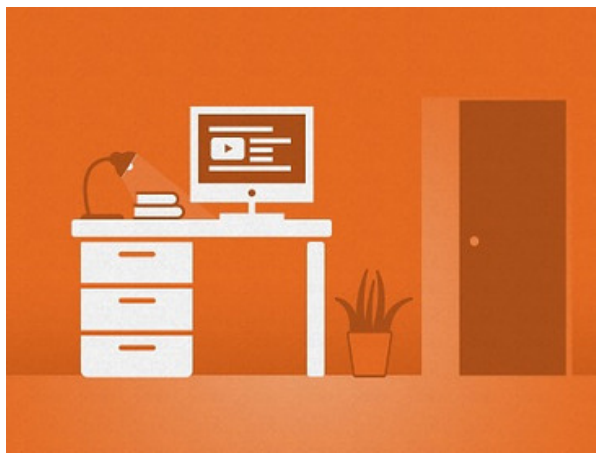
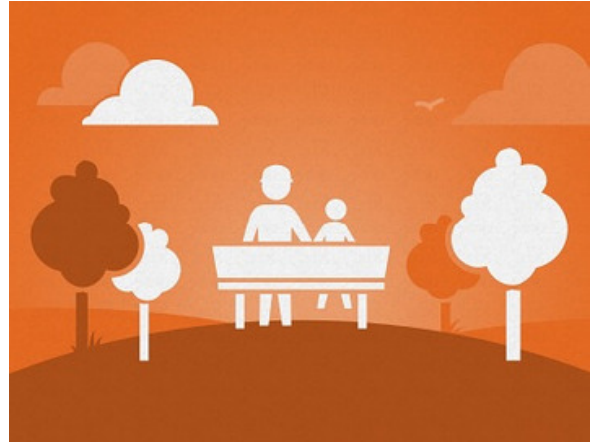




SCHIZOPHRENIA SOCIETY OF ALBERTA

SSA's Family & Caregivers Guide to Recovery



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What is schizophrenia?

Schizophrenia is a brain and behavior illness affecting how one thinks, feels and acts. People with schizophrenia can have trouble distinguishing reality from fantasy, expressing and managing normal emotions and making decisions. Thought processes may also be disorganized, and the motivation to engage in life's activities may be blunted. Those with the condition may hear imaginary voices and believe others are reading their minds, controlling their thoughts or plotting to harm them.

Most people with schizophrenia experience symptoms either continuously or intermittently throughout life and are often severely stigmatized by people who do not understand the illness.

Contrary to popular perception, people with schizophrenia do not have "split" or multiple personalities and most pose no danger to others. However, the symptoms are terrifying to those afflicted and can make them unresponsive, agitated or withdrawn. People with schizophrenia attempt suicide more often than people in the general population, and estimates are that up to 10 percent of people with schizophrenia will complete a suicide in the first ten years of the illness — particularly young men with schizophrenia.

While schizophrenia is a chronic illness, it can be treated with medication, psychological and social treatments, substantially improving the lives of people with the condition.

Recovery is possible

" When I was diagnosed with schizophrenia, the bottom dropped out of my world. Myself, family and friends had no idea what was next. But when we reached to the Schizophrenia Society of Alberta we learned that recovery is possible.

Now I live a happy and fulfilling life and know that I am an ordinary person with an extraordinary mind."

~ SSA client

What are the symptoms of schizophrenia?

Schizophrenia can have very different symptoms in different people. The way the illness manifests itself and progresses in a person depends on the time of onset, severity, and duration of symptoms, which is categorized as positive, negative and cognitive. All three kinds of symptoms reflect problems in brain function. Relapse and remission cycles often occur; a person can get better, worse and better again repeatedly over time.

- **Positive symptoms**, which can be severe or mild, include delusions, hallucinations, and thought disorders. Some psychiatrists also include psychomotor problems that affect movement in this category. Delusions, hallucinations and inner voices are collectively called psychosis, which also can be a hallmark of other serious mental illnesses such as bipolar disorder. Delusions lead people to believe others are monitoring or threatening them, or reading their thoughts. Hallucinations cause a patient to hear, see, feel or smell something that is not there. Thought disorders may involve difficulty putting cohesive thoughts together or making sense of speech. Psychomotor problems may appear as clumsiness, unusual mannerisms or repetitive actions, and in extreme cases, motionless rigidity held for extended periods of time.
- **Negative symptoms** reflect a loss of functioning in areas such as emotion or motivation. Negative symptoms include loss or reduction in the ability to initiate plans, speak, express emotion or find pleasure in life. They include emotional flatness or lack of expression, diminished ability to begin and sustain a planned activity, social withdrawal, and apathy. These symptoms can be mistaken for laziness or depression.
- **Cognitive symptoms** involve problems with attention and memory, especially in planning and organizing to achieve a goal. Cognitive deficits are the most disabling for patients trying to lead a normal life.

What are the subtypes of schizophrenia?

- o Paranoid schizophrenia — feelings of extreme suspicion, persecution or grandiosity, or a combination of these.
- o Disorganized schizophrenia — incoherent thoughts, but not necessarily delusional.
- o Catatonic schizophrenia — withdrawal, negative affect and isolation, and marked psychomotor disturbances.
- o Residual schizophrenia — delusions or hallucinations may go away, but motivation or interest in life is gone.
- o Schizoaffective disorder — symptoms of both schizophrenia and a major mood disorder, such as depression.

At what age do the symptoms of schizophrenia appear?

Schizophrenia affects men and women equally. It occurs at similar rates in all ethnic groups around the world. Symptoms such as hallucinations and delusions usually start between ages 16 and 30.

Men tend to experience symptoms earlier than women. Most of the time, people do not get schizophrenia after age 45. Schizophrenia rarely occurs in children, but awareness of childhood-onset schizophrenia is increasing.

Diagnosing schizophrenia in teens can be difficult because the first signs can include a change of friends, a drop in grades, sleep problems and irritability — behaviors that are common among teens.

How is schizophrenia diagnosed and treated?

A combination of factors can predict schizophrenia in up to 80 percent of youth who are at high risk of developing the illness. These factors include isolating oneself and withdrawing from others, an increase in unusual thoughts and suspicions, and a family history of psychosis. In young people who develop the illness, this stage of the disorder is called the "prodromal" period.

Currently, schizophrenia is diagnosed by the presence of symptoms or their precursors for six months. Two or more symptoms, such as hallucinations, delusions, disorganized speech, and grossly disorganized or catatonic behavior, must be significant and last for at least one month. Only one symptom is required for diagnosis if delusions are bizarre enough or if hallucinations consist either of a voice constantly commenting on the person's behavior/thoughts, or two or more voices "conversing." Social or occupational problems can also be part of the diagnosis during the six-month period.

Foundation-funded research to find markers, such as abnormal brain scans or blood chemicals that can help detect early illness and allow for quicker interventions is now being done. Scientists are also working to understand the genetic and environmental mechanisms that combine to cause schizophrenia. As more is discovered about chemical circuitry and structure of the brains of people with the illness, better diagnostic tools, and early intervention techniques can be developed. This is crucial for schizophrenia as it is believed that with every psychotic episode, increased damage is done to the brain.

Is there a cure for schizophrenia?

While no cure exists for schizophrenia, it is treatable and manageable with medication, behavioral therapy and community peer and support programs especially if diagnosed early and treated continuously. Those with acute symptoms, such as severe delusions or hallucinations, suicidal thoughts or the inability to care for oneself, may require hospitalization. Antipsychotic drugs are the primary medications to reduce the symptoms of schizophrenia. They relieve the positive symptoms through their impact on the brain's neurotransmitter systems. Cognitive and behavioral therapy can then help "retrain" the brain once symptoms are reduced.

These approaches improve communication, motivation, and self-care and teach coping mechanisms so that individuals with schizophrenia may attend school, go to work and socialize. Patients undergoing regular psychosocial treatment comply better with medication, and have fewer relapses and hospitalizations. A positive relationship with a therapist or a case manager gives a patient a reliable source of information about schizophrenia, as well as empathy, encouragement, and hope. Social networks and family member support have also been shown to be helpful.

"The hardest part of living with a mental illness is having not having someone around who understands the situation I live through and having someone to talk to about my symptoms."

J.M an SSA client

What Can We Expect When My Loved One Has an Episode?

Beginning (prodromal phase)

- o Loss of interest in usual activities
- o Withdrawal from friends and family
- o Confusion
- o Trouble concentrating
- o Feeling listless and apathetic
- o Prefer to spend most of their days alone
- o Preoccupation with religion or philosophy

Active illness (psychotic episode)

- o Continuation of prodromal symptoms
- o Delusions
- o Hallucinations
- o Marked distortions in thinking
- o Disturbances in behavior and feelings

Residual phase

- o May be similar to the prodromal phase
- o Listlessness
- o Trouble concentrating
- o Withdrawal

Schizophrenia Over Time: Each Person's Journey is Unique

- o Some only experience one episode in their lifetime while others experience many
- o Some long experience periods of wellness between psychotic episodes while others may experience psychotic episodes that last a long time
- o Some people experience a psychotic episode without warning while others experience many early warning signs

"The more knowledge I have, the better I can support my son. I love my son. I want to protect him and to help. But I've also learned how to let him live. I encourage his dreams. I treasure his intelligence, his sense of humor and his incredibly kind spirit."

~Ron an SSA Family member

What Does Treatment Include for People with Schizophrenia?



“Working for SSA is the best job anyone could ever ask for,” says Diana, who was diagnosed with schizophrenia 24 years ago. “I work with the SSA Outreach Program. Every week my job partner and I meet individually with people who have schizophrenia or a related disorder. There’s one man who at first refused to look at me. He wouldn’t talk, he’d just grunt when I asked a question. But now, a few years later, he talks and has a great time. I had him in stitches last month with my jokes.”

~ Dianne, SSA client and Peer Support Worker

Family Support is Crucial for People with Schizophrenia

Families are important partners in the treatment of schizophrenia and play critical roles in supporting the person living with schizophrenia on a daily basis:

- o Helping with activities of daily living
- o Providing social interaction
- o Promoting safety
- o Helping with treatment
(medication adherence, keeping appointments, etc.)

Summary:

Be Realistic, But Not Pessimistic

- o Schizophrenia is a serious illness, and this needs to be acknowledged and accepted
- o The way the illness affects people is different for everybody
- o People with schizophrenia often lack insight into their illness and health
- o With proper treatment and support, many people with the disease can achieve a good quality of life and be productive members of families and society

What Are the Key Goals of Schizophrenia Treatment?

- o Achieve and maintain remission from symptoms
- o Achieve functional recovery
- o Improve quality of life
- o Prevent relapses
- o Prevent progression of the illness

The Importance of Early Treatment for Schizophrenia

- o Fewer biologic abnormalities
- o Fewer relapse
- o Overall better long-term outcomes and cognition

The result of relapse

- o Greater chance of future relapses
- o More hospitalizations
- o Decreased function of time
- o Damage to the brain
- o Reduced ability to maintain a job and personal relationships
- o Less chance that medications will work as well
- o Greater chance of stopping medication

The Importance of Healthy Living for People with Schizophrenia

- o Makes one feel more energetic and more relaxed
- o Improve mood and outlook
- o Reduce stress
- o Be a natural way to meet people
- o Help prevent other health problems (e.g., obesity, heart disease)

Medication for Schizophrenia:

- o Medications for schizophrenia are called antipsychotics
- o There is no such thing as a miracle pill that helps all patients
- o Effects of medication vary greatly from individual to individual
- o Finding the right treatment for each person is usually a trial-and-error process
- o Often involves some attempts and adjustments before the right treatment is found
- o People with schizophrenia often require extensive support to keep taking their medication

How Does Antipsychotics Work?

- o Messages in our brains are sent by chemicals called neurotransmitters
- o In schizophrenia; it is thought that something goes wrong with this complex communication system
- o Antipsychotics work by helping to rebalance the communication system
- o Each medication has different effects on the various neurotransmitters, and every person's neurotransmitter system is unique
 - Medicines that work for one person may not work for another

Antipsychotics need to be taken correctly and consistently to provide the most benefit

Setting Up A Wellness Plan For People in Remission

Keep pertinent information accessible in one place such as:

- o Healthcare team information
- o Diagnosis, other medical information
- o Safety considerations if any
- o Medications
- o Activities requiring assistance
- o Life goals (including activities, interests)

Record of self-perception and plans for wellness - to consult and to help recognize changes suggesting relapse

- o Description of self when feeling well
- o Record of things that keep him/her happy and healthy
- o Description of what it feels like to be unwell or upset
- o Record of things that cause him/her to feel bad or upset
- o Ways to help when he/she is feeling bad or upset (e.g., family support)

Embracing Hope, A Summary: Schizophrenia symptoms can be managed

- o In planning ongoing treatment and support for someone with schizophrenia, it is essential to have a strategy that integrates both pharmacological and psychosocial interventions
- o Antipsychotic medication is a critical component of successful treatment
- o Early treatment is associated with the best outcomes
- o Find the best option for each patient. Trial-And-Error is sometimes necessary

Families are important partners in the treatment of schizophrenia

- o They play critical roles in supporting the person living with schizophrenia on a daily basis:
- o Providing stability
- o Helping with activities of daily living
- o Providing social interaction
- o Promoting safety

Acknowledging the Disease

- o Family members need to acknowledge the illness and recognize the impact it will have on the patient and the rest of the family
- o Living with any illness may change day-to-day lives for all
- o There is no need to try to hide the reality; talking about it openly is helpful to all
- o Adjusting to schizophrenia may take some time, but it is possible for people with schizophrenia and their families to lead full and enriching lives

Communication Tips

People with mental illness...	So you need to...
have trouble with reality	be simple, truthful
are fearful	stay calm
are insecure	be accepting
have trouble concentrating	be brief, repeat
are over-stimulated	limit input, don't force discussion
easily become agitated	recognize agitation, allow escape
have poor judgment	not expect rational discussion
have changing emotions	disregard
have changing plans	keep to one plan
have little empathy for you	recognize as a symptom
believe delusions	ignore, don't argue
have low self-esteem	stay positive
are preoccupied	get attention first
are withdrawn	initiate relevant discussion

Tips for Responding to Crisis Situations: A List of "Do"s

- o Try to remain as calm as possible
- o Decrease other distractions (e.g., turn off TV)
- o If other people are present, ask them to leave the room
- o Speak one at a time
- o Try saying, "Let's sit down and talk," or "Let's sit down and be quiet."
- o Speak slowly, clearly, in a normal voice
- o Make statements about the behavior you are observing
- o Avoid patronizing, authoritative statements
- o Repeat questions or statements when necessary
- o Allow the person to have personal space
- o Understand that too much emotion on your part can upset him/ her further
- o Affirm or agree with the emotions the person is experiencing, without agreeing to the contents of the hallucination or delusions

Tips for Responding to Crisis Situations: A List of "Don'ts."

- o Don't shout
- o Don't criticize
- o Don't challenge the person into acting out
- o Avoid continuous eye contact
- o Don't block the doorway
- o Don't rush
- o Don't argue with other people about what to do

Understanding Confidentiality

- o Sharing health information is governed by provincial privacy laws
- o In some provinces, whatever is communicated between a patient and members of his/her healthcare team is confidential and cannot legally be disclosed to others (even family) without written permission from the ill person
- o In other provinces, information can be shared with third parties without a patient's permission in certain circumstances
- o Patients can sign a formal document to give the healthcare team the legal right to breach confidentiality
 - Healthcare professionals are trained to seek this at the earliest possible moment
 - Family members can encourage loved ones to do this as soon as the person is well and cooperative enough to do so

Family Members Can Help Support Overall Health

People with mental health problems are at higher risk of developing other serious health problems

- o Cigarette smoking
- o High blood pressure
- o High cholesterol
- o Weight gain/obesity
- o Type 2 diabetes

Family members can play a crucial role in promoting healthy lifestyle choices

e.g., encourage and help achieve healthy diet, exercise, smoking cessation, discouraging alcohol & drug use

To Be Able to Help your Loved One, You Also Need to Take Care of Yourself!

- o Go for a walk or run
- o Practice meditation
- o Keep in touch with friends
- o Take a break; ask another family member or hire someone to provide care
- o Read a good book
- o Enjoy a pet
- o Go for a massage
- o Accept help
- o Let go of the need for everything to go right
- o Delegate chores
- o Stay with a routine
- o Enjoy nature
- o Take up a hobby
- o Maintain a healthy diet
- o Set limits and keep time for yourself

My brother's journey a "triumphant recovery".

"I'm looking towards the future when I might be the primary caregiver for him.

He's gone from having a constant stutter to being a confident public speaker. And he's gone from suicidal to wanting to share his story with everybody."

Remember That You Are Part of a Team!

You are only one part of the support system — don't try to do it all yourself

Don't hesitate to ask for help!

- o Healthcare team
- o Supporting peers
- o Other family members, friends
- o Professional associations, e.g.:
- o Schizophrenia Society of Alberta

Options for People and Families Who Need More Support: Community Treatment

Typical components:

- o Regular physician meetings
- o Regular meetings with a case manager
- o Monitoring of medications
- o Supported living environments
- o Attendance at group therapy
- o Skills training or other community activities
- o Plans for potential crisis/psychiatric emergency

Involuntary Assessment, Hospitalization or Treatment

o Family members, friends, and healthcare professionals can request that a person with schizophrenia undergo psychiatric assessment, be hospitalized and treated involuntarily if he/she is believed to be a threat to him/herself or others

- Different official forms for different situations
- Regulated by provincial/territorial laws

Planning for the future

What Will Happen When I'm Not There to Help Anymore?

- o The primary caregiver for a person with schizophrenia is often a parent
- o Plans should be made in advance about ongoing care should the caregiver no longer be able to provide it, e.g.:
 - Living arrangements
 - Financial management
 - Medical care
- o Another family member (e.g., sibling) may be willing to take on the responsibility
 - If no other family members are willing/able, arrangements should be made with the healthcare team/public health system

Educate Yourself:

Schizophrenia Society of Alberta (SSA) is the only organization in Alberta that directly supports people with schizophrenia and their family and caregivers.

Our branches in Edmonton, Calgary, Red Deer, Medicine Hat, Camrose, and Lethbridge offer free services and programming in person, over the phone, and online. The Schizophrenia Society of Alberta provides valuable programs and services for both those living with schizophrenia and their family members

Families and Caregivers

Family support Group
Strengthening Families Together Educational Workshop
Online Educational Series
Drop in, walk in or email support

Individuals living with schizophrenia

Adult Peer Support Group
Youth Peer Support Group
Your Recovery Journey Workshop
Branch activities, e.g., Art & Music and various other activities
Drop in, walk in or email support

For more information visit www.schizophrenia.ab.ca or contact your local branch

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