

Coping with an MS Diagnosis



“You have multiple sclerosis.”

The neuroradiologist was calm as he revealed my diagnosis. But I was stunned.

Suddenly everything made sense: the constant dizziness, double vision, taste changes. Even the numbness in my finger months before, the cloudy vision earlier that fall—it was all connected. But it was a terrifying and tragic moment, and the days and weeks that followed were some of the hardest of my life.

I think my low point was two days after my spinal tap, when I got so sick, I couldn't get out of bed. I was dizzy, weak and exhausted. I wondered if I would ever be able to do ANYTHING again. Previously an active and healthy family physician, I couldn't imagine how to move forward.

But I couldn't stay in that dark place. As my symptoms started to improve, I slowly learned to face my diagnosis and accept my fate. I got to know this unwelcome companion, who will be with me for the duration of my life's journey (or until we find a cure!). In the 9+ years since my diagnosis, I've learned to cope.

My strategy for living with MS still changes monthly, or even daily. I've learned the best approach is different for all people living with MS, just as MS affects each of us differently. But I think there are some near-universal recommendations that I would humbly share with my fellow MS Warriors:

1. Don't let MS take over your life. Try to stay active and involved in your community, your place of worship, your kid's school, wherever you can feel a part of something bigger

and you can make a difference. Make necessary adjustments, but if possible, continue to work, travel and have fun. Your life isn't over.

2. Build and nurture your support circle. Identify the people who will be there when you have a relapse, incapacitating fatigue, or feel the despair that attacks the best of us. I didn't keep my MS a secret. I know in some instances, a MS diagnosis can't be shared without negative consequences, but at least let those close to you know what's going on and how they can reduce the burden of MS a little.
3. Do whatever you can to stay healthy. Eat healthy and exercise. Get enough sleep. Don't smoke. Don't drink excessively or use drugs. See your primary care physician for preventive care and screening tests.
4. Take a disease-modifying medication. They are NOT full-proof or free of side effects. And they certainly are NOT cheap. But they are the best strategy currently available to slow the natural course of MS. I feel they have been key in my battle against MS.
5. Try some new strategies to cope with symptoms. I tried acupuncture, yoga, balance therapy, and very restrictive diets to no avail before I finally learned that avoiding caffeine and practicing meditation were more helpful than anything else for my chronic dizziness. Everyone is different, and you don't want to spend all your time searching, but a little healthy experimentation may help you find some tactics to feel better and live a more meaningful life.
6. Always have a goal—something to strive for, a reason to get up in the morning. I just finished riding the MS 150 for the second time. I want to get my memoir published. I want to give my daughters a great summer. I'm always working on a new project—it keeps me grounded and sane.
7. Use MS as an excuse to do more and do it now. MS creates even more uncertainty than the baseline uncertainty we all face. Since I don't know how much longer I'll be able to travel or run with my dog or work or swim or volunteer at the homeless clinic or drive my daughter to dance class, I'm doing it all now and trying my best to live in the moment and soak it all up.

An MS diagnosis can be a huge shock and disappointment. It was for me. But I've rebuilt my life and even become a little wiser along the way.