

## “Every day it works is good!”

by Nicole Reese

I would love to give you the smallest of details about my life but as someone who is only 25 and feels as though they are 50, it is kind of a thing you don't do. One thing I have figured out about being 25 and having MS is that you don't talk about it. You get “the look.” It reminds me of that uncomfortable silence you can experience with someone you hardly know. The only difference is you can experience “the look” with someone you thought you were close with.

To sum myself up as a whole person, I think the best word I can use is “excited.” I like to think I am excited about everything. I have an internal switch and it is either on or off. I have no in-between. This excitement is probably what makes

it hard for me to have MS.

I wouldn't exactly say MS is an upbeat conversation. To my surprise, I feel at my peak when I'm talking about it though. I just want to know I am being heard and not just getting a smile and a nod.

“Ask me a question!” Do people not know that they can ask me? Just one second of acting interested in me will get you a lifetime friend. I don't need to

be taken care of. I need to be in your thoughts. I want people to know that MS is the thing that has made me stronger and made me realize that health is not something you get or deserve. It is something you are blessed with.

I have two small children, a boy and a girl. One of the biggest worries when I first had children was how I would afford all of the costs. All I could tell myself then was at least we're all healthy.



JACOB THOMAS

**Have you ever gotten “the look” when you mentioned your MS?**

**What do you do?**

Email [editor@nmss.org](mailto:editor@nmss.org) or mail us a letter at **Momentum**, National MS Society, 733 Third Avenue, New York, NY 10017.

Well, I guess we know how that turned out. It's not to say I am not healthy, because in the larger scheme of things I am. At first I thought I had a tumor and I wouldn't be there for my children. To my joy the doctor said, "MS." He even asked if I would be alright and all I could do was smile and say, "I'm not dying. That is what's important, right?"

MS, like I said before, isn't really something I can discuss with anyone. It does, however, make me feel special. I have been taught at an early age how to truly appreciate some of life's smallest joys, from being able

to see and walk to being able to run around outside on a beautiful day. In our 20s most of us take our bodies for granted and assume it will be like this forever. Since I look at it a little backwards, I think I have the upper hand. Every day it works is good! It's another day I can love and cherish so if days of darkness come I can remember the days of sunshine. And if, in fact, days of darkness never come, what will I have wasted? Absolutely nothing!

Nicole Reese lives with her husband and their two children in northwest Ohio.

## Disclosure! Do's and don'ts

by Marcella Durand

**H**ow many dates **precisely** should you have before you tell your date that you have MS? When is the exact right moment to tell the college admissions officer—or do you have to tell at all?

Alas, disclosure is not an exact science. There are no hard and fast rules. Disclosure can depend on whether you are experiencing cognitive or physical symptoms. It can depend on the time, the place, and most especially the person. Sometimes the time to tell just will feel "right."

Even though there are no rules, there are some general guidelines to consider.

### **DO** tell school personnel

"I think it's important to let immediate school personnel know," said Pat A. Bednarik, MS, CCC-SLP, MSCS, a speech-language pathologist at the University of Pittsburgh MS Center. "You can run into problems if you don't disclose." For example, she said, "Your gym teacher may have you running laps in 80-degree heat." If you have cognitive symptoms, your teacher should know why you're having trouble taking notes in class or remembering directions. And if you have a sudden

## Web stuff you may want to know

- Are you on **MySpace**? The National MS Society is. Visit [www.myspace.com/mssociety](http://www.myspace.com/mssociety) and become our "friend." You can leave comments for us and other friends, get Society updates, and connect with lots of people who care about the MS cause.
- We also do **YouTube**. Go to [www.youtube.com/nationalms\\_society](http://www.youtube.com/nationalms_society) to catch the latest MS videos and get the links to share them.
- Go to **FaceofMS.org** where people with MS—and family and friends—tell their stories. Share yours! You can submit text, video, and photos.
- **MSWorld.org** has chat rooms and message boards. One is especially for teens. There's also an online magazine of art, essays, poetry, and stories. Read Dean Kramer's monthly column for her quirky view on living with MS.
- **Msactivist.blogspot.com** carries updates on MS policies, hot issues, and how MS activists are influencing decisions in the nation's capital. The blog also posts news articles, editorials, and videos on MS issues and comments by activists. Add your remarks. Dialogue is welcome.



exacerbation, such as vision loss, school personnel need to know where this comes from. (If you're still in high school, talk this over with your parents.)

### **DO** keep your private life private

If you don't feel like telling someone, then don't. "You don't need to keep it a 'secret' because there's nothing to be ashamed of," Bednarik said. "But there's a big difference between being secretive and being private. The whole world doesn't have to know your business. You can be choosy. Trust your instincts and tell people you trust," she advised.

### **DON'T** post it on the Internet

You should be in control of when and how you tell. Friends, enemies, potential dates, and possible employers shouldn't be able to find it out by Googling your name. So be careful about what you post about yourself

online. Make sure you don't reveal too much in chat rooms, blogs, or listservs. If you want to chat with others who are facing the same issues as you, try [www.msworld.org](http://www.msworld.org), for reviewed chat rooms specifically for people like you.

### **DO** communicate with your parents

Sometimes parents are overly worried. Bednarik believes parents should be okay about you dating, going out with friends, and sharing secrets. If you feel your parents are being too protective, try suggesting that you all meet with a third party, such as a counselor or someone from your Society chapter. To find your chapter, visit [nationalmssociety.org](http://nationalmssociety.org) or call 1-800-344-4867.

### **DO** be responsible for your MS

You're not obliged to tell a potential employer or a college admissions officer that you

have MS. But if your symptoms could affect your schoolwork or job, then you will need to say that you have "a medical condition" and explain how accommodations (like a parking place or using a digital recorder) will help you manage.

Bednarik tells about one young woman who wanted open book tests for college but didn't want to tell her professors why. "I explained to her it doesn't quite work that way, but once school personnel know about your symptoms, they should be only too willing to provide accommodations. Most colleges and universities are aware of disability issues," she said.

As for your job, be honest with yourself about what you can and cannot do. You may need accommodations to meet the requirements of a job, but the responsibility to ask for what you need is yours.

### **DO** tell your date *when you're ready*

Wait until you feel comfortable. It's not the first thing you need to say. The worst scenario—if you tell and then the person breaks up with you—remember that there may be other reasons why. "Rejection always hurts," said Bednarik, "but chances are the person just didn't click." And heck, that person probably wasn't worth it anyway.

Marcella Durand is on the staff of **Momentum**.