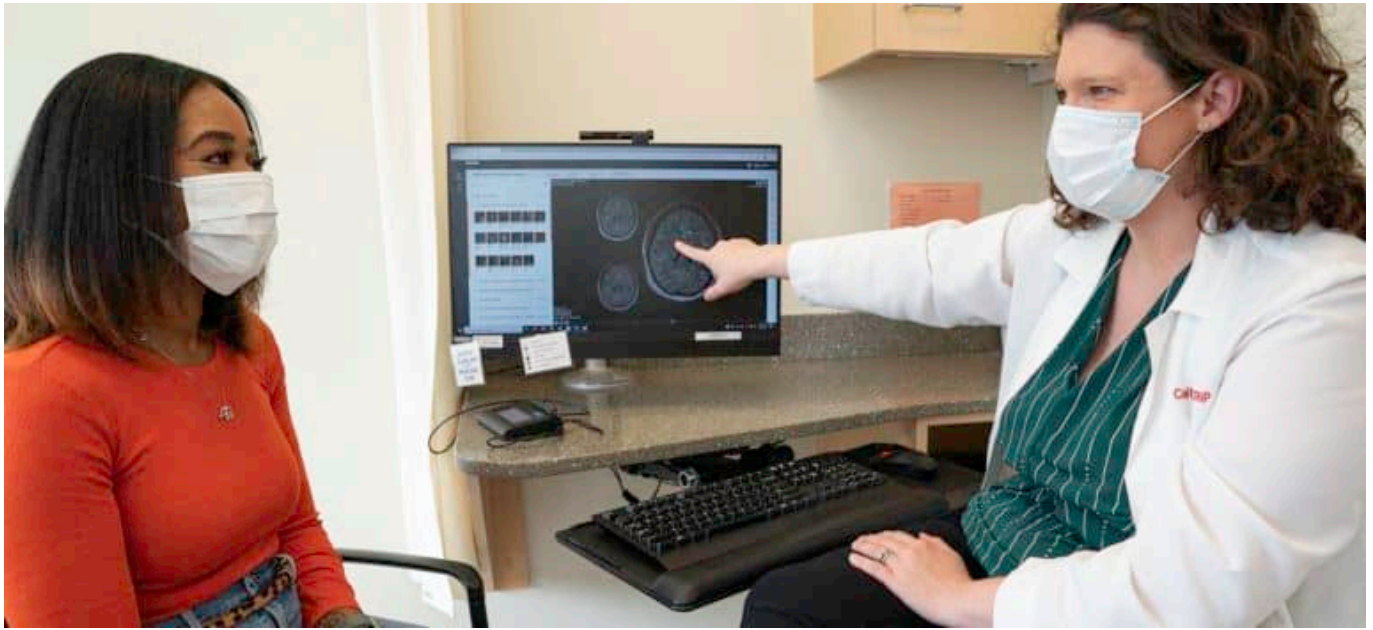


Talking about MS with your doctor



People with MS have a lot to say about what they want their healthcare teams to know.

By Brandie Jefferson

In my early 20s, living on my own for the first time, my hands stopped working. I couldn't grasp a pencil or button a shirt. If I wanted to pick something up, I had to smash it between my palms.

The change hadn't come on suddenly, though. It started with tingling in my hands shortly after I moved to New England from the Chicago area. The tingling became more intense over a period of months. And my vision had been a little off, but not in a way I was familiar with. It was like the adjustment period when you come inside after reading a book in the midday sun.

I explained all this to a doctor — a general practitioner I'd chosen because his office was close to where I lived. With a furrowed brow, he focused on my hands, moving them this way and that as I talked. The doctor said I likely had "a little bit of arthritis," but he wanted to be sure. It was winter, and it was cold, he said. Perhaps I just didn't handle the cold well. Despite not being able to shake his hand, he sent me on my way, telling me to return in the spring if things hadn't gotten better.

Many people with multiple sclerosis report similar experiences. Sometimes, even after receiving an MS diagnosis and finding a neurologist or MS specialist, they still have concerns they want their healthcare team to understand.

See me. Listen to me. Respect me

It wasn't until years after I'd seen the first doctor that I realized he worked with much older patients. I don't think he saw me as a 24-year-old who was used to cold weather. He simply saw a list of symptoms: pain that I didn't yet have the vocabulary for and loss of mobility, likely the result of the pain — or the cold. When he saw these symptoms in his older patients, they were symptoms of arthritis. He focused on a disease, not a person. He didn't pay attention to the other clues, such as vision problems, because they didn't fit the model of the disease he was familiar with. It felt like he hadn't seen me at all.

Chicago resident Nicole White had been experiencing symptoms for more than 10 years when, in 2019, she was diagnosed with MS.



Nicole White

“Everyone missed it,” she says. “Every time I went in with something — leg numbness; I couldn't walk; chest pain; I was passing out; I had optic neuritis — every time they said it was rooted in obesity.”

After a stroke — which was initially discounted, with a doctor saying she was “fine” — White was connected with another doctor who asked about her life, where she worked and how her days went. He told her, “Ms. White, we are going to figure out what's going on with you because you're too young to be here on this stroke floor.”

Then, he asked her how often she fell. “I was like, ‘Who told you I fell?’ ” He sent her for testing, suspecting “something.” Four months later, she discovered that “something” was MS. It was then that she understood that for years, her doctors had missed clues that the ER doctor picked up on in an hour. “Maybe they would've put the pieces together sooner if they had stopped and asked, ‘How do you experience life, Nicole?’ ” Instead, she thinks a condition like MS was never on her doctors' radars, not only because they continuously focused on her weight, but also because she is Black. “I wasn't in their textbooks,” she says.

Like many people with MS, Melissa Cook, a marketing manager at the Society who lives in Michigan, has seen several neurologists. The doctor who diagnosed her chastised her for crying and asked if Cook was fine with, “not having babies,” maybe as a way to scare her into action, Cook says. She’s also experienced the rigidity of a doctor who treats the disease, not the person.

“This isn’t a disease that a vaccine or a pill will fix; it’s very complex,” she says, and praises healthcare professionals who can see that complexity and work with it, not simply cite the latest research about the latest drug and send her on her way.

Cook has also had extremely positive experiences, including seeing a doctor who she says treated her with respect. “If I had a question, it wasn’t treated like it was stupid. I wish everyone had that experience as far as MS goes,” she says.

Seth Morgan, MD, is a retired neurologist in Maryland who also lives with MS. He says it’s reasonable for a doctor to have different concerns, but that people need to feel comfortable expressing their needs and asking questions.

“If your provider says, ‘Oh, don’t worry, that’s not an issue,’ on a certain level, that may be OK. But it is fair to ask, ‘Why isn’t it an issue?’ ” he says. “And if a doctor is put off by your questions, well, that says more about them than about you. If the relationship isn’t one of mutual respect and consideration that allows both sides to engage in conversation, there’s a problem.”



Melissa Cook

There is research to support this idea that such conversations aren’t happening. In a 2018 survey related to quality of life, doctors placed a much higher emphasis on physical function and limitations than people with MS did. People with MS instead gave nearly equal weight to such issues as vitality and general health. “It is essential to enhance communication in order

to better understand actual patient needs,” concludes the study, published in the journal *Frontiers in Neuroscience*.

Time, of course, is one of the biggest culprits when it comes to having productive conversations. Morgan says when he was practicing, it wasn't unusual for him to step into the waiting room and apologize to patients for running late. “I've always believed that whether it's an 'important' symptom or not, if a patient says, 'I'm having XYZ problem,' I can't blow it off.”

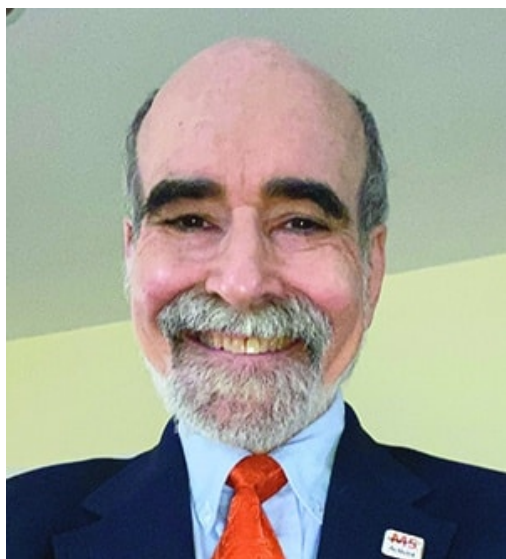
Mary Rouvelas, a Washington D.C.-based lawyer working at the American Cancer Society Cancer Action Network and a member of the Society's Activism Advisory Committee, knows that time constraints are often at play. “I want the medical professionals to know that I hear their crisis, that they don't get enough time. I don't know how you can fix the '15-minute appointment problem' without fixing the infrastructure.”

When it comes to communication, however, she says the burden doesn't need to be on her primary healthcare provider alone. If Rouvelas could go back to the doctor who told her about her MS diagnosis over the phone — while she was at work — she says she'd ask him to offer resources. “The first and most immediate thing a neurologist needs to focus on is treatment. But the next question should be, 'How am I going to keep the patient well holistically?' ” she says. “He could have referred me to the Society or to a social worker to get the mental health support I needed. “The neurologist certainly cannot be responsible for those components,” she adds, “but they could have a handoff plan. The moment of diagnosis and the decisions afterward are like a tornado in a person's life.” And it doesn't end with a diagnosis.

Teach each other

“It's such a lifelong journey with MS,” Rouvelas says. “It's never going to end.” And neither, unfortunately, will the paperwork.

“This road is going to be long,” says Krescence Greenwood-Campbell, a 36-year-old psychotherapist and counselor in New Jersey. She was diagnosed with MS in 2019. “Because I'm a therapist and I run my own agency, I understand dealing with insurance companies and diagnosis codes and all those things,” she says. But most people don't.



Seth Morgan, MD

Greenwood-Campbell would like to see medical and support staff help people understand why things don't always go smoothly when receiving care. "Explain to them that it's not because of the healthcare providers, it's because you have to go through this red tape with insurance," she says. "Let people know 'this is the paperwork insurance is looking for.' Tell them, 'It takes this much turnaround time for this kind of test.' Then tell them why it takes this long."

After helping her father at the hospital in his final days, White saw something she'd never seen in her four years of frequent interaction with the medical system: an internist who coordinated a team of specialists. "I have to call my primary," White says. "I have to call my neurologist. I have to call my eye doctor. I have to call my therapist. No one is talking to each other, and I have to do so much of the work to connect the pieces."

The struggle of deciphering insurance, finding appointments that fit into an inflexible schedule and the hit to the wallet that medical care can take can negatively affect MS symptoms. "You think stress and MS go together? Anxiety and MS go together? They don't," White says. "There has to be a better way to give people comprehensive medical care."

I was fortunate to once have what I consider an MS provider exemplar. After each MRI, we'd head into an office, he'd turn on two computer screens and carefully point out any changes between the current and previous images. He took the time to explain not only what was happening in my brain. He also showed me why I was lying in a machine for two hours hooked up to an IV with the taste of metal on my tongue. That felt like respect to me. It showed that he saw me as worthy of an explanation. But I never would have thought to ask.

Greenwood-Campbell tells her healthcare team what she needs. "I always ask my doctor to show me my brain. I need to see where the lesions are," she says. "Is it the temporal lobe? The prefrontal cortex?" As someone trained in the workings of the brain, she needs this

information to fully make sense of her illness. She's aware that there isn't always time for an in-depth discussion, but she still sees a way for both her and her doctor to get what they need. "If you can't spend that time, then send a follow-up email."

When it comes to choosing medications, having an expert take the time to explain options and side effects may be the best shot that someone without a solid understanding of pharmacology, neurology and statistics has at making truly informed decisions.



Mary Rouvelas

Instead of handing out brochures, White says, "doctors should be explaining to me and providing me with all the information that I need to make the best choice." That includes more than contraindications, but also things like the methods of delivery of disease-modifying therapies (DMTs), the time they'll take and the cost. Those explanations require doctors to be "present with the individual, and to answer questions fully to their comfort level," Morgan says. "The brochures are for physicians, they are not something most people can dive into."

Because of limited time, however, he says resources like the Society and other support groups are invaluable sources of expert knowledge.

By that same token, however, people with MS have expertise as well. Cook says she needs her team to understand that her knowledge is also integral to the conversation and treatment of her MS.

"We live in our bodies," she says. "We know our bodies. I don't feel like I know more than my doctor, but I do understand living with MS. I understand my body and day-to-day life."

White agrees. "I used to say, 'I trust you, you're the expert,' " White says. "And I do trust that my provider is an expert in MS. But I have to trust that I'm the expert of my body. I'm never

giving that up again.”

Empathize

Empathy shows up not only in words, but in actions. While her neurologist is phenomenal, Rouvelas says, most providers are set up only for people who can walk, adding more barriers to getting the best healthcare instead of adding stress. For example, Rouvelas hasn't been weighed in years because none of her regular doctors' offices, including her neurologist, general practitioner and gynecologist, has a scale that can weigh a person who can't step on and off safely on their own. None of these practices has felt comfortable helping her, preferring to accept her best guess.

From the day of diagnosis — which often leads to distress, confusion and frustration — to a routine check-up, the mental burden of a doctor's visit can be a lot, Greenwood-Campbell says. But it can still be mitigated. “Show me your empathy because even coming into the waiting room is anxiety provoking sometimes,” she says.

On a day-to-day basis, she adds, she can almost forget about MS. “But when I come into the office, I think, ‘Oh crap. This is real.’ So let this experience be as amazing as possible because if mentally and emotionally I don't feel well, physically I don't feel well.”

White says those feelings affect every area of her life, so the importance of her medical team cannot be overstated.

“They are a necessary puzzle piece to everything in my life,” she says. “Nothing else works if this part doesn't work. What happens in my doctor's office affects much of my mental state, my ability to work, my ability to function. Everything.” She cites her occupational therapy team as an example of just how great healthcare can be. “They sit with you. They make eye contact. They create an environment where you trust them. They understand your fears and the way you live,” she says. “Their plan is to restore my life, and they cannot do that if they don't understand my life. “We need to rethink the human aspect of this work. We have to include more care, compassion and empathy in medical care.”

Brandie Jefferson is a writer in St. Louis, Missouri. She was diagnosed with MS in 2005.