

# Finding neuro



## How to develop a positive relationship with your neurologist

by Mike Knight



**Julia Fritze-Singh found the right fit for her MS treatment only after seeing several neurologists.** Photo

courtesy of Julia Fritze-Singh

It was 2016 and Julia Fritze-Singh knew something was wrong. Diagnosed with relapsing-remitting multiple sclerosis in 2008, she understood her MS symptoms might worsen if she transitioned into the disease's secondary progressive state. But it wasn't just the disease Fritze-Singh was worried about—it was also the care she was receiving from her neurologist.

"I was getting progressively worse, but every time I went into [my neurologist's] office, she was telling me how I was fine, [that] things looked good," Fritze-Singh says. "I knew I wasn't fine, and things weren't good. I just felt like I wasn't getting the attention or the care I needed."

Fritze-Singh's neurologist agreed. "She was like, 'You know, I'm getting ready to retire. You seem to be wanting to get more advanced medication, and I'm just not keeping up on those anymore. Maybe it's time you see someone else.'"

Finding someone else wasn't easy, but Fritze-Singh, a vice president of a Denver-based software startup, saw her search as more than finding another neurologist. It was also a chance to develop a better relationship with a new neurologist, one with the background and focus she wanted and one who would make sure her perspective, questions, ideas and concerns factored into her MS care.

Fritze-Singh's search ultimately led her to the Mayo Clinic's Center for Multiple Sclerosis and Autoimmune Neurology in Rochester, Minnesota. She made her first visit to the clinic's campus in December 2017 and now goes twice a year. While she's there, she meets with a team of experts, including physical and occupational therapists, a urologist and others, then returns home armed with treatment directions she can carry out with local healthcare professionals. A patient portal on the clinic's secure website and videoconferencing let her communicate with her neurologist and others remotely.

Besides feeling better, Fritze-Singh is happy with the neurologist who oversees her care. "I wanted to be with somebody who's staying at the forefront and knows what's going on in the research area," she says. "It's been a really good fit with him."

Though Fritze-Singh found what she needed at the Mayo Clinic, other people living with MS find what they need at a clinic or practice closer to home. No matter the location, finding a qualified neurologist you trust and connect with is important to your MS treatment plan, long-term health and quality of life.

### **Finding the right fit**

Different types of neurologists treat people living with MS. General neurologists often care for people with MS, as well as others with stroke, Parkinson's disease, epilepsy and neurologic disorders. Some neurologists focus on MS, and some—MS specialists—complete additional education focused on the disease. MS specialists might work in private practice or in regional

MS centers. General neurologists practice in offices and clinics located in cities and communities across the country.

Lisa Fox, a certified physician assistant at the Johns Hopkins Precision Medicine Center of Excellence for Multiple Sclerosis in Baltimore, worked in general neurology before beginning her focus on MS. Fox compares finding the right neurologic expert to interviewing candidates for a job. As a first step, “Reference check your physician before you see [him or her] in order to know that this may or may not be the right fit,” Fox says. She recommends asking trusted healthcare providers, including general practitioners, OB/GYNs, physical therapists, physiatrists or family and friends for referrals. “Everybody knows someone with MS,” she says.

## **Building a positive relationship**

Here are things you can do to build a positive and collaborative relationship with your neurologist:

- Make sure you keep your appointment, and show up on time (or even better, get there early). Besides being respectful of your doctor and others, this will help make sure you get the most from your time with your healthcare providers.
- Create and keep a list of new symptoms and issues you want to talk about, preferably by priority, and share that list at the beginning of your appointment.
- Know that you may only have 20 to 30 minutes with your neurologist or physician assistant. It’s a good idea to raise the issues and questions that are most important to you first. Bring an up-to-date list of your current medications, allergies, other physicians and any other medical issues so that your MS provider can be aware of them.
- Be honest about your symptoms and adherence (or lack of) to your medication. Talk about what you want out of life, even with MS, and about your mood and feelings. MS is a multifaceted disease with many complications. Your provider can’t help with them if she or he isn’t aware of them.
- Be patient. MS is a complicated disease, and your doctor may need some time to understand your symptoms and help you better understand the state of your disease. It may take a few visits to get in sync and assess the relationship and fit.
- Work in collaboration with your neurologist to develop a treatment plan together that includes recommendations and prescriptions, then follow that plan. That will help your provider assess your treatment’s efficacy and address medication concerns or any side effects. It will also help your doctor prescribe additional healthcare services such as physical therapy, psychological help or mobility aids that will help you manage your MS. And if you don’t think that parts of your MS care are working for you, don’t hesitate to raise questions or concerns with your doctor.

You may want to also explore the possibility of being a “shared patient” of both your local

neurologist and an MS specialist at a regional center, says Jacqueline Nicholas, MD, an MS specialist at OhioHealth Neuroscience Center in Columbus, Ohio. Shared patients, she says, typically travel to a regional center once a year for MRIs and for updates about new treatments and research opportunities while they visit their local neurologist throughout the year. “That’s a nice collaboration where somebody is very comfortable with their local neurologist, but the patient can still check in with an MS specialist.”

The National Multiple Sclerosis Society has developed partnerships with many healthcare providers. These include Partners in MS Care who have demonstrated a keen interest, knowledge and experience in MS care. The Society’s [“Find Doctors and Resources”](#) allows users to locate providers throughout the country who are Partners in MS Care.

The Society’s MS Navigator service lets you chat online or by phone confidentially with navigators who can help you identify healthcare providers, Partners in MS Care and Centers for Comprehensive MS Care across the United States. For more information, call 1-800-344-4867.

### **How to prepare for your first visit**

Once you’ve identified a neurologist you’d like to see, you’ll schedule a “new patient” visit. You will need to sign a waiver giving your current neurologist permission to send your records to the new neurologist you’re considering. If you’re worried that may result in an awkward conversation, don’t be.

“You can say, ‘I would like for my records to be sent to this provider; I’m seeing them for evaluation,’” Fox says. “If you’re considerate and do it in an honest and respectful way, nobody will ever fault you for that.”

Fox recommends asking about what insurance the provider accepts before you go. If you don’t have the right coverage—or if you don’t have coverage, period—financial assistance may be available. Some centers for comprehensive care, including Johns Hopkins, have social workers who work with those who don’t have insurance, and many MS drug manufacturers offer co-pay assistance programs to help cover the costs. Local providers may be willing to create a payment plan to make it easier for you, too. The Society also might be able to point you to information or resources that can help.

### **It’s the connection that counts**

Like all good relationships, the one you have with your neurologist begins by establishing a personal connection and commitment to shared decision-making. It might take time and effort to create. Keeping lines of communication open and being honest with your provider are essential.

Donald Negroski, MD, a general neurologist practicing in Sarasota, Florida, also recommends developing good relationships with “physician extenders” that might include a physician assistant or advanced registered nurse practitioner, who participate in your care along with

the neurologist.

“Patients are the center of this multi-dimensional team,” Dr. Negroski says. “And if they don’t have the proper relationship with one of the lead members of the team, the neurologist, or the physician extenders, it doesn’t work as well.”



**Debbie Bright prepares for her doctor's visits by doing research and bringing a list of questions.**

Photo courtesy of Debbie Bright

Debbie Bright was diagnosed with relapsing-remitting MS in 1988 and has since transitioned to secondary progressive MS. She’s seen two neurologists in that time frame. Her first neurologist, she says with a laugh, was “a one-man operation” and definitely “old school.”

“He literally had a doctor’s bag that included a stethoscope, blood pressure cuff and reflex hammer that he would get out when I came,” she says. “One thing I loved about him was he would dictate notes in front of you from the visit. You heard everything.” When that doctor retired, Bright, who lives in Baltimore, began seeing a neurologist at Johns Hopkins. Though her treatment has changed over time, her approach as a patient hasn’t.

“I try very hard to go in with a positive attitude,” she says. “When you meet with the doctor, certainly it’s not their fault that you have MS. I also think it’s very important to go in with a list of questions. I mean, that’s kind of basic, but especially when you have cognitive issues, it’s very helpful to have your questions outlined on a piece of paper and to take with you so you don’t forget something.”

Like many people living with MS, Bright has access to a patient portal that allows her to send and receive secure messages with her neurologist and other team members. Bright tries to do her homework before asking for help. "I'm a fan of doing your own research, too, so you're educated before you are asking for their input or opinion," she says.

Regardless of what type of neurologist or MS care provider you choose, Fox says to trust your instincts. "If you have MS, you need to find a provider that you have a good connection with," she says. "You need to listen to your gut, because you're never going to trust anybody when your gut says 'Hey, something's off.'"

**Mike Knight is a writer in Indianapolis, Indiana. He was diagnosed with MS in 2013.**

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