First Person Account: Living With the Delusions and Effects of Schizophrenia

by Susan K. Weiner

The article that follows is part of the Schizophrenia Bulletin's ongoing First Person Account series. We hope that mental health professionals—the Bulletin's primary audience—will take this opportunity to learn about the issues and difficulties confronted by consumers of mental health care. In addition, we hope that these accounts will give patients and families a better sense of not being alone in confronting the problems that can be anticipated by persons with serious emotional difficulties. We welcome other contributions from patients, ex-patients, or family members. Our major editorial requirement is that such contributions be clearly written and organized, and that a novel or unique aspect of schizophrenia be described, with special emphasis on points that will be important for professionals. Clinicians who see articulate patients with experiences they believe should be shared might encourage these patients to submit their articles to Schizophrenia Bulletin, First Person Accounts, EEI Communications, 66 Canal Center Plaza, Suite 200, Alexandria, VA 22314.—The Editors.

When I was thirty-one years old what began as a good year disintegrated into a nightmare. Two years earlier, I had left a career teaching basic education and English at an alternative high school in order to study 17th century English history at a university on the West Coast. As a graduate student and research assistant I had been and was very happy. However, in that year, I experienced the onset of delusions, which spiraled very quickly into a psychotic episode and mental illness. This is an account of my delusions and their impact on my life.

In the sixth month of my breakdown, I woke early from the sort of dreams that typify psychosis. This one was bright and terrifying. More so than the night I drank blood from a rifle, even worse than the night a man raped me hard and vomited all over me. In this dream, I ran a thumb over the smooth inner covering of a skull and felt an erotic charge. This was the skull of a man I had killed and I liked it. When I woke up I felt violated, but it also dawned on me that I knew what it meant: the evil dictator had finally gained full access to my unconscious. He was going to make me into a serial killer, a part of his private army of psychopathic killers who were being used to terrorize and subdue the Nation. I turned on the TV to make an emergency communication with my allies. But the TV sent out a signal, a sort of homing beacon, revealing my location in the Arkansas mountains. By this time, there were implants activated in my teeth and I believed that DNA was being extracted through my eyes. I could no longer feel the sensation of love. I only remembered that I had felt love before. Thus, 3 weeks later, when I tried to electrocute myself, I was teetering on the edge. As I reasoned, it was better to be dead than to be Ted Bundy.

Schizophrenia is a disease of information. And undergoing a psychotic break was like turning on a faucet to a torrent of details, which overwhelmed my life. In psychosis, nothing is what it seems. Everything exists to be understood beneath the surface. A bench remained a bench but who sat there became critical. Like irony, the casual exchange of words between a stranger or a friend meant something more than was being said. The movies, TV, and newspapers were alive with information for those who knew how to read. Without warning my world became suffused with meaning like light. In response, I felt as if I had been only half conscious before, as ignorant of reality as a small child. Although my sense of perception remained unaffected, everything I saw and heard took on a halo of meaning that had to be interpreted before I knew how to act. An advertising banner revealed a secret message only I could read. The layout of a store display conveyed a clue. A leaf fell and in its falling spoke: nothing was too small to act as a courier of meaning. For instance, one day I saw a movie poster for "The Net," starring Sandra Bullock. The poster showed Bullock's character in flight from a shadowy organization that had stolen her identity and now threatened her life. Because she had brown eyes and brown hair as I did, I realized she was meant to represent me. Such a warning was alarming. In order to confirm it I went to the film where I discovered two scripts. One had been hidden within the screenplay.
for my benefit. This private text informed me that I had to change my name and move from my university into the city where I would be anonymous. I went to movies a lot after that. They helped make sense of what was happening to me by providing clues to clarify and organize my activity. In response to those data I changed my name at the DMV, broke contact with my family, friends, and school, colored my hair to hide my identity, and gave away all my belongings to begin a new life.

What I remember most is how disoriented and frightened I felt. With little warning, my world had simply shifted under my feet. Over a period of several months, I began to believe that messages were being left for me in graffiti across campus. I also began to believe that my phone was being tapped. My friends insisted I was mistaken. But no one knew enough to realize anything was wrong. And then one day everything changed. One afternoon I realized the people on the radio were talking to me, much the way one has an intuition about a geometry proof, a sudden dawning of clarity or understanding. This clarity was more compelling than reality. It took me several weeks to put the pieces together. What I had known all my life was wrong. My friends were not real friends: at best they were neutral, at worst they were spies for the CIA.

Graduate school was a luxury I was no longer allowed. There was a secret history of the world to which I now became attuned. It involved the NSA, the CIA, and the stealth bomber, which flew just out of sight in order to register details regarding my movements. An evil dictator was gathering power to himself, and he meant to perpetrate a holocaust on the Nation. Only the American resistance, of which I was now a part, stood in his way. As time passed I became proficient at reading code. Most of my days were spent reading and responding to the newspaper so that the resistance could gather its military and economic resources to retake territory that had been lost. I learned to communicate by deciphering bits of conversation, reading newspaper articles, and listening to songs on the radio. Everyone could read my mind so, unless I was engaged in conversation, I spoke mostly in my head. I could not read anyone else’s mind so I remained dependent on the media for information.

Within 6 months I became adept at coordinating different avenues of information. However, I was living a nightmare. When I shut my eyes I saw neon-colored cartoon characters that zoomed in and out of my field of vision. They were so bright it hurt. At night I would keep my eyes open until I fell asleep from exhaustion. I also lived in terror of the evil dictator and his minions. I never knew where they might be or how to evade them. I begged my superiors to have me killed. When it became clear that this was not going to happen, I took matters into my own hands. Within the course of a week, I tried to commit suicide four times. As each attempt failed, I tried another. One day this landed me in the hospital. Not having my best interests at heart, I thought the doctors were holding me for the arrival of the evil dictator. For this reason, I convinced the nurses to untie my restraints. When no one was looking, I pulled out an IV and ran from the hospital through an exit I found far away from staff and patients. I was sure I had narrowly escaped torture.

My last attempt at suicide involved the police who surrounded me as I considered jumping from the roof of a building. This time I was admitted to the psychological institute at my university. Although I was hospitalized for 18 days, the doctors did not know I was psychotic. Because I remained vague in response to their questions, the hospital psychiatric staff thought I might be depressed. At this point I did not believe my mother was my real mother and I again anticipated being the subject of medical experiments. I viewed the doctors and my family as spiders waiting to pounce. Subsequently, I did my best to protect myself, and the ideals of the resistance to which I adhered. Although I was given psychological tests and repeatedly questioned, I sought to minimize the information I provided, even trying to stifle my thoughts to avoid being discovered as the spy I thought myself to be. I was treated with haloperidol, but this proved to be ineffective. I continued to believe in my delusions.

When I returned to live with my parents, my antipsychotic was changed to risperidone. Within 3 days I woke up and it was as if a light had dawned across my life. For a few precious minutes I was myself again, and I realized something was horribly wrong with my world view. It was a momentary insight, but one that allowed me to bring my fears into the open. I took what I thought was a terrible chance and spoke honestly with my doctor. After a few weeks on risperidone, I was able to see clearly what he told me: the world was not in peril from an imminent apocalypse. I have never been so relieved in my life. However, this was not before I had tricked my doctor into giving me a prescription for approximately 40 tablets of diazepam, which I used with alcohol and other medications in another failed attempt at suicide.

It has been 7 years now since I became ill. In that time I have had three relapses. I have also had to learn to live with the side effects of the antipsychotic drugs and the regime of medications with which they are prescribed. I am very sensitive to the medication and these days I live my life as a semi-invalid. On a bad day, my body feels as if I were undergoing a round of chemotherapy, and my head feels as if someone has hit me with a bowling ball. On a good day, I have a little energy and can clean up around the house and garden. For a long time I searched for a lesson from my experience. What proved hardest was to watch as my dreams died one by one. What I
learned was to build a new life and new dreams based on what I find myself capable of doing today. I have found peace in Christ and support in the love of my family and church. God and my family are my strength and comfort. I have learned to work closely with my doctor to monitor and guard my health. I believe in the maxim from Winston Churchill, "Never, never, never give up." Many, many times I have felt broken. Then I rest, and in a little while I am ready to try again.