First Person Account: My Voyage Through Turbulence

by Ruth Malloy

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.

In young adulthood I watched a generous, brilliant, and respected father lose everything as a result of an undiagnosed and untreated mental disorder. He had several implausible stories he liked to tell about how he had outwitted people who were plotting against him. Could his mysterious breakdown have been due to a mild schizophrenia spectrum disorder? Perhaps!

When I married and had children, I tried to compensate with good parenting skills for any predisposition toward mental illness they might have inherited from their grandfather. Ironically, we also found mental illness in my husband's family later on. Moreover, childhood emotional trauma or skewed family relationships do not cause schizophrenia. When three of our eight children developed schizophrenia, it was probably inevitable.

Sylvia Geist, presently president of the Schizophrenia Society of Canada, in her doctoral thesis, called coping with schizophrenia a voyage through turbulence. Our voyage through turbulence began around our son's 18th birthday. We noticed an odd change in his facial expression. It might have been due to the abnormal eye tracking movements sometimes seen in people with schizophrenia. He started to come home from work rather late that summer and changed schools in the fall. His sister found a starter pistol in the trunk of his car. He started listening to the police band on a scanner. These incidents seemed more significant afterward than at the time.

Finally, he came to me with a story about a gang he was afraid might try to hurt his family. He had waited till late to sneak into the apartment after work. He changed schools to get away from them and had bought a gun to scare them. He could hear them plotting against him on the scanner. I began to suspect that he might be mentally ill, but his father believed the story. I went to the principal of his old school to check it out. The principal suggested seeing the board psychiatrist, but I knew from our previous experience with my father that persuading a loved one to consent to psychiatric assessment and treatment is one of the toughest challenges anyone could ever face. I decided to wait.

In January, after our son had a few beers alone at a local beer parlor, he smashed up some dishes and furniture and dumped the dining room table onto his brother's lap. Then, his face smeared with blood, he left the apartment and disappeared into the darkness. We reported the incident to the police and walked around the neighborhood trying to find him. We found drops of blood on the subway platform, so we concluded that he was on the subway and went home. His brother found him in the apart-

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ment house lobby at 6 o’clock the next morning. Soon after he fell asleep.

While our son was asleep, my husband and I talked. My husband told me to take him to a psychiatrist. That evening I was still not at all sure I could persuade him to go to the hospital. I went into his room, leaned over his bed, took a long deep breath, and said, “You’ve handled this alone long enough. You need help. Let’s go to the hospital.” Miraculously, he went with me.

He was not admitted to the hospital. They talked to him for a while and gave him an outpatient appointment. The doctor at the followup appointment referred him to a youth agency for counseling. This referral fizzled. After he answered a series of bizarre questions, the counselor suggested that he go back to outpatients. The next week a teacher at his school noticed that he was seriously disoriented and arranged for him to go to the hospital by taxi at school board expense. This time he was admitted.

Looking back on this admission, I realize that he received excellent care even though it was not at all what I expected. Ours was a functional family, but we were hardly the Waltons. I naively assumed at first that he was having a reactive psychosis brought on by skewed family dynamics. I also didn’t like the drugs they were giving him. When he said that he liked the drugs, that really unsettled me. I was afraid he might become addicted. After discharge he attended day treatment for several months, then was referred to the weekly medication clinic, and after a while entered a group home.

Our son’s first suicide attempt took place while he was in the group home. I had started playing Scrabble with him after his first hospitalization. We both loved the game. It did wonders for his self-esteem to beat his mother, and I am convinced it helped him regain some of his cognitive functioning. He won consistently except when he was decompensating. If I began to win, I knew he was due for a relapse. One evening we played Scrabble, then he went downstairs, swallowed a handful of pills, and waited to die. When nothing happened, he went to the hospital, hoping to talk to somebody. The pills hit him while he was waiting to be seen. He narrowly missed dying that evening, but I was not informed until he phoned me himself several days later.

I went on an 18-year suicide watch after that, and I slept with my clothes on for the next 10 years. There have been two more attempts since. He is not suicidal on his present medication, but I still keep enough gas in the family car to get to Emergency if the need should arise.

When our voyage through turbulence began, my husband and I were in our child-launching years. Now we are in young old age, but we still have a sweet and gentle but spirited 4-foot-11-inch daughter to launch. Her illness began at about age 14 with truancy and running away. She would suddenly disappear for several days. If you asked her where she had been, she would just say, “I don’t know.” I was so concerned for her safety that I sent her for martial arts classes, hoping she would learn to defend herself if she ran into trouble. It once took three men to restrain her in Emergency.

Finally, she went for help on her own. She spent her 16th birthday in a psychiatric unit, terrified of aliens from outer space who she thought were trying to abduct her. This hospital kept her for 5 days, then discharged her with no further treatment and a referral to a community-based youth counseling agency because she was too young for an adult unit and all the adolescent beds in our city were filled.

That evening, we tried taking her to a local children’s hospital whose motto is “No child shall knock in vain.” They gave her a complete physical, told me they had no beds, and said to phone for an appointment for an assessment in the morning. They added that the earliest she could be seen would be in 3 weeks. Dumbfounded, I protested vehemently, but I finally had to take her home.

We improvised at home for the next 7 weeks. When she finally got a bed, the accommodations and treatment were markedly inferior to the treatment her brother had had. Adding insult to injury, her therapist put her on token economy and refused to allow her family, which had been holding her together for the past 7 weeks, to visit her. She screamed for days. That unit has been upgraded since, but the supply of adolescent beds in our city is still desperately inadequate.

The effects of this admission were long lasting. Her trust in the system was gone. Over the next 10 years she was in and out of 10 hospitals, and on and off a half dozen antipsychotic medications. She rejected the help of untold community outreach workers and spent two more birthdays in psychiatric units. A major break came when she was accepted into the Community Integration Program at the Clarke Institute of Psychiatry. This program exercised a multidisciplinary treatment team approach. Each patient had a case manager and was assigned to a multidisciplinary team. I most sincerely hope the model will be widely duplicated now that the Clarke has proven its efficacy.

Our oldest child, now age 44, was the third of our children to get schizophrenia. Her official diagnosis is actually schizoaffective disorder. Her main symptom was hearing voices telling her to kill the kittens and to jump in front of subway trains. She was first diagnosed in her late thirties. She thought she was past the age of greatest risk, but schizophrenia can happen at any age. Fortunately, she has been compliant from the beginning and has a good understanding of the illness. She had been quite hostile toward her
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younger sister, but that changed when she developed schizophrenia herself: They have become quite close.

Things are much better now. All three children are stabilized on appropriate medication. Like many other people with schizophrenia, their vocational and social functioning is impaired because of negative symptoms, but we have had only one very short crisis admission this year. At this point, I would like to switch from our personal story to some of my favorite opinions and observations.

I feel strongly that people with schizophrenia should stay on their medication. If legal ways were implemented to force people to stay on their medication, fewer would get into trouble in the community. Moreover, the cost of restabilizing patients who repeatedly go off their medication is an expense that is becoming harder and harder to justify.

The following examples will illustrate what happens when people with severe schizophrenia stop taking their medication. My son decided to go off his medication to lose weight. After a couple of months, his symptoms suddenly started to come back. He got lost trying to get to Emergency. By the time he found his way again, he was in an acutely psychotic state. He was standing on his seat on the bus shouting obscenities at the other passengers. He was thrown off the bus and had to walk the rest of the way. One time our daughter decided to try faith healing. Some days we hardly saw her. Her brother noticed one day that we had not seen her for 3 days. He went to investigate and found her in bed, very thirsty and very hungry. She told him the “aliens” had placed force fields around her ankles and her wrists and would not allow her to get out of bed. We gave her something to eat and started her back on her medication. Next morning we had to call an ambulance because we couldn’t get her out of bed to take her to the hospital.

I also strongly believe that families need more education about the negative symptoms of schizophrenia. These can be very frustrating. If people with schizophrenia and their families were better informed about these negative symptoms, they would be less likely to blame the medication for the frustrating behavior and more realistic in their expectations.

I also have strong feelings about shock treatment. When my son told me he was going to have shock treatment, I was absolutely terrified, then simply amazed by the result. He was ready to come home a week later. Electroshock, as it is administered today, is altogether different from the old insulin shock. It is safe, effective, humane, and a highly sanctionable treatment. I firmly believe that the permanent memory loss formerly thought to be linked to shock treatment is actually a negative symptom of the schizophrenia. My son, who has had two courses of electroshock, has a far better memory today than his sister, who has never had shock treatment at all.

Finally, a word about family blaming theories, which have now fortunately become outdated. People with schizophrenia and their families need support. Family blaming was vicious and counterproductive and undermined their natural instinct to support one another and led them to place blame instead.

One more thing I believe with all my heart! Stress does not cause schizophrenia. Stress may exacerbate the symptoms, but it is not the underlying cause. Our voyage through turbulence was highly stressful. If stress caused schizophrenia, I and all of my family should be basket cases, and we are not! We may not be the Waltons, but we are a good strong family.

The Author

Ruth Malloy is a naturalized Canadian who was born in the United States. She received primary and secondary school education in the United States and has a BA and an MA from the University of Toronto. She retired in 1994 from a position as teacher of English as a Second Language and Literacy at Queen Street Mental Health Centre in Toronto, and is involved in voluntary advocacy and support work for persons with schizophrenia and their families. Ms. Malloy is past president of the Schizophrenia Society of Ontario, East York chapter.