

Going the extra mile

Being the primary support for a person living with MS can be overwhelming. But help is available.

by Mike Knight

Though she didn't know it at the time, Karin Prizio became a multiple sclerosis carepartner when she was just 22 years old. It was 1980 and she and her husband, Joe, then 25, were newlyweds. The couple married in August the year before and were enjoying life and planning their future together. After serving as a mechanic in the Air Force, Joe went to college and earned a degree in biomedical engineering. Karin began her career as a registered nurse.

All that was left was living happily ever after.

But Joe began experiencing double vision and other problems that year. Still in its infancy, an MRI wasn't possible and spinal tap results were inconclusive. MS was included as a possible diagnosis.

Upbeat by nature, Karin did what she could. "I didn't need to give [Joe] any real physical support," Prizio says, "because [his health problems] came and went. I was giving a lot of psychological support. I was his cheerleader."

Locked in a loop of "What if it is? What if it isn't?" Joe scoured the library searching for answers, carrying home stacks of neurology journals, hoping they might help him decode the mysterious disease, what it meant for him, and by extent, what it meant for his young wife, the family they wanted and their future together.

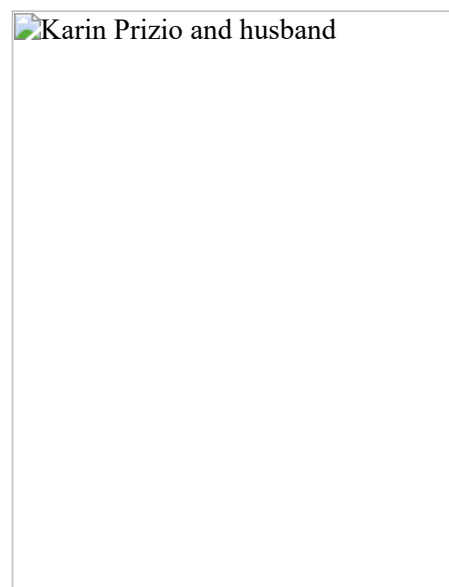
Karin began looking for information about caring for someone with the disease, what to expect and how to prepare for it. She found little for her efforts. "At that time, there was really nothing out there about the caregiver," she says.

In 1987, Joe was positively diagnosed with MS. Over the ensuing decades, the couple has used multiple resources to manage and address his changing abilities and needs. And though it hasn't always been easy, Karin has also found the resources she needed to take care of her husband, her family and perhaps most important, herself.

Like MS itself, caring for someone with the disease is constantly changing, challenging and sometimes, overwhelming. The good news is that practical, personal and emotional support is often readily available. The better news? It doesn't always cost a lot—sometimes it doesn't cost anything at all.

Talk the talk—with other MS carepartners

Perhaps the most important thing an MS carepartner can do is find an MS support group and then go to it, says Beverly Kidder, the director of the Aging & Disability Resource Center at the Agency on Aging, South Central Connecticut. "We encourage everybody to go to support groups," Kidder says. "You get support that's meaningful from other people who



Karin Prizio became a multiple sclerosis carepartner at age 22, when her husband, Joe, then 25, was diagnosed. Photo courtesy of Karin Prizio

know what the heck you're talking about and who don't get upset when you talk about anger, and don't get terrified when you do."

Kidder has facilitated support groups for the National Multiple Sclerosis Society and was also a longtime carepartner for her mother and husband.

Kidder says the unplanned changes MS imposes on care recipients and carepartners—and the new relationship it defines—frequently foster feelings of anger.

Care recipients experience anger because their role and sense of self is changing. Carepartners feel angry because their role and sense of self change, too. But according to Kidder, in the carepartner's case, that sense of anger can quickly spiral out of control.

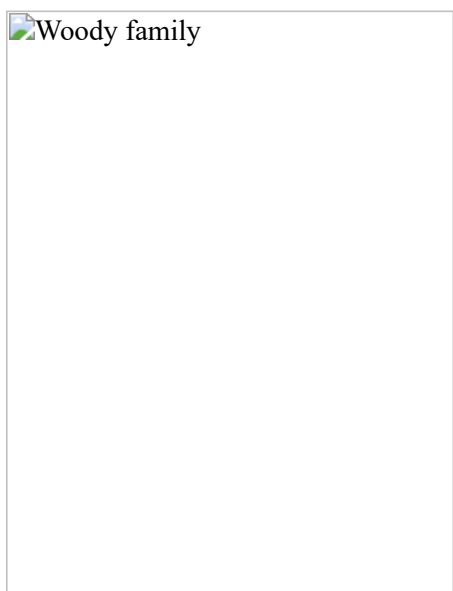
"So I feel the anger, then I feel guilty and I feel angry because it's not your fault," Kidder says. "You didn't want this. Because I feel guilty, I feel exhausted. Depression and anger and guilt are so exhausting that now I don't have any desire to do anything. And then I feel bad about what I didn't get done and exhausted about what I did."

Alane Shanks has facilitated the Metro-west MA MS Caregiver's Group since 2016. The founder and president of Renga Consulting, she's witnessed firsthand the impact support groups have. "I think it is important for people to be around others who are experiencing something so similar," Shanks says. "The drain on the caregiver is important for each to have the opportunity to acknowledge and also to be with other people who understand it. Often people come in very depressed but by the time they are leaving, everybody's laughing because they know the others in the group understand what they are going through and that it feels better to laugh than to cry."

To find an MS carepartner group near you, visit the [National Multiple Sclerosis Society's Self-Help Group locator](#). You also may contact an MS Navigator by calling 1-800-344-4867, emailing ContactUsNMSS@nmss.org or using the chat option on the Society website.

Overcoming guilt

Whether it's taking badly needed time away from caregiving for themselves, seeking outside assistance or even help from friends and family, the guilt MS carepartners often feel can keep them from getting the help they need.



Woody family

Victoria and Carnell Woody were married in 2007, and in November 2014, gave birth to a "very active" son, Isaac. Carnell was diagnosed with MS in 2012 and though Victoria does get support from family members, she is Carnell's primary carepartner. Guilt, she says, keeps her family from doing things together as well as her from doing things just for herself.

Though there are fun activities her whole family would enjoy, like snow tubing or hiking or water sports, Carnell's limited mobility makes doing them difficult.

"I don't want him to miss out on stuff," Victoria says, "and I don't want him to feel like we're doing things without him, so we don't go." Instead, they find other things they can all do together, like time outdoors.

Kidder suggests carepartners create as stable a plan and schedule as possible, identify ways of taking a break—what she calls a "respite"—and then blocking

Due to Carnell Woody's (left) limited mobility, the Woody family adapts their activities so that everyone can have fun. Photography by Riku Foto

out time for that respite, no matter what it is. "For some caregivers, that's going to get their hair done," Kidder says. "For others, it's going to the grocery store."

Photography by Riku Foto

Kidder also suggests incorporating at least a few minutes outside, and where possible, in nature. "Time spent in nature is extremely refreshing and invigorating for people, almost as much as sleep," Kidder says. "So, if the [care recipient] is in the house, and someone's with him or her, go out and sit in the backyard and just relax and breathe."

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Help from the outside in

For carepartners, getting help from outside the home—through family or friends, or professional in-home care providers—may lighten what can become an increasingly heavy responsibility as MS progresses. Pride, Kidder says, keeps many carepartners from asking for help, and even after they've gotten over that hurdle, they struggle to define the help they need.

"Most people, if you ask them for help, and you can be really specific about what it is and when you need it, will say yes and do it for you," Kidder says. But it takes time and effort to figure out what would be most helpful, how important it is and then trying to articulate that to others. "So oftentimes there can be more support for caregivers, but most caregivers don't access it because they don't do the work, and they don't want to face the fact that they can't do everything for the person," Kidder says. "And I say for myself, admitting that I needed help was really, really hard."

Carepartners and care recipients alike may be reluctant to engage in-home attendants, housekeepers, nurses or other professionals for a variety of reasons, including intrusiveness, how to find the professional help they need and of course, affordability. [Hiring Help at Home](#), a brochure available via the Society's website, likens the hiring of an in-home care resource to creating a new "job position." The brochure includes worksheets for creating a needs assessment, job description, conducting a search, interviewing applicants and other helpful tips.

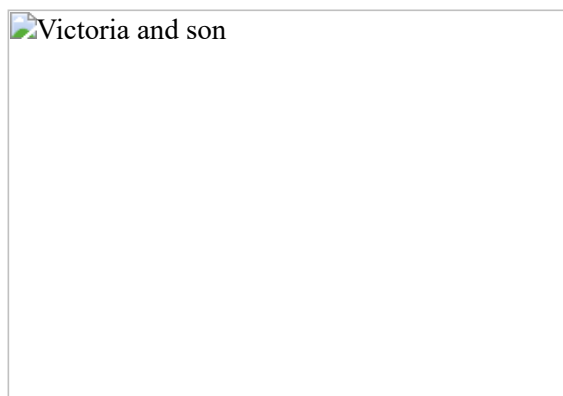
The Society website's [Find Doctors and Resources page](#) lets users search by ZIP code for a spectrum of in-home chore and personal care assistance and adult day programs. The site [Carepartner Support Resources](#) also includes helpful tips and ideas for support, plus it provides a downloadable document containing potential sources for financial support such as grants and veterans' assistance benefits.

Regardless of where you get help, Woody says the key is to get it. "It's critically important that you have not just one person, but a team of people you can reach out to," she says. "They say it takes a village to raise a kid. It takes a village to do anything."

Remember the love

Aug. 19, 2019, marked Karin and Joe Prizio's 40th wedding anniversary. Like any long-term relationship, they've seen their share of ups and downs. The couple had three children, Paul, born in 1985; Ryan, born in 1987; and Ashley, born in 1990. Paul, their eldest, died unexpectedly in 2016.

MS has taken a toll on both of their lives. Joe uses a wheelchair and now needs more extensive personal care and in-home assistance. Karin requires physical therapy to manage the physical toll caused by caring for her husband. They've been to couple's therapy. Karin has attended therapy alone to help her with her role.



The Woody family enjoys spending time together outdoors. Photography by Riku Foto

Yet Karin remains positive. Her respites include yoga, Zumba and quilting. She also loves to bike on accessible trails, while Joe wheels along next to her. Now 62, she's been a carepartner professionally and personally all of her adult life. She urges others following in her—and their—footsteps to remember their love for one another, to not focus on what they've lost, to not stop doing things together no matter how hard, and to let go of regret.

“When you let the regret go,” Karin says, “there's room for happiness and for enjoyment to come in.”

Mike Knight is a writer in Indianapolis, Indiana. He was diagnosed with MS in 2013.

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Learn about [resources for carepartners](#).

Find details about [hiring help for people with MS](#).