

A Sibling's Guide to Psychosis

Information, Ideas
and Resources



CANADIAN MENTAL
HEALTH ASSOCIATION

ASSOCIATION CANADIENNE
POUR LA SANTÉ MENTALE



A Sibling's Guide to Psychosis: Information, Ideas and Resources

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Visit CMHA's web site (www.cmha.ca) to find this guide and other materials produced by CMHA's early psychosis intervention initiatives.

Additional copies of this guide may be available for a limited time.
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As part of a national project to raise awareness about first-episode psychosis and support the needs of families affected by the illness, the Canadian Mental Health Association has developed this sibling resource guide – **a guide intended to provide information and support to teens and young adults who have a brother or sister experiencing psychosis**. This sibling guide represents one of the last resources to be produced by the project, which after six years is drawing to a close.

This guide could not have been created without the interest and participation of siblings across Canada. Through focus groups and interviews, fifteen adult siblings generously shared their stories in order to help us develop a guide that reflects the sibling experience of living with psychosis in the family.

This guide will be of primary interest to brothers and sisters who are new to the experience of psychosis in the family. We also hope it will assist others, such as parents, friends and service providers, in better understanding the challenges faced by this often neglected group of “significant others.”



Early Days...

"The first thing I noticed was that he wouldn't socialize with the rest of the family. He was very withdrawn and he wouldn't eat with us. I thought he was into some weird drugs or something."

"He was losing a lot of weight; he wasn't doing as well at high school and he wanted to be by himself a lot. He was doing a bit of marijuana. But it wasn't until I got a phone call from him and we were on the phone for an hour and all he did was cry, cry, cry... that call confirmed that something was really, really wrong."

"Being very quiet – that was one of the first things I noticed cause I always knew him to be very energetic."

"In retrospect there were so many signals from so far back. He started being less himself in many different small ways. But none of those things were like glaring indicators because he was a teenager."



In the early stages of psychosis, family members, friends or others might notice signs that "something's not quite right", such as:

- withdrawal and loss of interest in socializing
- loss of energy and motivation
- problems with memory and concentration
- deterioration in work or study
- lack of attention to personal hygiene
- confused speech or difficulty communicating
- lack of emotional response or inappropriate emotional display
- general suspiciousness
- sleep or appetite disturbances
- unusual behaviours.

A person with psychosis may experience one or more of the following symptoms:

- hear voices that no one else hears
- see things that aren't there
- believe that they are being watched, followed or persecuted by others
- believe that others can influence their thoughts, or that they can influence the thoughts of others
- feel that their thoughts have sped up or slowed down.



Early Feelings...

"It was scary. I didn't want my friends to come over anymore because he was so weird and was embarrassing. I didn't know what was happening."

"I was afraid, angry, couldn't understand why he was doing these things and I was angry at him for being a druggie. You know we were just convinced there was no other explanation for what he was doing."

"Yeah, I mean there was a kind of lack of information. For me that was the most scary thing – I couldn't pin it on anything."

Early signs of psychosis can be difficult to interpret. Family and friends may attribute odd behaviours to drugs – or simply to “being a teenager.” In fact, drugs may be part of the picture, though the primary problem is more likely the psychosis - not the drug use. The relationship of drug use and psychosis is complex. Recreational drugs, such as marijuana, may be used by individuals to relieve or mask symptoms of psychosis. But, in some individuals, drug use can actually prompt the onset, or recurrence, of psychotic symptoms.

While a lack of awareness about the signs of psychosis is a major barrier to people seeking appropriate help, the issue is further complicated by the fact that those experiencing symptoms may not recognize the changes in their own behaviour and may even actively resist others' attempts to engage them in seeking help.

"It didn't seem like the same person who was there."



Facing the Unknown: Understanding Psychosis

“He would always be laughing to himself and saying weird things that didn’t make sense.”

“I would attribute it to growing up or other immediate things, but deep down inside, I knew it was something more.”

“I didn’t have a clue what psychosis was. I had no idea. I think people need greater awareness of the illness and its behaviours and where to go for help. This should be in peoples’ general knowledge.”

What is psychosis?

Psychosis is a serious but treatable medical condition affecting the brain. It is characterized by some loss of contact with reality and can dramatically change a person’s thoughts, beliefs, perceptions and/or behaviours. It is difficult to know the cause of psychosis the first time it occurs. Psychosis is associated with a number of medical conditions including schizophrenia, depression, bipolar (manic depressive) disorder, and substance use, among others.

Sometimes psychosis emerges gradually over time, so that in the early stages symptoms might be dismissed or ignored. Other times, symptoms appear suddenly and are very obvious to the individual and those around them. Symptoms vary from person to person and can change over time. The initial experience of psychotic symptoms is known as the “first episode” of psychosis.

A psychotic episode occurs in three phases. The length of each phase varies from person to person.

Phase 1: Prodrome

The early signs are vague and hardly noticeable. There may be changes in the way some people describe their feelings, thoughts and perceptions.

Phase 2: Acute

Clear psychotic symptoms are experienced, such as hallucinations, delusions or confused thinking.

*“Why didn’t I
Google this?
I “Google”
everything!
I didn’t know what
to look up!”*



Facing the Unknown: Understanding Psychosis

Phase 3: Recovery

Psychosis is treatable and most people recover. The pattern of recovery varies from person to person. People recover from first-episode psychosis. Many never experience another psychotic episode.

Research has shown that there is no single cause of psychosis. There is some indication that psychosis is caused by a poorly understood combination of biological factors which create a vulnerability to psychosis during adolescence or early adult life. Environmental factors such as stress, drug use or social changes might trigger an episode of psychosis in vulnerable people.

While psychosis can happen to anyone, symptoms of psychosis most often develop during adolescence and early adulthood. It can be an extremely distressing condition for the individuals affected and for their families and friends. Because the first episode of psychosis can signal a variety of conditions, it is important to seek a thorough medical assessment – ideally from a health professional with first-episode expertise.

The common symptoms of psychosis*

Symptoms vary from person to person and can change over time. The most common symptoms of psychosis are known as positive symptoms and include:

Delusions

These are beliefs that the person feels to be true but others do not. The person is so convinced of their delusion, that even the most logical argument cannot make them change their mind. Two types of delusions are:

- **Delusions of reference:** a belief that the behaviour and/or remarks of others on the street, on TV, radio, newspapers, etc. are meant for them
- **Delusions of paranoia:** a belief that people are following or watching them or trying to harm or hurt them.

“When we were driving together she would cover her mouth with her hand and it looked to me like maybe she was hearing things and trying not to talk back to the things she was hearing in her head. That was one of the things that triggered for me that something was definitely not how it should be.”

Hallucinations

“Voices” are a common type of auditory hallucination. They are noises heard when there is nothing there, however they seem real to the person. They often sound like a person or a group of people talking about the person or to the person. “Voices” can be pleasant but are often nasty and may make the person distressed and uncomfortable.



Facing the Unknown: Understanding Psychosis

Hallucinations less common than “voices” can include:

- **visual hallucinations:** the experience of seeing things that are not really there
- **tactile hallucinations:** the experience of being touched or touching something that does not exist
- **olfactory hallucinations:** the experience of smelling something that is not really there
- **gustatory hallucinations:** the experience of tasting something (often experienced as unpleasant) that is not really there.

Other experiences include:

- **thought disorder:** problems with thinking, e.g., having trouble linking thoughts together
- **thought withdrawal or insertion:** a feeling or belief that your thoughts are either being taken away or put into your mind
- **thought reading:** a feeling or belief that other people can read your thoughts and know what you are thinking
- **experience of control:** a feeling or belief that you are under the control of an external force or power, e.g., aliens
- **thought broadcasting:** a feeling or belief that your thoughts are being broadcast out loud. This can often be very stressful leading to avoiding other people and not going out.

During a psychotic episode, people may also experience:

- a change in behaviour, e.g., becoming more isolated and withdrawn
- a loss of energy or drive
- a loss of interest and enjoyment
- a loss of emotions like not laughing at something they used to find funny
- feeling “flat”, e.g., feeling low and lacking emotion
- a reduction in ability to concentrate or pay attention, such as being less able to read a newspaper or remember what was on TV.

These symptoms are often referred to as “negative symptoms.” This list does not include everything – people can experience lots of other strange symptoms or peculiar feelings that are not mentioned here. You’ll find definitions of positive and negative symptoms in the Glossary section of this guide.



Facing the Unknown: Understanding Psychosis

Who's most likely to experience psychosis?*

- Psychosis can happen to anyone.
- Symptoms of psychosis most often begin between 16 and 30 years of age.
- Both males and females can be affected.
- Males tend to experience symptoms a few years earlier than females.
- Persons with a family history of serious mental illness are at an increased risk of developing psychosis.

Will I get psychosis?*

"There's a prevalence of mental illness in our family and I'm in that key age bracket. I found myself analyzing myself a lot more. I became a lot more aware of how I was dealing with stress."

"I was doing the same drugs my brother was doing. Will the same thing happen to me?"

Many people worry that, because someone in the family has experienced psychosis, they might be next. Being related to someone with psychosis does not necessarily mean that you will also develop psychosis.

As with many other health problems, a family history of psychosis will increase the risk for other family members, but the degree to which the risk is increased depends on the closeness of the blood relationship to the person affected.

- If there is no known family history, your risk of developing psychosis is 1%
- If a grandparent, uncle or aunt has psychosis, the risk of developing psychosis is 3%
- If a parent, brother or sister has psychosis, the risk increases to 10%
- If an identical twin has psychosis, the risk is 50%.

It is important to note that while having a relative who has experienced psychosis is a risk factor for developing psychosis, a combination of a number of different risk factors is needed to go on to develop psychosis.

**In large part, these sections were taken from "Information about psychosis for brothers and sisters". See Sources.*



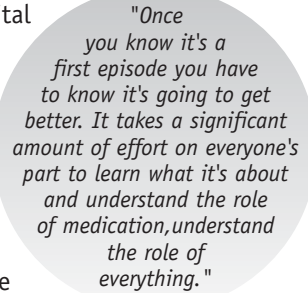
Facing the Unknown: Understanding Psychosis

How is psychosis treated?

Low doses of anti-psychotic medications are a key component of treatment, along with education and support for the individual and their family. Treatment strategies are aimed at allowing the individual to maintain their daily routines as much as possible. There have been tremendous advances in the treatment of psychosis during recent years, reducing the need for hospital stays and promoting faster, fuller recovery. Typically, psychosis does not disappear on its own. Instead, if left untreated, the condition can worsen and severely disrupt the lives of individuals and families.

Canada has numerous well-established early psychosis intervention (EPI) clinical programs and more are developing all the time. Still, the majority of communities in Canada lack ready access to comprehensive EPI services so the type of treatment that your brother or sister receives will depend very much on where your family lives. To find an EPI service close to where you live, check the Canadian Early Psychosis Intervention Clinical Programs section of this guide.

Moving through the experience of psychosis from identification to recovery is a journey for all involved. The following illustration contrasts the journeys down two very different roads to recovery.

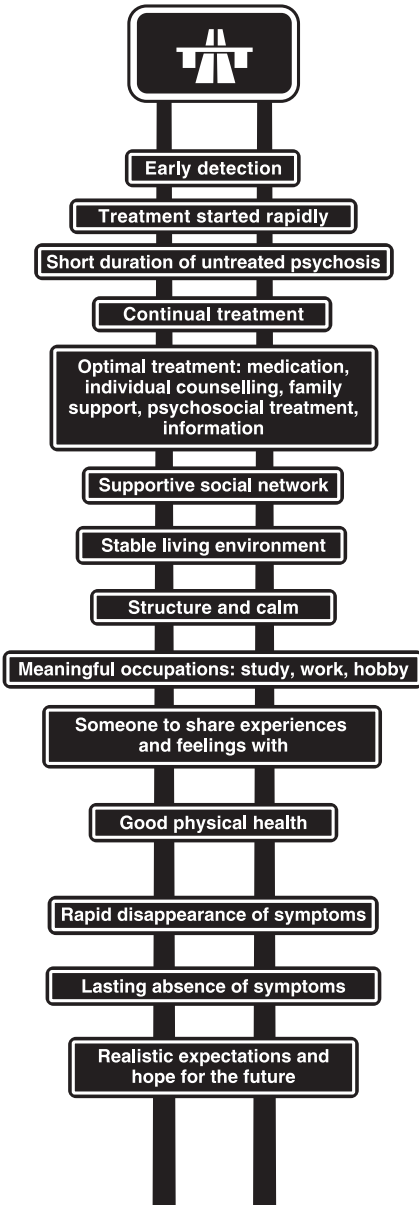


"Once you know it's a first episode you have to know it's going to get better. It takes a significant amount of effort on everyone's part to learn what it's about and understand the role of medication, understand the role of everything."



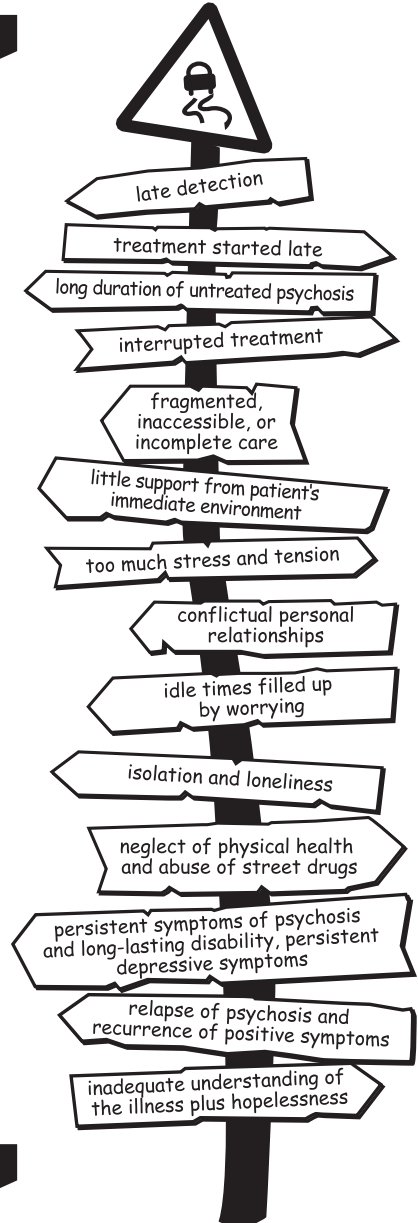
ROADS TO RECOVERY

The Smooth Road



PSYCHOSIS

The Rocky Road



RECOVERY

©EPO-publishing, Antwerp, Belgium (2000)



Facing the Unknown: Understanding Psychosis

Which one is the “road less travelled?” The answer is: the smooth one.

These stories present real life examples of the very different experiences encountered by youth and their families. Perhaps it's no accident that the accounts from the smoother road come mainly from the youths themselves, while the trip down the rocky road is described by the parents.

The Smooth Road

“Fortunately, early treatment of the disease resolved symptoms before they interfered with her ability to function and participate in her own care. My daughter was diagnosed and treated at the onset of the disease before psychotic symptoms fully developed.”

“The first year after my diagnosis was the most difficult. No eating junk food, no staying up late, and most importantly, no stimulants. I had to adopt a low-key life style that most teenagers aggressively avoid. I have taken up many quiet hobbies such as quilting and embroidery in an effort to remain stimulated yet not overly so.”

“The group program became very important to me because I was learning about myself and my experiences from other patients.”

“What has helped me the most is talking to select family and friends about what I am going through.”

“I've been able to work part-time and earn my own income. That's been so important. I took one computer course and got a grade of 95%!”

“Because I am taking responsibility for myself I believe that the outcome is positive. It will take me more time to accomplish all of my goals than most people, but I look forward to the challenge an uncertain future presents.”

The Rocky Road

“For 1 1/2 years we searched for appropriate treatment and support for our son and family as we struggled to understand and help our son. Our son began to withdraw from longtime friends and the support of his family.”

“Our son asks if he is ever going to be able to work. He wants to contribute too.”

“Our daughter had to drop out of high school. Her community mental health worker's suggestion was that we pay to have her employed in a sheltered workshop for the mentally challenged.”

“Once a promising athlete, a competitive swimmer, soccer player, student of Tai Kwan Do and an avid skateboarder, our son retreated from a world that once was safe and known to him and into a lifestyle fraught with risk, abuse, criminal activity and exploitation.”

“We live in a sometimes bizarre home. Tensions run high with anticipation of what might happen next and the police have been called several times.”

“Our son has dropped out of mainstream life and lives a marginalized life while homeless, living on the street. He has found acceptance for his distracted and quiet manner and his excessive drug use with other street people.”

“He sleeps in a park and lives minute to minute. I, his mother, pray for him and others like him.”

“Our daughter told us that if she died that we would be the only ones to grieve. She has lost all her friends.”

Source: *Family to Family, Issue 2, Summer 2001*



Facing Change: Impacts on the Family

“Things at home changed. Family life is different.”

Families are the central care providers for the majority of young people experiencing a first episode of psychosis. Psychosis brings tremendous stress to the entire family and families usually experience a difficult adjustment period and then their own recovery process. Family members deal with the issues presented by psychosis in their own way and at their own rate. A mother’s experience is different than a father’s experience and a parent’s experience is different than your experience as a brother or sister.

Family members may disagree regarding the best way to address any problems and there may be confusion about what is going to happen. There may be guilt about having possibly mismanaged the psychosis, anger at one’s self, others, ‘the system’ and fear about treatments, hospitalization and the future.

Coming to terms with the experience of psychosis in the family is a major challenge for all family members. Psychosis creates concern for the brother or sister who is ill, fear for the family, fear for the self and fear thinking ahead to the next generation and wondering what will happen.

“It made me weigh a lot of my choices and my own lifestyle. My brother’s lifestyle from Grade 10 has been the same as my lifestyle...we were doing the same drugs. I need to be more sure of my decisions and look at my life. A consequence has been brought to my attention. No one says ‘This could happen to you.’ But you never know!”

Individual family members are at risk for stress-related mental health and physical issues themselves. It’s important for all members of the family to talk openly about their feelings. By talking, things become clearer. Fears openly discussed become manageable. Fears not discussed grow.



Facing the Unknown: Understanding Psychosis

Facing Feelings: An Ongoing Process

"It's scary. So sometimes I'd read about it and other times not."

With the changes that psychosis brings to the lives of siblings, parents and the entire family come all kinds of feelings and thoughts that may not always feel comfortable. Siblings are likely to experience a range of powerful, conflicting emotions and feelings in response to the experience of psychosis in a brother or sister. It's important to acknowledge these feelings and share them with someone you trust.

Here are some expressions of the feelings that siblings may face.

Anger

Siblings often experience intense feelings of anger. The anger may be directed at their parents. It might also be directed at the brother or sister experiencing psychosis. Sometimes, it is directed at health professionals.

Anger can show itself in many ways – both outwardly and inwardly. Anger and hurt feelings that are turned inwards can lead to depression, drinking too much or misusing drugs. It's important to release angry feelings in appropriate and healthy ways.

Envy and Resentment

"My parents are only happy when my sister is happy. It seems that everything is about how she is doing!"

"He doesn't have any responsibilities ... Mum and Dad give him money all the time for gas, loan him the car...and I'm struggling along."

"My parents spoil her rotten."

"He gets all the attention in our house!"

It may seem like all the focus of the family is on the sibling who is ill and there is no time for other family members. Siblings reported feeling both envy and resentment for all the attention that their sibling was getting.

Families may be in crisis and parents may be totally focused on the sibling with psychosis. On top of this, siblings may be expected to look after their brother or sister who is unwell or do more work around the house. Siblings reported taking on a parenting role.

"Instead of just being a brother I'm doing more parenting on issues like what's appropriate behaviour."

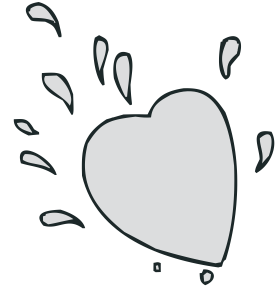
"He's living with me because he wanted more independence from our parents."



Loss and Sorrow

"He should have an easier life. I want him to have an easy life. He doesn't have that and I wish that for him."

Siblings may mourn for their brother or sister as they knew them and feel that they have lost a brother or sister who they could associate with and share important events. Grieving is an essential part of being human and is the way people let go of how things were or might have been, and move on in their lives.



Guilt

"I was afraid that all our 'roughhousing' when we were little caused his psychosis."

Siblings share that they often experience a feeling of guilt and a concern that they might have contributed to the development of their brother or sister's illness. This is an unfounded belief. **Psychosis is a medical condition.** No one can cause it. Some siblings also experience a form of 'survivor guilt', feeling guilty that their sibling is ill and they're not. Addressing such feelings can take siblings a step closer to acceptance and prepare them to move ahead with a realistic optimism about the future.

"It's not anybody's fault."

Stress Responses

Besides having all these feelings, when under stress your own physical health and behaviour can also be affected. There are many reasons why we feel or react as we do. Our reactions are determined by our personality, our relationship with those around us and our own way of coping with stress. These are normal responses to stressful situations and they don't last forever.

Common responses that you might experience include:

- difficulty sleeping
- difficulty concentrating
- crying
- loss of appetite
- feeling like acting out of anger.



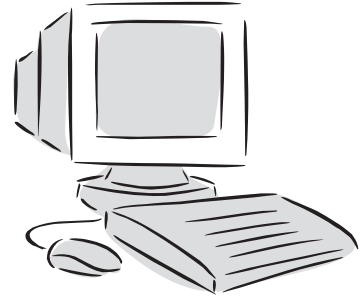
Learn as much about your brother or sister's experience as you can.

"Before my brother became ill, I knew nothing about psychosis and I wish I'd never had to know about it."

"You really do have to educate yourself. You need to find out what opportunities there are, what treatments there are, what support groups there are and what is available because it's not all obviously out there and easily accessible. It's something that has to be looked for."

"Psychosis in the family can be like a big cloud. It can be overwhelming. You think your family will never be the same. You need to keep it in perspective, and to do that, you need information."

Learn about psychosis. It's an illness like any other.



Talk honestly and openly with your family about your feelings.

"Don't go hide in booze, drugs, promiscuity. Talk to someone about your worries."

"I worry about my parents – I feel the need to protect them and worry about the impact on them."

"He's always been the big brother – always – he's always been the wiser one. He's asking for my help. Mum is asking for help to help with him."

It's important that your parents pay attention to your life as well – and it may be necessary to talk to them about this. It's tough to talk about feelings at the best of times and parents may find it just as hard to talk about the wide range of feelings that they are experiencing. However, it is precisely this kind of talking that enables families to get through difficult times. Handled well, crises can and will strengthen all members of the family.

Keep in contact with your friends. Stay involved with your regular activities, sports and hobbies.

"I realized that if I didn't start looking after myself, I wouldn't be able to be there for my brother."



Talk with others who have been through similar experiences

"You don't understand if you haven't been there. Good friends don't have a frame of reference. You're not alone. You're not the only one dealing with this!"

"I felt much better knowing that someone else had gone through it. Recognizing that it's fairly prevalent. Knowing that he will get better over time."

If there is an early psychosis service in your community or region, a clinician may be able to assist in contacting other siblings. Siblings can provide support by face-to-face meetings or chatting on the Internet. To find an EPI service close to where you live, check the Canadian Early Psychosis Intervention Clinical Programs section of this guide.

Consider starting a sibling support group. Find one other sibling – that's the beginning of a group. Check out the Self-Help Resource Centre at www.selfhelp.on.ca to learn more about starting a self-help support group.



We all need answers – otherwise it's very easy to concoct all sorts of explanations for what is happening.

“How involved should I be with my sibling?”

“It is very difficult, but – especially if you're older - you need to try to separate yourself and your life from the life of your ill sibling. Otherwise, your life can be overwhelmed by the illness.”

“We wouldn't have had this closeness. We're such good friends – I don't know if it would have been this close.”

It's different for every sibling. Some siblings become very involved, others less so depending on their unique situation. **What is most important is to do what works for you!**

“What can we do together?”

“The very best therapy for him (and for me) in the initial recovery was our doing activities together as soon as he was able. They would last for a very short time at first. We would try things when he was ready.”

“Try to choose things that she might want to be involved in. Ask ‘Do you want to do this? Maybe tomorrow...’”

“Be flexible – play it by ear. Don't go to public areas. Do one-on-one things like roller blading or going for a walk. Go for long drives.”

Your sibling who is dealing with psychosis will find it difficult to tell what is real from what is not real. They may lose control over thoughts and behaviours, feel overwhelmed by what is going on around and may feel confused, afraid, distressed.

It can be very difficult communicating with your sibling when they are experiencing psychosis and no one gets it right all the time. Be as respectful as you can.

In the Resources section of this guide, we have included “Dealing with Difficult Situations and Behaviours.” This section provides suggestions for dealing with situations that you may experience with your sibling.





“How long does recovery take? What can I expect to happen?”

“Keep the faith. It’s going to get better. Have hope!”

“Look at what you can do now because there is a lot that can be done and you kind of have to set yourself up and say ‘yah, I’m going to do something and these are the steps that we’re going to take and this is what we’re going to do. But don’t look at the yesterdays, look at the tomorrows and the possibilities in the tomorrows.”

Psychosis is treatable. People recover from psychosis and return to school, work and other roles. Recovery times vary. Some people recover quickly, others may be slower. Your sister or brother will gradually improve. It is common for people to experience some “left over” symptoms throughout the recovery time, e.g. they might hear voices occasionally or get nervous or worried when they go out in public.

Many young people who have experienced psychosis also feel down or depressed as they come to terms with what has happened and begin thinking about their plans for the future. **You can be supportive and helpful by:**

- being available to talk
- being positive
- encouraging your brother or sister to do things that they are good at
- giving your sibling genuine compliments
- being yourself and showing that you care.

“...don’t look at the yesterdays, look at the tomorrows and the possibilities in the tomorrows.”



“It’s changed my outlook. There are many shades of not normal and normal and there are all kinds of people.”

“There have been huge positives – he talks to me and lets it all spill. I’m getting to know my brother again. I’m in his circle now. He lets me in now.”

“I’m more tolerant of others now.”

“It’s brought our family to a new level of love, understanding and respect.”

“It’s not the way I expected it to be – but it’s ok.”

Psychotic illness brings enormous change to families, and both families and siblings talk about looking at the world differently. It can bring out the best in family members – a different sense of what is truly important. Siblings share that they have different and new relationships with their sibling who is experiencing psychosis and families share that their priorities have changed.

As time goes on, siblings report increased confidence and assertiveness. They let go of what they can’t change and become more focused on efforts to bring about the changes they see as necessary. They find and confirm their own identity while acknowledging the reality of the situation and its special demands.

Learning to live with a family member who has psychosis is often very difficult. Things are not the same and may never be the same.

But life continues...with room for love, laughter, joy, anger, tears and sorrow... just like before.

“It does get better and there’s a lot of learning and a lot of loving that can take place. And it can be good.”



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CMHA early psychosis resource materials:

“What Can Communities Do? A Community Action Guide to Early Psychosis Intervention Strategies”

The pamphlets *“Youth and Psychosis,” “Early Psychosis Intervention,”* and *“What is Psychosis?”*



DEALING WITH DIFFICULT SITUATIONS AND BEHAVIOURS

(Adapted from *“Information for Families.”* See Sources.)

Your sibling who is dealing with a first episode psychosis will find it difficult to tell what is real from what is not real, and may feel overwhelmed, confused, afraid and distressed. They may lose control over thoughts and behaviours.

It can be very difficult communicating with your sibling when they are experiencing psychosis. No one gets it right all the time, but try to be as respectful as you can.

“Knowing what to say was always a big struggle.”

“We’re kids still. Don’t expect too much of yourself. Do your best – be a friend – be there!”

“It’s ok if you don’t know what to say.”

Hallucinations

Hallucinations are when your sibling sees or hears things that you do not see or hear. Remember the hallucinations may be distressing to the person experiencing them.

Try to:

- Act calmly
- Distract your brother or sister if you can, by involving them in something else
- Ask your sibling to help you find something
- Engage your sibling in conversation.

Try to avoid:

- Assuming another breakdown is happening
- Figuring out what he or she is talking about or to whom he or she is talking
- Asking your sibling to try to force the voices to stop.

Strange Talk or Beliefs

“I agreed with him about something once when he was very delusional. When he was well he was really upset that I did that. He thought that I should have disagreed.”

Try to:

- Recognize that your sibling’s thoughts are very real to him or her and acknowledge the resulting emotions *“I can sure see that you’d be angry when you believe that we’re laughing at you.”*
- Say when you think something is not real, while acknowledging that it may seem real to your sibling
- Gently and matter-of-factly withhold agreement with strange ideas
- Show understanding of your sibling’s feelings and encourage him/her to talk openly
- Change the subject to something routine, simple or pleasant in real life
- Help your brother or sister tell the difference between reality and fantasy. Let them know *“It’s your brain chemistry that makes you think you’re seeing something – it’s not really there.”*



Try to avoid:

- Arguing about the strange ideas – arguing never changes the ideas and only upsets both of you
- Pretending to agree with strange ideas or talk that you can't understand
- Keeping up a conversation that you feel is distressing, annoying, or too confusing for you. It's ok to say "Let's talk about this later."

Sleeping or Withdrawing a Lot of the Time or Sleeping at Odd Times

"I'm getting used to his quirks like cooking a meal at 3:00am!"

"He is very docile, very quiet. He didn't want to do stuff."

"Try to choose things that he might want to be involved in. Ask 'Do you want to do this? Maybe tomorrow...'"

It is common for individuals who have just experienced a psychotic illness to:

- sleep longer hours during the night (or even during the day)
- feel the need to be more quiet and alone more than other people
- be less active and not want to do much.

These behaviours are natural ways of slowing down to help the brain and the body recover.

Try to:

- Remind yourself that your sibling may need to sleep more during the recovery phase
- Leave your brother or sister alone but make regular contact whenever they are up and about
- Let your sibling know that you are there if needed.

Try to avoid:

- Coaxing your sibling to come out of his or her room
- Fussing or worrying too much about your brother or sister
- Inviting a lot of visitors home as it may be too overwhelming.

It's important to carry on with your life. Don't sacrifice opportunities to go out and enjoy yourself with other people.

Aggressive Behaviour

"I left the house and stayed out in the yard until things had settled down a bit."

"We were both really upset. I left and came back when we'd both calmed down."

People with psychosis are often withdrawn. Aggression is no more common among people experiencing psychosis than in the general population. However, aggression may sometimes occur and you should know what to do if your sibling becomes aggressive.

Try to:

- Give a firm command such as "Please stop"
- Give your sibling space. If practical, move to quieter, more open surroundings. Don't rush or crowd your sibling.



- Discuss any threats and aggression openly in the family and with a clinician or doctor
- See what triggers the aggression and avoid that behaviour/situation.

Try to avoid:

- Saying angry or critical things which may upset your sibling
- Using the words “you” and “you should”
- Battling it out on your own – ask for help
- Staying around if your sibling doesn’t calm down.

It’s very important not to ignore verbal threats or warnings of violence made to you or others. Don’t tolerate aggression to you or anyone in your family.

Indications of Self Harm

Don’t panic if your sibling talks about suicide, but do take his or her feelings seriously and ask for help.

- Contact a clinician or doctor if thoughts about self harm or suicidal ideas persist and encourage your sibling to discuss their feelings. Take any suicidal talk seriously.
- If there is an immediate concern about your sibling’s safety, **get help immediately**. Involve other family members, call your local crisis service or the police, or take your sibling to the emergency room of your local hospital. Do not leave your sibling alone.



GLOSSARY

(Adapted from Breakthroughs in Antipsychotic Medications: A Guide for Consumers, Families and Clinicians and Trips & Journeys: Personal accounts of early psychosis. See Sources.)

In this section, we give definitions of some of the words that you may hear, or read as you learn more about your sibling's illness.

Acute phase (of illness) – A worsening of a person's positive psychotic symptoms, often leading to out-of-control or bizarre behaviour. Anti-psychotic medications are given to eliminate or reduce these symptoms.

Advocacy – Typically refers to activities that are used to raise the profile of an issue and mobilize the forces necessary to change public opinion, policy and practice.

Anti-depressant – Medication for the treatment of depression

Anti-psychotic – Medication for the treatment of psychosis

Bipolar disorder – A mood disorder characterized by periods of elevation in mood and depressive episodes.

Cognitive Therapy – (Also known as “cognitive behaviour therapy”) A therapy aimed at assisting the person to deal with some mental health problems by focusing on the way in which they interpret and react to their experience.

Conventional Antipsychotics – The group of antipsychotic medications developed between the 1950's and 1970's; also referred to as “neuroleptics” or “traditional” or “classic” antipsychotics. These medications are effective for positive (psychotic) symptoms and less effective for negative symptoms.

Delusions – Fixed beliefs that have no basis in reality.

Depot Therapy – A long-acting form of antipsychotic medication that is given by injection into a muscle approximately every 2-4 weeks.

Depression – is a mood disorder represented by feelings of sadness, loneliness, despair, low self-esteem, withdrawal from interpersonal contact with others, and symptoms such as difficulty sleeping and a decreased appetite.

Dopamine – A neurotransmitter in the brain. Antipsychotic medications slow down dopamine's ability to transmit messages between nerve cells in the brain.

Drug-Induced Psychosis – Use of, or withdrawal from alcohol and drugs can be associated with the appearance of psychotic symptoms. Sometimes these symptoms will rapidly resolve as the effects of the substances wear off. In other cases, the illness may last longer, but begin with a drug-induced psychosis.

Dual diagnosis – Literally the presence of two diagnoses at the same time. When speaking of psychotic disorders, the term is usually used to mean a person who has both a major psychiatric disorder such as schizophrenia, and a substance use or alcohol problem.

Genetic disposition – A term to describe the degree to which an individual is at genetic risk of an illness being passed on from one generation to the next.



Hallucinations – Unusual perceptions, for example, hearing sounds or voices that are not there.

Manic depression – see Bipolar Disorder

Medication noncompliance – Not following a doctor's recommendation. This is very common among clients who are supposed to be taking antipsychotic medications. In part, this isn't any different from other medical conditions, such as high blood pressure, where noncompliance is also very, very common.

Mood Disorders – A set of psychiatric diagnoses in which the major problem is mood regulation. Mood may be too low (depression), too high (mania), or too high at some times and too low at others (bipolar disorder).

Negative Symptoms – Think of these symptoms as features that are "taken away" or "subtracted" from the individual. They refer to experiences that should be present, but are absent. Some examples of negative symptoms include: blunted emotions, lack of energy or drive.

Neuroleptics – A term sometimes used to refer to conventional antipsychotic medications because they cause neurological (extrapyramidal) side effects. Because the newer atypical antipsychotics are much less likely to cause extrapyramidal side effects, this term is not used to refer to the newer medications.

Neurotransmitters – A chemical that is used to transmit a message between nerve cells in the brain. Two neurotransmitters that are very important in the treatment of schizophrenia are dopamine and serotonin.

Positive Symptoms – Symptoms that are "added on". They are features that are present but should be absent such as hallucinations and delusions.

Psychosis – Describes conditions which affect the mind, where there has been some loss of contact with reality. When someone becomes ill in this way it is called a psychotic episode. Psychosis can lead to changes in mood and thinking and abnormal ideas, making it hard to understand how the person feels. First episode psychosis simply refers to the first time someone experiences psychotic symptoms or a psychotic episode.

Prodrome – The first phase of a psychotic episode. The early warning signs are vague and hardly noticeable. There may be changes in the way some people describe their feelings, thoughts and perceptions.

Schizoaffective Disorder – A disorder in which the person has the symptoms of both a major mood disorder, such as major depression or bipolar illness and schizophrenia.

Schizophrenia – A psychotic illness in which the changes in behaviour or symptoms have been continuing for a period of at least six months. Symptoms and length of illness vary from person to person. Contrary to previous beliefs, many people with schizophrenia lead happy and fulfilling lives, with many making a full recovery.

Schizophreniform Disorder – This is just like schizophrenia except that the symptoms have lasted for less than six months.



WEB RESOURCES

“Internet based learning is really good. It’s informal and easy to access. You can go in the middle of the night and find out everything you wanted to know. It’s anonymous.”

On-Line Information: Fact or Fiction?

It’s important to remember that just because a document appears on-line does not mean that it contains valid information. It’s important to be sure of its source and accuracy. Following are some possible web-based resources to browse.

Psychosis

www.cmha.ca

Canadian Mental Health Association, National Office

The psychosis pages on this site offer information about a number of topics including: early psychosis intervention; Canadian early psychosis initiatives; resources for families and communities; a framework for strategic planning; and a number of links. Resource materials are available for download or order.

Family to Family: A newsletter for first-episode psychosis families

Developed and produced by first-episode families, this newsletter is sent to families across Canada and provides a venue for sharing information and support.

Three issues annually, available as PDF downloads at www.cmha.ca

Inquiries, contact the Editor at slsm@rainyday.ca

www.psychosissucks.ca

Early Psychosis Intervention Program (EPI)

The site offers easily accessible information on psychosis, treatment, associated problems, substance use and recovery. The downloadable PDF files include 15 excellent handouts that range from “What is psychosis?” to “Goal Setting” and “Problem Solving.”

www.pepp.ca

The Prevention and Early Intervention Program for Psychoses (PEPP)

The site includes information about a well-established family support group; family stories and excellent links.

Mental Health Resources For Youth

www.beyondblue.org.au/ybblue

A youth depression awareness web site from Australia

This site is about getting the message out there that it’s ok to talk about depression, and to encourage young people, their families and friends to get help when needed. The site hosts a whole range of new fact sheets, e-cards, depression and anxiety checklists and stories from young people.



www.getontop.org

Get on top-a guide to mental health

The site looks at depression, bipolar disorder, psychosis, substance use and other mental health concerns. There is also a personal experiences section with stories from young people who have dealt with a mental health problem.

www.cyberisle.org

Teen Net – University of Toronto

This youth site was developed with teens for teens. It is an interactive site all about young people and health issues, in a fun graphic style. Lots of links are provided to other sites about youth issues and health.

VIDEOS

A Map of the Mind Fields: Managing Adolescent Psychosis

National Film Board of Canada

2004. 56 minutes 30 seconds

From EPI South Fraser, British Columbia this video is part of a three part series which also includes “Beyond the Blues: Child and Youth Depression” and “Fighting Their Fears: Child and Youth Anxiety.”

To order: 1-800-267-7710 or **www.nfb.ca**

Identification #: 113C9104260

One Day At A Time

Canadian Mental Health Association, National Office

2001. 28 minutes

Several members of a first-episode psychosis parent support group describe their experiences as parents of young people with psychosis.

Order through **www.cmha.ca**



Canadian Early Psychosis Intervention Clinical Programs

Early psychosis intervention clinical programs continue to grow across Canada. Perhaps you will be able to find one near you!

British Columbia

Port Moody: Fraser North Early Psychosis Intervention (EPI) Program
Eagle Ridge Hospital
Tel: (604) 469-5152

Vancouver: Early Psychosis Intervention Program (EPI)
Vancouver Community Mental Health Services
Tel: (604) 225-2211

Victoria: Victoria Schizophrenia Service/Early Psychosis Intervention
Victoria Mental Health Centre
Tel: (250) 370-8175

White Rock: Fraser South Early Psychosis Intervention (EPI) Program
Peace Arch Hospital
Tel: (604) 538-4241

Alberta

Calgary: Early Psychosis Treatment Service
Calgary Health Region and University of Calgary, Foothills Medical Centre
Tel: (403) 944-4836

Edmonton: Edmonton Early Psychosis Intervention Clinic (EEPIC)
Edmonton Mental Health Clinic
Tel: (780) 429-7890

Saskatchewan

Saskatoon: Early Intervention Program in Psychosis and Schizophrenia
Saskatchewan District Health and University of Saskatchewan
Tel: (306) 655-6686

Manitoba

Winnipeg: Early Psychosis Prevention and Intervention Service (EPPIS)
Manitoba Adolescent Treatment Centre
Tel: (204) 958-9677



Canadian Early Psychosis Intervention Clinical Programs

Ontario

Hamilton: Psychotic Disorders Clinic
Hamilton Health Sciences, McMaster Site
Tel: (905) 521-5018

Kingston: Southeastern Ontario District Early Intervention in Psychosis Program
Hotel Dieu Hospital and Queen's University
Tel: (613) 544-3400 ext. 2550

London: Prevention and Early Intervention Program for Psychoses (PEPP)
London Health Sciences Centre and University of Western Ontario
Tel: (519) 667-6777

Ottawa: Champlain District First Episode Psychosis Program
Ottawa Hospital and University of Ottawa
Tel: (613) 737-8899 ext. 73062

Toronto: First Episode Psychosis Program
Centre for Addiction and Mental Health, Clarke Site
Tel: (416) 535-8501 ext. 4745

Windsor: Schizophrenia and First Episode Psychosis Program
Windsor Regional Hospital-Western Campus
Tel: (519) 257-5111 ext. 76945

Quebec

Montreal: Early Psychosis Intervention Clinic (EPIC)
Royal Victoria Hospital, Allan Memorial Institute
Tel: (514) 934-1934 ext. 34530

Verdun: Prevention and Early Intervention Program for Psychoses (PEPP-Montreal)
Douglas Hospital
Tel: (514) 761-6131 ext. 4121

New Brunswick

Fredericton: Fredericton Early Psychosis Program
Victoria Health Centre
Tel: (506) 444-5337

Newfoundland & Labrador

St. John's: Early Psychosis Program
Health Care Corporation of St. John's
Tel: (709) 777-3614

Nova Scotia

Dartmouth: Nova Scotia Early Psychosis Program
Capital District Mental Health Program and Dalhousie University
Tel: (902) 464-5997



CANADIAN MENTAL
HEALTH ASSOCIATION

ASSOCIATION CANADIENNE
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