

# DISCLOSURE

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 over-protective 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 your chapter 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 "if to tell" and "when to tell" the person to whom we are attracted cause 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?

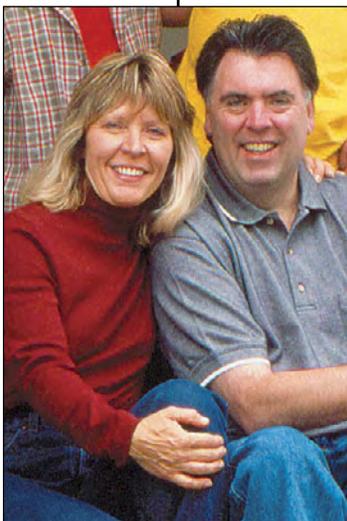
What can and can't you do?

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 co-workers would be better for you than remaining silent, then you should tell.

## Full or partial disclosure?

You should weigh carefully what your disclosure will be. An employee (or job applicant) does **not** have to give a

diagnosis. It is legitimate 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 disability-related problems on the job. With or without full disclosure, the employee has to discuss the problems, 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. 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 techni-

cal 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. Your nearest National MS Society office wants to be your ally in this process.

## During your meeting ...

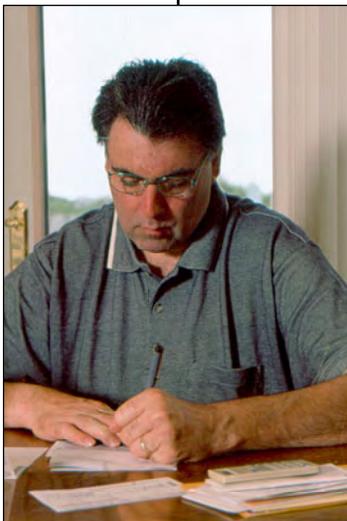
Be specific, brief, and non-apologetic. Stay focused on your employer's need to know about your ability to do your job. But as with telling anyone else, rehearse what you are going to say. Role-play with someone from the business world. Then speak confidently and positively of your ability, experience, and desire to do your job. You may want to offer copies of Society literature about MS. See page 7 for a list.

## What to tell in a job interview

Even if you are visibly disabled, we advise not disclosing MS in a job interview. Legally, you are not required to do so. Your interviewer may not ask you why you need your mobility device. Moreover, your

interviewer does not yet know what you can do and who you are. Trust has not been established. Many people with MS feel irrational guilt and this can prompt them to give too much information too soon. But nearly everyone interviewing for a job has something they would prefer not to tell: their blood pressure, their family problems, their credit card balance.

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

Dr. Beverly Noyes, director of Programs and Staff Development for the National MS Society, reports that quitting work is often the first thing recommended when the diagnosis is MS.

“Friends, family, even doctors will say, you have MS; you're not going to be able to continue working; the stress will be too much for you,” she said. “You'll be advised to get on Social Security Disability, get a monthly check and Medicare, and stop worrying.”

In Dr. Noyes' experience, that's simply not the case:

“Not only can people with MS continue to work, but in most cases it's in their best interests to do so. For the present as well as the future, people are better off psychologically and physically, if they stay on the job, and learn to manage their stress.

“Don't quit your job for fear of problems that might occur later,” she emphasized. “We advise people to wait out any immediate crisis, and then assess their situation—their job demands, limitations, options, and current performance barriers—before taking action.”

“It is, however, wise to remember that invisible MS may be more visible than you imagine,” Dr. Noyes added.

“Anxieties about MS can affect every aspect of life, including one's job performance.

“When employers suspect something's wrong, they often think it is drinking, drugs, or family troubles. In that case, open communication is preferred,” Dr. Noyes explained.

## **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.

## Supporting 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*
- ❖ *Knowledge is Power, Volume 5: Disclosing Your Diagnosis*

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Photos: The Lougee family. Photographs by John Noltner.

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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.