

Peer Pleasure - Not Pressure



One of the first steps I took when diagnosed with MS in 1984 was to visit a local National MS Society office and ask if there was someone with MS I could talk with. Someone in my shoes - a peer. My fear was overwhelming, and I didn't know how to cope.

The staff arranged a phone chat between a girl named Cathy and me. We were about the same age and both of us had a young child the same age. We clicked instantly, sharing stories and feelings. When I told her about my cold toes, she told me how she always had to wear a sock on her left foot. What a relief! We became friends and phone buddies for years.

Soon after, I began volunteering at that local Society office. They began developing new programs, one of them being telephone peer support. With nine other MS peers, I attended a training program that was designed and given by the Society and a major Pittsburgh hospital. It was gratifying to be able to help others who were in the same shoes I was in a couple of years earlier. To listen and understand in ways that others not living with MS can't; to reassure that the invisible symptoms were "normal" for MS and can be managed.

I wrote this in my personal journal on January 1986 — **"I find discussions with other MSers to be more helpful, informative, enlightening and therapeutic than I could derive from any book or resource. Somehow, only those with MS know exactly what it feels like and how frustrating it can be."**

I could let my hair down and not be pretentious. There's a place where venting, crying and complaining were understood.

But there was more to be gained beyond the emotional and mental support. The peer connections provided a 2-way avenue for resources and information. This included “private” information like bladder, bowel, and sexual symptoms. Although information on these sensitive topics has been written about in recent years, there is true comfort in connecting with real people about them.

The power with peers doesn’t stop and only grows over time. I’ve often said that one of the positives of having MS was becoming a part of an extraordinary community and network. This network includes people with MS who have become experts in things like fitness, diet, mental health and events.

The MS community also has peer support opportunities for family and friends of people living with MS. After all, they are living with MS in a different way and need to engage with someone in **their** shoes.

A peer is a lifeline. Finding someone to talk with that is living in the same shoes is invaluable. Patient to patient, caregiver to caregiver – it doesn’t matter what kind of illness, disease or problem that it is. Throughout life, I’ve had to talk to others about other things like parenting, grieving a loss and other health issues I’ve had.

I was a peer counselor 15 years for the National Multiple Sclerosis Society and continued to help other peers confidentially through referrals from acquaintances, my doctors and healthcare team, my website and social media. Currently, I’m a member of several online MS platforms to listen and offer help. Recently, while I was helping others in an online group, I learned some tips to help myself with [MS lymphedema](#). The two-way avenue!

I keep in touch with some peers who are now precious friends that I met over 30 years ago. This week, I received a lengthy email from a good friend in Pittsburgh. We met in 1990 at an MS peer group meeting. She said at 86 years old, she’s very blessed to be able to do the things she wants to do. It was pure pleasure to connect again.

Editor’s Note: Learn more and connect with people who share common life experiences for support, education and mutual aid on [the Society website](#).