

Disclosing your MS



The pros and cons of telling your family and friends.

by Aviva Patz

In 1993, British expat Rachel Padgett landed in the hospital with crippling joint pain stemming from a relapse of her multiple sclerosis, diagnosed four years earlier when she was 18. But for some reason the hospital tests didn't attribute her knee pain to MS. So Padgett's roommates concluded she had been faking her illness.



Rachel Padgett felt a renewed sense of freedom when she disclosed that she has MS. Photo by Eugenia Gordienko Photography

Instead of being supportive, they ostracized her, making her feel miserable. “So at age 22, I decided to stop telling people,” says Padgett, who’s now 46, happily married and living in Seattle. For 25 years, she hid her MS, blaming old injuries and weird viruses for symptoms that cropped up in public. “I thought no good would come from telling anyone.”

Padgett’s initial experience with disclosure illustrates a conundrum for people with MS. To tell or not to tell family and friends is a deeply personal decision with many social and emotional considerations. Neuropsychologist Paul Wicks, PhD, of [PatientsLikeMe.com](https://www.patientslikeme.com), a free website where people share their health information, has found that MS, ALS (amyotrophic lateral sclerosis) and epilepsy rank highest on conditions people tend to disclose. If you’re weighing the risks and benefits of sharing your MS with your social circle, here are some things to consider.

The downsides to disclosure

In our social media age, where even personal details are shared in tweets and posts, it can be tough to know when and where to reveal your MS. Certainly, there can be downsides, according to Peggy Crawford, PhD, a clinical psychologist who has worked with people with MS for decades. These are the most common:

Disbelief: Your news may be met with shock or even skepticism. “It’s not unusual for people who have no outward symptoms to hear, ‘Oh, but you look so good. Are you sure they made the right diagnosis?’” Dr. Crawford says. Padgett’s roommates didn’t believe she had MS and attributed her disclosure to just wanting attention.

Unsolicited advice: Your disclosure may seem like an open invitation for feedback. Dr. Crawford says that while the tips may be well-intentioned, it’s easy to perceive them as a criticism of your decisions—about where to go for care, for example, or which neurologist to see. Often, people think they’re doing you a favor by forwarding articles about new or complementary therapies.

Different attitudes: People may make assumptions about who you are and what you can and can’t do. Olivia Eveland, who was diagnosed with MS in 2015, has kept the news from others because, in the past, people who learned she had MS began looking at her as if she was fragile or needed special attention. “They stop inviting you to things because they think you can’t go, or they change plans when you’re involved because they don’t want you to feel left out,” she says. “They ask how you’re feeling 50 times a day and whether you need anything, forgetting that you’re still the same person you were before MS, just a little slower or a little weaker.” The upside to not disclosing, is that she’s treated like everyone else, says

Eveland, who blogs about her MS at [CloudyWithaChanceofPolkaDots.Wordpress.com](https://cloudywithachanceofpolkadots.wordpress.com). The downside: “When I’m having a bad vertigo or fatigue day, it’s difficult to pretend I’m OK.”

Relationship challenges: MS can present a challenge to some relationships. “There’s some risk that the other person will feel unable to cope, especially with the disease’s unpredictability and potential for disability,” Dr. Crawford says. Keep in mind, however, that secrecy is not a good foundation for a relationship, so if MS sends your date packing, he or she probably wouldn’t have made the best companion in the long term.

The upsides to disclosure

Your experience with disclosing MS will be as individual as you are. There’s simply no one-size-fits-all when it comes to how people will react. That said, these are some of the benefits that people may experience if they decide to open up.

Burden lifted: Keeping secrets is exhausting. “Disclosure can reduce this stress and lift some weight from your shoulders,” Dr. Crawford says. When Padgett finally decided to reveal her MS, she says “I felt a freedom I never felt before.” She stopped worrying that if she went to a party she wouldn’t be able to say she was tired and leave. She stopped fretting about not finding a parking spot—because she got a handicap sticker. She doesn’t worry about going down a flight of stairs because she’s free to cling to the banister or enlist friends’ support. “I didn’t know I was carrying around so much guilt about potentially inconveniencing everybody with my illness,” she says. “But I was also internalizing the shame of lying every single day to cover my condition.”

Shauna Longmire, of Helena, Montana, disclosed her MS following her diagnosis in 2006. “When you keep MS a secret, it’s like you’re ashamed. But you haven’t done anything wrong. When you don’t admit to something, you let it control you,” she says. “I have MS. It doesn’t have me.”

Emotional and social support: When friends know you have MS, it’s easier to ask for help—and get it. “Many people want to help, but don’t know what you need and, consequently, don’t offer, or offer too much, too little, or something that’s not even on your radar,” Dr. Crawford says. Padgett says disclosing her MS has helped her build an authentic support system. “Knowing you have a safe place to land at the end of the day—with a dear friend or a spouse who can be there for you unconditionally—is really important,” she says. “MS can be a lonely journey, and it can help to have people to hold your hand.”

Corrected assumptions: Odds are that people have observed some of your symptoms and made guesses about what’s up. Padgett’s coworkers thought she had cancer because she was always tired and often going to the hospital. In some cases, people assume symptoms like imbalance and gait issues are related to being drunk.

Strengthened relationships: When you share your MS diagnosis with someone, it shows your trust in them. Longmire says her disclosure helped her relate to other people who have

disabilities, which she believes is pretty much everyone. “Some are just more noticeable than others,” she says.

Better understanding: Telling immediate family, close friends and extended family about your diagnosis can prompt them to “learn more about the disease so they can try and gain some understanding and empathy,” Dr. Wicks says. Better understanding what you need could also help expand the care they might be able to provide.

Decisions about disclosure

Disclosure doesn’t have to be all or nothing. “Not everyone needs to know,” Dr. Crawford says. “Start with people you already trust, with whom you already have mutual respect and empathy, or people with whom you have the most contact or the most fun. If a relationship feels like it’s worth pursuing, it’s probably worth disclosing.”

Consider your motivation for disclosure when planning what you’ll say. Is it to share personal information with an important person in your life? To explain recent physical or emotional changes? To rally assistance and support? Once you know why you’re telling, you’ll be better able to shape your message, whether it’s how MS affects you day to day, the fact that it’s not contagious, or perhaps just that it can be unpredictable. Whatever your rationale for sharing, be prepared for a variety of reactions.

“Most everyone has been kind, supportive and has said things like, ‘Now I just think you’re even more amazing,’ and ‘What can I do? How can I help? What do you need?’ and ‘Thank you for telling me your story,’” Padgett says. After guarding her secret for years, she now happily tells strangers about her condition, saying things like, “‘I have bad balance because I have MS. I’ve had it for 25 years. What do you want to know?’ Being so open has been life-changing,” she adds. “It has turned my life around in an amazing way.”

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