

MSPerspectives™

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Practical Insights on
Multiple Sclerosis

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Please take a quick survey.



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Infusions, Injections, and Pills: Which Route of Administration Is Best for You?

Choosing a disease-modifying therapy (DMT) for multiple sclerosis (MS) can be complicated. As healthcare providers, we look at efficacy (how well the treatment worked in research trials and how well we think it will work for you) and safety, along with the risks and benefits for you individually. From your point of view as a patient, you will also be concerned about how you will take the drug (its route of administration). There are many ways to give today's DMTs, including by injection, by mouth, and by infusion, and we will review the pros and cons of each route in this article. (See the previous issue of *MS Perspectives* for more information on available DMTs; the issue is available at www.MSPerspectives.com).



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Injection Therapies

When you are considering taking an injectable DMT, you will want to think about how frequently the injection is given and whether you want to use a small needle, which generally goes just under the skin (subcutaneously, similar to the injections used by people with diabetes), or a large needle, which generally goes deeper into the muscle (known as an intramuscular injection). Subcutaneous injections usually need to be given more frequently than intramuscular shots, from daily to 3 times a week. Recently, however, monthly and bi-monthly dosing has become an option once you go on maintenance therapy with a subcutaneously administered DMT. Intramuscular injections are usually given once a week to every 2 weeks.

Other things to consider with injectable therapy include:

- Am I comfortable giving myself an injection? Most DMT shots have autoinjectors that have simplified the injection process.
- Does the medication need to be refrigerated and if yes, how long can it be left unrefrigerated? This is important if you travel frequently or if you live in a remote area or a region where your electricity goes out frequently.
- How will I dispose of needles once I have used them?
- Do I understand that I might experience skin-related issues with long-term subcutaneous injection use?

Disclaimer: The goal of this publication is to provide patients with multiple sclerosis with the latest information about the disease and its treatment. The information provided in *MS Perspectives™* is not a substitute for the advice of your healthcare nurse or doctor. Please consult a qualified healthcare provider for individualized care and information.

Cover photo credit: @krblokhin / iStock

Oral Therapies

Tablets or pills are the most common way people take medication. If you are thinking of taking a DMT as a pill, consider:

- How often do I have to take the pill? Once a day, twice a day, or more often than that? Research shows that you are more likely to remember to take a medication that only needs to be given once a day. Of course, you may be taking multiple oral medications for other health issues or MS-related symptoms in addition to a DMT, in which case you will want to get a pill box; program a timer, smart home device like the Alexa Echo or Google Home, or app to remind you to take your pills; and/or use a pill-sorting service.
- How big are the pills? This can easily become an issue if you have difficulty swallowing large pills or if your swallowing is impaired due to MS.

Infusion Therapies

Some infusions are given monthly while others require only twice-yearly visits to an infusion center. Infusions are usually given via the arm, so you will want to think about these potential barriers:

- How easy is it to insert a needle in your arm? Do technicians have trouble getting blood out of you when you need to have laboratory tests?
- Does the sight of a needle cause you extreme anxiety?
- How easy is it for you to come to the infusion center? How will you get there, and can you get time off from work or find someone to watch your kids while you are gone?

Other Issues to Consider

Logistics—or how will I get my medication? Will your medication come to you in the mail or at the local pharmacy, or will you have to travel to an infusion center to get it? And if you do have to travel, how often do you have to make the trip, how far is it, and how will you get there? You also need to ask yourself, “Do I have the ability to travel?” That means do you have a reliable and consistent means of transportation, and also how stressful travel will be for you physically if you have significant disabilities or other medical conditions.

Functional ability—or do you have the ability to administer your medication, or can someone be relied on to give it to you? If you have trouble with coordination in your hands or a tremor, an injection is probably not the best option unless someone in your household can give the injection to you. Likewise, if a pill is packaged in a way that makes it difficult for you to pop it out of its package, an oral DMT may not be the best option unless someone can be relied upon to open the medication for you. And as mentioned, if you have difficulty swallowing, you will not want to choose a pill formulation—especially if the pills are large and/or have to be taken frequently.

Accessibility—or can I afford my medication? Will your insurance company cover the cost of a medication you are thinking of taking? If it is covered, what will your copay be, and can you afford that? How many times do you need to get prior authorization from the insurance company to take the drug? Can you continue to get the branded formulation once it goes off-brand and is available as a generic? Will copay assistance still be available for

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WHY YOU SHOULD SIGN UP FOR A CLINICAL TRIAL

If you have been reluctant to participate in a clinical trial, that's understandable. There are no absolute guarantees of safety for a new medication, says *MS Perspectives'* advisor Barbara J. Green, MD, of the MS Center for Innovations in Care at Missouri Baptist Hospital in St. Louis, Missouri. "However, a medication is first tested in vitro (in a test tube), then in lab animals, and then in humans in very small phase I and II trials before it is brought to large clinical trials of individuals with MS," she says. What's more, trials are structured to assure safety along the way, with a committee that is constantly monitoring and analyzing study participants for any unexpected adverse effects. And if any serious problems arise, the trial is stopped early.

"You should also know that even if you are participating in a trial of a new disease-modifying therapy, or DMT, you will always receive some form of treatment. Placebo-controlled trials are no longer performed for DMTs because that is not ethical when we know that we have a set of marketed medications that are somewhat effective in preventing MS relapses and progression of disability. All trials compare new agents to older agents," she says.

Beyond that, there are many trials that look at symptoms associated with MS and not just DMTs, such as walking issues, fatigue, and bladder problems, as well

as rehabilitation treatments like physical therapy. "These symptom- and rehab-oriented trials have patients stay on their DMTs in addition to the experimental medication or intervention," Dr. Green assures, adding that "we are always enrolling patients in small clinical trials of these types of interventions in our offices, and they may go on for a short or long period of time, depending on the study."

Dr. Green says there are two excellent reasons to join clinical trials:

1. You get a better understanding of your disease, tests, and treatments. "Even patients who participate in trials that fail develop a more sophisticated understanding of the value of doing repeated magnetic resonance imaging (MRI) scans and the benefits of receiving more and closer attention from healthcare providers, which may lead clinicians to pick up health issues that might have been missed previously," she reports. There are also financial benefits because scans, lab tests, visits, and treatments given during clinical trials are free.
2. You contribute to advancing the science behind your disease process. "You will be part of the future, with the opportunity to potentially access a new medication or form of treatment such as a rehab strategy, a device, or a nutritional supplement before other people. This could be a great personal advantage if the treatment turns out to be beneficial for you," she explains.

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How to be a Proactive Patient and Share in Decision-Making

We now have so many disease-modifying therapies (DMTs) for multiple sclerosis (MS) that decisions about treatment are highly challenging and complex. You, the patient, need to be part of the discussion, partnership, and decision-making.

Here are the steps to becoming a proactive patient and making shared decisions about your care:

1. Be informed. You cannot be fully engaged in self-management activities if you are not familiar with your disease, symptoms, and the available treatments. Talk to your MS team and do research on the Internet—but be sure to visit only reliable websites, such as those of the National MS Society, MS Foundation, and the MS Association of America.

2. Be prepared and ready. Living with a chronic illness requires some planning related to your disease, your lifestyle, and your future health. Be ready to make treatment decisions and switches if your disease changes and you develop new symptoms.



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3. Know your preferences and values. Think about the risks that you are willing to take versus the potential benefits of treatments. Your preferences and values should guide the shared decision-making process as you and your MS team decide on the optimal medication for you.

4. Advocate for yourself. Familiarize yourself with available community resources through MS organizations and other groups.

5. Connect and communicate with your MS team. Often, you click with one specific member—a nurse practitioner, a physician, a social worker—at an MS center. Seek this person out to discuss your concerns and ask questions about the decisions you need to make related to DMTs and symptom management.

6. Prioritize your concerns. Make clear to your MS team what current or potential aspects of your disease bother you the most, and what things you care less about. For example, explain to your healthcare providers the types of medication side effects you will not tolerate, as well as medication effects that are priorities for your MS care.

7. Coordinate your care. Inform all of your providers about your MS and any other diseases you have. You can master the skill of shared decision-making by collaborating, communicating, and coordinating your care.

MANAGING TRAVEL OVER THE HOLIDAYS AND BEYOND

You're probably eager to get back to traveling and seeing far-away places and faces, especially as the holidays approach. But even in the best of times, travel can be challenging for people with multiple sclerosis (MS). You have to be cautious about not over-tiring or over-heating yourself, or you might end up spending more time in bed on your vacation than socializing and sightseeing. And if you have mobility issues and use a wheelchair or scooter, you have to be knowledgeable about disability accommodations that you can access on various forms of transportation and at different types of motels and hotels.

MS Perspectives spoke with Candy Harrington, a leading expert in the field of mobility-limited travel. She is the editor of *Emerging Horizons Magazine* and the author of numerous guidebooks for people who require access accommodations while traveling, including *Barrier-Free Travel: A Nuts and Bolts Guide for Wheelers and Slow Walkers*.

By Land, Air, or Sea

Ms. Harrington says that many routes of travel can be doable for people with MS-related disabilities, but road trips come first to mind. "Car trips are ideal because you have the most control: You can travel at your own pace, carry along whatever you need in terms of medical equipment, and take breaks along the way."

Next up come cruises, which have always been a good option for people with disabilities, Ms. Harrington says, thanks to the accessibility features of most ships, as well as the ability to unpack just once and to take breaks in your cabin during the day. As cruising comes back into the travel mix as COVID fades and safety measures are stepped up, people with MS may wish to look into both large ocean cruises and smaller river cruises. "I recommend shopping around for a cruise line that meets your access needs and has a proactive attitude about access. Cruise Critic (www.cruisecritic.com) is a good resource for information on cruise lines, since things are

constantly changing," she says. "They have a number of message boards, including one devoted entirely to disabled cruise travel."

Public forms of transportation—trains, planes, and buses—are other alternatives, and can be quite enjoyable. You get to see the sights while someone else drives, and all forms of over-the-road transportation are required to be disabled-friendly. "The American



Disabilities Act (ADA) mandates that all forms of transportation be wheelchair-accessible, and things are better than they were 10 years ago, but you still need to do advance planning to ensure you can safely and comfortably manage a trip," she reports. If you are booking a charter or tour, "the key to getting the services you need is booking early—in most

cases, at least 48 hours ahead, which is the minimum advance time required by law," she advises.

The fastest way to travel, of course, is often flying, which is guided by the Air Carrier Access Act (ACAA) for US flights. "You should read this act before you decide to fly so you know what accommodations you are entitled to," she says (<https://www.ecfr.gov/current/title-14/chapter-II/subchapter-D/part-382>). Also research Transportation Safety Administration (www.tsa.gov/) and specific airline rules for traveling with injectable medications and medical supplies. You may need to get a note from your healthcare provider to bring injection supplies aboard an airplane.

TO FIND OUT MORE ABOUT TRAVELING

<http://barrierfreetravel.net/>
www.CandyHarrington.com
www.youtube.com/watch?v=VzRK42HE7jo

National MS Society

www.nationalmssociety.org/Living-Well-With-MS/Work-and-Home/Travel

www.nationalmssociety.org/Living-Well-With-MS/Work-and-Home/Travel/A-Doctor-s-Travel-Tips

YOU CAN EXERCISE NO MATTER WHAT YOUR LEVEL OF DISABILITY

Exercise might seem like an unlikely activity for someone who has multiple sclerosis (MS) and is using a cane, a walker, or a wheelchair. But everyone with MS can and should exercise in some way, says Daniel Becker, MD, Director of the International Neurorehabilitation Institute in Baltimore, MD. “Research clearly shows that people with MS who exercise are more functional than are those who don’t exercise,” he says. “Inactivity is poison to the nervous system, while activity can help repair the damage caused by MS.”

According to Anna N. Berry, PT, DPT, Program Manager at the Andrew C. Carlos Multiple Sclerosis Institute at Shepherd Center in Atlanta, GA, “MS can lead to a vicious cycle of inactivity and deterioration: You are tired, so you stop moving, and because you’re not moving, you become weaker and lose your range of motion.” What’s more, she adds, “There are really no cons to exercise for people with MS—some people may experience temporary fatigue, overheating, or visual issues, but those symptoms will go away after they rest. In contrast, there are so many benefits. Exercise and physical therapy can help to rewire the brain, and they can prevent secondary effects of MS (the symptoms that are caused by changes from MS to the body rather than the MS itself).”

Repairing the Nervous System

“Our nervous system has all the tools it needs to repair itself, but it also needs the right environment,” explains Dr. Becker. “Areas of the body that are disconnected from the brain due to the damage caused by MS have difficulty maintaining their function.” Activity can restore communication within the central nervous system, helping it to rewire and work around the damage, a miraculous phenomenon known as neuroplasticity.

In some people with MS, however, exercise alone may not be enough to feed the nervous system and boost its repair. “We may need to amplify exercise’s effects by adding functional electrical stimulation—electrical activity that is applied through the skin with wearable devices to stimulate muscles and nerves, going up the spinal cord and to the brain,” he says.

Exercise Beyond Your Day-to-Day Activities

Exercise guidelines are the same for all adults, says Dr. Berry. We should try to get between 150 and 300 minutes of moderate aerobic exercise a week, plus engage in two strength-training sessions weekly.

It’s better and easier to build your general strength, endurance, and aerobic fitness up than to have to do targeted exercises due to weakness in specific muscles. “That’s why I encourage people with MS to take advantage of every kind of movement they can do,” says Dr. Berry. “If they can raise their arms up to the sky, do that. If they can only raise them halfway up, then do that since it will help strengthen those muscles and improve range of motion.”

Both Dr. Becker and Dr. Berry say that if you could do an activity before you were diagnosed with MS, you can find a way to adapt that exercise now to your current level of ability. They encourage people with limitations to find activities they love and can do with others, just like they advise people without impairments. “It’s all about finding activities you will continue to do for a very long time to restore and maintain your function—and even



improve it," says Dr. Becker. "If you are too weak to walk, go in the water and do aqua therapy to strengthen your legs. Do rowing or bike on a recumbent or stationary bike. There are many workarounds and adaptive equipment so you can be more active."

Of course, if you haven't exercised in a long time you want to start very slowly. "Start by doing one push-up a day for a week and then do two for a week, and build from there," advises Dr. Becker. "If you push yourself too hard too fast, you'll end up in bed for 3 days with fatigue and defeat the purpose of exercising in the first place."

Finding MS Exercise Experts

If you're lucky enough to live near an MS center, you should be able to find MS-specific exercise programs, physical therapists, rehabilitation physicians, and other experts there. If not, look to your local hospital, the National MS Society, the Multiple Sclerosis Association of America, Can Do MS, and other MS organizations for online and in-person programs. "The NMSS has peer support programs where you can apply to have a peer and/or be a peer, so if you want to start an exercise program, you could connect with others who want to exercise," says Dr. Berry. She also notes that Shepherd Center is partnering with the world's leading health, wellness, and social motivation platform, BurnAlong (www.BurnAlong.com), to launch special virtual exercise classes for people with MS and other neurological conditions. Anyone in the world will be able to access this platform and these classes when they launch, probably in 2022, she says.

Adaptive Exercise and Sports Programs

Beyond more typical forms of exercise, if you think that you can't do rigorous adventure sports like biking, skiing, or climbing because you have MS, that is not true. "If it is something you want to do, you can use adaptive equipment to do that sport," says Dr. Becker, who has been running sports programs for people with disabilities for more than a decade. "I've had groups including people with MS and spinal cord injuries where we have gone scuba diving, surfing, horseback riding, skiing, mountain biking, canoeing, and rafting. For me, it's almost a spiritual experience to help people do physical things they thought they couldn't do anymore. And we have found that people who had been paralyzed or injured for many years still have neural (brain and spinal cord) pathways that can be activated by activity."

ADAPTIVE SPORTS PROGRAMS

Contact Dr. Becker to find out about participating in one of his summer or winter trips

Daniel Becker, MD
International Neurorehabilitation Institute
Email: appointments@inirehab.com
Website: www.INIRehab.com

Contact the center below, which helps people with disabilities engage in outdoor adventure activities

Adaptive Sports Center
<https://www.adaptivesports.org/>
(970) 349-2296

INFUSIONS, INJECTIONS, AND PILLS (Continued from page 3)

the generic formulation? Can you continue on the same medication if you change insurance companies?

The good news is that almost every pharmaceutical company has a copay assistance program. For example, if your insurer chooses not to cover a medication as part of its plan and an appeal has been denied, the pharmaceutical company may offer its medication free of charge or through a foundation. You will need to do some paperwork to apply, but you may be able to get the drug at little to no cost.

For many people with Medicare, copays for MS medications can be quite steep. And although the pharmaceutical companies cannot assist with copays

for Medicare recipients, they can often refer you to foundations for financial support.

Making Your Choice

Once you've narrowed down your choices to your preferred route of administration, there are many resources that you can visit to do further research before making a final choice. (See the box on page 8 for many of these resources.) I recommend visiting both the pharmaceutical website related to the drug you're considering, as well as checking out the websites of organizations that offer nonbiased information about treatment options.

How to Find Clinical Trials

You can easily find out about clinical trials going on near you or virtually through:

- Your MS provider's office or MS center;
- The National MS Society (<https://www.nationalmssociety.org/Research/Participate-in-Research-Studies>); and
- The website www.clinicaltrials.gov. A search of this website using the term "multiple sclerosis" revealed that 528 trials are currently or will soon be recruiting participants. These trials range from studies looking at

emotions, nutritional approaches, whole-body positron emission tomography (PET) scans, use of the eye-health supplement lutein, resistance training, Pilates exercise, home-based tele-exercise, and many other topics in MS treatment and care.

You can also donate your DNA to MS registries and participate in survey-based studies like those run by the NARCOMS Registry for Multiple Sclerosis (<https://www.narcoms.org/>), and arrange to donate to tissue banks upon your death.

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

Bafiertam[®], Banner Life Sciences:

www.bafiertam.com/#patient_support, 1-855-3BANNER (855-322-6637)

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, 888-NOW-NOVA (888-669-6682)

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

Ponvory[™], Janssen:

www.ponvory.com, 877MyCarePath (877-227-3728)

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-ZEPOSIA (833-937-6742)

MS News, Support, and Self-Help Groups

Can Do Multiple Sclerosis

www.msando.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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