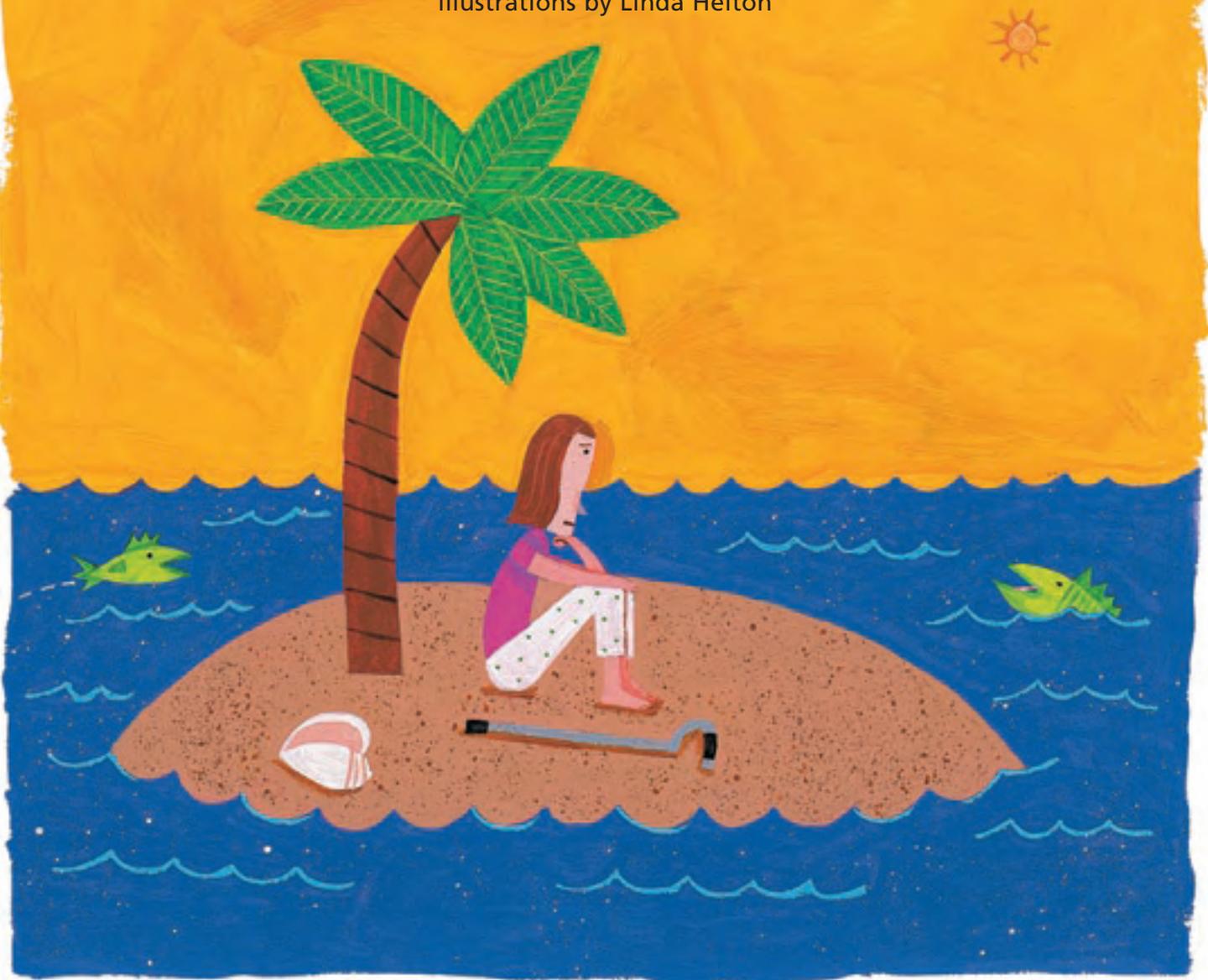


# ISOLATION

BY ALISON DALE

You can be in a wheelchair or without a visible symptom or hobbling somewhere in between, but anyone who has MS can experience isolation. It's just a question of degree.

illustrations by Linda Helton



I didn't think isolation affected me until my girlfriend called and asked me to volunteer for a fundraiser she was organizing. "As long as I don't have to stand," I said with zero enthusiasm. She cheerfully responded, "No problem. You can do the box office. We'll get you a chair."

Truthfully, the chair was the least of it. Other things concerned me, things that I really didn't want to get into with my friend. What if I didn't feel well that day? What if I had to cancel at the last minute? I imagined shaky fingers fumbling with those tiny ticket stubs. Would there be stairs, or even worse, a few steps that seem minor to most people but can present a major challenge to someone like me? Would the bathroom be convenient, the air conditioning adequate? Would I be exhausted all the next day?

Sometimes living in a non-MS world can make you just want to stay home and be isolated. I told my girlfriend I'd get back to her.

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When I interviewed Richard M. Cohen, author of *Blindsided*, for this magazine a few months ago, I asked him, with his active life—a career that spans a new book on the way, speaking engagements, interviews, plus a family that includes a celebrity wife and three teenage kids—if he ever experienced isolation? I half expected him to laugh and say, "I wish!"

He surprised me by answering, "You can have a support system, a family, a spouse, kids, you can have friends who are involved with you, but when all is said and done, you're still alone with yourself. It's just a part of illness."

"I take for granted that everyone is isolated. And then I find out if it's a problem," says Dr. Norman J. Kachuck, director of the MS Center at the University of Southern California. To make sure his patients are "really engaging with their coping issues," he asks all of them to see Dr. Gail A. Murdock, the psychologist at USC's MS Center.

Dr. Murdock observes, "I see how people hurt themselves above and beyond the disease itself. MS wreaks havoc. Then isolation, which is a secondary thing, happens to people and they don't anticipate it, which can be devastating."

While isolation does have some positive aspects—such as providing rest, recovery time, and stress reduction—research shows that people who are continually isolated don't do very well. In general, people who are healthier and live longer are people who are socially connected. There's a direct link between isolation and poor physical as well as emotional health.

### Emotional Isolation

"Emotional isolation starts early and often corresponds with the depression and sadness that comes with not having anyone to connect with and be truly understood," said Dr. Murdock.

Having MS stirs up many different emotions and reactions—and other people's responses to it are unpredictable. Dr. Cheryl Feldmann, a psychologist who has MS herself and practices in West Los Angeles, analyzes it this way: "Some people are able to be supportive while other people have their own personal anxieties really stirred up." That's why disclosure can be such a crapshoot.



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You’re under no obligation to tell everyone that you have MS, Dr. Feldmann pointed out, but, “It is important to have a couple of people who really know you in all of your aspects. Then you can choose what to tell the rest of the world. I think it’s very important to recognize you have control over that,” she said.

Dr. Murdock also points out that some of our isolation is imposed and some is a choice. If a person doesn’t go out because he or she doesn’t want to be seen in a wheelchair or using a cane, Dr. Murdock tries to help that person make a healthier choice. Staying out of sight lets the disease

define the person. “Tell yourself, ‘The cane is not me, it just happens to be something I’m using,’” she suggests.

She advises patients to start early figuring out how they’re going to manage the emotional aspects of MS.

“If you don’t work on it early, it’s likely to become harder later because you may develop a pattern of shutting down and pulling away,” she said.

### **Physical Isolation**

As physical disability progresses, so does the risk of becoming more isolated. One of the toughest situations is to be forced to live outside of the functioning world.

“Steve” has primary progressive MS and lives alone. His MS has progressed to the point where he uses a wheelchair even at home, and frequent falls have landed him in the emergency room many times. “It makes you think twice about

going anywhere,” he says in frustration.

Fatigue can also play a major role in causing isolation. When “Jenny” had to stop working due to MS-related fatigue, she went from having contact with over fifty people a day to being alone all day. “That was profound. I stopped having to interact with anybody. Initially, that was a big shock.

“By around noon, I feel like I’ve climbed Mt. Everest. I just can’t go on. I’ve got to get into bed.” Just having a conversation can exhaust her. “I almost never answer the phone now. I just let the machine get it. And I only respond to what is absolutely necessary.” But as a result, she feels she’s removing herself further and further from the mainstream of life.

## Avoiding Isolation

Despite severe problems with fatigue or mobility, most isolation is a choice. Moreover, it’s a habit. People often don’t recognize how small their world has gotten. They may not realize that they can reduce isolation—and feel better and healthier for it.

Drs. Feldmann and Murdock have some tips:

**Make social life a priority.** Plan activities with people for times when your energy is highest. Use adaptive equipment, whatever is required, to help you get out and about.

**Start small.** Think about changing your situation one small piece at a time, perhaps adding just one social activity per week. When you’ve gotten comfortable with that, then think about adding others.

**Take charge.** “If you can get people to

come to your house, do it. If you can get out of the house once a week, do it. You have to say, ‘I want this in my life, I want to take control over as much of my disease as I can,’” Dr. Murdock said.

**Consider professional help.** A mental-health counselor will focus on helping you figure out how you can still have a life you can love.

**Use the phone** to participate in life. The phone is essential for keeping up with friends and family. It can even help with health care. Some of Dr. Murdock’s patients continue their therapy over the phone.

**Rekindle your passions.** We all have to find something we feel passionate about. It may help to review the past. “It doesn’t matter where you are in life now,” Dr. Murdock commented.

**Utilize your Society chapter.** When people find out they need a wheelchair, they need to talk to other people about what that’s like. This holds true for every stage of this progressive disease. The Society’s peer counseling programs and affiliated support groups help link people who are facing the same things. No one is going to understand what you’re going through the way someone else going through the same things may.

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### What, no Web?

The Internet connects you to the world, but it's not a substitute for a human voice or face, Dr. Feldmann insisted. "I think the telephone is so much more valuable than an online chat!"

She summarizes the effort to maintain involvement in the world: "If somebody has a group of friends, they need to activate that group. If they have a husband, wife, or domestic partner, they need to enlist that person. If they belong to a religious community, they need to let other members know they want to start attending events; the same applies to joining a club.

"People say, 'I don't have the energy or I don't want to be bothered.' It's important to be bothered. Other people without MS continue to interact with each other. They may not notice that you've kind of slipped away. They may not seek you out. This puts the burden on you to seek them. You have to become the social

cheerleader in your own life," she said, knowing, as a person with MS, exactly what that means. "Not only will people with worsening MS have to work harder to have social interactions, they will need to invest more energy at a time when they have less."

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Two days before the fundraiser, I called my girlfriend and told her I'd do it. Upon arrival, I found some of my worst fears were true. A long flight of stairs, no air conditioning, and lights so dim, I could hardly see. But I had a chair, an easy job, and it went fine. I was tired the next day, but it was worth it. I had practiced the advice in this article: Use every opportunity to break free whenever and however you possibly can! ■

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