

Schizophrenics in constant battle against stigma

Toughest hurdles to overcome often found in our closest personal relationships

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This summer, it has been difficult to read the newspaper or watch the news. In early summer it was wall-to-wall coverage of a man who killed his entire family in Calgary. Then there was the horror on the Greyhound bus. Normal people, when they see such things on the TV or in the newspaper, will feel badly for the friends and family of those involved. They will feel sad, and perhaps say a prayer.

When I see these kinds of things, my first thought is, "Please, don't let it be someone with schizophrenia." Before anything was actually known about who this bus attacker was, a psychiatrist in Winnipeg had already told the media that the man must have had paranoid schizophrenia. Even professionals automatically jump to this conclusion.

I almost feel as if I have been fighting the stigma of schizophrenia since I was old enough to remember. My mother was diagnosed with schizophrenia when I was just five years old. Where the earliest memories that many of my friends have of their mothers are warm and fuzzy, one of my oldest memories is seeing my mother in a straitjacket. We lived in a small college town, and everyone knew my mother was ill. I was subjected to scorn and alienation. There was the constant fear of being placed in foster care, or of my parents divorcing. My greatest fear was that my father would die from his heart condition because of the stress of being her caregiver, and leave me alone to take care of my mother.

The stigma I have lived my whole life with made me believe when I was first hospitalized with schizophrenia myself that my life was over. I spend my life now fighting stigma and trying to change perceptions. It isn't easy to be this public. I'm sure my life would be much simpler if people didn't know I had this illness. Everywhere I go, people know I have a serious mental illness. It would be so much easier to just blend in or hide.

The silence that comes after people discover that you have this illness is deafening. Friends disappear. Family members are embarrassed by me. It did not matter who I was or what I had done before becoming ill. It has not mattered what I have achieved since, even including receiving the Order of Canada; I still feel that dread of knowing that some people fear me, are disgusted by me or are embarrassed by me solely because of my illness.

We face so many different kinds of stigma. There are the obvious ones. When doing joint research in my primary academic field, it is very common for my research partners to suddenly break off communication when they find out about my illness. My family and I had always expected that I would be an associate professor by now. Even if I was capable of taking a full-time professorship, I doubt there would be any

institution willing to hire me. Employment is an obvious stigma. People are afraid to hire us. I have been asked to serve on the boards of organizations that would not hire me for even a 10-hour-a-week job. In this labour market, that's hard to believe.

That's not the only kind of stigma I have faced. We expect to face stigma from employers, landlords and the community as a whole. The hardest stigma comes from our closest relationships, especially with ourselves. I have friends who are stable enough on their medications to "pass" as normal. They try to hide it from their employers or new friends. It makes their lives so much more bearable.

Another way that we can stigmatize ourselves is literally by trying to delude ourselves that we aren't sick. One of the biggest hurdles when dealing with someone with this illness is getting them to take their medication properly. I have friends who refuse to believe that they are ill. They go on and off their medications, making themselves sicker. Many would rather live on the street, eating out of dumpsters, than admit to having this illness and seeking appropriate medication. Once you start the medicine it is as if you are forever branded with a scarlet "S."

I am often asked to give speeches for the Schizophrenia Society at local high schools. I am eager to do this because high-school-age kids are the ones who are going to become sick or are going to watch their friends become sick. I have yet to give a speech where someone in the class hasn't had a friend or family member afflicted. One was particularly sad because his older brother had just gone off his medication, and he was afraid of him.

Fear seems to be the largest component of the stigma we face. During almost every speech I give at a school, someone asks if schizophrenia makes you violent. We know that those with schizophrenia are far more likely to injure themselves than others, but when one of us does become violent, it is usually in a dramatic fashion.

When I first met my future wife, I was afraid to tell her that I was ill. So many potential relationships have ended when women have discovered I had schizophrenia. When I finally broke down and did so, she said: "That's interesting, so what?"

At first I thought she just didn't understand what schizophrenia meant. What I didn't know is that she had a long history of working with the mentally ill homeless. She has this natural ability to separate a person from their disease. When I have breakthrough symptoms and think that the TV is talking to me, she very calmly tells me that maybe it is time to turn the TV off.

Sadly, not everyone can do that. When someone is first diagnosed with schizophrenia, often their best support is their family. That doesn't mean you won't face stigma at the hands of your friends and family. My wife's family was so upset at her marrying me, they boycotted the wedding. She actually received wedding announcements back "return to sender."

In my own family, I faced a different kind of stigma. I faced embarrassment. There are members of my family who become angry when I appear in the paper or give public speeches. They waver between wanting me completely sedated so they can make all my decisions for me and hide me in the basement, to wanting me to work a full-time job and live in the suburbs like normal people. My wife's family may have ignored our wedding, but mine actively tried to prevent it. I'm still not sure why, outside of their belief that I am not capable of making decisions for myself because of my illness.

I think the strangest brush I've had with stigma was when I first started introducing my wife to my friends and family. Almost everyone asked her if she had schizophrenia. She got so used to parroting, "No, I don't have schizophrenia," that she sometimes blurted it out when someone would ask her something completely unrelated. The funniest thing is that those who didn't ask just assumed, and months later were shocked to find out that my wife didn't have a mental illness.

If I was deaf or blind, no one would ask my wife on first meeting if she was likewise afflicted. For those of us with schizophrenia, people just assume we are so damaged that a normal person would not want to marry us. I even believed that for a long time. So you can see, stigma takes many guises, and rears its head when we are least expecting it.

So how do we fight stigma? By education, education and more education. As medications and treatments improve, we have to find a way to allow ourselves to reintegrate. It's almost as if we are going to have to learn how to forgive ourselves for being ill.

My wife says that all she expects from me is to live as healthy and happy a life as I am capable of. Now, I just have to give myself permission to be content with that.

Austin Mardon received the Order of Canada and the CM Hincks Award for his health advocacy on behalf of schizophrenics.