



Restoring Hope and Moving Forward:

*Stories from Families about
Coping with the Challenges of
Serious Mental Illness*



A REASON TO HOPE • THE MEANS TO COPE
SCHIZOPHRENIA SOCIETY OF ONTARIO
SOCIÉTÉ ONTARIENNE DE LA SCHIZOPHRÉNIE
UNE SOURCE D'ESPOIR • DE SOUTIEN ET D'ENTRAIDE

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Introduction

When someone in your family develops a serious mental illness such as schizophrenia, it can result in significant changes to your own life and to your relationship with the person who is ill. If your family member with a mental illness also ends up in conflict with the law, or if you experience traumatic incidents or abuse, the impact of these changes can be even greater. You may find yourself overwhelmed, isolated and in situations where it is difficult to cope.

The Schizophrenia Society of Ontario (SSO) has facilitated the development of *Restoring Hope and Moving Forward* to reinforce that you are not alone in your experience and to show that there are ways you can cope, even when encountering tremendous challenges.

The purpose of this resource is to provide the reader with personal stories from other families who have been through difficult times and have worked at finding ways to cope. Hearing stories from others who have been in a similar situation has been shown to help family caregivers through their own recovery process. Shared experiences can help restore hope, validate family involvement, normalize life occurrences and empower families to move forward in a constructive way.

This booklet is intended to supplement existing resources that are available to help families. Unlike other resources which provide factual information about mental illness or the mental health system, this resource is unique in providing personal accounts on how to deal with challenging situations. If you have had a particularly difficult time coping with your family member's experience with mental illness and find it comforting to hear about other's personal experiences, then this resource may be beneficial to you. If you are new to the system, are in crisis or are seeking information about your relative's illness, you may find other resources more suitable in meeting your needs. Some sources of information are listed in the resource section at the back of this booklet.

Restoring Hope and Moving Forward consists of nine stories, covering a diverse range of experiences. Each story is told from the personal perspective of a family member – a mother, father, husband, daughter and sister – in a close, caring relationship with the individual with a mental illness. Each of these family members offers some background about their situation and share how they have been affected by it. They also identify what and/or who helped them cope and recover from their experiences.

We are very grateful to the family members who showed tremendous strength and courage in sharing their personal stories for this resource. If you would like to share your own personal story, or if you have any questions, please contact the Justice and Mental Health Program at the Schizophrenia Society of Ontario.

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This resource offers personal experiences only, and the information provided within is not to be taken as factual information. It is not to be used as a substitute for advice from a legal or medical professional.



Family Stories

Awareness: Learning the hard way

James Weber

I met my first wife, Fang Li, in the spring of 1987 and we were engaged six months later. When I met her, she did not seem ill in any way. She mentioned she was taking medication, but I didn't know what it was or what it was for. One thanksgiving weekend, I began to notice strange behaviours in Fang Li. She was starting to talk to herself out loud, was somewhat aggressive and certainly out of character. It was obvious something was not right.

I had no idea what was going on. Fang Li, her sister and her family had never really spoken to me before about this – maybe because she had already lost friends and jobs because of it. But at least her sister, being a doctor, knew what was needed and we were able to give her some medication later that day. Once the medication was injected, you could tell that it had started taking effect. The Fang Li that I knew started to come back.

It was soon after we were engaged that I found out that Fang Li, my fiancé, had been coping with schizophrenia for the previous ten years. She had experienced her first episode while in university. She was seeing a psychiatrist regularly. Although I did meet her doctor once, I cannot say that the conversation was very helpful. I will admit that I remained quite ignorant about the illness.

The summer she graduated from the early childhood education program at the University of Toronto, her psychiatrist advised her to go off her medication for a few months to avoid any buildup and future side effects. However, as the medication left Fang Li's body over the next several weeks, the symptoms of the illness began returning. It started with symptoms of paranoia, which over the next several weeks escalated into a full-blown episode.

We were able to get her back onto medication quickly. However, her improvement was different – it was slower and, in hindsight, I can see that she was showing signs of depression. She had to leave her first job as a teacher within the first week because she was not fully stabilized. She wanted to be active, but couldn't. She was impatient to get back to a normal life, but it takes time.

On Tuesday, October 24, 1989, at around four in the afternoon, she called me at work. She wanted permission to kill herself. Her voice had a strange sadness that was not there before. I went home immediately and found her depressed in a way that I had not seen before. She felt hopeless. As she described it, she was struggling with a dark vacuum of thoughts that she could not control.

While I was in the kitchen preparing supper, she got up from the couch. She said, "Jim, I have to do it," opened the balcony door and rolled over the edge. That was it. She took her own life. It took all of about ten seconds.





Two days after Fang Li died, I received an information package from the Schizophrenia Society of Ontario (SSO), which was called the Ontario Friends of Schizophrenics at the time. I had mailed away for it just a few weeks earlier after seeing it advertised in the subway. Inside, I found a fact sheet. I read that 40 percent of people with schizophrenia attempt suicide, and 10 to 15 percent succeed. Until that moment, no one had told me about the risk of suicide. The information package contained a book list. I ordered the books and started reading.

How did this affect you?

It was hard coping with my memories – many of them happy ones. I do ask myself whether events would have been different if I had been more aware. However, in life you learn that you cannot change the past. You can only impact the present and shape the future.

I decided to do something worthwhile, to become involved and to learn more. I did not want to keep it to myself because I did not want anyone else to go through what Fang Li and I went through, and not be aware of this illness.

What or who has helped you cope?

Four months after my Fang Li passed away, I joined the East York Chapter of the SSO. Part of my education process was listening to other families' stories at chapter meetings, and meeting people who have the illness and speaking to them. I quickly learned that knowledge about the illness is not only in the books and brochures but also in the people who have seen and experienced it all. I met some families with over 30 years of experience coping with schizophrenia, and not only with one family member but sometimes two or three.

The information package from the SSO provided me with the means to learn about the illness. I will always wonder whether, if I had received this information earlier, things could have been different. Even though Fang Li was living with the illness every day, I truly do not know how much she understood it. I certainly did not. I will always wonder how she could have benefited if she had met other people with the illness. I am almost certain she could have been a benefit to them.

After 20 years, the memories are not as strong, but they are still there. In total, I knew Fang Li for three years – but those three years have changed my life forever. It is amazing how jokes about people killing themselves or about somebody “being crazy” either on the TV or radio or at work, are no longer “funny”. I have seen how real this can be and it is not “funny”.

There is a scar. It heals as best it can, but it will never go away. My eyes have been opened and I can no longer close them. I can no longer look at people who live on the street in the same way. I know they may have the same illness that she had – even though she did not end up on the street. I cannot deny my awareness of this illness. My task now is to help make everyone else aware, and to make change happen.

In life I have learned that you can only impact the present and shape the future. I decided to share my story because I do not want to keep this to myself. I do not want anyone else to go through what Fang Li and I went through, and not be aware of this illness.

– James Weber, partner of an individual who died by suicide.





One family's experience of violence, fear and stigma

*Catherine Silva**

My son, Jay*, had his first psychotic episode while at a summer job planting trees in British Columbia. He was 18 and between his first and second year of university. Our first entry into the mental health system went relatively smoothly: he first saw our family doctor, and subsequently went voluntarily to the hospital. It wasn't hard to convince him as he had some insight at that time – in fact, he appeared grateful.

When Jay was discharged, the doctor said he might be fine, but I thought Jay still seemed confused. I think the doctor was trying to give us hope. The doctor told us that you can't give a diagnosis of schizophrenia on the basis of one incident. So he said that Jay should just take the medication and maybe he would be okay.

But unfortunately, that was not the case. When I picked him up at the university to drive him home for Christmas break, I noticed immediately that he was unable to put any thoughts together, acted extremely paranoid, confused, and disoriented. When I took Jay to the hospital, the doctors told me there was nothing they could do until he hurt himself or somebody else. They said it was not against the law to be paranoid.

So I brought him home, and that evening, which was Christmas Eve, he physically assaulted his grandmother, grandfather and younger brother – everyone in our home except me.

That was the start of Jay being caught in the “revolving door” of the mental health system. Lack of insight would cause Jay to go off his medication from time to time. Before long, he would be in hospital again and become relatively stabilized. He was also quite good at telling the doctors what they needed to hear to allow his release from hospital. Once he was discharged, he would immediately go off the meds.

One night, Jay appeared at my back door, dirty, shoeless and very psychotic. I brought him in and made him a sandwich. He was clearly very sick. I could not allow him stay at our house because I did not feel it was safe, as he had already assaulted family members.

I knew I had to be firm. After considerable attempts at conversation, I said, “If you don't go to the hospital by yourself, I will have to call police and they will take you.” He became violent and I called police. When he threatened to kill the police, they laid criminal charges.

While receiving treatment in the forensic psychiatric unit at the hospital, Jay continued to act out violently, and even tried to strangle another patient with a cord. He was charged immediately, jailed and put into isolation. Fortunately, he was ultimately found Not Criminally Responsible (NCR) for his offence. If not for this NCR ruling, he would have been left in jail where he would not have received treatment for his mental illness. As it was, he was not able to access medication during the few weeks while waiting for the trial.





Jay has been in the forensic system for about nine years now, and sadly he repeatedly commits criminal offenses. When he improves, he's moved to a facility with less security. But when he's not so strictly supervised, he acts out violently. It's an ongoing cycle.

Jay's addiction to drugs is also a major problem. At one point, he was doing so well that he was able to live in the community and was even accepted into a social work program at a community college. However, unable to ignore the voices he was hearing, he began using drugs again. Caught in a random check, Jay was sent back to hospital.

Jay is 32 now. He's in maximum security in a long-term forensic psychiatric hospital. He is taking medication, but so far, does not appear to be gaining any insight.

How has this affected you?

With the first psychotic break, I was shocked and totally confused. But the person in our family most seriously affected is my younger son, Kevin*. Kevin was asleep in his bed when he suddenly awoke to find his older brother attacking him. He was not physically hurt, but was emotionally traumatized.

To this day, Kevin is afraid of Jay and doesn't want anything to do with him. He doesn't want Jay to know where he lives or who his friends are. He is aware of all that Jay has done over the years and of how strong and dangerous Jay can be.

I have supported Kevin's decision to stay as far away from his brother as possible and not be involved in Jay's life. I have often said to him that when the time is right, he may choose to be involved. I have emphasized to Kevin that he is not to feel guilty about his feelings, or his decision to stay away from his brother. I recognize that this is not necessarily the best way, ultimately, for Kevin to deal with his fear of his brother, but it seems to be the best way at this time. If Kevin decides to become more involved with Jay at some time in the future, that is entirely up to him. Kevin is the only one who knows his own capabilities for dealing with his brother's illness.

What or who has helped you cope?

I kept myself grounded and calm by focusing on trying not to alarm my younger son. Also, going to work regularly gave me structure and kept me in relationships with people outside my home. This helped me remain calm and keep the family environment calmer too.

I tried to maintain a healthy approach to supporting Jay by being constructive: listening to doctors, gathering information, taking a problem-solving approach, and sharing as much information with the medical staff as possible.

When Jay had his first episode, I went to the local chapter of the Schizophrenia Society of Ontario (SSO), where I heard about the National Alliance on Mental Illness (NAMI) course called "Family to Family". This course was amazing. The pieces started to fall into place, and after the fifth class, I had a very clear picture of what my role could be as a family member. I learned a wide range of strategies, including how to take action, and how to just back away if I needed to. I learned to communicate better with doctors and lawyers and with the Ontario Review Board – which I had found quite intimidating. For me, this course was the key to self-confidence and to knowing how I





could be involved in the most effective way. It helped me so much that I trained to become a facilitator and taught it for five years.

Later, as Jay got into the forensic system deeper and deeper, I changed my coping methods completely. At first, Jay was geographically near, so I could keep in touch with the doctors and social workers face-to-face. But when he was moved to a forensic facility far away from my home, the distance made it impossible to stay in touch as easily. All communication had to be done by letter, which was much more difficult than talking to people face-to-face. I could call, but it was hard to reach social workers that way, and I could rarely talk to a doctor on the phone.

At first I spoke to my colleagues at work honestly, but the stigma there was really bad. It was terrible, as if I had a communicable disease. I was very affected by the stigma, and felt isolated because I couldn't be open. So now I'm very careful with whom I share my story.

I still tried to be rational and maintain a problem-solving approach, but I decided that I couldn't be involved to the same extent. However, I still have to feel I'm doing something positive, so I'm looking for ways to support funding for brain research.

*All names in this story are pseudonyms.

Being heard and being understood: The benefit of compassionate professionals and family-to-family support

Anne Smith*

My son suffers from paranoid schizophrenia, drug addictions and anosognosia. Anosognosia, better known as "lack of insight", is caused by damage to specific parts of the brain and is the most common reason that individuals with schizophrenia and bipolar disorder do not take their medications.

Now 39, he had his first psychotic break in 1995 at age 25. During the last 14 years, he has been charged with various offences ranging from breach of probation and shoplifting to assault, bank robbery and even attempted murder. All of these offences were illness related. He was jailed 14 times and hospitalized 13 times in a forensic psychiatric facility. He was certified 11 times and in solitary confinement approximately 100 days total during this time – 29 of those days consecutively, with us – his family - not knowing what was going on (which was especially difficult as he was in British Columbia and we were in Ontario). He went Away Without Leave (AWOL) from a forensic facility twice.

On many occasions, he was released from hospital or jail to the streets and left to fend for himself – ill, using street drugs and without any money or support. During this time I spoke (by long-distance telephone) to three different psychiatrists, four different administrative crown or crown attorneys, each with conflicting explanations of what to expect. None of the people handling his case had read the almost 1200 page file on him and his illness. One judge even released him on his own recognizance! From October 1995 to the present, he has been found Not Criminally





Responsible (NCR) twice. One of these NCR findings was overturned a year and a half after the incident on a legal technicality.

My son refused medications each time he was in jail until four years ago when he was in a forensic psychiatric institution and taking medications was part of his treatment plan. He was there for one and a half years, and it was the longest he had ever been on medications for one stretch. It seems that he was better than ever before, and had gained a little insight, because he stayed on the medications after his release and is still on them.

How has this affected you?

Each time he was released from hospital or jail, we believed that we had finally come out on the other side of that warped revolving door that can cause so much unnecessary pain and suffering to a person with a serious mental illness. Each time, we prayed that this would be the end of our nightmare, the end of the middle-of-the-night phone calls. Each time, we thought this was the end of his being ill and on the streets, all those miles away from us, without any food or shelter. We prayed that this would be the end of the constant fear that one of those calls would be to inform us that he was dead.

He has been taking medications for over four years now. He knows he feels better on the medications, but is still not convinced he is ill, and has very little insight. He has also tried to quit taking street drugs – but without much success. He lived successfully in the community for about 14 months, but is now in jail again – this time for assaulting his girlfriend. I still fear that the day his supervision is done, he might go off his medications and go back to his drug use, and that the cycle will start all over again.

What or who has helped you cope?

We were very fortunate that many of the staff in the hospitals and many probation officers went above and beyond their job descriptions. They understood very well that many times his symptoms combined with his lack of insight made him too ill to make decisions regarding confidentiality, and that the best way to help my son was to maintain communication with me, his primary caregiver. These individuals were a godsend to us and I will be forever grateful for them. The information we exchanged is probably why my son is still alive today.

Through email and phone calls - even collect calls at times – they listened to my concerns and accepted what I had to tell them about his behaviour. They watched his behaviour closely and let me know when he was picked up by police and which jail or facility he was in. Because I was talking to him on the phone regularly, I knew when he was decompensating. The probation officers listened to the information I gave them, and would call him in more often when he began to decompensate. They also let me know when he had been picked up for any offences or breaches of his probation. They consulted with his psychiatric nurses (one of whom would even go to court with him and inform the court about his situation) to give him the best chance they could.

It was also very helpful that he was treated with medications immediately when placed in hospital (as allowed by the law in British Columbia). As a result, he did not have to suffer any more than necessary and he was safe, as was anyone else he might have come across when he was severely ill.





Having access to his social worker, who kept me abreast of what was going on, was invaluable. These caring, compassionate people understood that there must be give and take between the system and families. They understood the fears and frustrations of families – especially families who have been consistently involved, and who have made themselves available to give support to loved ones, even when they could not be physically present. They also understood that they were able to help him more if they also had the support of his family.

I have also completed the National Alliance of Mental Illness (NAMI) Family-to-Family course and am a trained course provider. It helps to continuously repeat my story. When I facilitate a course and see the room full of other families going through similar experiences, it reminds me that I'm not alone. In 2001, I also co-initiated, and am still a member of, an e-mail based support group called Advocates of the Not-Criminally Responsible Schizophrenia Suffers (ANCRSS), which has also been beneficial to me. I found that it was difficult to go into a regular support group for families of relatives with schizophrenia because people really didn't understand what I was going through being that my son had come into conflict with the law. The ANCRSS group was, and is, a great support because everyone involved are truly understanding of where you are coming from. They understand the fears you have and the alienation you feel. And being that I am from a rural area, this group allowed me to have the support I needed without having to drive to the nearest city or even leave my home. I would not have been able to move forward without it.

* A pseudonym name

We had to struggle alone for the first 7 years of my son's illness. My aim is to educate as many people as I can in hopes that this eases the burden of their journey through the traumatic and unpredictable maze known as the mental health and criminal justice system.

- Anne Smith*, mother of an individual living with schizophrenia.

When a child supports a parent: A young adult's lesson in love

Damien Hepburn*

When I was in my final year of high school, my mother began to show symptoms of serious mental illness. She was 55 and I was 17.

At first, it was difficult to distinguish the symptoms of the illness from her generally introverted nature. However, my mother became more withdrawn. She began exhibiting strange behaviour, such as having conversations on the phone when there was no one on the line. She was competent in all spheres of functioning, so our family did not know that there had been a severe problem developing, and we did not know enough about the signs and symptoms of mental illness.

In time, my mother was eventually diagnosed as having a delusional disorder with symptoms of schizophrenia. She was given medications and started improving. Though she underwent a short-term support program, she lacked the ongoing continuum of support at the level that she needed to





stay well, and her mental health began deteriorating again. She was not able to take care of her basic needs and was not able to communicate coherently with others.

She gradually regained her self-awareness thanks to a combination of appropriate medication, rest and support. It was a long process of recovery which spanned several years. In due course, she began receiving payments from the Ontario Disability Support Program (ODSP), which made it possible for her to support herself independently without having to worry about getting a job.

By the time she reached full recovery, my mother was participating in society by volunteering with the Canadian National Institute for the Blind. She studied Braille, eventually mastering it to help transcribe books. Not only did this volunteer contribution provide an external goal to concentrate on – perhaps a welcomed focus separate from recovery – it is a tremendous personal achievement.

How has this affected you?

As a young adult, I found the situation very overwhelming and destabilizing. My family sought advice from as many avenues as possible: hospital psychiatrists, a family friend who is a psychologist and my mother's family doctor. Doing the research and consulting are things that I expected and was ready to do. However, the emotional burden was heavy.

Doctor-patient confidentiality was often a barrier to gaining access to the proper care. While I appreciate doctors' concern for patient privacy, the process of accessing support for someone who is not completely self-aware is disempowering. Our family kept providing assurances to medical and legal professionals that my mother's best interests were always at stake. However, we were often met with wary skepticism, which is frustrating. We eventually went to a justice of the peace. The involvement of the justice system was another burden in the process of recovery – families have to learn to navigate the system and to become the liaison between the justice and medical professionals.

Given that mental illness is such a personal journey for both the individual who is ill and their family, the experience can be very isolating. The trials of mental illness are not often talked about openly, nor are they easily expressed. Unable to concentrate, I lost my university scholarship. I opted to take time off from my studies and work instead. I also sought counseling for myself, acknowledging that I would need help coping with my anxiety. I eventually returned to school to complete my undergraduate studies. However, I had to learn to be patient and adapt to the process of my mother's recovery, which revealed itself slowly.

What or who has helped you cope?

I found it helpful to keep track of all documents and incidents. I eventually prepared a binder with important contact information, a history of appointments and a chronicle of the development of the illness and medication taken. Keeping organized helped me feel less overwhelmed. The experience navigating various support systems becomes a bit less frustrating when you can present clear and complete information.

Out of respect for my mother and given my own need for personal space, it took some time before I felt comfortable sharing our story with friends and family. However, when the time came, sharing our story with others was a cathartic experience and I came to realize what a blessing it is to have





friends and family with sincere listening skills. I learned how to express myself and communicate difficult personal experiences in a way that others could empathize. It was about bridging gaps between people.

Loyal friends and close family members were helpful in reminding you that you and the loved one living with the illness are not alone. Ultimately, coping was a lesson in love. It was a process of developing a sincere respect for the loved one who is ultimately the one facing the illness.

What, if anything, did you try that was NOT helpful?

At first, I tried to do too much: balance school, work and family. I tried to keep up an unrealistic pace. Eventually, I had to slow down and distinguish what needs to be done, what can be done, and how to pace my life in order to recover from my own anxiety in dealing with what felt like an unrelenting crisis.

Also, it was not helpful to act as though I could control all aspects of someone else's recovery. There is a need to balance one's caregiver responsibilities with respect for the person's own rate of progress and ability to cope.

Is there anything you would like to add?

It is difficult to remain calm and collected when you see a loved one withdraw into a world of delusions. You want them to be okay; however, that focus can become blindingly intense to the point that you forget that the individual is still their own person, separate from the illness affecting their brain. You cannot heal for them, nor can you rush their recovery. I learned it was not helpful to become impatient and attempt to do everything for my mother. You need to be organized, dedicated and open to learning all you can to help your loved one, but you also need to let the individual have breathing space and recover at their own pace.

* A pseudonym name

A mother fights back: Turning heartbreak into advocacy

Ainslie Mistysyn

We started noticing strange behaviours in my son when he was 25 years old. For example, he would rearrange candles displayed on the sideboard, then look at us as if the new arrangement held a highly significant meaning to him, as if he were trying to share a secret message of some kind. We felt confused, puzzled, but ignored it.

At 26, my son tried to kill himself and we rushed to the hospital emergency room in a state of total disbelief. We were horrified, terrified, embarrassed and felt hopeless. We had no clue he was living with a mental illness as we had no education about that. We kept silent, didn't tell any of our friends or seek support because we felt humiliated and embarrassed. We stigmatized ourselves.

Within two years of his suicide attempt, my son experienced a complete psychotic break. He assaulted his stepfather, punching him in the eye after he'd been chastised for changing our radio





station without first asking. He came outdoors to find me, telling me about it himself, distraught about his unusual violent behaviors.

When I went to consult my MD with my son, he suddenly attacked me, punching off my sunglasses. I wasn't hurt, just alarmed, and recognized in a flash that he was mentally ill. The police came and took him to the hospital. We were horrified to see my son handcuffed on a stretcher; babbling nonsense in a high childlike tone of voice. My husband and I felt very alone. We had been told to go home; to await a phone call from a psychiatrist. There was no one offering us any support or even perhaps just a cup of coffee. We sat there, in silence, staring sadly at each other. We were trying to make sense of something unthinkable, unknown, and unidentified. We sat there a long time, in shock. The medications were effective, and by the next day he showed significant improvement. He was able to talk again. His diagnosis was paranoid schizophrenia.

Police laid eight charges including assault, property damage, resistance to arrest, and uttering threats. The court successfully rerouted my son into the medical system. The judge found him Not Criminally Responsible (NCR) and placed him on three years probation with medical conditions that he attend a doctor regularly, follow the doctor's medical treatment recommendations, and participate in groups as an outpatient. She said, "I think you're a wonderful, polite, young man and with these supports I hope to never see you in my court again. Have a great life!" But, sadly, it didn't turn out that way. Following another incident, my son spent another five years in forensic hospital.

After finally receiving an Absolute Discharge from the forensic hospital, my son had all his mental health supports withdrawn. He was suddenly left to find his own way. Of course, he was told about services in the community, and was given names and information about various voluntary programs. But my son didn't want, or welcome, any supports. He has his own opinions and was happy to finally be free of all restrictions.

He is now homeless, declining shelter services that have been offered by housing counselors and crisis workers, saying he needs no assistance or help from professionals. In his forties now, he states that he is a man well able to be responsible for himself and his needs. Although we do not know his current whereabouts, we hold out hope of eventually resuming contact. We leave messages on his cell phone answering machine; sending him our love and offering for him to call us collect, anytime. We are now in the process of accepting his free will.

How has this affected you?

Initially, when I heard the diagnosis of schizophrenia, I read every book I could get my hands on. I became more and more depressed. I found the non-fiction books frightening rather than helpful because I got the impression no one with schizophrenia ever completely recovers, and that there is nothing family members can do to influence recovery. But, in truth, no book would have been the right one for me at that time as I was handling my emotions by intellectualizing. I was in denial about the seriousness of mental illnesses, ignorant about federal and provincial laws, and hoping against hope that all would turn out well, somehow, at some time.

Emotionally, I was totally overwhelmed. I thought, "This is my beautiful young man." I was heartbroken, fearful and full of anger at the world. Mostly I was deeply sad. I grieved my son.





Since then, I have suffered emotional trauma continually. Even when my son was doing relatively well, I felt slightly traumatized, waiting for the other shoe to drop, sometime, somehow, eventually. I developed what is called “reactive depression”, which I must cope with day by day. As my coping skills have increased, my reactions have become less traumatizing. Today I manage much better than I did years ago.

Currently, we do not know my son’s whereabouts and have had no contact which makes us very sad. We miss him.

What or who has helped you cope?

The turning point for me was when I became angry enough that I became involved in improving the mental health system. I was frustrated that there were so few resources, no educational meetings, nobody taking hold of the fact that doctors were not adequately educated about mental illness, and often did not wish to take on a patient living with schizophrenia.

We became members of the Schizophrenia Society of Ontario (SSO), attended a few meetings and began to accept support and empathy from other family members in similar though different situations from ours. They listened, answered our concerns and gave us hope.

For 12 weeks, my husband and I drove through winter blizzards to a town many kilometers away to take the National Alliance on Mental Illness (NAMI) “Family to Family” course. We became empowered to cope day by day as we used the methods we had learned with other family members. After completing this course, I took a training course and became a member of the NAMI teaching team that presents educational programs to both family members and service professionals. We get “outstanding” evaluations from participants, which I find very gratifying. I discovered volunteer work eased my pain and made me feel useful, even happy.

We disclose our own experiences as part of teaching the course. It’s hard to do because all of our emotions come to the fore in the telling. But this is my self-care because I have noticed that I cope better with each incident as it happens. And I cope better with the reactive depression.

We attended Ontario Review Board (ORB) hearings as well which helped us understand the forensic system. We are also taking vacations, knowing we deserve to enjoy our own lives. It makes us stronger and more able to endure the chronic grief that we feel.

I am an advocate for appropriate and effective service delivery, care and treatment for people with mental illness and appropriate support for their families.

Is there anything you would like to add?

Because of the stigma, many people with schizophrenia would prefer to be labeled as a criminal rather than a “schizophrenic”. They decline assistance when offered, and do not wish to be caught in a medical system, where they may be held longer than in a jail.





My hope for the future is that with better public education and better public acceptance of some of the symptoms that don't go away, the public won't be scared and won't avoid people with schizophrenia. In an ideal society, people will become educated, discover compassion and empathy for those with mental illness, and become friends with them.

* A pseudonym name

In response to an interview published in the Globe and Mail, a woman wrote that I was a "hero." Initially I was stunned but eventually it dawned on me that there are way too many people still in the closet over their, or their relatives and friends, mental illness. Keeping mental illness a dark secret helps no one so I continue to tell my story to others.

- Howard Fluxgold, father of an individual living with schizophrenia.

A father advocates for his son: Put him in care, not in jail

Howard Fluxgold

I first noticed my son's behaviour changing when he was 20 and a student in university in Toronto. He did manage to get his degree but after graduating, he seemed to be doing nothing toward starting a career. He dropped out of graduate school after a few days and he was making copious use of recreational drugs.

He began talking about suicide and after several unsuccessful attempts to get an appointment with a psychiatrist he was eventually involuntarily committed by UBC hospital. He was 27.

This began a six or seven year odyssey of dealing with the healthcare and legal systems which can best be described as often disinterested, occasionally incompetent, sometimes untruthful and almost always unsuccessful in dealing with my son's mental illness. He spent five months in hospital on the first involuntary committal during which time he went AWOL (Away Without Leave) three times. On the second occasion I was informed that he was missing when I showed up for a visit, unaware that he was AWOL. No one seemed concerned and no one had thought to inform me. I had to insist that I be informed if it happened again. It did, and he was found sitting in a snow bank in a small town 300 kilometers north of Vancouver. He was not in a locked ward and anyone could enter or leave the ward easily.

At one point, the department head said they would discharge my son to a hotel residence in the drug-infested Downtown Eastside of Vancouver. I made sure this did not happen and found him a new psychiatrist. After an assault charge, suicide attempt and another half year in hospital he was released into the community, but still under the committal order (called a Community Treatment Order in Ontario). This meant he had to see the psychiatrist and social worker and take his medication. Some time later the doctor decided he was no longer a danger to himself or others and decided not to renew the committal order. Now it was up to my son to take his medication and maintain his doctor appointments. He did not.





In the following two years he was arrested 6 times in a six-month period in three different cities in three provinces. On every occasion I tried to get the police, Crown lawyers, and defence lawyers to have him assessed by a psychiatrist. I told them he had a mental illness and needed care, not jail. This fell on deaf ears until a judge in Toronto got the message and ruled him not criminally responsible on a sex assault charge. He was sent to a forensic mental health hospital where he is now making progress for the first time in a decade.

How has this affected you?

It has been mentally and emotionally exhausting. I'm 65, so when "all hell was breaking loose" it wore me out. At certain times, I stopped answering the phone because I knew it would be the hospital saying he had run away, or the police saying he had been arrested or perhaps attempted suicide again. I just felt, "I can't deal with this." But I always did.

This last arrest, where he was ultimately found NCR (Not Criminally Responsible), I wasn't going to do anything. I just thought, "I don't want to do this again. I just don't have the energy to do this again." But after a few days, I thought, "It doesn't take much to pick up the phone." In the end, I felt that he was my son, that I loved him as my son and that I could not abandon him – even though I felt frustrated with him and the so-called system.

I believe I kept helping because I have a lifetime commitment to my children. He is my son now just as he was when he was five years old. At that time he needed my help and guidance and I willingly gave it. I did not expect that as an adult he would still need the same level of support. Obviously he does. Abandoning him now would be breaking that bond. We cannot pick and choose when we would like to be a father to our sons and daughters. No matter what happens, he is always my son. In the end this is what has kept me going even when I really did not want to be involved.

I have not lost hope. In the forensic psychiatric hospital my son is in now, he's taking medications that are making him less delusional and able to see things clearer. I think he has a little insight now because he has said some things he never said before, such as, "Maybe the meds are helping."

But it's hard when I remember my son the way he was as a kid and then see the way he is now. In some ways, it's a wasted life. He's 33 now, and has nothing. I did have a lot of hope, and still have some hope. But all this involvement with the mental health and legal systems is soul destroying.

The way he was living on the street made me concerned he might come to harm or might harm someone. At least at the forensic psychiatric hospital, he is getting ongoing, long-term care. I know that he's in a good place right now. He's not on the street and he's getting treatment. Those are the thoughts that give me some comfort.

What or who has helped you cope?

What helped me cope most was that I had a goal: to get my son the treatment he needed and deserved. Whenever I was unsure what to do I asked myself (or others) whether what I was doing would help achieve that goal. Would it make his life better? This helped me stay focused and not become too frustrated or sidetracked with extraneous issues. I could decide not to fight a certain battle because it would have no positive impact on my son. And it helped ease the frustration. After my son was arrested several times across Canada, my goal was to get him long-term care in a





secure facility. That is what I said repeatedly every time I came into contact with, or wrote to, anyone in the mental health or legal community.

I have always taken the position that if my son could receive adequate treatment from caring professionals over a sustained period of time, he could lead a decent and productive life. As a father, I felt that he needed (although perhaps he did not want) my help; that I was the only person who was going to help him get proper care. So, in effect I was responsible for him because no one else was going to take that responsibility, not the legal or health care system. I was determined to make “the system,” the bureaucrats and functionaries who didn’t care, do their job properly. This is what kept me advocating for him.

There were several times when my advocacy got what my son needed. I wrote letters to judges, lawyers and doctors to further his case. I had charts sent from one hospital to another and provided the courts with relevant documents. On one occasion I got a Vancouver hospital to change its policy on releasing information to the police.

But I found the legal system totally and repeatedly unresponsive. Being a former journalist, I know what the media can do. In 2008, the Globe and Mail interviewed me as part of their special series on mental health. This was at a time when my son was fast approaching rock bottom and I was out of options. [See Andre Picard, “Put patients in care, not in jail,” Globe and Mail, June 26, 2008.] At the time, the Crown lawyer was intent on placing him in jail, not treatment, so we had nothing to lose and everything to gain. After about a year of delays the judge finally ruled that my son was Not Criminally Responsible (despite the opposition of Crown and defence lawyers) and sent him to hospital where he is receiving treatment and showing progress – for the first time. I believe this article was pivotal to the way the judge handled this case. I believe that he and the lawyers involved knew there was wider interest in this case and that the media may follow-up in the event that my son was ordered to jail.

Writing for various publications also helped me cope. I wrote my story for a few mental health magazines and newspapers, hoping it might help others or result in something different happening. It also seemed to help me let off steam.

Both the British Columbia Schizophrenia Society (BCSS) and the Schizophrenia Society of Ontario (SSO) were also very helpful to me. I took a ten-week course called “Strengthening Families Together” from the BCSS that explained the nature of mental illness and how the mental health and justice systems work. It brought me up to speed quickly. The BCSS also linked me to the SSO which I’m very grateful for. Since my son’s last arrest and court case – where he was found NCR – was in Ontario, I would not have been able to get anywhere in Ontario without the support of SSO. Their Justice and Mental Health (JAMH) program solved a huge problem for me as I was trying to figure out what was going on and trying to advocate for my son long distance from British Columbia. The JAMH staff went to court and represented me through the process. They didn’t have standing, but were familiar with the process and the Crown lawyers. They were able to talk in a low-key way to the Crown lawyers and keep me informed. During all the arrests across Canada, the worst thing for me was when I did not know where he was - in jail or on the street - or what was happening to him. Crown lawyers were unresponsive and seemed only interested in processing him out of the system after punishing, not treating, him. The JAMH program was able to keep me in contact with my son and keep me updated on how the system was treating him.





Is there anything you would like to add?

As I said to one police officer who had arrested my son a few times, “You can arrest him until the cows come home. But unless you facilitate mental health care, you will not deal with the problem.”

I chose to contribute to this resource because of the tremendous validation I found in meeting and speaking to others who shared similar experiences. For so long I thought my family was the only one who was dealing with intense and bizarre circumstances. I want other families and siblings to know that there is power in a collective conscious and it can also provide you strength to cope with your own family's personal struggles.

- Christina Jabalee, sister of an individual who died by suicide

In memory of Michael: A sister finds purpose and passion in helping others

Christina Jabalee

In July 2008, I lost my brother to suicide at the age of 25.

Michael first started showing symptoms of depression at 15. Unfortunately he never received early treatment. Over time he became agitated and impulsive which got him into trouble with the law. He stole a family member's car and assaulted my boyfriend. Over the next several years, Michael was in and out of the mental health and the justice system repeatedly treated for brief periods and then discharged without any plan to keep him well.

The lack of appropriate psychiatric treatment for Michael led to his continued interaction with the justice system. At one point he endured over one year in a correctional facility, where he remained untreated and his condition deteriorated. He was targeted and assaulted by other inmates. Once he was almost suffocated by being rolled in a rug, and another time he needed stitches for a facial wound. Then for his “protection”, he was placed in isolation for days to weeks at a time.

When he was released after that year, Michael was acutely ill. He was paranoid, delusional and hearing voices. He didn't sleep for days. Within three weeks, he succumbed to his psychosis and assaulted a family member and then attempted suicide. Michael was eventually found Not Criminally Responsible (NCR) for the assault and spent the next four years – the last of his life – under the Ontario Review Board (ORB).

The law regarding confidentiality made it very difficult for our family to help Michael. We knew a lot of information about him that we couldn't share with professionals. Michael signed the confidentiality form saying that we could be involved; however, there was still a lot of information





that he would not allow us to share, and he threatened us if we did because he feared being brought back into the hospital.

In the months leading up to Michael's death he was deteriorating mentally. Yet, we felt trapped by his fear driven threats, so we were unable to share those intimate details of his mental state that sometimes only family members see. Michael killed himself and as a family we felt powerless to prevent it.

How has this affected you?

As I was growing up, I became used to Michael's shocking, bizarre behaviours. One of the most extreme examples was a call I received in the middle of the night that he had set fire to a car. In time, I became numb to extreme incidents of this type.

I can look back now and see that I attempted to cope with my family life by constantly going out with friends to distract myself. I moved away from home a couple of times while in college, but was never successful in escaping the stressful situation at home because, emotionally, I continued to be in the loop. I was always involved in what was happening to Michael – not always directly, but because my mother would phone me every time something happened to Michael, and she would be very upset. So I was constantly worried about how he was doing.

I never felt like I was Michael's sibling, but more like a caregiver. I was subconsciously always trying to balance being caregiver with just being his sister/peer.

What helped you cope during the ten years that Michael was ill?

As I grew into my mid-20s, I began to learn how to relate to Michael better through my course work for my Bachelor of Social Work degree. I became more patient through a growing understanding of Michael's personal struggle.

Our family also found support through the Schizophrenia Society of Ontario (SSO). In the year before his death the psychiatric forensic facility that Michael was with referred my mother to SSO. We made the call and talked to the Justice and Mental Health (JAMH) worker. She invited us to attend a conference called "Demystifying the Mental Health and Justice System" in May 2008. It was really helpful. It was the first time I realized there were other families coping with the same thing. Until then, I had always thought our family's situation was unique because everyone I had ever spoken to about it could not relate or understand. I found comfort in knowing we were not the only ones.

My mother stayed connected to the JAMH worker for ongoing support. She also got connected to Advocates for the Not Criminally Responsible Schizophrenia Suffers (ANCRSS), SSO's email support group for families of people involved in the mental health and justice systems. My mom eventually had phone conversations with a few people and even met them for lunch. It was helpful for her to find people she could talk to and relate to. It helped me to know she has a support system of people who could understand. In turn I felt less pressure to always come up with a solution to the latest Michael crisis. However, the constant worrying for him - and for her - was always there.





What, if anything, did you try that was not helpful?

One thing I tried that was not helpful was arguing with my brother about his symptoms and behaviours. It would only make me frustrated and make Michael angry. I wish I had known then about the different ways of communicating and coping that I learned after his death through SSO's course, "Strengthening Families Together". I learned that you are supposed to focus on the emotion, empathize with the person feelings and find out what would help them feel better. And in some situations, giving each other space and time alone is important to reducing the stress in the home.

What helped you cope after Michael's death?

Michael's death has been the most challenging thing I have ever faced in my life. At first I attempted to cope with my grief by throwing myself into my social work courses and doing research on schizophrenia and suicide. However, through my studies and current work with SSO, I have learned that everyone needs to take care of their own mental health regardless of whether they have a mental illness.

After Michael died I was numb for many months. I first reached out 6 months later to a support group for survivors of suicide, and soon after began seeking counseling for myself. Through working as a family support group facilitator, I have noticed that caregivers often focus on helping the ill person and don't take care of themselves. I became even more aware that it wasn't enough that I just focused on helping my mother cope. I needed to take care of myself. I am finally focusing on my own mental health.

I have also been coping by using my experiences to advocate for change. I began by sharing our family's story at an SSO event for Members of Provincial Parliament. I also presented with my family to the Select Committee on Mental Health and Addictions about what we feel are necessary changes to the current mental health system. Through Michael's life and illness we were silent. We struggled alone. We didn't know what to do or where to find help. I have realized that it didn't have to be that way. Advocacy gives our struggle and Michael's tragedy purpose. I want to prevent families from struggling alone and silent. Michael's death gave our family the strength to speak out to help other families.

Nothing in life is ever permanent and struggle is inevitable. Death is a part of life, even though Michael's came a lot sooner than I would have wanted. I can never change what happened, but I can change how I live my life. I find my purpose and passion through helping others find peace and comfort in their struggles. I am hopeful that, together, we can help to reduce some of the challenges in the current mental health system.

Is there anything you would like to add?

In the groups I facilitate, I make sure that we talk about the risk of suicide. Forty per cent of people with schizophrenia attempt suicide; yet, nobody informed our family that Michael was at high risk. We never knew how to respond in crisis situations. I feel it is extremely important for families to know the facts, what their options are, and to have a crisis plan so they can feel more secure.





One final thought would be to remind people to see their relative as a person and not to see only the illness. Most of the time with Michael, we saw the illness taking over, and it was hard to remember that he was a person who was suffering too. Michael, the person, was hard to see sometimes because he was often masked by intense emotions, aggression and chaos. However, when I reflect on his life and the many notes and cards he wrote me, I see the loving, charming, caring, protective brother who always wanted to make sure I knew he loved me. He was struggling against his illness just as much as the rest of us were. At the heart of his being, he was, and is, a beautiful person.

Taking care of yourself too: The importance of self-care

*Jennifer Karadzic**

By my son's account he started having thoughts about killing people in grade nine although I couldn't/didn't/wouldn't see his illness until he had finished college. He was assessed as being gifted in grade five and had always been musically talented as well. He was an independent thinker with eccentric behaviour. With the teenage changes that were taking place and the gradual onset of his illness I just didn't see that he was sick.

In his earlier years he was obedient, quiet, opinionated, expressive, full of dry wit, and respectful. Later his eccentricities became more pronounced, such as shaving off just one eyebrow, or laughing to himself and not wanting to share the joke, or pulling apart things and not being able to put them back together. When I look back at all these separate events and group them together, I cannot believe that I didn't see anything.

My son went away to college, which made it even harder for me to see the problem. When we were all together it was usually a family celebration with little one on one conversation. It still didn't occur to me that he could be mentally ill. I knew nothing of that. It was not in any family history that I knew of, and my basic knowledge of mental illness was minimal. Drugs and alcohol were the obvious problem.

By the time he was nineteen, he was smashing telephones when they rang, throwing half full, large clay piggy banks down the stairs, smashing to pieces the door to the basement with a hammer, and so on. The odd behaviour escalated to the point where some of his care workers said he was the most floridly psychotic individual that they had seen in a long time. Forensic testing later showed him to have paranoid schizophrenia and to be capable of harming others.

How has this affected you?

When my child was diagnosed with schizophrenia, and when I accepted that reality (which took some time indeed), I grieved deeply for the loss of my son as I had known him. He lacked insight and refused medication. Without medication he would never recover. I felt a mourning that to me was as real, deep and painful as I might have if he had actually died.





Yet every once in a while he would do or say something that would make me think that a very tiny part of him knew he wasn't well, and that he really wanted me to help him. One example is when he sidled up to me one time when I was standing by the kitchen sink. He was holding a large kitchen knife in his hand, saying that he had been in the bushes in our backyard with the knife waiting for enemies to come by. Why else would he be telling me this unless he thought he needed help and that I was the one who could get it for him? It seemed as though he was checking his reality against mine.

I didn't believe that he would ever be well again. He seemed alien to me, not at all familiar, as if a space creature had invaded his body. The words he spoke were English but they didn't fit together in a way that would allow me to comprehend their meaning. His eyes looked flat and held no sparkle.

The happy ending/beginning is that eventually his insight was restored and, after several trials, he found a medication that works for him. How did he get to that point? He was deemed to be a potential danger to himself and others, and because I was his substitute decision maker, I was able to consent to his treatment with medication.

After two years of staying on the medication, his insight was restored. I was on vacation in Mexico and phoned him and asked, "How are you?" He answered in such a way that I knew something had changed for the better. There was a switch.

He worked with the doctor because he decided he wanted to be in control of his life again, to tell his psychiatrist what he didn't like and have input into his dosages. He formed a partnership with the psychiatrist and likes him now. He is getting better all the time. His sense of humour has returned. The sweet, caring, gentle son that I knew has come back home again and fortunately, most fortunately, no one was hurt.

Once he developed insight and started looking after himself, my life really changed. When I didn't have to be there monitoring every little thing, I was able to relax, but the truth is, I kind of collapsed. While I was dealing with my son's crisis, I didn't have time for my own feelings, but now my feelings flooded to the surface. I developed depression and gained 40 pounds. Now, I'm working on becoming healthy and fit again.

What or who has helped you cope?

I knew, as a single parent and mother of not just one ill son but of also another son with his own separate issues, that I had to stay strong and at my best so I could get my son well and be a fit leader for my little family. I worked out regularly at the gym. Even though all the while he was telling me that he hated me like he'd never hated anyone before in his life, my mantra was: "think of this as a business problem, I must get my son better, don't take this personally, this is the business of getting my son better."

I also took vacations to recharge myself. I wasn't able to turn it off completely, but at least I could put my feet in the sand and relax a bit.

* A pseudonym name





Together on the road to recovery: Have we always had sunsets like this?

Jane Russell

We began to notice some changes in my son Adam's behaviour when he was about 13 years old. He was becoming aggressive and not getting along with family the way he used to. We worked this out but then when he was 14, he became quite depressed. He began showing symptoms in a matter of weeks. He would laugh out loud day and night. He thought he saw aliens, and that everything he put into his mouth was poison.

By the time Adam was 18, I had probably called police about six times. I didn't know what else to do. One night when Adam was at my apartment, I called them again. The police said, "We can't just keep coming if you don't do anything." I told them, "It's not me. It's the hospital. They keep letting him sign himself out. He's legally an adult. What can I do?"

The police suggested I aggravate Adam so he would strike me. They promised they would take him to hospital. I wouldn't have done it if the police hadn't said to. I didn't know what else to do. In hindsight, I can see it was poor advice. But at the time, I saw it as my last resort.

Adam did strike me, and then he panicked because he had never struck anyone before in his life. He ran. The police chased after him, took him to jail and charged him with assault. I stood up in court and said, "If this young man goes to jail, as sick as he is, it's a crime." I was told to be quiet or leave the court. He was sent to a jail – not a forensic hospital – for three months. To the best of my knowledge, they didn't give him his medications there.

During his three months in jail, I was only allowed to visit him twice. It was awful. I was worried as I was given very little information, and phone calls were restricted. Fortunately, I knew someone who was a teacher at the jail. She looked out for Adam as best she could, and kept me informed.

Eventually, Adam was accepted into an educational program at a psychiatric hospital. That was a great relief for me. I saw the improvement in his mental state, but unfortunately, his physical health deteriorated while he was in the psychiatric hospital. He gained 150 pounds in six months – from weighing 160 to 310. He told me he had nothing to do at the hospital, so he just went to the mall and ate. So now he had an obesity problem and on top of that, he was smoking more to deal with the boredom and urge to eat.

There was a huge turning point in 2004 when Adam went on Clozaril (Clozapine). It was the only medication that really worked for him. In less than a year, we started to really notice a difference. His sense of humour returned. He began to draw again, to take walks and be more aware of his surroundings. I remember one afternoon around dusk, he looked out the kitchen window and said, "Look at that amazing sunset and the colours over the hills. Mom, have we always had sunsets like this?"

Adam lived with my partner and me until he was fully stabilized. I wanted to know everything and be sure he was okay. Now, six years later, he takes responsibility himself, keeping appointments with his psychiatrist, and for the required blood test once a month. He now has his own apartment





in a town where his father lives. His apartment is small, but really nice and within walking distance to downtown. He has made new friends and become reacquainted with some school friends. He pays his own bills and manages by himself.

This past Christmas, a branch of the Royal Bank in the town where he lives asked Adam to paint holiday scenes on their windows – all five of them – for a contest in which businesses were having their windows painted all over the downtown. Adam says with such joy and pride, “They asked me to do it!”.

How has this impacted you?

When Adam became ill I really thought I had caused all of it. Over and over I thought of anything and everything I had done as a mother that might have caused this illness. Everything from the day he hit his head as a youngster to the fever caused from a bad cold, to parenting techniques, the separation from his dad and so on. It took 9 years before I stopped outwardly blaming myself. I will never really know or understand but I feel it must be genetic. Once Adam was diagnosed I seemed to find another gear I didn't know I had. Although it was not financially wise I worked around Adam's needs, and tried to learn as much as I could about schizophrenia. It was very hard and the pain I felt was so intense. As far as I could see it would always be this way. Giving in was not an option. Losing friends, jobs and things I loved was. I wanted to be with him, find the best help and encourage everything he wanted to do.

What or who has helped you cope?

I'm in a different place now than I would be if this had never happened. As we were going through it, I lost friends and I drank too much and I cried too much. Adam required so much care and attention. I lost lots of jobs, lost money, lost everything. I thought, “What's his life like? He's a young man and he doesn't date, drive a car, have a job and has just a few, select friends.” I felt sad thinking of what might have been.

My life changed a lot; and some of the experience has been positive. I coped by finding the best doctor, by educating myself, and by not being afraid of schizophrenia. I am a lot stronger and able to make decisions I might have avoided in the past. I have a greater understanding of my immediate family. Everyone was so afraid of Adam; I had to keep everyone at arms length with their suggestions and good intentions. I cope now by being as involved with schizophrenia and that community as much as I can. I am taking it slowly and will increase my involvement in time. I returned to a past career, Employment Counselling, which helps with community connections and provides the availability to be within reach of agencies and politics.

Adam's own understanding of what has happened to him is more than I can ask. He never complains about his life, and his outlook has helped me be much stronger. We have struggled together to understand. Even to this day, Adam is haunted by his police charge and time in jail, and questions why he was sent there. Adam and I have talked about it and both of us have dealt with what happened and with the memories. We did it together, consciously.

In the end, I was able to cope because I have a very supportive family. They were a godsend. They saw me through a tough time. As I got stronger and less afraid, I stopped feeling sad. I now feel strong and I'm in the best place I've been since this happened, that's for sure!





I've moved ahead, but I know there is more to do to support Adam in his recovery. He has his own apartment, but he still needs structure and things to do. Adam may be at the stage of wanting and needing more activities outside the illness, but he's afraid to go too fast in case he slides back. At the same time, he's afraid not to do things because life will pass him by. Although I am still his main resource for motivation and activities, I am aware of his new and growing independence and it is good.



Mental Illness and Violence: Some Final Thoughts

As illustrated in many of these stories, when your relative is living with untreated mental illness or is not getting the help that they need, you can be directly impacted by destabilizing events, traumatic incidents and in some cases, even violence. This is the reality for some families despite the fact that the prevalence of violence across families of persons with mental illness is quite low.

There has been a great deal of research done on the relationship between mental illness and violence which does show that mental illness is not the cause of most violent crimes committed in our society. The belief that *every* mentally ill person could potentially be violent is a myth and people living with mental illness are actually no more likely than anyone else to harm someone in the general public. In fact, people with mental illness are more likely to become victims of violence compared to others in society and are also more likely to harm themselves than cause harm to others.

Yet, as illustrated in these stories, you could be faced with unpredictable, upsetting and even unsafe circumstances when your relative is showing signs of psychosis. This is especially the case if your relative is not receiving treatment and/or is using drugs or alcohol.

Behaviour like this may seem out of character for your relative and confusing to you and your family. It is important that if you do feel unsafe or concerned about the safety of yourself or of your relative, that you take this feeling seriously. If your family member is showing signs that they may be of harm to themselves or others, contact a mental health professional or bring this to the attention of your relative's healthcare provider. And if you ever feel that you are in imminent danger, call the police.

For more information about mental illness and violence, [click here](#) or contact the JAMH program at the Schizophrenia Society of Ontario (SSO).

Justice and Mental Health Program
Schizophrenia Society of Ontario
130 Spadina Ave, Suite 302
Toronto, Ontario, M5V 2L4
416.449.6830/1.800.449.6367
jamh@schizophrenia.on.ca
www.schizophrenia.on.ca



Helpful Resources for Families

There are many resources available in your community that can provide information, support and help to you and your family. If you're not sure where to look, phone the Mental Health Service Information Ontario (MHSIO) telephone information line (phone number below) and ask about what is available in your community. You can also look online for services in your area or talk to your family doctor about existing supports. If your relative is in hospital, ask the staff about community resources for you and your family. Your local branch of the Schizophrenia Society of Ontario (SSO) can also help you find the resources and help that you need.

Below is a list of provincial services that can help you find resources in your area as well as a list of books, websites and reading if you are looking for more information to read.

Where to Start Looking for Resources

ConnexOntario Health Service Information

www.connexontario.ca

Mental Health Service Information Ontario (MHSIO) – 1.866.531.2600

MHSIO is a central source of information about mental health supports in your community and across Ontario. The service is available 24 hours and is free, confidential and anonymous.

Schizophrenia Society of Ontario (SSO) – 1.800.449.6367

www.schizophrenia.on.ca

The Justice and Mental Health Program (JAMH) – Works in partnership with mental health and criminal justice services to provide education, individual and navigational support, and family-to-family support. For more information, phone SSO or email at jamh@schizophrenia.on.ca.

ANCRSS (Advocates for the Not Criminally Responsible Schizophrenia Sufferers) - ANCRSS (pronounced anchors) is a Canadian based e-mail support group supported by the Schizophrenia Society of Ontario. Members have a family member or loved one who suffers from schizophrenia, bipolar or clinical depression. They have also come into conflict with the law as a result of their illness and have become involved in the forensic/criminal justice system. For more information, phone SSO or email at jamh@schizophrenia.on.ca.

“Strengthening Families Together (SFT)” Course – This is a 10 session educational course for families and friends of individuals with schizophrenia and psychosis. These sessions are also available online on the SSO website. For more information, contact SSO or your local/regional chapter.



National Alliance on Mental Illness Ontario (NAMI) – 1.800.950.6264

www.namiontario.ca

Family-to-Family Education Program – NAMI offers a 12 week course for family caregivers of individuals with severe mental illness. Visit the NAMI website to find where the course is offered in your area or phone NAMI for more information.

Family Matters Resource Centre

www.familymattersresourcecentre.ca

A “one-stop shop” resource for families that provides collaborative information from the Ontario Federation of Community Mental Health and Addictions, The Mood Disorder Association and The Schizophrenia Society of Ontario.

Canadian Mental Health Association (CMHA) Ontario – 1.800.875.6213

www.ontario.cmha.ca

Justice and Mental Health Support and Services – CMHA offers a range of programs and services to people who are living with a mental illness and in conflict with the law. CMHA also provides information on the criminal justice system, forensic system as well as research and policy initiatives in the area of mental health and justice. For more information, contact CMHA Ontario or the branch in your region.

Support for Families and Caregivers – CMHA Ontario offers an online list of available support groups, recommended readings and family initiatives in the area of mental health. You can access these resources by visiting the CMHA Ontario website and clicking on the “Support for Families and Caregivers” link.

Mental Health First Aid (MHFA) – 1.866.989.3985

www.mentalhealthfirstaid.ca

Offers courses across Canada that provide the skills and knowledge so that you can better manage potential or developing mental health problems in yourself, a family member, a friend or a colleague. Also addresses how to manage crisis situations or circumstances where a person may be a danger to themselves or others. Visit the website or call the toll free number to find courses available in your area.

Bereaved Families of Ontario

www.bereavedfamilies.net

Provides information, education and support to families and individuals who have lost a significant person to death. Also, offers an online support group. Visit the website to locate supports in your area.





Suggested Books, Guides and Websites

The Justice Process: A Guide to Families. Schizophrenia Society of Ontario. See. www.schizophrenia.on.ca

Fitness to Stand Trial: A Guide for Families. Schizophrenia Society of Ontario. See. www.schizophrenia.on.ca

Diversion: A Guide for Families. Schizophrenia Society of Ontario. See. www.schizophrenia.on.ca

Guide to the Forensic Mental Health System in Ontario – Centre for Addiction and Mental Health. See. www.camh.net

A Family Guide to Concurrent Disorders – Centre for Addiction and Mental Health. See. www.camh.net

Coping: When someone in your family has psychosis – An educational resource for families on what is helpful when a family member is experiencing psychosis. See. www.psychosissucks.ca

I Am Not Sick, I Don't Need Help! By Xavier Amador and Anna-Lica (2007).

Promoting Recovery From First Episode Psychosis: A Guide for Families. By Lisa Martens and Sabrina Baker (2009).

Strengthening Family Resilience, Second Edition. (Guildford Family Therapy Series). By Froma Walsh (2006).

Learning about Schizophrenia: Rays of Hope. A Reference Manual for Families & Caregivers. Schizophrenia Society of Canada (2003).

How to Cope with Mental Illness in Your Family, A Self-Care Guide for Siblings, Offsprings and Parents. By Diane Marsh and Rex Dickens (1998).

Grieving Mental Illness: A Guide for Patients and their Caregivers. By Virginia Lafond (1994).

Hidden Victims, An Eight-Stage Healing Process for Families and Friends of the Mentally Ill. By Julie Johnson (1994).

