

Take control of your care



Living with MS is easier when you partner with your doctors.

by **Lori De Milto**

When Dax Peterson found out he had multiple sclerosis in 2011, he didn't really believe it—and he didn't think his first disease-modifying therapy (DMT) was helping him. So the 38-year-old Manhattan resident didn't always use it. Peterson felt sick, but he didn't call his doctor. "I never knew whether I was having an attack, so I kept stalling," he says. After about a month of this, Peterson ended up in the emergency department with an MS relapse.

"There's no perfect drug for every patient," says Dr. Michelle Fabian, Peterson's MS specialist and an assistant professor of neurology at the Corinne Goldsmith Dickinson Center for Multiple Sclerosis at Mount Sinai Hospital. So after his relapse was treated, Peterson began partnering with Dr. Fabian to find the best DMT for him. The second one they tried didn't work well for him either, but this time, Peterson called Dr. Fabian when he didn't feel right. She switched Peterson to a third medication, and he hasn't had an MS relapse in more than two years. "I feel close to normal," says Peterson.

Be safe, not sorry

Doctors need to know what's happening between visits to figure out whether a DMT is working for an individual, and to help manage side effects and MS symptoms. So they rely on their patients to be proactive and responsible partners in their MS care. That starts with informing the doctor about new or worsening symptoms and unexpected side effects or allergic reactions from medicines as soon as they happen, says Dr. Bruce Cohen, director of the MS Comprehensive Care Center at the Northwestern University Feinberg School of

Medicine.

It's a two-way street. Doctors also need to have upfront conversations with people about what to expect from treatment—including the expected benefits, side effects and risks, as well as any blood tests or other monitoring that will be needed after beginning treatment. This information should be reviewed at subsequent appointments.

For the most common side effects, doctors may provide suggestions in advance for how to manage them, such as taking Tylenol for flu-like symptoms from interferon DMTs. "People should try those strategies first," says Dr. Cohen. But if a side effect is unexpected, they should not stop treatment. Instead, they should call their doctors—immediately.

Reduce relapse risk

Taking a DMT for many years, especially when you feel good and the medicine is expensive and risky, can be hard. But stopping could open the door to more attacks (relapses), with damage that can't be reversed.

"We know from clinical trials that the risk for having attacks is much higher for individuals who don't take medications than it is for individuals who take medications," says Dr. Cohen. Peterson is convinced. "When you have an MS attack, it's like your world is upside down. I don't want to experience that again. I'll continue with my medication."

Peterson's now doing so well, in fact, that he was able to return to his job as a shipping specialist at a FedEx store and become more involved in caring for his three children.

Use responsibly

All but two DMTs (Copaxone® and its generic equivalent, Glatopa™) require regular lab work, usually blood tests, to monitor for side effects. Interferon drugs are safe most of the time, but in rare cases, they can damage the liver and decrease white blood cells, which help fight infection. Some newer DMTs carry greater risks.

"It's important to stay on top of them so we can minimize them and treat the patient early if there's an issue," says Dr. Fabian. Which tests you need—and how often—depends on the DMT. That's why it's important to discuss your individual history and concerns with your physician.

Be sure to also follow any precautions listed in the patient literature that comes with your medication, as well as any advised by your physician.

It's also important to store DMTs properly so they work right. Copaxone, for example, should be refrigerated in the container it came in, and the container must be tightly closed. It can be stored at room temperature for up to seven days but has to be away from bright light. Requirements differ by DMT, so follow your doctor's instructions.

Stay informed

Dr. Cohen advises people to stay updated on new medicines and new information on current treatments. New information is especially helpful if a DMT stops working for an individual or the side effects get worse. That's what happened to 39-year-old Rachel Carter. Diagnosed with MS in 2000, the Gilbert, Arizona, resident used several different interferon-based DMTs over the years, while she raised three children, worked and ran marathons. In 2012, Carter had a relapse and realized that her latest DMT wasn't working for her anymore.

With the help of her husband and a new physician, Carter researched MS treatments and switched to a new medication that worked well for her. Today, she's pain-free and back to taking care of her children. "You have to stay informed about what's going on. Keep trying to find something that works," she says.

Lori De Milto is a Sicklerville, New Jersey-based freelance writer.

For more on side effects and choosing the best medication for you, see nationalMSSociety.org/decisions, or download **Momentum** magazine's [Medication map](#).

To learn about the benefits, risks and side effects of specific medications, download the brochure, [The MS Disease-Modifying Medications](#).

For more on recognizing an exacerbation, read [Recognizing a relapse](#).