

Facing Down Stigma

Having an illness is nothing to be ashamed about.

People are often embarrassed to let others know they have an illness. It's as though they feel they will be judged because of it—that somehow, having a medical condition is their fault. This is not just paranoid thinking: There is a stigma attached to many diseases, and it can keep people from getting the help they need.

In this issue of *Neurology Now*, football player Samari Rolle decided to go public with his diagnosis of epilepsy. He reasoned that having a medical condition was nothing to be embarrassed about—and coming out with the truth was probably better than the rumors that were circulating about what might be wrong with him.

In some cultures, epileptic patients are still thought to be possessed by the devil, as a punishment for something evil they have done. Having an epileptic family member is a source of great shame in these cultures. Rather than getting medical care, epileptic patients are hidden, and their seizures get worse.

In our own society, the stigma has more to do with the frightening and unpredictable aspects of the seizures and the impairment that results afterwards. Epileptic patients who are not controlled on medications have many restrictions—for example, they aren't able to drive. Employers can be reluctant to hire them. All of these things can lead to isolation and a poor quality of life, which adds to the stigma. But as Rolle's story shows, epileptic patients with well-controlled seizures can live normal lives and even excel at professional sports. Biomedical research has discovered new treatments that make this possible.

On page 29, our story about fibromyalgia describes how this disorder has moved from a condition with another kind of stigma—that it is not a real neurological disorder—to a condition that is well defined and treatable thanks to progress in biomedical research. Many of our readers have been asking us to cover fibromyalgia. We initially decided to do a point-counterpoint story to illustrate the controversy surrounding this diagnosis. Somewhat to our surprise, there is no raging con-

troversy. We found many experts who discussed new research that has refined our ability to make the diagnosis. We found none who felt that fibromyalgia was not a physiologically-based neurological condition. Elegant brain-imaging studies described in the story show that the brains of people with fibromyalgia are over-stimulated by minimal physical stimulation compared with

those of us without this disorder. This leads to the sensation of pain rather than pressure. Current fibromyalgia research is also pointing the way to better treatments.

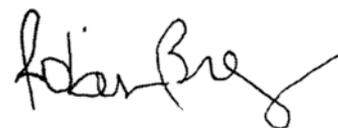
When I am working with a patient who has a problem that I cannot diagnose, or who is not responding as expected to a particular treatment, I always think to myself (and often share with the patient), “Despite the advances of modern medicine, there are still things that we aren't smart enough to figure out yet.” This was true for epilepsy a century ago and true for fibromyalgia until quite recently. It is often the things that we can't explain that lead to stigmatization for the person with the condition.

Having a disease is never really anyone's fault. Yet there are many illnesses for which stigma further increases the suffering of people with these conditions and their families: mental illness,

Alzheimer's disease, alcoholism, obesity, HIV/AIDs, and many others. Some of these conditions have many unanswered questions associated with them, and some need more public education to dispel myths about them.

If there are any myths you would like to dispel or ways that you or someone you know has positively dealt with stigma associated with a medical illness, please let us know. We would love to help set the record straight!

My very best,



Robin L. Brey, M.D.
Editor-in-Chief



Stigma about illness can keep people from getting the help they need.