

# The Joy and Meaning of Caregivers



**“You have MS.”**

**I remember hearing those words eleven years ago from a neuroradiologist in a dark room, huddled around my MRI films. The diagnosis explained my mysterious dizziness and double vision, but was unexpected, raising new questions and confusion. My husband, Don, thanked the radiologist and guided me back to our car. Both of us felt terrified and overwhelmed. What would MS mean? Could I work? Would I ever feel better? Could I exercise, travel, drive?**

In those early days after my diagnosis, it was all about me. How was **I** feeling? Which doctor would **I** see? What other tests did **I** need? Who would cover **my** shifts at work?

Don, meanwhile, was left to cope with the news largely on his own. Charged with comforting me and trying to navigate a new path for both of us, he had little guidance and support himself. I’ve realized since my diagnosis that a “life sentence” of MS can be just as hard on one’s partner or caregiver as it is for the person living with MS.

**What happens when your partner tells you they have been diagnosed with multiple sclerosis?**

The dynamic between partners may shift, and the person diagnosed with MS – who often gets most of the initial attention, well wishes, and medical care – may not realize the impact on their partner. Sometimes I’ve thought my husband Don has struggled even more than I have with MS. Anxiety, worries about his own health, fear of my MS progression, and the

consequences for our family surfaced soon after my diagnosis and have returned from time to time and with each relapse.

### **What does this mean for you as a caregiver?**

MS affects each person differently. It may be mild, with minimal symptoms; it may lead to severe disability and pain; or anything in between. Learning to live with uncertainty is one of the biggest challenges for both patients and their caregivers. If their partner is suddenly unable to work, the caregiver may face more financial pressure. If they have children, childcare responsibilities may need to be shifted.

Depending on the nature and severity of symptoms, the caregiver may serve as “just” the primary emotional support person or may be far more involved, sometimes serving as a full-time carepartner, tending to their partner’s physical needs as well. Usually the period immediately surrounding the initial diagnosis is the worst, but caregivers shouldn’t jump to conclusions or dismal predictions.

### **How do you handle your new role? What are the early steps you need to take? What organizations do you join? Websites to look at? Books to read?**

Becoming accustomed to your new role may take time. Don’t be too hard on yourself or expect to have everything figured out right away. Here are a few specific tips:

1. **Communicate with your partner about how MS impacts you both:** Grieve together if you need to. Ask your partner directly how you can provide the best support. Sometimes patients with a new MS diagnosis need space to process what has happened, or they may need distractions to escape those moments of despair. Find out how your partner wants you to help: Provide support at doctor’s appointments? Arrange for healthy meals? Deal with insurance companies? Don’t make assumptions and offer specific suggestions of how you can share the burden.
2. **Let MS bring you closer:** A diagnosis of a new chronic condition like MS can be a huge stress for all involved. But it can also be an opportunity to reprioritize what’s really important, to share your feelings and concerns, and connect on a new level.
3. **Remember to take care of yourself:** Exercise, get enough sleep, take a break (find respite care for your partner, if needed), call on your support circle – friends, family, colleagues, places of worship, neighbors – for help. Tend to your own health needs so you can be strong and available for your partner.
4. **Know that life will go on:** Medication options for MS are abundant; they are important for almost everyone with a new MS diagnosis and can dramatically lower the rate of MS progression.
5. **Connect with the National MS Society:** For support with all-things MS, the National MS Society is there for you. [Patient MS Navigators](#) can provide information about MS, locate an MS specialist and resources in your community, and help determine options for insurance coverage (if needed). The National MS Society sponsors events all over

the country (including virtual events), offering chances to meet other people affected by MS and to support their important work and research initiatives.

6. **Beware of “Dr. Google”:** A new diagnosis with multiple sclerosis is overwhelming and generates endless questions. Often the first tendency is to rush to the internet. But the internet is full of confusing, discouraging, often contradictory information. Ask your partner’s MS specialist for recommended resources, and you can always count on the National MS Society for up-to-date, accurate information.
7. **Books are helpful, but not necessarily “MS” books:** Don and I read Dr. Rachel Naomi Remen’s “Kitchen Table Wisdom” in the first days after my diagnosis, for comfort and perspective. I also recommend a good “escape” novel for when you’re sitting in waiting rooms or having trouble falling asleep. “MS” books may be helpful, but only after you and your partner have a better sense of what MS is likely to mean for you.

To the partners and caregivers out there – thank you! You bring joy and meaning to our lives and help us live our best lives possible.