

First Person Account of Schizophrenia: a Carer's Perspective

The following article is a first person account written by the sister of someone with schizophrenia.

My brother has schizophrenia. He is the youngest of the family. I am the oldest and I have two sisters. My father was a civil servant. My mother stopped work after marriage and took care of us full-time. The relationship between my parents was not a happy one, and my father lived away from us and Hong Kong for a time.

My brother was a bright child, always the first in class when he was small. The first evidence of his illness occurred when he was 15. He suddenly displayed difficulty with his schoolwork, could not sleep at night, heard noises, and became emotional. He cried in front of my mother, saying that he learned about my father's extramarital relationship. This coincided with a trauma he witnessed in school, where one of his classmates died in an accident.

In the following few years, my brother struggled with his study. Schooling was on and off, but he managed to finish high school and sit the school certificate exam with passes in English and Mathematics.

He received treatment from an outpatient psychiatric unit of a regional general hospital in Hong Kong from the time of his first illness. He was hospitalised a few times and given 'shock' therapy. He also received some occupational therapy training in the outpatient department.

Later, we helped him find a job in a printing company through a newspaper advertisement. He worked there as a messenger for about 2 years. After that he remained idle at home for more than 20 years. Socially, he was rather isolated. He was almost solely taken care of by my mother, and to a lesser extent, by my father. Both of my parents were highly protective. My brother was never required to do any household work. He never missed a single medical appointment, nor a single dose of his medication, due to my mother's close supervision.

Even though my mother was the one who provided most of the care for my brother, he became more attached to my father. My father took him out for meals in restaurants or for other forms of entertainment regularly. He planned much of his daily activities, including calligraphy and diary writing. However, my brother's condition did not improve. In fact, it continued to worsen, so much so that he displayed serious symptoms of confusion and was easily agitated. He developed poor eating habits and table manners. He looked unkempt. He kept on scolding my mother, sometimes fiercely. We began to worry about his potential for violence.

In 2005, I retired from my career and with more free time, I assigned priority to dealing with my brother's problem. My sister and I asked for a meeting with his case doctor, during which I gave the doctor the full picture of my

brother's condition at home. Up to this time, my mother had been the one who took my brother to see the doctor every 3 months. Her descriptions of my brother's condition to the doctor were usually incomplete. I do not think she was trying to hide information. She just did not see too many problems or new problems with her son, whom she loved so much and tolerated. It was hard for her to note changes in my brother's condition, to maintain interest in telling the doctor detailed stories, or to have expectations for his recovery. Indeed, she had been taking my brother to see the doctor for all his medical appointments for 35 years!

While my mother never allowed my brother to miss any medical consultation or any pill, she had a negative view of psychiatric hospitals and absolutely rejected the idea that my brother be admitted to hospital for treatment. Every time the idea was raised, she became very emotional and reacted strongly saying, "No, unless I die!" My sisters and I felt we were in a dead end in terms of my brother's treatment options.

Following my meeting with the doctor in early 2005, my brother's medication was changed. In addition, arrangement was made for periodic home visits by a community psychiatric nurse, who was friendly and helpful. During one of my conversations with the nurse, I incidentally learned about the Clubhouse, a special unit established by the psychiatric unit for people with psychiatric illness. Clubhouse members are people receiving rehabilitation. Activities are jointly organised and shared by Clubhouse members and hospital staff.

I took the initiative to visit the Clubhouse, and was greatly impressed by its vision and services. I then took my parents to inspect it. With their consent, I arranged for my brother to join the Clubhouse. To avoid problems and give my parents peace of mind, I arranged for my parent's domestic helper to take my brother to the Clubhouse in the morning and back home in the afternoon, all by taxi. My brother found he liked the Clubhouse. He went there 2 to 3 days per week and enjoyed its activities tremendously. When he was there, his behaviour was close to normal. He looked different. He became relaxed and cheerful. He made friends. We were very happy to see this change, and we got to know the Clubhouse staff.

Unfortunately, while my brother's behaviour was fairly normal at the Clubhouse, as soon as he returned home, he became disturbed. Things went on like this for almost a year. Towards October 2006, his condition deteriorated so much that he refused to go to bed at night, kept wanting to visit the Clubhouse, and my parents just could not control him. My husband and I felt we had no choice but to take him to the accident and emergency department of a nearby hospital. He was readily transferred to a psychiatric unit and

has since remained in hospital.

During this period in hospital, my father has visited him every morning, while my mother, my sisters and I have taken turns to visit him during other hours. On average, he has had two lots of visitors a day. He has had good care in hospital, including occupational therapy and physiotherapy. He likes staying there rather than returning home. We believe his good feelings towards the psychiatric unit stem from the good times he had in the Clubhouse the preceding year. My parents are obviously relieved; their current concern is that the hospital will discharge their son.

My brother's condition has remained unstable while in hospital. Some time ago, the Hospital Board convened a meeting, concluding that following discharge, my brother should enter a Long Stay Care Home. With the assistance of a medical social worker, my brother has been put on the waiting list for such institutions. Waiting time is projected to be no less than 7 years.

All along, my mother has been the major contributor to my brother's care, while my father's involvement has increased in later years. Other support from within the family was fairly minimal for a long period, as my sisters and I were pre-occupied with our own families, work, and career. Since 2005, however, we have become more actively involved and are happy that we have taken this step. We are thankful to the institutions and professionals concerned for their service. Our reliance on their support has increased significantly in the last 2 years.

My brother is now 51 and my parents in their late 80's. It is likely that within 10 years, my parents will not be here to take care of my brother. As my sisters and I grow older, our ability to take care of him will decline. Our reliance on institutions and professionals will accordingly increase.

Regarding the attitude, reactions, and problems of carers, I have described my mother in detail. She has a very strong character and a high level of endurance. She is a role model to us for handling difficulties in life. Her declining hearing ability is a blessing in disguise, for she can no longer hear my brother's scolding of her. My father also loves his son and takes care of him. He comes up with 'creative' problem-solving ideas sometimes, such as investment in a nursing home, to try to commit someone or some institution

to take care of his only son indefinitely.

The impact of my brother's illness on my sisters and me has been significant in 2 particular areas. Before our children grew up, we were very concerned about their mental health, for we understood that schizophrenia is genetic. We were also concerned about the financial implications of my brother's illness. Besides being chronic, Wikipedia identifies schizophrenia as the third most disabling disease, after quadriplegia and dementia. We were hesitant to let my brother see private doctors due to the high medical bills involved, even though we were told that new medications only available through private doctors might have less side-effects. Our hesitancy might have deprived my brother of better health.

For 2 years, my brother worked as a messenger in a printing company, with a supportive employer and supervisor. While labour was scarce and courier services were less developed in Hong Kong at that time, we found people generally civil and sympathetic. With the emphasis on corporate social responsibility, we hope people recovering from psychiatric problems will be given more opportunities in the future.

We highly appreciate the medical and social services provided by the government for psychiatric care. The services are comprehensive, professional, and affordable. The Clubhouse is a remarkable concept. Its contributions and effectiveness are proven. It changed my mother's attitude, from absolutely refusing to let my brother enter an institution for treatment, to appreciating his hospitalisation. It was a breakthrough, which paved the way for us to find a long-term solution for my brother's problem although I understand this is not the Clubhouse's purpose. It is meant for rehabilitation of psychiatric patients. My brother still remembers the happy days he had in the Clubhouse and asks to go back. I hope he will be able to do that soon.

I also hope more resources could be allocated to the Clubhouse model, and that there could be more publicity and promotion about the services it offers. We consider ourselves lucky to have discovered the existence of the Clubhouse.

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