

Why Did I Wait So Long to Join an MS Support Group? Misguided Fear.



I was diagnosed with relapsing-remitting multiple sclerosis in July 2014. Upon receiving my diagnosis, I reached out to the National MS Society for information. Included in the materials I received were contact details for MS support groups in my area. But despite the fact that I was perfectly able to attend a support group, I resisted.

Why?

I was petrified to sit, face-to-face, with my potential future.

My early online searches for information about MS had chastened me, as I found many misguided messages that suggested MS is a one-way ticket to disability, debilitating symptoms and early death. Couple this with the overwhelmingly negative depictions of MS in popular culture, and I didn't feel as though I could face going to a support group if what was waiting for me were scary tales about what lies ahead.

While I tend to be reserved in large groups, I'm not averse to joining them. For example, when my twins were infants, I joined a local mothers of twins group and, through bonding and conversing with these women, sought and received great advice about the particular challenges of raising twin babies and later, twin toddlers plus their baby brother. In those meetings, I found friendship and emotional comfort. I was not in this alone.

But living with MS is an entirely different topic than raising twins. Attending an MS support group would be about me, my current symptoms, and my worries that my condition will inevitably transition to a harsher form of the disease. MS, to me, was a fearful topic, whereas raising twins was not.

It took me visiting MS support groups via Zoom while promoting my MS-centric memoir, "[Uncomfortably Numb](#)," to change my mind.

When word went out to New England-based MS support groups that I, a Boston area writer, would be willing to join their Zoom meetings, read excerpts of my book, and discuss my MS experience, several took me up on my offer.

These virtual MS support group meetings (virtual because of COVID) would start with members checking in with one another, casually bantering like old friends. Those attending the meetings, I learned, represented a wide variety of MS cases: from folks who use mobility assistance devices to those who didn't, from some who are employed to those who've had to stop due to MS complications, and from folks who've lived with MS for decades to at least one newly-diagnosed person who had a deer-in-the-headlights look in her eyes that I once wore.

Surprisingly, nothing about the meetings turned out to be scary. In fact, I found the meetings fascinating as I listened to people talk about the medicines they were taking and what effects they experienced, as well as discuss techniques for cooling off if one's MS causes heat sensitivity (something with which I grapple). The groups had the vibe of small families who offered abundant virtual hugs and good-natured, knowing humor borne from shared experiences.

At the end of the meeting with a group in my area, after I'd finished talking about my memoir, I made an impulsive decision: I wanted to join. I let the organizers know and they put me on the distribution list. After my third virtual meeting, I went on Facebook and sent friend requests to the members, including that member who'd just been diagnosed and who seemed a bit overwhelmed. Maybe I could help her, I thought.

I was no longer frightened about what I might hear about MS and how it progressed (or didn't progress) for various members. The emotion I experienced was gratitude because I didn't realize how much connection I'd actually been craving, how much I wanted to be able to talk about MS symptoms with people who understood. It was an echo of that same, comfortable feeling of being understood that I enjoyed when I met with those mothers of twins many years ago.

As my local MS support group signed off at the final meeting of 2020, I regretted that it had taken me so long to become a part of their MS community, wait, let me rephrase, of **our** MS community.

*Editor's Note: To find an MS support group in your area, [**visit the Society website.**](#)*