

# First Person Account: Paranoid Schizophrenia—A Daughter's Story

by Jackie Powell

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 *First Person Accounts*, Division of Clinical and Treatment Research, NIMH, 5600 Fishers Lane, Rm. 10-85, Rockville, MD 20857.—*The Editors*.

I can clearly remember my formative years as a time of confusion, anxiety, and desperation. My mother was 25 years old when she was first hospitalized after becoming aggressive toward my father because of his adulterous ways. Their 4-year marriage had been onerous for my mother. As I remember, there was a gradual change in her behavior over a few months. She was no longer able to provide the personal fortitude needed to keep the family together. My father spent most of his time working or drinking. I remember the arguments when he would come home the next day intoxicated and smelling of smoke and alcohol. Arguments became an integral part of our family dynamics. Occasionally the arguments progressed to a pushing and shoving match, but on this particular day, it escalated into something more lethal. My mother approached my father with a shotgun after he attempted to walk away from the argument.

I do not remember the details after he ran out of the house and she continued after him. I ran to my grandmother's next door, and my uncles tried to intervene. The sheriff's entourage arrived shortly after my uncles' intervention. I vividly remember her screaming when the sheriff and deputies struggled with her on the ground as they tried to place handcuffs on her. Not really understanding the magnitude of my mother's pain and misery, I stood with my paternal relatives as people from the community gathered around whispering derogatory comments and making speculative statements.

During those few months before the hospitalization, it was difficult for my mother to remain in her work environment in a hosiery mill. Although supervisors described her as an excellent employee, she suddenly started accusing co-workers of plotting against her. The delusions were vague but tenacious. She had exceeded the limit on all her credit cards, and long-distance phone calls exaggerated the usual expense of the phone bill. She called relatives, high school acquaintances, and any other soul who came to her mind. Some discussions were cordial and reminiscent of times shared, but other calls accused people of harassing her or of being "jealous" of her. The calls were usually made late at night or during the early hours of the morning. She was unaware of the inappropriateness of her behavior.

She slept 2 to 3 hours a night and spent most of her time pacing in the house or walking up and down the road in clothing inappropriate for the weather or for societal expectations. She altered some of her clothing into a new form of fashion. She gave other items away to people in the community or threw the items in the trash, noting that she no longer needed them. She had developed a hostile, almost sarcastic character. There was no reasoning with her at this time. To confront her meant igniting her anger and belligerence. By age 6, I realized that it was better to

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observe her behavior from afar and to remain confused about why she seemed to be having a conversation with "someone" I could not hear or see even when she was not on the phone.

The small African-American community where we lived provided little support or empathy for my mother or my family; my mother merely assumed the persona of someone crazy or having "bad nerves." There was an awareness in the community of the need for medication to treat her bizarre behavior, therefore, when my mother returned and her symptoms had abated, people inquired about her compliance with her medication and her "state of mind." They would say, "Sally Mae, are you still taking your medication?"

It was 6 weeks before my mother returned home. I visited her once at the State hospital. My mother and I cried through most of the visit. To my mother, being in a State hospital was like being in an abattoir. Before the visit ended, she gave me a monkey she had made out of socks during one of her therapies. I kept this monkey for many years. Later, it reminded me of the pain I experienced seeing my mother in the hospital.

She appeared very different when she returned. She moved slowly and she had gained weight. Her eyes appeared dazed, her speech was slurred, and at times her hands trembled. I tried extremely hard not to be afraid of her, but I did not know this person who used to be my mother: The mother who made me laugh when we watched television together, the mother who listened to music and danced with my friends and me, the mother who combed my hair for school each day, and the mother who made sure I was safe at night did not return home. She was no longer exuberant, and enjoyment seemed foreign to her. She appeared numb to the world that she felt had destroyed her life. From this time forward, my life was no longer the same. Somehow we became symbiotically united, and I knew that I would always need to take care of her in some way.

My mother and father divorced shortly after her release from the first hospitalization. She returned to live with her mother. Their home was about 13 miles from the house I had called home for 4 years. My father's family decided to have my father and me stay with my paternal grandmother. Monday through Friday, I went to school pretending to have a "normal" life, but knowing that other kids knew about my mother's hospitalization through their parents. On Friday nights my father drove me to my maternal grandmother's home where I stayed until Sunday night. This pattern continued until I went away to college.

My mother was no longer my mother. She no longer felt comfortable making the parental decisions that I needed her to make, nor was she able to set limits on my

acting-out behavior. She passively allowed my father's family to be responsible for child-rearing and I merely visited her. Gradually, I found myself treating her like a child and thinking that I knew what was best for her and me. I loved her dearly, but I resented her even more for taking away my childhood. Somehow this disease stripped her of her charisma and excitement about life and left a shell that ruminated about the past, no longer connected or interested in day-to-day events. She was able to verbalize her love for me, but her affect did not demonstrate affection: Something was missing. She was no longer available to help me face the normal vicissitudes of life. There were no longer any boundaries on language or information. If my mother remembered something, she spoke it. She impulsively verbalized historical family garbage and ill deeds and dumped this information into the lap of a child.

I learned to live two lives, the life with my mother and a more superficial life in the community. I learned to call my paternal grandmother "Mother," and the community soon learned the same. During acute psychotic episodes my mother would rage about how I was taken away from her and how cruel my father's family had been to her. She would reveal frightening stories that I could not remember, such as being made to sleep on the floor, or being dragged by the sheriff. Unfortunately, there was no way to validate my mother's accusations. No family member would talk about her condition. It appeared that they wanted her medicated and paralyzed. So the task for me was to differentiate between what was delusional and what was real for my mother during these episodes. I believed that the truth was somewhere in the middle and that for my mother her perception was 100 percent reality. I soon followed my family's strategy. My mother became a secret that I learned to avoid exposing in order to protect the two of us from being scrutinized.

After the first hospitalization, it was almost predictable that every 4 years my mother's behavior appeared to change in the fall. I would find myself becoming prepared for her to decompensate and looking for subtle changes in her behavior. In my mother's community, no effort was made to explain mental illness to family members. The effort focused instead on medicating the patient without treating the entire family, a strategy that perpetuated the lack of support and understanding in this particular community. Although my mother tried desperately to recuperate from each psychotic episode and each arrest, she became increasingly reclusive and paranoid. Each episode was precipitated by an erotomanic delusion or delusions of persecution in the workplace that followed shortly after the psychiatrist decided to taper her antipsychotic medications.

As the taper began, my mother would believe that she no longer needed to take medication and that nothing was wrong with her: Everyone else was crazy. For the first 10 years or so after her first hospitalization she worked in factories and restaurants. However, after a few years, the taper would occur and she would create elaborate stories about her co-workers plotting against her.

She would also obsess about married men, fantasizing that they were going to leave their wives to be with her. Occasionally this would progress to her calling the wife or waiting for the man at the diner. The result was usually trespassing issues and threatening behavior. Men would come and go, but my mother continued to yearn for the family she never had and the marriage she dreamed of incessantly. Eventually, she gave up the idea of maintaining a full-time job.

Now my mother's income is derived from disability Social Security income and any financial support I might give. Over the years her ability to maintain a logical conversation has diminished. One has to search to find a connection between the theme of a dialog and my mother's response. Her language in jest is more nonsensical and tangential. She has become increasingly perseverative about minuscule things. She lives alone in an apartment, making lists (mostly the food menu for the day) and posting them on the walls. She spends most of her time cooking, thinking of new ways to "create" dishes that usually taste very strange to me. She is very cynical and critical of others. There is an obvious air of grandiosity and entitlement. She goes to the grocery store and will occasionally walk around the neighborhood to "clear her mind." She avoids going to the laundromat and now washes clothes by hand at home. She also avoids answering the phone and uses the answering machine to screen all her calls. She still feels that most people are not benevolent. After 25 years of neuroleptic treatment, she has discontinued all medications and periodically will call her case manager. She is convinced that she no longer needs medication. People in the community continue to ask her about her medication and now she lies to them.

As for my relationship as an adult with my mother, I would be lying to say that I do not think about her condition daily. I also grieve over the loss of my mother as I knew her before the first episode. For brief moments, my mother gets better and she is more aware of who I am as my own being. Sadly, I have to acknowledge the brevity of this connectedness and merely treasure the moment. I visit her once or twice a month and this seems to be enough for

her. The visits are short and usually involve her cooking and updating me on what has been going on in the neighborhood. I often invite her to visit me, but familiarity is important to her and she typically declines the offer. When she does visit, I get very little rest because she is awake throughout the night eating, watching TV, reading cook books, or just sitting in a chair. When my friends happen to be around the two of us, I typically say that my mother is very odd to forewarn them in case her conversation becomes tangential or she injects a neologism. Most of my friends accept this without question, but others feel it necessary to inquire more. I usually ignore their questions or minimize the significance of her thought disorder.

My mother calls me once a week and I quickly assess her mental functioning and her medical status. She is 50 pounds overweight for her height and body frame. Approximately 5 years ago, she was also diagnosed with hypertension. She sees an internist only when her symptoms interfere with daily events (that is, shortness of breath on minimal exertion and headaches). When antihypertensive medications are prescribed, she takes them until the symptoms subside. She is unaware of the severity of her medical condition and of the impact of her obesity on her overall health.

My mother's condition has greatly marked my career as well as my personal life. Ironically, I am a mental health professional and I work primarily with patients who have schizophrenia. I have deliberately adjusted the language of this article to reflect more of my emotional anguish and less of the psychological and psychiatric terminology that I think would take away from my personal account. I am no longer the 6-year-old who saw her mother taken away, but I struggle daily with what is real and what is delusional where my mother is concerned and how I can protect both her rights and her safety in an era of limited psychiatric involvement caused by elevated health care costs. Heavy caseloads and minimal patient contact do not allow the continuity needed to provide adequate care to the chronically mentally ill of our nation. I hope that my personal account will touch readers in a way that will encourage the reevaluation of health care systems and policies.

### The Author

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