

Any chronic illness is a curse. Schizophrenia is no different—its only ‘saving grace’, if you will, is that as far as I know it’s not a fatal disease. One of the reasons that it’s a curse is that the nature of the beast is a complete loss of control—of your emotions, of your intellect, your instincts, your common sense—basically of your sense of yourself, a really frightening aspect of this insidious disease. Living with schizophrenia is a not only a curse but oftentimes a nightmare. I’m not sure how others diagnosed and recovering from this disease experience living with it but I experience it as a need for constant vigilance; I examine my psyche meticulously each and every time I feel a ‘blue funk’ coming on, every time I experience a ‘flashback’ to bad behavior(s) I exhibited when I was truly ill, every time some vestige of the obsessive behavior(s) I exhibited re-emerge to cause me to doubt my control, my sanity. It’s the like the proverbial “Sword of Damocles’, living with this illness.

Another reason is that I have always known that I am not always aware when I am symptomatic, when I am ill. I am ALWAYS aware when I’m well, but the vigilance doesn’t stop just because of that.

Intelligence is not a defense against the onset of this illness as I’ve discovered after more than ten (10) hospitalizations. In fact, it is a sad corollary that my intelligence impeded my release from many of the hospitals I found myself in—I try not to think about that because my intelligence has always been an object of pride for me. It has served me well over many difficult periods in my life and is the source of many of my beliefs. Even the smartest people/persons in the world could not function in the realm of normalcy with that monkey on their backs. Additionally, the aspect of constantly examining oneself is tiring emotionally and draining emotionally. I have infrequently been given to self-doubt, but living with this disease causes me to. What if my medication fails me? I ask myself, will I know if it does?..Will the illness overpower its effectiveness?..When?...Where?...Will I be aware enough to notice if such an incident occurs?..Will anyone notice?—no one did when I first started to fall ill...Is that a delusion, I ask myself, my belief that I am worthy of respect and a ‘normal’ happy life? Was that sound I heard, I ask myself, really carried through sound waves or was it all in my head? Such questions, thoughts are not constantly occurring, but when they do occur, it causes in me a very real but simple depression that I find it difficult, sometimes, to fight my way out of.

On a day-to-day basis, the knowledge that in certain quiet moments, certain unguarded moments, even during periods of ‘normal’ reflection I will experience these flashbacks is disturbing. When I wrote “Schizophrenia—The Jumbled Journey” many years ago, it was with the intent of purging myself of some of the horrors, read incidents or memories, that were

enacted while I was extremely sick. It didn't work entirely because there are so many memories and they pop out of my psyche, at will it seems, at the most inconvenient moments.

I can be doing something quite 'normal', washing dishes, taking a shower, cleaning my apartment, sitting reading or just quietly—when suddenly, I'm remembering the ride in a cab with a stranger intent upon sex or the occasion of my defecating on a public street because I was so dirty that I couldn't get any shopkeeper or restaurateur to allow me past the front door, or changing clothes in a public bathroom because "they" wouldn't be able to find me if I did or that impulse driven trip to Philadelphia where a cab driver tricked me into leaving my clothing and some other things in his car while I stepped out to get a fast food burger—he left with my belongings. Memories of roaming the streets of New York in the wee hours of the morning are particularly disturbing because on more than one of those occasions it was my intention to find a public place to kill myself—I carried a knife, you see, and was working up the courage to slice through a vein. These memories are what I had hoped would fade, with time, but it seems that when these flashbacks occur I'm right back in the middle of the illness, or anticipating being there.

Schizophrenia happened to me when I was almost thirty years old, late in my life, and it has had a major impact on my life, my career, and my relationships. I never have been a finger pointer, several people who should have known better have had a hand in how I entered recovery from this awful disease. I am always surprised by how these 'caregivers' reacted to the fact of my recovery with disbelief. Several of them were extremely close to me and, as I've written before, were unready, unwilling or so mired in denial and/or stigma ideation that they wouldn't or couldn't believe that I was well. I cannot express how much that hurt me. And then the rumors began. The evil lies. The un-truths. Persons close to me told others that could've helped me regain my 'normal', happy life that I was, essentially, damaged beyond repair or redemption; that I'd had a 'nervous' breakdown or had a 'nervous' condition; that I could no longer work or look after myself. My nuclear family especially disappointed me--my extended family too. They essentially placed me "at arm's length". I felt myself isolated and mostly alone...without their company or succor. They encouraged me not at all. They stopped calling, inviting or visiting. I was left to the tender mercies of a series of doctors and other mental health professionals who tended to believe my caregivers (?) rather than me, despite what they saw and heard from me. I suspect that these doctors chose the path of least resistance where I was concerned and based their professional decisions on descriptions, stories and conversations with persons, family mostly, who don't and didn't really know me. What's that old adage: "You always hurt the one you love?" This is/has been very true where I and my familial relationships have been concerned.

My sister and my Mom feel/felt that the industry I chose to devote myself to was the cause of my illness. I am an IT/MIS professional and proud of it. I'm very good at what I do although, I admit, at times it can be a high stress profession—deadlines must be met, budgets; problems exist that require very specific skills/knowledge. None of my family, nuclear or extended, knows what I do, really, and never asked. As far as my mother was concerned, anything relating to computers was anathema. In addition, they, my nuclear family, made assumptions that have led to misunderstandings and hurt. This is not the fault of me or the illness. It is a manifestation of stigma, the stigma attached to anyone with the diagnosis of a mental illness.

Definition of STIGMA (www.merriam-webster.com)

1

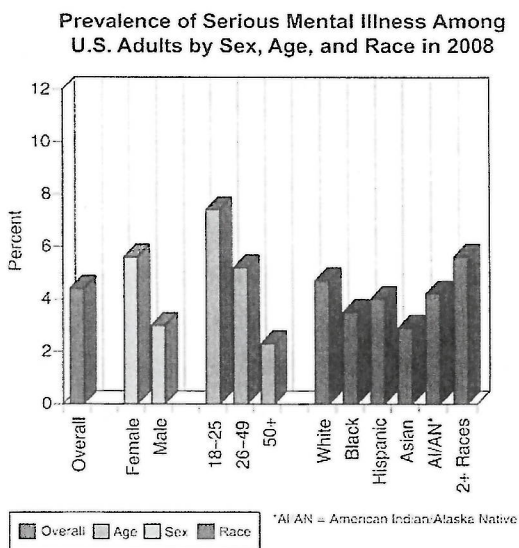
aarchaic: a scar left by a hot iron : **BRAND** *b*: a mark of shame or discredit : **STAIN** <bore the *stigma* of madness (mental illness) > *c*: an identifying mark or characteristic; *specifically*: a specific diagnostic sign of a disease

I've included the definition of stigma in this essay because those who practice it should be reminded of what it means and, conversely, the damage it does to those it is directed at. It has to do with how those who are actively mentally ill or in recovery from mental illnesses are perceived by people who do not understand their illnesses. Generally speaking, those who don't suffer believe the worst of those of us who do. We're treated with suspicion as liars who can't be trusted to control ourselves. We're asked to accept less than our natural rights to life, liberty and the pursuit of happiness. Often, our movements are curtailed by well meaning caregivers who believe that only by 'keeping a close eye' on their afflicted charges can they be kept safe. We're rarely employed in the mainstream (unless, like me, we hide our affliction(s)), and end up living on the periphery of life, accepting the dictates of someone who should know better who controls or tries to control where we go, who we see, what we spend, what we do. All of the above is a prescription for misery, the misery of those who experience full blown mental illness and have enough to deal with—and this includes those who are demented only, probably by old age or Alzheimer's disease. These last are relegated to nursing homes by well meaning officials and/or family members who can't be bothered with a citizen or a relative who isn't "whole". They can rarely accept that their own embarrassment, selfishness and shame at our afflictions is at the core of their actions, a posture known psychiatrically as "denial" and often receive praise and support for their care of poor Joe or Jane or Grandma Lily from those around them who are equally embarrassed by the presence of the mentally ill amongst them. The saddest aspect of this sort of marginalization of the mentally ill is the fact that many remain untreated (the incarcerated mentally ill, the homeless mentally ill) and suffer terribly. We are all aware of the plight of the homeless mentally ill; we see them on our city streets on a daily basis—some in crisis and out-of-control, some silently suffering. We are all aware of headline

news stories about persons with serious mental illness who commit horrendous acts of violence—a minority of the mentally ill. We are all aware of the all too frequent news stories about the mentally ill who come up against law enforcement instead of mental health professionals and end up dead. We should all be aware that these circumstances represent very, very serious problems that need addressing. Baldly stated, **some** of the problems are:

- Teaching law enforcement how to deal with the mentally ill in crisis so as to prevent another “Gompers” incident. Many years ago, here in NY, a very large woman named Gompers was killed by police by shotgun because she was perceived as a ‘threat to the safety’ of several grown men who were also police officers. They used deadly force to subdue her because **they were not trained sufficiently in how to engage the mentally ill in crisis**. This was not an isolated incident.
- The homeless mentally ill have to be housed and **treated**, somehow
- The incarcerated mentally ill must be adequately treated and prepared with some sort of support system that will “take over” their treatments, read medication schedules and therapy, if any, to prevent incidences of hostile or violent behaviors upon release.
- Some methodology should be put in place to identify persons **undiagnosed** but at risk of developing mental illnesses amongst the population—i.e. soldiers returning from theaters of war, children exhibiting bullying behaviors, adult children of depressed parents, men/women hiding eating disorders, etc.

The above is a wish list of mine that I generated during a period of reflection on the plight of other’s like me. It has never been lost on me that the old adage, “There but by the grace of God, go I” could as easily apply to me, and having said that, I will get down off my soapbox.



Stigma causes people to treat you differently. Even people who know you, when informed that you are mentally ill assume things about you that aren't true. It is a practice that must be stamped out. Mental illness is just that, an illness, a treatable illness and most of the public needs to be educated about that fact.

I've lost several jobs because of stigma—jobs I was succeeding at. I've gotten to the point where I now tell any employer who asks that I am "semi-retired" to avoid explaining, endlessly, that I have schizophrenia and that no, I won't go postal and yes, I can handle more than normal stress (es) and no, I am not taking Thorazine, and no, I won't be getting bouts of depression that'll make me miss work and that yes, I take a medication daily to control it and that no I don't act crazy and no, I don't require special handling, thank you very much. Many of the people I come in contact with don't know I have a mental illness on initial meeting as I am not symptomatic. Without knowing that I suffer, they treat me like any other person in their orbit, especially employers. I've been told I make good first (1st) impression. I count on that. It is a leg up that I require as I have difficulty enough finding work (like 8.5% of the public) without having to fight sigma as well.

As I mentioned, I've lost several jobs due to stigma. In one (1) case, I was working for a non-profit agency who had a need for a "technical assistant" for a less than tech savvy Director of Operations. This woman worked me very hard, challenged me and trusted me with several extremely important special projects. She also let me educate her about technical issues. We had what I thought was an excellent working relationship. After a time, while I was at work in one of my 'blue funks' brought on by activities involving my malicious sister, I told her that I suffered from schizophrenia, that it was under control and that there was a "personal problem" that I had to deal with. Within two (2) weeks of that conversation, I was told that she regretfully had to "end our business relationship", no explanation given when I asked why. THAT is a very good instance of the hurtful aspect of stigma—a good working relationship ending because of what my employer ASSUMED about me. It is a side issue that the salary I was earning was sorely needed. The termination was completely unexpected as I had forgotten the entire conversation but it was not lost on me that the only explanation was stigma.

So, now you have a pretty good idea of what it's like living with this disease—flashbacks, depressions and stigma. It tends to break relationships that should last a lifetime, provides for a stupefying amount of isolation and, if allowed to, can significantly affect one's self-esteem. In fact, if I were a weaker personality, this litany of negative experiences would have broken me. I am positive that in the case of others, sadly, this occurs.

What have I done about this state of affairs? Well, it's not all negativity. I have found a strong support system in my church home dealings. They know I suffer and still accept me. They provide the succor I am still not receiving from family and some old friends. They trust and

support me, offer assistance financially and emotionally and bring me ever closer to a God who I know loves me. I've begun therapy with the wonderful Naomi—a mental health professional—who listens, converses with and advises me and has me convinced that I am still a person of worth. She, hopefully, will notice and tell me if she observes the behavior(s) associated with this awful disease emerging and will perhaps become a friend.

I smile rarely, but I am surviving.