

Supporting the people you care about



Insights from family members, friends and colleagues who are connected to someone diagnosed with MS

By Matt Alderton

Bryan Rodriguez was just 16 years old when his mother, Luz Loeb, was diagnosed with multiple sclerosis. A single mom of three who balanced family, education and career, Loeb moved to Philadelphia from Puerto Rico as a child, became a parent at 18 and began college a year later on a full-ride scholarship to the University of Pennsylvania, where she often attended class with her two oldest children in tow. She was used to challenges.

But MS was a different kind of challenge. Not only for Loeb, who has faced periods of vision loss, immobility, numbness and fatigue, but also for her children, who had to grow up prematurely.

“I didn’t even have a driver’s license, but I had to drive my mom to her appointments downtown. I had to make sure my brother and sister went to school and got home safely after,” says Rodriguez, Loeb’s eldest, who is now 27 and living in New York. “There was one week where I was basically living at the hospital with my mom and had to send my homework to my teachers.



Bryan Rodriguez (right) helped take care of his mother, Luz Loeb (bottom center), when she was diagnosed with MS. He also helped take care of his brother and sister. Photo by Roberto Defreitas

I had to become the man of the house.

“I had to prioritize my mom’s health and well-being as my No. 1 priority and be a rock for my entire family because my younger siblings were looking to me for answers and strength,” Rodriguez continues. “I was tired physically and emotionally. It was tough.”

And yet, what was hard also was healing. “Over time, I’ve learned how to address my own emotions while also supporting my mom,” Rodriguez says. “That’s one of the hardest things if you love someone who has MS. You have to learn how to emotionally adjust to this new chapter in your life.”

What’s true for parents and children also is true for spouses, siblings, friends and even work colleagues: Chronic illnesses affect not only the individuals who have them, but also those in their orbit. If you love someone with MS, you can support their wellness and yours by learning healthy strategies for connecting, communicating and coping.

Connecting

Multiple sclerosis can be a “disease of disconnection,” says Evan Smith, PhD, a rehabilitation psychologist and clinical assistant professor at the University of Michigan, where he is an attending psychologist at the University of Michigan Multiple Sclerosis Center.

“Depending on the cognitive, emotional and physical implications of their disease, people with MS over time can end up feeling less connected to the things they value,” Smith

explains. “One of the antidotes to that is building connection with other people.”

If you’re close to someone with MS, you can make it easier for them to connect with you by embracing education and nurturing empathy.

“If you’re a loved one, friend or coworker, you don’t know what you don’t know. And that makes it challenging to support someone with MS,” Smith says. “One way to build that knowledge base is to do independent learning on what MS is and what it’s like to live with MS. What you learn might not be exactly how your loved one experiences MS. But coming to the table already knowledgeable in some ways about MS can reduce the emotional and cognitive labor that a person with MS routinely has to do in order to relate to other people. You’re lowering the barrier to entry for conversation, which can be a nice way to let the person with MS know that you care and that you’re committed to your relationship with them.”

Licensed clinical social worker Susan Wegener agrees. “MS can create feelings of uncertainty and fear for either the person diagnosed with MS and/or their loved one, friend or carepartner,” says Wegener, who has a private practice in Austin, Texas. “Once a loved one or family member gains a better understanding about MS it can foster more hope and potentially make it easier to navigate issues that arise in relationships.”

That resonates with Marcel Steinbach, whose wife has MS that affects her short-term memory. Learning about MS has helped him differentiate the person from the disease, he says. “My wife is very forgetful. She’ll ask me something and I’ll say, ‘I just told you that 10 minutes ago.’ She’ll say, ‘No, you didn’t,’ but I know that I did. It can be very frustrating,” says Steinbach, who lives in Hanover, Germany. “I have to constantly remind myself that she has MS.”



Wendy Haase during the 126th Boston Marathon. She was

sponsored by the Greater New England area of the National Multiple Sclerosis Society.

Education also has been invaluable for Adrian Dickerson and Shari Ajayi, who work together at Saatva, a New York and Austin-based maker of luxury mattresses and home furnishings. Dickerson's wife, Elaine, was diagnosed with MS a few years ago, and both Dickerson and Ajayi have a colleague, Saatva Project Coordinator Bethany Torkelson, who also has MS.

"When she was first diagnosed, it was a little bit depressing," Dickerson says of his wife, with whom he has two young children. "It was easy to go down these wormholes of worry ... But the more education I got, the better I felt because I realized it was something we could manage together."

Saatva recently partnered with the Greater New England area of the National Multiple Sclerosis Society by sponsoring runner Wendy Haase during the 126th Boston Marathon — an experience that gave Ajayi an opportunity to learn more about MS and Torkelson's experience with it, she says. "With all that I have learned, I now understand the ways it may affect her on a daily basis, and that has made me aware of how I can be supportive," Ajayi explains.

Communicating

One of the biggest roadblocks in MS relationships is communication. "Making assumptions about what someone is thinking or how someone is feeling can lead to feelings of being misunderstood," Wegener says. "It's easy to assume things about someone with MS, but your assumptions might be false. So, it's important to ask about what their experience actually is and how they're really feeling."



Adrian Dickerson and his wife, Elaine, who lives with MS.

One of the most important things to communicate is expectations. “Sometimes when there’s conflict, it’s because we’re not focusing on the support that would be most helpful for that person,” Smith says, adding that some people want emotional support and others want instrumental support. “Emotional support is a listening ear — someone to provide advice when it’s asked for and to just be present. Instrumental support can be anything from providing reminders throughout the day to picking up groceries to helping with [wheelchair] transfers.”

The best way to determine what kind of support someone needs is to ask. Imagine, for example, someone who uses a four-wheeled walker. A stranger sees them carrying groceries to their car — two bags of groceries hanging on either side of their walker — and insists on helping by taking one of the bags.

“Well, now this person is on the floor because their walker is out of balance,” Smith says. “A stranger assumed they needed help when in reality this person goes to the grocery store all the time and had a well-made plan to help them balance while they navigated the parking lot.”

In this scenario, both people want the same thing — for the person with the walker to make it safely to their vehicle — but the stranger has no idea how to accomplish it. If they had asked whether to help and how, disaster could have been averted.

Because MS ebbs and flows, a person’s needs and capabilities might fluctuate from month to month, week to week or even day to day. Communication should therefore be constant without being overbearing, says Smith, who suggests that friends and family members develop their own shorthand with loved ones.



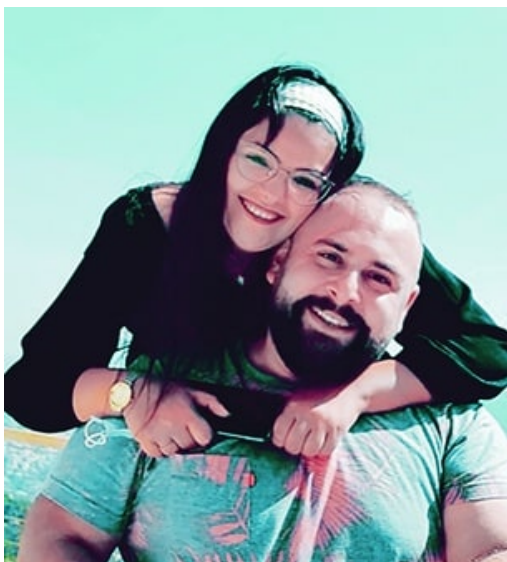
Shari Ajayi

“For example, on a day where fatigue is leaving them without the resources they typically expect, your loved one with MS might say, ‘On a scale of 1 to 10, I’m usually an 8, but today

I'm a 5,' " explains Smith, who recommends having premeditated plans ready for different scenarios. "What that means is: Today you're going to pull out the plan for what to do when a 5 is happening. For example, if the person with MS usually gets up in the morning and takes a full standing shower, on this day they may need you to bring the shower chair into the shower and help them use it. Or if they usually make a full breakfast for the family, it may be the case that today is a frozen-breakfast-burrito day, and it's up to you to heat up those burritos. Or maybe they usually take the bus to work, but on a day that's a 5, they'll need you to drive them."

Another common shorthand is known as "spoon theory," which a woman with lupus developed to explain her energy levels to a friend. Imagine a row of 10 spoons laid out on the table that represent how you feel when you wake up with all your energy. On a day when your loved one is experiencing MS symptoms, they might have only a few spoons on the table instead of the usual 10, or they might burn through their spoon supply more quickly than usual. In that case, Smith says, you might have to decide together how you want them to prioritize and allocate their limited spoons. If a husband is planning a date night with his wife who has MS, for example, he might ask her in the afternoon, "How many spoons do you have left?" If she only has two spoons left, he might opt for a movie night at home instead of a fancy dinner out.

Although shorthand can be useful for navigating everyday conflicts, it's sometimes necessary to have deeper, more direct conversations about the impact of MS on your relationship. In those instances, Smith and Wegener offer the following pointers:



Marcel Steinbach with his wife, Lina Halawani, who has MS.

Schedule conversations: "Timing is everything," Wegener says. "If you're having a disagreement or you need to work through an issue, find a time when you are in a calm

mind-space, and free of distraction — so you can sit down, focus on each other and have an authentic conversation.”

Use ‘I’ statements: “Lead with, ‘I’m feeling this way,’ ” suggests Wegener, who says leading with ‘you’ statements has the effect of blaming the other person for issues related to the MS disease process or the treatment they are receiving. “For example, if someone is taking certain medications that may have a downside of increasing one’s irritability and anxiety, their behavior might seem unusual and even frustrating. It is important to communicate about what is happening, but also realize that the person’s behavior might be a consequence of the disease process and medication side effects, and not about you or something that you are doing.”

Be patient: “Depending where they are in the lifespan of their disease — it could be that they’ve just been diagnosed, for example — someone with MS may not be ready yet to have these conversations or may not be quite sure how to convey what they’re thinking and feeling. And that’s OK,” Smith says. “In that instance, I recommend affirming that you hear them. Say, ‘I know you’re not ready for this talk right now, but I’m here when you are.’ Just knowing that a loved one is there to talk when they’re ready can open the door to more productive conversations.”

That last point hits home with Rodriguez. “Sometimes, the person with MS has to process things themselves before they can tell you how they feel, and you can’t rush that,” he says. “For example, I’ve been trying to get my mom to see a therapist, and that’s been a battle for quite some time. When you love someone, you want them to get better as fast as possible, so you push different remedies and solutions. But you can’t force it. They have to be ready for it. In the meantime, all you can do is ask, ‘What can I do?’ It might be something as simple as providing a listening ear, going for a walk or getting ice cream.”

Often, a good outcome of successful communication is compromise. Until recently, for example, Steinbach and his wife lived in Dubai, United Arab Emirates. Because the heat exacerbates his wife’s MS, however, they decided to relocate to Steinbach’s native Germany. “I like to live next to the beach, but it’s too hard for my wife,” explains Steinbach, who says the couple also negotiates things like vacations. “I love traveling, but it’s not always easy on my wife. Last year, for example, we took a trip to Istanbul — but we went only for a day. That was our compromise.”

Coping

There’s no denying the positive impact of good communication. What friends, family and colleagues of people with MS often need most, however, are coping strategies that help them manage the things they can’t change.



One of Luz Loeb's ways of coping is through her photography.

For Rodriguez, who wrote his college admissions essay about his mom's MS, creative pursuits like writing and drawing are helpful. "Putting everything that's stuck in your head down on paper is a great way to relieve stress, clear your mind and reset," he says.

Talk therapy — with a professional therapist or even just a trusted friend — is also helpful. "Something I've learned is that it's really good to talk to somebody about how you're feeling," Rodriguez continues. "I have very close friends who I've known for over a decade who understand me because they've seen the entire progression with my mom and everything we've gone through. They've been amazing listeners, and I'm so thankful for them."

If writing, drawing and talking don't work for you, maybe it's knitting, running or gardening. What's important is that you "acknowledge your own needs and take breaks," says Smith, who says it's important to treat relationships like airplanes — in case of an emergency, put your own oxygen mask on before you help others with theirs. "If you don't appreciate what your own needs are, that can lead to physical and emotional burnout," he cautions. "That can lead to compassion fatigue, which makes it a lot more challenging to be present with the person you love."

One of Luz Loeb's way of coping is through her photography. Managing your schedule can be just as important as managing your emotions. "Fatigue is a good example," explains Wegener, who says people who experience MS-related fatigue often flourish in the morning, then hit a wall in the afternoon. "If you have a friend with MS, you can still do things together. But you have to be flexible. Instead of having dinner, maybe you go to brunch."

Flexibility can be especially important at work. "Three of the biggest challenges she typically faces are limited energy, tough days and getting enough rest," Ajayi says of Torkelson, her

colleague with MS. "If she asks to reschedule a meeting or has days where she feels depleted, I do my best to go with the flow and make sure that I give her time back to rest and recuperate."

Finally, it helps to focus on silver linings. "When something like MS happens, you start to think more about your own mortality. But the flipside of that is that you become much more appreciative," Dickerson says. "My wife and I have been through a lot, and we're going to get through this, too. It's made us stronger and has brought us closer together."