Making the team



When Cermit's left hand stopped working after he fell asleep in an uncomfortable position in his wheelchair, he knew who could help. He reached out to his MS specialist who gave him a hand brace, and healthy function returned in just a few weeks. Cermit's specialist had years of experience treating MS and knew right away that his injury wasn't related to the disease. So, she was able to quickly offer the right solution.

Like many people living with MS, Cermit's story shows why it's important to surround yourself with a team of healthcare professionals who can partner with you to manage your MS. They are the key players on your team who will support your MS journey and help you navigate the big obstacles, like changes in mobility, and the everyday ones, like symptom management. And everything in between.

"High quality healthcare means someone that understands my multiple sclerosis," said Cermit, who was diagnosed in 1998. "In the past, I had different doctors that were not MS specialists. Today, my doctors are. It's nice when you talk to somebody who understands."

For Cermit, including an MS specialist on his healthcare team was a major priority. He needed someone who really understood MS, its symptoms and the most effective treatment options. And knowing that he wasn't her only patient with MS or on the associated medications really mattered to him.

To make the most of the time he spends with his specialist and the other doctors on his team, Cermit prepares a written list of questions prior to each appointment.

"Most of the time, I get all my questions answered during the visit and don't have to wait for two weeks for her to come back," he explained. Finding the right doctors and specialists can be a challenge for many people living with MS, but Cermit recommends reaching out to the National MS Society to connect to healthcare providers and other resources in your area. And according to Dr. Mariko Kita, Cermit's MS specialist, working with providers who are connected with the Society comes with a major benefit.

"If an MS center or a physician caring for MS patients is closely connected with the National MS Society, that's an automatic win for the patient," said Dr. Kita. "We already have a relationship and we can take care of that patient as a team."

Putting together a team of healthcare professionals is a crucial first step towards living well with MS. If you aren't sure where to start, the Society can connect you with comprehensive health care resources, support groups and more.

Download "Now What? Resources to Keep You Moving Forward with MS" to get started!

Where do you find support?

Support means more than finding the right healthcare. From family members to local support groups and the National MS Society, personalized support comes in many ways and may be closer than you think. We asked our community to tell us who they turned to when they first learned of their MS diagnosis. Here are some of their responses.

"When I was first diagnosed in 2001, my new girlfriend, now wife, Allison, was the first person I told. Lacking knowledge of MS, I thought this was a death sentence. With her constant support, we did research and found that this is not a life ender — it's more like a life changer. Over the years, we learned to adapt and never give up. Now, I see multiple sclerosis as something I have, and I will lead by example to inspire others to never give up, but I will never let MS fully define me."

Dan. from Facebook

"My husband was the first person I told. I said, "It isn't a stroke or cancer, so let's deal with the fact that this is a positive." Telling my children was harder. I played it down for them because I felt okay, looked okay, and didn't really believe there was an issue. Eleven years later, I take each day as it comes. If I wake up feeling good — woohoo! But on bad days, I head for the sofa and snuggle with my dog. Life still goes on with MS, and I consider myself lucky."

Loraine, from Facebook

"Because I am a doctor, I was able to have my husband and two close friends with me in the radiology room. When the image came up on the screen, I remember thinking, "This could be really bad." But I was also very acutely aware of my husband standing behind me with his hands on my shoulders and my two friends crouched on either side of me, holding on to me. These two things are linked in my mind. Now, I know that my life is going to change, but

come what may, I sit securely in a pocket of support and love."

Marissa, from Facebook

"My mom was sitting right next to me, holding my hand, as I squeezed hers tightly. After the confirmation of diagnosis came from the neurologist, I turned to mom and hugged her and cried. Then, I was comforted by the amazing medical assistant and the neurologist."

@kt hugs, from Instagram

"My corporate boss at the time knew someone who worked for the National MS Society, so I gave them a call. A sweet lady, not much older than I was, walked me through getting all the literature I needed as a newly diagnosed person, how to navigate concerns with my job — everything. She was such a comfort. The National MS Society was there for me from the beginning. Now, I direct newly diagnosed people to their website. They are THE source."

@deh615, from Instagram

"After my diagnosis was confirmed, I called my mom. She told me she was relieved that it was nothing that would kill me, but would change my life. As I held the phone crying, her exact words were: 'I beat cancer, you can handle this." Her words still give me strength on my bad days. She contacted my cousin who also has MS and got us talking again. My cousin has been my touchstone on crazy things that are happening and a great leader when I need to vent. I am a strong woman because I have strong women supporting me."

@jls9915, from Instagram

"My husband was on my side and the community on Instagram really helped me. Just talking to others with multiple sclerosis made me feel less anxious and more hopeful about this disease."

@beatingmyms, from Instagram

"My fiance, family and best friends were all there for me. And the people on Instagram who are writing blogs and sharing their stories inspired me to start my blog. It's so helpful to connect with people who know exactly what you're going through."

@jaymariedixon, from Twitter

Find out <u>how other people find support in their MS journeys and get connected to helpful</u> <u>resources</u> from the National MS Society.