

# Turn Staring Into Caring

The stigma of a neurologic disorder can be stressful—and can make symptoms worse. Patients and doctors teach us how to turn negative reactions into positive encounters.

BY STEPHANIE STEPHENS

**W**hen Stephanie Schroeder rolls and blinks her eyes, shrugs her shoulders, or opens her mouth and stretches her tongue, people sometimes stare, and she feels it.

“People may think my contacts are bothering me or that I have a neck ache,” says 51-year-old Schroeder, of Brooklyn, NY. “When I first moved to New York, kids on the subway would laugh and point. Riding the subway definitely gave me a pretty thick skin.”

That thick skin helps protect Schroeder from the unwelcome reactions of strangers to the visible symptoms of Tourette syndrome, with which she was diagnosed 24 years ago. She’s happy to “tell all” to those who ask about her tics and is often amused by the responses. “Once I told someone at work and he just chuckled uncomfortably, ‘That’s cool. I don’t know anybody else with Tourette’s.’”

Of course, the discomfort others feel toward her tics hasn’t always been so benign. In fact, she thinks she has probably failed in job interviews because of her condition. “I just knew they wouldn’t hire me, even though I have no proof of that. Maybe they thought, ‘Why is this crazy lady moving around so much?’” (For more information about workplace discrimination, see “Work Disclosure: When Is It Safe?” on page 38.)

Tourette’s is just one of many neurologic conditions with visible symptoms that can make strangers uncomfortable, afraid, or react inappropriately. And dealing with those negative reactions can be upsetting for the recipients—and can even exacerbate certain symptoms.

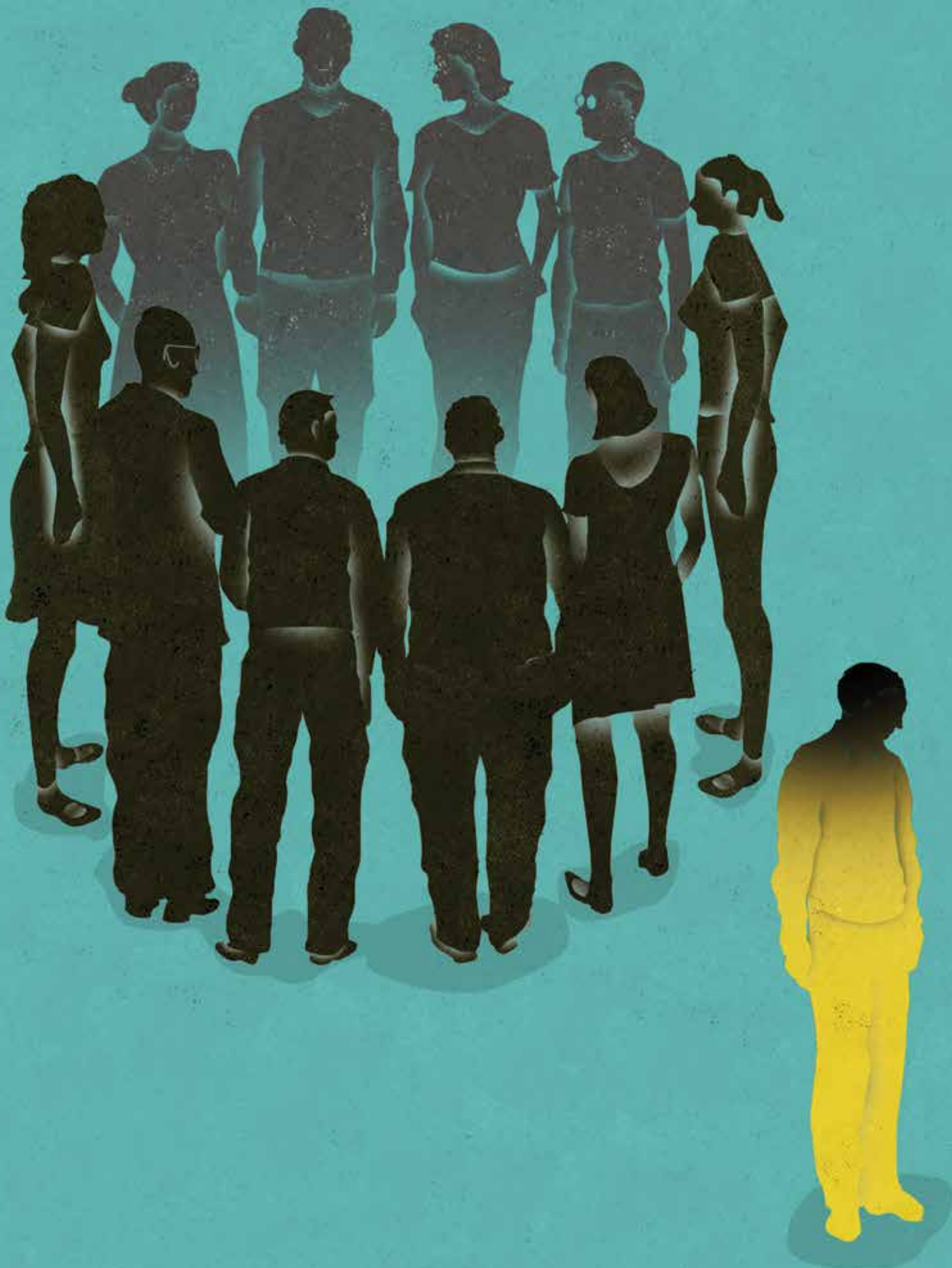
## STIGMA CAUSES STRESS

“If you come see me as an adult patient and you have frequent and noticeable motor and/or vocal tics, I know you’ve probably been the victim of a fair amount of stigma,” says James Frederick Leckman, MD, a professor of pediatrics and psychiatry and the Neison Harris Professor in the Child Study Center at Yale School of Medicine. Being repeatedly singled out and mimicked can even cause a form of post-traumatic stress disorder, or PTSD, he says. He’s known patients to report flashbacks and nightmares. Some avoid places where they experienced painful teasing, while others remain wary and watchful and have trouble concentrating.

Sometimes even well-meaning people can contribute to the stigma, says Dr. Leckman. A teacher who doesn’t understand or recognize the symptoms of Tourette’s, for instance, may ask a child to “stop” his or her “bad” behavior. If the teacher subsequently disciplines that child, the teacher may be unknowingly encouraging other kids in class to mistreat that student, causing more stress and potentially making the tics worse.

## USING FAME TO COUNTER SHAME

Parkinson’s disease is another neurologic disorder with outward symptoms that are frequently misinterpreted. A tremor can be misread as anxiety or nervousness, an unsteady gait can mistakenly convey intoxication, and slurred speech may falsely suggest intellectual disability, all of which can make social interaction difficult, says Rachel Dolhun, MD, a medi-



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cal communications specialist for the Michael J. Fox Foundation for Parkinson’s Research. In some cases, the disease can cause a loss of facial expression, making it difficult for Parkinson’s patients to convey their emotions, which others may interpret as unfriendly or standoffish, she adds.

The stigma of the disease may have been why Michael J. Fox, the *Back to the Future* actor and one of the more famous faces of the disease, waited seven years before disclosing his condition. Since going public and christening his foundation 14 years ago, Fox has earned international respect for his efforts to find a cure and eradicate stigma by being open and honest and by raising public awareness. As he told a *New York Times* op-ed columnist, “many Parkinson’s sufferers feel shame,” and he has worked to help take the shame out of the disease.

On his television comedy, *The Michael J. Fox Show*, which aired on NBC between September 2013 and January 2014, his character, Mike Henry, had Parkinson’s. Like the actor, Henry openly acknowledged his condition, as well as the unwanted

attention it brought, often with humor.

During an appearance last November on NBC’s *Today* show with co-host Willie Geist, whose father, *CBS Morning* correspondent Bill Geist, has the disease, Fox acknowledged the shame that accompanies having any illness, including Parkinson’s. But he said he’s proud to be the public face of the disease. “Since I made my diagnosis known, it’s been a tremendous opportunity and a tremendous privilege,” he said.

### SEEKING AND GIVING SUPPORT

“I recommend surrounding yourself with a network of people dealing with the same problem,” says Nancy Mulhearn of Asbury, NJ, who was diagnosed with Parkinson’s in 2006 at age 44. That’s what she did after years of denying the disease and hiding her symptoms. “I didn’t want to be pitied or stared at, and I didn’t want the world to change for

## Reach Out to Reduce Stigma

Limited communication and interaction between patients with neurologic disorders and the general public can increase the misunderstandings that lead to stigma, says Patrick Corrigan, PsyD, principal investigator at the National Consortium on Stigma and Empowerment and distinguished professor of psychology at the Illinois Institute of Technology.

Dr. Corrigan advocates for more “face time” between the two communities, advising people to “meet and get to know that person with the disorder. Sitting at church or working alongside someone can disarm prejudice and reframe misconceptions, while combining different points of view,” he says.

► **Get Connected.** Health care providers can help, too, says Deepa Rao, PhD, an associate professor in the departments of global health and psychiatry and behavioral sciences at the University of Washington. For example, they can connect patients with similar conditions who can support one another. That’s what Dr. Rao sought out for her daughter, who has a medical condition; she asked her daughter’s physician for the names of other families who were dealing with the same challenges.

The Health Insurance Portability and Accountability Act (HIPAA), which governs patients’ privacy rights, prevents

physicians from sharing names, Dr. Rao notes. But patients can sign a privacy release form to give their doctor permission to share their names. “This helps us feel like we’re not alone,” Dr. Rao says. “We all learn coping mechanisms by modeling each other’s behaviors.”

- **Be Kind to Yourself.** “Self-stigma is an egregious impact of stigma in general, a diminished sense of self-esteem leading to a ‘Why try?’ attitude in many people,” says Dr. Corrigan. He thinks that the focus on “patient-centered outcomes” in the Affordable Care Act presents an opportunity for the health care profession to empower patients with neurologic disorders. “We can help them better determine their health care options and personal goals and learn to make decisions for themselves. All of that reduces self-stigma.”
- **Dare to Share.** Talking openly about symptoms can take a bite out of stigma and its effects. That’s why Stephanie Schroeder does it. “My tics are part of who I am and don’t really bother me unless I’m unduly stressed,” she says. “What does bother me is the amount of negative energy other people spend trying to shame me and others with Tourette’s. It says more about them than about me or the disorder.”



## Ode to Tourette's

I have Tourette's,  
With no regrets.  
I'm not sick,  
I just tic.

Muscles tense;  
Makes no sense.  
It comes in spurts;  
It often hurts.

People stare.  
I really don't swear.  
Sounds outrageous?  
I'm not contagious.

I'm not mentally ill;  
I just can't sit still.  
I'm an enigma;  
But I can't take the stigma.

Please don't scorn.  
It's how I was born.

—Submitted by Neurology Now reader  
S.K. Beagle (aka Susan Kleinman)

me and my condition," she explains.

When she could no longer disguise her symptoms, Mulhearn attended a Fox Foundation conference to learn more—and that changed her life. She says she was motivated and inspired to get involved by those she met at the conference. Now, at age 53, she's helped raise more than \$100,000 for the foundation by organizing gala events. She's also a member of Team Fox, the grassroots community fundraising program, for which she mentors people who have been diagnosed with Parkinson's.

"I've experienced every emotion: depression, denial, and more," says Mulhearn. "I know what they are feeling and I can help."

As for strangers' curiosity, she addresses it head on. "If I'm fumbling for change, I say, 'I have Parkinson's disease,'" she explains. "I could go hide, but if other people see I'm OK with this, they're usually OK, too."

### COUNTERING THE CULTURE

Sometimes, people are frightened by neurologic illness simply because what they've heard about the condition and its symptoms is far worse than the reality. That's especially true with epilepsy, says Wendy Miller, PhD, RN, CCRN, an assistant professor at the Indiana University School of Nursing and a member of the

professional advisory board for the Epilepsy Foundation.

"Movies and media can totally misrepresent epilepsy," says Dr. Miller. "It's important to explain that, yes, you may have seizures, but that doesn't mean you'll soon be falling on the ground. You may just stare into space for a while."

In 2013, Jerry Krill, the head coach of the University of Minnesota football team, noticed that his epileptic seizures were becoming more frequent. When he had one on the field during a game, some people called for his resignation.

The public outcry had a positive outcome. It forced Krill to reassess his workaholic habits and it prompted moral support from the university and the football team. Today, Krill eats healthier and gets enough sleep, and hasn't had a seizure in more than a year. And he has scored high points for helping to eradicate stigma.

The Epilepsy Foundation urges people with epilepsy to explain how their seizures look to those with whom they are in daily contact. "Tell them this is not a mental condition and it's not contagious," Dr. Miller advises.

### FIGHTING SKEPTICISM

A lifelong migraineur (a person who experiences migraines), Anjan Chatterjee, MD, MPH, MBA, is intimately familiar with the

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debilitating pain, nausea, vomiting, and sensitivity to light caused by migraine headaches, making him particularly empathetic to his migraine patients. He recalls the lack of sensitivity he encountered in medical school and during his residency, when studying for tests and working unreasonably long hours exacerbated his migraines and caused him to retreat for long periods of time.


That didn't go unnoticed, he says. “Even the most caring neurologist might say, ‘It's just a headache, now, isn't it?’ You may not be criticized if you had Parkinson's, but others may think a headache is just an excuse. People with migraine face that stigma time and time again and may worry about losing their jobs.”

That skepticism doesn't happen only at work, Dr. Chatterjee adds. “Patients have separated and divorced because their partners just don't believe them.”

When consulting with headache patients, Dr. Chatterjee, a member of the American Academy of Neurology and a Fellow of the American Headache Society, invites the entire family to learn more about what their loved one is experiencing. “I think 99 percent of the time, when you clearly explain this condition, a person's attitude changes from one of cynicism to extreme support,” he says. “Patients are the best people, even more so than health care professionals, to advise other patients about how to deal with stigma.”

## BATTLING BIAS

Obvious symptoms often invite stares and whispers, but hidden symptoms such as some cognitive deficits associated with brain injury can be judged even more harshly, says Donna Langenbahn, PhD, a clinical associate professor at Rusk Rehabilitation at NYU Langone Medical Center. People with brain injuries—whether from car accidents, sports injuries, falls, or assaults—may be deemed “stupid or inept without an understanding of the underlying cause,” she says.

That bias may render them “less of a person” in the eyes of others, says Dr. Langenbahn, who urges people to let go of their biases and learn more about brain injury and how it may affect aspects of life such as work, school, play, leisure, and intimacy. “That allows the person to maintain an active role in society and, ultimately, a sense of dignity.” 

### KNOW THE BASICS:

- ▶ Parkinson's Disease: The Basics—[bit.ly/basics-PD](http://bit.ly/basics-PD)
- ▶ Epilepsy: The Basics—[bit.ly/Epilepsy-Basics](http://bit.ly/Epilepsy-Basics)
- ▶ Migraine: The Basics—[bit.ly/Migraine-Basics](http://bit.ly/Migraine-Basics)
- ▶ Traumatic Brain Injury: The Basics—[bit.ly/TBI-Basics](http://bit.ly/TBI-Basics)
- ▶ Tourette Syndrome: AAN resources for patients—[bit.ly/AAN-Tourette](http://bit.ly/AAN-Tourette)

## Work Disclosure: When is it Safe?

**M**any people with a neurologic disorder who want and need to work are dogged by the question: to tell or not to tell? Indeed, there's a lot at stake, says Patrick Corrigan, PsyD, principal investigator at the National Consortium on Stigma and Empowerment and distinguished professor of psychology at the Illinois Institute of Technology.

“People who can hide a neurological disorder must decide carefully whether they want to [reveal their condition],” he says. “‘Coming out’ or disclosing can be a huge decision, especially if the condition is misunderstood. For example, just because I see you having symptoms, doesn't mean I understand what the disorder is or does. And just because the medical community understands, doesn't mean the public does.”

The employment arena is rife with discrimination, says Dr. Corrigan, who has published studies on the topic. “People with neurological conditions are less likely to be hired and less likely to be provided reasonable accommodations guaranteed by the Americans with Disabilities Act of 1990.”

The law prohibits discrimination and ensures equal opportunity for persons with disabilities in employment, state and local government services, public accommodations, commercial facilities, and transportation, he says. “If you're in a wheelchair, your employer is legally bound to provide accommodations for you, like revamping your workplace for accessibility. The same is legally true for people with neurologic disorders—those accommodations might include a job coach or a social worker.”

“Remember that you can't be fired for having a disability,” says Wendy Miller, PhD, RN, an assistant professor at the Indiana University School of Nursing and a member of the professional advisory board for the Epilepsy Foundation. “Not everyone you work with needs to know, but disclosing to those in close proximity may be a good idea to the degree that you're comfortable. The worst thing could be that no one knows you have the condition, and they don't know what to do when you need them.”

### WEB EXTRAS:

- ▶ For how to combat stigma or to listen to a podcast about stigma and epilepsy, go to [bit.ly/NN-stigma](http://bit.ly/NN-stigma)