

Disclosure

THE BASIC FACTS

MULTIPLE SCLEROSIS



To tell or not to tell is a question faced by everyone with MS. The question is really many questions: Whom to tell? When to tell? How to tell? Do you tell someone you've just started to date? Do you tell your employer? Do you tell when you get your diagnosis or when your illness makes you miss a week or a month at work? How do you know what to tell? And is it ever better not to tell at all?

Before focusing on MS, it's good to reflect on why we reveal ourselves at all and why we don't. The need to be known, to be liked and loved for who we really are, is a universal need. It is also a need that is often not met. We treasure those moments when we can truly be

ourselves, say what we feel, not play a role, and be unguarded. This openness is frequently lacking even between husband and wife or parent and child—the relationships where the need to be known is the most intense.

“Don't let me be misunderstood”

Kevin J. is a quiet man who has known he has MS for six years. He hasn't told anyone:

“I went to a doctor because I had a serious fall. He decided to run some tests and a week later he told me that I have MS.

No one can tell when they look at me. I've learned how to cover losing my balance. I'm only thirty-two. I'm not going to tell anyone because they might think I can't do my job. I'm sure not going to tell any woman I want to date. What's she going to think—I'm a cripple?"

Rhona M. belongs to a sorority at a small college in Massachusetts. She, too, dreaded the consequences of disclosure:

"I didn't want to be seen as handicapped or weird. I didn't want to be different. But I had to stop going to parties and stuff and some of my sorority sisters got hurt and angry. Then they started ignoring me. I almost dropped out of school. Finally, three of them confronted me and said, 'Rhona, what the hell is going on?' It was such a relief to get it all out finally. They've been so cool. I should have told them long ago."

Many people with MS are like Kevin and Rhona—reluctant to admit their illness to friends for fear of being different, misunderstood, and thought of as a burden or an object of pity.

Such fears are well grounded. Our society prizes health and is often not tolerant of difference and imperfection. But in disguising the truth of their condition, people like Kevin and Rhona don't allow their friends to know them or to give them support. They cut themselves off from activities to hide their problems. Or, pressured by the need to conceal the truth, they may even hurt themselves by trying to do more than they should.

Disclosure and family

Andrea is a young editor at a publishing firm in New York City. Three years ago, she moved from a small town to take this job. Her parents were terribly anxious about her move:

"They did everything to discourage me short of begging me not to go. Whenever there was a crime in New York on the national news, I knew that I'd be getting a call from my mother. If she was overprotective about where I lived and worked, you can imagine how afraid I was that she wouldn't be able to handle the news that I had been diagnosed with MS.

"I finally told her about my diagnosis six weeks ago and I haven't had any peace since. My mother can barely talk to me without her voice choking."

Andrea's experience is one that we all fear. But most people learn how to handle family members' initial reactions and even use the opportunity to develop better relationships. Less often, it becomes clear that further disclosure is simply not possible with some people.

Telling one's children can be a challenge, especially for parents of young children. The thought of causing them insecurity and sadness is agonizing. Our experience in counseling families is that even four- and five-year-olds can be told in a way that doesn't terrify them. Sometimes they are actually relieved because the truth is not as terrible as what they have imagined.

Keep S'myelin, a colorful, award-winning newsletter for children published by the Society, is filled with stories, interviews, games, and activities that highlight a variety of topics about MS. Each issue has a pull-out section for parents. Contact a MS navigator for more information.

Mary remembers this conversation with her eleven-year-old son, Matthew:

“He had not talked about my illness since he had been told about the diagnosis. Then one day he came into my bedroom and said, ‘I just want to know one thing. Are you going to die?’ I assured him that I was not. Ever since, he asks questions about my MS with apparent ease. That question seemed to break a barrier within him and between the two of us.”

Disclosure and romance

Nowhere are we more vulnerable than when we are beginning to fall in love. It's not surprising that deciding “if and when” to tell the person to whom we are attracted causes so much anxiety. Having good friends who know about your MS can be essential. A support group of people who share similar concerns, or National MS Society peer counselors can provide relief, understanding, and direction.

When romance is developing, timing is critical. Telling every person you date would be a bore, but not telling when the relationship progresses toward intimacy is unfair. We suggest this rule: tell not too soon as to be unnecessary and not too late as to be a threat to the trust that is developing between you.

How to tell

The person you tell needs **information**, not a label that provokes frightening images. What form of MS do you have? What are the symptoms right now? How are you affected daily? What can and can't you do? You will need to tailor the information you give to fit the person you are telling, whether it is your child, your neighbor, or your oldest friend.

Talking about any sensitive personal subject requires skill—skill that comes with effort and practice. We recommend writing down what you want to get across and doing some role-playing with someone you trust.

Sometimes this sharing and role-playing can be done in self-help or support groups, or with a counselor who has MS experience. When you have practiced, your confidence will increase and you'll be more able to speak openly and without apology.

It helps to remember that it will take time for the person you tell to absorb what you have said. Think how long it has taken you to accept your illness. With your disclosure, you have begun a discussion with that person, and more communication will be required as time passes.

Disclosure at work

Telling family, friends, even someone you are beginning to fall in love with, involves telling people you know and trust and who (you hope) care for you. The emotional climate of the workplace is different. There you confront the question of disclosure in the context of concern about your present and future livelihood. Yet, even at work, the degree to which you feel comfortable will help guide your decision about if, how, and when you will tell. Preparation as described above will be needed—and more.

When to tell on the job

If your MS has not created any limitations for you, you may decide to say nothing. But if you feel confident that disclosure will not be used against you, and that telling your boss and coworkers would be better for you, you may decide to tell.

Full or partial disclosure?

You should weigh carefully what your disclosure will be. An employee (or job applicant) may **not** need to give a diagnosis. It is often enough to describe your problems as due to “a medical condition.”

If your job performance is threatened by your symptoms—for example, if you need time for a nap, or a workspace near the bathroom—then you need to seek an **accommodation**. These are

workplace adjustments that compensate for limitations. For most employees, they are guaranteed by the Americans with Disabilities Act (or ADA) a federal law, so long as the accommodations don’t present an “undue hardship” for the employer.

ADA protections apply only when the employee discloses that the problems are disability-related. With or without full disclosure, the employee has to provide some medical information, in order to obtain accommodations. It is up to you, the employee, to find out whom to meet with for this discussion and to request a meeting. It is up to you to suggest the possible solutions as well.

Employers with fewer than fifteen employees are not covered by ADA, but may be covered by state protections. Employees of the federal government are covered by the Rehabilitation Act of 1973. Employees of state or local governments are covered by ADA but may not sue for monetary damages or lawyer’s fees.

Before your meeting

We think it is essential to get technical advice before you tell an employer. There is much at stake. You need facts about ADA and advice about the kinds of accommodations that have worked well for other people with similar problems. We also think you’ll need some psyching up—just as you do for telling people in your personal life. The National MS Society wants to be your ally in this process.

During your meeting

Be specific, brief, and non-apologetic. Stay focused on your employer's need to know about your ability to do your job. But as with telling anyone else, rehearse what you are going to say. Role-play with someone from the business world. Then speak confidently and positively of your ability, experience, and desire to do your job. You may want to offer copies of Society literature about MS. See page 6 for a list.

What to tell in a job interview

Legally, you are not required to disclose your MS in a job interview and the interviewer may not ask disability-related questions. Those with visible disabilities may choose to discuss how their disabilities contribute to their success as employees, though, since the interviewers are aware of them. However, nearly everyone has something they would prefer not to tell, and it is important to avoid giving too much information out of a sense of guilt or secrecy.

The issue in an interview is the match between an individual's abilities, training, and experience and a given job's requirements. Even if you need an accommodation to meet some of those requirements, keep your focus on your experience and qualifications.

The pressure to quit working

Family, friends, and even your doctor may encourage you to quit working once you receive a diagnosis of MS. However, according to Dorra Blacker, Clinical Supervisor at Rusk Vocational Rehab, "There are so many benefits of working, particularly if you have MS. One is, it's important to remember that work defines who we are. To identify yourself as somebody in a particular field and to do work that you enjoy is very important emotionally.

It's also important because it gives you a social network of people that you see every day, because when you're isolated you think about how you're not feeling well or feel bad for yourself. And lastly are the financial reasons: an income and benefits."

It is generally best to step back and assess whether you can continue doing your job before making any drastic decisions. You may be able to continue working once your health has stabilized. Take time to explore whether changes to your current employment situation, or even possibly a different career tract, will allow you to manage your MS and your employment. There are resources and legal protections in place to assist you in making changes. You need to address any employment performance concerns you may be having, but it's possible that with the right accommodations you can continue working successfully for quite some time.

MS and health insurance

Once you have been hired at a new job, act quickly to take advantage of any group health-care insurance offered by your new employer. It is important that you do not lie on any health-care insurance application form or try to intentionally hide the fact that you have MS. You must respond honestly and fully to any question. However, you do not have to volunteer any information that is not requested. This information cannot be used by your employer.

Going on

It is possible that you will experience prejudice, ignorance, even rejection, because of MS. On the job, knowing your rights should help you to protect yourself. At home and elsewhere, knowing yourself should help you to maintain your self-esteem and your openness to warmth, goodness, and intimacy from other people.

Having at least one friend or family member who knows what you're going through can ease the burden. A good confidant can help a person decide how much to tell other people. The whole world doesn't need to know. Moreover, there's a time and a way to tell so the person with MS can control who is told what, and when.

Support literature from the Society

- What is Multiple Sclerosis?
- Information for Employers
- Should I Work? Information for Employees
- The Win-Win Approach to Reasonable Accommodations: Enhancing Productivity on Your Job
- ADA and People with MS

To download these materials, visit nationalMSSociety.org/all-brochures, or call 1-800-344-4867 to have copies mailed to you.

* The National Multiple Sclerosis Society is proud to be a source of information about multiple sclerosis. Our comments are based on professional advice, published experience and expert opinion, but do not represent individual therapeutic recommendation or prescription. For specific information and advice, consult your personal physician.

nationalMSSociety.org

For Information: 1-800-344-4867)

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