

Working together



Shared decision-making gives people with MS more say in their care.

by Robert Lerosé

Gail, a 51-year-old business owner from Pennsylvania, grew up in a family where healthcare was one-sided. You went to the doctor, reported your problem and followed the doctor's instructions without question or discussion.

But when Gail was diagnosed with multiple sclerosis at age 32, she took a different approach. "I felt I needed more control over my healthcare. By trial and error, I was able to learn how to talk to my doctors. After reading articles and [considering] my own experiences, I came to shared decision-making," says Gail, who asked that her last name be withheld to protect her privacy.

Shared decision-making is a communication process where the patient and the healthcare provider work together to agree on a course of treatment. The provider supplies information to the patient on specific options, evaluating the risks and benefits of each. Then, they'll discuss what is paramount to the patient — things like values and lifestyle — before reaching a mutually satisfactory decision.



Kera LaBonte, who has MS, with her fiancé, Todd, and his son, Ayden. Photo courtesy of Kera LaBonte

Shared decision-making helps make sure the “patient’s needs are met from a social standpoint, a health standpoint and a physiological standpoint,” says Megan Esch, MD, Gail’s neurologist at Geisinger Health System in Pennsylvania. “We [want to] ensure that we can give the best treatment possible to prevent relapses, make the patients feel good and get buy-in from both parties.”

For example, after a positive MRI following her first treatment with the medication Lemtrada, Gail’s second scan found additional lesions. Esch gave her the option of switching to Ocrevus. Together, they looked at recent studies of Ocrevus and discussed how it would affect Gail’s lifestyle. Gail knew what to expect with the effects of Lemtrada on her daily routines and decided to continue with it. It was a joint decision with plenty of input from both sides. “We really do have a good back and forth,” Gail says.

Open communication

When 34-year-old Kera LaBonte was diagnosed with MS at age 22, she “wanted nothing to do with it,” and went into denial. Even though she admits to being outspoken, she felt that some of her early doctors didn’t listen to what she really wanted regarding her choice of prescription medication. After learning about shared decision-making from her mother, it has become an integral part of her life.

For example, LaBonte would like to have a baby, but her current treatment could affect her chances of conceiving. Together, she and Esch looked into weaning her off the drug and switching to something that could be less problematic in a planned pregnancy.

“She listens to everything I am saying and comes up with solutions with me. I don’t feel like I have to pick what she decides. [Shared decision-making] makes me feel at ease and that my voice is being heard,” LaBonte says.

Open communication is essential in a shared decision-making relationship. Healthcare

providers work to ensure that their patients have a solid understanding of the risks and benefits of any treatments, and people with MS must be honest about their goals and fears beyond their MS — including their lifestyle, values and plans for the future — to come up with the best possible treatment plan.



Jennifer Frame, who was diagnosed with MS at age 19, feels empowered when she is open and honest with her doctor, and they make decisions about her care together. Photo courtesy of Jennifer Frame

“People have their own way of thinking about things,” says Matthew Carraro, MD, systemwide director of MS and neuroimmunology at Novant Health in North Carolina. “If you stop somebody’s MS, but they’re miserable all the time, what is the point? They have a horrible quality of life for a different reason. It’s really important for them to feel invested in the treatment.”

Doctors also have their own way of thinking about things, Carraro says, pointing out that there is no right way to treat MS. Healthcare providers need to explain these different factors to help their patients come to an informed decision and be honest with them about their own biases.

“I want you to be aware of where I’m coming from because I don’t know what your thoughts are for treating your condition,” Carraro says. “Being that thorough may help to dampen some of [our] biases and help patients make a choice that’s more appropriate for them, instead of a doctor saying, ‘I have this way of doing things and that’s how we’re going to do it.’ We are always influencing patients’ decisions, but when they’re informed and they’re [involved in] shared decision-making, it serves to eliminate or reduce some of that bias, which is good.”

Empowerment

For 50-year-old Jennifer Frame of Huntersville, North Carolina — who was diagnosed with MS

at age 19, just as she was starting nursing school and learning to be an advocate for others — shared decision-making can best be summed up by the idea of empowerment.

For example, she had to make several changes to her medication recently — a long, involved process. Being up-front with Carraro, her doctor, about her fears and asking him to clarify things that she read about different medications eased the burden. “It boils down to communication and being knowledgeable,” she says.

It also means recognizing that at the heart of shared decision-making is creating a safe space where no question is off-limits. Patients “should not be afraid to ask any question they have, as silly as they think it may be. We would rather that the patient ask the questions or voice the concerns, instead of harboring them, so that we can guide them in between each of their visits,” Esch says.

Esch doesn't put any limitations on how much her patients look things up on Google or Facebook, provided they discuss it with her. “I might have data to either support or refute that, and I can help them understand how it might improve the way they're feeling or how it might even harm the way they're feeling,” she says.

To make the best use of your limited appointment time with your healthcare provider, make sure to make time for conversations about shared decision-making. Here are a few suggestions:

- Open with your three most important issues and then move on to other concerns.
- Take notes or bring someone to take notes for you.
- Record the visit on your phone or digital recorder, but get your doctor's permission ahead of time.
- Before your appointment, find out what information your provider needs ahead of time, such as a CD of your MRI, films, lab test results and office notes.
- Be prepared to provide a timeline of your symptoms.
- Bring someone who knows you well — a spouse, best friend or family member — who can give the doctor a picture of you over time, describe changes in your abilities or provide other supportive history.

“Shared decision-making is critical because we need to try to hit your goals, not just ours, and that's just completely different than it was 10 years ago,” Carraro says. “You should feel inspired by where you're getting care.”

At the doctor's office

While every person will have their own individual concerns, issues that might come up during an office visit could include:

- Will I die from MS?

- Will my kids get MS?
- Is there an MS diet or foods/supplements that I should consider?
- Will I be able to work?
- If I can't work anymore, can you help me with applying for disability insurance?
- What are the risks of taking this medication?
- Will the medicine make me feel sick?
- Can I have kids? Do I need to stop the medicine before trying to conceive?
- What type of exercise is best?
- Can MS affect my sex life?
- I am having trouble learning new information. Is this due to my MS, or am I just getting older?
- What do you think about this information I found on the internet?

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