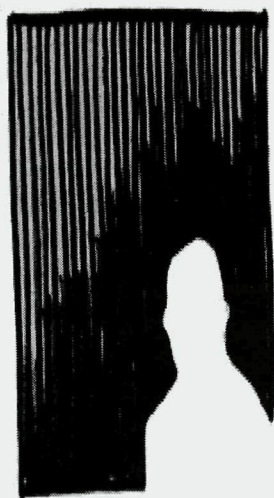


The Never-Ending Story: Robert's Lament

This narrative provides a snapshot of what it is like to deal with a loved one stricken by mental illness. Stories and poems have served the author well, as she learned to express and process the pain and hurt of living with her son's condition. It has been a difficult road to travel, and the author expresses the difficulty of imagining the meaning of her son's life as a schizophrenic. This narrative, therefore, is written as a reflection of her struggle in hopes it may light the way for those who must travel the same road.

by
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Robert—Genius Boy

As I look back, Robert was a brilliant little boy who was raised by me, a single mother, until his stepfather, Jorge, came into the family when he was five years old. He did not have a history of abuse—physical or psychological—although he recently recalled memories of child sexual abuse perpetrated by the daughter of his family day care provider.

Robert was fun, creative, and an extremely intelligent child. He could read when he was four, and at five he could read a book upside down. I remember him using this as a ploy to impress other adults around him when we would attend community meetings or other public events.

"Look! Look! I can read this book upside down," he would say to those who would listen to him. With deep-set wide eyes and a modified Beatle haircut, looking as cute as a button, Robert seldom lacked the attention he sought.

When he began kindergarten, however, there were some

changes in my son. He became afraid of everyday things. For example, his first year of school, after he learned to walk to and from school, I would often be called at work to pick him up because he was afraid of the dogs in his walking path.

"Mom, come and pick me up. The black dog scared me. I don't want to walk by myself. Please, please, come and pick me up." It took him more than a year to walk home from school, but the extreme fear remained. I would experience multiple disruptions at work to pick him up and take him to his family day care home.

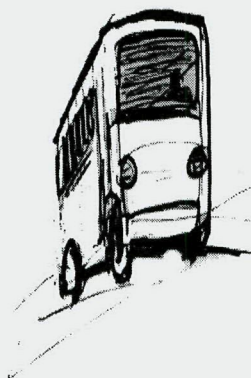
My son never had an easy time making friends. I don't recall a single friend from his elementary school years and only one friend from middle school. Family served as the core of his ability to socialize. When he entered high school in the ninth grade, he attempted to penetrate the narrow and parochial peer groups there in a desperate attempt to fit in. He tried all the groups available to him, but the "druggies" were the only ones willing to include him. They, like my son, understood what it was

like to be high school outcasts.

Despite his difficulties making friends, his overactive imagination, and his extreme fear as a young child, it was not until Robert was nearly sixteen that I began to notice clinical symptoms. It was then that he began to experience olfactory hallucinations and to become compulsive about self-grooming, taking two to three showers a day. Our family was baffled by this behavior, but we assigned it to the difficulties of adolescence.

My Firstborn Son

Late spring of 1990, when he was 16, I sent Robert to México. He was experiencing a very difficult adolescence and doing terribly in school. My husband and I were at a loss about his borderline anti-social behavior. Robert



was truant from school, did not want to study, broke curfew, and refused to find a job. So, we sent him to stay with Tía Juanita and Tío Gabriel.

My tíos both were wonderful, nurturing, and caring persons who had raised eleven successful

children. Along with that, they lived in the town where my mother was born and raised, which would give my son an opportunity to meet and get to know both sides of my family.

His stay lasted less than six months. When Robert came back, he seemed to be increasingly angry. He attempted to pick up the pieces by returning to school, finding a job, and reintegrating himself into our family. In his ambivalence whether to become an adult or to remain a child, Robert fought us all the way; he refused to be held accountable for his behavior, for example, smuggling a girl into his bedroom. After that situation, Robert moved out to a seedy side of town with his two friends, a pregnant 16-year old girl about to give birth and her boyfriend, Bruce.

Soon after Robert had been "on his own," Bruce came to tell me that Robert lacked the maturity for independence. (Robert survived on the food we bought him and kept clean by washing his clothes at our house.) Bruce also expressed concern over my son's suspected drug use. "Rob is a little kid. He needs your help, but does not know how to ask you. Go pick him up."

I took Bruce's advice. The next day, I got up early, went to the house my son shared with his friends, and knocked on the door. No one responded to the first two or three knocks. I persisted. Finally someone heard the knock and Bruce answered the door. I asked if Robert was home. "Rob is in his room," Bruce said, as he ushered me in. The house was filthy: cat droppings all over the

place; a kitchen sink filled with dishes; and clothes strewn on the floor. With my insides at my throat and my stomach churning, I knocked on Robert's tiny loft.

"Robert. Get up! I have come to take you home. You have no choice but to come with me. I am taking you out of here."

He groaned and babbled, and still half-asleep Robert said, "I'll be right there."

Agreeable and docile he came down with all his belongings. His appearance did not signal any warning signs. Apart from his disheveled and uncombed hair, he was clean. His weight had not fluctuated greatly; he was the same size. When he saw me, he sighed as if to express relief and gratitude.

In the car, Robert and I did not speak to each other for what seemed an eternity. The silence gave me time to think through a plan of action. My husband and I had agreed that he could return home, with the expectation that he would have to follow the rules of the house. My mother and my brother also had made themselves available to Robert if he wanted to change his environment and return to school. Since he did not like living with us or the rules we had for him, Robert chose to go live with my mother. He was to have stayed there until he graduated from high school.

At a family meeting, we laid out the expectations: he was to attend high school and graduate; if he dropped out of school, he was to go to work; he was expected to contribute and help with the household needs. He agreed to all conditions. The way we saw it, these expectations were estab-

lished to help Robert transition into adulthood.

In the fall 1990, Robert went to live with my mother, my brother, and my brother's girlfriend. I'm sure respect for those persons who wanted to help him influenced Robert's decision.

Pre-Onset Behaviors

In late 1990, Robert broke his agreement with my mother and brother—he did not graduate from high school or hold consistent employment and moved into his girlfriend's home, into shady dealings, and into the illegal drug trade. His girlfriend's family, which actively participated in the gang and drug life of our town, became his haven. He severed relationships with all of us and became immersed in the lives of his girlfriend and her family. Opting for a lifestyle that was not of our liking, Robert became estranged from us as he became an integral part of his fictive family. However, there were times when he would call and tell us he needed money or food for the children he babysat for. We were suspicious of his requests.

"Mom. I need money for groceries. The children haven't eaten. We have nothing to eat in the house."

"Grandma. Lend me some money. I'll pay you back."

"Tía Felisa. Do you have some money you could lend me? I need to help and I'm out of work. Can you help me?"

More often than not, my brothers and sisters and my mother or I would help him. But, there came a time when we grew tired of his calls.

I recall the countless times,

refusing his request, I said, "Roberto. She gets welfare for those kids. What does she do with her money? That's it! They're not my responsibility. Don't ask me for money anymore," as I refused his request. Soon, he stopped calling, and he stopped asking for money.

Robert remained distant for months at a time. However, sometime in July of 1991, I got a call from María, his girlfriend's mother.

"Robert is tweaking." She said, without even identifying who she was.

I had no idea what Maria was talking about. Even though I had worked in and around youth and families who used drugs, her statement made no sense to me.

"What do you mean?" was all I could say.

She quickly responded: "He took an overdose of crank. The only thing I know that will bring him down is a shot of heroin. I'm going to give him a shot."

"No! Don't you dare!" I shouted.

Drawing from my experience as a professional who worked with drug users, I said, "Give him plenty of fluids: Orange juice, cranberry juice, waters, and make sure he eats." I feared she would make a *tecato*, a heroin addict, out of my son. I didn't know what else to say or do.

"That's the only thing that works." Maria repeated.

Without telling her I would be at her home, I hung up and flew the 37 miles over the Santa Cruz Mountains to see about my son.

I was there in record time. Robert was incoherent and completely out of it. I wasn't sure he

even recognized me.

"I tried to kill myself," I heard him say to me with a conviction that frightened me.

Fearing repercussions, Maria asked me to take Robert home. "*Llévatelo. Yo no quiero problemas!*"

I took him home. Once there, Robert seemed a bit more relaxed. However, the paranoia and fear intensified. My son did not want to be left alone or out of my sight. It became an unbearable situation, a week of pure hell!

Traveling Through Madness

After his break, I could see why my son had been attracted to a drug-friendly environment. Use of drugs, the literature states, is not an uncommon response for pre-onset individuals. Mentally ill people use drugs as a means of normalizing the irrational fears, dealing with the "not fitting-in" experiences, and coping with the unexplainable behaviors.

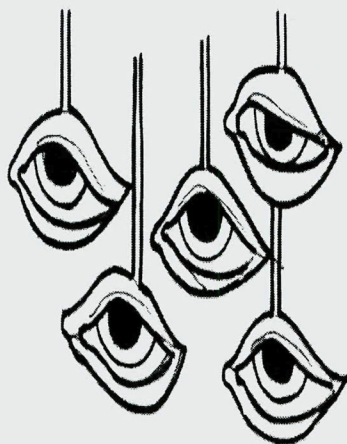
Still, as his mother, I was willing to see his mental problems as drug induced because there was a possibility of recovery. In that light, my quest to get help for Robert began.

I initially approached two drug-rehabilitation clinics. When I took him to the first one, he was extremely agitated. He refused to get out of the car and would not go into the facility because he took the workers for devil worshipers and accused them of engaging in bizarre behaviors. In his reality, every car that passed and every person he saw was somehow connected to "those people who want to hurt me."

Time and time again, drug facilities refused to help Robert

because they perceived his problem as something beyond their control. Employees at these facilities expressed regret but also shared their concern that his need was beyond what they could treat.

Next, I tried to get my son help with Community Companions, a community-based program for mentally ill. This, too, proved useless. Although Robert was begging for help, this agency refused him assistance because it did not serve dual diagnoses clients. With every viable option closed to him, we returned home. I made sure he ate and gave him plenty of liquids, intending to flush out whatever drug residue



remained in his system.

These were difficult times for our family, and me in particular, as a professional and his mother. To me, it was obvious that Robert was medicating himself to normalize the confusion he was experiencing. I found myself voiceless and powerless, despite having the knowledge necessary to help my son. I could not get for him what I had many times before provided for others as I

helped them gain access into mental health and drug facilities. I had opened doors for others that would have remained closed were it not for my advocacy efforts. Yet, in our personal situation, when seeking support for my son's condition, my professional entrée and knowledge dissipated. As the mother of a mentally ill son, I found my professional status to be irrelevant.

All the while, I struggled with the tension between professionalism and motherhood. It is one thing to read about mental illness in books and another to diagnose mental illness, especially when it is your own child living the symptoms. It was a grueling and difficult experience.

Robert talked about eating human flesh in the pizza. He was suspicious of everything he put in his mouth because, he said, it tasted like blood. I could not go anywhere. I could not leave the house because I was the only person he trusted and with whom he felt safe. He didn't even trust his younger brother.

"Don't mess with me, Mom. I know Corky is seeing Vicky, my girlfriend. He is in it with them and wants to kill me."

After three more days at my house, it became obvious that I could not help Robert. Again, acting on the premise that this was a drug problem, I sought help from Victory Outreach, a church-based drug program that agreed to accept him in their East Palo Alto facility. He agreed to go. The church affiliation seemed appealing to him somehow. When I got home, I had a message that Robert was found on Highway 101, walking against the traffic toward San José. On a

courtesy drop, the CHP took him to my brother's house. By this time it had been close to two weeks since Robert had taken the overdose. I drove to my brother's to see what I could do.

I felt stretched between professional obligation and my feelings as a mother as I encouraged my son to voluntarily sign himself into a mental ward. While I did not want to see him in a mental ward, I knew the best place for Robert was a psychiatric hospital—I feared for his safety and the safety of others.

I struggled with the hospital to hold him longer than the initial 24 hours. I wanted my son to be helped. Finally, after much persuasion and additional data, his 72-hour hold was expanded to 14 days, but his girlfriend came and took him out under the pretense of wanting to help him. She convinced him that all would be well once he was drug free and no longer "tweaking" from the overdose.

In a delusional stupor, Robert went to Lake Tahoe and married his girlfriend. He felt he would be safer around her family. Marrying her gave Robert the false sense of safety he needed to be around them.

Robert stopped taking the medication the hospital gave him, on the advice of his mother-in-law and his new wife, who told him to "ride it out." The psychosis returned without the medication. When the paranoia intensified, my son was on the telephone asking me to come get him.

"I don't feel safe in my in-law's house," he claimed. "Mom, I'm sure they are going to kill me."

I brought him home again. In

trying to get him help, I was referred to various drug programs. I did not fight the referrals, preferring to believe that my son had a drug problem instead of a serious mental health problem. I could see a possible solution to his problem if I looked at it from this point of view.

Angels at My Table—*Guardianes y Amigos*

Feeling completely hopeless, I called Lorelei, a clinical social worker friend of mine. I asked her

what happened? This is not like Robert."

Robert seemed to feel comfortable there, yet he asked to sleep with the lights on and also locked his room from the inside. The next morning, Robert managed to put forth a facade that convinced us that he was feeling better. We went home; Robert stayed in Philo.

The day after he got there, I got several calls both from my friend and from Robert. She was seriously concerned that Robert's

for their safety, Lorelei hid the cutlery and any other sharp object in her house. She became concerned over the potential harm that could come to her and Robert.

When she had done all she could, she called and told me that he needed more help than she could give him. "Joze, I told Robert he could no longer stay with me. I asked him where he wants to go. He said he wanted to go to Modesto with his aunt." Lorelei bought him a greyhound ticket to Modesto.

Seeking a "Home"

The constant spatial movement experienced by my son is not uncommon for individuals who are mentally ill. Movement was the one constant my son experienced in the initial phase of his illness. Only twenty-one years old, he had moved in and out of four counties in the period of four months. Running away from and to became metaphors for the confusion and displacement Robert felt.

On his bus ride to Modesto, where he expected to find respite from the paranoia and delusions, Robert fell asleep and ended up in Sacramento. He got off the bus and took a ride from a drunk driver. They were in an accident.

He called me from Lodi Hospital. "Mom. I've been in an accident. Please come pick me up." I refused. He was 250 miles away, and I was determined to abide by the limits I had set for him.

He finally ended up at my sister Margaret's in Modesto but my sister, afraid of Robert, had her husband, Joe, drive him to our brother Juan's.

As soon as they arrived, I got



to help me with Robert. Knowing the urgency of my academic deadlines, she agreed to take him in until we could all figure something out or until I took my oral exams to advance to candidacy. This was mid to late August of 1992.

With some trepidation, but knowing that Lorelei had expertise with mental illness and drug abuse, Jorge and I drove Robert to Philo, California. Lorelei lived on a ranch that had previously served to treat extremely emotionally disturbed children. Lorelei, who had known my son for about six years, said, "Joze,

problem was more than the results of a drug overdose and felt that all Robert's symptoms pointed to mental illness.

As Lorelei told me, "Robert was hearing things, seeing things, and still extremely agitated. While he fronts some rational sense of his surrounding, he cannot cover his delusional thoughts."

My son wanted to sleep in the same room where she slept, and his explanation was that he was afraid of the creatures that lived in the town and wanted to hurt him. By the third day of his stay, Robert expressed a desire to protect himself with a weapon. In fear

a call from my brother. "Josie, Robert has been dropped off at my door step. He needs you to come and get him."

I talked to Robert. Knowing that Mendocino, the county he had just returned from, had been receptive to helping him, I convinced Robert to return there. Promising to find him emergency housing in a homeless shelter, Lorelei had offered to connect him with a mental health and homeless advocate and to help him begin the process of applying for General Assistance (GA) and medical insurance. Juan bought him a Greyhound ticket for his return to Ukiah where Lorelei worked.

Santa Clara County, Robert's county of residence, had refused to treat him. Lorelei and I thought that since Robert was in the system at Mendocino County, he would be better able to receive services. Robert returned with the intent of establishing residency. However, he was unable to complete his application and requested help with the forms. When he was finally able to complete the forms, he found out there was a 30-day residency requirement for processing his application. He became frantic because his housing would run out two weeks before he met his eligibility requirements.

I got a call from him, pleading, "Mom, please! I only feel safe at your house. Please! Let me come live with you."

As heartbreaking as it was I had to tell Robert no. I was very clear from the beginning—with him and myself—that his living with me would not be good for either of us. As a professional, I

knew I could not help him. As his mother, I lacked the degree of patience and compassion necessary to be his caregiver.

Every time Robert called, I repeated that he could not live with me. "We need to get you some help and the process there has been the most humane and receptive to your needs," I said to him. County personnel there had been the only ones receptive to his needs. Also, he had begun to make connections with homeless and mental health advocates and other support systems.

The last call I got from Mendocino County sounded extremely desperate. Rightfully, he was frightened about the prospect of ending up in the streets.

His Return

I told Robert he could come back, but only if I could find a homeless shelter or mental health service that would take him. I reiterated that under no circumstances would he be able to come and live with me. He agreed to these conditions.

Tim, Lorelei's husband, drove Robert to Santa Clara County's Valley Medical Center where I picked him up. As much as it broke my heart, and as much as he obsessed about coming home because it was the safest place for him, I refused. Dealing with a son who was in active psychosis was something I could not take on nor was willing to assume. I wanted Robert to get professional help. As his mother, I was clear I could advocate for him and support him, but I knew I could not take charge of his affairs or be a primary caregiver. I lacked the time and the patience to assume this

role.

I took Robert to Julian Street Inn in San Jose where he lived for about three weeks. In early November of 1992, he entered an experimental dual diagnoses program called Virginia Street Project. He was placed in a board and care facility.

Since then, Robert, my husband, my younger son, and I have established a relationship that makes sense for our schedules. My extended family has been apprised of his condition. With some reservations on some family members' part, they are beginning to understand that he is schizophrenic. He is included at family gatherings. He attends birthday parties. He is invited to dinner and occasionally is taken to the movies or sporting events.

While my family of origin does not fully understand Robert's condition, they are there to support him as he attempts to deal with his illness. I hope they and we can handle the arduous road to come, particularly as we confront impending relapses.

In the Fringes of Madness—*En el Margen de la Locura*

In 1994, after I completed my fieldwork, Jorge and I moved to San Antonio, Texas, where we were offered academic positions in the same community. I made the move with the expectation that I would have to continue advocating for my son's treatment as he navigated the cycle of mental illness.

"A woman called you. She said Robert tried to hurt himself again." Cautiously and laboriously attempting to protect me from the pain embedded in the mes-

sage, Jorge repeated the messages for the day, "Robert tried to kill himself. You better call her."

I decided to wait and eat my meal, having just arrived from teaching a class. I sensed Jorge glancing at me through his peripheral vision. My response baffled him; he was confused by my new strategy for coping with the ever-present crises in Robert's life. Was I learning to handle the situation? Could be!

"Please tell her to call by nine" the note said. I waited until almost nine to return her call. I needed the time to gather my wits.

"I'm returning your call," I heard myself say to Ms. Salud.

Without an attempt on her part to soften the blow (I'm sure this was not the first such call she has made about a resident in her board and care facility), she told me: "Robert has cut his wrists."

"Are the wounds superficial?" I said, attempting to assess the seriousness of the situation.

She responded. "I think it's just a cry for attention from your son. He is very lonely."

I spoke to Robert. He talked of feeling empty, tired of being perceived as incompetent and incapable of handling his life. "Mom. I wish I could live on my own. I would be all right." This has been part of the magical-thinking aspects of his illness.

He explained that he feels trapped by the paranoia and delusions. He curses the schizophrenic condition that controls his life.

Robert is not the only one affected by his illness. The paranoia and delusions have enveloped all family members. It's no wonder he feels lonely. His illness is cumber-

some, although we cope with it the best way we can. I, two thousand miles away in San Antonio, feel insulated by the distance. However, the protection afforded by the miles also binds me in constant engagement with my son's condition.

His physical absence did not blot him or erase him from my mind. He was embedded in my daily interactions. He was with me, despite the distance. Just as he contended with the voices and exaggerated fears, I lived with the impending crises of his illness.

Is it a Dream? *¿Dónde Estoy?*

It's summer 1996. I live with the potentiality of an impending crisis. I live with the expectation of a call. From week to week I fear the past repeating itself. I dread a replay of the calls and of days gone by.

"Robert is homeless."

"Robert killed himself."

"Es tu hijo, ¡cúidalo!"

"You are his mother. He's your responsibility. Take care of him."

When does mothering end? When are my caregiving responsibilities accomplished? Do I have to be fused to my son? Or, do I attempt to create the recommended distance that supports his empowerment and self-sufficiency? Therein lies the answer, in the tension of the unknown, the unpredictable, and the uncontrollable. The answers are tenuous, as is his condition. The answers change along with his prognosis.

When talking to strangers about my son's illness, I often hear myself say, "My son is mentally ill. His condition can be managed with medication. He has a mind of his own. He has a case manager

and services at his disposal. He needs autonomy and independence. He needs the clarity necessary to learn the coping skills that will help him and us live with his illness." With this speech act, I am trying to humanize and normalize my son's illness. However, when interacting with family members, my speech changes into a more active and invested self as I say, "You don't have to help him if you don't want to. He has a support network. Send him there." These words play out in my conscious mind and in my dreams like a broken record, as I engage Robert's illness even in its dormancy. Like his delusions or his voices, my concern for him plays a complementary self-talk that never ends.

There are times when I relive or dream about conversations or calls I have received. For example, the times my brother Juan José called about one of the many psychotic episodes that my son was experiencing, I was choked by the emotions welling up in my throat, unable to respond.

I can still hear Juan, his voice crisp with frustration, resenting having to confront Robert's illness one more time, say, "Josefina, Rob is here."

"He really believes someone is going to kill him. I don't feel safe with him here." Fearing for his family, Juan adds: "María [his wife] and Max [his son] are at risk."

Hasn't he learned that the harm is imaginary? I think to myself.

I want to say, "At risk of assassination by imaginary demons," but I remain silent. I swallow the words and his attacks on my mothering, exhausted by my

already frayed emotions. My sad heart and empty soul weep.

"He is your son. He's your responsibility. You don't give a shit about your son. He needs to be with you. He needs your care."

"¿Por qué no me dices lo que sientes? Why don't you really tell me what you feel?"

He doesn't mouth it, but I hear him loud and clear: "I'm tired of dealing with your son. I don't know how to tell him to stop coming to me every time something is wrong. I don't know how to turn him away. Get him out of our lives. I want to continue living in the safety of our isolation, away from all the hurt he brings us."

I mean to be empathetic and say, "I hear you Juan." Instead, a dam of tears caught in my throat bursts. I'm voiceless. I can't and won't engage his judgments and criticisms. I allow myself to break down, as I am engulfed by the misery of it all.

Finally, I break through the tears. Clearly and precisely, I tell Juan that Robert is having another episode. "Did Robert take his meds? How long has it been since he took them? Has he gone to see his case manager? When was the last time he saw his case manager?" Juan hears only my questions. He fails to sense the emotions that tug at my heart as he imagines me in the safety of the distance between us. After all, I am two thousand miles away and Robert is there. My brother wants me to make it all go away. I can't.

I finally gather my wits about me and tell Juan to send Robert to Downtown Mental Health. "Have him go ask for help." We hang up.

These recollections keep me connected to how I have felt and still feel about my son's illness. I feel put down and less of a mother to my son when interacting with loved ones about my son's illness. I know Robert's schizophrenia imposes additional burdens on the family and particularly on those he trusts and relies on for support. I ache for them, as Robert's incursions into their life disrupt the "normalcy" of their daily life. As his mother, I live with impending needs of my son.

These dreams and conversations with myself remind me that I live with the knowledge that someone—any one of my family members, a mental health worker, or Robert—can call me at any time to inform me that something has gone wrong. When that happens, I will have to resume the never-ending cycle of his condition.

Reflection

I have been living an emotional roller coaster since Robert's diagnosis. The feelings that I had learned to reawaken in myself as I healed from past hurts and mistreatments are sometimes buried and hidden within me because I have been resorting to internalizing and hiding the pain I feel as a result of his illness. It is a form of protection. Perhaps I am using a misplaced strategy for coping with the unknowns of dealing with Robert's mental illness. But, if I am to survive and continue to learn from the experience, I must resort to what works while I learn the personal skills for survival.

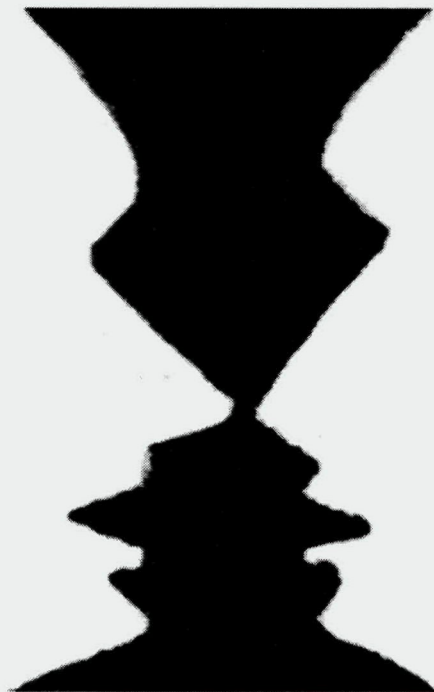
Still, all is not lost. My creativity has resurfaced. I am writing

poetry, keeping journals, and documenting my son's experiences. This creativity serves me well and helps me to focus on the learning that comes from living with a loved one who is haunted by the specter of schizophrenia. All those around my son, my family, and I grow with every interaction we have with Robert. As a mother, I have become more patient, compassionate, accepting, and insightful. I am also learning to trust myself. The professional books did not prepare me to live with my son's mental illness.

As a professional who is intimately familiar with the mental health system, I have learned that I cannot diagnose or treat a person in the family for mental illness. However, as I interact in my son's life, I find myself having to use my knowledge and skills to document, analyze, and name the sets of behaviors I observe in his illness and to advocate for his treatment. I am using what I know. I aim to learn more about the disease as I try to better use the intuitive, emotive, and educational aspects of my professional life to support my son. I want to help him achieve as much self-dignity as is possible in this culture that is so driven by normalcy.

In the past, I could not sit idly and accept the conclusion that Robert was ineligible for social security benefits because some bureaucrat perceived him to be able to perform unskilled work. Now and in the future, I will continue to hold accountable those individuals and institutions that provide services to my son as I advocate for a humane approach to treating mental illness. I feel entitled. I have been inside the

madness and the pain as my son and our family deal with the spiritual, psychological, and emotional pain of his illness. His words say it best: "Mom. Because I'm schizophrenic does not mean I don't feel. The only difference between you and me is that I have at least eight televisions going in my head at all times, which make my attention and concentration difficult to achieve. Maybe now you can see how I get lost inside the goings on of my head."



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