

The friend zone



Learn to navigate changes in friendships.

by Aviva Patz

When the Beatles sang, “I get by with a little help from my friends,” they could have been thinking about living with multiple sclerosis. When you have MS, friends often provide practical assistance, like a ride to a doctor’s appointment, plus emotional support and the ability to relax, enjoy life and just be yourself. “It is absolutely essential to have a network of individuals who are important to you and to whom you’re important,” says Deborah M. Miller, PhD, a social worker at the Cleveland Clinic Mellen Center for MS. “It’s part of being human.”

But relationships are tricky, and MS can make them even more so. “Friendships do change after an MS diagnosis,” Dr. Miller says. MS can scare or push some people away, or it can bring them closer. It can change the qualities you look for in relationships and shape how you meet new people and how you spend your leisure time.

How things change

Often, friends don’t know how to react or what to say after you’re diagnosed or have an exacerbation. “It’s uncharted territory for them—they may not know much about the disease or how to help,” Dr. Miller says.

Rebecca Kuchar, of Detroit, noticed that people treated her differently after learning she had MS. “They didn’t joke like they used to, or they put an odd distance between us,” says the 38-year-old. “I had to work to ‘normalize’ my friendships again and not make our conversations about my health all the time.”

“How it goes depends on the nature of the relationships,” Dr. Miller says. “If a relationship is

truly about friendship, it can remain strong and positive, but if it's more superficial, that may fall away." That dynamic is especially common among younger adults, whose socializing often revolves around being active—interests that may not be MS-friendly, depending on symptoms.

Karin Rebnegger, a Philadelphia-area woman diagnosed at age 29, lost pace with some of her fellow 20-somethings. "I'd think: If you're going to a ballgame and you're going to sit in the nosebleed seats and climb all those steps, I don't want to do that," she says. True friends did accommodate Rebnegger's modified needs, but there were some acquaintances who didn't make the effort.

Fear, too, can get in the way of friendships. "If people have been close to someone who became disabled or died, they may anticipate a loss and not want to deal with it," says Peggy Crawford, PhD, a clinical psychologist with decades of experience working with folks with MS. Kuchar had a close friend who didn't speak to her for six months. "She was finally brave enough to say she was terrified that I was going to die and didn't know how to talk to me about it," says Kuchar, who was diagnosed in 2013. "I educated her on the disease and we're fine now."

Regardless of why certain friendships fade, it's perfectly OK to grieve for them, but be specific about the source of the loss, Dr. Miller advises, whether it's that one person, an activity or a slice of your identity. "Rather than thinking, 'My life is over now,' frame it as, 'That part of my life has changed,' " Dr. Miller says. She encourages people with MS to focus on the relationships they do have and what they can offer.

The flip side of change

Sometimes the loss of contact goes both ways. Lauren Hansen, 35, of Lansing, Michigan, remembers that during the years when she had severe symptoms, before she went on medication, she was the one who would often cancel events or just not reach out to friends. "They would stop calling or feel offended or hurt," she says. "I would always be honest, but I can't fault them for not thinking of me the next time."



Lauren Hansen, with “Bhima,” a gyr, a breed of Indian cattle, at the Sanctuary and Safe Haven for Animals in Manchester, Michigan, where she volunteers. Hansen started a nontraditional support group for younger people with MS.

Photo courtesy of Lauren Hansen

People with MS sometimes weed out friendships on purpose—particularly those that are already floundering—because their priorities shift. “When you have limited reserves, you become selective about what’s of value to you,” Dr. Miller says.

When friends started to slip away from Rebnegger, she let them go. “If you’re not going to put your energy into a relationship with me, I’m not going to waste my time and energy with you,” she says.

However, Rebnegger once had a neighbor in Michigan, where she lived, who was like a second mother to her, meeting her at the hospital and regularly walking across the lawn to bring her dinner. “Those are the people I need to pay attention to because they’re paying attention to me,” she says.

And many existing friendships get stronger. Justin Weiss, 44, of Long Island, New York, had the majority of his friends rally to his side after his diagnosis. “I feel like some of these people came into my life because of MS—even old friends I hadn’t seen in a while came out of the woodwork,” he says. “They heard I had a fundraising team and they were like, ‘Let’s do this.’” Weiss’s friends run, walk, bike and volunteer to raise money for “Team Phoenix,” his fundraising team through the National MS Society. “They’re the most amazing people,” he

says.

Hansen says that once she got her symptoms—and her perspective—under control, her friends were incredibly supportive. “They can’t understand exactly what I’m going through, but they’ve been wonderful. They want an education—they want to know what it’s like.”

Dr. Crawford confirms that quality trumps quantity when it comes to friends. “The people you want to be connected to are honest, respectful, and you and they have a mutually positive regard,” she says.

Forging new connections

Expanding your social circle when you have MS is tough, but one way to find instant community is to pursue a hobby or join a club, even if it’s one you never considered before or one you’ve been meaning to pursue, such as mahjong, beading, photography or investments. “The MS diagnosis can be the kick in the pants you need to take an idea off hold and do something about it,” Dr. Crawford says, “especially when there will be other people around with like-minded interests.”

Hansen, a self-described introvert with limited physical energy, has found ways to say yes to social situations. On a recent weekend, she took a hiking trip with people who were new in town. She told them about her MS and they took breaks and opted for shorter trails as needed. “There were moments that were uncomfortable, but I need to foster those support networks,” she says. She also volunteers at an animal sanctuary, which has expanded her social network even further.



Kit Minden enjoys connecting on Facebook with other people who have MS. She co-founded Living for a Cure, an internet support group. Photo courtesy of Kit Minden

When you’re not up for leaving the house, the internet offers a wealth of social opportunities. Five years ago, when Kit Minden, 60, of Midlothian, Virginia, couldn’t think straight or sit up

due to her MS symptoms, an introduction to another woman with MS on Facebook raised her spirits. The two started a Facebook support group, Living for a Cure, which now has nearly 2,000 members. She loves that on Facebook she's able to connect with "great women and men who understand me without explanation," she says.

A personal video that Kuchar posted on the internet inspired Weiss to reach out to her. The two—who are "worlds apart," in Weiss's words (he's a biker dude and she's a suburban mom)—have now been trusted pals for the last three and a half years. "I chat with her every day," says Weiss, noting that each of them also has a parent with MS. "She can write things on Facebook and I know exactly how she's feeling in that moment." Sometimes Weiss will vent online and Kuchar will text him, asking, "You OK?" "It means everything," he says.

Having friends with MS, who truly understand what you're going through, can be invaluable. Hansen started a nontraditional support group for younger adults with MS shortly after her diagnosis at age 24. They met at restaurants and coffee shops and went on outings together. "Some of them are people I have a lot in common with and might have been friends with anyway, but other people less so, and we can still be there for each other," Hansen says.

While bonds among people with MS can be deep, what's most important is to make sure you have quality relationships in your life. "People who don't have social connections wind down—they sit at home in front of the TV and lose engagement in life," Dr. Miller says. "Don't let that happen to you," she adds. "Good living is the best revenge against MS."

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Rebecca Kuchar and Justin Weiss discuss their relationship and their commitment to the MS movement.