

## Becoming carepartners



### **Create a balanced relationship even with MS in the mix.**

**by Kelly Pate Dwyer**

Robert Berry always had a project going on around the house, whether it was splitting firewood, building cabinets or working on his Jeep, until his multiple sclerosis limited his physical abilities. Though the 68-year-old from Cliffdell, Washington, now uses a wheelchair, he still rolls up his sleeves every chance he gets—to set and clear the dinner table, put away folded laundry and drive the car. “I can still use a screwdriver. I can change the batteries in the clock,” Berry says. “That sort of thing is satisfying.” These tasks may not be as complicated as the ones he once did, but they all lighten the load for his wife and primary caregiver, Patti.



**Patti and Robert Berry, who live with MS, acknowledge that life isn't always easy, but they have found ways to work through the difficult moments.**

Photo courtesy of the Berrys.

“In the mornings, I get to relax for a bit and he gets us our tea,” says Patti, noting that she readies it to brew the night before. Patti adds that he not only helps around the house but comforts her when she’s down and helps keep her grounded.

The Berrys, who have two sons and three grandchildren, maintain a strong relationship in spite of the increasing challenges Robert’s MS brings, in large part because they embody the concept of “carepartners.”

## **Partnership starts with giving**

Couples who strive for balance and partnership are better equipped to manage the effects of living with and caring for someone with a chronic illness, experts say. Below are some practical tips to get started.

**Seek support.** Speak with a counselor or join a support group to learn communication and coping tools and to connect with others in similar circumstances. Likewise, you can chat with others in the self-help group for caregivers at [MSconnection.org](https://www.msconnection.org).

**Share the load.** If you have MS, you may no longer be able to do certain tasks (or it may take longer). Decide what tasks you want to spend your energy on. Look for new ways you

can contribute, such as managing finances or helping kids with homework. Ask your partner what you can do to support him or her. Say yes when a neighbor offers to make dinner, and if you can afford it, hire help where you need it most, be that with household chores or personal care, suggests occupational therapist Laura McKeown, PhD.

**Caregivers: Set aside “me time.”** Attend your favorite exercise class or meet a friend for lunch. Time on your own can help you maintain a sense of self, recharge and avoid feeling resentful of your role as a caregiver. “You have to be a good self-advocate,” says George Willey, who cares for his partner Michael Nesson. “You have to take care of yourself before you take care of others.”

**Do activities you enjoyed together before MS affected your life,** which can help you reconnect outside the sphere of MS. This may be as simple as setting aside an hour to watch a favorite TV program.

**Find new ways to do what you used to enjoy.** Robert Berry, who has MS, used to mow his lawn and work in the garden. Now he hires kids to do outdoor chores while he oversees their work. Plus, “that gives me some ‘me time,’ ” his wife, Patti, says. They also go dancing, only now Robert is on wheels.

**Keep a sense of humor.** A few years ago when Robert used a walker, he tripped on a doorjamb and fell. He wasn’t hurt, but couldn’t stand up on his own and couldn’t reach a phone to call for help. Fortunately, he knew his son had planned to stop by. “When he arrived, he said, ‘Dad, what are you doing?’ ” Robert recalls. “I said, ‘Oh, I’m just lying here meditating.’ ”

“If people can smile and laugh to ease the stress of a situation, they are more likely to let some of the frustration roll off their back,” rehabilitation psychologist Kevin Alschuler, PhD, says.

### **The carepartner dance**

“With carepartners, there is a true partnership, in which the person with MS gives back to the person caring for him or her,” explains Nancy Law, executive vice president of Programs & Services for the National MS Society. “In a balanced partnership, each partner gives and receives, and both feel like they make valuable contributions to the relationship—even if they do it in different ways than before MS came along,” she adds.

Couples can create that balanced give-and-take, and relieve stress on the primary caregiver, in a variety of ways, including sharing household chores, Law says. “And there are simple ways of giving back to one another, such as saying ‘thank you’ and being a great listener.”

There are also practical tips for becoming carepartners (see sidebar at right), but the first step for any couple living with MS is to address the ways that the disease has changed their relationship. That starts with communicating openly about feelings—such as fear, anger,

guilt, frustration, sadness and resentment—along with learning to accept the disease and nurturing intimacy, all of which feed into one another.

### **Ditch the blame game**

Just as MS is different for every individual, so is caregiving. One person takes to that role naturally, while the next resents it. One person living with MS is fiercely independent, while another wants or needs more help. Or one caregiver may work full time because her partner's relatively mild symptoms allow it, while another caregiver may have taken early retirement to help his partner because of the severity of his disease. Common to many couples however, is a reluctance to open up about their feelings, says social worker Mary Rzeszut, MSW, LCSW, who counsels people with MS and their families at Winthrop University Hospital in Mineola, New York.

"Day-to-day life with an illness is so overwhelming, many people don't stop to think about how to communicate," she says. What's more, they feel vulnerable opening up. "If someone is frightened about his or her partner having MS, the tendency may be to hold back feelings so the person with the disease won't think, 'My partner's not strong enough to handle it' or 'My partner can't be supportive enough,' " because the person with MS already has so much on his or her plate.

However, displaying vulnerability builds trust and fosters open communication, says Rzeszut, who uses a "mirroring" technique to help couples get started. For instance, a woman tells her husband with MS that she feels overwhelmed with work, kids and bills and that he doesn't acknowledge her stress. Her husband listens without interruption, then echoes what she said, which may be, "I hear you saying that you feel overwhelmed and that I often don't see how stressed you are."

Then it's his turn to share. Through this process, the two validate each other's feelings without judgment or blame and work together to figure out possible solutions.

"Sometimes the day-to-day gets to you," Patti Berry says. "You have to recognize it and admit it out loud to each other, so you can get rid of it." She admits communication isn't a perfect process. "If I get frustrated and mad—and I do—I'll rant and rave and cry," she says with a laugh. "I know that when it's done I have to apologize."

### **The art of acceptance**

Some people are shocked when they receive an MS diagnosis or develop new, debilitating symptoms, says occupational therapist Laura McKeown, PhD, who has researched the experiences of MS caregivers and teaches at the University of Ulster in Northern Ireland.

"Until the person with MS can accept they have this lifelong condition, they aren't going to be open to having any support," McKeown says. Likewise, caregivers need to be ready to offer support, she says.

Accepting the disease also prepares those with MS and their loved ones to make tough decisions around necessary work and lifestyle changes, says rehabilitation psychologist Kevin Alschuler, PhD, who counsels people with MS and their families at the University of Washington School of Medicine in Seattle. He encourages them to develop a flexible mindset and think beyond “what I have always done,” and try different approaches to achieve their desired outcomes.

“Flexibility is not just about, ‘What do I do about fatigue today?’ but, more broadly, ‘How do I adjust to a new symptom later?’ ” he explains. “We as humans often don’t do particularly well with uncertainty, unknowns, constant changes. We like to stick with our strategies that have always worked.”



**Michael Nesson, left, who has MS, and his partner, George Willey, practice mindfulness exercises to help cope with ups and downs.**

Photo courtesy of Michael Nesson

Michael Nesson of Newburyport, Massachusetts, and his longtime partner, George Willey, compare living with MS to playing Whac-A-Mole. “We wonder what’s going to pop up next and how we are going to tackle it,” says Nesson, 54, who was diagnosed in 2009.

With a sense of humor and flexible mindset, the two work through exacerbations of Nesson’s constantly changing symptoms—which include fatigue, left-side weakness, and vision and vocal changes—and through the effects of his disease-modifying treatment.

On Fridays, Nesson injects his medication, which produces flu-like symptoms all weekend and leaves him feeling more fatigued and emotionally worn out by Sunday night.

“He wants less of my help,” during those days, Willey says. “When I say something that (upsets) Michael, he can shut down. I used to pull my hair out. I’d think, ‘What happened?’ ”

After two years struggling through these challenges, Willey has learned that when a conflict arises during those three days, it’s best to either let it go or bring up the problematic subject later.

Alschuler sees similar situations play out in his practice. He worries when side effects of a medication significantly interfere with relationships. He also commends Nesson and Willey’s flexibility: “It sounds like they are wrestling with whether this is the right medication going forward. But in the meantime they are learning how to cope effectively with the side effects.”

Both Nesson and Willey practice mindfulness exercises, which Willey says helps him to remain flexible and prioritize all that’s on his plate: “I am more calm, centered.”

The partners, who have an adult son, know their days are numbered in the 225-year-old home they renovated together. They will likely trade out their dream of retiring in Florida for a ranch-style house in Massachusetts in order to maintain continuity of care with Nesson’s doctors there. While the two lament this loss, they focus on positives in their lives.

“Michael is always going to have health challenges and I will always be willing to be a carepartner,” Willey says. “The best and strongest thing we have going is our 30-year relationship.”

### **Intimacy creates trust**

Talking about the challenges of living with MS—including losses such as retirement plans gone awry—nurtures intimacy, which in turn encourages more communication and builds trust, Rzeszut says. “Each person needs to state what their needs are to the other person, their challenges, what is making them anxious or worried,” she says.

As well, couples need to establish emotional intimacy before they can define what physical contact feels good, Rzeszut says. If couples no longer can enjoy a full sexual relationship, they need to acknowledge that loss, then talk about what does or does not feel good to each of them.

“You have to love what you have and let go of what you don’t, or it will just drive you down,” Patti Berry says. “Intimacy for us is communication, laughter, holding hands, holding each other. And that’s OK.”

**Kelly Pate Dwyer is a freelance writer in Denver.**

For more information on how you and a partner can foster positive communication, call 1-800-344-4867 and ask for the Society’s **Relationship Matters** workbook.

How has your relationship changed as a result of MS? Discuss it with others at [MSconnection.org](https://www.msconnection.org).