First Person Account:
"Freedom" Means Knowing You Have a Choice

by Zan Bockes

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, Center for Studies of Schizophrenia, NIMH, 5600 Fishers Lane, Rm. 10C-16, Rockville, MD 20857.—The Editors.

Abstract

The following essay is my contribution to the First Person Accounts section of the Schizophrenia Bulletin. After a description of the development of my schizophrenic illness, I briefly address the issues of treatment noncompliance, institutionalization, and how they have affected my life. The main focus of my article is on personal control over the illness and on recognizing when medication is necessary. I give a personal example of how I have controlled some minor symptoms without medication, with the understanding that when symptoms become too disruptive, medication is helpful and certainly indicated.

A person with a disease is automatically limited in the choices he can make for himself—schizophrenia, as a mental illness, is no different in this respect. Unfortunately, the disease of schizophrenia often affects one's ability to make the proper decisions in addition to limiting the choices. For this and other reasons, the diagnosis of schizophrenia has long been one with frightening implications for me.

In considering the development of my schizophrenic illness, I find it very difficult to tell when it started. I'd always been very quiet, somewhat of a "loner," usually energetic, and a good student with a particular interest in literature and creative writing, but the illness began disrupting my schoolwork and job performance when I was 19 years old.

During my third semester at the University of Iowa, I became very depressed, dropped out of school, and moved back to my parents' home. When they recommended that I see a therapist early in 1978, I made my first visit to a psychologist. He looked at my MMPI profile and said, "Well, you're schizophrenic, which means you've had trouble with your mother." He told me that any other doctor would want me hospitalized, but that he didn't believe in hospitals and would not see patients who were taking psychotropic medication. My parents and I strongly agreed with him at that time, and I continued to see him for almost 2 years, with little improvement. All in all, I lived somewhat of a roller-coaster existence, paying for my own

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therapy and apartment by working at a variety of jobs.

In 1979, I moved back to Iowa City, completing the fall semester before I was hospitalized for a suicide attempt and committed for 3 months. Since the major problem seemed to be depression, I was given antidepressant medication and ECT, neither of which improved my condition enough to prevent my transfer to the State hospital. I returned to school after my discharge.

My symptoms gradually worsened over the next 6 months. Although the depression lifted, I increasingly heard voices (which I'd always called "loud thoughts" or "impulses with words") commanding me to take destructive action. I concluded that other people were putting these "loud thoughts" in my head and controlling my behavior in an effort to ruin my life. I smelled blood and decaying matter where no blood or decaying matter could be found (for example, in the classrooms at school). I had difficulty concentrating. I fantasized excessively, and I had trouble sleeping and eating. When I began responding to the voices' commands by breaking windows in my apartment and starting fires, I was committed with a diagnosis of "chronic hebephrenic schizophrenia."

Regular fluphenazine decanoate injections stabilized me enough to complete the spring semester, but those months seemed to drag on forever. Physically, I didn't feel too uncomfortable other than being stiff and "slowed down" most of the time, but what bothered me most was my inability to get interested in anything, to be curious about anything, or to feel any emotion about anything. I often wondered if fluphenazine was causing my profound lack of interest and energy, or if I was just being "lazy." I made efforts to exercise, to meet new people, to read new books, to write regularly in my journal—all to no avail. I spent most of my free time lying on my bed in my apartment. When I tried to refuse the injections, the doctor told me that since I was on an outpatient commitment, he'd have to notify the court and have me rehospitalized. I pleaded with him at least to lower the dosage, which he eventually did.

In May of 1981, I moved to another state and lived there for 2 months before I entered another hospital. Until 1983, I personified the epitome of the "revolving door phenomenon," functioning fairly well between hospitalizations but never for more than 6 months. The diagnoses have included "schizoaffective schizophrenia," "paranoid schizophrenia," and "chronic undifferentiated schizophrenia," with a few other variations.

I must say that with the exception of a few incidents, my treatment at these institutions was quite good. I found the staff usually kind, competent, and extremely tolerant of me and my fellow patients. Although at times I felt hostile about methods used to treat me, I realize that these methods were entirely justified considering my behavior, current medical technology, and my inability to pay for more specialized treatment.

As my illness developed, my dependence on psychiatric institutions also escalated, since I often responded to real and imagined stressors in my life by entering hospitals. My reasons for becoming "psychotic" again were not just because I'd stopped taking medication, for there was always the enticing possibility of a hospital stay lingering in the back of my mind. And at those points in my life, the safety (albeit restrictive safety) offered by an institution was preferable to the responsibilities I felt I could not handle outside.

I must also confess to a reputation for being noncompliant with medication, although I have periodically been able to function quite well without it. Some possible reasons for my noncompliance were sheer obstinacy and the desire to abandon responsibility for my actions, but the main reason was my belief that I just didn't need medication. I agree that my history seems to illustrate that medication has been helpful in the past, and I'm no longer inclined to quibble with that notion. Too, I'm no longer inclined to quibble with the notion that it may periodically be necessary in the future, when disruptive symptoms recur.

Since March of 1983, I have successfully completed three semesters of school and have remained out of the hospital. My parents have been very supportive, as have my doctor and my therapist. I believe that I owe my current success to the combined effects of medication, psychotherapy, social support, financial assistance, education, and experience.

Over the last 7 years, I have begun to realize and acknowledge that I have more control over my life than I once thought. In December of 1983, I stopped taking 100 mg thiothixene and 900 mg lithium a day, and I functioned very well for a period of 5 months. Over those 5 months, I had to deal with occasional hallucinations, recurrent illusions, increased energy (which, believe it or not, has a few drawbacks), and periods during which I found myself indulging in various paranoid and grandiose thought patterns. Since I had learned to recognize these for what they were and had been able to appreciate the ultimate consequences of reacting to them, I was capable of
preventing them from drastically affecting my behavior. They did not disrupt my schoolwork or my relationships with other people, but when they began to do so toward the end of the semester, I began taking a lower dose of thiothixene again so that entering a hospital was not necessary.

I recall one recent example of how I prevented further escalation of some irrational suspicions. In March, I became increasingly uneasy about something which I could not pinpoint, until I was quite fearful that some personal disaster was rapidly approaching. On my way to school one day, three large birds passed over me, stalling briefly in the air above my head. In my class, I noticed that a woman in front of me had a large black bag marked with white letters which read, among other things, "URGENT" and "CONFIDENTIAL." I heard a woman in the hallway say, "You won't go to jail." And my professor said during his lecture, "The choices you make are not inevitable," which angered and frightened me because I misunderstood him to mean, "The choices you make are inevitable." These events loomed in my head, and I interpreted them as warnings of impending disaster. With great difficulty, I suppressed my impulses to cry out and to strike the nearby professor, and I tried to concentrate on the lecture. I managed to get through class and then hurried to my favorite isolated place on campus to get better control of myself.

I spent several hours there, thinking and writing in my journal, and I arrived at two basic conclusions: (1) that by trying to ward off whatever calamity seemed to be approaching, I would inevitably bring on a calamity of my own creation by acting prematurely; and (2) that perhaps I'd noticed the "strange" incidents simply because I was already uneasy, and I noticed them in order to justify my growing fear. Afterwards I felt a bit better, and the uneasiness gradually diminished over the next 2 days. No "disasters" occurred.

I acknowledge that although I have much control over my behavior, some control over my thinking, and some control over my feeling, there remain a few things over which I have little or no control—i.e., hallucinations. The trick is to realize when or if the hallucinations are truly disrupting my thoughts, feelings, and behavior, and to take appropriate action by using medication before things get out of hand. Gradually I am learning where to draw the line—when medication is helpful and necessary and when I can manage safely without it.

As of yet, I still have a long road ahead of me. There is much that I don't understand about schizophrenia, but I realize I am not alone in my lack of knowledge about the illness. Slowly I am learning to accept the limitations of my illness, and I feel that I am beginning to make more constructive choices than I have in the past. Life puts various limitations on each person, but within those limitations there is always the freedom to make certain choices—an insight that I find relieving as well as revealing.

The Author

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