

EARLY PSYCHOSIS

Helping Your Family Member

11TH edition

British Columbia Schizophrenia Society 2015

"We'd Like to Change Your Mind"

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Foreword

Imagine a world where ...

- First episode psychosis is identified early and is well managed
- There are no delays in receiving appropriate medical treatment and care
- Families are knowledgeable and can help a young relative affected by psychosis live a full life without interruption in school, social life, recreational activities, or career goals

This is the goal of early intervention

This booklet is dedicated to all families who have experienced the onset of psychosis in a young person.

In the following pages, you will find information to help you understand what psychosis is, how it affects the individual, and what you can do to help.

"Psychosis should be treated like a heart attack. No one should have to experience a second one."

- Person with schizophrenia

What is Psychosis?

Psychosis is a medical condition that affects the brain. It is characterized by a loss of contact with reality. A person experiencing psychosis finds it difficult to tell what is real from what is not real. They may also find they are overwhelmed by sights and sounds of things around them.

**Psychosis
is a loss
of touch
with
reality.**

When this happens, it is called a *psychotic episode*. A psychotic episode is a period of time when symptoms are intense and interfere with a young person's life. It may last only a short period of time - or it may continue for weeks, months, or even years unless the person receives proper medical treatment.

"First episode psychosis" refers to the first time someone experiences psychotic symptoms. Often, the person will not understand what is happening. Symptoms are unfamiliar and frightening, causing confusion and distress. If the person has no education or knowledge about mental illness, their fear may be increased by negative myths and stereotypes.

We often talk about psychosis as if it were one illness, but it is actually a cluster of symptoms that can occur in a number of medical disorders, or sometimes as a consequence of drug or alcohol use.

Types of Psychosis

Bipolar Disorder (Manic Depression)

Bipolar disorder is characterized by unusual shifts (extreme highs and lows) in a person's mood, energy, and ability to function. Severe episodes can include psychotic symptoms.

Brief Reactive Psychosis

Psychotic symptoms may arise suddenly in response to major stress in someone's life, such as a death in the family or other important change of circumstances. Symptoms can be severe, but the person makes a quick recovery in only a few days.

Delusional Disorder

Strong beliefs that are not based in reality. Paranoia (belief that you are being persecuted) is the most common type of delusion.

Drug-Induced Psychosis

Psychosis can emerge with the use or withdrawal from certain drugs. Recreational drugs and hallucinogens such as PCP, amphetamines, cocaine, marijuana, or alcohol may trigger a psychotic reaction. Symptoms usually disappear as the substance wears off, but sometimes the psychosis remains. Some people who abuse drugs and alcohol may also have an underlying chronic psychotic illness.

Major Depression

Psychotic symptoms sometimes occur in severe depression.

Organic Trauma

Psychotic symptoms may appear after a head injury or infection that disrupts brain functioning. There are usually other symptoms present, such as memory loss or confusion.

Postpartum Psychosis

Psychosis associated with childbearing is rare, but when it happens it usually occurs after a baby is born rather than during pregnancy.

Schizophrenia

Psychosis is common in schizophrenia, a brain disorder characterized by hallucinations and delusions. Other less dramatic symptoms include social isolation, withdrawal, disorganized thoughts, unusual speech, bizarre behavior, lack of energy, and lack of interest in routine activities.

Schizophreniform Disorder

This diagnosis is usually given when psychotic symptoms have lasted for less than six months (but more than one month).

Schizoaffective Disorder

A person diagnosed with schizoaffective disorder shows symptoms of schizophrenia *and* a mood disorder (depression or bipolar disorder), occurring at the same time or alternating over time.

"Two months before we got help, my daughter started accusing me of taking her things.

Gradually, we noticed she was starting keep to herself more and more. We would observe her smiling to herself and mumbling."

Phases and Symptoms of Psychosis

"He would sit and stare at his hands for hours. When I asked what was wrong with his hands, he would say they were *different* than they use to be."

Families often recognize problem signs in a loved one—mood swings, problems with school or friends—and are troubled by them. These changes can be the first signs of emerging psychosis. But it can be hard for the family to identify the emerging illness, or to know what to do about it.

Most psychotic episodes have three phases. These vary in length from person to person. Symptoms also vary from person to person, so individuals may have very different experiences.

Phase 1: Prodrome

In the beginning phase, clear signs of psychosis have not yet appeared. Early signs are often a combination of minor changes that are barely noticeable. But they are enough to make someone *feel* different, and often to *seem* different to those who know them well. Prodrome is often described as 'something is not quite right'. Signs are fairly general, so they may be seen as normal adolescent behaviour or "just a phase". Or sometimes changes are attributed to drug use.

"In phone calls, my brother's voice no longer had the usual tone of excitement, interest or humour. Instead, it was very flat. At the same time, he began to tell us about a situation at work that just didn't seem possible. He was complaining that a group of fellow workers were out to get him."

Early signs can include:

- Feeling sad or depressed most of the time
- Withdrawal from family and friends
- Decline in school or work abilities
- Irritability
- Reduction in energy or motivation
- Feeling paranoid or suspicious about other people and their actions
- Noticing a change in the way things look or sound
- Noticing things that other people don't notice
- Feeling anxious
- Memory or concentration difficulties
- Sleep disturbances

Phase 2: Acute Phase (Psychotic Episode)

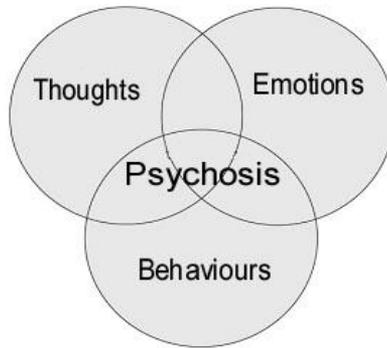
"A few months ago, I was happy and full of life. Now i don't want to be around my friends. It's really hard for me to focus on school and i get confused. I hear voices that say mean things. No one believes these voices are real. I don't understand what is happening to me."

Typical psychotic symptoms emerge in the *acute phase*. These are hard to miss as they interfere with the young person's day-to-day functioning. They are intense, active and continuous. In the acute phase of psychosis, people lose touch with reality. Thoughts, feelings and perceptions can all be seriously affected.

"Our friends said it was just a teenage phase. But I knew something wasn't right with my son. He just wasn't himself. He used to be sociable and outgoing in his early teens. Now he was very withdrawn.

He seldom left the house because he thought people were after him. He didn't seem able to think straight. His schoolwork went from 'A's to barely passing. He felt like everybody hated him because of something he had done. Everyone in the family was uneasy."

Psychosis can cause changes in thinking, emotions, and behaviour.



The main symptoms during the acute phase are grouped into 3 categories: Positive, Negative, and Disorganized (or Cognitive) symptoms.

Positive Symptoms

"Positive" as it is used here does not mean *good*. It refers to having symptoms that ordinarily should not be there. Positive Symptoms include:

Hallucinations: Hearing, seeing, tasting, smelling, or feeling things that are not there. Although these perceptions are not real, they feel very real to the person experiencing them. People with psychosis often hear voices. Sometimes the voices are threatening or condemning; they may also give direct orders such as, "kill yourself". *There is always a danger that such commands will be obeyed.*

"It's difficult to try and rationalize with an irrational mind."
- Mother of a young person with psychosis

People who are ill may also have visual hallucinations—a door in a wall where no door exists; a bird, a tiger, or a long-dead relative may suddenly appear. Colours, shapes, and faces may change before the person's eyes.

There may also be hypersensitivity to sounds, tastes, and smells. A ringing telephone might seem as loud as a fire alarm bell, or a loved one's voice as threatening as a barking dog. Sense of touch may also be distorted. Someone may literally "feel" their skin is crawling. Or, conversely, they may feel nothing, not even pain from a real injury.

Delusions: False beliefs that have no basis or evidence in reality. Again, the person is convinced these beliefs are true and cannot be swayed by arguments or logic. Attempts at reasoning or discussion usually lead only to anger or mistrust.

Examples of common false beliefs include:

- Being followed or monitored
- Being plotted against
- Having special abilities or "powers"
- Overheard comments or song lyrics are being specifically directed to the person, and may contain secret messages or meaning
- Thoughts are being controlled by others (people or forces)
- Thoughts are being broadcast so others can hear them

Someone who is experiencing such profound and frightening changes will often try to keep them a secret.

There is a strong urge to deny what is happening, and to avoid other people and situations where the fact that one is "different" might be discovered. Intense misperceptions of reality trigger feelings of dread, panic, fear, and anxiety—natural reactions to such terrifying experiences.

Negative Symptoms

"Negative" refers to a *loss of normal function* - everyday things the person used to do or express that are now lacking. Examples of negative symptoms include:

- Loss of energy or motivation
- Trouble starting or pursuing goal-directed activity

- Loss of everyday skills the person had before they became ill

- Lack of spontaneity and difficulty in conversation
- Social withdrawal
- Self neglect -- poor diet and hygiene
- Loss of pleasure in events, objects, and relationships with others

In addition to the positive and negative symptoms described above, psychosis can also affect **cognition** — the ability to think, plan, make decisions, and remember — as well as **emotions** and **behaviour**.

Disorganized Symptoms (*Cognitive Deficits*)

Psychosis can cause difficulties with concentration and the ability to remember things. A person with psychosis may appear to be preoccupied or daydreaming. Cognitive problems affect the ability to plan, make decisions, complete tasks, follow a conversation, or remember details such as keeping an appointment. Thoughts may seem to go "too fast", or "too slow".

Such cognitive difficulties can be observed in conversation. Jumbled thoughts or thoughts that are speeded up, or that come very slowly, make it hard for others to follow what the person is saying.

Emotional Symptoms

Changes in emotion are often reflected in emotional responsiveness. There may be lowered responsiveness - often referred to as a "*blunting*" of emotion.

Speech may lack normal inflection. Facial expression and gestures seem mechanical. Eyes may gaze blankly at nothing in particular. Even when the emotion is there, the person's expression may not appropriately reflect their feelings. There may be an absence of typical responsiveness. Some people report they no longer experience pleasure and their sense of caring is reduced. Others describe a loss of ability to react emotionally and a restricted range of emotions.

On the other hand, someone with psychosis may express feelings that are completely out of line with a typical response - for example, laughing at a sad story. Laughing inappropriately or becoming angry or upset for no apparent reason are common symptoms of psychosis.

"He would often be up all night, pacing around his bedroom after barricading the door with furniture so that the unseen enemy couldn't get him. Then he would sleep until 2pm or 3pm - only to get up, eat, and then sit down to stare into space."

- Parent of a son with psychosis

Behavioural Symptoms

Changes in behaviour are subtle at first, but become more pronounced as the illness progresses. A person with psychosis may have trouble with everyday tasks such as bathing or preparing meals. Or they may display odd behaviours such as muttering aloud, shouting or swearing in public, or dressing inappropriately, e.g., wearing many layers of clothing on a hot day.

General deterioration in normal school or work activities and withdrawal from family and friends are also commonly observed. Other behavioural changes may include becoming very lethargic, neglecting basic hygiene, sitting around all day, or staying up all night.

Psychosis is usually very upsetting for the person experiencing it, and quite incomprehensible to others. Most people with psychosis are totally unaware of the strangeness of their behaviour, but will suffer feelings of embarrassment once the episode has passed. Most episodes of psychosis can be effectively treated with medication.

Phase 3: Recovery

Psychosis is treatable and most people recover. The pattern of recovery varies from person to person. For some people, symptoms disappear quite quickly, and they are able to resume their lives with minimal disruption. Others may take more time (several weeks or months) to recover. A small proportion of people who experience psychosis will need ongoing medication and support for many years.

Following recovery, a significant number of people will never have another psychotic episode. The risk of relapse is greatly decreased when treatment is continued and monitored regularly. Learning to manage stress and avoiding drugs and alcohol also decreases the risk of relapse.

People recover from first-episode psychosis.
Many never experience another psychotic episode.

Why is Early Intervention Important?

A first episode of psychosis can be very stressful and frightening for a young person. It is also distressing for family and friends. The onset of a psychotic disorder usually occurs at a critical time in development. Typically, it happens just as the young person is establishing their self-identity, forming key relationships, and pursuing education and career goals.

Treatment delays result in damage to the person's ability to function, strained family relationships, social isolation, and disruption in education and employment. Untreated psychosis also increases the risk of depression, suicide and violence. The earlier psychosis is recognized and treated, the better the outcome. This means fewer hospitalizations, less severe symptoms, earlier remission, fewer relapses, less disruption to the young person's development, and an improved quality of life.

Being able to treat psychosis early greatly increases the person's chances of enjoy a healthy and productive future.

Benefits of Early Intervention

- Individuals do not suffer unnecessarily
- Faster, more complete recovery
- Reduced disruption of activities
- Better prognosis (outcome)
- Less disability and fewer relapses
- Decreased risk of depression and suicide
- Less interference with psychological and social development
- Less strain on relationships, family, and social supports
- Less disruption of study and/or employment.
- Less disruption of parenting ability if the person has children
- Lowered risk of substance abuse, violence or criminal activity
- Lowered risk of unnecessary hospitalization
- More able to maintain self esteem, self-identity, and confidence

So What's Happening in the Brain?

Although the human brain is an incredibly complex organ, it can be thought of as governing four basic functions:

- Perception: Our senses of sight, sound, feel, taste, and smell
- Thinking: Memory, reason, judgment, decision-making
- Feeling: Emotions
- Behaviour: How we act

When our brain is working well we can

- Test reality
- Control anxiety
- Match our thoughts and feelings to our situation
- Learn from past experiences
- Maintain a sense of self
- Develop and maintain relationships



Like any other organ of our body, the brain too can become ill and malfunction. In psychosis, four of the brain's basic functions are impaired:

- Perceptions are altered—things that are not real seem real
- Thinking becomes jumbled—unfounded beliefs develop
- Feelings and emotions are numbed or exaggerated
- Behaviour changes—may be unusual or bizarre

Medications help to some extent by correcting the imbalance of chemicals in our brain.

Did You Know?

- Psychosis often strikes young people in their prime. Usual age for occurrence of first-episode psychosis is 15 to 24.
- About 3 out of every 100 young people will experience a psychotic episode, making psychosis more common than diabetes in young people. *Most people make a full recovery from the experience.*
- Psychosis distorts the senses, making it very difficult for the ill person to tell what is real from what is not real.
- Men and women are affected with equal frequency,
- Medical assessment and treatment are necessary.
- Early assessment, treatment and education greatly improve outcomes for the individual and their family.

Causes of Psychosis

Over the years there have been a several theories about what causes psychosis. While the brain is not yet fully understood, most researchers believe there is no single cause of psychosis. Like other illnesses such as heart disease or diabetes, psychosis may be caused by a combination of biological and environmental factors.

Biological factors include genetic predisposition to the illness (family history of psychosis), brain injury or infection, prenatal infection, or birth complications. These factors may mean a person is more vulnerable or susceptible to developing psychosis.

Environmental factors are often referred to as "stressors" that might trigger an episode of psychosis. Stressors could include drug use or situational anxieties (e.g. starting college, moving to a new city, loss of a parent or grandparent, etc.)

As with any medical condition, it's not someone's fault if they become ill with psychosis.

Our degree of vulnerability varies from person to person. Likewise, the amount or type of stress that might trigger psychosis would differ for each individual. For example, a person with low vulnerability could experience lots of stress but not develop psychosis. By contrast, someone with high vulnerability may not be able to withstand even minimal amounts of stress.

Vulnerability to psychosis is not a weakness and it is not the result of poor parenting.

Diagnosing Psychotic Disorders

When someone has psychosis, it can be difficult for doctors to make an exact diagnosis because symptoms are not unique to one particular disorder (e.g., psychosis can occur with schizophrenia, bipolar disorder or depression.)

Psychiatric assessment and physical examination are the main methods used to help identify a diagnosis related to the psychosis. A thorough physical examination and laboratory evaluation can help exclude general medical conditions that contribute to psychotic symptoms.

Blood and urine toxicology screens for commonly abused substances are helpful in detecting substance or alcohol related disorders.

Families have an important role to play in this assessment.

Families can provide valuable information about family medical history, birth and childhood history, physical or emotional trauma, school adjustment and achievement, plus history of the presenting problem—including how the young person was functioning prior to onset of symptoms, and what changes the family has observed.

Distinguishing between disorders is difficult in the early stages. For this reason, medical professionals may not attempt to make an initial diagnosis.

Determining a specific type of psychotic disorder requires assessment of symptom patterns, sometimes over many months. An individual's diagnosis will depend on the type of symptoms experienced, how long symptoms last, and whether something might have triggered the illness.

In some cases, a diagnosis will change as the doctor learns more about the specific pattern of symptoms. Some people's diagnosis will change over time as different symptoms emerge.

Families may find it difficult to understand when physicians do not make a specific diagnosis following the first assessment. We all want definite answers to troubling questions.

However, as noted earlier, psychosis is associated with a variety of conditions.

Even if your doctor cannot provide a clear diagnosis, this will not delay treatment. Rather, treatment will focus on the presenting symptoms.

A person suffering from psychosis should have a complete medical assessment to rule out any underlying problem that may be the cause (e.g., brain tumour, viral infection)

Treatment for Psychosis

Medication and Other Treatments

Antipsychotic medication is the primary treatment for psychosis and the foundation for recovery. Typically a person will be put on a low dose of an antipsychotic drug with careful monitoring for side effects.

Side effects sometimes occur within the first hours or days of treatment. Most side effects from antipsychotics are not serious, but they can be unpleasant. These include tiredness, dizziness, dry mouth, blurry vision, restlessness, irritability, stiffness, constipation, and sometimes muscle spasms. Weight gain is a potentially serious side effect, so a healthy diet and exercise are important.

When side effects appear, the doctor may lower the antipsychotic medication dosage, add a different medication to reduce side effects, or change to another antipsychotic. Fortunately, side effects tend to diminish over time.

Most professionals recommend that medication be continued even after symptoms have lessened or been relieved. Stopping the medication increases the risk that symptoms will return. This is sometimes difficult for a young person to understand - especially if they are feeling well again. But as with many other illnesses, staying on medication helps prevent symptoms from recurring.

In most cases, treatment includes more than just medication. Education about psychosis, early warning signs of relapse, and how to minimize risk of relapse is essential for any young person who experiences a psychotic break.

Other treatment strategies may also be recommended. Cognitive behavioural therapy (CBT) can reduce stress, improve negative symptoms, and help the young person manage symptoms that may not be fully alleviated by medication. Counselling and lifeskills training are also valuable. Education and counselling for family and friends is also very helpful.

Sometimes it is necessary to begin treatment in hospital. Typically, these stays are short and followed up with community treatment that enables the person to be at home.

"But I'm Not Sick!"

In some circumstances, people need to be hospitalized *involuntarily*. Your family member may refuse to get medical help for a number of reasons - out of fear, because they don't want to be labelled "crazy", or because psychosis itself sometimes causes lack of insight and awareness.

In fact, one puzzling feature of psychosis is often a total lack of insight into the unusual, strange or bizarre nature of one's own experience or behaviour.

People who are ill often seem completely unaware that their hallucinations and delusions are very unrealistic, or that they might actually have a medical problem.

Medical professionals use the term "anosognosia" to refer to a lack of insight or impaired awareness of one's illness.

The word "anosognosia" comes from the Greek for disease (nosos) and knowledge (gnosis).

It literally means "to not know a disease."

Awareness, of course, varies between individuals, and throughout the duration of a psychotic episode. A person may fluctuate over time in awareness—being more aware when the illness is in remission (no symptoms), but losing that knowledge if they relapse.

Support from family and friends is crucial and can greatly reduce isolation. Education, companionship, recreation, employment programs, and supported housing can also be central to recovery.

Family education is key. Families need understanding, support, plus detailed knowledge about their relative's illness, behaviour, and treatment plan. Family members who have a good understanding of the facts can cope better as a family and help facilitate the recovery process.

Research shows that family education and support combined with medication leads to better outcomes for the individual. People with first episode psychosis usually still live with their families. This means family members can have a great impact on recovery rates.

People with psychosis need understanding and reassurance that they will not be abandoned.

Families need patience, patience, and more patience.

How Families Are Affected

"Psychosis hurtles individuals and families into a whole different world—from normalcy to total devastation almost overnight."

— Father of a young woman with psychosis

When people learn that someone in their immediate family is suffering from psychosis, they often experience a wide range of feelings. There is no right or wrong way to feel. Not everyone feels each emotion, nor do emotional states follow any particular order.

Family members report the following:

- Confusion about the ill person's behaviour and how to respond
- Compassion and sympathy
- Sorrow and anger (it's not fair!)
- Not knowing how often to visit hospital or what to say
- Optimism and initial belief that a loved one's mental illness can be "fixed"
- Feeling it is their duty to somehow "solve the problem"
- Initial relief, or shock, or even denial ("maybe it will just go away")
- Uncertainty about diagnosis, cause, and potential duration of illness
- Frustration at caring for someone who is not "getting better", who is unable to express gratitude for help received, and whose illness constrains one's own life
- Profound sadness because the illness might be long-term
- Grieving the loss of the person they once knew and feeling that person is somehow lost to them
- Feelings of isolation; thinking no one else understands
- Resentment or embarrassment because their life is so different from that of other families

"I admire her strong commitment to learning all she can about her illness, as well as her hard work at preventing relapse."

- Mother

- Feeling they are somehow responsible for the illness
- Withdrawal from social activities and family get-togethers
- Excessive searching for an explanation of why this happened
- Eventual acceptance; giving up need to "cure" the disease and to be in control
- Relief and optimism for the future when family member starts to recover from psychosis
- Admiration and respect for loved one who struggles with the unimaginable difficulties of mental illness

"Having hope is the only thing that can get you through, because if you don't have hope that it's going to get better, you don't really have anything."

- R. Bland, Y. Darlington

Perspectives in Psychiatric Care, Vol. 38, 2002

"I am grateful in some ways because mental illness has strengthened my relationship with my daughter. We have never been so close."

- Father of a teenager daughter with first episode psychosis

Just like many other serious illnesses, psychosis affects not only the person suffering from the illness, but also their family and friends.

Families should expect that they may have to adjust their own lifestyle and expectations.

Guidelines for Families and Friends

LEARN TO RECOGNIZE RELAPSE "TRIGGERS"

Some people learn that psychotic symptoms only occur in certain situations - called "triggers". By avoiding or figuring out how to control "triggers", it is possible to prevent or reduce symptoms.

Common triggers are:

- Stress
- Isolation or inactivity
- Health problems
- Poor nutrition or sleep habits
- Alcohol & drug use

IDENTIFY SIGNS OF RELAPSE

Relapse is a worsening of symptoms or reappearance of symptoms that were in remission. Relapse may occur for no apparent reason, or it may be related to medication or stress.

Signs of relapse are usually similar to those observed in the early stages of psychosis (i.e., the prodromal phase). These signs indicate potential relapse and should be seen as an early warning system. By taking steps early on, your family member may be able to prevent a full-blown relapse. These steps could include trying to reduce stress if present; consulting the doctor to increase antipsychotic medication; seeking counselling with a mental health professional.

"I know the psychosis is back when I start hearing music that no one else can hear. It plays over and over - it's like a radio playing beside my ear."

Warning Signals

- Change in sleep habits - sleeping too much or too little
- Restlessness
- Tension, agitation or irritability
- Less or more talkative
- Changes in usual behavior
- Decreased ability to concentrate or focus
- Change in eating habits
- Social withdrawal
- Deterioration in personal hygiene
- Unusual, disturbing, or recurring thoughts
- Remember: Signs may be unique to your family member

Things That Can Help Prevent Relapse

- Taking medications
- Stable, structured lifestyle including adequate nutrition and good sleep habits
- Avoiding alcohol and street drugs
- Stress management
- Supportive relationships and adequate community resources
- Being able to identify early warning signs
- Effective help-seeking strategies

GET HELP EARLY!

Staying well means getting help at the earliest sign of trouble.

TAKE THE INITIATIVE. If symptoms are occurring, encourage your family member to see their doctor or mental health professional.

Family members and friends are usually the first to notice warning signs. Keep in mind though, if the ill person accepts hallucinations and delusions as reality, they may resist going for help. Don't be afraid to ask how they're feeling. Be sympathetic to the fact that it may be difficult for them to know what's real from what is not real. Families may need to contact mental health providers to alert them of changes and possible relapse.

Provide plenty of support and loving care. Help your family member accept their illness by dealing with it in a matter-of-fact manner. Try to show by your attitude and behaviour that there *is hope*, that things can be managed, and that life can be satisfying and productive.

Help your family member maintain a record of information about:

- Symptoms that have appeared
- Medications, including dosages
- Any medication side effects
- Effects of various types of treatment (medication, counselling, CBT, group activities, etc.)

CONFIDENTIALITY

Mental health professionals may feel torn between wanting to help support the family and their legal obligation to protect patient confidentiality. The protection of personal health information in Canada is shared among different levels of government with a "patchwork" of legislation, policies, security regulations, and voluntary codes of practice.

In British Columbia, there is a provision for sharing health information to ensure continuity of care. The BC Ministry of Health's Fact Sheet, "Freedom of Information and Protection of Privacy: Releasing Personal Information to Third Parties" can be found in BC's *Guide to the Mental Health Act* is available through the Ministry of Health Services website:

www.healthservices.gov.bc.ca/mhd/pdf/MentalHealthGuide.pdf

This important Fact Sheet describes guidelines for *sharing health information without patient consent* with family, friends, other agencies and professionals where necessary to allow for continuity of care.

See also www.bcass.org/wp-content/uploads/Obtaining-and-Providing-MH-Info1.pdf

MANAGING FROM DAY TO DAY

"Think of how it would be if you could not decide between two simple choices. Or if you lost the ability to sequence and could only do one step until someone gave you the next step. This is what your family member may be struggling with." - Mental Health Professional

Help Maintain Ongoing Treatment and Care

This means helping your family member to take medication as prescribed, keep any ongoing appointments for cognitive testing, psychosocial education and rehabilitation, and working with mental health providers to maximize the recovery plan.

Provide a Structured and Predictable Environment

People recovering from psychosis have problems dealing with too much sensory information. Reduce stress, keep routines simple, and allow the person time alone each day. Plan non-stressful, low-key regular daily activities, and keep "big events" (e.g., large family gatherings) to a minimum.

Be Consistent

All family members and friends including the ill family member should agree on a plan of action for troublesome behaviour and follow it. If recurring concerns are handled in a predictable manner, it reduces confusion and stress for the person who has been ill.

Set Limits on What Behaviours are Acceptable

Some abnormal behaviours are more tolerable than others. Others are unacceptable under any circumstances (e.g., physical abuse, destructive/harmful behaviour to self, others, or property, extreme emotional abuse, or criminal actions). Decide what behaviours you are willing to live with. Develop clear rules about what the family is not willing to tolerate, and what consequences will happen. It is important to be firm.

Maintain Peace and Calm at Home.

Thought disorder can be an ongoing problem for some people. It generally helps to keep voice levels down. When the person is participating in discussions, try to speak one at a time, and at a reasonably moderated pace. Shorter sentences can also help. Above all, avoid arguing about delusions (false beliefs).

Be Positive and Supportive

Being positive instead of critical will help the person much more in the long run. People who have experienced psychosis need frequent encouragement, since self-esteem is often very fragile. Encourage all positive efforts. Be sure to express appreciation for a job even half-done, because the person's confidence, initiative, patience, and memory have often been undermined.

Help Set Realistic Goals

Most people who have experienced psychosis need lots of encouragement to regain some of their former skills and interests. They may also want to try new things, but should work up to them gradually and not take on too much at a time. The point is to avoid excessive stress, so goals should be reasonable, and nagging should be avoided.

Even if your family member is ill and may not seem appreciative, he or she loves you and needs you very much.

Many young people say their parents' unwavering support was the main reason they were able to get through their illness.

Gradually Increase Independence

As participation in a variety of tasks, recreational and social activities increases, so should independence. It is important for young people to continue with social activities, education and employment if possible.

If school or work are not possible, try to keep up social and recreation activities, and help the person plan to use their time constructively.

Learn to Cope With Stress Together

Try to anticipate the ups and downs of life and to prepare accordingly. Your relative might need help learning to deal with stress in an acceptable manner. Positive role modelling can help. Sometimes just recognizing in advance that something might be stressful and talking about it can help.

Encourage the Person to Try Something New

Offer help in selecting an appropriate activity. If requested, go along the first time for moral support.

Have a Sense of Humour

Humour is an important coping strategy. It provides relief and good feelings, the space to face difficult realities, and the opportunity to reframe challenging experiences in a safe way.

Never Give Up Hope!

Things will get easier. Don't feel discouraged if your family member doesn't recover immediately. Treatment takes time and some medications take several weeks to a few months before symptoms are controlled. Recovery can be a gradual process.

And Finally...

Sometimes it's helpful to just "be" with your family member. Sitting with them without talking can let them know you are there for them.

LOOK AFTER YOURSELF AND OTHER FAMILY MEMBERS

Be good to yourself. **SELF-CARE** is very important, even crucial, to each individual—and ultimately improves the functioning of the entire family. Psychosis is not anyone's fault. Maintain your own independence as much as possible.

Value your own privacy. Keep up your own friendships and outside interests, and try to lead as orderly a life as possible.

Do not neglect other family members. Brothers and sisters often secretly share the same guilt and fear as their parents. They may worry that they might also experience psychosis. When their concerns are neglected, they may feel jealous or resentful of the ill person. Siblings of people who have experienced psychosis need special attention and support to deal with these issues.

GET SUPPORT... Learn from others who have similar experience. Check for resources in your community. Mental health clinics and hospital should be able to provide you with family support resources. If someone in your family suffers from psychosis — it helps to know *you are not alone*.

Family support groups are good for sharing experiences with others. You will also get useful advice about your local mental health services from those who have "been there."

- ✓ Call the Mental Health clinic in your community. Ask about family education and support programs
- ✓ Look for family support organizations in your region
- ✓ Join the **BC Schizophrenia Society**. Call (604) 270-7841 or visit us online at www.bcscs.org

Recovery - How to Help

Studies show that families and friends who are supportive, non-judgmental, and, most especially, *non-critical*—can do much to help recovery. On the other hand, people with psychosis who are around chaotic or volatile family members usually have a more difficult time. It's important to remember that it is the illness and not the person that is testing your limits.

People recovering from psychosis commonly suffer from depression, social anxiety, and lowered self-esteem. Encourage your family member to take their medication and consult with doctor or therapist if they are having difficulty managing their illness.

Below are some suggestions that can help in the recovery from psychosis:

- Encourage your relative to take prescribed medications and keep appointments for other treatments that can help
- All family members should be educated about the illness so everyone understands what has happened and what they can do to help prevent a relapse
- Your relative may find it helpful to talk with others who have experienced psychosis. Check to see if your local mental health clinic offers "peer support" programs or support groups in your community.
- Encourage a gradual return to social, educational or work roles
- Learning skills such as stress management can help prevent relapse and reduce any ongoing symptoms
- Share your opinions and experience as a caregiver with the professionals looking after the well being of your family member
- Ask the doctor or mental health professional for advice about helping your relative. If you find something is not working, tell them.
- Talk over problems with someone else or join a family support group.

- Work out an action plan with your family members (including the person with the illness) before problems arise.
- Look after yourself and other family members.
- Attend case management meetings

It is also helpful to:

- Feel positive about your relative - be optimistic
- Be calm and understanding
- Maintain a realistic perspective - it may take a long time for your family member to get better
- Encourage your family member to acquire new skills and knowledge
- Praise your family member when they make small steps towards progress
- Have a life of your own.

It is not helpful to:

- Be demanding and critical
- Be intolerant, angry, or intrusive
- Have unrealistic expectations about change
- Be pessimistic
- Ignore or under-value progress
- Concentrate your whole life on your caregiving role.

Things that Promote Recovery

Medication
Stable accommodation
Someone to talk to
Good information sources and support
Ability to manage stress
Sense of hope
Reasonable financial security
Strong social and friendship networks
Activities such as employment, school, or hobbies
Good physical health- good diet & exercise

Things that Delay Recovery

Stressful situations
Conflict in personal relationships
Financial and accommodation problems
Using drugs and alcohol

How Psychosis Can Affect a Young Person At School

Recovery Takes Time

After a first episode of psychosis, the ill person will likely need some time to recuperate and regain their strength. When they feel up to it, suggest they try to start building their life back up again. As they do, they will likely find their confidence gradually returns, especially if they can keep physically and socially active.

There are many resources within the school system (including special educators, psychologists and social workers) that offer support to help students work to their fullest potential. Talk to the school counsellor about the type of supports and special accommodations that will make it easier for the person to get through high school. They may be able to get special help in the classroom and with homework assignments, as well as with tests and exams.

Take it one step at a time. The young person's full-time job is regaining their health. Having the patience to allow them to pace themselves is a very important part of recovery. Don't expect your family member to be able to pick up immediately where they left off before they became ill. It may feel like too much at first, so encourage them to take it slow. Discuss whether it might be better to return to school part-time, and later take on more when they're ready. Other options may be to take fewer courses, or to limit "homework-heavy" courses. Simply reducing course loads can enable students to finish high school, even if it means delaying graduation by one or more years.

If someone wants to return to school, the skills they need may have been affected by their illness. Rehabilitation specialists can help to figure out which skills are still intact through tests and discussion. If memory or organizational abilities have been affected, the person and the specialist can create a plan together to help enhance these skills.

Low Motivation

Some students (especially if the young person also has depression) may go through periods of low motivation or even apathy. It is beneficial to keep end-goals in mind. Work with your family member to set small, achievable goals, and plan rewards for reaching them. Sometimes it is helpful just to "go through the motions".

Difficulties with Concentration

Cognitive problems may be caused by the illness, or may be a side effect of medication. Such difficulties can be incredibly frustrating and anxiety-provoking. Audio taping lectures to supplement notes can often help, as can sharing notes with other students.

"My teachers were very understanding and extended deadlines for me, and didn't ask questions when I had to leave class."

- Young person with psychosis

Missed classes

The young person may occasionally need time out from school due to illness or even hospitalization. This doesn't mean studies have to be deferred. By working out a contingency plan with the teacher or counsellor, simple strategies can be put in place to minimize disruptions. These might include a note-taker for missed sessions, extension of assessment deadlines, and special consideration for exams. It is advisable to contact the school counsellor or counselling services as early as possible to discover what assistance can be offered.

Supporting Your Family Member in School

Meet with the teacher and school counsellor to discuss support and recovery; spend time educating them about psychosis and how it has impacted the student's abilities. Having a note from the doctor, or perhaps giving written permission for the teacher/counsellor to talk to the clinician or doctor is helpful. Ask what kind of special accommodation the school has made for students disabled by mental illness.

Education and Psychosis: “I’m a Teacher— What Can I Do?”

Professionals ... must help people set realistic goals. I would entreat them not to be devastated by our illness and to transmit a hopeless attitude to us. I urge them never to lose hope; for we will not strive if we believe the effort is futile.

— Esso Leete, person who has had schizophrenia for 20 years

1. Educate yourself about psychosis

Early onset psychosis is very common. It strikes in the mid to late teens and early twenties. You need to be aware that:

- Early intervention and early use of new medications lead to better medical outcomes for the individual
- The earlier someone with psychosis is diagnosed and stabilized on treatment, the better the long-term prognosis for their illness
- Teen suicide is a growing problem. Teens with psychosis have a *50% risk of attempting suicide*.

2. Bring psychosis into the open

- Discuss the physiology of the brain and the facts about psychosis in class.
- An good educational resource such as *Reaching Out: The Importance of Getting Help Early* helps to dispel myths and encourages young people to help friends who may be showing signs of psychosis (See Box below)
- Provide information on precipitating factors, such as drug abuse.

3. Be alert to early warning signs of psychosis

- Young people are sometimes apathetic, have mood swings, or experience declines in academic performance. But if these things persist, you should talk to the family and encourage a referral for assessment.

REACHING OUT!

"Reaching Out" is an important tool to help students learn about brain function, mental illness and the importance of getting help early. Contact the BC Schizophrenia Society at www.bcscs.org for more information.

4. If you have a student in your class who has experienced psychosis:
 - Learn as much as you can about the illness so you can understand the very real difficulties the person is struggling with
 - Reduce stress by going slowly when introducing new situations
 - Help set realistic goals for academic achievement and extra-curricular activities
 - Establish regular meetings with the family for feedback on health and progress. It may be necessary to modify objectives, curriculum content, teaching methodology, evaluation formats, etc.
 - Encourage other students to be kind and to extend their friendship. Some may wish to act as peer supports if symptoms recur and help is needed to catch up.

5. Teachers and counsellors can also help raise awareness by:
 - Holding information sessions about early psychosis at parents' meetings and student assemblies
 - Setting up displays for special occasions (such as Mental Illness Awareness Week) in the school library or counselling office
 - Ordering up-to-date resource materials for your library, finding current information on the internet, and discarding out-of-date literature.

"PARTNERSHIP" Education

In-class *Partnership* presentations are an invaluable aid for helping students understand the nature and prevalence of mental illness. The *Partnership* program brings together a three-person team (one with a psychiatric diagnosis, one family member, and one mental health professional) to talk about psychosis. They come into your classroom together, each to tell their personal story.

Partnership presentations elicit immediate and thoughtful class participation. Mental illness is demystified. Students' questions are answered directly by people with first-hand knowledge and experience.

The *Partnership* program helps fight ignorance, prejudice, dusty old Hollywood myths, and hurtful stereotypes. It also presents vital facts about the physical nature of the brain and psychosis, and helps many individual students whose family members have suffered from mental illness.

For more information about the *Partnership* Education Program, contact the
BC Schizophrenia Society
604-270-7841 or toll free 1-888-888-0029
prov@bcss.org www.bcss.org

FAQ's — "Frequently Asked Questions"

1. Q. What are my chances of developing psychosis?

A. Approximately 3% of people worldwide will experience an episode of psychosis in their lifetime; about 1% will develop schizophrenia. Since schizophrenia, bipolar disorder and clinical depression tend to run in families, your chances may be higher if someone in your family has an illness. For example, the rates for schizophrenia in family members where relatives have the illness is as follows:

- If one parent or a brother or sister is ill, the risk factor is about 7-9%
- If both parents are ill, the chances are about 37%
- If a non-identical twin is ill, the chances are 10-15%
- If an identical twin is ill, the chances are 35-50%
- If a grandparent, aunt or uncle is ill, the chances are about 2-3%
- Schizophrenia does not discriminate between the sexes. Young men and women are equally at risk for developing the illness.

2. Q. Can children develop psychosis?

A. Yes. In rare instances, children as young as five have been diagnosed with psychosis. Most people do not show recognizable symptoms until adolescence or young adulthood.

2. Q. How can I tell if my family member has psychosis before it becomes serious?

A. Early signs vary from person to person. Family may notice:

- Changes in behaviour
- Deterioration in studies or work
- Becoming more withdrawn or isolated
- Decrease in normal activity level
- Depressed and lacking interest in things
- Mood swings
- Sleep problems
- Appetite changes
- Difficulty concentrating or remembering
- Trouble understanding meaning of language

None of these signs are specific to psychosis. They could be caused by other disturbances, or they could be normal responses to stress.

However, if problems occur without any obvious cause or if they persist, it is a good idea to seek medical help. If changes are considerable or clearly interfering with study, work, or friendships, it is important to seek help quickly. This is very important since *early diagnosis and treatment can mean a better long-term outcome.*

4. Q. My friend had an episode of psychosis. How can I help?

A. We all need friends who stick with us through good times and bad. People who have had psychosis will value your friendship. They may be discriminated against by others due to ignorance about brain illnesses. Many individuals who develop psychosis have high IQs. Unless someone is actively experiencing symptoms of psychosis, there will be nothing particularly unusual about their behaviour.

You can help by trying to understand your friend's experience, and by educating others. Let them know the facts. Also, if possible, get to know your friend's family. They can let you know if your friend is sometimes overwhelmed or discouraged because of persistent or recurring symptoms. If you know that someone's experiencing problems, you can help by just being supportive and encouraging during these rough times.

If you're planning social activities with your friend, it helps to remember:

- People who have experienced psychosis should keep a fairly regular schedule, and get adequate sleep and rest.
- Because there may be some residual thought disorder, term papers and studying for exams can't be left until the last minute
- Using street drugs is very dangerous because they can trigger a return of symptoms (a relapse).

5. Q. Do street drugs ever cause psychosis?

A. Yes. Certain street drugs can cause psychosis — but most psychosis is *not* drug-induced. Street drugs may trigger an episode of psychosis in a person who is predisposed to becoming ill. Also, some people with untreated psychosis sometimes get involved in drugs and alcohol to mask behaviours, since psychotic symptoms in the setting of *getting high* might be seen "normal."

6. Q. Does a history of psychosis in a family mean there is a greater risk of having a psychotic episode if the person uses street drugs?

A. Yes. Evidence indicates that if someone has a predisposing genetic factor, drugs like cannabis or cocaine may trigger an episode of psychosis. This may or may not clear up when the drug use stops. If your family has a history of psychosis, extra caution would be wise.

Street drugs can be risky for anyone, but for people who have experienced psychosis, they are particularly dangerous. As mentioned earlier, certain drugs can cause relapses and make the illness worse.

All street drugs should be avoided, including:

- Cocaine/crack
- Amphetamines
- Marijuana and other cannabis products
- Ecstasy
- Crystal Meth
- PCP (angel dust)
- LSD

7. Q. What about alcohol, coffee and tobacco?

A. Occasional use of alcohol (one or two glasses of wine or beer) doesn't seem to trigger psychotic symptoms, but heavy use certainly can.

People on medication should be especially careful. Since alcohol is a depressant, it can be life-threatening when combined with medications like tranquilizers (clonazepam, Rivotril, Ativan, alprazolam, Valium, etc.) Each multiplies the effect of the other— often with disastrous results.

The following have also been shown to trigger symptoms of psychosis:

- Large amounts of nicotine and/or caffeine
- Cold medications and nasal decongestants.

Giving young people the necessary supports to recover and live with dignity in their communities helps overcome the old myths and stereotypes.

Glossary: Understanding the Language of Mental Illness

If you have a relative, friend, or student with psychosis, you may find medical professionals and others using words you are not familiar with.

This is a short glossary of some of the most commonly used terms.

Bipolar Disorder

A mood disorder characterized by mood swings from mania (high elation or excitability) to deep depression. Formerly called *manic depression*. These extreme mood changes are often very abrupt and unrelated to changes in the person's environment.

Delusion

A fixed belief that has no basis in reality. People suffering from this type of thought disorder are often convinced they are famous people, are being persecuted, or are capable of extraordinary accomplishments.

Depression

A mood disorder characterized by sadness and loss of interest in previously satisfying activities. Other symptoms may include a negative view of the self and hopelessness, passivity, indecisiveness, suicidal intentions, loss of appetite, weight loss, sleep disturbances, and other physical symptoms.

Diagnosis

Classification of a disease by studying its signs and symptoms.

Schizophrenia, bipolar disorder and depression are among the many possible diagnostic categories used in psychiatry.

Hallucination

An abnormal experience in perception. Seeing, hearing, smelling, tasting or feeling something that is not there.

Involuntary Admission

People are usually admitted to hospital *voluntarily* and are free to leave whenever they wish. People who are very ill with brain disorders may be admitted to hospital against their will, or *involuntarily*. There are two ways this can occur:

- Under medical certificate or renewal certificate
- Under special court order if the person has been charged with a criminal offence. In this case, they may be held in a forensic hospital facility.

In British Columbia, before someone can be admitted involuntarily, a physician must certify that the person is:

- Suffering from a mental disorder and requiring protection and medical treatment in hospital
- Unable to fully understand and make an informed decision regarding treatment, care and supervision

- Likely to cause harm to self or others, or to suffer substantial mental or physical deterioration if not hospitalized.

Medications

In psychiatry, medication is usually prescribed in pill or injectable form. Several different types of medications may be used, depending on the diagnosis. Ask your doctor or pharmacist to explain the names, dosages, and functions of all medications, and to separate generic names from brand names to reduce confusion.

- 1) **Antipsychotics:** Medications that reduce agitation, diminish hallucinations and destructive behaviour, and may help with some thought disorders. Side effects include changes in the central nervous system affecting speech and movement, and reactions affecting the blood, skin, liver and eyes. Periodic monitoring of blood and liver functions is advisable.
- 2) **Antidepressants:** Relatively slow-acting drugs—but if no improvement is experienced within three weeks, they may not be effective at all. Some side effects may occur, but these are not as severe as side effects of antipsychotics.
- 3) **Mood Stabilizers:** Used in manic and manic-depressive states to help stabilize wide mood swings that are part of *bipolar disorder*. Regular blood exams are necessary to ensure proper medication levels. There may be some side effects such as thirst and burning sensations.
- 4) **Tranquilizers:** Generally referred to as *benzodiazepines*. These medications help calm agitation and anxiety.
- 5) **Side Effect Medications:** Also called *anticholinergics*.

Mental Health

Describes an appropriate balance between the individual, his or her social group, and the larger environment. These three components combine to promote psychological and social harmony, a sense of well-being, self-actualization, and mastery over one's environment.

Mental Illness/Mental Disorder

Physiological abnormality and/or biochemical irregularity in the brain causing substantial disorder of thought, mood, perception, orientation, or memory—grossly impairing judgment, behaviour, capacity to reason, or ability to meet the ordinary demands of life.

Mental Health Act

Provincial legislation for the medical care and protection of people who have a mental illness. The Mental Health Act also ensures the rights of patients who are involuntarily admitted to hospital, and describes advocacy and review procedures.

Paranoia

A tendency toward unwarranted suspicions of people and situations. People with paranoia may think others are ridiculing them or plotting against them. Paranoia falls within the category of delusional thinking, often based on hallucinatory experience.

Psychosis

Hallucinations, delusions, and loss of contact with reality.

Schizophrenia

Severe and sometimes chronic brain disease. Common symptoms— personality changes, withdrawal, severe thought and speech disturbances, hallucinations, delusions, bizarre behaviour.

Side Effects

Side effects occur when there is drug reaction that goes beyond or is unrelated to the drug's therapeutic effect. Some side effects are tolerable, but some are so disturbing that the medication must be stopped. Less severe side effects include dry mouth, restlessness, stiffness, and constipation. More severe side effects include blurred vision, excess salivation, body tremors, nervousness, sleeplessness, tardive dyskinesia, and blood disorders.

Some drugs are available to control side effects. Learning to recognize side effects is important because they are sometimes confused with symptoms of the illness. A doctor, pharmacist, or mental health professional can explain the difference between symptoms of the illness and side effects due to medication.

Treatment

Refers to remedies or therapies designed to cure an illness or relieve symptoms. In psychiatry, treatment is often a combination of medication, education about the illness, counselling (advice), and recommended activities. Together, these make up the individual patient's *treatment plan*.



A REASON TO HOPE. THE MEANS TO COPE.
BRITISH COLUMBIA SCHIZOPHRENIA SOCIETY

Support for Families

The BC Schizophrenia Society (BCSS) has Branches and Regional Coordinators throughout the province. Check your local telephone directory or contact the BCSS Provincial Office. You can also find contact numbers and email addresses for resources near you through our website:

www.bcss.org

Helpful Websites

www.bcss.org

www.reachoutpsychosis.com

www.psychosissucks.ca