fetus.

"The future of MS therapy appears to be using more aggressive and high-potency drugs like Kesimpta® and Ocrevus®," says Dr. Green. "The sooner we can shut down the disease process, the better the outcomes for patients."

NMOSD and MOG Antibody Disease: ALIKE AND YET DIFFERENT FROM MS

Neuromyelitis optica spectrum disorder (NMOSD) and myelin oligodendrocyte glycoprotein (MOG) antibody disease are rare disorders that cause inflammation in the central nervous system, and are similar to multiple sclerosis (MS). In fact, until recently, many patients with these diseases were diagnosed with MS.

Today, these conditions are recognized as separate diseases that need to be treated differently—and happily, three new therapies have been approved for NMOSD in the past year or so.

NMOSD

NMOSD develops when the body, for unknown reasons, mounts an immune response that targets the aquaporin-4 water channel—a channel that is found mainly in the brain, and in higher concentrations in the eyes (the optic nerve) and spinal cord. The immune system begins to produce antibodies—substances it produces normally to fight off bacteria and viruses, but that attack the body itself in NMOSD—leading to sudden attacks of severe inflammation where this water channel is located.

NMOSD is believed to affect around 15,000 people in the United States, and impacts more women than men (almost 3/4 of people with NMOSD are female). It typically starts in the early 40s, but can affect younger and older people, too.

When NMOSD attacks occur, people can experience numbness, tingling, weakness in the legs and difficulty walking, and visual changes like blurriness or loss of vision in one or both eyes. These are all common symptoms of relapsing MS, too. But the symptoms tend to be more severe in NMOSD than in MS. For instance, many patients lose the ability to walk during an attack of spinal cord inflammation. People with NMOSD may also experience unique symptoms, such as severe nausea, vomiting, and hiccups, or narcolepsy-like sleep attacks, symptoms that are almost never seen during MS relapses.

NMOSD is diagnosed with the aid of a blood test, which looks for a marker for the aquaporin-4 antibody. Most people (70%) with NMOSD will test positive for

this antibody compared with 0% of people with MS. Beyond that, clinicians will take a medical history, do a neurological examination, and perform a magnetic resonance imaging (MRI) scan to look for spinal cord lesions, which can distinguish NMOSD from MS. They may also perform a spinal tap, eye and vision exams, and perhaps other tests to rule out other disorders.

“It’s important to get the diagnosis right, because it has long been known that some standard MS treatments can worsen NMOSD,” reports Michelle Fabian, MD, a neurologist at The Corinne Goldsmith Dickinson Center for Multiple Sclerosis at The Mount Sinai Hospital in New York City. “In the third of people with NMOSD who don’t test positive for the aquaporin-4 antibody, we can still diagnose the disease using other tests and looking at their symptoms,” she says.

NMOSD Treatments

There is no cure for NMOSD, but three drugs were recently approved by the Food and Drug Administration (FDA) to prevent attacks:

- Soliris® (eculizumab) is delivered as an infusion every 2 weeks. A once-a-month version is currently being tested, says Dr. Fabian.
- Uplizna® (inebilizumab) is an infusion that is given every 6 months after two initial infusions delivered 2 weeks apart.
- Enspryng® (satralizumab) is a subcutaneous (under the skin) injection that can be self-administered once a month after an initial 6-week “onboarding” period.

According to Mark Tullman, MD, a neurologist at Missouri Baptist Medical Center and the director of clinical research at the MS Center for Innovations in Care in St. Louis, MO, “This is a remarkable time for the NMOSD community. We’ve gone from an era with no proven therapies to one with three highly effective therapies that have been approved by the FDA in less than a year and a half. It’s like going back to before MS was a treatable disease in 1993, and then the first disease-modifying therapy was approved—only in this

case the initial therapies are more than just modestly effective at stopping the disease process.”

Dr. Tullman explains that “These drugs are all monoclonal antibodies and are highly effective in preventing attacks, but have different mechanisms of action, which means that if one doesn’t work for a specific patient, we have other good options.” They also have different safety and side-effect profiles, which might also influence treatment decisions. And the fact that they have different dosing schedules also figures into the decision-making process, so that patients can choose the route of administration and schedule they prefer.

In addition, Rituxan® (rituximab), an older monoclonal antibody that is FDA-approved to treat rheumatoid arthritis, lupus, and certain types of cancer, is prescribed by many clinicians to manage NMOSD. “I am still prescribing rituximab for people with NMOSD because it is a convenient twice-yearly infusion that has a long track record of being effective, and is less expensive than the newer drugs,” says Dr. Fabian.

For a person who is having an attack of NMOSD, high-dose corticosteroids are typically given intravenously to reduce inflammation in the body. If steroids don’t work, plasmapheresis (where the liquid part of blood is replaced with a plasma substitute) may be performed to reduce the amount of aquaporin-4 antibodies in the blood.

“Unlike MS attacks, which tend to last a few weeks regardless of whether a person gets treated or not, NMOSD attacks often continue to worsen until they’re treated with steroids or plasmapheresis,” says Dr. Fabian. Each relapse leads to more neurological disability, and if NMOSD isn’t treated, it can cause permanent paralysis, blindness, and even death. “That’s

why we then put patients with NMOSD on a preventative therapy—if you can prevent the attacks, you can prevent disability,” she notes.

The monoclonal antibodies can have some serious side effects, causing infections, kidney and blood cell disorders, and blood clots. These side effects aren’t common, and the risks are outweighed by the benefits of the medications in preventing attacks, according to Dr. Fabian, who says, “These drugs are fairly safe considering how serious NMOSD is.”

All three drugs cost more than \$500,000 a year, but are typically covered by insurance—although your clinician may have to advocate with the insurer for you to receive them.

MOG Antibody Disease

MOG antibody disease is a poorly understood condition that overlaps with MS and NMOSD. “It tends to start in the 20s and 30s, and we see it affecting women and men equally,” says Dr. Tullman. “It also seems to mostly affect Caucasians rather than those of African or Asian descent.”

Patients appear to have symptoms that are similar to those of NMOSD, such as visual disturbances, eye pain, and back pain/weakness, but test negative for the aquaporin-4 antibody. “In the last 5 years, we’ve come to realize that there is another antibody syndrome that is causing similar symptoms to NMOSD, but is different, namely MOG antibody disease,” says Dr. Fabian, “and we can now test to see if patients have MOG antibodies in their blood.” About 40% of people who appear to have NMOSD but are negative for aquaporin-4 antibodies are positive for MOG antibodies.

There is some disability that accumulates from MOG antibody attacks, but patients tend to recover better from MOG antibody disease relapses than from NMOSD relapses and have longer periods of remission between attacks, says Dr. Tullman. The attacks are treated with steroids and then patients may be placed on monoclonal antibody treatments like rituximab.

A Brighter Future

“Ten years ago, NMOSD and MOG antibody disease had bleak outcomes,” concludes Dr. Fabian, “but there have been incredible advances in thwarting these diseases and today we know they are serious but treatable conditions. The treatments work and people can live long and healthy lives.”

NMOSD Resources

Consult these sources for more information about NMOSD

- **Guthy-Jackson Charitable Foundation**
<https://guthyjacksonfoundation.org/>
- **Mayo Clinic**
<https://www.mayoclinic.org/diseases-conditions/neuromyelitis-optica/symptoms-causes/syc-20375652>
- **National Multiple Sclerosis Society**
[https://www.nationalmssociety.org/What-is-MS/Related-Conditions/Neuromyelitis-Optica-\(NMO\)](https://www.nationalmssociety.org/What-is-MS/Related-Conditions/Neuromyelitis-Optica-(NMO))

Telemedicine/Telehealth Services

Telemedicine, also called telehealth and defined as the use of phone and video visits with healthcare providers, has been around for approximately 50 years. Until recently, however, insurance companies put significant restrictions on the use of telemedicine in terms of how and where providers could offer it and how well they would be paid for the services, leading to limited use. The COVID-19 pandemic has loosened many of the restrictions on telemedicine because it is safer than an in-person visit for many Americans.

Telehealth Pros and Cons

Telemedicine is an amazing concept for many reasons. For those who are employed or are stay-at-home parents, it is very convenient and reduces disruptions to your daily routines. You don't need to take half a day off from your normal activity to drive to the office, find parking, sit in a waiting room and then an examination room until a healthcare provider is able to see you, and then return to your office or home. You just need to take a few minutes of personal time for the visit. And if your healthcare provider is running late, you can continue with your regular routine until the office sends you a message that the provider is ready to start the visit.

Telemedicine is also an awesome concept for those who have difficulty with mobility, like many people with multiple sclerosis. You don't have to leave your personal environment to be evaluated or arrange for transportation, which can be an expensive and even difficult undertaking for some patients and their families, especially if your provider's office is far from where you live.

Telehealth also reduces your risk of exposure to the COVID-19 pandemic and other communicable diseases and infections. And providers can prescribe medications, treatments, and testing just like they do during a regular office visit.

What's more, if you are worried about the confidentiality of telehealth visits, don't be. These visits are performed using a secure channel and are compliant with the Health Insurance Portability and Accountability Act (HIPAA). Your privacy is maintained just like it would

be in a provider's office, and all of your health information is protected.

Although telehealth visits often have a copayment just like an office visit depending on a person's insurance policy, the visits often cost less than in-person visits. Some insurers waive these charges to policy holders to encourage use of telemedicine services. Just be aware that the cost of the visit is not within the control of the healthcare provider, but is set by insurance companies.

Despite all of these pros, telemedicine isn't a perfect solution. Oftentimes, there are technical difficulties regarding Wi-Fi or cellular availability, and storms can interfere with transmission during a visit. Some people may not know how to use the technology and may not have a family member or caregiver around to help them. Others may not have a smartphone or other device that they can use for the telemedicine visit. In addition, a provider won't be able to perform a comprehensive medical examination, and is limited by what you are able to share with him or her through your device.

Making Telemedicine Work for You

Given all the benefits and the safety of telemedicine during the COVID-19 pandemic, here are some things you can do to make your visits work well for you and your provider.

1. Make sure you understand how the technology works before your visit is scheduled to occur, or have someone there to assist you in making the connection.
2. Keep your device on so it is available to receive the call, email, or text message to get the visit started. There might be multiple communications coming to you before the visit, including check-ins with the front desk staff to verify your insurance information and a nurse to verify the medications you're taking and other



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Your Journey to WELLNESS

Finding Wellness During the COVID-19 Pandemic

Taking extra care of your body and mind have never been more important or more challenging than in 2020. During this time of uncertainty and constant change, have you noticed an increase in your levels of anxiety and fatigue? The disruption to our normal routines and the challenges of dealing with things that we can't control take more energy than we realize, so it is all the more important for us to take extra care of ourselves. Here's my advice...

Nutrition. Be sure you are eating a vitamin-and-mineral-rich diet to keep your immune system as healthy as possible and your energy levels up. If you have not had your vitamin D levels checked recently, talk to your provider about getting a blood test because research is showing a possible link between low vitamin D levels

and a higher risk of contracting COVID-19 (not to mention links between low levels of vitamin D and multiple sclerosis). Your provider can recommend a vitamin D supplement if your levels are low.

Exercise. We know that exercise helps our bodies remain healthy and improves energy levels, but sometimes we forget that exercise also helps to relieve stress and improve our mood. Studies show that enjoying nature decreases anxiety and boosts feelings of well-being. Going outside for a few minutes each day can also help the body make vitamin D.

If going outside is not an option for you due to inclement weather or disability, look for online exercise opportunities. Many organizations are providing free virtual group classes such as yoga, Zumba, tai chi, and even meditation. Participating in group exercise activities not only helps us be active, it also provides opportunities for human interaction.

Maintain a schedule and routine even when you don't have to. Our bodies and minds work better when we maintain a regular schedule. Routines help free up our minds to focus on something other than what we need to do next. Maintaining regular bedtime and morning routines helps promote good restorative sleep that our bodies and minds need to function optimally.

Stay connected and informed—Staying connected is especially difficult right now and requires more effort, but it

(Continued on page 14)



Tracy Walker, F-NPC
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JOURNEY TO WELLNESS (Continued from page 13)

is essential for our mental health. Try and schedule some regular check-ins with friends and coworkers to maintain human interaction and prevent feelings of isolation. Have a group of friends you used to have dinner with on a regular basis? Reach out and see if you can set up a “virtual” dinner date instead via Zoom, FaceTime, or phone.

Limit your exposure to news and social media.

Staying informed is important, but be sure you are getting your information from a variety of reliable sources. News programming and social media can take a toll on your mental health, so limit your exposure to them. Studies have shown that during times of natural disasters, people who watch a lot of news programming have more anxiety and sleeping problems than those who limit their news exposure. So be sure you are taking time to unplug from your devices and give your mind a rest from the constant barrage of information that is a fact of life in 2020. Stick to viewing news and social media platforms once per day and never at bedtime so you don't disrupt your ability to relax and get a good night's sleep.

Don't expect too much of yourself. We are taught to push ourselves, but right now, it's important to give yourself a break and actually expect less of yourself. As I mentioned earlier in this article, the stress of managing our lives during the pandemic takes a lot of physical, emotional, and intellectual energy without our even realizing it. So don't worry if you don't finish everything you planned to do today; it's more important to rest and restore your body and mind right now. There's always tomorrow...

Maintain a positive attitude. It is hard right now to stay upbeat—especially in the face of so much uncertainty and concern for ourselves and our loved ones. Cultivating gratitude helps us focus on the good things in our lives. Making an effort to show compassion and patience to others (and ourselves) can make a big difference in our interactions. Remembering that we are all in this together can help us understand and have empathy when others are having a difficult time coping. Finding ways we can help others can be a great way to take our focus off of our own problems and give us a sense of control and satisfaction in contributing to our communities. And finally, whatever takes you to your “happy place”—whether it is crafting, reading, or hiking—be sure you are including that in your schedule!

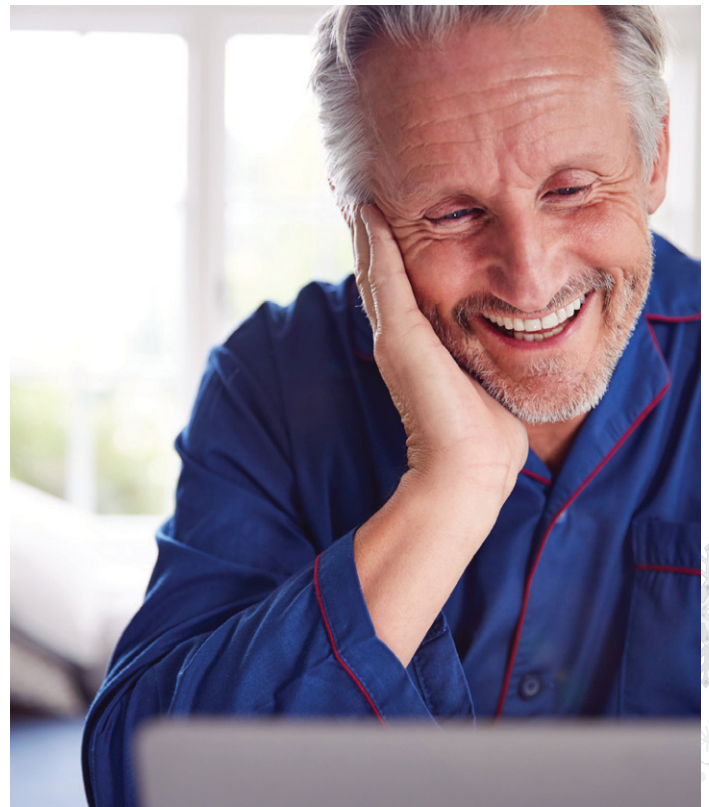
TELEMEDICINE TIPS (Continued from page 12)

pertinent medical information, as well as a message from your provider when he or she is ready to begin the visit. Keep in mind that different offices have different procedures, so be sure to confirm with the office in question exactly what to expect.

3. Choose a stationary place for your visit. This means you shouldn't be in a moving car while talking to your provider, not as a passenger and certainly not as the driver. If you are in a moving vehicle, you might go through cellular or Wi-Fi dead zones, disrupting your visit or even disconnecting your call. Your provider also can't do a useful examination if you're in a car due to the confined space. He or she can't see you walk, for instance.

If for some reason you have to be in a car at the time of your visit, stop the car for the duration of your call.

4. Choose a private place in your home for the visit. Ask your family members to be quiet and remove animals from the room, and make sure there is no music or a TV playing in the background.
5. Check out your image and background on the device screen before the call starts. Make sure your provider can see you well (you may need to turn on more lights) and that there is room for you to stand up and walk for the provider.



THE YEAR OF THE NURSE

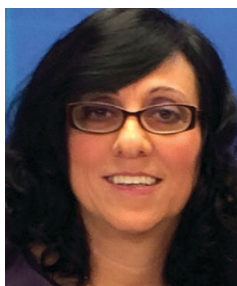
Remember Florence Nightingale? She was the founder of modern nursing, and 2020 marks her 200th birthday! In recognition of her contributions to medicine and the contributions of nurses, the World Health Organization has designated this year as the “International Year of the Nurse and Midwife.” Nurses play a vital, first-line role in caring for people around the world, and as you undoubtedly know as a person with multiple sclerosis (MS) or a caregiver, nurses profoundly impact the lives of their patients.

Here are *MS Perspectives*' Dr. Aliza Ben-Zacharia's reflections on what it means to her to be an MS nurse...

The year of the nurse came at the time of a pandemic, which definitely changed our life and our health care. However, this is as suitable a year as any other to recognize the role of the nurse in our diverse communities.

I have been a nurse and a nurse practitioner for more than three decades. Most recently, I saw patients at The Corinne Goldsmith Dickinson Center for Multiple Sclerosis (MS) at The Mount Sinai Medical Center in New York City. My experiences at Mount Sinai have taught me so much. Patients and their caregivers have trusted my judgment and care over the years, and I feel so thankful to them for allowing me to be part of their lives. My patients and their partners have shared their happy moments, as well as moments that were unfavorable and sad. There are so many patient and caregiver stories that have shaped my understanding of MS and what is going on behind and beyond the scene.

Over the past year, I have moved away from clinical care to teaching nursing at Hunter College, Bellevue School of Nursing, in New York City. I am responsible for training new nurses and advanced-practice nurses to grow and dedicate their careers to improving the delivery of healthcare services, providing excellent patient care, and improving patients' quality of life. Education



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truly is power, but it is important to also implement our knowledge in our practices and everyday life, which is what I am trying to share with my nurse students.

Multiple sclerosis remains my specialty, and in my role as an assistant professor at Hunter College, I am conducting multiple research studies related to MS and symptom management.

The journey continues for all of us through this unpredictable year marked by COVID-19, and I am so fulfilled to have chosen this profession of nursing. I have practiced as a clinician, a provider, a teacher, and a researcher, and these roles have been truly rewarding in contributing to my growth as a person and a healthcare provider. And I know I have made a difference in the lives of my patients with MS. I know, as a nurse, that I am living a life with purpose and meaning.



Support Programs for MS Disease-Modifying Therapies (DMTs)

Aubagio[®], Genzyme Corporation:

www.aubagio.com, 855-MSONE2ONE (855-676-6326)

Avonex[®], Biogen:

www.avonex.com/en_us/home/above-ms-program/join-biogen-support.html, 800-456-2255

Betaseron[®], Bayer HealthCare:

<https://www.betaseron.com/why-betaseron>, 844-788-1470

Copaxone[®], Teva Neuroscience:

<http://copaxone.com/AboutSharedSolutions.aspx>, 800-887-8100

Extavia[®], Novartis:

www.extavia.com/info/PatientSupport/patient-support-program.jsp, 866-EXTAVIA (866-398-2842)

Gilenya[®], Novartis:

www.gilenya.com, 800-GILENYA (800-445-3692)

Glatiramer Acetate Injection, Mylan:

www.glatirameracetate.com/en/patient-support, 844-695-2667

Glatopa[®], Sandoz:

www.glatopa.com, 855-452-8672

Kesimpta[®], Novartis:

www.kesimpta.com, 855-KESIMPTA (855-537-4678)

Lemtrada[®], Genzyme:

www.lemtrada.com, 855-MSONE2ONE (855-676-6326)

Mavenclad[®], EMD Serono:

www.mslifelines.com, 877-447-3243

Mayzent[®], Novartis:

www.mayzent.com, 877-MAYZENT (877-629-9368)

Ocrevus[®], Genentech:

www.ocrevus.com, 844-OCREVUS (844-627-3887)

Plegridy[®], Biogen:

www.plegridy.com, 800-456-2255

Rebif[®], EMD Serono:

www.mslifelines.com, 877-447-3243

Tecfidera[®], Biogen:

www.tecfidera.com, 800-456-2255

Tysabri[®], Biogen:

www.tysabri.com/en_us/home/join-biogen-support/join-biogen-support.html, 800-456-2255

Vumerity[®], Biogen:

www.abovems.com, 800-456-2255

Zeposia[®], Bristol Myers Squibb:

www.zeposia.com/support-program-for-patients/, 833-937-6742

MS News, Support, and Self-Help Groups

Can Do Multiple Sclerosis

www.mscando.org

MS Views & News

<http://www.msviews.org/msviewsandnews4>

MS World

www.msworld.org

Multiple Sclerosis Association of America

<http://mymsaa.org>, 800-532-7667

Multiple Sclerosis International Federation

www.msif.org

Multiple Sclerosis Foundation

www.msfocus.org, 888-MSFOCUS (888-673-6287)

National Multiple Sclerosis Society

www.nationalmssociety.org, 800-344-4867

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