

Melissa Sherak-Glasser and devoted husband Danny share a bubbly moment.



# Sex, Love, and Multiple Sclerosis

**F**orming and maintaining an intimate relationship is challenging under the best of circumstances, but toss a debilitating disease into the mix and you have a recipe for romantic disaster, right? Not necessarily.

Multiple sclerosis (MS) usually starts between the ages of 20 and 50, when people are in the prime of their lives and planning for the future. But while some patients feel like MS is a strike against them on the relationship front, many couples report that it has brought them closer together. "It makes them feel like a team facing a common enemy," says Rosalind Kalb, Ph.D., associate vice president of the Professional Resource Center at the National MS Society and author of *Multiple Sclerosis: A Guide for Families, 3rd Edition* (Demos Medical Publishing, 2006). And for those who aren't already coupled, MS may be an easy way to weed out less-than-suitable partners.

**SHOW YOUR CARDS**

When you're single, determining when and how to broach the topic of MS with a prospective significant other is almost as scary as the disease itself.

"Even though I have no major impairments now, I recognize that I'm potentially a lot for someone to take on," says 34-year-old Rachel Green,\* who was diagnosed when she was 30. "I went through the whole thing: Do I tell the person right

Some people crave more intimate contact with their partners as the result of MS symptoms.

From first dates to wedding bells, an inside look at how romantic couples successfully navigate the unpredictability of MS.

BY AMY PATUREL, M.S., M.P.H.

away? Will it completely sabotage the relationship if I let them know? Is it dishonest not to tell them early on?"

Ultimately Green didn't have to "break the news" of her disease to her fiancé: They had been acquaintances for years, so he knew about her condition even before their first official date. Now that Green is in an emotionally healthy relationship, she recognizes that her desire to keep the MS a secret was a way of rejecting herself—of not believing she deserved to be loved.

"Society definitely paints a picture of what the perfect woman is, and it doesn't include MS," she says. "Beyond every woman's normal insecurities, I had to go into a relationship knowing that I could be in a wheelchair in five years and wondering whether

somebody would love me in spite of that."

While experts agree that telling potential partners you have MS should be like pulling off a band-aid—quick, deliberate and relatively painless—that doesn't mean you have to come clean on a first date.

"A first date is not a time when you're required to do anything except decide if you want to go on a second date," says Dr. Kalb. She tells her patients to think about when they would want to know similar

information about the person they're dating and use that as a guide. You may not want to blurt it out before the appetizers arrive, but why not put it on the table early in the relationship, when the stakes are lower?

That's the approach that 33-year-old Melissa Sherak-Glasser took. Her secret came out on her first date with Danny Glasser, the man who would become her second husband. "Danny had conversations with a mutual friend, so he already knew a little bit about me," Sherak-Glasser says. "At dinner he asked, 'Why did you run with the Olympic torch?' and 'Why do you write inspirational books?' That was my moment."

After sharing her illness with Danny, Melissa pleaded with him not to read about MS on the Internet but to learn about the condition through her instead. He agreed. "It was scary, sure," says Glasser, "but MS wasn't a reason for me not to fall in love with Melissa. Today she has MS; who's to say that I won't have cancer or some other illness tomorrow?"


While Danny's response to Melissa's news was overwhelmingly positive, Dr. Kalb recommends patients be prepared for anything from dead silence to the person reacting like you already have one foot in the grave.

"It's all in how you convey the disease," says Traci Seidman, Ph.D., a clinical psychologist in Sunrise, Florida, who also has MS. "If you come at the conversation from a sense of doom and gloom, your partner is going to take that cue. You have to learn not to live your diagnosis."

## ROLE PLAYING

Whether you're telling a new beau you have MS or living your day-to-day with your spouse of 20 years, you're likely to notice a significant shift in roles following news of the diagnosis. MS symptoms typically come during a life-stage that's equated with productivity, child rearing, and accomplishment. It's a time when your significant other may expect to play the caregiver role for an elderly parent or a new baby but not for a spouse.

"Many partners have a reaction of grief, almost like their Aunt Susan died," says John Corboy, M.D., professor of neurology and director of the University of Colorado's Multiple

A photograph of a man and a woman embracing in a doorway. The man is on the left, wearing a plaid shirt and jeans, with his arms around the woman. The woman is on the right, wearing a light-colored dress, with her arms crossed. They are both looking towards the right, away from the camera. The lighting is warm and soft, suggesting an indoor setting with natural light from a window or door.

61 percent of people surveyed by the National MS Society reported that communication with their significant other improved after an MS diagnosis.

Sclerosis Center. "People go through the typical stages of grief: denial, anger, sadness, and then accepting the illness." And with acceptance come role changes.

A February 2005 study in the *Journal of Neuroscience Nursing* found that healthy partners often shift the most. Women tend to focus on keeping their husbands involved, functioning, and independent. Men, on the other hand, typically try to protect their wives' energy, learning to give injections with the least amount of bruising and pain, taking over household chores, and accompanying their wives to medical appointments. A condition like MS can bring out supportive and nurturing qualities in partners.

Nevertheless, the line between caregiving and pity can get blurry. "My first husband didn't want to stress me out or upset me," Sherak-Glasser says. "I realized he saw me as a victim, which to me is so, so sad. He wasn't being true to himself and in the long run, he wasn't being true to me."

Some couples are stifled not by role changes but by different coping styles. Forty-five-year-old Peter Simmons\* didn't want anyone to know about his illness, so his wife Stephanie\* had to stay mum, too. "It was really hard on her because she wasn't able to tell her friends and she didn't have an outlet," says Simmons. "She was a real trooper to stick with me through this."

But at what price? In some cases, partners sacrifice their own needs and desires to the point where they lose themselves in their spouse's illness—and ultimately, the relationship itself dies.

Beyond the partners' roles in the relationship is the disease itself. Many couples view MS as the third person in a marriage—one with demands, desires, and a disposition all its own. Just like with a person, it can take time to find the right way of relating to the condition.

"What's hard for partners is that you're not in a position where you can do anything but be reactive," Glasser says. "When Melissa has an exacerbation, it's a very tricky line that I walk. On the one hand, my role is to be supportive and encouraging, but on the other, I want to help get her moving again and shift into a proactive pattern."

Flexibility and creativity are two of the key qualities that couples and families who manage MS successfully learn to develop. "MS is very unpredictable and changeable, so couples have to navigate that by flexing a bit on their usual roles," says Dr. Kalb. "If the affected person usually takes care of the laundry and cooking, their partner might have to pick up that slack."

## THE PARTNER'S SIDE

"The first thing to recognize is that MS affects everyone in the family, not just the victim," explains Dr. Corboy. When MS hits, partners and spouses may find themselves in a position of needing support at the same time that they're required to provide it. The partner also experiences losses in terms of role and relationship changes, career and financial difficulties, and reduced physical intimacy. Each of these issues places additional strain

Many couples view MS as the **third person** in a marriage—one with demands, desires, and a disposition all its own.

on the relationship. Some partners even feel as though the relationship journey is easier for the person who has MS.

"It's just like sports," Simmons says. "When you're in the game and doing your best, it's much easier to accept losses than if you're a fan of the team, because the fan has no control over the situation"—and no coach orchestrating the next move.

Spouses need to get support, says Nancy Fleming Courts, Ph.D., R.N., associate professor emerita in the Adult Health Department at the University of North Carolina. "The issues for the spouse are not the same as the person who is afflicted."

For the partners, it's often a question of stamina: How long can they sustain the required level of caretaking? Most experts emphasize that people can't be good caregivers unless they take care of themselves first. "It's like when you get on an airplane and the flight attendant instructs you to put on your own oxygen mask before assisting the person next to you," explains Dr. Kalb. For some partners, that's just too much.

Despite these challenges, research shows people with MS stay married and get divorced at the same rate as the general population. According to the National Multiple Sclerosis Survey, two thirds of patients surveyed claimed their relationship stayed the same or improved following their development of MS.

The important thing is making sure spouses and partners have an outlet for the stresses of caregiving. "If I go and do something that allows me to engage my body and not my mind, I'm usually better off," Glasser says. "I also have a very strong support network, including Melissa's family and the friends I've known since I was 6 years old."

## LET'S TALK ABOUT SEX

Not surprisingly, the impact of MS eventually trickles down and is reflected in the couples' sexual relationship. With 56 percent of patients experiencing some impairment in sexual functioning and many others facing a devastatingly low libido, it's no surprise that many couples dealing with MS report a reduction in sexual activity.


"At early stages of the illness, depression and anxiety play a big role in terms of reduced libido," says Dr. Corbo. At the other end of the spectrum are women who crave more intimate contact with their partners, particularly since the only real sexual limitation for women is a lack of sensation due to the peripheral damage that occurs with the disease.

"In some ways, dealing with MS makes me want more intimacy," says Sherak-Glasser. "When I don't feel good physically, I want to experience that level of closeness with Danny."

Men who have MS, on the other hand, often experience sexual problems, usually in the form of an erectile disorder. The exception is premature ejaculation, which affects 35 percent of men in the general population compared to only 16 percent of men with MS.

"For men, the obvious advantage is that there are drugs available, like Viagra, Cialis, and Levitra, that increase blood flow to the penis," says Dr. Corbo. "These medications are remarkably effective in men who have MS—they have an 80- to 90-percent success rate."

Despite the impact of MS on quality of life, almost half of patients surveyed by the National Multiple Sclerosis Society say MS has had some positive impact on their lives, often in the form of developing inner strength, meeting new friends, or becoming involved in new activities. Perhaps even more importantly, 61 percent reported that the quality of communication with their significant other had improved.

"The most important thing is for couples to communicate their wants, needs, desires, and fears—even more so than usual," says Dr. Corbo. "They're going to be dealing with a great deal of uncertainty. Things will change rapidly. They need to be as flexible and open as possible." 

\*Names have been changed.

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## MS AND RELATIONSHIPS RESOURCES

**DivorceBusting.com:** Provides help for sexually troubled marriages

**Enabling Romance: A Guide to Love, Sex and Relationships for People with Disabilities (and the People Who Care About Them)** by Ken Kroll and Erica Levy Klein (No Limits Communications, 2001)

**The Marriage & Family Health Center:** Offers sexuality education and therapy programs ([passionatemarriage.com](http://passionatemarriage.com))

**Multiple Sclerosis: A Guide for Families**, 3rd Edition, by Rosalind Kalb, Ph.D. (Demos Medical Publishing, 2006)

**The National MS Society:** [nationalmssociety.org/Intimacy](http://nationalmssociety.org/Intimacy)