

First Person Account: Susan's Cello

by Marie-France Demers

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 *Schizophrenia Bulletin*, First Person Accounts, EEI Communications, 66 Canal Center Plaza, Suite 200, Alexandria, VA 22314.—*The Editors*.

I used to play a lot of music. I played piano beginning at age 5. I eventually taught it to pay for college and university. I never really wanted to become a professional musician, even if I admired talented people who make music for a living. I decided to become a pharmacist. Through music, I met extraordinary people with exceptional talent. I will always consider music a gift and treasure the chance I had to learn it and to be able to share its magic by playing with others. Susan is one of these others. In fact, she is the one. We used to go to high school together. I played piano. She played cello. She is a true artist. She has this extra thing that makes you feel you are with someone with a special gift, someone who will become famous and have a great career. I felt lucky to play with her. I always will. She was so strong, so affirmative, so able. Every single day, she went to school, then went to the conservatory for her music lessons and practiced overnight to perform her best. She was very disciplined, very demanding of herself and of others, like me, who played with her. She

was beautiful and healthy, with a natural blush on her cheeks and large blue eyes, making her look like a pretty doll. She was cherished by all of us. In fact, I think that lots of us admired her. She had it all. In 1985, our last year of high school, we were preparing for our annual school concert of chamber music. We were putting a lot of efforts in accompanying singers and several musical instrument's players. Susan was the leader, the most talented among us. That night, she played a Concerto of Saint Saëns with rare emotion and virtuosity. The audience was captive under her charm. At the end of this concert, she received an award for her accomplishment at school and was ready to start a musical career. She also received a grant from the conservatory to go to Europe to study cello with a well-known musician in Strasbourg. I left school that year with the strong conviction that I would hear from Susan in the next few years, and I admired the courage she had to choose the road of music.

Fifteen years later, I work as a pharmacist in an outpatient psychiatric clinic. People attending our clinic are first episode psychotic patients. Our team has put in place a multidisciplinary program to help patients, with the hope that early intervention will make a difference.

At first, I couldn't believe it was she. She was so devastated. She had just left the hospital. She was hospitalized without her consent because she had threatened a dishwasher repairman with a knife, convinced he had come to her mother's house to hurt her. Her beautiful hair was a mess. She had pulled out a tuft of hair, leaving a big spot on the bottom of her scalp. She had several cutaneous lesions she had inflicted to herself on her face and arms. She had acne and hirsutism and had gained weight. She was frankly psychotic, with grandiose preoccupations, talking about NASA, about other worlds. She had absolutely no insight into her condition and was convinced she was in the middle of a plot. She nevertheless recognized me easily. She even helped me to deal with this strange and painful situation by not letting me ask her

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too many questions. She minimized her condition or, at least, never fully described it to me. She talked very fast, referring to the past and our successes together. It was like her life had stopped there. For me, it was the beginning of a series of accomplishments. For her, it was the beginning of her deterioration. I was shocked. I felt immensely sad. I felt like I had witnessed her apotheosis and now was the witness of her decline. My colleagues evaluated her and planned pharmacological and psychosocial therapeutic interventions.

Susan had her first symptoms in Strasbourg, where she was hospitalized and given haloperidol. This experience was very stressful for her; she went through a painful dystonic reaction that finally led her to leave the hospital without consent. She managed to come back to her mother's house. She was hospitalized twice and then disappeared. From what we learned after, she left for another city and lived as an itinerant for 1 year, untreated, alone, unable to get even social assistance. Her living conditions were extremely harsh. Finally, her mother got her back home and managed to bring her to our clinic for a first evaluation, pretending it was not a psychiatric clinic because Susan would have refused to come. Then she had to be hospitalized without her consent when the repairman incident happened.

At first, she was treated with risperidone. She responded very well in terms of positive symptoms reduction. She rapidly became free of any hallucinations or aggressive behavior. However, she still had no insight and had persistent negative symptoms, particularly sadness, avolition, and lack of interest. Anxiety was also present. An antidepressant was added and helped her mood. She reported amenorrhea. Her mother also noted light galactorrhea. A pregnancy test was performed and proved negative. Marked weight gain was also present. The risperidone dosage was reduced, and laboratory tests were performed. Considering all these side effects, it was decided to stop risperidone and start olanzapine.

It has now been 3 months since this new treatment was begun. Susan remains fragile, with no insight, marked apathy, and a tremendous need to be taken care of. Her menses have returned, and galactorrhea is no longer present. The recent neurocognitive assessment reveals an average intellectual capacity, inferior to what would be expected of someone with her education level. Deficits of executive functioning, particularly in planning tasks and elaboration of complex strategies, are observed.

Susan still lives with her mother. She does not play the cello anymore and is very anxious about her future. Every time I see her, it hurts. I cannot accept what the illness has done to her. Life is now so hard on her. I can see the harsh and devastating impact of a severe psychiatric illness left untreated for too long, with undeniable sequelae.

As a professional, this experience gave me a new understanding of patient and family grief about the loss of a hoped-for successful life. Learning to deal with a new life perspective is a painful aspect of the illness and one important step of the remission process. Obviously, I also learned that I cannot be a health care professional and a good friend at the same time. My clinical judgment is biased. It had been decided early on that I would not be professionally involved in Susan's case. But this experience has changed my practice. Recently, I went to a meeting of families where, as a pharmacist, I shared some notions on medication and on side effects. I felt more touched by the questions, the fears, the anxiety of these people than I ever had before. I felt their hope and their fear, and I shared their outrage at not being able to cure this disease.

As a friend, I learned that, as life goes on, challenges you would not have expected come along. It brings you back to simple things: family, love, health. I still grieve and hope optimal treatment can offer Susan a new freedom to be herself again, a new self different from what I knew, but hopefully still inhabited by this unique flame that is her essence. I hope to play music again with Susan one day. I hope this day is not so far off. Most of all, I hope she and I will regain the joy of sharing simple things, simple thoughts, simple notes.

Epilogue

More than 2 years have passed since this paper was first written.

In July 2001, Susan committed suicide. That night, she amazed everybody with her joy and serenity, playing music and singing at a family reunion, something she had not done for a long time.

I have to admit the pharmacological treatments did not reach her level of expectation: Susan never really had a full remission and experienced unacceptable side effects all along. Because of her apparent lack of insight, it was sometimes thought that her suffering was limited and that she was, consequently, protected from the crude reality of her life. I never really believed that and, in a way, I am not surprised by her decision, even though it is hurtful.

Her fight has touched us profoundly. Her quest contributed greatly to further push our goals in research. Our team is about to start an important research project on metabolic and endocrinologic side effects induced by atypical antipsychotics and Susan was our initial inspiration. She is constantly a part of my motivation as a clinician, as a researcher, and as a woman who cherishes a unique friendship. I will forever treasure her talent, her courage, and her willingness.

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