

Tell it like it is



Practical tips for everyday living with MS

by Mike Knight

You are about to begin your dream vacation — one you've put off for years due to anxiety about traveling with multiple sclerosis. Your plane has landed. A wheel from your wheelchair returns from baggage claim no longer round, but a sad oval instead.

Two hours into a five-hour long infusion, your need for the men's room is escalating into a "situation."

Barring a dramatic growth spurt, your balance issues and cane won't let you safely reach the deluxe mac and cheese mix on the top shelf of your kitchen cabinet. The package taunts you.

You've fallen. It won't be pretty, but you can get up. A small group of helpers who won't take no for an answer encircle you — Good Samaritan sharks coming in after the spill, unaware they're about to make matters worse.

MS and uncertainty go hand in hand. Mobility, balance, bowel and bladder issues, fatigue and cognitive problems all can present unexpected challenges that might be impossible to conquer on your own. Yet asking someone else for assistance isn't always easy either.

People living with MS and healthcare professionals alike weigh in on who to ask for help, when and how to tell others what you need so you can better manage the variety of situations you face every day.

Your favorite four-letter word: Plan

“The good thing about MS is you have to plan,” says Alexa Kane, PsyD, clinical health psychologist at the Mellen Center for MS Treatment at the Cleveland Clinic. “The bad thing about MS is you have to plan.”

Though tedious (and no friend to spontaneity), a detailed plan, Kane says, will help you pinpoint where the going might get tough and anticipate the specific assistance you’ll need to keep going if it does. “When it becomes challenging is when we aren’t able to communicate our needs,” Kane says, “or on the flip side, don’t even know what our needs may be.”

Besides identifying your needs, Kane says the planning process can help you develop more precise requests for addressing them. That precision helps limit the need for interpretation, which leads to better results and reduces frustration, stress and anxiety for everyone.

Asking for help buttoning your cuffs, for instance, is more specific than asking for help getting dressed, which is more specific than just asking for help. “We assume people will know,” Kane says, “or if they are medical staff, they will know what we need, and I don’t think that is necessarily true.”

Kane recommends asking those who know your MS challenges — trusted friends, family, neighbors — for help thinking through your plan and identifying your needs.

When things get personal: Keep calm, be direct, carry on

Some doctor’s appointments are more intimate and personal than others, MS or not. Mobility and capacity issues, fatigue and frustration caused by MS can all make them worse. Getting undressed, into a gown and then dressed again, up and down from the exam table, even stepping onto the scales (as if you want to) may be hard without the right kind of help.

Cathy Kiler is a peer mentor at Independence Care System, a care management organization based in the Bronx, New York City, that helps about 400 clients with MS direct their care. Kiler, who was diagnosed with MS in 2000, recommends letting the doctor’s office know the type of assistance you’ll need — in detail — when you make the appointment. If someone you trust can accompany you to the appointment, all the better.

You may also be more comfortable receiving that help from somebody of the same sex, a request that may be easier to make in person instead of over the phone. And if you’re worried about making that kind of request, Kiler says, don’t be.

“You go right for the desk and say, ‘Oh yes, I’m here for my annual but I have a problem with my mobility. I would prefer assistance from a female nurse or practitioner,’” Kiler says. “Yes, you can definitely ask for that because some people aren’t comfortable.”

Kiler emphasizes using an assertive but not aggressive, direct approach when asking for help for all needs, great or small. Just don’t chicken out.

“Do not hesitate to ask for help,” Kiler says. “That is the first and foremost thing. There is always someone who is there for help. Don’t be embarrassed. Say, ‘I need some assistance please.’ And when you get that help, and this is what I tell everybody, say ‘thank you.’ No matter what.”

The end of flier’s remorse

Gina Emrich is the senior manager of customer accessibility at American Airlines, a new department “whose only focus [is] customers traveling with any type of disability.” She says the airline serves 2 million passengers annually, and she’s quick to point out that her airline and others have “lots of opportunity to improve in the space” while also noting airlines share best practices in an effort to improve.

According to Emrich, following a few key steps can reduce some of the turbulence you might experience while flying with a disability.



Photo: iStock

The first is letting the airline know that you have a disability when planning your trip. Though they are happy to make arrangements upon your arrival at the airport, letting them know in advance allows them to update your passenger record, which gets shared throughout your flights.

“That information is helpful for our reservations agents, for our gate agents, for our flight attendants on board,” Emrich says. “So we would have that information in a person’s record, so that we know how best to help them.”

Let them know if you are bringing mobility devices such as scooters and wheelchairs; that will generate a special wheelchair bag tag and ticket that helps track your device. Emrich says most needs can be handled by the general reservationist, but for those that can't, a special assistance desk exists that can.

Finally, know that there is additional help when all else fails. Emrich says "Complaint Resolutions Officers" (CROs) are trained to step in and keep you on your way and are located at every airport. And though airlines try very hard to handle mobility devices gently, Emrich says accidents do happen. Most airlines have staff wherever they fly to make things right (American's is called the Global Repair Group). "They immediately get you another chair, and they work to repair your chair," she says. "Some of them can repair it right there on site."

Whatever you do, Emrich says, don't go away mad. "Don't just leave the airport in anger," she says. "Let us know as soon as you know there's something wrong with your chair, and we'll get it going as fast as we possibly can to get it fixed or repaired or replaced."

To find out more about a specific airline, try an online search using the keywords "ADA information" along with the airline's name.

How to avoid friendly fire

Sometimes, it's easier to not ask for help. John Haupt was diagnosed with MS when he was 16 years old. Now 63, Haupt has lived the better part of his life managing his disease. To say he is an overachiever is an understatement. Though he uses a wheelchair, Haupt works out regularly and competes in road races with his hand cycle. He also learned how to wakeboard in 2019. Wakeboard? That's a water sport in which a rider standing on a short board — the wakeboard — with foot bindings is towed behind a motorboat across its wake.

Haupt says he rarely asks others for help. He doesn't have to. "Usually, they see me struggling with whatever," he says, "and they just offer." For Haupt, sometimes the bigger problem is getting people not to help.

It was winter and Haupt, who lives near Milwaukee, Wisconsin, was dead tired, sitting on the ground in a shopping mall parking lot as he struggled to get his wheelchair into his car. "I had to call out to some guy and have him come over and tell him, 'Listen, it's kind of hard to explain, but I'm unable to stand up, can you help me out?'"

But Haupt's would-be assistant didn't know how to help Haupt manage his weight and center of gravity while he got his feet under himself. "He wrapped his arms around me, it was like giving me the Heimlich maneuver," Haupt remembers.

Haupt says he's been there before.

"If you pick up a normal person, you just assist them and then they get to their feet. As long as you do 50% of the job, they can do the rest themselves," he says. "Not so with me."

“I tell people that if you want to help me, you’re going to have to do the whole job, you’re going to have to take my entire weight. I’ve got to get my feet under me before I can stand up.”

Haupt frequently waves their help off because it’s faster and easier. “I’m always thankful for the offer to help and I make it a point to say so. However, I usually don’t want to go through the process of teaching people how to help when I don’t really need help. My way of doing simple tasks may look difficult or awkward to others but, frankly, it’s a source of pride to be able to do them.”

Take a hero, make a hero

But there’s also the flip side. “People love to be a hero, even if it’s for a moment,” says Yvette Rojas. “They love wanting to help someone else. And we don’t give people that opportunity as much as we ought to.”

Rojas should know. She was diagnosed with MS in 1989, 10 years after her father’s diagnosis. In time, she became her father’s primary caregiver and witnessed his MS- related challenges firsthand. She was also the co-founder of a grassroots comprehensive care MS center and is now the director of the Norton Neuroscience Institute Resource Center in Louisville, Kentucky.

Whether it’s help getting your wheelchair out of your car, counting your change back to you twice because you’re fuzzy-headed or tired, or just helping you up some steps, Rojas advises to just ask. “There are so many people out there that are kind and want to help,” she says. “Give them that blessing. Just ask someone for help.”

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

Spring 2020

Check out the Society’s online community at [MSConnection.org](https://www.msconnection.org). Find virtual support, read the blog or start a discussion.