

A safe space



People with MS find support, information and friendship in the National MS Society's Facebook community.

by Robert Lerosé

Tom Bellas has a gift for words. He describes himself as “a casual writer,” but there is nothing lackadaisical about his prose. He has three unpublished novels under his belt, but arguably his most important writing is for discerning readers grateful for his sensitivity and honesty.

Bellas is a regular contributor to the National Multiple Sclerosis Society Community, the Society's official online Facebook group for people living with MS to share experiences and perspectives. “We bond, we connect and we realize our lives still have meaning. Our voices will still be heard,” Bellas says.

Started in November 2019, the community has nearly 11,000 members from around the globe. The majority live in the United States, followed by the United Kingdom, Canada, Australia and India. Thanks to Facebook's translation capability, members from countries such as Croatia, Iran, Lithuania and China can also participate.

Most American members live in major metropolitan areas (New York, Los Angeles, San Antonio), but membership is robust in cities across the country (Boise, Idaho; Toledo, Ohio; Buffalo, New York). Members range in age from 13 to 65 or older, with most in their late 20s to mid-40s, and a higher number of women than men.

Add it up, and the community has clearly achieved one of its goals: To be a safe space where anyone with MS — the newly diagnosed, those living with the disease for a long time, their caregivers, partners and family — can gather to vent, have their fears and worries assuaged, get questions answered, find support, make friends or just open up about their lives.

“We’re always talking about the need for finding connections any way you can, so that you don’t feel lonely, because this can be a really isolating disease at times,” says Philip Anzada, senior manager, virtual community engagement at the Society.



Tom Bellas connects with others living with MS through the Society’s online Facebook group.

“I think that being able to get those types of connections when you’re potentially in a darker space is a nice opportunity for people in the group.”

Not surprisingly, questions about symptoms come up frequently — not just from the newly diagnosed who might be experiencing, say, optic neuritis for the first time, but from those who have been living with MS for a long time and are seeing a change in their condition. Also, some members write long posts that offer encouragement or talk about what it’s like living with their MS on a given day.

Online community leaders, or moderators, try to maintain a safe space where all members feel comfortable contributing. They keep a light but vigilant touch on the discussions, steering conversations away from emotionally charged subjects such as politics or religion. Attacks on fellow members, unsubstantiated medical advice, links asking for money or anything else that tries to take unfair advantage of members are dealt with promptly.

“Online community leaders direct message and talk to folks in the group when they’re struggling. They’re trained and have the resources to connect it back to the Society when someone is looking for specific information. They’re providing that peer support in the group, which melds nicely with this community,” Anzada says.

Like a family

As the assistant principal at an elementary school in South Carolina, 42-year-old Shelley Krebs is used to being on the go. Her days are filled interacting with supercharged youngsters. So, when she felt her right arm turn completely numb and tingly, she expected it to be something minor like a slipped disc. Instead, her neurologist diagnosed her with MS in April 2021.

Her condition is never far from her mind, and fatigue is her most severe limitation, but modifying her lifestyle has made a positive impact. “I’m healthier than I was prior to diagnosis just because

I changed my eating and exercise habits. Day to day, I feel like I’m doing pretty well,” Krebs says.



Shelley Krebs (middle) is a community leader in the National MS Society’s Facebook group.

Her neurologist recommended the Society as an authoritative source, which led Krebs to the Facebook community. While she appreciated the Society’s wealth of information, the thoughts and experiences of community members resonated deeply with her. “It was nice to be able to go there and hear from other people who also were living with the same thing and being able to communicate on a regular basis,” she says. “I really like the community aspect of people who know what you’re talking about.”

A lot of topics are symptom-based (“My foot is numb today. Has this happened to you?”). Other members will post positive quotes to keep up people’s spirits. Having a community to engage with proved especially valuable in the early stages of the COVID-19 pandemic, Krebs says, when there was a lot of concern about how lockdowns might affect MS therapies.

Krebs got further involved in the Facebook group by becoming an online community leader. She works to ensure that everything posted is evidence-based and research-based, and to keep conversations respectful and cordial. Krebs works with other moderators to make members aware of the Society's advocacy work, such as Walk MS and Bike MS, and help them get the word out.

Krebs recalls some instances where members either talked about being depressed, feeling hopeless or even feeling suicidal because of their MS. While those instances required sensitive handling, the thing that impressed Krebs was the outpouring of the group. "There are going to be 50 comments almost immediately about how that person is loved, and to provide resources and help any way that we can," she says. "The first thing I think about the group is, it's a little bit crazy to me how much of a family it becomes. People really do watch out for each other."

Opening up

Long before he was diagnosed with MS in 2003, 50-year-old Bellas saw its impact up-close. His sister had been diagnosed earlier, and they often talked about her symptoms and emotions. When Bellas began experiencing his own symptoms — pins and needles in his right hand, numb feet, mental confusion, noise sensitivity — a diagnosis confirmed his instincts.

An American who had worked in IT, he relocated to Holland in 2005 "to live with the girl of my dreams. I knew beforehand that my decision needed to be made soon, as primary progressive MS has a way of changing any future desires. So, I plunged into the unknown. A new land and my final great adventure."

After he was confined to his bed in 2019, he joined the Facebook community "on a whim, just to try it out. Turns out, it became my home away from home. Here is a place that understands me."

In the beginning, he posted questions and provided answers for others. Then, the empathetic artist in him gradually kicked in. He began composing long posts about how to live with MS, how to have hope, how to smile and still dream, and how to live life fully and gratefully.

Like any artist who opens a window to their soul, Bellas held nothing back in an effort to take away embarrassment and make it easier and safer for others to talk about their issues — from what it felt like to wear a diaper when he went to sleep to sexual dysfunction due to MS.

"To my surprise, that topic exploded. People wanted to talk about it, but they were too afraid to bring it up themselves," he says. "I opened my private life to the public, making myself vulnerable, but it was a risk I was willing to take. And it paid off."

Robert Leroose is a writer based in Long Island, New York.

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