First Person Account:
Living in a Nightmare

by Alyce Kagigebi

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.

"You little ...! I thought parents were supposed to help their kids. I'm going to get a restraining order so you can't call me or come near me." My son said this to me when I told him he couldn't come home to live. I was real surprised that he called me a name because he has never called me names. My first reaction was that it was funny, but deep down it hurt. I know he said those things because of his mental illness, but it can still hurt.

My son, Burt, is 24 years old, and 2 years ago he was diagnosed with schizophrenia. This is when the first living nightmares began. Burt had always been an easy child with no unusual problems. But when Burt was 16, my husband, Dan, and I started having behavioral problems with him. It was as if Burt's personality changed overnight. He started drinking and running with a wild crowd. I thought Burt was chemically dependent. Dan is his stepfather, and Burt's biological father is an alcoholic and uses drugs. I joined Ala-non, went to therapy, and eventually learned about "Tough Love." Burt became emotionally distant with Dan and me. He used drugs and alcohol and missed a lot of school. He also had a job at a grocery store and had plans of becoming manager some day.

In Burt's last year of high school we realized he wouldn't graduate because he had missed too much school. That same year he only lived with us part of the time. Each time Burt came home we had him sign a contract as to the rules to follow while living in our home. We asked Burt to leave twice that year because he had broken two serious rules. Once he was smoking pot in his room, and the other time he was selling drugs from our house. It was very hard and painful for me to follow through with these consequences, but Burt had to know that I meant business and he couldn't walk all over us.

It nearly killed me when Burt didn't graduate. I still feel sad

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about it. Now I realize that Burt was probably using drugs and alcohol to ease the sound of the voices he was hearing and to ease the imaginary things he was seeing. How hard it must have been for him when all this was going on. How could you tell anyone that you were seeing and hearing things that no one else was? They would have thought you were nuts. He must have been scared to death.

When I was going through these troubled times I thought, "This must be a living nightmare." Little did I know that the real living nightmare would come later. This was just openers.

At age 19, Burt was living in his car. He lost his job because he couldn't make it to work due to too much partying. He had run out of places to stay. With no money to pay rent, no one wanted him. He came home to visit one night and wanted to move back in with us. By this time we couldn't handle him or trust him to follow through with anything he said. It was so hard not to take him in and take care of him. I love him so much. Dan and I told Burt that if he went to treatment for drugs and alcohol we would let him come home. I lied to him and I didn't feel very good about myself for it. I had no intentions of having him come home. After treatment I wanted it to go to a halfway house. If he could prove to me that he was serious about changing his life, then I would let him come back home. It was very hard for me to follow through with what I said. Burt agreed to go to treatment. While he was in treatment I told him I changed my mind and he couldn't come home. That was one of the hardest things I have ever done. He looked like I had stabbed him with a knife. His counselors helped him through the pain he was in. He never brought up the fact that I lied to him, but months later I wrote him a letter asking for his forgiveness. Burt never replied. I don't think he could.

After treatment Burt went to a halfway house in Minneapolis. He stayed there until he was 23 years old. I knew he wasn't growing emotionally and I couldn't figure out why. I didn't think he was drinking or using drugs, but he was emotionally distant. Dan and I visited Burt once a month and wrote often. He never wanted to come home, but I wasn't sure why.

On one monthly visit we picked Burt up and went to shop and lunch. Burt was very strange. He looked like he was on drugs. His body language was odd, and his motor movements seemed slow and different. He talked about lifting weights and said a bar fell on his head. I felt panicky. I was worried about brain damage and I still wondered if he was on drugs. After our visit, I called him that evening. He seemed distant but OK. He wanted to come home for a weekend. I was surprised and said we would be happy to have him come home, but I was still feeling frightened about his behavior. Burt came home the following weekend. I took one look at him when he got off the bus and knew he wasn't on drugs. I knew he had a mental illness. I felt so scared. I didn't know what to do. I knew I had to get him to a doctor but I also knew he wouldn't go. I felt so helpless.

When Burt got off the bus he was holding a Styrofoam cup and he carried it with him all weekend. He also had a tube of toothpaste in his pocket, and he ate toothpaste and spit it into the cup constantly. I couldn't believe it! I went up to him and I nearly started yelling at him. I wanted to say, "Put that darn cup away. Don't you know how crazy you look?" Something stopped me and instead I talked gently to him and asked him why he was doing that. He said, "Because it tastes good. You know?" He was in pretty bad shape. That evening he became frantic and said his heart was pounding and he was in pain. I was working. He woke up everyone in the house and said he needed to go to the hospital. Dan called me and I dropped everything and drove home. I was scared. I decided to call an ambulance because I was afraid Burt might jump out of the car on the way to the hospital. (We live 40 miles from the nearest psychiatric hospital.) I called the ambulance and waited for them to come. I tried to explain to the police what was going on. When the ambulance arrived I was afraid to tell Burt because I thought he might get angry and they would have to force him to go, but he went very willingly. Dan and I followed in our car. Burt was going to the hospital for the pain in his chest, and I was going to see if I could get him committed. Dan and I had never been through anything like this in our lives.

I couldn't believe what was happening. I was in shock. I didn't know what to think. Could Burt have gotten some bad drugs that had damaged his brain? Could the bar that fell on his head have damaged his brain? Did a bar really fall on his head? The biggest question was, was he going to be normal again?

First Burt saw a general practi-
itioner who thought that Burt's chest pain was not a physical pain but a mental pain. Burt then saw a psychiatric doctor who wanted him to stay at the hospital for observation. Burt wouldn't stay, and the hospital couldn't force him to stay because he wasn't a danger to himself or to others. We all tried so hard to talk him into staying, but he wouldn't budge. It was so hard. It was a nightmare. We took him home. I was exhausted. We had been at the hospital for 5 hours and both Dan and I were drained of emotions.

The next day I was to drive Burt to the halfway house, which was 100 miles away. But he agreed instead to go to a hospital in Minneapolis where he lived. Again, Burt was going to the doctor for the pain in his chest, and I was taking him for the pain in his head. I felt that a hospital in Minnesota was worth trying because one of the doctors in Wisconsin (where we live) said that the laws in Minnesota were more liberal, and we would have a better chance of getting help for Burt. The doctor was mistaken. The laws are the same, and we went through 7 hours of hell only to find out nothing. The hospital couldn't hold Burt unless he was a danger to himself or someone else. I was devastated and exhausted. I was hitting a dead end. I still didn't know any answers to why Burt was acting so strange. Inside I was asking, "What does a person have to do around here to get some help?" All the medical people agreed that there was something drastically wrong with Burt. I wonder if any of them thought their hands were tied because of the laws.

I had to give Burt a ride back to his halfway house. I dreaded the ride because we were in the inner city and I wasn't used to driving with all the traffic. I was tired and also very angry with Burt for not cooperating. Actually, I was feeling so many emotions I didn't know which end was up. I just wanted to go home and get away from Burt. He asked me if we could stop at a fast food restaurant and get something to eat. I told him no because I had to get home. I felt instant guilt for not taking the time to have dinner with him.

After I dropped Burt off, I drove to the nearest grocery store and bought a sandwich and a pack of cigarettes. I had quit smoking 2 years before, but I started smoking again that day. I smoked five cigarettes before I got home. I needed some comforting, and my familiar friend cigarettes helped. That was 2 years ago and I'm not sorry I started smoking that day. A lot of people can't understand that. I wish I didn't smoke but I'm not sorry.

The following day I called the halfway house and talked to their psychologist. Her name is Lori and she has been a great source of strength to me. She has also become a close friend. Lori said that she thought Burt had schizophrenia. That was the first time I had heard the name schizophrenia in reference to my son. She explained that schizophrenia was a virus in the brain and that to her knowledge it is a biological disease. She also told me that this type of mental illness strikes teenagers and young adults. I felt as if I had been knocked off my feet. I was feeling all kinds of feelings at once—shock, fear, helplessness, and frustration.

Lori also informed me that Burt had been demonstrating bizarre behavior. He had been wearing strings to "hold up his arms." She also mentioned Burt's toothpaste routine. On several occasions, Burt said the radio was talking to him and for some reason he tried to put his bed on his dresser. I didn't know what to think about all this. My mind was spinning. Lori was in the process of trying to place Burt in a board and care facility because the halfway house wasn't equipped to handle his illness. She was having a hard time placing him because he had to see a doctor first, and he wouldn't see a doctor because he didn't think anything was wrong with him.

When I got off the phone I looked up schizophrenia in our medical book. After reading their information I didn't see much hope for Burt. I felt depressed. I blamed myself. It had to be someone's fault. Maybe I shouldn't have smoked when I was pregnant. Then, I remembered I had quit at that time. Maybe I never should have married my ex-husband because he was an alcoholic and verbally abusive. Maybe I shouldn't have been watching my weight so closely when I was pregnant. I was driving myself crazy. I called friends and they were very supportive. I sent for books on schizophrenia, and they have helped me more than anything. The books told me it wasn't my fault and talked about what I was feeling. Most important, the books talked about what other families had gone through. This helped me feel that I wasn't alone.

Several months after I talked to Lori, Burt was placed in a board and care facility. The day he entered the facility I remember thinking that his friends are going to college and my son is going to a mental institution. It was heart-
breaking. I looked at the other patients there and wondered how my son could be going here. I felt a lot of pain. I cried all the way home.

Burt was at the board and care home for a year. He refused to take medication and wouldn't participate in any of their activities. He ate junk food and the nurses had a hard time getting him to clean up his room. Finally his doctor said he was a nonpatient and he was discharged. The caseworker at the board and care home said that Burt would have to go to the shelter because there were no other facilities that would take him because he refused medications. I panicked! I had heard terrible stories about shelters, and Lori had said “Whatever you do, don’t let Burt go to a shelter.” I had all kinds of frightening thoughts going through my head. I was afraid he might get raped, murdered, or beat up. I was afraid his belongings would get stolen from him. I was afraid that he would use drugs and alcohol. I was afraid he would get AIDS. These thoughts were very real for me.

I was told that Burt’s doctor had suggested that he go to the shelter. I called his doctor and asked him if he thought the shelter was the best place for Burt. He hesitated for a long time and then said, “I don’t know.” That said a lot to me. I feel that Burt’s doctor didn’t know what to do with him or how to help him, so he just threw him away to the shelter. He also said that when Burt got tired of living at the shelter he would ask for help. I can’t believe an educated person would say something like this about a person who is delusional. I believed that when Burt got tired of living at the shelter he would be living in a cardboard box and telling me, “This isn’t so bad, Mom.”

At this time my husband and I considered having Burt come home to live with us. We had gone over and over this subject. The bottom line is we can’t handle Burt. He has not lived with us for 3 years and he isn’t the same person he was when he left home. I would end up smothering him to death. He wouldn’t have to do anything for himself. We would all go mad. I feel that I have a responsibility to help him, and I feel guilty because he can’t live with us. The hardest thing I ever had to do is tell Burt that he couldn’t come home to live. Think about telling your adult child that he can’t come home to stay.

I hate schizophrenia. I hate it! Schizophrenia robs its victims of everything that is important in life. It’s ugly, selfish, and takes away simple joys in life such as laughing, holding down a job, and being able to have a conversation with anyone. Schizophrenia causes enormous emotional pain, fear, anger, frustration, resentment, and disappointment to the families and the person with schizophrenia.

One of the things that Burt misses is working. He worked from age 14 through age 20, and he doesn’t understand why he can’t work now. He thinks if he “kicks back and rests for awhile” that he will be able to work. But he has been kicking back and resting for 3 years now.

What must Burt be going through? I ask him if he is happy and he says he is. But what is happiness to him now? He listens to his head phones and watches TV most of the day. He also goes to the store and buys pop and candy. He smokes but not a lot, and at times smoking bothers him. Sometimes he eats in the dining area and sometimes he doesn’t. He says the meat looks rotten to him. He used to go to the movies once a month, but he doesn’t do that anymore. He doesn’t wear strings on his arms anymore, and he doesn’t eat toothpaste. He stopped doing those things after he moved into the board and care home. I think that is a big accomplishment. Of course, he takes no medications, and he looks depressed. Once in awhile we will see his real laugh. We count how many times he laughs when he is with us. Once we counted four real laughs from him. It makes our family feel good to see him laugh. It is important to us.

Then there is the crazy laughter—when Burt’s face twists and he laughs at something only he sees or hears. When I first heard that crazy laughter come out of him, I couldn’t stand it. I wanted to say “Stop that stupid laughing. Don’t you know how dumb you look?” It embarrassed me. But I didn’t say anything and afterward I felt compassion.

If you don’t have a close family member who has schizophrenia, you don’t really know what it’s like. I don’t care if you are a doctor, nurse, or case manager and have had thousands of patients or clients with the disease. You can’t feel the gut-wrenching grief that a mother, father, or siblings feel from losing a son, daughter, brother, or sister to schizophrenia. It’s as if that person has died and here stands a different person who is your loved one but who looks and acts like a crazy person. You love them but you wonder where your old loved one has gone, and you long for his or her return. I miss the old Burt. I miss his companionship, his laughter, and the
Mother’s Day and birthday cards he used to remember. But most of all I miss his love and his hugs. Right now, he doesn’t want anyone to touch him. I cry for the old Burt and remember the good times. It seems long ago.

I have had to force myself to get to know the mentally ill Burt. As you can see it is hard. Sometimes he’s OK and we can do things together, but it still isn’t the same. Sometimes his hair is dirty and his clothes look like he slept in them. On one occasion, we were standing in line at a fast food place. The lady standing behind Burt looked at his dirty hair and the rest of his appearance and stepped back from him and whispered something about Burt to her companion. I fought back tears because that really hurt me. To think that someone thought my son was too gross to even stand behind.

But I can’t help but think that I might have done the same to someone’s daughter or son given the same situation. You never know.

As I am writing this story, Burt is going to a shelter. I am turning Burt over to God. I have written letters and made numerous phone calls to find a safe place for him to live, but I have gotten nowhere. God will have to take care of Burt. I am at a dead end.

I will manage. I will not desert by son no matter how painful it is for me. I know if I had schizophrenia the old Burt would stand by me. I don’t see much hope for Burt’s future. I understand and can accept the way he wants to live his life. People tell me there is always hope, but I ask them how you can have hope when things have just gotten worse for years. I would rather accept the present than have false hope. I can have some peace with that. I don’t believe I will ever have my old son back and anything else isn’t enough. It just isn’t. It’s OK and I can handle it and I will be grateful for any progress Burt makes, but it will never be enough.

I hope my words will give insight to the effects that schizophrenia has on patients and their families. This is the end of this essay but it is not the end of Burt’s story.

The nightmare goes on and on and on!

The Author

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