

When the caregiver has MS



People living with MS face a dual challenge when they also care for someone else.

by **Robin L. Phillips**

Diane Robbins, diagnosed with primary-progressive MS in 1998, hadn't spoken to her mother for several years. "But when her husband passed away, Mom was alone," says Robbins, who lives in Orlando, Fla. "So I moved her to a house down the street to make it more convenient for us."

Like many people with MS who take care of family members with their own health issues, Robbins discovered that the challenges of managing two sets of needs can be intense, to say the least. "Lately, I've had to set some boundaries," Robbins explains. "If I'm having a bad day with my MS, I have to be clear with her. I'll say, 'I can't go to the grocery store today, but I will go in the next few days.' I've also put some space between us by spending time doing something I love, which is volunteering at a local food bank. If you don't take time for yourself, you won't be well. You will drown."

Life steps in

"Adult children with MS feel anxious and perhaps guilty that they may not be able to care for their parents," says Rosalind Kalb, PhD, a clinical psychologist and vice president of Clinical Care for the National MS Society. "However, once they put those concerns and feelings on the table, they can start thinking about the future, plan for everybody's needs and help one another," she says. "It's really all about communication."

Dorothy Northrop, vice president of Continuum of Care for the Society, agrees. "Good

communication between persons with MS and those for whom they are providing care is crucial. This is particularly important because so many MS symptoms are variable and can be invisible,” she points out. “Open communication enables problem-solving together.”

Shana Spooner, 61, who also lives in Orlando and was diagnosed with MS in 2007, learned this after caring for her mother for several years. “She was a very strong-willed person and never forgot a thing. And then, all of a sudden, she started forgetting everything and needed help,” says Spooner, whose mother passed away last year. “I realized very quickly if I didn’t take care of myself and my MS symptoms, I wouldn’t be able to care for her. So, I always took some time for myself, whether it was 10 minutes of meditating each day, or hiring a caregiver so I could take a long weekend away every few months.”

“Most of us are caregivers at some point because having a chronic illness doesn’t relieve you of your role as a family member,” explains David Rintell, EdD, a psychologist with [Partners MS Center](#) in Boston, part of Brigham & Women’s Hospital, and the [Partners Pediatric MS Center](#) at Massachusetts General Hospital. “Many people with MS are very active in helping to care for members of their families.”

More resources

A list of helpful websites relevant to [caregivers with MS](#).

However, just because it’s a common situation doesn’t mean it’s easy. “Taking care of your needs as a person with MS and helping care for someone else’s needs can feel like a 24/7 responsibility,” continues Dr. Rintell. He strongly advises staying in touch with friends and other family members. “Social isolation is a real health risk that enormously reduces quality of life. Make an effort to engage in social activities, such as attending religious services or meeting friends for dinner. It’s important to keep your social contacts.”

Reach out—and relax

No man (or woman) is an island. Many hands make light work. These sayings may be clichés, but they are popular for a reason. Trying to do everything on your own without asking for help or taking a break can lead to increased health problems, which doesn’t do anyone any good down the road.

Marylucia Arace, 50, diagnosed with MS in 2010, found ways to reach out while giving care to her 89-year-old father with Alzheimer’s. “I now live with my dad in the home I grew up in, and our neighbors are like family,” says Arace, who resides in Southern California. “One neighbor’s husband has early-onset Alzheimer’s, so we help each other out. I’ll give her a break and she’ll give me a break.” She also plugged into [California’s Caregiver Resource Centers](#) network. “It’s a great place to get support,” she explains. “It’s a one-stop shop with workshops on caregiving, programs for respite care, support groups and good referral

services for any kind of health issue.”

“A big help for me was our Area Agency on Aging,” says Ann Style, 60, who lives in Tucson, Ariz., and who was diagnosed with MS when she was 21. She cared for her mother, who has Alzheimer’s disease and recently moved to a senior living facility. “They have great resources such as respite care. I had someone come in two days a week, so I could have time for myself.”

If you can identify the activities in your life that need to happen, such as grocery shopping, preparing meals or going to the doctor, then it becomes easier to find people in your network or family who can help support you. “It’s much easier for people to help when they know exactly what you need,” says Dr. Kalb. And often people are even better able to help with one specific task, such as picking up groceries.

Society partner [CaringBridge](#) enables caregivers to post online health updates and requests for help with tasks from friends and family members. The whole network can then see the requests, and coordinate them among the group.

Creative solutions

Meeting your own daily needs along with those of another person requires creative thinking, Style notes. Her MS symptoms are relatively mild, but caring for her mother can still be challenging.

“Look for opportunities to care for yourself at the same time you’re caring for someone else,” Style advises. “For example, I signed my mother and myself up for the same exercise class. It helped us both.”

“Recognize your own limits, have honest discussions about those limits with your care partner and solve problems together,” recommends Deborah Miller, PhD, associate professor of medicine at the Cleveland Clinic, where the [MS Center](#) serves about 4,000 people with MS each year.

The Internet can also take some of the burden off caregivers who have MS. Sandra Greenwald, 64, of Rockledge, Fla., diagnosed with MS in 1986, doesn’t drive, so she knew it would be difficult when she took on the task of caring for her 83-year-old mother who is in the beginning stages of dementia. “I can’t even go out to get groceries and take a break, but I know I need a break,” she says. “I do not spend a lot of time on the Internet, but I know it is always there waiting for me to use—not so much to relax, but to do something different.”

Social networking through the Internet can also offer a place to relax and share problem-solving strategies, says Dr. Kalb. “Take advantage of online communities to ask how other people have managed similar situations,” she says. “You’ll get some good ideas and the support of people saying, ‘I hear you.’” Connect with others with MS through the Society’s online community at [MSconnection.org](#), or through the Society’s MSFriends telephone

support program. Call 1-866-673-7436 or visit nationalMSSociety.org/MSFriends.

When caring for someone else, it's all too easy to neglect yourself and your own MS issues. But remember the airplane safety rule: In case of emergency, put on your own oxygen mask first. Otherwise, you won't be any help to those in need around you.

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Start or join a group for caregivers at MSconnection.org.