

Find Your Place of Power: How Online MS Support Groups Can Enrich Your Life



Support groups are powerful places. They can be safe harbors, where we find friends, shoulders to lean on, or someone who will actually listen. How rare is that when we need those things the most?

I'm no expert, but after 30 years with MS, I've seen my share of support groups. As many as I've seen, I still wish I'd joined even more and met even more people who shared my situation – because a good support group is such a lifeline. It's a fire in the hearth on the longest night of the year, and in good times, is a wind in your sail because you know that somewhere is a group of people who know you're not lazy, not "crazy," and are fully deserving of dignity and respect.

One of the most insidious enemies for me and others with MS is isolation. While we're battling the five-alarm fires of MS (you know what they are) with everything we've got, isolation is doing its quiet work in the background, building up brick by brick. When mobility impairments, fatigue, [depression](#) and a host of other symptoms arise, so do barriers and isolation from the rest of the world. The terrible irony is that right when we need support the most, the barriers creating isolation in the first place are also turning the effort of going to group meetings into more a stressor than a safe harbor. That's where online support groups become such a blessing.

I received my diagnosis during the stone ages of the internet, when dinosaurs roamed the earth with names like America Online, CompuServe, Prodigy. The idea of faceless online

support groups was a novelty: Can that actually work? Well, this was also a time when it was taking me 3 to 4 hours to go anyplace, if I didn't fall. You bet I was trying online!

The rewards were immediate. I'll never forget (in 1993, yikes!) when the [first treatment for MS, Betaseron](#), was approved by the FDA. This was big news everywhere, but to truly appreciate how momentous it was to the MS community, I wish I could show you the support group posts that day. We raced online to pour out our hopes and elation in ALL CAPS and "!!!!!!s" and "I'm typing this through tears of joy - can't stop crying" posts. It was also the place we returned to in the months and years afterward, when the costs of the drugs sank in and we realized that it was a treatment but not that kind of treatment, not a cure. And we continued on, in our support groups, together.

Back then, when there was only one disease-modifying therapy, and now when there are around 20, the groups accomplished the same things: friendship and solidarity, information, and important examples - an attitude, really - that a life with MS can indeed be fully lived. You can probably boil all of that down to one word: hope.

Those days I wrote a weekly column. It wasn't very good, but it spurred a thread or two of conversations, commiseration or ideas. I'll never forget the people who shared their thoughts and feelings. There was Tereva, who hosted weekly chats. Jerry posted medical research so dense my brain would begin to melt (Regis, I'll use my Phone-A-Friend. Oh, uh, can I get another one?). "Hey fuhgetaboutit," Marcia gave us the Jersey snark we craved. And as steadfast and beautiful as a Tennessee oak, Pat gave us acorns of peace and acceptance we needed, simply in the way she treated people. There were others, too, who I won't forget, and they all played a role. To this day I'm using their examples when I meet those who are angry, afraid or shellshocked at having a bomb called "You Have MS" dropped in their laps. In all, we wove together a community, and it was virtual, yes - but it was real, because we kept showing up day after day to our safe harbor, to our powerful place.

You'll find one of these powerful places now at The Mighty's new [Multiple Sclerosis Connections](#) in partnership with the National MS Society. Come lend your strength to our community, as we offer you ours. We're glad you're part of our support group. Let's build up one another, and together, build a community that's Mighty!

Editor's Note: Visit [Multiple Sclerosis Connections](#) and click Join Community on the left. Share something about yourself and your journey, or just say hello!