

FEATURE STORY
Disclosure



The Disclosure Dilemma

by Andrea Sachs

Deciding if, when, how and who to tell about your MS is a big deal.

Karen Ball, the White House correspondent for the **New York Daily News**, had just returned home after two grueling trips abroad with the president. It was the summer of 1995 and, as usual, the capital was sweltering. But a few weeks later, Ball, then 33, found she couldn't walk in the heat without falling down. After bouncing from one doctor's office to another, she finally had an MRI, and was diagnosed with multiple sclerosis.

Ball knew next to nothing about MS, but she knew well that the press corps in Washington, D.C., thrived on gossip. "In that very insulated world in which I lived and worked, it would travel like wildfire once it became known," recalls Ball, now a freelance writer in Kansas City. So she immediately devised a plan. "I gave a disclosure statement to an assistant secretary with the White House press office, and I spun it strong. I was very careful in the way I worded [my disclosure]: 'It's not a big deal. They think I have a mild case. I'm going to be fine.'"

A personal decision

While not everyone with MS needs to be quite as strategic as Ball was, many still must decide when—

and how—to have The Discussion: Who will they tell and how much will they say? The choices that people with MS make are myriad. "Some people are just an open book; some will not tell a single family member," says Tova Epstein, LCSW, a social worker at the Corinne Goldsmith Dickinson Center for Multiple Sclerosis at Mount Sinai Medical Center in New York City.

Take your time

Those who have found the answer to their health puzzle after years of unexplained symptoms may have a strong impulse to tell the world. But since disclosure, once made, is irreversible, many experts advise thinking it over first. Says Rosalind Kalb, PhD, a clinical psychologist and vice president, clinical care, at the National MS Society, "We encourage people, if they can, to take a little time to sit with the information themselves and make a thoughtful, educated decision about who needs to know."

People often live in more than one realm: family, friends, dating and work. To the degree that those worlds are separate, people with MS may find themselves faced with the issue of disclosure



Family

When disclosing to young children, start with simple, basic information and add more complexity as they understand it.

repeatedly. There's no one way to handle it, but a thoughtful plan may prevent later regrets.

All in the family

A strong support network is key for coping with a chronic disease like MS, and for the majority of people, the family is the linchpin of that network. A spouse or partner, a sibling, or someone else in the family who was at their side during the search for a diagnosis, is often the person they tell first.

A harder call is deciding when to disclose to your children and what to say. "Think about how you talk with them about other complicated or confusing subjects," advises Dr. David Rintell, Ed.D., a psychologist at the Partners Multiple Sclerosis Center in Boston.

Start simple

Dr. Kalb suggests using age-appropriate language to talk about MS. "I tell people to approach it like sex education," she says. "You start with simple, basic information, and add more complex information as your children develop the ability to understand it." With very young children, for example, you can explain that MS is not like the flu or chicken pox, and tell them they're not going to catch it and you can still hug and cuddle.

When discussing it with a young child, adds Dr. Rintell, "Make it concrete; make it specific to what

is observable, and don't go too far beyond that." For example, a parent could say, "Mom is having some trouble with her legs so she doesn't walk as well as before. But she's OK and can still take care of you."

Teenagers can understand much more about the illness. Still, he says, they should rely on their parents or healthcare providers for information; they're better off not researching MS on the Internet because they may come across unreliable or frightening information.

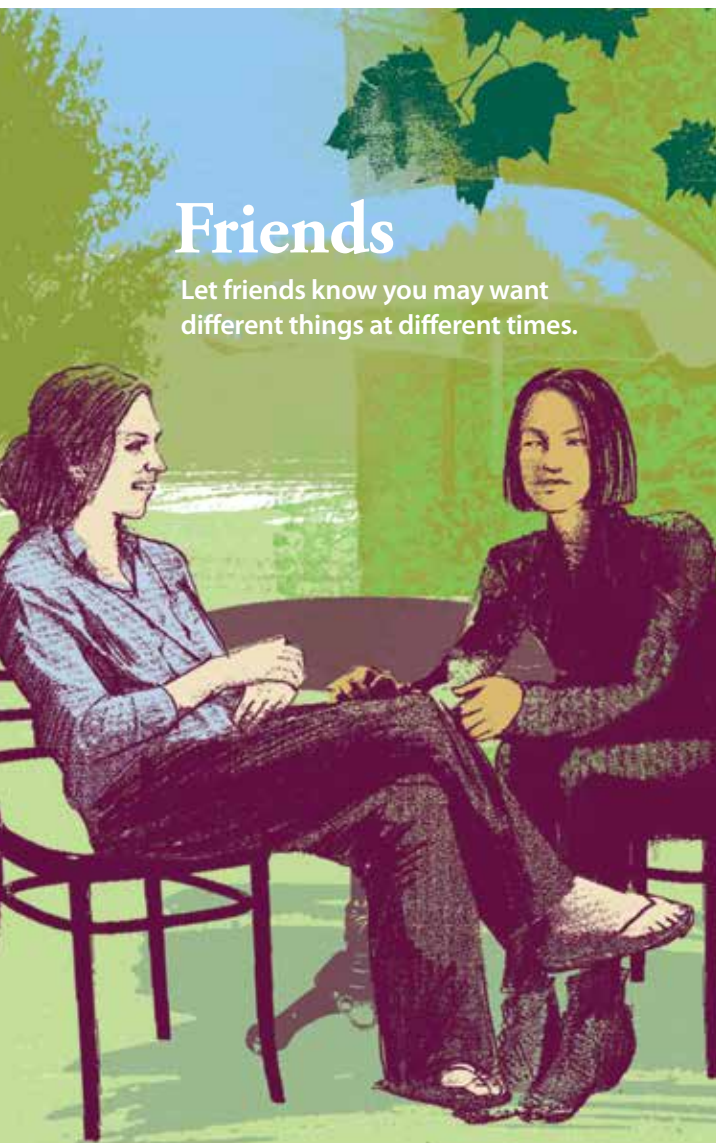
With grown children, the conversation is generally easier. Bob Sweitzer, 62, a retired transportation executive near Denver, immediately told his kids after he was diagnosed in 2004. "Our youngest of five was in college at the time," says Sweitzer. "The others were either in the latter stages of college or early stages of their own working careers. They were very supportive. And for the most part, they wanted to learn more."

Timing the disclosure is often determined by the severity of the illness. When MS causes changes in family routines, it's probably a good time to discuss what's going on. "If parents are very worried or depressed or anxious about all of this, their physical symptoms may not show, but their children are certainly picking up that something's amiss," says Dr. Kalb. "When you don't fill kids in, their imaginations typically come up with answers that are even scarier than reality."

Dr. Jennifer Finkel, the primary psychiatric consultant at the MS center at Mt. Sinai Medical Center, agrees. “If patients have obvious disabilities that even small children would notice, that warrants a discussion immediately. You can’t pretend that something’s not going on when it’s perceptible to anybody.”

A friend in need is a friend indeed

Outside of the family, friends are usually the next stop in the process of disclosing. David Keer, a researcher in the federal government, found great comfort when he revealed his diagnosis to his friends: “I’ve lost a lot of friends to AIDS, so health is a very open discussion in my circle.”



Friends

Let friends know you may want different things at different times.

“It is so important that there be a person in your life that you can be completely honest with,” says Epstein. “It is stressful enough dealing with symptoms.” Telling a friend about your health concerns can present a teachable moment—the opportunity to educate someone about the nature of MS. It also allows friends to ask questions, and find out how they can help.

Still, disclosure to friends doesn’t always go just as you wish: You tell them the news and they burst into tears. And guess what? You have to comfort them, just at the moment you need comforting yourself.

Says Dr. Rintell, “It’s important to signal to people that you really don’t want to hear negativity, or the story about the neighbor down the street who was diagnosed and days later was carried out of the house on a stretcher.” To evoke a more positive reply, Dr. Rintell suggests that people with MS model how they would like their friends to respond. “I’ve been diagnosed with MS, but I want you to know that I’m doing well. All that I need now from my friends are words of support.”

Know that what feels supportive may change as you adapt to your new reality. “I think it’s human nature to want different things at different times,” says Epstein, “and to let your friends know that.”

The dating game

Dating, for anyone, means exposing oneself to a certain degree of vulnerability: Is this person the right one? Does this person really care about me? Add to that a diagnosis of MS, and the discomfort level can rocket.

Molly (not her real name), a 21-year-old college student in California, has learned this through experience; since she was diagnosed at 19, she has had several relationships fizzle after disclosing her MS. “It’s made me a little more hesitant and anxious,” she admits. “I’ve always thought it might be my age group; it’s a little more of a ‘me age.’ So it’s hard to figure out how to deal with something like this.”



Dating

Some people tell their romantic partners about MS early in the relationship. Others wait until the time is right for them.

Telling your romantic partner

In reality, says Dr. Kalb, there is sometimes reason to be concerned about disclosing to prospective romantic partners, regardless of age. “The fact is that some people will run to the hills,” she says. “It’s just extra baggage they don’t want to deal with. But many people don’t run. I’ve been working at the Society since 1980, and I have seen many couples get together with MS in the picture, with one or both of them, and it’s just one thing that a relationship has to deal with.”

On a date with someone you’re meeting for the first time, you have no obligation to share your medical status. “A first date is basically to find out if this person is worth spending any more time with,” Dr. Kalb says. “If you have a very visible symptom—you walk with a cane, for example—then you have a choice to explain what it is, or not. Once you’ve decided that this is a relationship that is worth putting some time and effort into, that’s when I think it is important to talk, not just about MS, but about anything about you that is important for that other person to know. You don’t build a very strong, sound relationship on secrets or half-truths or lies.”

Still, some people take a chance and tell someone early in the relationship. “Sometimes it doesn’t scare the person away,” says Epstein. “Sometimes it does.” Margo Wald Rubens, a divorced Detroit mother of three, met a man using an online dating service, and told him about her MS on their first date. “I liked him, and he was nice, and I thought, if we continue on together, I better tell him so he knows he can get out at any time. And he said, ‘No big deal to me.’” They were together until his death eight years later.

Dana Snyder-Grant, a Boston therapist, was also forthcoming about her diagnosis from the start. Snyder-Grant, 57, told her now-husband on their second date, when he asked her to go for a walk. “We started walking around the pond, and I pulled out my collapsible cane and it dramatically unfolded. And I said, ‘Meet my cane.’ And he asked, ‘Oh, what’s that for?’ and I said, ‘I have MS. I’ve had it 10 years now. This is what MS is. Symptoms can come and go. And it’s not going to kill me. It’s just a pain in the neck.’”

Office politics

Fern Berman was used to living her life in the headlines. At the pinnacle of a successful career in public relations, Berman represented those at the top of the food chain—literally. Among her clients were Julia Child and the famous New York restaurant Le Cirque. Berman was also out as a lesbian, and her wedding was one of the first gay marriages covered

in **The New York Times**. But starting in 1993, when she was diagnosed with MS, Berman began a new lifestyle of keeping secrets.

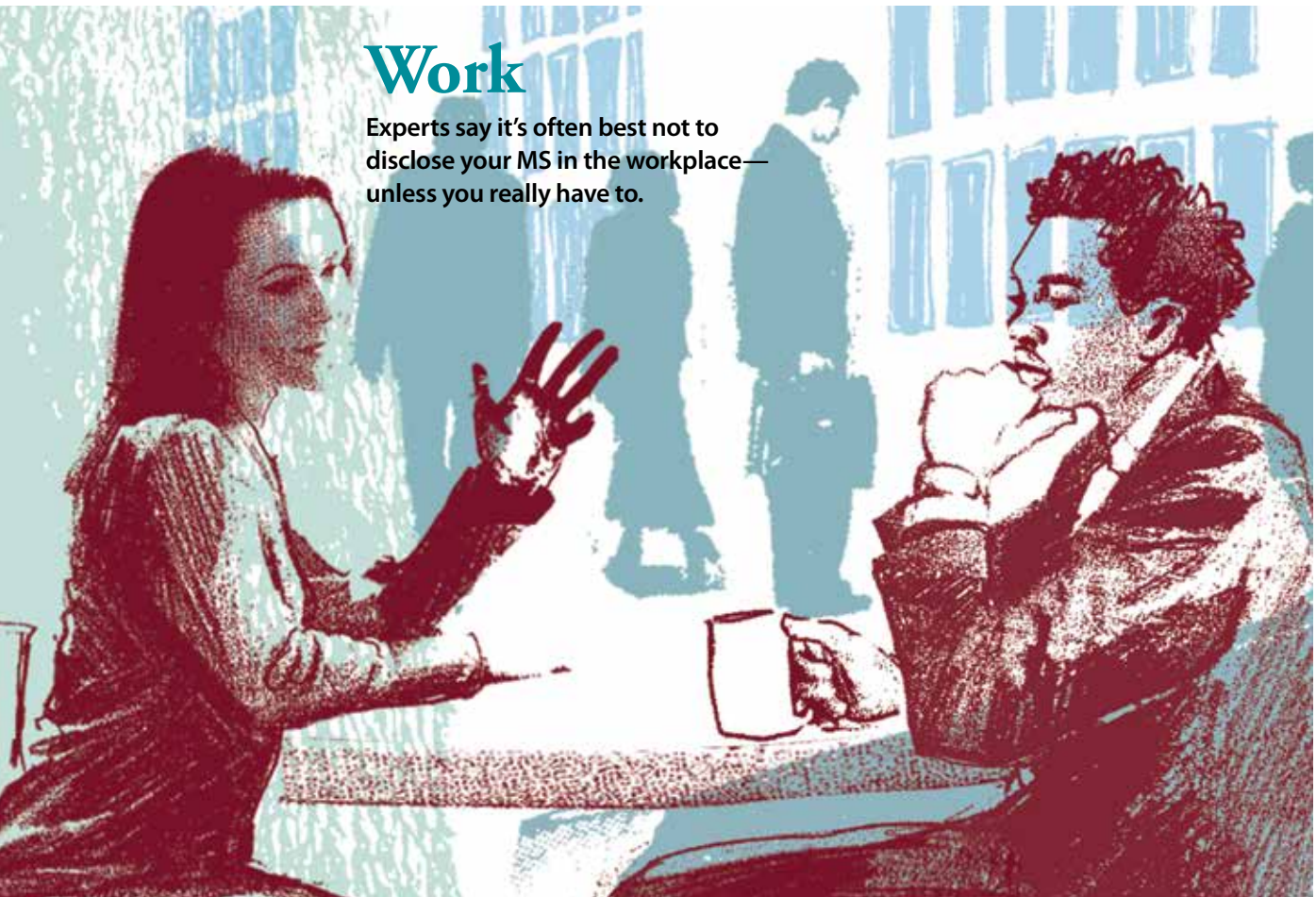
“I lived in constant fear of my clients and colleagues discovering that I had MS,” says Berman. “I thought, ‘I’m dead. My career is over if they find out.’ I didn’t want people to think, ‘She’s really good, **even though** she has MS.’ I didn’t want it to be part of my identity.” But as Berman’s MS worsened, it became harder to shield that part of her life. “I felt beyond vulnerable. I wasn’t envisioning any future for myself.”

In the summer of 2012, Berman began walking with a cane. “People would ask me, ‘What’s wrong with you?’ and at first I would say, ‘Oh, I hurt my knee.’ Then finally I said to myself, ‘I’m not lying anymore.’”

I started to tell people, ‘I have MS,’” she says. “I started telling more and more people the truth.” Though Berman left her high-powered job and New York City for a quieter life in Madison, Conn., she is now pursuing her passion for photography.

Know your rights

For others, disclosing in the workplace is less dramatic but still requires finesse. The Americans with Disabilities Act (ADA), a federal law passed in 1990 and amended four years ago, provides some protections for those with MS who work for companies with 15 or more employees. But Linda Carter Batiste, a lawyer with the Job Accommodation Network (JAN), an agency supported by the U.S. Department of Labor’s Office of Disability Employment Policy, cautions that the law is



Work

Experts say it's often best not to disclose your MS in the workplace—unless you really have to.

“not a simple fix where you call somebody and they immediately come in and protect your rights in the workplace and you never miss a day of work.” For that reason, according to Barbara McKeon, the Society’s director of Employment Programs and Services in the New York City area, “We recommend that people consider not disclosing unless they have to. They might have a really good experience; their employer might be very understanding and very helpful. But on the other hand, it could go the other way and there’s no way for them to really know that.”

Much of the time, employees disclose to their employers when they need some sort of accommodation to do their job. This might include such adjustments as making the workplace accessible, modifying a schedule, allowing leave time or providing reserved, close-by parking space.

“Initially, you only need to let them know that you’re having trouble because of a medical condition and you need an accommodation,” Batiste explains. “Often, the employer doesn’t ask for any more information, and that’s the end of it.” But if you request an accommodation, the employer is allowed to ask for proof that you have a disability, which usually means your diagnosis and your limitations.

No obligations

An employee who has visible symptoms but doesn’t require any kind of accommodation has no legal obligation to tell the employer. But if symptoms could lead an employer to misconstrue their significance—fatigue as laziness, or balance issues as substance abuse, for example—it might be better to disclose. Charles Goldman, a disabilities lawyer in Washington, D.C., warns employees with MS to proceed with caution. “I think we still live in a world where people are afraid of the unknown, and that comes into play when people have hidden disabilities such as MS.”

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Goldman learned that firsthand from Keer, the federal researcher, who became Goldman’s client after his employer refused him permission to work at home at times.

Although Keer ultimately won a settlement and has been working happily for 16 years at a more accommodating agency, he shudders at the memory of going up against his former employer.

Employees should know, says JAN’s Batiste, that “they are not 100 percent protected just because they happen to disclose. There may be times when someone discloses and an employer has a legitimate reason to terminate them, for example, if they cannot do their job anymore even with

accommodation.” The Society offers an online tool that can help a person decide if, when and how to disclose in the workplace. Visit nationalMSSociety.org/workplacedisclosure for more information.

Be prepared

If an employee were getting ready to disclose, says Goldman, “We would say to them, first let’s work with someone to practice, such as someone at your local MS chapter, so you don’t have to hire a lawyer. You can practice what you’re going to say to whom and how you’re going to do it.” (For help finding a local employment program that can help you practice, call an MS Navigator at 1-800-344-4867 or JAN at 1-800-526-7234.) He adds, “You need to get your doctor lined up; let him [or her] know that he may be asked for medical information. You can’t just sort of put your toe in the water when you make disclosure. You’ve got to be prepared.” ■

Andrea Sachs is a senior reporter at **Time** magazine. Diagnosed with MS in 2009, she disclosed to her employer in 2012.