



Sarah Keitt is a stay-at-home mom, not because of her MS but because Lucy is 3 and Tess just 22 months. Sarah's an active volunteer at National Capital Chapter—and is raising money for MS with a sailboat race—"Freeze Your Mast Off"—this November. She and husband, George, believe two-way communication keeps them on an even keel.

# Through Thick & Thin:

In this article you'll meet five couples who are working on their relationships.

## Making Relationships Work

by Katherine Shaw

**R**elationships are tough. Add MS to the mix and they get tougher. A partner's ability and willingness to be a caregiver can run the gamut from totally unwilling to constantly overprotective. Likewise, the person with MS can be an easy person to help, or so fiercely independent that help can't be given. To this, add both partners' fear, grief, anger, and stress.

Yet even with all of these issues, couples survive and thrive. Or some do. What do they learn that makes their partnerships work?

### Clarity

There weren't any big surprises for Carlos and Kate.\* Or so it seemed. They met and married in their late 30s after Kate's diagnosis with primary-progressive MS. Carlos was well aware that as Kate tired, her balance worsened. Yet he needed clarification after they married.

"She'd want to hold my hand when we were out walking," he said. "I thought she was being affectionate but I'm just not one for PDAs."

"I was terribly hurt," recalled Kate. She immediately feared that if her MS progressed and she needed more than just a hand, Carlos wouldn't be there for her. Happily, they talked about it. After much discussion, they concluded that Carlos would always be there. But now, Kate is careful to state the situation clearly, distinguishing between **wanting** and **needing** his hand.

Open communication has always been a terrific asset for Jen and Suzanne. Partners now for more than 10 years, Jen decided to attend a support group for caregivers.

"When I listened to others in the group, I realized how well we were doing," she said. "I attribute our success to Suzanne's absolute openness about her MS." Jen and Suzanne have successfully navigated everything from changes in employment status to housecleaning and cooking challenges, the need for a lift and transfer system, and wheelchair accessibil-

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\*Most of the couples interviewed preferred to preserve their privacy; all of their names have been changed.

ity. “Her symptoms can be a moving target. I have no idea what she’s really going through. But if she tells me, I can be a much better partner,” Jen said.

Even tough issues haven’t stopped their willingness to be clear. Jen is retiring soon and the couple will relocate to Oregon. “Living in California, we have a domestic partner act that’s provided us with many of the same protections as marriage,” said Suzanne, who used to practice law before MS. “When we get to Oregon, we’ll have to address health-care power of attorney and check that our wills are in order,” Jen explained. “I need to make sure that once we move, there won’t be any surprises if Suzanne has health issues.”

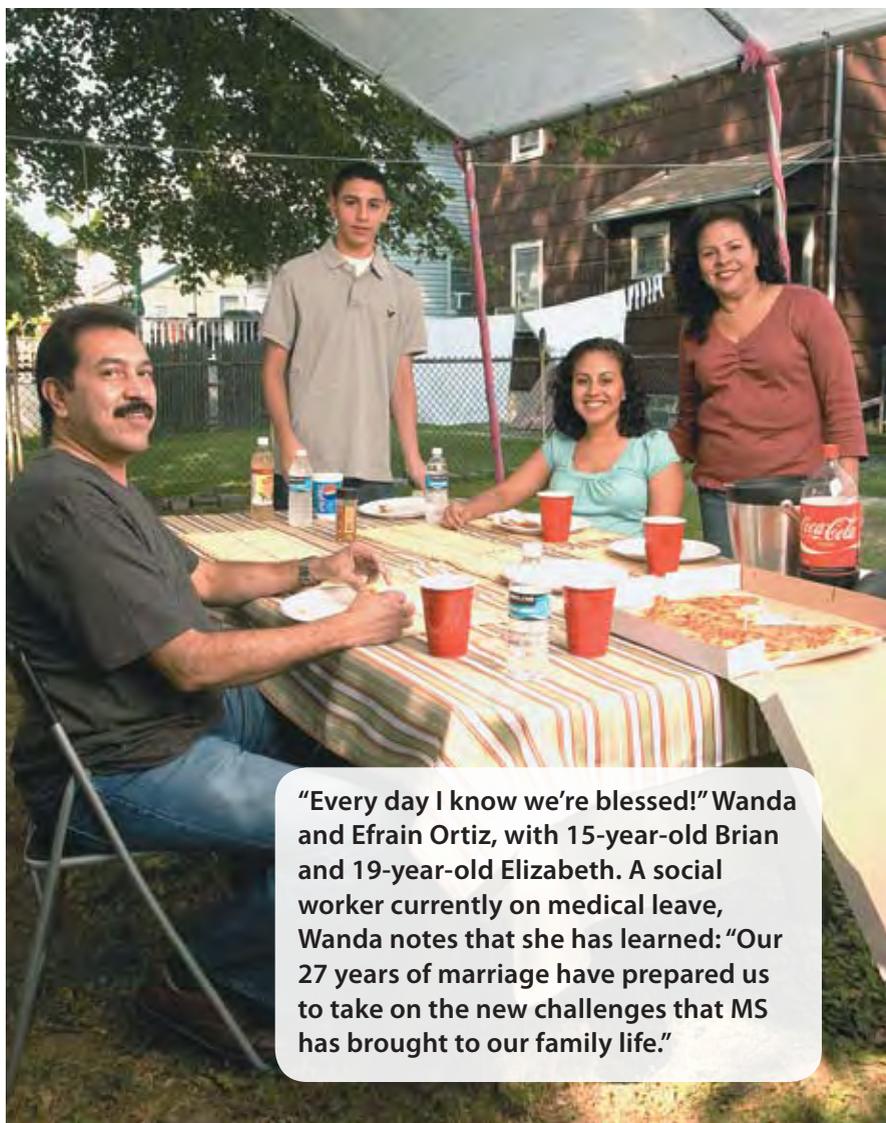
### Tough love

Emily is an artist who travels a 300-mile radius from her home to sell her wares at art festivals. At first her husband Steven traveled with her and helped with the laborious task of setting up and tearing down her booth. This was critical help to Emily as she frequently became fatigued during the process. But after a time, Steven tired of the routine. He explained that if shows were too much for Emily to do alone, maybe she should consider another outlet for her artwork. Or, better yet, he suggested, Emily should hire someone to help.

“I was hysterical!” Emily remembered. “But then I hired the help I needed. Sure, I wish Steven wanted to travel with me. But in the end, I was empowered—I could do the shows without depending on him.”

### A continuing process

For Grace, being a good partner to her husband Les is a work in progress. Grace, 42, and Les, 37, had



“Every day I know we’re blessed!” Wanda and Efrain Ortiz, with 15-year-old Brian and 19-year-old Elizabeth. A social worker currently on medical leave, Wanda notes that she has learned: “Our 27 years of marriage have prepared us to take on the new challenges that MS has brought to our family life.”

been married 10 years when Les was diagnosed. Initially, Les managed the news well, but within a year he’d fallen into a severe depression and isolated himself from the family. “He was short with the children and with me and did little around the house. I finally gave him an ultimatum: we get help or I’m leaving.”

The couple began counseling sessions, attended a seminar on **MS and Parenting**, and Les’s physician prescribed antidepressants. All of this helped Les talk about his biggest fear: not being able to provide for his family, not being strong. Grace was able to assure him that she wasn’t leaving. “The foundation of our relationship is a very strong friendship. That’s what’s helped us get through this,” Grace concluded.

### It's all about communication

Through counseling, Les learned that he needs to tell Grace what he can and cannot do on a daily basis. And Grace has learned she must ask, too. Prior to this, Les was closemouthed about symptoms and Grace made assumptions based on books she'd read.

"It's taken three–four years for us to really learn to communicate," Grace said recently. "I know Les finds it difficult to ask for help, but it's so much easier for me when I know what's going on." Grace has also had to learn how to talk to the couple's three children, who'd rather question mom about why it is always *their* daddy who can't go hiking or biking.

Grace and Les have established a routine after Les visits a doctor. He calls home immediately to debrief. "I'm uncomfortable going to the neurologist with him," Grace admits. Sometimes other patients in the waiting area are deeply upsetting to her. But recently Grace signed up to be in a study that compares MRIs in people who have MS to those of people who do not.

"She's never had an MRI, so I was thrilled that she was willing to participate. She'll better understand what I go through," Les said.

In addition to counseling, the couple has attended workshops and retreats to sharpen their communication skills. They've developed little signals—if Les leans on Grace's shoulder, she knows that he needs help with balance. She's learned to walk a bit slower, and to tell Les when her shoulder is getting sore, so he can switch to the other side.

### Getting by with a little help ...

Grace has also learned how much having friends to confide in can help. "At first, I didn't talk about Les's MS with my friends, but they cornered me one day. They said that the MS was part of my life and told me to share more. It's helped so much to be able to open up to them. Because I can vent there, I can be a better partner to Les."

Grace also began attending church more regularly and eventually Les came along. Now, the couple's shared faith and extended church family are also a source of strength.

### Making self-care a priority

Jack has had to learn to make time for himself. Now 68 and retired, he is the primary caregiver for his wife, Vel, who is unable to leave her bed. He has learned to cath her, bathe her, give injections, keep track of her meds, arrange all of her appointments, and see to all the household tasks that Vel used to do.

Because Vel has also experienced some cognitive impairment, Jack has had to deal with feelings of isolation. Vel no longer shares many of their memories. "It's difficult," he said bluntly.

**"It's taken three–four years for us to really learn to communicate."**



This year Jack had an opportunity to go to Europe to see his family. "I made the tough decision to put Vel in a nursing home so I could make the trip," Jack said. Vel wasn't pleased but realized that Jack deserved some respite. While he was away, Jack arranged for their grown son, who lives across the country, to visit; he also made sure Vel's friends would come by the nursing home.

I got to know these extraordinary people in the course of writing this article for **Momentum**. What they do sounds simple, but it isn't. What they have together sounds wonderful, and it is. ■

Katherine Shaw is a freelance writer based in Portland, Oregon. She was diagnosed 10 years ago and wrote an article about disclosure on the job for a special issue on Employment in 2006.

# A Professional View:

An interview with Kathy Orosz, MSW, LISW

by Katherine Shaw

A seasoned professional shares her view of what couples may need to keep growing together.

“ always remind the healthy partners to take care of themselves—to exercise, eat well, get some downtime, maintain outside friendships, and attend support groups,” said Kathy Orosz, a social worker who facilitated a couple’s retreat offered last year by the Society’s Ohio Buckeye Chapter.

Orosz recognizes two recurring themes for couples living with MS: communication and depression. She recommends medical attention for depression, since medication is often needed to manage it. To address communication, Orosz begins by encouraging her clients to bring their partners with them for counseling sessions.

“Family members often make either negative or incorrect assumptions about what the person with MS is going through,” she said. “When the person with MS is silent on the subject, it’s a recipe for hurt and misunderstanding.

“It’s all too common for a person who has MS fatigue to say nothing but to refuse a night out,” she continued. “If the partner knew that fatigue was the issue, they might order pizza in and even invite friends over.” Bottom line? “Both parties need to be able to articulate their needs and their fears,” Orosz said.



RANDY MAYS

“I also try to help each partner identify his or her positive contributions to the relationship. While the contributions may evolve, discussing them reaffirms their commitment. It helps to hear what each partner brings to the relationship and to know that even with the changes that are occurring, each is appreciated and valued by the other.

“Being good partners also means discussing sexuality together,” she said. “This is so important because sex often changes through the course of MS. Each partner needs to be able to communicate needs and desires and to recognize that intimacy can be many things.” She likes to remind her clients to give each other honest compliments about the other’s appearance. MS can make it hard to feel attractive.

“I often recommend that partners journal. Some things are simply too hard to talk about. Writing can help clarify or even be enough of a release that an incident can pass without conflict,” Orosz said. “I know of one couple who send each other e-mails. The wife says this allows her to think about what she wants to say and to choose her words carefully, resulting in less emotion and more clarity. Her husband has time to consider the e-mail and respond when he isn’t rushed.”

### Moving ahead

Just as one person’s MS can look completely different from another’s, so too can the way different partners work together to manage what MS may do. Orosz concluded with her top 10 list:

## KATHY OROSZ’S TOP 10 FOR PARTNERS IDEAS

**1. Be supportive.** What that means will vary—attending doctor visits, words of appreciation, giving a hand for balance ...

**2. Be creative.** Maybe you and your partner can’t take a hike, but you can watch nature videos together. Think of new activities to share.

**3. Ask questions and listen.** Don’t assume yesterday’s symptoms are the same as today’s. MS isn’t like that.

**4. Take care of yourself** or you won’t be able to take care of your partner.

**5. Have a few select friends** to confide in.

**6. Separate the MS from your partner.** Remember that this is the person you love, who just happens to have MS.

**7. Stay smart.** Use the National MS Society, its publications and Web site, to find community resources, counseling, information, self-help groups (both online and in person), and the latest on research and treatments.

**8. Let your partner take care of you.** Give your partner time to be a good listener. Maintain give-and-take in your relationship.

**9. Be positive.** Speak of hope and a future, even when you have to talk about grief and loss. Say **us** and **we**, rather than **I** and **you**. You’re both in this together.

**10. Be flexible.** Peanut butter and jelly together can be better than beef stroganoff without your partner at your side.