Janice Airhart

ADVOCATING FOR MENTALLY ILL FAMILY MEMBERS

Lessons for Mental Health Policymakers

Disability Studies

Collection Editor
DAMIAN MELLIFONT

LIVED PLACES
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Dedicated to family members who advocate for loved ones with serious mental illness. I am honored that they trusted me with their stories.

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Abstract

This book includes firsthand stories from family members who have a loved one struggling with a serious mental illness. Each story was told in an interview with the author, describing the characteristics of the mental illness experienced by their relative and the effects of that illness on their loved one's ability to live a satisfying life and to maintain relationships. The intent of sharing these stories is to provide mental health policymakers with a deeper understanding of the effects of mental health policy and treatment practices on the family systems of those they serve. Recommendations for improved policy are provided.

Key words

Serious mental illness; psychosis; family involvement; mental health policy; HIPAA; involuntary hospitalization; advocacy; peer support; National Alliance on Mental Illness (NAMI)

Content warning

This book contains explicit references to, and descriptions of, situations which may cause distress, including:

- Suicidal thoughts, intentions, and actions
- Psychotic delusions and hallucinations
- Attempted violent assault

Please be aware that, due to the primary theme of serious mental illness, references to potentially distressing topics occur **frequently** and **throughout** the book.

Contents

Learning objectives

1. Define "serious mental illness" (SMI) and identify how it differs from a "mental health condition."
2. Describe the frustrations experienced by family members whose loved ones have a serious mental illness but refuse or struggle with psychiatric evaluation and treatment.
3. Identify how reading and understanding actual accounts of families who support family members with mental illness can be helpful for other families and for mental health practitioners.
4. Compare and contrast the benefits and drawbacks of HIPAA law as it applies to persons with serious mental illness.
5. Explore the value of involving family members in the treatment of patients or clients with serious mental illness.

1

Mental health stories matter

Introduction

Our individual stories matter, and our collective stories create a more complete picture of human experience. Some stories are harder to tell than others, however. One of the most difficult stories to disclose is one in which someone you love struggles with a mental illness. These are stories of loss and grief, but not in a traditional sense. The loss of an anticipated future with a loved one is like death, but it leads to a different kind of ongoing, recurrent grief that few people understand. Ongoing grief, in turn, can lead to silence and alienation.

Too often, those diagnosed with a mental health condition are feared or ostracized for behaviors that appear odd or simply different from others. Their behaviors can cause fractured relationships with family and friends. Sensational stories of violent acts by individuals who are deemed mentally unstable drive broader fears. However, according to an article in the Association of Health Care Journalists, those with a mental illness are more likely to be the victims of crime than the perpetrators of crime (Gray, 2022). Dispelling those fears requires understanding the dynamics of mental illness and its effects on both those who are diagnosed and those they are closest to. In addition, public policy should address the availability of mental health resources that will most effectively provide stability for families and their communities. While those who suffer from mental illness can and should make their voices heard to receive the care they need, family members have unique roles in supporting and advocating for each other. Depending on the affected individual's condition, the stories of those who love them may be the most relevant, reliable, or comprehensive accounts. In addition, stories of real people in real situations can have a greater impact than the presentation of academic principles.

This book includes lived experiences of **parents, children, siblings,** and **partners** of individuals diagnosed with a mental health condition. Some stories are complicated by multiple diagnoses, or by multiple individuals in a family who suffer from mental health conditions. Family members are inevitably affected by their loved one's condition, but in different ways, and some are left to shoulder sole caregiving responsibility. A sibling's obligation toward a sister or brother is quite different from a partner's obligation, however. This is why it's important to hear stories from multiple relationship categories.

Process

Interview subjects for this project were recruited through mental health agencies, personal or professional networks, or through online recruiting. Some participants were recommended by friends or acquaintances of the author. Others were invited to participate after sharing with the author personal experiences with family members diagnosed with a mental health condition.

Interviews were subsequently scheduled and conducted with individuals within the four relationship categories identified previously to bring to light the frustrations and successes experienced in caring for or supporting a loved one. While a consistent basic question framework was used to begin every interview (see Appendix I), each situation elicited additional questions to create a richer story. The goal was to identify useful resources or strategies that effectively control the negative effects of a loved one's illness. If efforts were made to advocate for them with mental health professionals or services, the results of those efforts are described. Brief descriptions of each of the mental health conditions mentioned in the book, along with hallmark symptoms appear in Appendix II.

In most stories, names have been changed to protect the privacy of the individuals interviewed and their families. Because some interview subjects previously published books about their family's encounters with mental illness, their real names are used. Each participant signed a "Consent to Participate in Interview Research" form prior to the interview, and each was allowed accommodation or accompaniment by another person of their choosing, if they requested it. Interviews were conducted in person when possible, or via Zoom online meeting, and often recorded to ensure accuracy in transcription. In whatever form they occurred, notes, transcriptions, and audio or video files are stored securely, accessible only by the author, and will be destroyed one year after the book's publication.

My story

My mother was diagnosed with schizophrenia in 1953 when I was an infant. Shortly after that, she was institutionalized in Mandeville, Louisiana, four hours from our family's home. I was ten months old. Aside from a few weekend home visits, my siblings and I did not see our mother for four years. Her hospital chart from that period, which I obtained in 2005, records visits by my father to see her, but none that included their three young children: my sister, my brother, and me. I have no recollection of her before 1957. Needless to say, I had no role in caregiving or monitoring her treatment.

In 1957, Mother was transferred to another facility in Pineville—Central Louisiana State Hospital—only two hours away. This meant the whole family could visit, but we only made the trek a few times a year. On these visits, we often took car rides into nearby Alexandria for ice cream. Mother generally sat, inert and quiet, in the front seat and interacted little with any of us kids in the back seat. I give my father credit for ensuring we made the trip so that we would see our mother, but I always wondered if she knew who I was. In the end, the bigger question for me became, "Who was my mother?"

When I was five years old, the year before I started first grade, Mother was considered stable and was discharged from Central State, provided she continued her regular Electroconvulsive Therapy (ECT) at a local hospital. I recall riding along to drop her off at the hospital and then visiting a local ice cream shop while we waited to pick her up. Ice cream obviously figured prominently in our visits with Mother. After each treatment, Mother was withdrawn and unusually quiet for a few days, though the calm never lasted long. While my memory is admittedly far from perfect, there are no memories of affectionate words or touch.

Meanwhile, I was fascinated by this woman called Mother and spent a good bit of time simply watching her. I imagine it was unnerving for her, but she never remarked on my tendency to lurk. While she was out of the hospital, my father took the opportunity to plan a trip from Louisiana to New Jersey to visit her parents, who cared for Mother's younger sister and her two children. My Aunt Mary had also been diagnosed with schizophrenia, but her parents chose to have her partially lobotomized. I don't know if she agreed to this surgery, and there was no one left to ask by the time I learned of it. In my grandparents' care, my aunt and her children were closely monitored and kept safe. It was the first of only two times I saw my grandparents.

My scant memories of Mother between June of 1958 and May of 1959 involve a lot of Coca Cola drinking and cigarette smoking. I often lay on the floor outside the bathroom and peered in fascination under the door to see what she was doing inside. Then there's a fuzzy memory of her making me open my mouth and stick out my tongue for her inspection. She was looking for evidence that we were being poisoned, and I dutifully complied. I don't remember thinking it odd at the time, which is intriguing in its own way.

Before my first grade year ended, things took an ugly turn. Her doctors evidently believed Mother could resume her role as mother and wife, as long as she continued her ECT and psychiatry visits in Lake Charles. They were wrong. The loud and angry arguments coming from my parents' bedroom at night frightened my siblings. Ever watchful, I must have been aware of the contention, but if so, I've forgotten it, along with most everything else.

Apparently, Mother was convinced Dad was trying to kill her. Maybe this is where I got the idea she thought we were being poisoned. She accused him of planting a spy in our home, as she was suspicious of the woman Dad hired to help her around the house during the days when he was at work. She complained she was being watched and that the housekeeper was thwarting her care of us. She lunged at him with a butcher knife once, as my brother recalls, but Dad was able to disarm her. I learned much of this later, after asking my siblings for their memories and after I'd obtained her hospital records, which included my father's account of their relatively short married life together.

The situation came to a head one day when my father was at work and my sister had a friend over to visit. Mother apparently went berserk over something my brother said or did and began hitting him and screeching in the front yard, a very public humiliation. My sister's friend ran home in a fright. Neighbors called my father at work and sheltered the three of us until he came home. Later, a police car arrived to escort Mother back to the hospital. She never came home again and died there eight years later.

Not only did my mother disappear from our presence, but it seemed my father erased her from our family. Though we continued to visit her a few times a year, he never mentioned her in between visits. I interpreted his silence as, "Don't talk about her. Pretend she doesn't exist." And so I did. As the silence grew, so did shame and guilt. No one else I knew had a family member who behaved the way my mother did. No one else's mother lived in a psychiatric hospital. Was there something wrong with our family? She'd been pregnant with me when her psychotic break occurred. Was I the cause of her illness? Would I also get the disease? I knew no one who could—or would—answer any of these questions.

After my mother's death in 1966, there was a certain amount of relief. My mother was dead; she no longer lived in a lunatic asylum, the insulting term everyone else used to refer to the hospital she lived in. Her death was more acceptable to divulge. I knew a couple of other kids at school whose mothers had died. Having a deceased mother elicited a measure of sympathy, which was a novelty. Disclosing that your mother lived in a psychiatric hospital got a very different reaction.

Not long after I turned 14, my father remarried a widow with three daughters, one of whom was a good friend of mine. My older sister married soon after, and my brother went away to college not long after that. I was left feeling alone and apart from this new family and the new school I was forced to transfer to. I no longer had a deep, dark secret about my family to hide, but I was thrown out of a familiar environment into a new home, a new school, and a completely new set of classmates. I kept mostly to myself.

Over the next four years, I felt like a fraud in my new family. My stepmother, whom I was delighted to call Mom, was not my "real" mother. My stepsisters were wonderful people, but we had different interests and different perspectives. Their mother was theirs, not mine—I didn't dare make too many presumptions. I married and left home less than a year after graduating from high school and moved on to a new life.

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When I was 30 years old, the age my mother was when she was diagnosed with schizophrenia, I finally found the courage to ask my father a simple question: “What was my mother like? You never talked about her.”

“I thought you weren’t interested,” he said, surprised.

I felt as though I’d been searching for the answer to this question all my life, and I found it hard to believe my father wouldn’t have known it. By this time, I had two children of my own and sometimes struggled to mother my children without a role model. I’d had a caring stepmother, but we had different sensibilities, and I was mostly grown by the time she and my father married. I had no clue how to parent young people. Dad had also been a wonderful father in most ways, but I knew a mother’s relationship with her children was quite different from a father’s.

In answer to my question, Dad sputtered some basic information about my mother and listed some of her preferences. He told me how they’d met when he was in basic training in the Army during World War II and she was a young college student. They’d married as soon as he returned, wounded, from serving in Germany in 1946. In the next hour and a half, he told me more than I’d known all my life about a woman who had been little more than a stranger to me, yet he told me only disconnected facts. She liked playing card games and drinking daiquiris. She was a good student and typist. Her favorite color was blue. There were no fond stories.

And then he said nothing more about her. Ever. He died twelve years later.

I began investigating on my own in 2005 and felt extremely fortunate to obtain Mother's medical records from her first hospitalization at Southeastern Louisiana State Hospital. They are still the most concrete evidence of her existence that I have. Surprisingly, Central State, where she spent her final eight years, had no records aside from admission and discharge dates and a few demographic details. Mother's admission records in 1953 include my father's account of her first symptoms that led him to seek a judicial order for her commitment. He had told me none of this. When Mother was first admitted to the hospital, Dad reported several years of happy marriage prior to Mother's apparently abrupt change in behavior. However, the period just before and just after her hospitalization was the most painful of his life. He seemed caught off guard, unable to understand why she suddenly insisted neighbors were gossiping about her—neighbors whom he thought of as friends and who sometimes babysat at the last minute when needed. When Mother marched into her obstetrician's office in 1952, during her pregnancy with me, and demanded he declare his love for her, Dad became alarmed. She was referred to a local psychiatrist, with whom Dad seemed to disagree about her treatment, but with whom he eventually agreed that separation from the family was in everyone's best interest, for both Mother's safety and the safety of their three young children. He filed the papers to commit her to the hospital on the advice of her psychiatrist in 1953 and was left to parent us alone.

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During my mother's first four years of residence in Southeastern State, treatment consisted mostly of Insulin Coma Therapy (ICT) and Electroconvulsive Therapy (ECT). The purpose of the first is self-explanatory. Her hospital notes documented how much insulin was administered and how many minutes of coma it resulted in.

From November 20, 1953:

> *This patient started treatment on August 28, 1953. She finished on November 20. She had a total of sixty insulin treatments with fifty-one comas … She first went in to coma at 260 units, finished at 310 units. Her highest dose was 420. She showed some clinical improvement through therapy, was increasingly flat in disposition. However, her basic pathology did not change. The patient apparently had a secondary the night of October 12, or the morning of October 13. No other was reported. She, on occasion, went very deep but would lighten rapidly. She went very deep on September 16, had a very hyper-excitable period on November 6. The patient received 2,195 minutes of insulin coma or 36.58 hours.*

Not long after this, my father requested the hospital discontinue ICT, although I don't know why. I've since learned that ICT, first used in the 1920s, was never an appropriate treatment for schizophrenia and fell out of favor in the 1960s.

However, ECT was and is still used for several mental health conditions as a "brain reset" of sorts. While primitive shock treatments are represented as barbaric in black-and-white movies and horror novels, current ECT procedures are safe and effective in treating certain cases. There are drawbacks, long-term memory retention being one. Over the four years Mother was a resident, her chart recorded ongoing and frequent accounts of her ECT treatments, accompanied by seizures and occasionally by injuries sustained from thrashing about or falling out of bed.

In addition to ICT and ECT therapies, my mother was often given barbiturates, codeine, or an anti-anxiety medication called Equanil, presumably to calm excitability or sometimes aggressive behavior. Ironically, she was also given anticonvulsive drugs to control the seizures brought on by the ECT. Since the effect of all three forms of treatment was to dull a patient's reactions and lead to coma or coma-like states, it's clear that the primary treatment objective at the time was simply controlling external behaviors. My mother was prone to delusions and persecutory thoughts, which would have been minimally affected by any of the treatments. In addition, the effects of any of these treatments long-term would have been damaging to her body. It is no wonder that she died "in her sleep of a heart attack" at age 42—or so we were told.

I have no records of her treatment beyond 1957, but I presume my mother benefited from some of the early antipsychotic medications like Thorazine or Haldol that were introduced in the 1950s and 1960s. If these were part of her regimen during the final years of her life, they apparently did little good. Her condition never improved enough for her to be released, and she died at Central Louisiana State Hospital in 1966.

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The only time I visited Central State after my mother's death was in 2019, after the death of a sister-in-law who lived in Pineville, where the hospital was still located. It was no longer used for long-term residential treatment but housed a small clinic that included short-term hospitalization in one of the newer dormitories. The hospital was built in 1906 as the Louisiana Hospital for the Insane. Dozens of abandoned buildings and residence halls, in varying levels of disrepair, dotted the 409-acre campus in 2019, along with several brick buildings on the National Historic Register. The hospital, at its peak, housed more than 3,000 patients in the 1950s, around the time my mother lived there. It's now a ghost town and appears on several online lists of haunted sites. For me, the recent visit was both a homecoming of sorts and a reckoning with my past. I hadn't been there since 1965, when our family's church hosted a picnic in my mother's honor on the grassy-green rolling hills that make up the hospital grounds, sloping down to the historic dairy barn complex, once the site of positive employment for residents. These were the only features I recalled from my youth.

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I've had decades to dream about what might have been possible for my mother, had she been born fifty years later than she was. Schizophrenia is not a "curable disease"—at least not yet—but many people, including at least one whose story is told in this book, find treatments that control their most troubling symptoms. Because many with diagnosed conditions lack the self-awareness or rationality to seek appropriate care and to conscientiously adhere to prescribed regimens, family members are their best allies in maintaining good mental health. For this reason, counselors, therapists, and physicians who treat the mentally ill should include family in any treatment plan. No patient or client can be treated in isolation.

Unfortunately, there were no services available to our family in my mother's lifetime, and my father did the best he could to cope with what few resources he had. It has only been in recent years that I've sought any support for my motherless childhood. Schizophrenia deprived me of the love and care a mother might have provided, but how could I know what I was missing? It's hard to grieve the loss of something you never had, but that was my dilemma. At the same time, I often chastised my adult self for not "getting over it."

Several years ago, I discovered the National Alliance on Mental Illness (NAMI) chapter near me and took a couple of their classes designed for family members. Unlike me, everyone else in the classes had a loved one they were currently caring for or advocating for. Over the course of several weeks, participants were educated about specific mental illnesses and treatments and provided resources to consult for accessing appropriate diagnosis or treatment help. Some of the stories I heard in those group sessions were heartbreaking. Many were frustrated by the lack of providers covered by their insurance or the lack of providers altogether in their community. Even when a provider was located, appointments could be months away. Some could not get a specific diagnosis for their loved one and therefore could not get appropriate treatment. Others found that because their family member had multiple diagnoses (not uncommon), treatments were very complicated. At each meeting, though, the sense of sharing frustrations with others who understood them was overwhelming. I kept thinking what a lifesaver this kind of community would have been to me in my teens, my thirties, or even my fifties. Instead, for years I dealt with my emotions mostly alone, while journaling.

Writing my full story, in the form of a memoir called *Mother of My Invention* was a great help in putting my childhood experiences in the context of decades of adult experiences, particularly those as a parent. I also consulted a therapist while writing it, and she helped me focus on painful incidents. At the same time, my editor kept advising me to "lean in" to the discomfort by writing more deeply about difficult situations. Reflecting on them from a more distant perspective took the sting out of them. I'm a firm believer in the value of writing to process emotions. For me, it's the best therapy. Others find relief in community.

Once my book was published, I held multiple book events where I could talk freely about the impacts of my mother's mental illness on me. Telling my story gave others permission to tell theirs. After each discussion, I'd hear from someone: "My aunt was in an institution, but my mother said never to talk about it," or "I just found out my grandmother suffered from mental illness. I wondered why I didn't really know anything about her, but my dad never talked about her." Hearing their stories led to my determination to give these family members a voice. One young woman had been treated for cutting and depression. After one of my talks, she approached me with tears in her eyes. "I'm worried about my mom," she said. "I know what I'm doing hurts her, but I can't seem to stop." This one broke my heart.

Those who struggle with mental health conditions also deal with persistent and pervasive stigma. Their family members feel it, too, as I did as a child. Reassurance that there is no one to blame for a mental illness is important. While we don't understand as much as we'd like about what causes a person's reasoning ability to malfunction, there are physical, genetic, and biochemical causes, just as with any illness. The fear of contagion and the notion that an individual's refusal to "act right" is to blame persist, however. Odd behaviors generate fear, and too often we blame others for our fear. The homeless man who pushes a shopping cart down Main Street stuffed with the entirety of his belongings is not to blame for his schizophrenia. He isn't to blame for the posttraumatic stress disorder (PTSD) he developed after serving in Afghanistan or Iraq any more than my mother was to blame for her disease. At least my mother wasn't homeless, even if the last place she called home was a psychiatric hospital in Pineville, Louisiana. When I drove through the campus in 2019, after an absence of more than five decades, I was ready to let my mother rest. The hospital grounds are deceptively serene, and I like to think she benefited from the peaceful wooded trails, nearby Lake Buhlow, and the tall canopy of pine trees that stand like caretakers around today's ramshackle buildings.

In 2024, all the services once housed at Central State were moved near another mental health facility in Pineville, which seems to benefit clients of both. About half of the acres it once occupied are being subdivided into tracts for single-family homes and townhomes, a couple of parks, and office spaces. The cemetery, where around 3,000 former patients are buried, and a few of the historic buildings will be preserved. It will no longer be a ghost town. I don't know how future residents will feel about the history of the land their new homes sit on, but I like to think a vibrant community will soon redeem the haunting memories of the tens of thousands of lost souls who once lived there.

2

Parent stories

Introduction

Every diagnosis of bipolar disorder, PTSD, or schizophrenia is unique. No mental illness follows the same progression as another's, as evidenced by the diverse stories included here. In addition, a study of 180,000 Danish psychiatric patients revealed that 47% of patients in the study received a different diagnosis within 10 years of their initial diagnosis, demonstrating the dynamic nature of mental disorders over a lifetime (Neuroscience News, 2022). Some individuals struggle with more severe symptoms and find treatment a greater challenge than others do. Some find that prescribed treatments control symptoms for a time and then, mysteriously, they don't anymore. These uncertainties pose a challenge for the diagnosed individual, their mental health practitioners, and their families.

Just as the course of disease can vary greatly from one individual to the next, each family is also unique. Demographics, location, economic situation, and other factors play a role in a family's ability to effectively support a loved one with a mental illness. In addition to these variables, the relationship one has with their loved one changes the dynamics as an advocate or caregiver.

A parent's role in caring for a child is quite different from a spouse's role in caring for their partner or the limited role a child often plays when dealing with an ill parent. Societal expectations for appropriate parenting prescribe to some degree what a healthy relationship and healthy family dynamic look like.

As Ann's story demonstrates, mothers sometimes feel a disproportionate degree of responsibility for their children's health and happiness. However, fathers and mothers both invest emotionally in their children's well-being. For Beth and Walter, heartbreak at their son's disappearance will likely never heal. And for Sarah and John, caring for a son who resents and defies their care—while they now care for the teenage grandson their son cannot adequately care for—ensures they will remain engaged in this contention as far into the future as they can imagine. Like most parents, those who tell their stories here persevere with stubborn hope, committed to their children's welfare despite the often devastating challenges mental health conditions pose.

Ann

I chatted with Ann Batchelder over Zoom from my desk at home as she waited at a hospital for her husband to receive a bone marrow transplant for blood cancer. She described the follow-up to his transplant, which entailed diligent care on her part to ensure he doesn't contract an infection from his environment—she's an impressively dedicated caregiver for her family. Since Ann has published a book (*Craving Spring*) about her journey as the mother of a daughter with clinical depression and accompanying addiction issues, she suggested I use her real name and