I guess a lot of people in a lot of areas need more training; they need to be made aware. And in the schools, of course, the teachers and guidance counsellors and I think some of the general practitioners maybe should look a little more deeply into this. Because if a parent takes a child and they say “Well, he or she is not like they used to be” maybe the doctor could listen a little more carefully and dig into it a little more deeply.

– Simon’s Grandmother
Introduction

Approximately 3 out of every 100 people worldwide will experience a psychotic episode at some stage during their lifetime. Psychotic disorders affect people of all races, cultures, religions and socio-economic classes.

Usually a first episode of psychosis occurs in adolescence or early adulthood, which is a critical time for long-term psychological, emotional, social and vocational development. The onset of psychosis is typically a distressing and disruptive experience for both the affected individual and their family. The longer the psychosis is untreated, the greater the risk that other serious problems will occur such as declining performance at school or work, social isolation, depression, self harm or suicide, drug or alcohol abuse or aggressive behaviour.

Unfortunately, numerous studies have shown that there is often a significant and unacceptably long delay in initiating appropriate treatment for individuals affected by a first episode of psychosis. Although these delays can vary widely from one individual to the next, studies have shown that the average length of time between onset of psychosis and initiation of treatment (duration of untreated psychosis) is often greater than one year.

Many factors can contribute to delays in initiating appropriate treatment for individuals affected by a first episode of psychosis.

Failure to recognize that something is wrong, lack of understanding of psychosis and stigma associated with mental illness can lead to delays in seeking help. Even when an affected individual or their family seeks appropriate help, delays in diagnosis and treatment may result from gaps in knowledge and skills in health care professionals regarding the detection and treatment of first episode psychosis.

One of the major aims of specialized Early Psychosis Programs such as The Nova Scotia Early Psychosis Program is to facilitate earlier identification and treatment of psychotic disorders. One way that early detection and intervention can be achieved is by increasing community awareness through education.

Key Point

Psychosis is treatable. Early detection is important. The sooner... the better.
Who will find this information useful?

- You may be a person who has been told that you are experiencing a first episode of psychosis.
- You may be a person who:
  - has noticed changes in your mood for no apparent reason
  - is having difficulty functioning at school or work
  - is having difficulty with concentration or memory
  - has thoughts or experiences which are unusual or disturbing
  - has received comments from family and friends that “you aren’t yourself”.
- You may be a person who has had a member of your family diagnosed with a psychotic disorder.
- You may have a family member or friend or may know someone whose personality seems to have changed or who may not be acting the way they usually do or whose behaviour seems to be unusual.
- You may be a teacher, counsellor or community youth worker who has known a young person where “something didn’t seem quite right” and wondered, “Is it just a phase or something more serious?”
- You may be a health care professional who would like to have an education resource to assist you in explaining psychosis to your patients, their families, other health care professionals or community groups.

If you are any of these people, the Sooner the Better: Get Help Early for Psychosis package will be useful in providing you with basic information about the brain disorder psychosis.

What is contained in the “Sooner the Better” package?

- A video consisting of interviews of two young people and their families that describes their experiences with psychosis and the process of recovery.
- Written information that provides an overview of psychosis including early detection, signs and symptoms, the different types of psychosis, causes of psychosis, appropriate treatments, complications, course and outcome and prevention of further episodes.
- A video discussion guide with suggestions for individual and/or group activities which provide an opportunity to explore feelings, attitudes and knowledge about psychosis and an opportunity to reflect on what you have seen in the video.
- A poster identifying the early signs of psychosis which we encourage you to post in your office, community centre, school or any other suitable place you know where it will help inform people about psychosis.
After you review this information guide and watch the video you will be able to:

- define psychosis
- identify the symptoms of psychosis
- state who is at risk for psychosis
- describe the causes of psychosis.
- explain why early detection and early appropriate treatment is important and describe strategies to promote early detection and intervention
- describe the role of specialized Early Psychosis Programs in the detection and treatment of psychotic disorders
- identify how to refer persons who need help to appropriate health care professionals
- describe the different types of psychosis and the stages of psychotic disorders
- describe how psychosis is treated
- describe other conditions that can occur in individuals with psychotic disorders.
- describe the course and various outcomes of psychotic disorders including the process of recovery and the prevention of further psychotic episodes

The Sooner the Better: Get Help Early for Psychosis Information Guide

How to Use This Guide

This guide is divided into two sections:

- **Section I** provides written information on psychosis.

We recommend that you watch the video first and then read through the information in Section I of the guide.

- **Section II** provides suggestions for individual and group activities that may be used in conjunction with the video “The Sooner the Better: Get Help Early for Psychosis”.

To explore your own understanding of psychosis before watching the video, we recommend that you refer to Section II and choose the preview activities that are appropriate for your learning needs. After watching the video and reading Section I, we recommend that you complete the post-view activities that are applicable to your learning situation.
Information on Psychosis

In this section you will find information on psychosis. This information is meant to supplement the information that was provided in the video.

Key Point

What are the symptoms of psychosis?

- The term psychosis is used to refer to brain disorders in which there is a distortion of or a loss of contact with reality. Psychotic disorders are conditions in which psychosis appears.
- When a person becomes ill in this way it is called a psychotic episode.
- Psychosis affects a person’s ability to think, feel, perceive and act.

Most people with psychosis are aware of and distressed by their experiences.

- Just like any other illness, psychosis has a specific set of symptoms.
- Symptoms of psychosis may involve changes in thinking and speech, in behaviour and daily functioning, in mood and in perception.

Symptoms are not the same for each person and may vary over time.

The specific changes and disturbances that can occur are defined as:

- Positive symptoms
- Negative symptoms
- Mood symptoms
- Cognitive symptoms
Positive Symptoms

- are changes that occur in a person’s perception (five senses) thoughts, feelings and behaviour.

- refers to the presence of symptoms, which should not be present and used in this way doesn’t mean good.

- are often called psychotic symptoms.

Positive symptoms include:

- Hallucinations
- Delusions
- Thought Disorder
- Disorganized or Bizarre behaviour

Hallucinations:

- are sensory perceptions that occur in the absence of any real external stimulus but appear to be the result of faulty messages in the brain.

- can affect any of the senses. The person may hear, see, smell, feel or taste sensations that are not there. The hallucinations are very real to the person and may be very distressing.

- may affect a person’s thinking, mood and behaviour. Hallucinations may make it hard for a person to carry out their everyday activities and may interfere with their sleep or ability to concentrate.

Examples of hallucinations include:

1. **auditory**- hearing voices or other sounds that are not there. Voices may either comment on the person's behaviour, talk about the person or tell the person to do things.

2. **visual**- seeing images or objects that are not there.

3. **tactile**- feeling sensations that are not there such as a sensation of something crawling under the skin.

4. **olfactory** experiencing unusual smells that others can’t perceive.

5. **gustatory**- experiencing strange and unpleasant tastes in one’s mouth even when there is nothing in it.

Delusions:

- are fixed false beliefs, or ideas held only by the person experiencing the psychosis.

- are believed to be very real even when the person is told they are not.

Examples of delusions include:

1. **persecutory**- believing, for example, that one is being spied on or that one’s conversations are being taped.
2. grandiose- believing, for example that one has unique powers that no one else has or that one is unusually bright or famous.

3. religious - believing, for example, that one is a messenger from God or has been given a special mission in life from God.

4. somatic- believing that one’s physical appearance has been distorted or changed in some way or believing falsely that one has a physical illness.

5. delusions of reference- believing, for example, that one is receiving special messages from the t.v. or radio.

6. delusions of control- believing that one’s thoughts, feelings or behaviour are being controlled from outside the person. The person may believe that thoughts are being inserted into, or withdrawn from their mind; that their thoughts are broadcast aloud to other people; that others can read their thoughts or that they can read others’ thoughts.

Thought Disorder

• A person with psychosis may think and communicate less logically and have difficulty organizing their thoughts.

• The person’s thoughts may be confused, speeded up or slowed down.

When they speak, you may find that their conversation is unclear and does not make sense. They may jump from one topic to the next, stop in the middle of a sentence, make up words or simply be difficult to understand.

Disorganized or Bizarre Behaviour

People with psychosis may behave differently than they usually do. They may become extremely active or agitated, may laugh inappropriately or display inappropriate appearance, hygiene or conduct. For example, someone who believes he is God may want to spend their time preaching to people. Others may stop eating because of fear their food is poisoned. Often these changes in behaviour are associated with other symptoms (e.g. hallucinations, delusions) that the person is experiencing and their interpretation of them.

Negative Symptoms

Negative symptoms refers to behaviours or experiences that have been reduced or lost because of the illness.

A person with negative symptoms:

• may be slow to form thoughts and have difficulty generating ideas.

• may say very little or may answer questions with only one or two words. (poverty of speech or content of speech known as alogia).

• may seem to have no motivation, initiative or drive. (known as avolition)

• may have low energy and appear slowed down. Everyday activities such as getting dressed and washed may seem like a huge task. The person

“I felt like everyone knew what was going on with me”

- Anna

“She didn’t sound like herself. We both picked up on it. She started to cry and talk about things we didn’t know where they were coming from...and we felt something is going on here”

- Anna’s Parents

“She seemed different, almost like she was drugged or something”

- Anna’s Brother

“She took luggage and put it in the hall. Things Anna would never do”

- Simon’s Parents

“Simon was becoming more withdrawn from the family around grade 10 and 11.”

- Simon’s Brother

“She didn’t sound like herself. We both picked up on it. She started to cry and talk about things we didn’t know where they were coming from...and we felt something is going on here”

- Anna’s Parents

“She took luggage and put it in the hall. Things Anna would never do”

- Simon’s Parents

“Simon was becoming more withdrawn from the family around grade 10 and 11.”

- Simon’s Brother
may not take care of themselves like they used to.

- may not have any interest in participating in social activities and relationships with other people. They may prefer to stay in their room and avoid their family and friends.

- may show little or no expression on their face, in their voice tone or in their gestures (blunted or flat affect).

- may experience little or no pleasure from the activities that he/she used to enjoy (known as loss of pleasure or anhedonia).

- The person may be anxious or irritable and feel strange or cut off from the world. The person may become very depressed, display low energy and show little interest in activities happening around them.

- The person may be angry and unpleasant to others, often because of delusions that they are experiencing, such as persecutory delusions.

Negative Symptoms

These symptoms can often be very distressing for their family and friends. It is important to remember that this behaviour is the result of their illness and not due to laziness.

Mood Symptoms

- The person may be anxious or irritable and feel strange or cut off from the world.

- The person may become very depressed, display low energy and show little interest in activities happening around them.

- The person may be angry and unpleasant to others, often because of delusions that they are experiencing, such as persecutory delusions.

- The person’s feelings and mood can change from one extreme to another (such as from happiness to anger to depression) over short periods of time, for little or no apparent reason.

Cognitive Symptoms

- be unable to focus and sustain attention which can interfere with activities such as school, work, meeting and getting along socially with others and personal care skills

- find it hard to filter out all the various stimuli in their environment. As a result, the person may be highly sensitive to sounds, lights and even the regular activities occurring in their immediate environment.

- find their ability and speed in processing information and their reaction time may be slowed

- experience difficulties with their memory, problem solving ability and judgement.
• find it hard to organize activities in their lives, for example to manage the time and tasks needed to get their schoolwork completed.

Psychosis can happen to anyone regardless of where they live, their race, culture or socio-economic status. The onset of psychotic disorders usually occurs in adolescence and early adulthood.

First episode psychosis means that a person is experiencing psychosis for the first time.

Psychosis associated with the brain disorder schizophrenia affects men and women equally.

Who gets psychosis?

Psychosis can happen to anyone regardless of where they live, their race, culture or socio-economic status. The onset of psychotic disorders usually occurs in adolescence and early adulthood.

• First episode psychosis means that a person is experiencing psychosis for the first time.
• Psychosis associated with the brain disorder schizophrenia affects men and women equally.

How common is psychosis?

• Approximately 3 in every 100 people will experience some type of psychosis during their lifetime.
• Approximately 1 in every 100 people will experience the type of psychosis known as schizophrenia in their lifetime.

The good news is that psychosis can be treated. People can recover and can go on to live satisfying lives.

What are the causes of psychosis?

• Psychotic disorders are brain disorders.
• Although the exact causes of psychotic disorders are not known, current research provides evidence suggesting that psychosis arises from changes in brain functions which affect connections between different areas of the brain (referred to as brain circuits).
• These abnormalities in brain functions can involve neurotransmitters (the chemical messenger systems in the brain). Different signs and symptoms of psychosis have been associated with too much or too little of these neurotransmitters resulting in a “chemical imbalance” in various regions of the brain. Many different neurotransmitters, including dopamine, serotonin and glutamate have been associated with the development of psychosis.
• These abnormalities in the brain may be due to:

1. Neurodevelopmental abnormalities:

   Current scientific evidence suggests that psychotic disorders can be due to abnormalities in the way the brain develops.

2. Genetics:

   A family history of psychosis is associated with an increased risk of vulnerability to psychosis. For
example the risk of developing psychosis associated with schizophrenia is 13% for children of a person with schizophrenia compared to 1% for the general population

3. **Complications of pregnancy or childbirth:**

Problems during pregnancy such as viral infections during the second trimester and complications around the time of delivery have been associated with an increased risk for psychotic disorders such as schizophrenia.

4. **“Stress-Vulnerability Model”:**

The onset and course of psychotic disorders can be viewed in terms of interactions between an individual’s unique biological vulnerability (e.g. genetic and neurodevelopmental factors) and the level of stress they face in their daily life.

As the figure below illustrates, the greater the biological vulnerability, the lower the levels of stress that can result in the onset of psychotic symptoms and vice versa.

(INSERT FIGURE Early Psychosis, a Guide for Physicians, MHECCU, 2001)

Experimentation with alcohol and “street drugs” is common among young people. Although alcohol and “street drug use” has not been shown to cause psychotic disorders such as schizophrenia, use of psychoactive substances such as ecstasy, marijuana, cocaine or LSD can trigger the onset of a psychotic episode in a person with a pre-existing biological vulnerability.

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**Key Point**

It is important to remember that psychosis is not caused by:

- Family upbringing.
- Problems with other people.
- Having a “weak” character.

**The Stages of Psychosis**

You often hear people describe disease in terms of stages or phases. Psychotic disorders occur in the following phases.

- Premorbid
- Prodromal
- Psychotic/Acute
- Recovery/Stabilization
- Residual/Stable

**Premorbid Phase**

This refers to the period in time before the person develops any symptoms.

**Prodromal Phase**

In this phase the person begins to experience changes in their feelings, thoughts, perceptions and behaviour. They do not have clear psychotic symptoms such as hallucinations, delusions or thought disorder. The changes that occur may vary from one person to another. The length of this...
phase also varies from person to person but on average lasts from 2 to 5 years.

Prodromal signs and symptoms can include:

1. **Changes in Emotions**
   - Anxiety, depression, mood swings, irritability or anger

2. **Disturbances in Thinking**
   - Difficulties in concentration, attention or memory
   - Feeling that thoughts are slowed down or speeded up
   - Difficulty organising or expressing thoughts
   - Odd ideas or preoccupations

3. **Changes in Behaviour**
   - Deterioration in functioning in home, school or work
   - Social withdrawal or isolation
   - Loss of usual interests
   - Decline in energy or motivation

4. **Physical Symptoms**
   - Sleep disturbances
   - Changes in appetite
   - Physical complaints

5. **Changes in Sense of Self, Others or the Environment**
   - Feeling different from one’s usual self or from others
   - Suspiciousness
   - Feeling that things in the environment seem different

It is important to note that the changes that occur during this stage are sometimes very subtle and non-specific and can result from a number of different physical or psychiatric disorders.

**Psychotic/Acute Phase**

During this phase the person starts to experience psychotic symptoms, including delusions, hallucinations and thought disorder. The onset of these symptoms may be sudden (acute) or slow and insidious. The length of time between the onset of psychotic symptoms and the beginning of appropriate treatment is referred to as the duration of untreated psychosis.

**Duration of untreated psychosis (treatment delay)** is quite long; months and even years. This results in unnecessary suffering, and deterioration in social relationships and occupational development. With better education of the public and professionals, the treatment delay can be significantly reduced.

**Recovery/Stabilization Phase**

In this phase, with appropriate treatment, the psychotic symptoms begin to resolve. The process of recovery of functioning varies from person to person and takes different lengths of time for each person.

**Residual/Stable Phase**

Following optimal treatment of a first episode of psychosis some people will no longer have symptoms, will have a good recovery and will not experience a recurrence of psychosis. Other people continue to experience some symptoms which may not always cause distress but may interfere with functioning, or may experience future episodes of psychosis (relapses).
Strategies for the prevention of and early recognition of relapse will be discussed later in this booklet.

(Insert figure of phases, Dr. Milliken’s slide)

Mental health professionals classify psychosis into different types according to:

- the factors that are believed to have contributed to causing the psychosis.
- the specific pattern of symptoms that occur with the psychosis.
- the duration and outcome of the psychosis.

Because many psychotic symptoms (such as delusions and hallucinations) are common to all psychoses, the boundaries between the different types of psychoses are sometimes blurred. When someone has a psychotic episode they are usually diagnosed with a particular psychotic disorder. Diagnosis refers to the identification of symptoms, which are consistent with a particular illness or disorder.

There is no physical test, x-ray or blood test relevant tests to rule out other possible physical causes. The doctor or mental health professional will ask questions to get a sense of what the person is usually like, what changes have occurred and what is the nature of their current symptoms. To help reach a diagnosis, it is important to include information from many sources, including the family, to better understand how the illness developed. The most important approach by the doctor at this stage is to identify whether a psychotic disorder is present rather than focus on making a definite DSM IV diagnosis.

There are many disorders that can cause psychotic symptoms. The following are the most common:

**Schizophrenia**
The person experiences symptoms of the illness for at least six months including at least one month of psychotic symptoms (e.g., hallucinations, delusions, thought disorder). The person demonstrates either a significant decline from their previous level of functioning, or for adolescents, fails to achieve the expected level of functioning.

**Schizoaffective Disorder**
The person experiences symptoms of both schizophrenia and a mood disorder at the same time but also has a period of illness during which delusions and hallucinations are present in the absence of mood.

What are the Types of Psychosis?

Recovery from psychosis varies from person to person and takes different lengths of time for each person.
Psychosis NOS (Not otherwise specified)
Psychotic symptoms are present but it is not possible to make a diagnosis of a specific type of psychosis because of insufficient information or because the pattern and duration of symptoms do not meet the criteria for any specific psychotic disorder. The illness may completely resolve or may persist and progress to other psychiatric diagnoses such as schizophrenia.

Delusional Disorder
The person experiences non-bizarre delusions (e.g., delusion that they are being persecuted) but does not have symptoms of schizophrenia.

Substance Induced Psychosis
Using drugs such as marijuana, cocaine, LSD, ecstasy, PCP, amphetamines, and alcohol can sometimes cause psychotic symptoms. In this type of psychosis the psychotic symptoms will resolve when the effects of the drugs wear off.

Bipolar Disorder (manic depressive illness)
This disorder is characterized by alternating periods of extreme moods. The person may experience mood changes ranging from being overly elated (mania) to being sad and hopeless (depression). Psychotic symptoms may occur. The frequency and the nature of the mood swings vary from person to person.

Psychotic Depression
The person has a severe depression with symptoms of psychosis.

Why is it important to avoid delays in getting treatment?

The Sooner the Better:
It is important to treat psychosis as soon as possible. At present some people go months and even years without receiving treatment and some people do not receive treatment at all.

Research suggests that a longer period of untreated psychosis is associated with a slower and less complete recovery.

The experience of psychosis can be very distressing for a young person. Psychosis disrupts their life at a critical stage of social and psychological development.

- School and work performance may decline.
- Education and career plans may be interrupted.
- Family relationships may suffer as both the person and their family try to understand and cope with what is happening.
- Feelings of fear and confusion and an inability do the things they usually do shakes their confidence and self-esteem.
- If the psychosis remains untreated, other possible complications may develop such as substance abuse, depression, aggressive behaviour and risk of self-harm and suicide.

The key to early recognition is to have a high index of awareness. Keep the possibility of psychosis in mind if you see a young person experiencing persistent changes in their behavior and functioning for no apparent reason. This is particularly true if you know...
there are other risk factors, such as a family history of a psychotic disorder.

How is Psychosis Treated?

With effective treatment, many people have a good recovery from a first episode of psychosis.

Ideally, treatment should be started on an outpatient basis before crises such as self-harm or aggression occurs.

Inpatient treatment may be necessary if the symptoms are very severe, if there is significant risk of self-harm or aggression or if there are insufficient supports in the community to treat the individual as an outpatient.

In some cases when a person is actively psychotic, and there is significant risk of harm to themselves or others but the person is unwillingly to accept treatment, the person may be involuntarily hospitalized and treated (depends on local mental health legislation)

Optimal treatment of first episode psychosis needs to focus on the biological, psychological and social aspects of the disorder. Treatment needs to be comprehensive, individualized, and based on a thorough assessment.

The goals of effective treatment of first episode psychosis are:

- reducing /eliminating symptoms
- improving social and occupational functioning
- promoting healthy development
- treating/preventing other conditions particularly depression and substance abuse
- preventing further psychotic episodes

A comprehensive treatment program should include:

- development of a partnership between the patient, family and health care providers,
- the use of medications,
- education for the patient and the family
- psychosocial treatments
- realistic optimism

Development of a partnership between the patient, family and health care providers

Services for patients with early psychosis, and the approaches of teams providing services have changed dramatically. Today, with more patients being treated as outpatients, effective treatment is best provided with the active involvement and co-operation of the patient. A confiding and trusting relationship with a health care professional creates the opportunity for the person to discuss important issues concerning their illness, treatment and recovery.

It may take considerable time before a person is able to accept that they have psychosis. A calm, supportive approach that focuses on the person’s distress and concerns is essential in engaging the person in treatment.

The patient’s family are often the major caregivers and source of support. They should therefore be included in both the assessment process and treatment planning. Optimal treatment involves, whenever possible, building
a partnership that includes the patient, family and treatment team.

Sometimes a patient will refuse to have their family involved. This must be respected by the treatment team because of issues of patient confidentiality. Efforts should be made to deal with the patient’s concerns and distrust and to educate the patient about the benefits of involvement of family members and significant others in their treatment and recovery process.

**Use of Medications**

Medications are essential to the treatment of psychosis.

- The medications used to treat psychosis are called “anti-psychotic” medications.
- If necessary, the clinician may also prescribe other medications such as anti-anxiety medications, sedative/hypnotics, antidepressants or mood stabilizers.
  - Anti-anxiety medications (e.g. benzodiazepines) may be used initially to control agitation and anxiety.
  - Sedative/hypnotics may be used initially to treat problems with sleep.
  - Antidepressants may be given if the person is experiencing a major depression along with psychosis.
  - Mood stabilizers such as lithium are used in the treatment of people with bipolar disorder.

**Key Point**

- Psychosis results from changes in brain chemistry. Anti-psychotic medications appear to work to help the brain to restore its chemical balance.

**Types of antipsychotic medications:**

- Anti-psychotic medications currently available can be classified into two categories; the older “typical” agents and the newer “atypical” agents.

**The older “typical” anti-psychotic medications include:**

chloropromazine, flupenthixol, fluphenazine, haloperidol, loxapine, methotrimeprazine, perphenazine, pimozide, pipotiazine, thioridazine, thiothixene, trifluoperazine, and zuclopenthixol.

**The newer “atypical” medications include:**

clozapine, olanzapine, quetiapine, and risperidone. Ziprasidone, also a new drug, is currently not available in Canada (as of the date of this printing).

**Choosing an antipsychotic medication**

While more research is needed, it appears that “typical” and “atypical” agents are equally effective in treating positive psychotic symptoms (e.g. hallucinations and delusions). The “atypical” agents may be more effective in treating negative, cognitive and mood symptoms.

- The “atypical” antipsychotics, however, have far less risk of causing extrapyramidal side effects (e.g. tremor, stiffness, abnormal involuntary movements) compared to the “typical” antipsychotics. For this reason alone, it is generally recommended that “atypical” antipsychotics (olanzapine, quetiapine or...
risperidone) be used in the initial treatment of a person with first episode psychosis.

- Antipsychotic medication is started at a low dose, which is slowly adjusted, based on the person’s response (“start low, go slow”).

- It is generally recommended that only one antipsychotic medication be used at a time. Combining different antipsychotic medications has not been shown to be more effective and can cause more side effects.

- It can take several months for an antipsychotic medication to be fully effective.

- If satisfactory improvement in the patient’s symptoms is not achieved by 6-8 weeks, a second “atypical” antipsychotic medication should be tried for another 6-8 weeks.

- If positive psychotic symptoms persist after trials of two different antipsychotic medications, it is important to assess if the patient is taking the medication as prescribed or if there are serious problems with substance abuse.

- In cases where a person is not taking the oral medication as prescribed and remains seriously ill or has frequent relapses and hospitalizations, it may be appropriate to use a long acting injectable “typical” antipsychotic. Currently, in Canada, there are no long-acting injectable “atypical” antipsychotics available. (As of this printing)

- Clozapine is a very effective atypical antipsychotic agent. However, clozapine can cause agranulocytosis in 1% of people who use it. This is a rare but serious condition in which the body does not produce the white blood cells, which are needed to fight infection. Therefore, it is recommended that clozapine only be used when a person has not responded to trials of two other antipsychotic medications. With regular blood tests, clozapine can be safely used.

Minimizing the side effects of medication

In the early stages of treatment, several medication adjustments may be needed to find the medication and dosage that works best for the person.

Atypical antipsychotic medications allow treatment with minimal risk of extrapyramidal side effects.

Weight gain is a potentially significant side effect of many antipsychotic medications, including most of the atypical agents. Significant weight gain is associated with increased risk of serious physical problems such as cardiovascular disease and diabetes. It is important to carefully monitor weight as well as periodically testing for diabetes and for cholesterol and other lipid abnormalities.

Antipsychotic medications should continue to be taken long after psychotic symptoms are gone.

How long to take antipsychotic medication
People being treated for psychosis commonly ask about how long they will need to take medication. In first episode psychosis, the optimal length of time that antipsychotic medication is needed to minimize the risk of relapse is not yet known.

Currently most clinicians recommend that antipsychotic medication be continued for at least one or two years after all psychotic symptoms have ceased. (maintenance antipsychotic treatment)

Even when symptoms are no longer present there is a high risk that the psychotic symptoms will return if the medication is stopped. Various research studies report that from 50-90% of people who stop treatment for psychosis will experience a return of their symptoms. It is also well documented that when symptoms return and treatment is started again the recovery that follows may not be as rapid nor as complete as occurred when the psychosis was first treated. For these reasons many clinicians recommend that antipsychotic treatment be maintained at a low dose indefinitely.

It is important that individuals take their medication as prescribed by their doctor. The person should not stop taking their medication without the co-operation and supervision of the physician and the support of their family.

The person who decides to stop taking their antipsychotic medication should be educated about the risks and about early signs of relapse and should continue to be followed closely.

Education for the patient and family

Each person who is recovering from a first episode of psychosis should be actively involved in their own treatment and recovery. It is essential that the person be given an opportunity to learn about the illness, its treatments and how to prevent further illness episodes.

The recovery process will be smoother if the recovering person

- learns how to manage stress and cope with day to day problems
- develops a social support network
- engages in activities important to them, such as work, school or leisure.
- learns how to recognize warning signs or symptoms of relapse.

Education can occur in groups or on an individual basis through contact with a knowledgeable doctor, nurse, social worker or other mental health professional.

Education is also essential for family members. Education helps family members to understand what the person with psychosis is experiencing. Family members need to learn about the symptoms of psychosis, its treatment, and the recovery process. They may need help and guidance with how to relate to and support their family member who is ill. Family members can attend a family support or education group. If their relative agrees, they can also meet with the attending physician and clinician or case-manager on an individual basis.

Psychosocial Treatment

It is important that treatment includes psychosocial interventions that allow the person to maintain a sense
of self, facilitate their understanding of the experience of psychosis, minimize the loss of social, educational and vocational skills and promote healthy development.

The experience of psychosis can isolate the person from their social networks and may result in loss of confidence, and doubts and fears about their future. While needs for supports will vary between different individuals it may be helpful if they include:

- having a friend, family member or even a member of the mental health team that they can connect with on a regular basis to help the person through the ups and downs of the recovery process.
- having a peer support group of other people who are further along in recovery who can provide hope and encouragement.
- having assistance with structuring daily activities and with training and vocational skills to give them a sense of a meaningful role in life.
- having assistance, if needed, with financial or housing concerns.

Realistic Optimism

Optimism is important. Young people with early psychosis and their families need to know that the treating team believes they can get better. Early diagnosis and current improvements in treatment give reason for this hope and optimism. It is important that team members communicate a message of hope, without downplaying the seriousness of the illness.

What are Some of the Other Conditions That Can Occur With Psychosis?

Substance abuse

Misuse of substances such as alcohol, marijuana and other street drugs is a problem for many people with psychosis. For example, studies have found that at least 50% of people diagnosed with schizophrenia also have a substance abuse disorder at some point during their lifetime.

For some people substance abuse begins before psychotic symptoms appear and may speed up the onset of psychosis. For other people substance abuse begins later and may be an attempt to “self medicate” the psychosis.

The use of alcohol, marijuana and other drugs hinders and delays recovery from psychosis. Even with treatment, ongoing substance abuse may cause relapses.

Helping people reduce their use of substances (harm reduction) or maintain recently achieved abstinence is an important part of treatment for psychosis. It is important to maintain antipsychotic treatment even if a person continues to abuse substances.

Depression

Depression can occur along with psychosis. In many cases depression is the first sign of illness, starting before the psychotic symptoms appear. For some people depression begins after the psychotic symptoms have been successfully treated. (Post-psychotic depression) It is important to identify and treat depression when it

After awhile I saw signs I was getting back to myself. I can talk on the phone at least a few minutes...I got back into sports, track and field and back to school, seeing everyone and talking to everyone.

- Anna
occurs. Untreated depression can contribute to suicidal thoughts and actions.

**Aggression**

When a person is experiencing intense psychotic symptoms their behaviour may become irrational and there can be the potential for aggression and violence. In cases of aggressive behaviour or when there is a risk of potential violence, it is important to ensure the safety of the person with psychosis and those around them by notifying the appropriate authorities. In the vast majority of cases, the potential for violence becomes minimal with effective antipsychotic treatment.

### Recovery: How long does it take to get better?

With the treatments available today, the majority of people with a first episode of psychosis will have a remission of the positive psychotic symptoms.

The recovery process is an active process for both the patient and family and is affected by many things, including the duration of untreated psychosis, the type of psychosis, and the person’s adherence to treatment and whether other problems such as substance abuse are present.

Recovery does vary from person to person. With medication, some people find that their psychotic symptoms may subside quickly, but for others this process may take months. Some people who experience psychosis recover well and never experience another episode. Others will continue to have further episodes. Some may experience persistent symptoms and need on-going support to live independently or to get back to work or study. Everyone is different. Sometimes what works for one person does not work for another. For any particular person, it is best to talk to a health care professional who is knowledgeable about psychosis and who is familiar with that person’s situation.

A major factor in getting better is the need to reduce the length of time that the person experiences symptoms, especially psychotic symptoms. Specialized early intervention programs have been developed in various parts of the world (including Nova Scotia). These programs focus on ensuring psychosis is identified early and effective treatment is started as soon as possible. Check to see if there is such a program in your area.

### Recovery: Getting Back On Track

Often when the person begins to feel better they may want to get back into activities they were involved with before they became ill or they may have different interests. Each plan and choice of priorities or activities is individual.

*It is important that the person discuss their ideas/plans with their treatment team. Taking on too many responsibilities at once may have a negative impact on recovery.*

Careful planning with members of the mental health team, such as an occupational therapist, social worker or nurse can be helpful to identify the type of activity or challenge that is best for the person at various points in the recovery process. The support, guidance and direction provided by the team and their family and friends can be very helpful.

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Before the couch was my favourite place to stay and now I am able to go to stores. I started out going to the video store, restaurants, and shopping malls. I try to play tennis twice a week.

-Simon

- Simon
How Do I Refer for Help?

If you think someone you know may be experiencing the symptoms of psychosis, notify their family doctor or local mental health professional immediately. The Sooner… the Better.

“If you think that there is any possibility that this is happening to a loved one of yours… if you think that something is wrong don’t delay, seek out advice, seek out help and be diligent. Work until you get the answers you want. If you don’t get it from one health care provider, find someone else who can give it to you because the person that you love deserves only the best.”
- Simon’s Mother

“There is help out there. That’s the biggest message that needs to come across. There is help… don’t be afraid to get it. Don’t let your child slip away from you.”
- Anna’s Father

SECTION II

Activities

In this section you will find individual and group activities, which provide an opportunity to explore feelings, attitudes and knowledge about psychosis and to reflect on what you have seen in the video.

This section includes:

- An activity to be completed before and after viewing the video and reading the information guide.

- Activities to do:
  - Before viewing the video
  - After viewing the video

Insert Picture of Anna
#100-0084
Before you watch the video and read this information guide, take a few minutes to complete the following quiz to see what you know about psychosis. (Individual or Group Activity)

Complete the following true or false statements. Simply place a “T” beside the statements you believe are true and an “F” beside the statements you believe are false.

When you are finished, viewing the video and reading the guide, complete them again. The answers are on page ___. Note if there were any changes in your answers.

1. Psychosis is a brain disorder. T
2. Psychosis in young people is rare. T
3. People with a psychotic disorder, such as schizophrenia, have split personalities. F
4. Young people with psychosis always get prompt treatment. F
5. Once you have a psychotic episode, you never recover. F
6. People who get treatment for psychosis more quickly tend to have a better recovery. T
7. Psychotic symptoms can emerge in response to stress and drug use. T
8. People being treated for psychosis are more likely to be aggressive or dangerous than other people. F
9. Memory, concentration and problem solving skills can all be impaired as a result of psychosis. T
10. People with a psychotic disorder, such as schizophrenia, cannot be productive members of society. T

Before watching the video or reading this guide, take a moment to stop and reflect about your experience or understanding about mental illness or early psychosis.

There are two different options for this activity. Choose the one that is most suitable for your learning situation.

Purpose: To provide an opportunity for participants to explore their experiences and understanding of mental illness and psychosis.

Activity A

Think for a moment if you have had an experience with a person diagnosed with psychosis or any other mental illness.

1. What was the attitude toward the individual in your school or community?
2. Do you remember anything about how the person got help for their illness or if it took a long time for them to get help?
3. What are your feelings or beliefs about people who are diagnosed with psychosis or any other mental illness?
4. If you are a person recovering from psychosis how would you describe what it has been like for you?
5. What do you hear in your community about mental health and mental illness? Are there public lectures or forums? Have you seen or heard any presentations in newspapers, on the radio or on TV?

6. Do you ever talk about mental illness or psychosis with people in the community?

7. What would you say to someone who came to you and said they needed help for a problem related to their mental health?

**Activity B**

**Open-ended Statements**

There are no right or wrong answers to these statements. They are intended only to help you think about your attitudes and feelings about mental illness and psychosis. Complete each sentence with the first thing that comes to your mind.

1. Mental illness is…

2. In my opinion, schizophrenia is…

3. People who have psychosis can…

4. Psychosis in adolescents happens because…

5. If someone I worked with or went to school with had psychosis I would…

**Discussion**

1. What was this experience like for you?

2. What was the most difficult sentence to complete? The easiest? Why?

3. What were your feelings and thoughts as you completed this exercise?

4. Was it easier to write or talk about your attitudes?

5. What did you learn about your attitudes toward mental illness or psychosis from this exercise?

6. Did the activity raise awareness of issues that you had not thought about or not experienced before?

**Video Discussion Activities**

“The Sooner the Better: Get Help Early for Psychosis”

The “Sooner the Better: Get Help for Psychosis” is the real life account of two young people who have experienced a first episode of psychosis. Simon and Anna describe how they became ill, their signs and symptoms, their journey to get help and their recovery. Their families provide their perspectives on the illness and their experience with getting help and supporting their family member’s recovery.

In the following sections, you will find a number of activities, which can be used for discussion concerning the video. Choose the activities that you find suitable for your situation (whether an individual
Activity 1: Before viewing the video

**Purpose:** To provide an opportunity for discussion on psychosis, to explore what the participants know, and to stimulate the participants’ interest prior to video viewing.

- In your opinion, who gets psychosis?
- Why would it be important to diagnose psychosis early?
- Why do you think it would be beneficial to know about the signs and symptoms of psychosis?
- Who do you think should be educated about psychosis? How should it be done?
- What could be done to get help for persons with psychosis in your community?

Show the video “The Sooner the Better: Get Help Early for Psychosis”. After viewing the video, this activity can be done on an individual basis or with small groups.

**Purpose:** To provide an opportunity for participants to express their feelings and responses to the video.

Activity 2: After viewing the video

**Group process:** If you have 12 or more participants, divide the large group into 4-6 participants each. Give them flip chart paper; have them choose a person to lead the group discussion (facilitator), record the results of the group discussion (recorder), and someone to report the results to the larger group (presenter). The group members are to review all the questions and provide their feedback. As each group presents their results, the facilitator can add to their answers as necessary to clarify and emphasize the key points. The information provided in the Section I of this information guide will be helpful for this activity.

**Video Discussion Questions**

1. What were some of the symptoms that Anna and Simon experienced?
2. What is your response to the way Anna described her experience of illness?
3. What is the difference, if any, between Anna’s onset of illness and Simon’s?
4. As mentioned in the video, most people experience psychosis in adolescence or young adulthood. What would be some of the barriers, if any, to recognition of illness during this developmental stage?
5. What were some of the differences in Anna and Simon’s experience of getting help?
6. What helped Anna and Simon to recover? What factors were important to them?
7. What role do you think family members play in respect to getting help for psychosis?
8. What are your feelings/responses to their recovery?

9. If someone you know becomes ill, what could you do to help them? Who would you go to? Identify your sources of support. (In school? In the family? In the community?)

**ANSWERS – What Do You Know About Psychosis? Quiz**

1. Psychosis is a brain disorder. **TRUE.** Psychosis is a brain disorder that results from a disturbance in brain function. Current research using technologies, such as Magnetic Resonance Imaging (MRI), demonstrates that there are differences in brain structure and function when they compare brain images of some people with psychosis are compared to those of people without psychosis.

2. Psychosis in young people is rare. **FALSE.** For both men and women, an initial episode of psychosis most often strikes between the ages of 16 to 35. It is estimated that three out of every hundred people will experience a psychotic episode over the course of their lifetime.

3. People with a psychotic disorder, such as schizophrenia, have split personalities. **FALSE.** People with psychosis experience distortions of reality. They may hear voices when no one is there, or believe that people are out to get them. This is very different from those people who seem to have two or more personalities. Such people have a completely different disorder. (Which is very rare)

4. Young people with psychosis always get prompt treatment. **FALSE.** Unfortunately, although psychosis is quickly recognized when it begins in some people, others can go for a year or even more before it is recognized and effective treatment starts.

5. Once you have a psychotic episode, you never recover. **FALSE.** Research demonstrates that, with proper treatment, as many as 85% of people make a significant recovery from a first episode of psychosis. Continued treatment can help prevent a recurrence of psychotic symptoms in many people.

6. People who get treatment for psychosis more quickly tend to have a better recovery. **TRUE.** Research has shown that the shorter the duration of untreated psychosis, the better the outcome.
7. Psychotic symptoms can emerge in response to stress and drug use. **TRUE.** Although stress or drug use do not cause psychotic disorders such as schizophrenia, some people are prone, or predisposed, to psychosis, based on their genetic make-up and other factors that might affect their brain development (infections during pregnancy, birth injuries or head injuries after birth). For a person prone to psychosis, the stress of drug use or other situations can be enough to trigger a psychotic episode, or cause a recurrence of psychotic symptoms even if they are receiving treatment.

8. People being treated for psychosis are more likely to be aggressive or dangerous than other people. **FALSE.** A person receiving effective treatment for a psychotic disorder who does not have other problems associated with a risk for psychosis (e.g. substance abuse) is no more likely to be aggressive or dangerous than anyone else. However, when a person is actively psychotic, but is not receiving treatment, their behavior may become unpredictable.

9. Memory, concentration and problem solving skills can all be impaired as a result of psychosis. **TRUE.** Although psychosis involves some loss of contact with reality, for many people it also includes deficits in memory, concentration and problem solving abilities. Standardized tests are available to test these skills and determine whether or not they are impaired.

10. People with a psychotic disorder, such as schizophrenia, cannot be productive members of society. **FALSE.** With proper treatment, including medication and psychosocial interventions, adherence to medications and follow-up support, people with a psychotic disorder, including schizophrenia, can lead active and productive lives.

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**Resources: Useful Websites**

- [http://www.iris-initiative.org.uk](http://www.iris-initiative.org.uk) Early Psychosis Initiative in the United Kingdom
- [http://www.mentalhealth.com](http://www.mentalhealth.com) Canadian mental health information site.
- [http://www.schizophrenia.ca](http://www.schizophrenia.ca) Schizophrenia Society of Canada
- [http://www.schizophrenia.com/](http://www.schizophrenia.com/) Site providing information on schizophrenia and other common mental illnesses.
- [http://www.cmha.ca](http://www.cmha.ca)
  Canadian Mental Health Association’s main site

  National Institute of Mental Health