First Person Account: Living With Schizophrenia

by Evelyn Smith

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 Research, Schizophrenia Research Branch, NIMH, 5600 Fishers Lane, Rm. 10C-16, Rockville, MD 20857.—The Editors.

My daughter, Cindy, and I get together every 2 weeks for lunch—something we can now both enjoy. Sometimes we eat in a local restaurant, sometimes in a snack bar on the grounds near her dorm.

She is in her mid-thirties and I notice with sadness that she has a few gray hairs. The sadness is because she hasn’t really enjoyed or participated in life yet, but nature continues its march. Now she and I both have gray hair. Our conversation is rather disjointed, as Cindy has difficulty understanding my words most of the time. She struggles valiantly to answer my questions, and occasionally an appropriate response comes forth. Now, after 17 years, we sometimes exchange two or three sentences which actually have the give and take of real conversation.

Cindy has been living under the shadow of schizophrenia these past 17 years. She has a severely debilitating form of this devastating and demoralizing brain disease. Schizophrenia is caused by a chemical imbalance in the brain that produces a break with reality—not a split personality—and the distorted dialogue going on in her head controls her thought processes with often bizarre results. She has been a patient at a State hospital for 11 years and was in and out of the hospital for 5 years before that. This “fog,” as she calls it, descended on her at age 20 when she was starting her third year of college. During the first 5 years she got progressively worse, a course that has led to a long-term stay in a mental hospital. The best we can hope for is that someday she will be able to live in a group home; at this point we’re a long way from that goal.

During lulls in our conversation, as we sit in the snack bar, I observe other patients as they come and go. One is having an imaginary conversation in her head; she smiles at something humorous only she understands. I see the pleasure on a young man’s face as he’s asked to share a table. I watch the expressive eyes of a lady, whose own grasp of reality seems all too tenuous, as she tries to understand the conversation of another person who is not making much sense. This is the “normal” life...
of those suffering from mental illness.

The saddest thing of all is to realize that the stories of family life and previous achievements that were a part of the past lives of each of these people are no longer important to them. It's as though their past lives never existed. They are basically alone in the world because sustaining or contributing to a relationship of any kind is beyond the realm of possibility. To see a life stopped in its tracks by this ogre, schizophrenia, is a heart-rending thing to witness. The highlights of Cindy's week now are the Monday evening dances and the Friday morning bowling trips. There are many other activities at the hospital; some she participates in and some she doesn't, depending on her mood.

As we enjoy our lunch, memories of Cindy's very normal childhood and adolescence flood my mind. Memories of a girl who loved to read and who devoured many books; of a young girl practicing the piano and being able to play tunes and advertising jingles she'd heard on the radio and television; of a teenager on the swimming and diving team at the local YMCA. Memories of a good student in school; of a cheerleader in junior high school and of a member of the field hockey team in high school; and of a waitress during the summers earning money for college.

Nothing in her growing-up years could have prepared us for the shock and devastation of seeing this normal, happy child become totally incapacitated by schizophrenia. What we knew about schizophrenia in the beginning we could have written on the head of a pin. What we learned over the next few years was confusing and frightening. Theories were archaic and pertinent information hard to come by and not easy to understand. Following Cindy around and trying to convince her of the inappropriateness of something was a time-consuming and futile activity. Every ounce of my physical strength and mental stamina was directed to helping Cindy. In the beginning I had no idea how enormous a task that would be—or how impossible. I found myself neglecting my other three children, and though they said otherwise, I felt I had almost abandoned them.

Cindy has a delightful sense of humor, which still appears from time to time. She can hit the nail on the head quite often and her language sometimes is a bit salty! She will occasionally sit down and play a few tunes on the piano—all from memory—and she frequently quotes unusual passages of scripture from a Biblical translation only she has knowledge of.

Family members learn to live with schizophrenia encumbered by a great sense of loss and frustration. Friends have fallen by the wayside because "staying in touch" with their friend is pretty much an impossibility. Cindy's relationships with her sisters and brother are as close as she can allow. She has a twin sister whom she loves dearly, which is always evident when they are together. The break in their relationship has left a void in both of their lives.

I know from Cindy's many references to her "husband" and "children," neither of which she has, that family life is very important to her. I sense her feelings of loss because this aspect of life will never be a reality for her. A Raggedy Ann doll I had gotten her a few years ago became her little girl for a year or so. She would place the doll in a chair and feed it lunch or prop it beside her on the couch.

‘Mom, you don't know the hell in my head,' was the way Cindy described what was happening to her during the early stages of the disease. Many times she would burn herself with cigarettes or cut herself with razor blades. In her mind there were good reasons for these actions: the fact that there was no pain associated with them made her oblivious to the danger. On one occasion she missed her jugular vein by one-quarter of an inch. Yet, as we drove her to the emergency room, she sat and talked as though nothing had happened, completely ignoring the blood-soaked towels around her neck.

When you think of the utter helplessness these victims of schizophrenia must feel and all the wasted years their lives represent, your heart cries in despair. According to statistics, 1 in 100 suffer from schizophrenia in varying degrees of severity. In this day of modern medicine, we have become so conditioned to taking a few pills to alleviate or cure an illness that faith in this process turns to disbelief when symptoms are not alleviated and no cure takes place. Some people with schizophrenia do not respond well to medication, and Cindy is one of them. However, their reactions to life are like ours—"they call 'em as they see 'em,"—and their actions are perfectly logical responses to what is going on in their heads. The anguish is that this demon, schizophrenia, having completely deranged a brain and ravaged a life, has now released an empty shell of a person, as though shaking it like a rag doll and throwing it to the ground. Coping with the world and understanding it is still too great a task for Cindy and most of her conversation is irrelevant or incomprehensible.
Cindy's habits of daily living and personal grooming are very poor, though she sees a rhyme and a reason for the things she does. Taking a shower means just standing under the water, usually cold, and two pats with a towel and she's dry. She enjoys using fingernail polish and lipstick but can do so only under supervision, as she likes to apply it to her nose and cheeks. There are certain shoes that keep her legs thin and are worn for this purpose occasionally, and keeping track of her glasses is really beyond her capabilities.

Coming to grips with the thought of your child living in a mental hospital, possibly for many years, leaves you with a gnawing sense of helplessness that never really dissipates. You live with it the best you can. Remembering all the years of nurturing and healthy meals and dental checkups that went into the life of this daughter of mine, I am engulfed by the feeling that it was an exercise in futility. Now, as a heavy smoker, she stands a good chance of getting lung cancer. Now, she may be hit by a car, because she doesn't think to look before she crosses the street.

It's only been in the past year that Cindy can let herself glance at family snapshots. The chasm between her real life and a remembered past makes looking at them too painful. During her visits home I stay near her all the time, as it's almost like having a 3-year-old around. For Cindy, living by any kind of a routine is completely unimportant. As everyone is sitting down to dinner she finds it imperative to smoke a cigarette. Often, 20 minutes before we have planned to leave the house she has fallen sound asleep.

At the hospital the staff oversees her activities in a constructive, patient-oriented atmosphere. From observation, I can see that Cindy's relationships with the staff and patients are sometimes friendly, sometimes antagonistic, sometimes disinterested. She makes the best of the world she finds herself in.

Down through the ages the lives of the mentally ill have been a living hell, and the only salvation for those afflicted today will be the answers we find through continued research. We are fortunate that there are now several research programs that hold the promise of producing those answers. There is also a dynamic organization, the National Alliance for the Mentally Ill, with affiliates in every State, which is pursuing goals too long overlooked by many of those entrusted with the care of the mentally ill. A new drug, Clozaril, developed by the Sandoz Pharmaceutical Company, has been hailed as a major breakthrough in the treatment of schizophrenia and is working "miracles" for some patients. An initial price tag of approximately $9,000 a year, however, put it virtually out of reach for most of those who so desperately need it. Several lawsuits have been filed against Sandoz seeking to reduce the cost of Clozaril and its very stringent monitoring system. The company has announced a price reduction, but at this time it is unclear exactly what that means. The anguished pleas of family members and the medical profession continue to bombare Sandoz.

In the past year a new Cindy has emerged. Where once there was a rather unfriendly, often unpleasant girl, there is now an amiable, more responsive person. Cindy smiles more these days, something a person with schizophrenia doesn't do very often. For years her face was a solemn mask, and she could neither give nor receive affection. She knew something terrible had happened to her and could not understand why no one would rescue her from the hell in her head. In the past few months she has become quite loving, and the smiles that now light her face light mine as well.

I treasure the times Cindy looks at me and tells me I'm beautiful, when she tells me my dress is pretty, or when she apologizes for some verbal abuse uttered months ago. This is the "real" Cindy speaking—my sweet, generous, funny, intelligent daughter.

How I wish she could shed this awful affliction and be that person!

The Author

Evelyn Smith is the mother of four children, one of whom, Cindy, developed schizophrenia. Cindy's twin, Sandy, has recently been diagnosed as schizoaffective. Ms. Smith has worked as a transcriber for a court stenographer for 18 years and as a school secretary at a middle school for 14 years. Her hobbies include crocheting, cross-stitch, reading, playing Scrabble, and gardening.