# A Mother's Story: Twenty Years Fighting for Mental Healthcare

*By Jackie, Mothers for Mental Health Care Reform*

I am the mother of two sons, A and E, who have been diagnosed with schizophrenia. (I'm calling them A and E in this letter to protect their privacy.) Today, both are in a much better place and continuing their journey toward meaningful recovery because of treatment. But getting here took twenty years of suffering, repeated crises, trauma and relentless advocacy.

As Ontario considers reforms involving involuntary treatment for addiction, I am asking that severe mental illness be included. Our family knows what happens when someone is too ill to recognize their need for help, when treatment stops being effective, and when families cannot find a timely path to care.

We were a close family of five. We had our children young, bought a home, built a business and provided a loving childhood with friends, extracurricular activities, extended family and vacations. We had the usual struggles of young families, but overall, we built a happy home. To anyone looking from the outside, we were a "normal" family. Mental illness can affect families in every walk of life. Nothing prepared us for watching two of our children become seriously ill about a year apart.

The impact reached every member of our family. Our daughter's education and mental health suffered as she watched her brothers struggle. I stepped away from work to care for our sons, research treatments and search for support. I absolutely refused to give up hope. Sometimes, hope was all I had to carry on.

Although both sons have the same diagnosis, their experiences are very different. A's illness has involved intense paranoia, delusions, anxiety and social withdrawal. E has experienced persistent voices and delusions, yet remains sociable when he is well. Finding effective treatment for each has required individual attention and ongoing reassessment.

For both sons, meaningful access to assessment and treatment came through the justice system, after we had struggled to obtain medical help. Court was traumatic, but it opened doors that had otherwise remained closed. We were seeking healthcare. Our sons should not have had to face criminal charges before they could receive it.

A had been an outgoing young man with close friends, a girlfriend and plans for his future. After his first year of college, we noticed frightening changes during a family trip to Europe. He became disoriented and repeatedly got lost. His younger brother kept finding him and telling us something was wrong.

At home, A became convinced that gangs were threatening our family and business. His attempts to protect us created serious danger, including trying to connect gas to our furnace. At another point, he travelled back to Germany alone. For two weeks, we could not locate him. We contacted hostels and barely slept, terrified that our seriously ill son was lost overseas.

He refused to see any doctor. At times, his behaviour made it unsafe for him to remain at home. Telling my son he could not come home unless he sought help broke my heart. I thought that perhaps setting that boundary would persuade him to accept care. I did not know what else to do.

During one crisis, police confronted him at a gas station with their guns drawn after neighbours had seen him

carrying a knife. My husband and I pleaded with them to understand that he was ill and needed hospital care. We were terrified that his confusion and fear could get him shot. He went to hospital, but was released fourteen days later -- the revolving door our family would come to know.

Later, during severe paranoia, he entered a store with a knife and demanded money. He was arrested, and our journey through the courts began.

A absolutely refused to accept that he might be mentally ill. He told his lawyer that we were wrong and trying to label him. He would rather go to jail than accept a mental health diagnosis. We attended hearings and pleaded for help, but he refused efforts to divert him into mental healthcare.

Because A was legally an adult, he could ask that we not be involved, and we were told that information about his care could not be shared with us. The family who loved him, knew his history and would be caring for him at home was left outside discussions and decisions about his care. We could see how profoundly ill he was, but we struggled to have our observations heard and considered.

We wanted him to have privacy, independence and a voice in his treatment. But his refusal to involve us was happening while he believed we were against him and could not recognize his illness. Being his parents did not give us authority to make decisions for him. We were desperately trying to help, yet felt powerless and shut out when he needed us most.

Then a judge asked to hear our account. I described the son we knew, the changes we had witnessed and our unsuccessful attempts to get him care. For the first time, I felt someone in authority was truly listening.

The judge carefully suggested an assessment as a way to settle whether anything was wrong. A agreed. It was approximately three o'clock on a Friday afternoon, and he was due to return to jail. The judge insisted that nobody leave until a hospital bed was found. About an hour later, a bed was located at the hospital now known as Waypoint.

That judge, and the doctor and caseworker who subsequently cared for A, changed the trajectory of his life.

But admission was only the beginning. A was diagnosed with schizophrenia and remained in hospital for approximately eight months, still refusing medication. Eventually, his doctor told us he could soon be released without treatment and explained the process through which we could pursue involuntary treatment.

We faced one of the most painful decisions of our lives. Taking away our son's choice was not something we considered lightly. We wanted to respect his independence, but he could not recognize how ill he was.

I looked at what the previous two years had become: custody, time on the streets, severe paranoia and delusions, and a promising future slipping away. He was only twenty-two. I feared that leaving him untreated would mean a lifetime of jail, homelessness and suffering, and that we would eventually lose him. I felt I would be giving up on his future.

We asked E for his thoughts. His answer was immediate and matter-of-fact: "Mom, A would want to get better. Do it." He knew and loved his brother deeply. His certainty helped me make my final decision. Years later, that memory also strengthened my resolve to advocate for him when he became ill.

The thought of pursuing treatment against A's wishes was agonizing. But leaving him untreated had consequences too. The decision became clear: leave him at the mercy of his illness, or give him a chance to recover. I knew the son we loved would want a life. We pursued involuntary treatment through the process

his doctor explained.

A was angry and initially refused to see us. That was heartbreaking. But treatment began to help. We could have conversations again, discuss his future and hope for a meaningful life. Eventually, he returned home and began working.

After a later relapse when he stopped medication, A recognized for himself that he needed it. The young man who had once preferred jail to a diagnosis began managing his own treatment. Treatment had helped him regain the understanding needed to make informed decisions about his care.

This experience is central to why I advocate for compassionate access to involuntary treatment, with appropriate safeguards, when severe mental illness prevents someone from recognizing their need for care. Our goal was to restore A's health and independence.

Yet recovery did not end his need for support. His psychiatric follow-up eventually ended, his probation finished and his family doctor retired. Later, his medication no longer adequately controlled his symptoms, while higher doses brought difficult side effects. Even while taking medication, he declined over approximately two years.

At one hospital visit, A himself asked to be admitted because he felt unwell, but was sent home. A later admission connected him with his current psychiatrist. Eventually, with his doctor and me supporting the same recommendation, A agreed to try clozapine. That began his second meaningful recovery.

By then, A was in his thirties, and we were approximately twenty years into his journey. Twenty years of fighting for care, holding on to hope and watching him work to rebuild his life, only to become seriously ill again. Something had to change.

He is now working again, managing his medication and banking, caring for himself and driving to medical appointments. He still has challenges, but he is rebuilding his independence.

E's illness began while he was a teenager. We had moved our family and changed his school hoping for a fresh start, but at his new school he experienced bullying, depression and increasing marijuana use. Watching A become ill was deeply upsetting. We believe marijuana contributed to the difficulties both boys experienced.

An incident during what we later understood to be psychosis brought E into the courts. Drawing on what I had learned through A's experience, I advocated for mental healthcare. E was willing to accept help and entered the HOPE program.

Early treatment helped. But after a doctor-supervised attempt to withdraw medication, he deteriorated. Hoping to avoid another lifelong diagnosis, I pursued supplements and a naturopathic approach rather than immediately returning him to medication. His illness worsened, and he required a three-month hospitalization during which he became catatonic. I carried guilt for years. We were frightened parents trying to make the best decisions we could.

With treatment, E recovered enough to finish high school, study at university, work, cook, enjoy friends and follow his sports. But further setbacks followed. Sometimes he stopped medication; at other times, he remained severely ill despite taking it.

During the crisis years, including the pandemic, he experienced more than two years of persistent psychosis.

He heard voices, paced and yelled for hours, and struggled with meals, personal care and ordinary conversations. He needed constant supervision. During this period, he also lost approximately $60,000 he had previously saved through investments.

There were frightening emergencies. A cigarette discarded in the garage started a fire that could have spread to our home. During another crisis, following a rapid hospital discharge, four of us had to intervene to prevent him from seriously harming someone. I was injured. We repeatedly felt we had to emphasize danger before the severity of his illness would be understood.

I even consulted a lawyer about guardianship because E was too ill to agree to the care he needed. At that point, he could not be left alone -- not even for fifteen or twenty minutes. He was so deeply ill that it was dangerous to leave him by himself. Thankfully, I was able to be there for him, but many families can't provide twenty-four-hour care. They have jobs and responsibilities. Imagine having to ask a lawyer how to obtain medical help for your desperately ill child.

His ACT team doctors helped us advocate for care at CAMH and access to clozapine. It brought substantial improvement, although finding an effective combination has required years of adjustments. Today, E is taking an online university course, enjoying his interests and hoping for a relationship and a home of his own. He still needs considerable support, but he enjoys life and wants a future.

Both sons now take clozapine, which has been the most helpful medication overall for each of them. Their progress has required different doses and, for E, additional treatment. They continue to need care tailored to their individual symptoms and goals.

Our family had advantages many others do not: a home, a business that offered work and purpose, extended family, and the ability for me to step away from work. Even with those resources, we struggled for twenty years. What happens to people without someone who can make the calls, navigate the system, provide housing and keep advocating? What happens when families face language barriers or do not know where to turn?

I helped establish Mothers for Mental Health Reform alongside other mothers whose children were suffering. We could not keep watching our loved ones fall through the gaps.

We are grateful to the professionals who listened and refused to give up. But access to life-changing care should not depend on the good fortune of encountering a particular judge, doctor or caseworker.

Could meaningful recovery have begun within a year instead of taking twenty? A deserved that chance. Both my sons deserved that chance. So do people experiencing homelessness and the families desperately trying to get their loved ones help.

Mental healthcare is healthcare. Access to it should be a human right, just as it should be for any other illness. It is inhumane to leave people suffering on the streets when severe mental illness prevents them from recognizing their need for treatment.

I am asking Ontario to provide timely specialist assessment, effective and sustained treatment, continuity after discharge, and meaningful consideration of what families and community care teams observe. Families need a meaningful way to contribute what they know while respecting privacy and appropriate safeguards.

When illness prevents someone from understanding their need for care, there must be a compassionate path to involuntary treatment, with appropriate safeguards and the goal of restoring health, decision-making ability

and independence.

My sons are more than their diagnoses and their most frightening moments. They are good human beings with interests, relationships, abilities and lives worth protecting.

Families -- and the wider community -- should not have to wait for a preventable tragedy before someone receives care. In our sons' most severe periods of psychosis, they firmly believed threats that were not real. Their fear and impaired judgment created dangerous situations for them, our family and others. We needed help before another emergency occurred.

Protecting the person who is ill and protecting the public are connected responsibilities. Waiting until someone meets a crisis threshold can mean waiting until somebody is hurt. Timely, effective treatment gives us a chance to prevent that suffering.

When a person with dementia cannot understand their condition or safely care for themselves, we recognize their need for protection and support. Families facing severe psychosis need that same recognition when their loved one cannot understand their illness or the consequences of refusing care. These are often young people with entire lives ahead of them. Leaving them without effective care does not give them independence -- it leaves them vulnerable to their illness.

We need a compassionate path to treatment, with appropriate safeguards, before lives are lost or permanently changed. A person should not lose twenty years while everyone waits for the next emergency.

I refused to give up on my sons. Access to care should not depend on whether a family has the resources and strength to fight for years.

-- Jackie, Mothers for Mental Health Care Reform