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Comprehensive **U**nderstanding via **R**esearch and **E**ducation into **S**chi**Z**ophrenia

The Long Road: Navigating Schizophrenia and a Pathway for More Effective Care

My son was diagnosed with schizophrenia In 2007, fundamentally altering the trajectory of our lives. While research into the complexities of the brain and advancements in psychiatric treatment have come a long way, our societal and legal frameworks for supporting individuals with severe mental illness still have significant ground to cover. This is particularly true for ensuring that those most profoundly affected receive the care they desperately need, even when they lack the insight to seek it themselves.

My son's journey into young adulthood was marked by immense academic promise. He was accepted to Johns Hopkins University with a full scholarship, a testament to his intellect and drive, highlighted by an impressive 564-page biography and a compelling video. The University's parent orientation, however, offered an early, unsettling glimpse into the challenges ahead. Parents of incoming students were explicitly told not to contact the university with questions about our children's performance, grades, or well-being. The message was clear: our children were now adults, and all communication should flow directly through them. This institutional stance, while ostensibly promoting independence, would soon underscore a profound disconnect in how we approach the care of young adults, especially those on the cusp of a severe mental health crisis.

This policy made the eventual phone call from the Dean of Student Affairs even more alarming. She informed me that my son was failing every class. With his stellar application and high school transcripts, she recognized that typical collegiate distractions weren't the cause. "I don't believe he's partying," she confided, "I believe something more chronic is happening." She requested an urgent meeting where the depth of his detachment from

Kristan Kanyuch, *Executive Director and Co-Founder, SeizingPsych*

reality began to surface. Unbeknownst to me, he had never attended some of his registered courses. Instead, he described that he had been "auditing" other classes at the behest of a "secret government agency." The seeds of a profound break with reality had been sown.

His behavior became increasingly erratic and disquieting. He appeared in classes presenting himself as an unofficial government observer, and his comments grew increasingly bizarre and paranoid. I recall a particularly distressing instance when he refused an invitation to his grandmother's house for a spaghetti dinner, claiming "she was putting her insides in the food" in an attempt to "get closer to him." These were not the quirky eccentricities of a brilliant mind; they were instead the initial signs of a mind under siege. The university, recognizing the severity, offered a medical leave of absence, requiring him to see a psychiatrist to understand what was causing these inexplicable thoughts and actions, mandating that he follow the psychiatrist's recommended treatment plan.

Unfortunately, the situation escalated, leading to his first hospitalization when my stepfather found him in the kitchen, holding his hand over the sink, meticulously cutting into it with a paring knife. He was convinced a simple blister from lacrosse practice had become gangrenous requiring him to "bleed it out" to prevent its spread and save his life. Upon my arrival, my son inquired "Can't you see the gangrene, Mom?" He pleaded, his eyes wide with a conviction that I could not understand. "Why don't you want me to stop it from spreading? If I don't bleed it out, I will die. Why would you want me to die?" All I saw was a minor blister, now bleeding from self-inflicted wounds. The next day, the psychiatrist, however, saw something far more serious: a young man in the throes of a psychotic episode. He was immediately remanded to the psychiatric unit.

My son's experience is not isolated. Across the country, countless young adults undergo first hospitalizations when they meet the baseline criteria as an imminent danger to themselves or others. Just a few days after his first psychiatric discharge, my son reported that he needed to "kill Brian and Shontell because they are telepathically trying to give me a stroke and kill me, and if I don't kill them, they'll kill me." These terrifying delusions, rooted in a profound distortion of reality, often lead to involuntary commitment and an eventual diagnosis.

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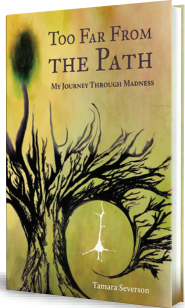
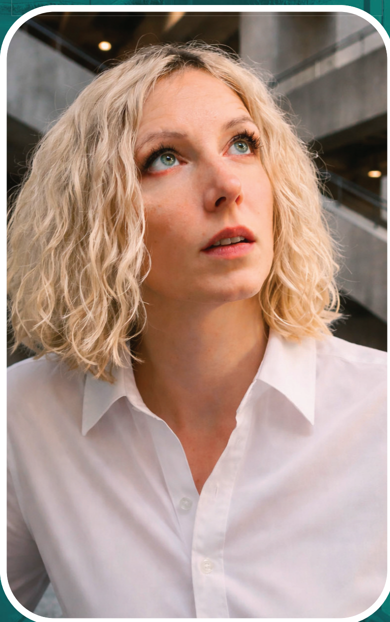
SCHIZOPHRENIA SURVIVORS

Tamara Severson *(Pseudonym)*





Psychosis is suffering. It dismantles identity, trust, and reality itself. My journey was painful and often humiliating. I lost time, relationships, and autonomy. But I have come to accept my past fully. Every part of it brought me here.

Recovery did not mean returning to who I was before. It meant becoming someone new, grounded in truth and resilience.

With the right medication, consistent medical care, and unwavering family support, I reached a stable and functional baseline. Today, I live a full life.

~Tamara Severson

I woke up this morning happy, energetic, and symptom-free. For someone with schizophrenia, that is often described as a miracle. For me, it is now my normal. My story contains real suffering, but it also ends in something I once believed was impossible.

My childhood was largely normal. There were difficult moments, but nothing that stood out as traumatic or unusual. I did not show signs of mental illness growing up. I have two brothers whom I love deeply. My mother has been a constant presence, giving far more time, patience, and emotional labour to my recovery than anyone should reasonably be asked to give. Her support and willingness to be firm when necessary played a defining role in my survival.

In my final year of high school, I received early acceptance into an engineering program and graduated in four years while working part-time. Life unfolded in expected ways. I experienced breakups, changes in housing, and moments of stress. At times I spiralled emotionally and likely struggled with anxiety, but nothing severe enough to require treatment or intervention.

Less than two years after graduating, I married my ex-husband. Our marriage was stable and communicative, and we spent a great deal of time together. We also drank together daily. In hindsight, I believe alcohol played a significant role in the deterioration of my mental health. When I stopped drinking after becoming pregnant, a quiet distance began to grow between us. At 25, after having my child, I was deeply committed to motherhood and focused on building a safe and loving life for them.

After having my child, I began drinking regularly again. My marriage started to feel confusing and hollow. I wanted a meaningful life and felt increasingly unfulfilled. We spent much of our time watching television, and our connection weakened. We fought often. My thinking became distorted, and I developed grand, delusional beliefs about saving the world from climate change. About a month after my 29th birthday, our marriage ended. Almost immediately, my cognition collapsed, and I entered psychosis.

At first, I was euphoric. I woke the next morning full of energy, made pancakes, took my child to the park, and visited family. I felt relieved and alive. Within days, my mood became wildly unstable. I swung rapidly between joy and despair. I danced, screamed, cried, and attempted to meditate, which only intensified the chaos in my mind. Family members noticed that my behaviour was unusual. It did not pass.

Soon my beliefs became frightening. I was convinced my ex-husband would magically harm someone close to me. I created rituals I believed were protecting others. I filled notebooks with lists, notes, and drawings that made sense only to me. When my family tried to reason with me, my paranoia worsened. After I drove to a nearby convenience store with my dog, became overwhelmed with fear, and walked home leaving my car behind, my family intervened. I was hospitalized.

I believed the hospital was evaluating me for recruitment into the CIA. I refused medication because I did not believe I was ill. I believed I was chosen and responsible for keeping others safe. Eventually, a cousin convinced me to take medication by explaining it would otherwise be forced. I remained hospitalized for about a month. Although my symptoms improved, I did not return to baseline and struggled to function after discharge.

For the next two years, I cycled on and off medication. I would take it until my symptoms were controlled, then reduce or stop due to side effects. I tried many medications, none of which allowed me to function well enough at the required dose.

This pattern culminated in an 18-month period of severe illness. During that time, I received a DUI, declared bankruptcy, lost custody of my child, and lived in a tent in northern Manitoba for four months during the winter with my dog and a space heater. I was completely disconnected from reality. I believed I was married to a celebrity, in regular contact with national leaders, and working as a senior executive at a major tech company.

Eventually, my mother discovered where I was living. She drove to Manitoba and brought me and my dog back to Calgary. She insisted I be hospitalized. There, I met a doctor who saw through the version of myself I was presenting. I was placed on injectable medication and a community treatment order.

The medication reduced most of my symptoms, but I continued to struggle with disorganized thinking and daily functioning. Over the next three years, my doctor worked patiently with me. Eventually, I was prescribed a combination of Abilify and clozapine. At a low dose, clozapine restored my ability to focus. I could think clearly again. I could work. I could live.

During this period of stability, I wrote my book, *Too Far From the Path.* Writing it allowed me to make sense of what I had endured and reclaim my narrative. I have now been sober for two and a half years, a choice essential to my stability. As the book was being published, I met a man who worked as a teacher at my child's school. Our connection was steady and deeply supportive. We moved in together after a few months. Six months later, we exchanged rings. After nineteen months, we were married.

He is my equal and partner. He never treated my illness as something to manage or correct and never mistook support for control. He met me as I was, trusted my judgment, and respected my independence. He has formed a genuine relationship with my child, and together we have regained joint custody. Our home is steady and real.

CureSZ News

The Difficult Journey to Understanding My Brother

Rohail Kahn

My relationship with my brother was unusual for siblings – it was shaped not by interactions, but by shared silences. Faraz was ten years older, often away at school or out of the house. When he was around, we found quiet ways to connect – camping trips with my dad, video games, and snacks after school. My parents weren't around much.

A month after I was born, my father was incarcerated at the San Quentin prison for criminal charges because he killed a man in a driving accident. My brother was in the front seat, traumatized by the incident.

My mom used to work 16-18 hour shifts as a nurse. At home she could not cope and had emotional outbursts with yelling that created an intense and difficult environment for us.

I sometimes felt invisible at home, but when I was with my brother, I felt seen, and I trusted him. Deeply. He was my rock.

Until he wasn't. The first time I noticed a change, he told me not to look at him – said my eyes were infected. I thought he was kidding; I laughed, waiting for his punchline. But it never came. Instead of laughter, I saw fear in his face. And something cracked between us.

He got expelled from college because he drew graffiti and slurs on the campus walls and started living at home. He scribbled all over his bedroom walls with pencil, journals filled with rants about his expulsion in dark graphite. There were nights he'd scream, or go missing, or get hospitalized under 5150 holds, which is a term for placing a 72-hour psychiatric hold on individuals who pose a danger to themselves and/or other people.

Words were thrown at me – schizophrenia, bipolar, 5150. I was only twelve. I didn't know what these words meant, but I stored them in my memory. All I was certain of was that the brother I knew was no longer there.

I pretended nothing was happening. When Faraz threw a battery at me and split my forehead open, I kept quiet. I scrubbed the blood off my hoodie sleeve in the bathroom, then sat back down to finish my history homework. I didn't know what else to do. My parents, too, were paralyzed by what was happening, and remained silent.

When the silence became too heavy for me to carry alone, I started writing. At first, it was just a notebook where I kept track of what I saw and felt. Eventually my writing uncovered how distant I felt from my family as Faraz's illness was destroying us. The more I wrote, the more I found my voice. I started asking questions about the brain, illnesses, how families fall apart and still find a way to sit at the dinner table together. By high school, my reflections became more focused. I sought answers not to escape my past, but to make sense of my present, and hopefully rebuild my relationship with my brother.

Through this search for answers, I found out what my parents had been keeping from me for all these years: my brother had schizophrenia. Once I realized his diagnosis, I dug deeper. My journal turned into a blog, leading to a **published article*** about my experience with the International Society for Schizophrenia Research. I cold-emailed a UCSF medical student/doctoral candidate working on schizophrenia research. My brother was a smoker, and I asked if I could assist with his study on the connection between smoking and schizophrenia. We worked together for two years, and our findings were published.

When I was younger, I didn't have the language to describe what was happening at home. In those moments, I'd turn to prayer, whispering to God because even if I couldn't make sense of it, I believed God could. That act of surrender shaped how I now approach science as a practice of listening, of patience. Five years later, I don't flinch at the word "vulnerable." I understand that telling the truth about the burdens we carry is a form of strength. I have learned that families are complicated, pain doesn't always look clear, healing isn't linear, and it all begins with self-awareness.

It's been a decade since I talked to my brother the way we once did. He is still in and out of hospitals. I call him weekly and visit him monthly.

I hope that by better understanding schizophrenia, I will one day be able to sit across from him again and achieve what I've always wanted – a chance to truly reconnect.

My brother currently takes antipsychotic medication such as Abilify and Risperdal, but we are looking for a newer, more effective medication, such as clozapine.

By working with The CURESZ Foundation, my family and I seek to better understand emerging treatment options, access reliable clinical guidance, and advocate for care that looks beyond symptom management to quality of life.

Rohail Kahn

CLICK HERE to read Rohail's published article.

visit us at CureSZ.org

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The Long Road: Navigating Schizophrenia and a Pathway for More Effective Care (continued from page 1)

A crucial, yet often misunderstood, aspect of these illnesses is anosognosia. This isn't denial; it's a symptom of the illness, a neurological impairment that prevents individuals from recognizing their own illness (Lehrer & Lorenz, 2014). My son genuinely believed by cutting his hand and killing the neighbor he was saving his life and acting in self-defense against perceived telepathic threats. He couldn't grasp that his mind was distorting his reality. This lack of insight is precisely why the current system, often prioritizing individual autonomy above all else, frequently fails those who most need intervention.

More alarming is that in many jurisdictions, individuals don't qualify for hospitalization until their illness progresses, and they are deemed an "imminent danger to themselves or others." This threshold is tragically high, and preventative or early interventions are missed. Even more perplexing is that once hospitalized, individuals are often given full autonomy over their treatment upon discharge. This approach, rooted in well-intentioned but often misapplied "person-centered models," allows individuals suffering from anosognosia to refuse medication management. They are released back into the community, unable to comprehend that they have a brain illness and thus they terminate their necessary ongoing treatment.

This creates a tragic cycle: the person who was ill enough to be hospitalized for attempting to "bleed out" a non-existent gangrene, or for believing they needed to kill others in self-defense, is now in charge of their own treatment. Their refusal of medications often results in a revolving door of repeated hospitalizations, or worse, incarceration, or tragically, even death. Our jails and prisons have, by default, become the largest mental health institutions, a damning indictment of our current approach.

The mindset that mandates absolute anonymity and unfettered person-centered decision-making in the face of psychosis-induced anosognosia, especially for individuals hospitalized as an imminent danger, borders, in my opinion, on criminal negligence and abandonment. This is where mandatory assisted outpatient treatment (AOT) becomes not just an option, but a moral imperative. AOT programs provide a structured framework for stabilization and a roadmap to recovery during first episodes of illness and beyond (Treatment Advocacy Center, 2025). By mandating treatment adherence, including medication, AOT can prevent the escalation of symptoms, reduce hospitalizations, decrease homelessness, and significantly improve quality of life for individuals and their families. It's about providing care, not coercion. It's about freedom from illness, not freedom to deteriorate.

The implementation of AOT is not without its critics, who raise concerns about individual rights and respect for autonomy. However, it is vital to recognize that liberty is not found in the depths of untreated psychosis, locked in a hospital ward, in the confines of a jail cell, or forever buried in a box. As Dr. Darold Treffert, a vocal advocate for compassionate intervention, powerfully articulated (Treffert, 1995, as cited in Torrey & Snook, 2017, para. 22):

> *It is not freedom to be wandering the streets, severely mentally ill, deteriorating and getting warmth from a steam grate or food from a garbage can; that's abandonment. And it is not liberty to be in a padded jail cell instead of a hospital, hallucinating and delusional, without treatment because that is all the law will allow.*

His words resonate deeply and articulate the urgent need for a paradigm shift. We must move beyond a system that waits for crisis and instead embrace proactive, compassionate interventions that prioritize recovery and well-being.

If my son were to become critically ill in my absence, I hope someone would care enough to mandate medication management. This would provide him a fighting chance for a better life – a life not defined by the cycles of untreated illness, but by the dignity of recovery and stability.

We owe it to our loved ones, and to ourselves, to ensure that our systems of care truly serve those who are most vulnerable.

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Your contribution will help provide education and referrals to persons with schizophrenia, their families, and those who work with the seriously mentally ill. CURESZ informs the general public to better understand this serious brain disorder, and to provide scientific advances showing that there is hope for recovery, and a return to a fulfilling and normal life. The CURESZ Foundation is a 501(c)(3) nonprofit organization. All contributions are tax deductible.

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