

## A Journey with My Sister and Mental Illness

I lost my sister on Sept.4 after a lengthy battle with mental illness. I wanted to write this story to help other families dealing with mental illness. I cannot do anything more for my sister but I can honor her memory by helping another family.

My sister Abigail was born Oct 4, 1959 in Gulfport, Miss. She was deaf at birth and went on to graduate the Miss School for the Deaf in Jackson, Miss. She was a star basketball player and excelled academically. After graduation she was scheduled to attend Southern Miss. University. She started to exhibit extreme paranoia that summer and was hospitalized. She was ultimately diagnosed with schizophrenia and sent to the State Hospital at Whitfield. She was there for 19 years without a lot of family interaction. Every year I would visit on her birthday. We were so happy to see each other and she seemed so well behaved. We would go out to eat and shop without incident .I would then take her back to Whitfield and return to Okla. I asked many times about her transferring to Okla. and in 1997 during a visit Whitfield said they would contact Okla. On Oct 1 she arrived in Okla. City escorted by a social worker from Whitfield and met by Paul Summerville; director of Griffin, Bill Erickson and myself.

1997 began a roller coaster ride of extreme highs and lows through a broken mental health system in our state. I will tell you these last ten years has been the most difficult journey of my life. I loved my sister very much and until I spent those first visits with her I never understood the depths of her illness. I believe when I went to Miss. we were so busy making up for lost time I only saw what I wanted to see. After she got to Okla. and I was directly involved did I really understand. Abby was truly extreme in her psychosis and being deaf made her treatment virtually impossible. She was not understood and could not communicate her real feelings so she yelled most of the time. Once in awhile she would be provided an interpreter but most of the time it was paper and pencil. Bill Erickson tried early on to insist she always had an interpreter but because of cost I think he was finally shut down.

I went to court and became her legal guardian. I enrolled in college for sign language and even entertained the idea of becoming an interpreter. After 4 years of school I new I wasn't cut out to be an interpreter but at least I could communicate more effectively with my sister. I joined TSHA (which provides services for the deaf) and ultimately became Vice President. I joined NAMI-Tulsa and attended Family to Family classes with John and Mary Taddiken.I attended meetings, became a board member, and went on to be Vice President. Without the support of these organizations and many wonderful people I am not sure how I would have made it through the last ten years. I always worked full time but I knew I had to dedicate as much time as I could to get my sister the services she deserved.

I assumed the services would be the same for Abby in Okla. as they were in Miss. but I was so wrong. I had no idea Eastern State would be closing when I brought her here. She was sent to Griffin first then transferred to Northside Nursing Home in Sapulpa. I was very naive at that time and thought this was a great idea. She would be close to me and I could visit her almost daily. . When Abby came to Okla. her primary medication was Haldol and she weighed 165lbs. After medication adjustments she skyrocketed to over 300lbs. that first year. The director at the nursing home referred to her as Gentle Ben because she was kind but very large. The people there cared about her deeply and she was happy for about a year. Her psychotic episodes started to gradually increase and she was hospitalized several times. I really started to worry because I felt they were prematurely releasing her back to the nursing home each time. I was afraid during one her tirades some frail little elderly person would be hurt because of her size. She would end up making the rounds at the hospitals in Tulsa because they did not know what to do with her.

I had a standoff at Parkside on Thanksgiving Day with John and Mary Taddiken as my witnesses. It was awful; they insisted on releasing her with nowhere to go. They only had her overnight and during the night she threw coffee at a nurse. I refused to take her back to the nursing home and repeatedly tried to explain my fear of someone getting hurt, to no avail. Finally a staff member came out and said Dr. White was on the phone. I did not know who he was but I spoke to him and he assured me he would send COPES to move her to Doctor's Hospital. She stayed there until she was sent to Grace Living in Jenks. I was told by the social worker at Doctor's that Grace Living would be good because they had a mental health wing. She was accepted for about 3 months and then they got a new director. He said her yelling got on his nerves, and he wanted her out. I did not know what to do because he actually threatened to put her bags on the sidewalk. I panicked and called Dr. White. He intervened again and sent her to Brookside and with Commissioner Terry Kline's help she was sent on to Eastern State at Vinita.

Eastern State went smooth and the staff took care of her with no real complaints. I communicated with Marty and really thought a lot of him and the staff. I would visit regularly and we would go out for the day. By this time I had a new granddaughter and Abby was doing so well I would take her with me to visit. Abby was so sweet with my granddaughter, Chloe, and looked forward to each visit. I should have known it was too good to last. My husband and I were sitting with a cup of coffee and reading the paper when I read "Eastern State Final Closing". I called Commissioner Kline and he said he would see to it Abby would go back to Griffin. In all of my conversations with Commissioner Kline, he always acknowledged the severity of Abby's psychosis. The only way to assure that legislators and caregivers understand this is by putting faces to mental illness. I took every opportunity to advocate for my sister and share her story.

When she was transferred back to Griffin I went down to help with her transition. I visited regularly, we went out to eat, shopping, and just riding around. She did real well until Griffin went smoke free. I have never understood this because she learned to smoke in a mental institution and now it's not allowed. Most people think a nicotine patch should work but it has nothing to do with nicotine it has to do with a mind that doesn't work. She new routine and had no short-term memory so all she new was she smoked yesterday. I would personally rather she didn't because I have never smoked but she had so little pleasure in life.

Her distress became very evident and her agitation increased. When I would visit I would rarely take her out because all she wanted to do was go to a store to buy cigarettes. I was tempted but I knew I could never do this because it would only increase her withdrawal. Her weight continued to increase and so did her lack of mobility. In July of 2005 she broke her leg and after returning back to Griffin from the hospital she quit breathing. She was rushed to the hospital and put on a ventilator. I went down and stayed a week with her in ICU. It was the beginning of many pulmonary problems. She went back to Griffin and even though her agitation remained she stayed fairly stable. After that social workers from Griffin were constantly reminding me that Griffin was not long term care and she needed to be placed somewhere. I had no idea where to put her but I told them if they wanted to try another nursing home I would agree. A nursing home in Jones, OK was contacted and agreed to take her on a trial basis. I think she was there overnight and sent back. They told Griffin she was too agitated for a nursing home.

In December 2006, Abby was hospitalized with cellulitis and deep vein thrombosis for about 3 weeks. She went back to Griffin in a wheelchair but ultimately started to walk again. In February 2007, Griffin called me and she had broken her ankle. When I arrived at the hospital she was in ICU. The doctor informed me that her breathing was not stable so they had her on a bipap machine which helps her breathing and is not as invasive as a ventilator. He said her ankle would need to be set but he was concerned about whether or not she would make it through the surgery. I called all of my family in, just in case. She came through with no problems but she was highly agitated. Norman Regional and Griffin's social workers visited with me and ended up meeting each other. I was told by Norman Regional that Griffin would not take her back because they were not a skilled facility. Griffin recommended a nursing home in Norman that regularly takes mental patients. I went online to research it and discovered they were not a skilled facility. I called and spoke to Rand Baker (the interim commissioner) about the situation. He reminded me there was no long-term care at Griffin but he would look into it and call me back. He never returned the call but the next day Griffin's social worker called me and said sorry I thought they were skilled care. She then again explained they could not take care of Abby so it was up to Norman Regional to place her. I never did receive a call from the commissioner.

In an effort to place her near me Norman Regional had an agreement with Manor Care in Tulsa to take her. I went to Manor Care to do paperwork and hopefully be there when she arrived. I had a prearranged engagement so I had to leave before they arrived with her. I came home later that evening and I had the following voice messages.

Manor Care: Stephanie, your sister just arrived and she is too agitated. There is no way we can take care of her. We called Green Park and they will take her.

Green Park: Stephanie, your sister has a catheter on. There is no way we can take care of her. We are sending her back to Manor Care.

Manor Care: Stephanie, they just sent your sister back here but we would not let them leave her. We called Green Park and told them that they have already accepted her so they have to keep her.

Green Park: Stephanie, your sister is here can you call or come by.

I was devastated and just broke down. I felt so sorry for my sister, who was riding around in an ambulance all day and having people slam the door in her face. Even worse was getting online and seeing Green Park was about to be closed for abuse allegations. I felt completely helpless.

I went to Green Park the next day and they sent her to Tulsa Regional for assessment. She stayed there for about a week and with medication adjustments was sent back to Green Park. I was trying to be hopeful so I fixed up her room and bought her new clothes. I visited daily and for the most part she was settling in. Her leg was always dark and swollen but after it got worse she was sent back to Tulsa Regional. She stayed there another week and remained agitated because she could not smoke. When I would visit she would continuously look back over her shoulder wide-eyed. I felt she was exhibiting bouts of paranoia so I spoke to the nurse about it. The next day she was sent back to Green Park. She stayed at Green Park another week and then one night I received a call from an ER doctor at Tulsa Regional. He said, "I have your sister and I don't know what I am supposed to do with her. She is yelling a lot and I need to know how to make her stop." I explained she was deaf and a paranoid schizophrenic. He told me they were not going to keep her because he had heard that Green Park was dumping their people so they could close. She was sent back to Green Park. I was assured by Green Park's staff that they would remain open until everyone was placed. They had no luck with Abby and she was sent to Laureate the day Green Park shut the doors.

The first day she was there I went after work to visit and it was truly the lowest point in my ten-year struggle. She was in a glass-enclosed room with an attendant watching her. I asked why and was told she might be a danger to others. I had no problem with her being isolated for a day or two to monitor her behavior but why a glass room where she can see everyone else moving around and she can't participate. She is already deaf and isolated and now she has an attendant who doesn't know sign language. The attendant even picked the

shows on TV that they wanted to watch and there was no closed caption on the screen. She really cried and it was all I could do to hold myself together until I got out of there. It had a small backroom with her bed and bathroom but other than that it reminded me of a fishbowl. By the time I got to my car I was crying hysterically. I remember praying to God to please give her peace. I have prayed for her a lot in ten years but never as desperately as I did that day. The social worker called me daily pushing for a place to put her. I was completely beside myself at this point and every time I would visit her "fishbowl" I would reach a new low. They called one day and had discovered a nursing home in Ohio for mentally ill people. Can it really get any worse? Finally they called me about Calloway Nursing Home.

I called Calloway and spoke to the Director. He said they were in Sulphur about 150 miles south of my home. I was sad about that but ultimately wanted what was best for Abby. He assured me that Laureate had given him all the information. I said you know she is deaf, incontinent, yells a lot, schizophrenic, paranoid, and just overall hardheaded. He said he knew and felt they could take care of her. He said they had people that understood sign language and they had one other deaf lady. He assured me they could take care of her and I agreed.

I went to see Abby and overall she seemed settled. I spoke to different people on different shifts and they all said they loved her. They said she was funny and had such a sense of humor. My husband, granddaughter and I stopped to see her on our way to Texas for a graduation. It was a Friday so I met the director and his wife. I thanked them for taking care of her and asked if they need anything from me. They said no, we finished our visit and went on. The next few weeks I was blindsided by phone calls about getting her out of there. He finally said he was going to issue an eviction notice and I would have to come get her. I called the nursing home regulator's office in Okla. City. They said even if evicted they had to help me find placement for her so don't panic about threats.

A few days later (about July 10) I received a call from Family Care Center in Kingston, OK. They said we have your sister here and I was shocked. Apparently they had been contacted by Calloway and were told that I agreed to a transfer and would they come get her. The director took his social worker and his director of nursing up to meet Abby. They met her, spent time with her and agreed to the transfer. They were really surprised when they found out I had not been contacted and wanted to know if I wanted them to send her back. I filed a complaint with the Health Dept against Calloway for an unauthorized transfer. I asked about their nursing home and the director told me he had worked for the Dept. of Mental Health and really wanted to be able to help people like Abby. I was encouraged by his mental health background and by the fact that they had actually met Abby. He was worried that it was now 200 miles for me but I explained I would deal with it if they would take good care of my sister. Three days later I went for a visit and found out he had quit. Inwardly panicked I waited for the signs of wanting her out. Abby was hospitalized that week in Madill for

pneumonia. She was very unstable in her breathing and they transferred her to Ardmore. I was called at work and asked about the DNR. I was hysterical but I made it to the hospital. When I walked in her room I was mortified. There were three female and one male nurse in the room and she was completely exposed. She was yelling and they were changing the bed but she had no gown and no sheet to cover her. I wonder was it because she is mentally ill and don't understand. I was livid and cleared the room until she had a gown and sheet on. I wrote the following note on the board in her room "My sister Abigail is Deaf and has schizophrenia, she is a human being and deserves compassion, Please take care of her". A few days later I returned home and she was released to go back to Kingston.

I again went to visit on August 8 and all of the staff gathered and teased Abby and laughed with us. I was so encouraged and we really had a nice visit. When I got ready to leave she started crying and said she missed me. I was upset and vowed I would keep contacting facilities near me and see if I could find someone that might agree to care for her. They had all been exhausted by phone calls but I thought as emotional as I was someone would feel compassion for us.

I contacted a nursing home that did agree to take her but now my mother was in the hospital. I decided to wait to move Abby because my sisters in Texas and I were trying to get my mother moved from Indianapolis to Texas. I would have to be out of town to help move her things and I did not want to be gone during Abby's transition. I called the staff at Kingston and they actually wanted her to stay there so I was really torn. I decided to wait until my mother was all settled because she needed open heart surgery, then I would visit Abby again and make a final decision.

I always prayed for God to grant Abby peace. On September 4th at about 6pm when he could not give her peace on earth he took her home. I received the call at the hospital in Texas just before I had gone in to visit my mother. Nancy from Kingston called me and I will never forget the tremendous amount of compassion she showed me. I remember being so grateful that she was where people cared about her. The thing that helped me keep going was always the people that showed compassion for her. For the people that provided her a hug, a touch or a smile, I hope God blesses them.

I know most people genuinely have a good heart and if not they will have to answer for that. However, the system of mental health in Oklahoma does not have one. Everyone that ever took care of Abby openly admitted it was a 24/7 job so it wasn't like I could do it. She was very delusional and sick. When Eastern State was closed and there was no system in place to care for the sickest individuals that was a tragedy. I know Abby is not the only one out there like this and it breaks my heart that they are treated no better than animals. Whether they are in jail or sleeping under bridges the torment must be the same. Our state legislators have the power in their hands but where are they. I believe if you are

an elected official you have a moral responsibility to all of the people especially those that can't help themselves. I am not sure where Abby would have been if I had finally been beaten down by the system and given up.

You know, to be told by the Commissioner of the Dept. of Mental Health we have no long term care in Oklahoma ... what does that mean? What is a family to do when you have other children or jobs that do not allow you to care for your loved one? I have asked many times why there are not small nursing home facilities for the sickest individuals. We have homes for Alzheimer's and dementia which are also diseases of the mind. Why not mental illness?