

# Superwoman in Slow Motion

Multiple sclerosis may have slowed me down, but it hasn't stopped me.

BY DANA KNEZEVICH

I'm not shy about my diagnosis of multiple sclerosis (MS). On the contrary, I love to share this fact about me with people I meet. When the subject comes up in conversation, there is usually a long pause—hesitation on their part about how to continue—before their eyes slowly move to my legs. This triggers me to start my new acquaintance on an educational journey about MS. Inevitably, one of the first questions is, “How long have you had it?” I always respond by saying, “I don't know exactly, but I've been diagnosed with relapsing-remitting MS for some 20 years now.” This form of MS involves episodes of attacks followed by partial or complete recovery periods.

You may be wondering how I could forget something like the exact year of my diagnosis. Well, I know I have MS, and I can't change that, so, oddly enough, I don't think about it that much anymore. I also know that I used to be Superwoman; now I'm Superwoman in slow motion.

I do remember that when I was first diagnosed, I went through the emotional gauntlet of sadness, anger, self-pity, mourning the loss of the old me, and finally acceptance. Many people who get a diagnosis of a chronic condition think, “Why me?” Now I think, “Why *not* me?” It can happen to anyone. I spent years journaling about my symptoms after they first appeared, but eventually I felt it was not making a positive impact anymore. I realized education about my disease and the treatments available were my most valuable resources.

The most debilitating part of MS for me is the fatigue: I walk around with what feels like mega-sleep deprivation. My neurologist has found a wonderful balance of medications to help me function. It is vital

for any person who has a lifelong disease to communicate honestly and openly with his or her doctor.

I have tried several of the disease-modifying medications for relapsing-remitting MS over the years. These drugs have helped many people, but they didn't seem to have any effect on my rate of flare-ups—plus, they have side effects. So I suggested to my long-time neurologist that I stop taking them to see if they were really helping. I reassured him that I was willing to live with the consequences to find out. Going off the meds felt like jumping from an airplane without a parachute, but I found out that the drugs were not improving my condition. This decision to stop taking them—which was based on weighing the benefits and side effects—made my neurologist nervous, but he has continued to monitor my health closely. Obviously, this is not a safe path for everyone, but it was the right choice for me.

The one treatment I have continued is an intravenous steroid, which I have been receiving every month for close to 20 years now. I feel I have perfected the management of my symptoms from this beast of a drug. My neurologist isn't 100-percent sure that it's keeping my symptoms in check, but as he says, “If it ain't broke, don't fix it.” Actually, my body tolerates the steroid pretty well, and since I also have been diagnosed with psoriatic arthritis, the steroids keep that in check, as well.

I still think I can do anything. One of my proudest moments was finishing a 2,000-foot elevation hike to the summit of Mt. Washburn in Yellowstone National Park, WY, in July 2011. Even if I'm clumsy and slow, I get there eventually.

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*Dana Knezevich shares her life with Andrew, her soul mate of 32 years. They live in McMurray, PA.*

