

Power of connection



Support groups offer a sense of community for people with MS.

by Shara Rutberg

When Chloe Cohen met Laura Wieden in 2005, “it was one of the most amazing moments of my life,” she recalls. Cohen had been diagnosed with multiple sclerosis in 1998 at age 20. The two met at the National Multiple Sclerosis Society’s Portland, Oregon, office after Cohen had asked if anyone at the Society knew of any recently diagnosed people her age.

“It was pretty awesome,” says Cohen, now 40. “Finally, we could share our experiences.”

The two women formed a support group for young people. Today, 13 years later, the group is still going strong.

Sense of connection

Across the country, more than 900 MS-specific groups meet to offer that sense of connection, says Monica Aden, manager of program development for the Society. There are groups based on region, age, shared interest and demographics. Some are just for people with MS, others also welcome family members, others are just for family and friends. Members determine how often, where and how long groups meet.



Jim Fairchild and Chloe Cohen are both members of the Society's Portland, Oregon, support group. Photo Courtesy of Chloe Cohen and Jim Fairchild

"It's amazing the connections that are made, they're just so powerful," Cohen says. "Especially when you're first diagnosed. You don't know what your future's going to hold." For Cohen and Wieden, the fact that they were both young was critical. They had both gone to other groups but hadn't found the right fit so they started their own.

Their group discussed topics specific to being young and living with MS, like handling the stress of college, when stress can be a trigger for the disease. More powerful than information around particular topics, Cohen says, was the feeling of not being alone, of connecting with other like-minded people with MS.

Supporting one another

Because the disease is different for each person, "with MS, you don't get it unless you got it," says Jim Fairchild, 48, of Vancouver, Washington, who has been a member of a group in Portland for 10 years. "It's nice to be around positive people who get it."

"You can feel so isolated," says Revella Levin. And she should know. The 91-year-old psychotherapist underwent 50 years of stigma, misdiagnosed by 26 neurologists, feeling contempt from her family who believed she had hysteria. When she was finally diagnosed with MS in 2008 and found a group for women over 40 nearby in Queens, New York, she began attending and has been a regular member for years. "I'd absolutely encourage others to go," says Levin, who has found "great comfort" in the meetings.

"There's a sense of relief that you know there's a place you can go regularly and where you know you're going to talk with people who truly understand what you're going through," says Fairchild, who sometimes feels himself holding certain things in until the group's monthly meeting.

"You get asked 'how're you doing' all the time," he says. "And you say 'OK' or 'fine.' How

often do you really get to answer that question? This group is people who really care. They've got your back. You're not alone. The biggest thing for me through the years has been that connection, just knowing there are people there I care about who care about me." That feeling of connection can help grow confidence, says Karen Johnson, who leads a group for African-Americans in Oakland, California.

Members can find inspiration at groups, especially during dark times. Cohen, who says she turned her life around with "luck, hard work and a different drug," went from not being able to move the left side of her body and feeling like she was 80 when she was 20, to feeling at 40, like she's 30—maybe 25. When she was first diagnosed she "never heard positive stories, it was always stories of people getting worse. She says sharing her story throughout the community has positively impacted hundreds and hundreds of people with MS.

Levin also finds inspiration in her group, especially in the example of how another member, who uses a wheelchair, lives her life. "She handles it so magnificently," says Levin, who notes that the woman, a photographer, still gets out with help to take pictures.

Get out there

Stop Googling. Go to a meeting. That's Fairchild's advice on fighting the "over-Googling we all tend to do," he says. "Any time you Google, 1,000 things come up that can make you nervous. WebMD can scare the hell out of you. Talking to a person, especially a positive-minded person who has been there, is so much more helpful."



Stephanie Pelton helps people find resources for MS as a group leader in McKinney, Texas. Photo courtesy of Stephanie Pelton

Groups also can serve as conduits for reliable information and resources.

"Groups help point to so many of the resources the Society has available for us," says Stephanie Pelton, 57, a group leader in McKinney, Texas, who has also attended meetings in the Dallas-Fort Worth area.

Members learn from leaders and one another about topics ranging from navigating travel with MS to preparing for a doctor's appointment. They can also share recommendations for care. "I found my current neurologist, whom I love, through someone at my meeting," Levin says.

Friendships that begin at group sessions often go beyond meetings, says Bruce Southwick, 62, who leads a group in Silicon Valley, California, and attends several others. Members of one group meet regularly at a rec center to work out. Others go for lunch after meetings. "We'd have 20 to 30 people at IHOP doing more talking than eating," he jokes. "The waitresses weren't thrilled." Members of the group he leads continue their discussion throughout the month via online forums. While he begins his own meetings with a presentation about an MS topic he's researched, he's seen groups splinter off based on special interests, like photography and music.

For some people with MS, talking to others of the same race and culture is key. "Culture and language can be a connector, especially among people who were not born and raised here," says Elsa Rivera, 68, who leads monthly meetings of bilingual Spanish-speakers in Oakland, California, and attends two other groups. Most of her members are native Spanish speakers, born outside the U.S. They meet at a Mexican restaurant and once a year in a member's home. Rivera, a daughter of Mexican immigrants, started the group after spotting a flyer for a meeting for African-Americans with MS at the local Society office and asking if there was one for Latinos.

Finding community

"I didn't feel like I identified with anybody I saw at my neurologist's office," says Cynthia Ignacio, 32, of the mostly white faces she encountered. "I hadn't seen anybody who looked like me." When she saw a notice about Rivera's group, she "mainly went to see if it was true," she says. She's been attending for several years. Besides speaking Spanish, "there are cultural things we can all relate to," she says. "Little things that help us relate, like, everyone has that one aunt that keeps giving you Mexican herbs to cure your MS."



Elsa Rivera leads a bilingual meeting for Spanish speakers in Oakland, California. Photo courtesy of Elsa Rivera

Johnson relates. Though she now leads monthly meetings for African-Americans with MS, when she first saw a flyer about another one she was surprised that “there were even enough of us to have a meeting,” she says. Though discussions can cover topics specific to her community, such as whether people feel they’re getting the same treatment as people of other races, discussions often center on subjects that are not specific to African-Americans and range from sexuality and MS to alternative therapies. “I learn something every time,” she says.

Not every group is right for every person, say the leaders and group members. “Go to several groups until you find one you enjoy,” Rivera says.

Ask yourself how you feel when you leave the meeting, suggests Fairchild. “If you feel worse than before the meeting, that’s not the group for you,” he says. “Find a group where you look forward to meetings, where you want to continue conversations you started after the meeting is over.”

Don’t be afraid of groups. “It can be very scary,” Fairchild says. “You don’t know who you’re going to meet.” He recalls resisting going to a group when he was first diagnosed. “My biggest fear was seeing what the disease was really like. Don’t let fear stop you from the growth you can find. There’s a huge benefit from groups.”

Core members of his group, including Cohen, have become a family over the years. When the meetings first started, it was called The Under 40 Group. “Then it became the 50-ish Group,” says Fairchild with a laugh.

“Now,” Cohen says, “we just call it happy hour.”

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Learn more about groups, find a group in your area or inquire about starting your own group at [Join a Local Support Group](#).