

MS on the Job



B Y K E N N E T H B A N D L E R

The numbness always is there, in my feet and hands. Often I wiggle my fingers and toes to make sure the blood is circulating so I know that when I get up, I will be able to walk, or when I take a pen or open a laptop, I will be ready to write or type.

I'm in the middle of a business meeting. Suddenly, the numbness spreads, up the legs, through the arms, quickly enveloping my face. No one in the room knows what is happening just below my skin. If I am fortunate to keep a poker face and not slur any words, my secret will continue to be safe. No one can tell that a surge in my MS symptoms is underway.

Uncertainty unlimited

How long this numbness will persist also is impossible to predict. Will it be an hour this time, or the rest of the day? Does it signal the beginning of a real exacerbation, continuing for several days, or maybe a week or longer? It is only ten 10:00 a.m., and I need to be creative and responsive.

The majority of people with MS do not exhibit distinct signs of the disease. "You look much better than you should," my neurologist declared when he confirmed in May 2003 that the long dormant disease had advanced.

How to manage fatigue—an MS symptom as unpredictable as exacerbations—and stress—a factor that can impact adversely on MS—are continual, emotionally draining challenges, especially when one is determined to sustain secrecy while striving to perform well at work and maintain an active family life.

Do I tell or not?

Only a few in my family knew about my MS. I was hesitant, fearing the reactions of colleagues and friends. Besides, I believed my condition would change for the better, so why go public?

That illusion evaporated when my doctor reminded me that currently there is no cure for MS, that the interferon I self-inject is used to contain its progression. How I feel today would likely continue indefinitely.

I continued to work hard as the public relations director for a national advocacy organization—not a stress-free job.

All would be fine as long as I found ways to keep pace.

When my boss asked why I suddenly was seeing doctors so regularly, I told him there was nothing to worry about, that whatever I have is not life threatening, which was true. But to avoid further questions, I decided to not tell anyone at work again when I was seeing a doctor, and I tried to schedule appointments during lunch time.

Yet, increasingly, I realized that I would need to tell my boss. Telling at least would ease the emotionally taxing debate in my head. But when would be the right time?

Long talks with family and with staff at my MS center in New York convinced me that telling would be personally salutary. I was reassured that since I had been in my position for more than five years, my record would speak for itself—and would outweigh any doubts about my ability to continue.

But who really knew? Could I trust the advice? In the end, it came down to one person's decision. Could I even trust my own judgment?

When do I tell?

There never was a right moment. Several times I thought I was ready, but pulled back, worried about negative reactions. As I passed the first anniversary of starting on interferon, I decided I could wait no longer. On a Friday evening, when the busy workweek had quieted down, I shared my situation with my boss.

My health is normally a private matter, I explained, but something had

changed in the past year that needed to be shared with him. Recalling our conversation seven months earlier about my frequent visits to doctors, when I stated that what I have is not life threatening, I reaffirmed that was true. What I have is MS, I've had it a long time, but since there has been a change in my condition and the disease is totally unpredictable, I wanted him to know.

The immediate reaction was shock—and concern. “I always wondered what your secret elixir is,” said my boss, who, like many, had seen only a healthy and energetic colleague. Since he knew little about MS, we continued the conversation. I explained MS, my experience dealing with it, and the uncertainty that lies ahead.

“Will you be compelled to resign?” he asked, and I replied, “Of course not.”

I left him with weekend reading, an article I had written about the loneliness of coping with MS. I wrote it several months earlier, initially as a form of therapy, but I had become eager to publish it—indeed, the few who knew about my MS were encouraging me to do so. A few weeks after our conversation, the article was published in the **International Herald Tribune**, which actually made it easier to tell others.

Almost as quickly as an exacerbation could hit, news of my MS permeated my place of employment and beyond. It yielded many calls and e-mails of empathy and admiration. But understandably, only a small percentage of my colleagues came forward to say something. It certainly is not easy to figure out what to

say to someone you know who is dealing with a disease.

And now?

Since going public, conversations at work have showed no indications that those attitudes of empathy have changed. Months later, work is the same. I work. I travel. I attend and run meetings.

Adjustments persist, given the uncertainty of the disease. Are there difficult days? Sure. What is essential is conveying honestly that the work can be done. When an opportunity came up for an overseas business trip, my boss questioned, out of concern, whether I should go. Without hesitation I said I'd tell him when I'm not able to travel.

Significantly, the burden I carried for so long, struggling whether to tell or not, is gone. If I need to take a break, I can comfortably say why. When something developed suddenly that required taking a day off to meet with doctors, there was understanding.

True, each person with MS must evaluate his or her own personal employment circumstances. But, as I learned, we need not necessarily fear telling others. Agonizing over whether to tell or not definitely creates more unneeded tension and stress—a thing we people with MS do not need. ■

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