

What can we do?



Finding ways for family and friends to provide help and support

by Mike Knight



Krystal Windley (right) can count on her daughter and friends to help her navigate her MS. Photo

courtesy of Krystal Windley

Krystal Windley sat in her neurologist's office in disbelief. It was July 2017, and Windley, a 35-year-old single mother living in Malden, Massachusetts, could barely open her right hand. Searing pain hit her when she did.

Windley was diagnosed with multiple sclerosis in 2010. She'd had flare-ups and other symptoms before. But this one was different.

This one was disabling.

This one scared her.

"Just to touch it was excruciating, like pins and needles times one thousand," Windley says. "I couldn't put on a shirt by myself, I couldn't close my car door." But, save for steroid injections that might reduce inflammation in her hand, there was little to be done except wait for the flare-up to pass.

"I kind of broke down crying," says Windley, whose family lives four hours away. "They were telling me I would be back to normal in six months," she says.

"I thought to myself, 'I've got my daughter. There has to be something you can do, just do something to open my hand. At least let me use it.' And there was nothing."

But Windley was right: She did have her 10-year-old daughter, Jaiden. "She was in the doctor's office with me," Windley says. "She knew that [news] was huge. She came and sat right next to me and held my hand and said, 'It's going to be OK. I'll help you.'"

And for a moment at least, that was all Windley really needed.

Even when it's no more than calming reassurance, help and support are musts for those living with MS. But building a support network for the incurable, lifelong disease isn't always easy. The complexity of MS can make it frustratingly hard to explain, making it difficult for family, friends and others to understand, which makes it harder for them to know how they can help. Determining what kind of support you'll find valuable may not be any easier, and even asking others for help may feel awkward or uncomfortable. And some may be reluctant to help no matter what you do.

So how do you create a support network if you have MS? What can you do to encourage your family, friends and others to hop on your MS bandwagon? And where do you—or they—start when it comes to looking for more education and information along the way?

Winning the head game

The first step, says Lisa Kemppainen, 53, a Colorado-based psychotherapist, is learning to ignore the voices in your head. "Truthfully, most people know how to ask for help. They know

the words,” Kempainen says. “What they don’t know is if their request will actually be heard. And that keeps many people from asking in the first place.

“Lots of us have experienced as kids saying, ‘This is what I need,’ and having a parent say, ‘No it’s not’ or somehow shutting us down,” she says. “And we carry that as adults.” Further compounding the problem is a “pull yourself up by your own bootstraps” mentality that may cause people to go it alone.

Diagnosed with MS herself in 1998, Kempainen says people create horror stories that they use as shields against the scarier fears of the unknown and the vulnerability that fear creates. “What you find is that human beings resist, resist, resist because they have all these stories in their heads,” Kempainen says. “‘No one is going to show up for me,’ ‘I shouldn’t have to ask for help,’ and ‘If I ask for help, I’m weak.’” And that can become just as disabling as the disease itself.

“The risk is isolation because you just can’t physically do what it takes to put yourself out in the world,” Kempainen says. That isolation feeds on itself by straining your ability to connect emotionally with others—which leads to more isolation. Yet when people do ask, they almost always discover that the fear was unfounded. “If you take the risk, 9.9 times out of 10 it will be beneficial,” Kempainen says.

Once you’ve quieted those voices, Kempainen recommends creating an inventory of what your needs really are. “Is it a person to listen to you for 10 minutes? Is it someone to sit with you while you cry? Is it someone to go to the grocery store for you or walk your dog?”

Mastering the approach can pay long-term dividends to both parties. “When [people] do this, they start to figure out that when you ask for what you need, you give other people permission to do the same thing,” she says. “It doesn’t have to go one way just because you’re the one with MS. Because healthy friends still have needs, right?”



Janet Werner (right), with her husband, Ernest, believes that it's important to educate people about MS before they're comfortable enough to help. Photo courtesy of Janet Werner

Help your helpers help you

Now retired, 66-year-old Janet Werner spent her career teaching high school science in Long Island, New York. She was diagnosed with MS in 1986. Perhaps not surprisingly, Werner believes others might need to be educated about the disease and its effects before they're comfortable enough to help.

Werner points to a lesson she shared with a biology class before she disclosed having the disease. "We did a whole program on MS symptoms without telling them that I had it," she says. Some students were asked to stand on one leg with their eyes closed to mimic imbalance. Others held a 2-liter bottle of water in front of them while standing on one foot to compound the effect. Some held dark paper over their eyes to replicate impaired vision. "They were all laughing, and we had a good time with it," Werner says. "And I said, 'You all felt what a symptom of MS is like.'"

Once she disclosed her MS, her students were tireless supporters, as were teachers and staff. After explaining to the school principal that her classroom was very hot and how that affected her symptoms, she asked for an air conditioner. "I had it in the next day."

That type of experiential education, Werner says, can also help those who are skeptical about

the disease and its effects come around. “When people see what kind of lifestyle you do have, what your needs are and how you handle it,” she says, “They go, ‘OK, now I understand.’ So instead of just telling somebody, they have to see it.”

Windley says she’s even taught her friends about MS while she educated herself. “Because of my flare-up I had to change medications,” she says. “I was given an encyclopedia of a pamphlet to read through about the medications and it was kind of overwhelming.”

Windley shared her dilemma with a friend, who then brought her boyfriend over to Windley’s to decipher the dense language. “We read through all of the materials, and we each made a little speech about which one was best or about the pros and cons about each of them,” Windley says. “I’m down to two options right now just because they took the time to do that.”



Autumn Scott (center), a mother of two living with MS, helps empower others with MS by leading a self-help group and sharing MS resources. Photo courtesy of Autumn Scott

Plenty of help to go around

A school librarian from Memphis, Tennessee, 39-year-old Autumn Scott was diagnosed with MS in late 2013. Married and the mother of two sons, Scott is also a self-help group leader for the Society in her area. Scott says there are “ample” resources for the diverse community of those with MS and those who want to help. Online and in-person programs, services and information that explain the disease, its symptoms and how they affect people with MS are available from the [Society](#) and [Can Do MS](#), a Colorado-based national not-for-profit organization.

Both sites feature “Resources” sections. The Society’s website also offers “[A Guide for Caregivers](#),” a downloadable brochure featuring caregiving activities. It also includes suggestions for soliciting—and receiving—support. “[Someone You Know Has MS](#)” is a brochure meant to help children understand MS and simple ways they can help. Can Do’s

website features in-person events and monthly live and pre-recorded webinars, including [“Together in MS: Supporting Family and Friends of People with MS,”](#) to help those with MS and their supporters “identify the skills, strategies and tools needed to live fully with MS together.”

People also can contact a Society MS Navigator at 1-800-344-4867 or ContactUsNMSS@nmss.org.

No goes, no shows and moving on

Not everyone you ask for help will react as you expected or hoped. For Windley, that included her daughter’s father. “He wasn’t super supportive,” Windley says. “One of the first things he said was, ‘How do you know I want to be around to deal with this [MS]?’”

Kemppainen says that’s not uncommon. “Some people are uncomfortable around people who are sick, and they’re uncomfortable around somebody who’s sick for no rhyme or reason,” Kemppainen says. And people often don’t know how to talk about things that make them uncomfortable, so “they just avoid.”



Lisa Kemppainen, with her son Issac, encourages people to be direct about asking for help and to always prepare for a Plan B or alternate supporters.

Kemppainen says it’s important to be prepared for that possibility by including it in your “story”—or expectations—and by “front-loading” your request for help by noting that it’s OK to say no for any reason. That can give others the space they need to talk about it honestly with you, which can be valuable in and of itself. Then be sure to have a Plan B of alternative tasks or supporters.

That approach worked for Windley. “I’m an independent person and I don’t like asking people

for help,” she says. “But this year taught me that I can’t be like that anymore.” During her recent flare-up, Windley made a trip to the hospital emergency room and asked her daughter’s godfather for help.

“I didn’t know it would be a long stay,” she says.

“He picked [Jaiden] up from me [at the hospital] and took her to his work where he needed to work a bit and back to my home.” The two waited there until Windley was discharged and joined them.

“So he stepped into that, he came and got her [from the hospital] and he checked in on me and he took her home for me,” Windley says. “I would say, ‘Don’t worry if you can’t, I understand,’ and of course he dismissed whatever I was saying and said, ‘That’s what I’m here for.’”

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

To contact an MS Navigator, email ContactUsNMSS@nmss.org.

Learn more about navigating [relationships while living with MS](#).