

I certainly never expected to be here today. By this time in my life, my family had expected that I would be a professor teaching geography somewhere. By the time I was 30 years old, I had a Bachelors and 2 Masters degrees, and was working on a PhD. I had been to the Antarctic with NASA looking for meteorites, decorated with the US Navy's Antarctic Service Medal, and routinely presented research papers at scientific conferences. Then one day like a veil coming down, that all ended. I was diagnosed with Schizophrenia.

I of course knew what that word meant. My mother was diagnosed with Schizophrenia when I was just 5 years old. We were "That" family with the sick mom. As it turns out, perhaps that was actually a blessing for my life. I'm convinced I have never gone off my medication in part because I saw what that did to my mother. I'm sure it also helped that I was older when I had my first psychotic break. I had an extra decade's worth of education and life experience to draw upon to aid in my recovery.

Even so, on the old first generation medications, I just existed. My world wasn't much larger than my small basement apartment. When the atypical medications came on the market, my world expanded dramatically. I began to volunteer. It got me out of the house, and out of myself. Even if I couldn't hold a full time job, I could once again become a contributing member of society. The interaction aided my cognitive abilities to the point I was able to return somewhat to my academic pursuits. I couldn't do field work, but could do research and write short academic papers. Being able to present research papers at conferences again gave me some of my lost self esteem back.

In my recovery the biggest helps and hindrances have been relationships. I believe that I could have been sick for some time, but breaking up with my girl friend was the final stressor that caused my first psychotic break. My father helped me when I was first diagnosed understand the need to take the medication. I'd never had good social skills probably due to prodromal

symptoms. I suppose that the friends I made in the Schizophrenia community were the first real friends I'd had in my life. Unfortunately that can be good or bad. Support groups for those with mental illnesses are like AA groups. Some are healthy groups filled with people invested in their recovery, and some groups aren't as healthy. Getting into a circle of friends that aren't really interested in recovery can hamper your own.

My first wife had a serious mental illness. We could have been support for each other to work towards a healthier future. As they say though, it takes two to tango. She ended up completely lost and chose homelessness in Hong Kong over our relationship. The loss of that relationship harmed my recovery in a thousand ways. Therapy could have been a real aid to me then, but as I've found out repeatedly, therapists don't like dealing with us. They think as long as you are on your medication, there is nothing more they can do for you. It's as if once you come down with Schizophrenia, all other issues in your life no longer

matter or affect us. We are like everybody else. Aren't we also entitled to have family of origin issues, or trust issues?

So I have to fight for my needs. In Canada we have programs for tax credits and matching funds for retirement accounts based on disability, and I had to fight for both. Something that might mean an extra hundred dollars a month seems like pocket change to a doctor, and may not be worth his time to fill out the forms on your behalf. On the other hand, to someone on a small fixed income, that's a lot of money. I'm lucky to have both a personal physician and psychiatrist who will work with me on what I need. They may not understand why it is so important to me, but they are willing to help. That's not the case for everyone. I have friends who have been waiting over two years for the paperwork they need for certain government programs. That's inexcusable. Something my wife has to remind me is that doctors are just our employees. If they won't fulfill their duties to you, fire them, and find a doctor who will.

Sometimes the most important things in our recovery are things that others might discount. I might not look like it, but I am very careful about my diet, or at least my wife is for me. I believe that a diet that is low in fat and high in fiber is not only good to combat a few side affects of the medication, but also to hopefully stave off diabetes. I also believe in taking vitamins, especially fish oil and turmeric. I don't often speak about it to groups of consumers though, and I think that is a real shame. In Alberta we have a gentleman who is allowed to market a former pig vitamin as a cure, not a treatment, but a cure for bipolar and schizophrenia. I'm afraid if I discuss how certain vitamins and supplements can help with our recovery or stability, that I may be giving someone an excuse to go off their medications entirely.

It's the stigma we carry with us. We are vulnerable to snake oil salesmen offering cures. We would almost do anything to no longer have this illness and the labels that go along with it. 25% of all people diagnosed with Schizophrenia go into remission, and

can go off their medication. If someone has cancer, and they go into remission, they have parties. They tell all their friends and family the good news, and they go out and do cancer walks as a survivor. Yet, they still know that for the rest of their lives they will need to monitor their condition for relapse. Someone who is able to go off schizophrenia meds won't do the same. If they speak about it at all, they will tell people that they had been misdiagnosed. The fact that they should monitor themselves because they may be susceptible to relapse or to dementia, will probably go unsaid.

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. 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 labor 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. One goes by his first name among those he works with, and by his middle name with his fellow schizophrenics. That way he never has to worry about making a mistake and letting something slip.

Another way that we can stigmatize ourselves is literally by trying to delude ourselves that we aren't sick. I don't have to tell you present today that one of the biggest hurdles when dealing with someone with this illness, is getting them to take their medication. I have a friend who refuses to believe that he is ill. He's deeply religious, and says that the only reason he agrees to take his medication is as a personal

penance. 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.

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 more likely to injure themselves than others, but when one of us becomes violent, it is usually in a dramatic fashion.

I think the greatest weapon we have to fight this stigma is hope. When a parent is sitting across from a doctor being told for the first time that their child has schizophrenia, all the hopes they had for their child's future seem to be gone—college, career, marriage, and grandchildren. It's at that moment they need to understand that there is hope for the future. Perhaps the normal life they thought was going to happen won't. The idea of a 9 to 5 job, and a big house in the suburbs may have to be replaced with the goal of stability and a healthy, happy life instead.

When I was first diagnosed, the doctor told me that my life was basically over. That the meds would shorten my life substantially, and that I would get cirrhosis of the liver by the time I was this age. Not terribly helpful. For some reason that I can't explain, I never gave up hope. I never gave up the hope of finding someone to share my life with. I never gave up hope of having my own home. I never gave up hope of being able to

contribute to society. That hope kept me fighting. It kept me on my meds, it gave me a reason to get up in the morning.

Whenever I talk about stigma, and how it can damage us, I tell a story about something that happened in Edmonton two summers ago. A young man with a history of violence and drug use pounded on his brother's house late one night. The man had his younger brother arrested, and the next morning went out of town for the day. While he was gone, his younger brother was released from jail. He got in a taxi to his older brother's house. When arriving, he beat the taxi driver to unconsciousness, broke into his brother's house, and violently killed his sister in law. When the police responded to the taxi driver's attack, this troubled young man walked up to the police car and got into the back seat.

The family was very vocal about the need for changes to the justice system so that victims would be informed when their attackers are released from jail. They lobbied for extra treatment beds for drug addicts, and harsher treatment for drug dealers.

Buried deep in the reports was that this young man had schizophrenia and had used street drugs for years to self medicate. No one in his immediate family ever mentioned that this young man had a mental illness.

When he came to trial, his attorney never admitted any evidence in court about his illness. In fact, he put on no defense at all and called zero witnesses. He went off quietly to jail for the rest of his life. His older brother ran for public office on a platform of getting tough on criminals. It was easier on this family to believe that their brother/son/nephew was a violent drug addict than to publicly acknowledge that he was ill and needed treatment. It was easier on this young man to accept punishment for a crime he committed during a psychotic episode than to admit he had an illness.

If one of my sisters had committed a similar act, I think that I would be comforted by the idea that she wasn't responsible for her actions because of her illness. I would be campaigning for

more psychiatric beds, more research, wider availability of new medications, and even for the application of community treatment orders. This is the face of stigma when it is easier to admit that your sibling is a crazed killer, than to admit they have this illness.

The stigma we place on ourselves can be much worse than the stigma placed on us by society. We stigmatize ourselves when we hide. It isn't easy to be a public face of schizophrenia. Everywhere I go, people know I have a serious mental illness. It would be so much easier to just blend in or hide. Fear seems to be the largest component of the stigma we face. We stigmatize ourselves when we tell ourselves that we can no longer do something because of our illness. I have friends who don't believe that they can get married because they have schizophrenia. They don't believe they can hold a job or be a contributing member of society. Every barrier we break down is one less barrier that someone has to cross who comes behind us.

A few weeks ago, my wife and I were giving a presentation at the University of Alberta's Hospital's grand rounds to the entire psychiatric department. One of the older doctors who has been practicing for decades says that he no longer makes diagnoses of schizophrenia. He will treat them for the condition with the proper meds without actually putting a name to it. He says he does it to lessen the stigma his patients have to deal with. I do understand why he does it, but it makes me sad. I enjoy giving speeches to groups of doctors and nurses. For some of them, I might be the only person with schizophrenia that they will deal with who isn't actively psychotic. That is especially true when I give speeches to groups of police officers. In many jurisdictions, police officers are the first professional to come in contact with someone suffering from a psychotic break.

I'm very grateful to live in a country where my medical needs are taken care of. I'm grateful to live in a time where there are medications for my illness. That wasn't the case in my great-

grandmothers time. When she came down with schizophrenia after the birth of her last child, it was called dementia praecox. She was warehoused in a Victorian era sanitarium. I can't imagine living in one of those places for 2 days let alone 20 years. I pray for an eventual cure, but am still so grateful that I live in a time and place where treatments are available. My wife points out that if I had lived 1000 years ago, I'd either have been a shaman, or been burned at the stake. Still, even with the available treatments, too many of us fall through the cracks.

I live where it routinely gets down to -40 degrees in winter. One day last winter we were the coldest place in North America, and the second coldest place in the entire planet at -70F. I can not fathom how someone lives on the street in weather like that, but we have over 3000 people in Edmonton who are absolutely homeless. At least 1000 of them and probably closer to 2000 of them have a serious mental illness. If a couple of thousand women with breast cancer were wandering the streets, homeless

and without treatment, there would be such an outcry that the government would fall. Yet we allow these things to happen to those with mental illnesses.

We do have a well developed mental health movement in Canada, but it tends to be split between consumers on one side and family members, mostly parents, on the other. Unfortunately, they are often on opposite sides of issues. As someone with schizophrenia, but also the son of someone with schizophrenia, I straddle that divide. An example is Community Treatment Orders. Parents of adult children who have very little resources available to them to help their children, were very much in favor of CTOs. Consumers and personal liberty advocates were very much against them. I lobbied the legislature in favor of them. Not for myself, but for my wife. If I were to go off my medications or if they stopped working for me, and I entered a psychotic state again, I frankly wouldn't care. I'd be happy in my own little world. I know that my wife would be the one dealing with the

consequences of my psychosis, and wanted her to have all the tools she would need to deal with the situation. I wanted her to have the tools that my father never had in dealing with my mother.

Finally, I want to talk about the future. When dealing with the challenges that come daily living with a chronic illness, it can be hard to think about or plan for the future. With each new genre of medication that comes down the pipe, my world, my life has expanded. The old medicines allowed me to survive. The next wave allowed me function, and the latest medication change has allowed me to thrive. I believe that we are on the cusp of a time when treatments will allow us to re-engage with society as if we had no illness at all.

There was time when anyone given the diagnosis of AIDS knew it was a death sentence. They would cash in their life insurance, go on one last trip, prepare their affairs, and wait to die. Then the triple cocktail happened, and they started to survive, and actually had to start living again. For some, that was

extremely difficult. My wife told me the story of one of her clients who was sitting on some moving boxes in the middle of his recently sold home pondering what to do. He had prepared all his affairs, sold his home and most of his possessions, and prepared to enter the hospice. Then his doctor told him he wasn't dying after all and no longer qualified for hospice. He asked her what he should do. She didn't know what to say. Those who know my wife know she is rarely at a loss for words.

What are we going to tell people when there is a cure? For the newly diagnosed, it will be easier. They can take the treatment, and go right back to school or work or to their families without a major disruption. It's those who have lived with the illness for years or decades that will be the hardest to deal with. What kind of social services will we need for someone who has spent their entire adult life psychotic on the streets, or hiding in their aging parent's basement? I don't know, but I hope I live to

see that day. Until then, I am going to live as happy and as healthy a life as I am capable of.