First Person Account: The Evolution of a Person With Schizophrenia

by Jeffrey A. DeMann

The article that follows is part of the Schizophrenia Bulletin's ongoing First Person Accounts 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 First Person Accounts, Division of Clinical and Treatment Research, NIMH, 5600 Fishers Lane, Rm. 18C-06, Rockville, MD 20857.—The Editors.

I have just returned from the local library. I try and visit the library once every 2 weeks as part of my ongoing therapy. Tonight I read an article about Lionel Aldridge (a famous football player) in the Reader's Digest. He is diagnosed as having paranoid schizophrenia. I too have paranoid schizophrenia, and feel a need to share experiences of this illness. I will present some of the positive and negative aspects of life, and that despite the illness, I have affirmed to myself on a daily basis that I am blessed in many ways. I trust I will convey some hope and understanding to friends, family, the general public, and to the 2.3 million Americans diagnosed with schizophrenia.

I feel I must give some background information leading up to my schizophrenic condition because of its possible relevance. At the age of 16, I was involved in a serious automobile accident in which I was thrown from the car. Some say the car rolled over 10 times! I consider it a miracle (miracle #1) to have survived the intensive care unit experience. To complicate matters, in a followup visit, after release from the hospital, it was discovered that I had a cervical fracture of the spine. A prominent neurosurgeon readmitted me to the hospital, and he said that it was truly a miracle that I was not paralyzed (miracle #2). The neurosurgeon said that he would like to attempt a very difficult surgical procedure. I recall that there was a 60-percent chance I could become paralyzed from the neck down. I opted for surgery, which went well, and I survived with no paralysis (miracle #3). As best I can recall, there were no signs of schizophrenia. To this day, no one knows if the trauma and pain I endured in that accident could be related to the schizophrenia.

In 1980, I graduated from high school. I applied and was accepted at a 4-year public university. To say that my freshman year was...
arduous is an understatement. I didn't finish my first year, my first semester marks were relatively low, and I was placed on academic probation. Although present, the first signs of schizophrenia (loss of motivation, withdrawal from others, and confused thought processes) went undiagnosed. Because of this, I failed or withdrew from all college classes.

The years following 1981 were very difficult for all involved. I lived at home with my parents except for 3 months in 1982, when I moved to a nearby city and was considering attending the university there. Unable to support myself with a part-time job, I returned home.

By 1985, I had been working odd jobs for some time. Relationships with family members were slowly deteriorating, especially with my parents. My father grew more intolerant of my behavior and inability to hold a full-time job. I started to withdraw socially. For example, I would go to the unfinished basement, set up an old 12-inch black and white TV, and watch game shows or movies. While watching TV, I thought I had mental telepathy. I started destroying objects, and erupted into heated arguments with almost anyone who crossed my path. I felt there was no way out, no sense of escape both mentally and physically. My father made a comment that I could stay at the "Y" downtown because he didn't want me living there anymore. On a couple of occasions the police were called when arguments started, but they would do nothing once they arrived. This type of incident continued, but I would always destroy just my own belongings. I tried to direct my anger at objects rather than people. I didn't understand the inner workings of my mind, although I was aware of my actions and the consequences. I had destroyed a part of myself.

Thinking that my writing would help keep things in perspective, I started to keep a journal. I made attempts to be positive despite what was happening. Here is an excerpt from that journal:

If only one could know and understand the thoughts sailing through my mind as I sit at my desk and stare at that white wall in my room, straight ahead—A bulletin board that carries many adages, mostly optimistic thoughts. I don't like to think negatively. However, I do recognize that there is a rhyme and reason to the negative, even though sometimes I won't understand it. Everything seems to be changing at such a significant pace. That's what makes things difficult. Yet, I realize I can and will cope with change. It's just the dynamics of it all. Sometimes, I wish we could remain static in time just to savor what's going on around us. But life would become dull and redundant if this were so...."  
The journal writing was an effective outlet for a while, but then the symptoms worsened. Finally it happened! In late 1988, in my maladaptive behavior, I destroyed my desk, hurled a new television set down a flight of stairs, and cut myself and wrote messages in my own blood on the bathroom mirror. The police were summoned. This time officers were present. I could actually hear the slamming of my mother's body on the table while being administered the deadly shock. I truly believed my mother was now dead in my place. I also recall curling up on an old wooden bench and repeatedly chanting the words "Die quickly now." Unaware of how many hours had passed, I remember a hospital staff member saying that he was going to give me a shot of Prolinix. The details of this particular moment are fuzzy since I was probably actively psychotic. I recall going before a panel that had asked me to sign some legal papers. Pausing momentarily, I then told the panel I didn't trust any of them. A female social worker said, "Do you trust me?" "Maybe," I said. I reluctantly signed what turned out...
to be my transfer papers to a general hospital with a psychiatric floor. I would spend the next 6 weeks as an inpatient at this hospital, which was much closer to home.

I felt heavily sedated yet still able to conduct my affairs. No handcuffs were involved this time, just a quiet hour-long ride from one hospital to the other. I remember feeling so free when being escorted off the grounds of the State Hospital! I was even so bold as to ask if we could stop somewhere along the road and I could just breathe the air. The driver complied.

Upon my arrival and after going through admitting, a very likeable psychiatrist (one I could understand) talked to me for the first time about schizophrenia. He also gave me a medication information sheet and told me I would be put on an oral medication called Haldol. As an inpatient, I would take very high doses of oral Haldol, which made me very tired.

The hospital would allow visitors, although only at designated times. During the day I spent my time resting, playing cards, and engaging in an activity I abhorred. That activity was occupational therapy and is mandatory for all patients capable of participating. Group therapy would meet for 1 hour on alternate afternoons. Participation in this activity is also required as part of overall treatment. Different levels of personal rights were also granted. Finally, I made level three, the highest level attainable for an inpatient. At this level I was allowed 30 minutes of unaccompanied time off the locked psychiatric floor. I would sometimes wander down to the first floor coffee shop where I would buy a newspaper with the spare change I had.

Medications were continued and much improvement was shown. As it turned out, the first medication tried (Haldol) seemed to be working well. This is not always the case. Many times when it comes to the antipsychotic medications, it is often a trial-and-error approach. Side effects also must be considered.

One of the more serious side effects of antipsychotic drugs is tardive dyskinesia (TD). TD refers to a group of involuntary movements, usually occurring in the facial muscles. However, it can show up in any muscle group in the body. TD manifests itself in approximately 20 to 25 percent of chronic cases. There is no known cure for TD and it is irreversible once it sets in.

After 5 weeks as an inpatient, it was time for the next step in treatment. This step was an overnight stay at a local for-profit adult foster care facility in which I was eventually placed after release from the hospital. This situation proved to be very frustrating and untherapeutic. There is a great need for States to regulate these private care homes that prey upon the mentally ill. This is to ensure that the basic psychological and physiological needs of the individuals being cared for are met. I moved out of the adult foster care setting and returned home to live with my parents. This was, however, only a temporary situation.

With the help of my family, I leased my first apartment. By this time I was receiving a government Supplemental Security Income disability check every month and by living with my parents for a few months, I managed to save just enough money for the security deposit and first month's rent. I had to place an ad for a roommate if I was to continue to live independently. I was so proud of myself! After interviewing and screening six persons who responded to the ad, someone compatible was located. As it turns out, we get along well and he is a trustworthy individual. For example, my roommate has worked for the same employer 12 years and has perfect attendance awards. I consider myself lucky having found someone compatible and responsible. After developing a trust in him, I revealed that I was diagnosed with schizophrenia. He was open-minded and treats me as a "normal" individual.

It has now been approximately 4 years since my initial hospitalization. I have had no relapses except for occasional hallucinations (occurring before sleep) and vivid, sometimes frightening dreams. The illness appears to be in partial remission. I have chosen to stay on my medication despite strong fears of TD, although I recently reduced the dosage against medical advice. The wellness I experience presently is due to a number of factors. One of the primary reasons is the social networking I have forced myself to undergo even though it has been very difficult at times. Some of the social networking and personal therapy included joining a support group, walking in the park, going to the nearby university library, and swimming occasionally at the public school pool. All of these activities are financially within reach.
Aftercare is particularly important. Currently, I am under the care of a psychiatrist once a month for medication administration and consultation if needed. There also is a psychologist who sees me for individual psychotherapy on a biweekly basis. All of this takes place at a community mental health clinic.

In conclusion, I must state my personal beliefs regarding schizophrenia. Simply stated, I believe schizophrenia is a biochemical imbalance dealing with disruptions of neurotransmitter chemicals in the brain. Schizophrenia is a biological illness. One of the challenges we face today is convincing those in the insurance industry to treat this as a biological illness and to provide coverage for individuals and families. Schizophrenia is a devastating illness to live with, yet there is hope through family, friends, the Alliance for the Mentally Ill, community-based treatment, and especially ongoing research efforts. I will leave you (the reader) with an adage in which I believe: "The only thing truly worth envying is peace of mind."

The Author
Jeffrey A. DeMann is a freelance writer born and raised in Grand Rapids, Michigan. In addition to writing, Jeff is also interested in photography, the theater, and has an appreciation for jazz and some of the oldies. He works as a part-time service clerk at a major grocery chain one afternoon a week and as a volunteer at one of the city’s general hospitals. Jeff also is working on becoming involved with political fundraising, awareness issues concerning mental health, and completing an associate degree at Grand Rapids Community College.