

Disclosing your MS at work



Issues ranging from legal to emotional affect whether to tell your employer and colleagues about your disease.

by Lisa Mulcahy

People with multiple sclerosis face a variety of complicated issues when deciding whether to disclose their MS at work. In addition to practical and legal considerations, there also are emotional issues to weigh.

“Disclosing is a personal decision,” says Christina Forster, benefits and employee specialist and a certified rehab counselor with the National Multiple Sclerosis Society.

If you’re wrestling with this choice yourself, read on for answers to five essential questions to consider so you can do what works for you, professionally and personally.

1. What are the legal guidelines surrounding whether I should disclose my MS at work?

According to the U.S. Equal Employment Opportunity Commission, an employer can ask disability-related questions during the conditional job phase as long as it does so for all entering employees in the same job category.

Once an employee starts work, an employer can ask disability-related questions and require medical examinations only if they are job-related and consistent with business necessity.

An employer has the right to ask you if you can perform a job and how you would do it, which

could mean you might have to discuss physical limitations. If you're concerned about how to handle these kinds of questions, prepare ahead of time. "It's always good to get legal advice before a job interview," says Helen Russon, an inactive lawyer who has investigated many civil rights cases with the Oregon Bureau of Labor and Industries.



Helen Russon

Russon has both legal and personal experience, as she lives with MS. "When I was finally diagnosed, it was actually a relief because my neurologist had said that I possibly had a brain tumor," says Russon, who was diagnosed in 1998. "MS sounded pretty good by comparison. I also felt relief at finally knowing why I had started walking "wobbly" and falling down. Of course, that relief was accompanied by grief and depression, as well as a great fear about how much my disease would progress. I can now say, 25 years later, that the progression has been very gradual."

Russon didn't worry about disclosing her MS because she worked for an agency that enforced civil rights laws. "I also did not need much accommodation," she says.

The Americans with Disabilities Act requires employers to provide reasonable accommodations for workers, which could include wheelchair accommodation, schedule changes and time off for treatment. Still, you may choose not to access your right to these considerations. "Under the ADA, an employee does not have to disclose," Russon notes.

You may, however, be confronted with a more nuanced issue. "Let's say you're interviewing for a job and your prospective employer says, 'We have a softball team, do you play?' You might feel like you have to disclose then but you always have a choice," Russon says. "If playing softball is not essential to your job, you can say, 'I'm a wheelchair user. Could I keep score for the team?'"

Or you could use this situation to take the temperature of how being a part of this workforce would be. If it seems like employees are forced to take part in extracurricular activities, chances are you might not want to work there anyway.

2. What are the practical issues related to disclosing?

It's absolutely your right to discuss accommodations that might be required for you to do your job. "For instance, the office you are going to work for may have stairs for an entrance, but no wheelchair ramp," Russon says. "You can certainly ask for one to be built — that's a minimal accommodation."

COVID-19 changed the landscape in an unexpected way in that it's allowed for more privacy because of remote work. "A lot of people were working from home, of course, and didn't necessarily have to disclose in that situation. They may have been able to make the accommodations they needed at home without the employer being involved in that," Forster says. "Then as the pandemic eased, many employers said, 'You have to come back to the office.'" For those with MS, the question then becomes: Is this the time to disclose?

It depends largely on what your needs are. If you've found that working at home has made a great difference in your physical comfort, which helps your productivity, that's an important asset to both your health as well as your ability to do your best work. "Maybe you've been able to take the extra breaks you need at home, and going back to the office would be a hard adjustment now," Forster says. If this is the case, it may be right for you to choose disclosure.

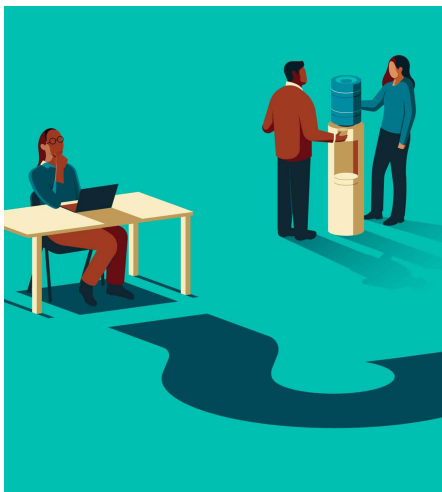


Illustration by Beth Goody

3. What emotional considerations should I weigh?

If you've been at your workplace for some time, you might wonder if it would just be easier to disclose your MS, considering you've gotten more comfortable with your supervisor and co-workers. First, think about whether you like the work you're doing and the atmosphere you're doing it in. "Keep in mind that once you disclose, you can't take it back," Forster says.

The key is to disclose in a risk-free way. "Ask yourself who you're going to disclose to," Forster says. "Human resources legally has to keep that information confidential. The only thing HR will tell your employer is that you need accommodations. Your supervisor is not going to know why unless you tell your supervisor as well."

Things can get murkier when it comes to disclosing to your colleagues at work. “In terms of your fellow employees, it’s important to decide carefully who to tell,” Forster says. “Will the person you disclose to tell other people? They have no obligation not to tell your supervisor or other co-workers. If you don’t want that, it’s important to look for red flags about that person. Do you see them being supportive to others? Do they like to gossip? If you’re not sure, that could be good reason to keep your information private.”

4. What can I learn from someone else’s experience?

Chuck Edward, head of global talent acquisition at Microsoft Corp. in Redmond, Washington, sees disclosure from two important perspectives. Edward, who was diagnosed with MS in 2012, found making the decision to disclose at work a freeing, positive experience. “It took me seven or eight years after my diagnosis to do it, and I should have done it sooner, because I felt such relief,” he says. “You can build up so much negative self-talk about the risks of disclosing but I found that people were so kind. I heard things like, ‘I wish I’d known so I could have helped you.’

“It was the most empowering thing. Now, if I’m having a bad day, if I’m having a symptom, I can say to the people I work with, ‘Here’s where I’m at, and here’s what I need.’”



Chuck Edward

As an employer, Edward understands that many people are nervous about disclosing to their supervisors. “You worry, of course, that your performance might be judged,” he says. “However, a good manager will want to have authentic, transparent dialogue with you. Your manager should ask you what you need to be at your best. Managers should want their employees to do well — it benefits the company.”

Edward says that disclosing can also help your colleagues. “You will be a role model for others,” he explains. “When you disclose, others will feel they can come out as well, and will thank you for speaking up first.” This can be vital motivation for speaking your truth.

5. Should I listen to my gut?

Definitely. Your personal comfort level is what's important and should always be your guide. "Walk through this at your own pace," Russon advises. If you've had positive experiences telling your family and friends about your MS, it may feel natural to want to share with other people. If you feel strongly about keeping life and work separate, though — or if your intuition is telling you that workplace trust might be an issue — don't feel obligated to disclose. The only legal reason you must disclose is if you need accommodations and don't want to put your job at risk. You come first. Honor your feelings and preferences, and you can't go wrong.

Lisa Mulcahy is a writer in Fitchburg, Massachusetts.

The National MS Society has a [Benefits and Employment Support team](#) who can help. Please call 1-800-344-4867 for more information.

Learn more about disclosure and accommodations at [The Job Accommodation Network \(JAN\)](#) or call 1-800-526-7234.