



**making sense of your world
and the people in it!**



Schizophrenia Society
of Saskatchewan

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A letter to young people, educators, parents and significant others:

Dear Reader:

I think that we can all agree that the human brain is a wonderful resource! Its extraordinary powers and capabilities to receive, interpret, store and retrieve information is often taken for granted by most of us. In spite of its powerful and positive influences on our lives, the brain is not invincible. **The brain can become ill too!** When this happens the affected person may not even realize that something is very seriously wrong! Such can be the experience of persons affected by a neurobiological illness of the brain called schizophrenia.

This 8th edition of a handbook developed by the Schizophrenia Society of Saskatchewan Inc. is meant to provide awareness about and a deeper understanding of what schizophrenia is and what it is not. It also provides realistic options to help the families and friends to come out of isolation and be heard and believed.

No publication on this complex topic would be complete without the exploration of the stigma, myths, and misconceptions attached to all forms of mental illness, those affected and their families. Even in this modern age, these negative influences can still greatly hamper the early assessment, detection, diagnosis and treatment that is so vital to one's recovery and rehabilitation.

We would appreciate hearing from you and receiving your comments on the usefulness of this educational resource as well as your ideas for future improvements.

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Introduction

“*Schizophrenia*” is just another word in the dictionary. If an inaccurate meaning is attached to it however, there can be very serious implications for the lives of those directly affected by this brain illness, and their families, friends and caregivers. Maybe you’ve used it on occasion to describe somebody who acted oddly or “*differently*.” It is a word that you may not think much about, but for thousands of Canadians schizophrenia is an illness that can be frightening, isolating, and exhausting — in part because it is so terribly misunderstood by the rest of us.

What is the biggest problem for people living with mental illness? Most say it’s the fact that even when they are feeling better, others do not accept them. There are many myths and misconceptions that still persist into the 21st century. People suffering from schizophrenia feel the sting of discrimination in almost everything they do. They become isolated — cut off from society. Some, in desperation, as a last resort, end their lives by suicide.

Imagine if you were to go to the hospital for surgery! Your friends and family would likely call or visit. If you were admitted to the hospital for a psychiatric reason, friends and even some family members and medical staff may be uncomfortable and may avoid you or speak of you as a “*schizophrenic*.”

Yes, even spelling schizophrenia is difficult. But trying to live with it is much more difficult, especially if the person remains untreated.

It is important to know that people with schizophrenia can be adolescents, adult men and women, family, friends, neighbors, and persons like you and I.

- > Schizophrenia is a neurobiological brain illness.
- > Schizophrenia is not a “split personality.”
- > One out of every 100 people will suffer from some form of schizophrenia in their lifetime.
- > Schizophrenia is treatable.
- > Schizophrenia costs Canadians nearly \$5 billion per year.
- > One out of every five homeless Canadians suffers from chronic mental illness.

To be forewarned is to be forearmed!

Information is liberating! Application of information is power! By reading the following information you will be liberating yourself from myths, misunderstanding and stigma. You will begin a powerful journey that can possibly “*offer a future with hope*” to those living with schizophrenia.

What are the Facts About Schizophrenia?

First of all, no one is to blame.

It is not uncommon for family members and friends who are most helpful and supportive to the person with schizophrenia to be blamed by the affected person and/or members of the general public that they somehow caused the illness or attributed to it. The truth of the matter is that, *“People do not cause schizophrenia, they merely blame each other for doing so.”* E. Fuller Torrey, M.D.

Schizophrenia is a common illness.

- > It is found all over the world in all races, cultures and social classes.
- > Worldwide, it affects 1% of the population (1 in a 100).
- > Over 10,000 people in Saskatchewan are affected or will be affected in their lifetime.

Schizophrenia is a bio-chemical brain disorder.

- > It is a serious mental illness with symptoms of “psychosis.”
- > It is an illness that affects a person’s perceptions, thinking, feelings and behaviour.

Schizophrenia is one of youth’s greatest disablers.

- > Most frequently the illness occurs in the 16 – 30 year old age group.
- > Very often the individual has a perfectly normal childhood until the onset of the illness.
- > It can also appear later in adulthood. However, onset after the age of 35 is less common, and after the age of 40 is rare.

Men and Women are affected with equal frequency.

- > Generally men between the ages of 16 – 20 will experience schizophrenia for the first time, with an average age of 19 years.
- > Generally women between the ages of 25 – 30 will experience schizophrenia for the first time, with an average age of 27 years.
- > It is thought that women may be protected for these extra years by the estrogen and progesterone produced in their bodies.
- > Each person is unique and the illness may occur in children 12 years old and younger, though this is very rare.

People with schizophrenia sometimes become suicidal.

- > Depression is the most prevalent cause of suicide for people suffering from schizophrenia.

- > Four in ten sufferers will attempt suicide and one in ten will die.
- > 70% of the suicides occur before the age of 33, particularly with young males, who may be recently discharged from hospital. It is important that there be adequate supports and services in place in the community.

We are all affected.

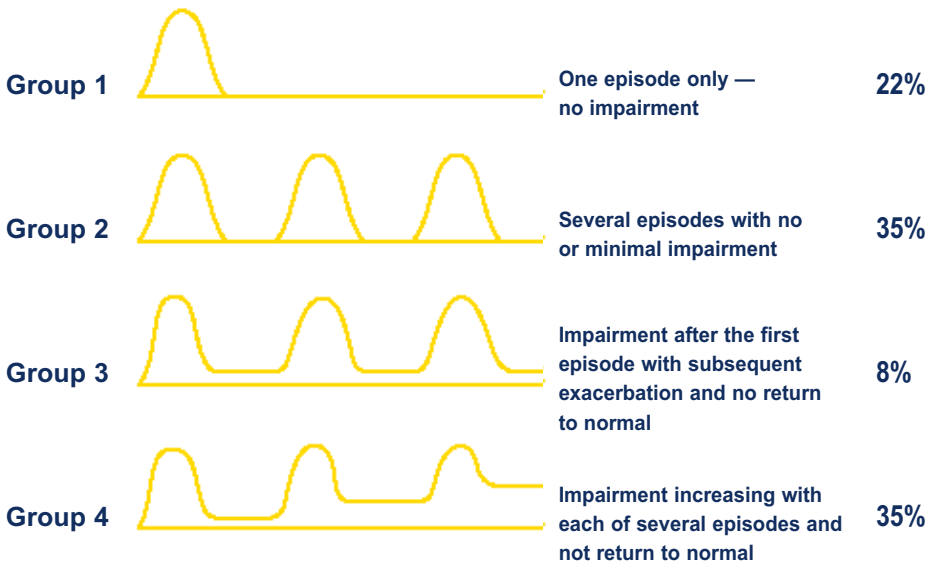
- > The costs to society due to hospitalization, disability payments and lost wages approach 5 billion dollars annually.
- > The cost of losses associated with individual potential, family hardships, and shattered personal hopes and dreams are impossible to measure.

There are Different Outcomes for Different People.

The misconception that people cannot recover from schizophrenia leads to hopelessness and despair. This may cause service providers, friends and families to hold a negative perception towards recovery. BUT, the disorder takes many different courses and varies with each individual.

Some people have episodes of the illness lasting weeks or months with full remission of their symptoms between each episode. People with schizophrenia are not always psychotic! Others have a fluctuating course where symptoms are continuous but rise and fall in intensity. Some people have little variation of their symptoms over time.

At one end of the spectrum the person has a single episode followed by complete recovery. At the other end, there is the illness that never abates.



“Most people don’t understand it is an illness. They say: ‘Can’t you just discipline your thinking?’ But you can’t discipline a virus, cancer or a broken leg.”

Dean Kernohan – violinist with a Music Degree. CONSUMER.

What is Schizophrenia?

Our perception of the world around us is largely shaped by our five senses ... what we see, hear, smell, taste and touch. It is these senses that provide for our base of reality and our sense of self. The way our brain receives and interprets the information picked up by our five senses on a minute-by-minute, hour by hour, and day to day basis is often taken for granted. What if that portion of the brain that we depend upon to perform these functions failed in some way to accurately receive and/or interpret a message or a series of messages? The outcome would be that our reality base would change and the world around us would appear different. The decisions we would be compelled to make based on this changed reality would be different from the decisions made by others. We would not only behave differently we would also appear to be out of step with others around us. In such circumstances we would experience great difficulty in gaining acceptance of others and in being heard and understood. Such is the experience of most persons affected by schizophrenia, a neurobiological illness of the brain, which is often accompanied by severe paranoia and depression.

No definition of schizophrenia can adequately describe all people with this illness. It is an extremely complex mental illness. Schizophrenia is a neurobiological illness, in the same medical cluster as Alzheimer's, Parkinson's, Temporal Lobe Epilepsy, Huntington's etc.

It is clear that schizophrenia is an illness that makes it difficult for the affected person to decide what is real and what is not real, which obviously affects every aspect of the person's life.

It is also clear that this brain disorder can affect normal, intelligent people in all walks of life.

Schizophrenia is characterized by a group of symptoms including hallucinations, delusions, disturbances of thinking, emotion and behavior, and a deterioration of social functioning. Cognitive function is also often severely affected.

SCHIZOPHRENIA

- ...is a real illness (or group of illnesses).
- ...has concrete and specific symptoms.
- ...is different from other mental illnesses.
- ...is the result of flawed brain biochemistry.
- ...may be treated successfully by specific antipsychotic drugs.
 - ...often has a genetic connection.
 - ...in some cases the illness remits.
 - ...is treatable.

With adequate supports (family, medical, social) many people can learn how to deal with the illness and lead productive comfortable lives with hope.

What Causes Schizophrenia?

Scientists are almost certain that schizophrenia has more than one cause, although this is not yet precisely understood.

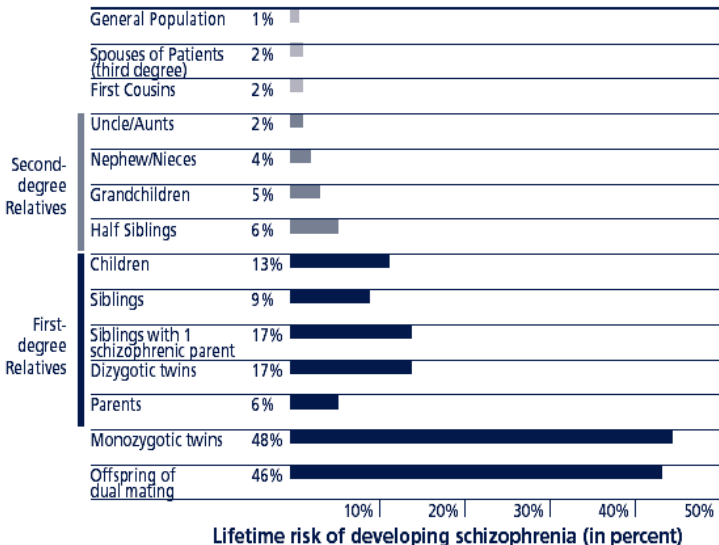
The Genetic Hypothesis

Genetic factors appear to be important in the development of schizophrenia, but they are not sufficient to explain the entire pattern of occurrence. If an illness is entirely caused by genetic factors then identical twins share the same risk of the illness. That is, if one identical twin has the illness, the other should too. In fact, in most studies of identical twins in which one twin has schizophrenia, only about half of the other twins are affected.

A number of genes are probably involved in schizophrenia, known as “hot spots” on a cluster of genes. Researchers believe that a predisposition to develop schizophrenia is inherited, but an environmental “trigger” must also be present to bring the illness to the surface.

These triggers are stress factors experienced at any point of the person’s life. The role of stress is unclear; however, it is acknowledged that stress can trigger or worsen symptoms when the illness is already present. Stress is very individual but could be instrumental when accompanied with an exam, a move, a loss of someone, a difficult relationship etc. to trigger symptoms of schizophrenia if one is genetically or otherwise predisposed to it.

The average risk of developing schizophrenia for relatives of a person with the illness; compiled from family and twin studies conducted in Europe between 1920 and 1987.



Viral Infection

Another strong theory is that a viral infection is responsible for schizophrenia. This viral infection would take place during the second trimester of pregnancy. A virus, somewhat like the flu, invades the child through the mother. This infection could affect brain development. As a result, during adolescence schizophrenia could be triggered.

Neurodevelopmental Problems

Again, as the fetus develops, the development and placement of brain nerve cells is critical. A lack of or misplacement of these nerve cells could result in schizophrenia later in life. The brain is still developing up to and including the period of adolescence.

Birth Trauma

Some researchers feel that schizophrenia may be the result of complications during the mother's pregnancy or labour.

Drug and Alcohol Abuse

A distinction must be made between “*drug/alcohol induced psychosis*,” which may be temporary. Yet, it can trigger full-blown schizophrenia. So, substance use and abuse can trigger schizophrenia if a person is genetically or otherwise exposed to it.

“Research has demonstrated that there is a severe negative interaction between drug and alcohol use and the vulnerable brain, as well as the brain which has already become disordered in its functioning due to mental illness. The special vulnerability of persons who have already developed or are at risk of developing psychiatric disorders is such that even very small amounts of alcohol, drugs or substances may produce severe psychiatric symptom reactions. These symptoms – depression, anxiety and psychotic thought disorder are common and may produce an incorrect psychiatric diagnosis, if the altered state or brain functioning due to the presence of drugs is not taken into account.”

(Bert Pepper, MD, The Journal. “Mentally Ill, Alcohol and Substance Abusers,” Vol. 2, Issue 2.)

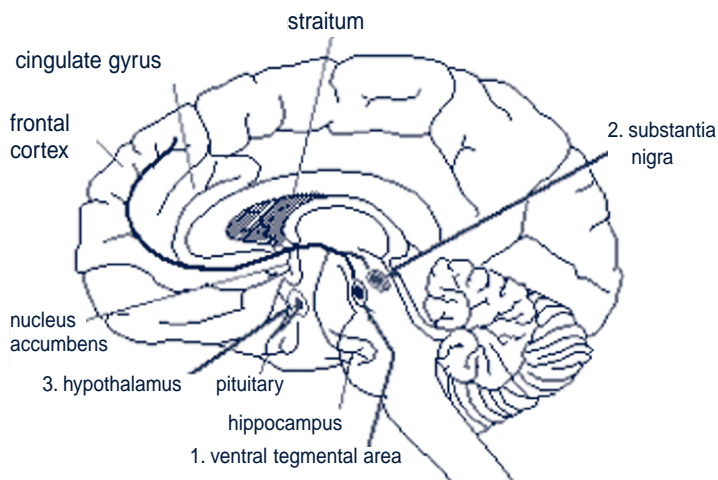
Chemical Brain Imbalance

Research has shown that people with schizophrenia definitely have problems with certain types of brain cells and their function. There are billions of nerve cells (called neurons) in the brain. Each nerve cell has branches that send and receive messages from other nerve cells. Between each nerve cell there are gaps called a synapse. How then do brain signals cross these gaps? That's where NEUROTRANSMITTERS come in. Scientists have discovered approximately 100 neurotransmitters in the brain. These chemicals which are released from nerve branches carry the message from the end of one nerve branch to the cell body of another. In the brain of a person with schizophrenia, something goes wrong with this communication system.

Two neurotransmitters in particular have roles to play in schizophrenia. These neurotransmitters are called DOPAMINE and SEROTONIN. Evidence suggests that there is too much dopamine in certain areas of the brain, and this results in over-stimulation and excess sensory information which causes difficulty with concentration, thought process, reality orientation, feelings and behaviour. New evidence shows that abnormalities in serotonin activity also play an important role in the illness. The effect is that the person has a “sensitive brain” as if the nerve cells were “sandpapered.”

Nutritional Theories

Orthomolecular medicine is the study of the effect of nutritional deficiencies in the body and how these deficiencies in vitamins, minerals and amino acids contribute to sickness. A few doctors feel that mental illnesses are partly the result of such and that diet and vitamin/mineral therapy are an important part of treating schizophrenia. Replicating nutritional studies, however, has been problematic.



Dopamine Pathways in the Brain

1. Ventral tegmental area to frontal cortex.
This is the pathway through which dopamine-blocking drugs are thought to produce their helpful, antipsychotic actions.
2. Substantia nigra to straitum.
When blocked by antipsychotic drugs, this pathway may be responsible for movement disorders/extra-pyramidal side effects.
3. Hypothalamus to pituitary.
Here, dopamine-blocking drugs can cause hormonal imbalances such as menstrual irregularities in women.

Adapted from – Hyman and Nestler: The Molecular Foundations of Psychiatry, 1993

What are the Common Myths Surrounding Schizophrenia?

Schizophrenia is NOT caused by

- ...poverty
- ...poor parenting
- ...domineering mothers and/or passive fathers
- ...childhood experiences
- ...failure, guilt or misbehaviour
- ...“demonic” influence (evil spirits or witchcraft)
- ...“sin” – (God’s punishment)

Myth: Schizophrenia is a split personality or multiple personality disorder.

Fact: Confusion arose because the word “*schizophrenia*” comes from two Greek roots meaning “*split mind*.” This splitting refers to the fragmentation of the individual’s thinking and feeling process, NOT the splitting of the person into two personalities.

The person always had only one personality and will continue to have only one personality.

Myth: Men and women with schizophrenia are mentally “*retarded*.”

Fact: Schizophrenia and mental retardation (now called developmental disability) are entirely different conditions. Schizophrenia occurs in people of all levels of intelligence, often in talented and creative men and women. Schizophrenia does cause some cognitive problems such as poor concentration and difficulty with abstract thinking, however it does not affect overall intelligence.

Myth: Men and women with schizophrenia have to be institutionalized.

Fact: Many people with the illness can be treated in the community with no admission to hospital. Innovative alternatives such as supported living in the community can be highly effective. Even those who are acutely psychotic may be treated in carefully supervised and professionally staffed community settings.

Myth: People with schizophrenia are not able to make decisions about their own treatment.

Fact: Most people with schizophrenia are both able and eager to participate in decision-making about their treatment. They know how they feel when on a certain medication better than anyone else does. However, during the onset of the illness or during a relapse that may occur, the person may experience a degree of lack of insight, and require more help and support. Research shows that patient and family involvement improves outcomes and increases the likelihood of adherence to a treatment plan.

Myth: People with schizophrenia cannot work.

Fact: Several studies show that men and women with major mental illnesses fare better if they work. The ability to hold a job is not necessarily related to the severity of the person's illness. British and American studies have shown that people with schizophrenia are more likely to stay out of the hospital if they are employed at meaningful work. While many people are able to work successfully in full-time employment, for others, part-time, casual or volunteer work are best. Work is a vital part of rehabilitation. It increases self-esteem, reconnects with the community, gives a sense of belonging and provides a meaningful use of time.

Myth: Men and women with schizophrenia are likely to be violent.

Fact: Unfortunately, mental illness and violence are closely linked in the public mind. Sensationalized reporting by the media and motion picture depictions of people with schizophrenia bear much of the blame. However, those with schizophrenia, in general, are no more dangerous than healthy individuals from the same population.

Schizophrenia related violence contributes approximately 1 to 2 % to the overall incidence of crime in the community. Violence and schizophrenia are quite independent of each other. However, for the small group of people with Schizophrenia who commit acts of violence, three factors are involved: 1) They are medically non-compliant when they should receive medication to control symptoms, 2) There is a history of violence or volatile behaviour and 3) There is the use/abuse of alcohol and drugs.

A man or woman with schizophrenia is far more likely to be violent towards him/herself, (self-harm, suicide) than towards others. If a person suffering from the illness is in crisis and feels "cornered" by those aiding him, then he/she may be violent towards the helpers. This is a natural reaction many people would follow. (Therefore, knowledge and education for the public on how to respond to someone in acute psychosis or "crisis" is very beneficial to both parties.)

Myth: Schizophrenia is caused by evil spirits or witchcraft.

Fact: Schizophrenia is a neurobiological illness that has nothing to do with the demonic, a curse or evil eye, punishment for sins, lack of faith in God, or poor spirituality, etc.

Myth: Poor parenting causes schizophrenia.

Fact: Psychiatrists since Sigmund Freud have regarded the family environment as the key factor in the development of the personality. It seemed clear to many that a disturbed individual must be the product of a disturbed family. Under Freud's influence researchers and clinicians identified many traits such as contradictory expectations and covert rejection which supposedly characterized families of people with schizophrenia. These studies were almost always retrospective; they often lacked controls and they failed to consider that family tumult might be the result of, rather than the cause of, the presence of a family member with schizophrenia.

As late as the 1970's, textbooks still blamed "*schizophrenogenic*" mothers for causing their children's illness. Many families have suffered shame, guilt, and stigma as a consequence of the widespread acceptance of such theorizing. There is no evidence to support the theory that family environment causes schizophrenia. There is very strong

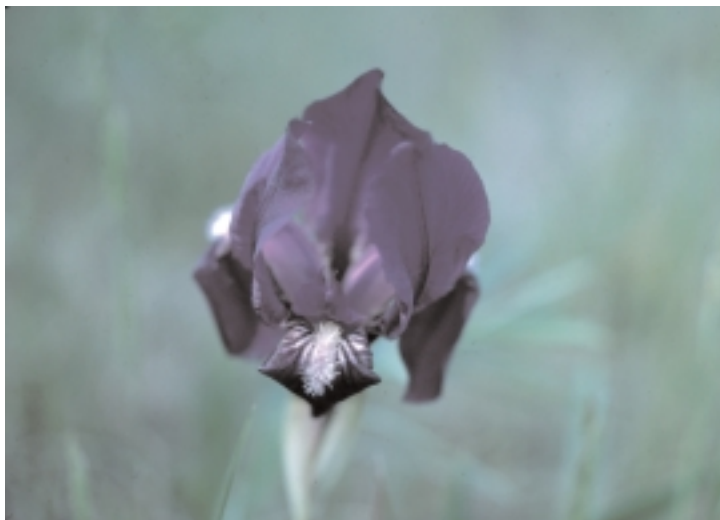
evidence that supports **biological factors as the primary cause**.

Coping with a family member who has schizophrenia is extremely demanding. Many families break up under the strain or abandon their ill family member. Families need empathy and support just as those with schizophrenia do.

TO BE ABLE TO SEE THOSE WITH SCHIZOPHRENIA
AS MEN AND WOMEN, BROTHERS AND SISTERS,
HUSBANDS AND WIVES, WE NEED TO LOOK
BEYOND THE MYTHS, MISCONCEPTIONS AND
PRE-JUDGMENTS THAT CONFUSE AND FRIGHTEN PEOPLE.



In 1994, the Schizophrenia Society of Canada (SSC) chose the iris flower as its national emblem. Throughout folklore the iris has been regarded as a symbol for faith, hope, and courage; one for each set of three petals. The iris was given as encouragement to anyone who was suffering. With time it became symbolized with warriors and soldier kings.



SSC hopes the iris will also serve as a symbol of hope for persons affected by schizophrenia and their families.

What is Stigma and What Causes it?

“Change our thinking and we can change their world”
“One thing I find really hard about my illness is the stigma.”

– Shawna, CONSUMER.

“The worst thing about having schizophrenia is the isolation and the loneliness.”

– Dr. Phillip Long, Psychiatrist

Stigma means “*damage to a reputation.*” It’s the subtle and not-so-subtle shame and ridicule our society places on mental illness. Stigma keeps mental illness in the closet. ***It prevents people from seeking treatment.*** It stifles funding for services and research. Stigma closes minds and fuels discrimination.

Stigma is one of the greatest disablers and challenges of living with schizophrenia. It results in prejudicial attitudes, perpetuates misunderstanding, and leads to discrimination in employment, housing and social supports. Stigma hurts!

In 1996 the World Psychiatric Association embarked on a worldwide program to fight *stigma and discrimination faced by those with schizophrenia.* Stigma attached to schizophrenia creates a vicious cycle of alienation and discrimination for those who suffer from it and often for members of their families. Stigma can become the main cause for social isolation, inability to find work, alcohol and drug abuse, homelessness and excessive institutionalization, all of which decrease the chance of recovery.

What causes stigma? Chris Summerville, Executive Director, Manitoba Schizophrenia Society tells audiences in his presentations on schizophrenia that the formula is a simple one:

$$\begin{array}{c} \text{Lack of understanding (Ignorance)} \\ + \\ \text{Lack of exposure to people with schizophrenia} \\ \times \\ \text{Fear} \\ = \\ \text{STIGMA} \end{array}$$

That’s why public education and awareness about the truth about schizophrenia are most important.

WHY DO PEOPLE FIND MENTAL ILLNESS SO UNACCEPTABLE?

Fear of Danger

Many people are afraid that people who have a mental illness are dangerous, unpredictable and aggressive. The truth is, very few are dangerous. In reality, emotionally and mentally disturbed people are usually anxious, fearful of others and passive. The myth of danger is based on inaccurate and outdated popular culture – false images that often portrayed people with mental illness as violent.

Fear of Criminal Intentions

People with psychiatric disorders are no more likely to commit crimes than the general population. However, if mental illness is left untreated and allowed to become progressively more severe, people who are acutely ill may inadvertently end up in jail. Another common confusion has to do with the nature of involuntary hospitalization, which is sometimes necessary to treat and safeguard someone who is very ill. Hospitalization for medical treatment to regain one's health should never be falsely equated with incarceration in the criminal justice system.

Lack of Insight into Mental Illness may prevent access to help

During acute phases of the illness where paranoia and false beliefs are experienced this is often the time that some affected persons are not willing to voluntarily consent to receive help. This places the family and/or significant others who care about the person in very difficult circumstances as to what to do.

If a person is dangerous to themselves or others or when their condition has deteriorated, as a last resort, the only option left to the family is to lay information before a judge or magistrate to get help for their ill relative. Laying of information by a family member is an extraordinary burden that is very trying and emotionally draining. In no other area of medicine, does a family have to go through such an ordeal! It is not uncommon for the family member laying the information and the ill relative to thereafter experience a very strained relationship. (However it is the correct procedure to undertake by a family/friend who sincerely cares about and wants to help an ill person in these special circumstances. At this time there is no other recourse.)

Note: If a family or another community member wants to further explore the involuntary admission to hospital procedure please call your family doctor or your local mental health centre for specific details!

Fear of the Unknown

People often fear what they do not understand. And when they don't understand, they often make wild guesses. Some cultures believe mental illness is the work of evil spirits, while others believe it is caused by bad blood, poisons, or lack of moral integrity. As people learn more about the real nature of mental illness, many of these harmful beliefs fade.

Aversion to Illness

After hundreds of years, “mental illness” has finally been identified to have a physical base, just like epilepsy, Parkinsonism, or diabetes. But this change from the realm of the witch doctor to the medical doctor doesn’t erase all negative feeling – only lessens it somewhat. The public still has a very strong aversion to hospitals, disease, and doctors.

Better health education programs can help do away with old myths and misunderstandings.

• • •

Giving patients the necessary supports to live in their own communities will also help overcome the general prejudice against people with mental illness.

- > Slang words like “nuts,” “wacko,” “psycho,” and “lunatic” are dehumanizing affronts to people who struggle to cope with symptoms of mental illness.
- > “Schizophrenia,” “manic-depression,” “psychosis,” and “insane” are clinical or legal terms. Such terms need to be checked carefully for accuracy. For example, it is incorrect to call a government “schizophrenic” or to dub a well person’s behaviour as “psychotic.”
- > Labels like “loony bin,” “nuthouse,” and “funny farm” are humiliating to those who require medical help from mental health inpatient facilities.
- > “Psychopathic” is not the same as “psychotic.” Psychosis is an inability to distinguish real from unreal experience, and it generally responds to antipsychotic medication. Psychopath (antisocial personality disorder) describes a pattern of irresponsible and often unlawful behaviour. Psychopathic symptoms do not generally respond to anti-psychotic medication.
- > It is offensive to depersonalize people who have a biologically based disorder. “He has symptoms of schizophrenia” is preferable to “He’s a schizophrenic.”
- > When referring to mental illness, use standards of accuracy and good taste that apply to any serious illness.

“Most people think it’s some kind of Dr. Jekyll and Mr. Hyde thing. Every serial killer and axe murderer on TV is said to have schizophrenia. This kind of ignorance just makes it worse for men and women who live with it.”

Alvin Viera – painter / sculptor
who has lived with schizophrenia for 16 years

“Stigma is harder to deal with than the disease itself.”

– A Consumer

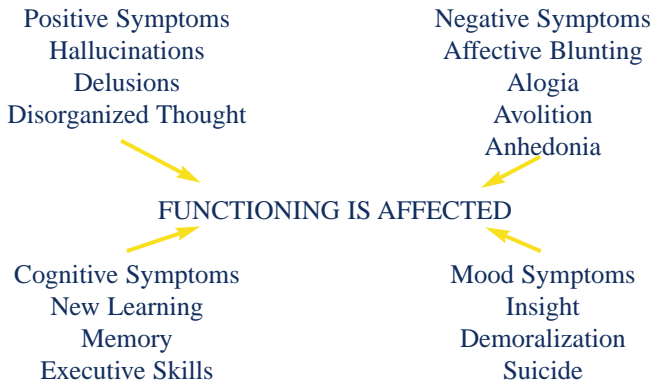
What Are the Symptoms of Schizophrenia?

Schizophrenia always involves deterioration and changes from a previous level of functioning. Family members and friends often notice that the person is “*not the same.*” Without treatment, the symptoms of schizophrenia nearly always get worse!

The person with schizophrenia has difficulty in separating what is real from what is unreal. With the stress and demands of day to day living, the person may withdraw and the symptoms become more pronounced. Deterioration is noticeable in areas such as:

- > Work or academic achievement.
- > How one relates to others.
- > Personal care and hygiene.

Components of schizophrenia



“*Positive*” means something added to the personality that should not be there. “*Negative*” means something taken away from the personality that should be there.

Positive Symptoms

The most common symptoms of the acute or (psychotic) phase, are:

- > Hallucinations – can affect all five senses. People may see, hear, smell, taste and feel things to the touch that are not really there but are very real to the affected person. Most often the hallucination involves hearing voices.
- > Delusions – These are fixed beliefs that have no basis in reality. There may be the false belief of being persecuted or having supernatural powers or being a famous film star. Often there is a connection to religious or technological imagery.

Negative Symptoms

Negative symptoms usually appear before the positive symptoms. They are often not recognized as early signs of schizophrenia and may be confused with adolescence. They include:

- > Social withdrawal and isolation.
- > Lack of motivation and concentration.
- > Difficulties with expressing emotions.
- > Inability to enjoy pleasure.
- > Extreme tiredness.
- > Difficulty with abstract thinking.
- > Poverty of speech (conversation).

Cognitive Symptoms

Disturbed thought process with cognitive deficits is a part of schizophrenia. The person's "*executive skills*" are affected in terms of memory, concentration, decision making and new learning. This may be accompanied by incoherent and illogical reasoning shown by fragmented speech and jumbled talk.

Mood Symptoms

The person experiences depression, lack of insight, demoralization and may struggle with suicidal ideation.

Characteristic signs of schizophrenia may be noticed by family members in several of the following areas (This is known as the prodromal stage of schizophrenia.):

- > Personality changes are keys to recognizing schizophrenia. They may be subtle at first, and difficult to notice. A normally outgoing person may become withdrawn, quiet, moody, inappropriate or aggressive. Emotions (affect) may be altered e.g.: when told a sad story, the person may laugh or there may be no reaction at all.
- > Thought changes. One of the most profound changes is the barrier to clear thinking. Thoughts may be slow in forming (poverty of thought), come extra fast, or not at all. Conversations may jump from topic to topic in an incoherent way, with difficulty reaching easy conclusions.
- > Perceptual changes turn the world of the ill person topsy-turvy. The brain's ability to decode sensory messages from the eyes, ears, nose, skin and taste buds become confused and jumbled, and the person experiences sensations which are not real. (hallucinations)
- > Frequently, people with schizophrenia hear voices in their heads or from outside their head condemning them, making them laugh or giving orders such as "*hang yourself*". There may be hyper-sensitivity to sounds, which appear to be at the very loudest pitch all at the same time. Touch, taste and smell may all be distorted, e.g. feeling there are insects crawling over the skin. Sometimes there is no sensation to touch so the person may not even feel pain and could injure him/herself.

- > Loss of sense of self. When one or all five senses are affected, the person may feel out of time, space, disembodied and non-existent as a person. The person will struggle with identity issues of worth, significance and security.

*THE PSYCHOLOGICAL PAIN OF THESE SYMPTOMS
WILL BE INTENSE, CAUSING FEELINGS OF
PANIC, FEAR AND ANXIETY.*

It's not difficult to understand why the individual who experiences these profound and frightening changes will seek to keep them secret, deny that anything is happening or avoid people and situations where they may be discovered. Never underestimate the impact of stigma around mental illness.

The pain of schizophrenia is further accentuated by the person's awareness of the worry and suffering they may be causing their family and friends.

*THIS IS WHY THOSE WHO SUFFER FROM THIS
COMPLEX AND OFTEN DEVASTATING ILLNESS
REQUIRE SO MUCH UNDERSTANDING, PATIENCE AND
REASSURANCE THAT THEY WILL NOT BE ABANDONED.*

*"I was first diagnosed with schizophrenia when I was 26 years old.
My parents were still there to hug me when I cried. And back then
I cried a lot"*

- Dean Kernohan. 29 yrs old. Orchestral violinist



What are the Types of Schizophrenia?

To make the diagnosis and treatment of schizophrenia easier and more effective, psychiatrists have attempted to classify schizophrenia into several types. These classifications are based on years of experience and research with symptoms and feelings described by patients and observations made by family members, nurses, doctors, and psychiatrists. Since single symptoms of schizophrenia may be caused by other diseases or illnesses, it is most important to seek help early from physicians and psychiatrists.

Before identifying the specific type of schizophrenia, the doctor or psychiatrist should look at the family history and personal history of the person affected, do a thorough physical examination, and order laboratory and x-ray examinations. Once all of the information is analyzed, and if the person has schizophrenia, a diagnosis may be made using one of the following categories of schizophrenia.

Disorganized Type (or Hebephrenic Type)

- > Early symptoms include poor concentration, moodiness, confusion, strange ideas.
- > The person's speech is frequently incoherent, difficult to understand, rambling.
- > Delusions or false beliefs are not well established.
- > The person shows no emotions or they are inappropriate, i.e. silly, giddy laughter.

Paranoid Type

Characterized by extreme suspiciousness, delusions, and/or hallucinations with persecution, or less commonly, an exaggerated sense of self importance. Other features exhibited for no apparent reason may be: anxiety, anger, argumentativeness, jealousy, and occasionally, violence.

Catatonic Type

- > Catatonic stupor (marked decrease in reaction to one's environment) or mutism.
- > Motionless resistance to all instructions or attempts to be physically moved.
- > Maintenance of a rigid or bizarre posture.
- > Excited physical activity which seems purposeless, not influenced by the environment.

Undifferentiated Type

Sometimes the major psychotic symptoms cannot be classified into any category listed, or may match the criteria for more than one type of schizophrenia. This is where the undifferentiated type of category may be used.

Residual Type

This category is used when there is at least one recognizable episode of schizophrenia but no ongoing obvious psychotic symptoms, though less clear signs of the illness continue such as social withdrawal, eccentric behavior, inappropriate emotions and thinking, etc.

What is Schizoaffective Disorder?

(Excerpts from an article by Anne Brown adapted from a NARSAD Newsletter.)

It is one of the most complex illnesses identified by psychiatrists, and its name marries two distinctly devastating neurobiological disorders: Schizoaffective Disorder.

The parent diseases of schizoaffective disorder are schizophrenia and affective disorders, and its chief symptom is a mental state that oscillates between the poles of schizophrenia-like psychosis, and the highs and lows of affective disorders.

Like both of its parent diseases, schizoaffective disorder is caused by an imbalance in the brains' neurotransmitters. Sufferers of this disease experience a combination of symptoms associated with both diseases. To be diagnosed with schizoaffective disorder, an individual must 1) at one time experience both schizophrenia and mood disturbances and 2) experience psychotic symptoms without affective symptoms.

The two major affective disorders are unipolar depression and bipolar disorder. Depressed individuals lose interest in everyday life, feel continually sad or tired. It is often difficult for these individuals to be decisive or to concentrate. Disruptions in normal sleeping or eating patterns occur, and they may have thoughts of death or suicide. Those with bipolar disorder also experience mania. Manic symptoms include an expansive, cheerful and talkative mood, coupled with distractibility and impulsivity. However, mania can easily evolve into irritability, paranoia, and rage.

Patients with schizophrenia appear apathetic and emotionally flat. Their thinking is confused, and they suffer from hallucinations and delusions. While individuals with affective disorders usually appear normal between episodes of illness, and do not become more disabled over time, persons with schizophrenia rarely appear normal, and their conditions usually worsen.

The differences between these two illnesses are hard to decipher. Persons with mania can suffer from delusions and hallucinations, leaving mania often impossible to distinguish from symptoms of schizophrenia. Likewise, apathy in schizophrenia can easily be mistaken for the loss of interest in everyday life that is symptomatic of depression.

What is a Psychosis?

The word psychosis is used to describe medical conditions that affect the brain, where there is loss of contact with reality. When someone becomes ill in this way, it is called a psychotic episode.

Psychosis is most likely to occur in young adults and is quite common. About 3 out of every 100 people will experience a psychotic episode, making psychosis more common than diabetes. Most people make a full recovery from the experience.

Psychosis can happen to anyone. Like any other illness, it can be treated.

What are the Symptoms?

Psychosis can lead to changes in mood and thinking and to abnormal ideas, making it difficult for others to understand how the person feels.

In order to try to understand the experience of psychosis, it is useful to group together some of the more characteristic symptoms.

Disorganized Thinking

Everyday thoughts become confused or don't join up properly. Sentences are unclear or don't make sense. A person may have difficulty concentrating, following a conversation or remembering things. Thoughts seem to speed up or slow down.

Hallucinations

In psychosis, the person sees, hears, feels, smells or tastes things that are not actually there. For example, they may hear voices or see things that aren't there. Things may taste or smell bad, or even can be interpreted to be poisonous.

Delusions (False Beliefs)

It is common for a person experiencing a psychotic episode to hold false beliefs, known as delusion that even the most logical argument cannot make them change their mind. For example, someone may be convinced that because cars are parked outside their house, they are being watched by the police. Someone believing they are Jesus Christ may spend all day preaching in the streets.

Changed Feelings

People's feelings may change for no apparent reason. They may feel strange and cut off from the world, with everything moving in slow motion. Mood swings are common, so they may feel unusually excited or depressed. Emotions may seem dampened, people may feel less than they used to, or show less emotion to those around them.

Changed Behaviour

People with psychosis behave differently than the way they usually do. A person with psychosis usually experiences irrational fears. They may be extremely active, or be very lethargic, just sitting around all day. They may laugh inappropriately, or become angry without apparent cause.

Behavioural changes are often associated with the symptoms described above. For example, a person may call the police or be too scared to sleep because of what they believe they've seen or heard. They may stop eating if they think their food is poisoned. Symptoms vary from person to person and may change over time.



How to Help Someone When Critical Information is Considered Confidential?

Confidentiality law is designed to protect the person with the illness. It is a basic principle in the practice of medicine. However, for some people with a serious mental illness like schizophrenia, who may lack insight into their condition and/or who may present a danger to themselves or others this law can in fact be hurtful. Confidentiality may undermine genuine efforts to help a needy person!

On the other hand, families of ill relatives with schizophrenia also have rights. The information they share with members of the treatment team may also need protection. Families have been known to be seriously hurt when a mental health professional releases information to their ill relative which they wanted (and requested) to be kept confidential.

Even though their hands may be tied because the patient has not given written consent to release his/her information, most mental health practitioners recognize that the psychiatrically disabled persons will need special supports for a long time. Front and centre of that support in the majority of cases is the patient's family, especially if the patient resides with the parents/relatives!

Clinical research has shown that the families involvement is often critical to the success of the community treatment plan. Most families are willing to participate meaningfully in the assessment, treatment provision and monitoring process. However, for reasons often associated with the illness, (e.g. extreme paranoia that the family is part of delusional plot or conspiracy) an individual may not only refuse treatment but also shut-out the family from accessing information that they may desperately need to help and support their ill relative. This gap in information may include the expected course of the illness; references to suicidal ideation; signs of possible relapse; side effects of medication; and methods of dealing with specific crisis at home.

So, what can realistically be done to improve communications between the patient, mental health practitioners and the family? While there is no known shortcut to address the challenge that confidentiality can present to open, and often much needed communication, it is in the best interest of the patient in many cases that special efforts be made to address this concern.

It is clear that in the short term mental health professionals are going to be pressured to be more creative in developing avenues to exchange vital information without violating confidentiality. In the long term these professionals must work hand in hand with families to bring about a legislated solution. One such solution may be to bring interpretations or changes to privacy legislation that would facilitate the involvement of family members as part of the treatment team. Since the treatment team may be provided with necessary and vital information without the patient's permission, the current confidentiality concerns may be greatly reduced.

In the meantime, here are some practical ideas to help facilitate communications without jeopardizing confidentiality laws:

1. Be patient and respectful of one another. (Families should not assume that mental health professionals don't care and the health care providers should always be mindful that families often genuinely need more information and want to be involved).
2. Ideally, written authorization for the doctor/case manager to release information to the family should be obtained when the patient is well enough and willing to provide it.
3. If the patient is unwilling to give consent to release information try asking the doctor whether there is anything you can do to help obtain it.
4. Keep in mind that while the psychiatrist, caseworker or nurse may be prevented by confidentiality laws to provide you with the information you require, there is nothing preventing you to forewarn the doctor, in person or by telephone of some critical information you may have about the patient. (For example, if your ill relative is suicidal or has attempted suicide; has threatened you or anyone else; is armed; or is hearing voices telling him to do harm to others, these concerns should be reported to the doctor as soon as possible.) Through this additional dialogue the doctor may realize that you are already aware of the information that is considered confidential by your ill relative. Such revelations may open up the communications to everyone's benefit.
5. Usually a doctor will tell the family if there is any risk of physical violence to them.
6. Usually one can be reassured that a patient has been admitted or if they are still in hospital by calling the information desk at the local hospital(s).
7. If the attending doctor can't find time to talk to you consider approaching one of the shift nurses assigned to your ill relative. The nursing staff/case managers can usually sense a families genuine interest to help their ill relative through their repeated visits and telephone inquiries. They may be able to reassure you how your ill relative is doing in general. ie. sleeping, eating and adjusting to the ward and treatment. (Sometimes it takes time for the patient to feel better and to be able to accept visitors. Be patient with the staff and your ill relative).
8. Specific questions about medications and their side effects should be addressed to the attending doctor or nurses on the ward. If you are aware of the medication your relative is on you may ask your pharmacist to provide a print out for each medication.
9. For more in depth involvement in the assessment, treatment and recovery of your ill relative ask if you can attend some of the team meetings or consultations with your ill relative. Some patients are more willing to have you attend these meetings than to sign a consent form for release of information.
10. The attending psychiatrist may often look to the family to provide the background history about the patient. At the doctors discretion, this information may be released to your ill relative. When releasing information it is probably wise to assume that the psychiatrist may share this information with others including the patient. That being the case, the family may need to use discretion as to what information it releases if it wishes to protect its relationship with the ill relative.
11. Family members can approach someone/or concerned group to advocate/speak on their behalf.
12. For more general information on schizophrenia, families should contact the local office of the Schizophrenia Society and consider joining a support group.

What are the Early Warning Signs of Schizophrenia?

Family members whose ill relatives have schizophrenia developed the following list of warning signs. Many behaviours described are within the range of normal. Yet families sense that – even when symptoms are mild – there is a vague but distinct awareness that behaviour is “unusual”; that the person is “not the same.”

The number and severity of these symptoms differ from person to person; however, almost everyone mentions social withdrawal. While the following list is very broad, it is not all inclusive or a checklist. It is an attempt to include many variations.

Caution: *Concerned family members, friends and/or significant others should not be attempting to diagnose what the real problem is based on their observation of one or several of the symptoms listed below. Have the person see a psychiatrist or family physician.*

- > Deterioration of personal hygiene
- > Depression
- > Bizarre behaviour
- > Irrational statements
- > Sleeping excessively or inability to sleep
- > Flat, reptile-like gaze
- > Social withdrawal, isolation, and deterioration of social relationships
- > Shift in basic personality
- > Unexpected hostility
- > Hyperactivity or inactivity – or alternating between the two
- > Inability to concentrate or to cope with minor problems
- > Extreme preoccupation with religion or with the occult
- > Excessive writing without meaning
- > Indifference
- > Dropping out of activities – or out of life in general
- > Decline in academic or athletic interests
- > Forgetting things
- > Talking about death or suicide
- > Losing possessions
- > Extreme reactions to criticism
- > Inability to express joy
- > Inability to cry, or excessive crying
- > Inappropriate laughter
- > Unusual sensitivity to stimuli (noise, light, colours, textures)
- > Attempts to escape through frequent moves or hitchhiking trips

- > Shaving head or body hair
- > Drugs or alcohol abuse
- > Refusal to touch persons or objects
- > Strange posturing or fainting
- > Staring without blinking - or blinking incessantly
- > Cutting oneself; threats of self-mutilation
- > Rigid stubbornness
- > Peculiar use of words or odd language structures
- > Sensitivity and irritability when touched by others.

Studies show that families who are supportive, non-judgmental and most especially, non-critical – can do much to help patients recover. On the other hand, patients who are around chaotic or volatile family members usually have a more difficult time, and may have to return to hospital more often.

Since we now know this, it is important for family members to assess their coping skills and try to anticipate and adapt to the ups and downs of the illness. Calm assurance, assistance, and support from family members can make a difference to the person with schizophrenia. The more that families learn about schizophrenia and its impact on their ill relatives and other members of the family, the more prepared they will be to cope more effectively and support the affected persons.

What is Involved in the Treatment of Schizophrenia?

Schizophrenia is a treatable illness! Its precise causes are yet unknown. There is no cure but the symptoms are treatable!

Reintegration into one's community and a better quality of life on the part of persons directly affected by schizophrenia can best be achieved with a *combination of regular intake of medication and an effective community support system.*

1. Role of Medications

The cornerstone of effective treatment of schizophrenia is medication. Medications to treat schizophrenia are called neuroleptics (or anti-psychotics). There are scientifically researched new medications available now that are specifically designed to correct the imbalance of chemicals in the small part of the brain that cause schizophrenia and with fewer side effects.

Recent research has shown that the earlier the person with schizophrenia gets on the right medication, with the correct dosage, the better the outcome! These medications have to be taken regularly as prescribed throughout one's life. In the same way, as patients with diabetes, heart disease, other long term illnesses are required to do.

"There is no way at present to predict who will respond best to which medication". E. Fuller Torrey.

A. Categories of Medications

- i. Typicals** - These are the older or "standard" neuroleptics introduced in the 1950's (Haldol, Modecate, Mellaril, Chlorpromazine etc.).
- ii. Atypicals** - These newer neuroleptics began to be introduced in the 1990's. The atypicals that were available by the end of 1990's included the following: Risperidone (Risperdal), Olanzapine (Zyprexa), Clozapine (Clozaril), and Quetiapine (Seroquel).

The atypicals have less severe (though still unpleasant) side effects, and work on negative as well as the positive symptoms. Often, with the older medications, the person had to take a second medication to control the side effects such as muscle rigidity, tremors, and involuntary movements. Side effects from the newer medications may be nasal congestion, obsessive compulsive symptoms, and impaired glucose tolerance. Side effects can cause the ill person to be reluctant to continue with the medication. Some persons benefit being on injectable medication.

NOTE: For more information on new and other medications ask the attending psychiatrist/physician. The local pharmacist can also be helpful in giving you printed information on medications and their potential interactions with other medications.

B. Reasons for Switching Medication

The rule of thumb is that if a medication works effectively don't fix it! The most common reasons for switching from a standard to an "atypical" Neuroleptic are:

- > Persistent positive symptoms (hallucinations, delusions, etc.) despite taking medication regularly;
- > Persistent negative symptoms (blunted emotions, social withdrawal, etc.) despite medication;
- > Severe discomfort from side effects, little or no relief from the usual side effect medication;
- > Tardive dyskinesia – (Abnormal and voluntary movements which may appear after prolonged treatment with antipsychotics.)

In most cases, switching medications from standard to "atypical" can be done at any time. The person who is ill should give very serious consideration to changing over to another medication and discuss it with their psychiatrist and family. Patients should also be aware that atypical neuroleptics might have side effects of their own, such as weight gain and sexual dysfunction. It's true that the newer medications tend to produce less side effects – but they may still cause some, and need to be monitored.

2. Access to Comprehensive and Efficient Community Services that Provide Continuity of Care

In addition to the regular intake of medications prescribed for the treatment of schizophrenia by a psychiatrist/physician, individuals with this brain illness also need access to an effective continuum of community services that integrate financial, social, educational, vocational, work and housing supports.

The World Health Organization reports that recent studies clearly demonstrate that unmet basic social and functioning needs are the biggest predictors of poor quality of life among individuals with severe mental illness.

3. Role of Families

It is important to note that families also play a vital role in the assessment, treatment, and recovery process of persons with schizophrenia.

Families frequently have the most crucial background knowledge regarding the affected persons general and mental health history, their likes and dislikes, and what experiences and stressors trigger their ill relatives symptoms and so on.

The main sources of emotional, physical and financial support for a person living with schizophrenia that are so integral to the individual's entire treatment process are often families, other caregivers, friends and significant others.

In addition, families have knowledge that is vital for professionals to access and monitor a person's progress and promote the continuity of care!

4. Hospitalization and Regular Follow-Up

When acutely ill, the person with schizophrenia most often requires hospitalization.

This will allow the patient to be observed, assessed, tested, diagnosed and started on medication under the supervision of trained staff. **Most persons needing admission will voluntarily consent for treatment. If they are unable or unwilling to do so, there is a provision under the Mental Health Act where a person can be admitted involuntarily. Ask your family physician or psychiatrist or intake worker at the local mental health clinic about conditions for involuntary admission and laying of information before a judge/magistrate.** Hospitalization protects the patient from injury to self or others, and gives family members a needed break. Once the condition is stabilized and the patient is discharged from the hospital, regular follow-up should be provided by mental health professionals to help reduce the chances of relapse and provide the required support to the patient and the family.

5. Education for Patients and their Families

Patients and their families should learn all they can about all aspects of this illness by reading as much as possible. They should also be directly included in planning the treatment program. Families should know about the types of services that are available in their community including self-help groups, supervised housing, financial support, vocational/work opportunities and recreational programs as their relative will likely require long term treatment and case management.

6. Family Counselling

Family education and support groups have been proven to be extremely helpful. Since the patient and the family are under enormous emotional strain, it would be advantageous to consider regular counselling.

7. Self-Help Groups

Families can be very effective in supporting each other and in advocating for much needed research, public education, and community and hospital-based programs. Ex-patients can also provide a network of support to one another.

8. Nutrition, Sleep and Exercise

Recovery from mental illnesses, as with any physical illness, is aided by well-balanced meals, adequate sleep, and regular exercise. However, schizophrenia type illnesses and the side effects of medication can complicate healthful eating, sleeping and exercising. There can be a loss of appetite or weight gain, lack of motivation, and withdrawal from the normal cues for activity. The person may simply forget to eat, or become very suspicious about food. Isolation from other people and their daily routines can be a constant problem. Supervision of these basic functions may be required, especially if certain foods must be avoided for medical reasons. Be patient, and don't take their carelessness or disinterest personally.

9. Electroconvulsive Therapy (ECT)

Some persons with schizophrenia, like anyone else, can and do experience depression. If their depression persists and does not respond to anti-depressant medication, ECT may be considered by the psychiatrist through discussion and written consent of the patient. ECT is the application of a controlled level of electrical current to the brain under anesthesia.

What About Unwanted Side Effects from Medication?

The following chapter is taken from COPE Consumer Guide, a resource program from AstraZeneca..

Although medications can have great effects, they all come with some risks. This is called the medication's safety profile. Prescribers must sometimes balance the positive effect of medication against any possible harm it might cause. Everyone responds differently to various medicines, so several may be tried to see which is the most effective with the fewest side effects.

Psychotropic medications are relatively safe. However, the safety of their use also assumes that:

- > A proper diagnosis has been made.
- > Other medical conditions that could contribute to or imitate mental illness have been identified, treated, or ruled out.
- > Proper medical follow-up is being done.

Symptoms versus Side Effects

It is unlikely that you will confuse hallucinations and delusions with side effects. However, other symptoms, such as ambivalence, avoiding people, problems with organizing thoughts, or feeling flat, may be harder to characterize. While some of these feelings and behaviours could be medication-related, they may also be negative symptoms of psychosis. Keep your treatment team informed; especially the professionals involved with monitoring your medications.

The following groups are key behaviours or signs to look for and report to your treatment team. This may-or may not-be caused by your medicine. (There are more technical names for these and definitions in the appendix glossary.)

- > Movement irregularities – These could include Extrapryamidal symptoms of muscle spasms or stiffness, slow or exaggerated movements, twitches and facial tics.
- > Sleep or appetite disturbances – Any extreme behaviour in sleeping or eating patterns from too much to too little, a sudden change in your usual sleep/wake cycle or appetite, and fixations about certain types of food (color, smell, etc).
- > Sexual issues – Either inability to have sex or an unusual change in level of desire, problems with or a lack of menstruation, male or female breast engorgement and dripping.
- > Mood problems – Feeling agitated and restless, acting out aggression (throwing things, slamming doors, hitting), verbal abuse (screaming, cursing), and erratic driving, irrational fears etc.

- > Thinking problems – Being unable to change focus (saying the same phrase over and over or constantly repeating the same action).
- > Body changes – Weight gain or loss, constipation, problems urinating, dry mouth or nose bleeds, unexplained changes in vision or hearing, upset stomach, skin rashes, ears ringing, pounding headaches, a racing heart rate, feeling light-headed, and breathlessness.

That's why these medications must be ordered and monitored by a prescribing specialist, usually a psychiatrist. Some medications have mild side effects that often go away in a short period of time. However, more serious side effects are possible. The most common side effects for psychotropic medications are grouped into anticholinergic effects and extrapyramidal symptoms.

Anticholinergic Effects

Anticholinergic effects are caused when a medication interferes with acetylcholine, one of the chemicals the body makes to help nerve cells communicate with each other. Muscles and glands may be affected.

Anticholinergic effects may include:

- > Confusion
- > Blurred vision
- > Constipation
- > Dry mouth and nasal passages
- > Light-headedness
- > Difficulty with urination
- > Problems with bladder control
- > Palpitations

Sometimes these effects lessen as the body adjusts to the psychotropic medication. Many can be managed with small adjustments to the dose. Other nonmedical management methods can include sucking on hard candies for dry mouth or adding more fiber to your diet to relieve constipation.

Extrapyramidal Symptoms (EPS)

There is a network of nerve pathways in the brain known as the extrapyramidal system. This influences messages sent from the brain to the muscles. Certain medications – usually older types of antipsychotics – may disturb this system.

This can lead to:

- > Involuntary movements such as tremors, writhing movements, rigidity, and jerking motions.
- > Problems with muscle tone and making the desired movements – such as slowed movement and rigidity seen with Parkinson's disease.

- > Many consumers do not develop EPS. For those who do, adjusting the medication dosage may solve the problem. If the problem continues, the prescriber may change to another medication or add another medication.

Tardive Dyskinesia (TD)

Another possible side effect involving the extrapyramidal system is called tardive dyskinesia. It is a persistent side effect, that is most often caused by the long term use of the older medications, that does not go away when the medication is stopped. The symptoms which are involuntary jerky muscle movements most often appear in facial movements, e.g., of the mouth, tongue and lips. Sometimes it appears as jerky movements of the limbs, or other muscle systems. The risk of TD increases with age, and with the length a person has taken the TD-triggering medicine.

It is believed that the newer atypical products are less likely to cause TD! As these medications become more common in the treatment of psychosis, EPS may become a less frequent problem.

Other Side Effects

A rare but serious side effect is neuroleptic malignant syndrome. This may occur when the person is experiencing a prolonged episode of rage and is resisting assistance to calm down. This involves unusual muscle rigidity and elevated body temperatures. Vital signs may be unstable, and the person may drift in and out of consciousness. If a person has these symptoms, seek immediate medical attention.

As discussed earlier, side effects related to hormones can include breast enlargement and fluid discharge, impotence, and other sexual problems. There are fewer of these problems with the newer medications.

Some consumers may become light-headed or feel dizzy when they get up from lying down. This is called postural or orthostatic hypotension. Usually getting up slowly and sitting on the edge of the bed for a moment or so before standing can help it.

Early intervention may prevent or lessen these and other serious side effects. Let your treatment team know if you have any problems that might be related to your medicine. Also, the diaries and records you keep can help your treatment team see both your progress and problems.

How Common is Suicidal Behaviour in Schizophrenia and Depression?

Get the Facts

Most of us are uncomfortable speaking about suicide, but it's a topic that we need to deal with openly and honestly.

People who are thinking about taking their lives believe that suicide is the only way to escape the inner pain they are going through. They may be overwhelmed with loneliness, helplessness, and depression, or they may be experiencing a major loss, such as the death of a loved one, losing a job, or the break-up of an important relationship.

Suicide is a particular risk for people with schizophrenia. In fact, it is the main cause of death for people with this illness. The suicide rate among people with schizophrenia is ten times higher than among the general population. Forty percent of people who have schizophrenia attempt suicide, and ten percent die.

Suicide sometimes happens during a psychotic episode, but people with schizophrenia are most likely to commit suicide for the same reasons as anyone else - unemployment, homelessness, social isolation, hopelessness, and depression - all factors that are created by having a mental illness.

Who is most at risk of suicide?

- > People who are depressed or who have strong feelings of hopelessness.
- > People who have attempted suicide before.
- > People who have thoughts of suicide or who are preoccupied with death.
- > People with schizophrenia or another serious mental illness, who are aware of how their illness limits them.
- > Young men who have frequent relapses of their illness.
- > People with a history of substance abuse.

What are the warning signs of suicide?

- > Talking or writing about suicide.
- > Depression or sudden calmness.
- > Getting one's affairs in order, or giving away prized possessions.
- > Hearing voices that talk about doing something dangerous.
- > A previous suicide attempt.

What can families and friends do?

- > Be alert to the warning signs of suicide.
- > Take any talk of suicide seriously.
- > If you think someone is having thoughts of suicide, don't be afraid to talk about it. Bringing up the subject will not cause the person to act upon it.
- > Don't keep weapons or large quantities of drugs in your house.
- > Contact a doctor or other health care professional immediately if someone you know is talking about or attempting suicide. You can also call your local distress line or crisis centre.

Suicide is far more common than people realize. Most people considering suicide have very mixed feelings about ending their life. So by talking about it, you may help the person with suicidal thoughts feel less lonely and isolated. Your support and concern can make a difference.

This information should not be used as a substitute for the advice of a professional. Consult a physician, psychiatrist or a lawyer where legal matters are involved, to discuss your individual facts and circumstances.

(Taken from an article by the Schizophrenia Society of Ontario.)



How Does Schizophrenia Affect Family Members and Friends?

“The typical family of a mentally ill person is often in chaos. The parents look frantically for answers that usually can’t be found. Hope turns to despair, and some families are destroyed no matter how hard they try to survive.”

– Parent of Teen with schizophrenia

When parents learn their child has schizophrenia, they experience a range of strong emotions. They are usually shocked, sad, angry, confused, and dismayed. Some have described their reactions as follows:

- > Sorrow (*“We feel like we’ve lost our child.”*)
- > Anxiety (*“We’re afraid to leave him alone or hurt his feelings.”*)
- > Fear (*“Will the ill person harm himself or others?”*)
- > Shame and guilt (*“Are we to blame? What will people think?”*)
- > Feelings of isolation (*“No one can understand.”*)
- > Bitterness (*“Why did this happen to us?”*)
- > Ambivalence toward the afflicted person (*“We love him very much, but when his illness causes him to be cruel, we also wish he’d go away.”*)
- > Anger and jealousy (*“Siblings resent the attention given to the ill family member.”*)
- > Depression (*“We can’t even talk without crying.”*)
- > Total denial of the illness (*“This can’t happen in our family.”*)
- > Denial of the severity of the illness (*“This is only a phase that will pass.”*)
- > Blaming each other (*“If you had been a better parent...”*)
- > Inability to think or talk about anything but the illness (*“All our lives were bent around the problem.”*)
- > Marital discord (*“We had severe difficulty in sharing feelings and thoughts about the changed family experience.”*)
- > Divorce (*“It tore our family part.”*)
- > Preoccupation with “moving away” (*“Maybe if we lived somewhere else, things would be better.”*)
- > Sleeplessness (*“I’ve aged double time in the last seven years.”*)
- > Weight loss (*“We’ve been through the mill, and it shows in our health.”*)
- > Withdrawal from social activities (*“We don’t attend family get-togethers.”*)
- > Constant uncertainty as to what to do or say next (*“We felt that we were constantly walking on egg shells.”*)

- > Excessive searching for possible explanations (“*Was it something we did or didn’t do to him/her?*”)
- > Increased use of alcohol or tranquilizers (“*Our evening drink turned into three or four.*”)
- > Concern for the future (“*What’s going to happen after we’re gone? Who will take care of our child?*”)

*“My Emotions, inwardly, were at a Fever’s Pitch
and it seemed to me that I was only feeling, not thinking.”*

**“A Sister’s Need” by Margaret Moorman
New York Times, September 11, 1988**

“My sister Sally is mentally ill. Now 47, she was first hospitalized almost 30 years ago, during her senior year in boarding school. Labelled schizophrenic then, she is now diagnosed as having bipolar – or manic-depressive – illness. Generally speaking, schizophrenia causes thought disorders and bipolar illness causes mood disorders. When Sally has been manic, she has given away possessions, become obsessed with elaborate projects, stopped eating and finally, suffered from delusions.

Sally has not worked for pay since 1980, when she was forced to retire from the part-time position she held as a government clerk. For almost two years after losing her job, she lived in various apartments, halfway houses and rented rooms. In 1982, our mother brought her home.

I missed most of the crises of Sally’s 20’s and 30’s. At first, being eight years younger, I was just not old enough to understand or even to pay much attention. As a teenager, I tried to ignore Sally because she was different, and I was afraid of being different myself... I went away to college, after graduating, I moved to Seattle – about as far as one can get from Arlington. I kept in touch by phone, but I visited infrequently.

It isn’t unusual for someone with a chronically mentally ill sibling to try to run away from family tensions. It was only by physically removing myself that I felt I could survive. I was abetted in my escape by my mother, who loved for me to be happy and was, I know, relieved to have one independent child. Unfortunately, like many escapees, I had mixed feelings about it, including guilt and dread.

I once thought that when my mother died I would rather kill myself than have to take care of Sally as she did. It seemed clear: either I would go back home to monitor Sally, or I would fail my sister utterly and be unable to live with myself. It was just a choice of which way to give up my life...”

*“NEVER BECOME A MOTH around the flame of self-blame...
It can destroy your chance of coping, FOREVER.
It can destroy YOU...”*

- Dr. Ken Alexander, 14 Principles for the Relatives

The “Blame and Shame” Syndrome

“People do not cause schizophrenia; they merely blame each other for doing so.”

– E. Fuller Torrey, MD

Unfortunately, there is a common tendency among people with schizophrenia and their family members to blame themselves or to blame one another. Sisters and brothers often share the same worries and fears as their parents.

In the following story, a parent describes “*blame and shame*” from personal experience...

“I have two sons. My older son is 22 and is in an advanced stage of muscular dystrophy. My younger son is 21 and has been diagnosed as chronically mentally ill.

The son who is physically disabled has many special needs. He gets emotional support everywhere he turns. His handicap is visible and obvious and the community, family and friends open their hearts to him and go out of their way to make his life better.

My other son, on the other hand, is misunderstood and shunned by all. He is also terribly disabled...but his disability is not visible.

His grandparents, aunts, uncles and cousins all think that he’s lazy, stupid, weird and naughty. They suggest that somehow, we have made some terrible mistake in his upbringing. When they call on the phone they ask how his brother is and talk to his brother but they never inquire about him. He upsets them. They also wish that he’d go away.”

– Excerpt from *Alliance for the Mentally Ill of Southern Arizona Newsletter*

WHAT FAMILY MEMBERS NEED IN ORDER TO COPE

Time

A good understanding of the illness

Support from others who are experiencing the same challenges

As families learn to share their feelings with each other and with other families, they realize the futility and harm of blame and shame. In this process, many families discover great strength, and deep reserves of love for one another.

Is There Hope and Help for Hurting Family Members?

“Once we began to realize that the ‘afflicted person’ is not the only affected person, it became clear that for any kind of normalcy to be regained (or gained for the first time), EVERYONE in the family system must be seen either part of the problem or part of the solution.”

- Earnie Larsen, from Hidden Victims, Hidden Healers by Julie Tallard Johnson (Social worker whose brother has schizophrenia.)

There is more information about schizophrenia than ever before. And the resources are greater than they have ever been. Support groups and informational meetings are available through many hospitals and the local chapter or provincial office of the Schizophrenia Society.

With a good understanding of the illness and support from others who are experiencing the same challenges, family members can learn to share their feelings and discover healthy coping styles and *“strength for the journey.”*

Family members are important partners within the treatment team working with the person suffering from schizophrenia. They must be as informed as the person who has the illness. This educational process is known as **psychoeducation**. Knowledge and understanding about schizophrenia helps all family members cope more easily. So often the illness is *“hidden”* and that is when false knowledge or myths can be devastating. Yet this stress can be avoided. In addition to psychoeducation, some families will require specific interventions and supports to assist them in coping with their relative’s illness and to equip them with the necessary skills and strengths. There IS support out there. Don’t be afraid to ask!

The Schizophrenia Society of Saskatchewan will endeavour to help you as much as it can. Staff and volunteers will also be there to talk when you have questions. Recognized as a source of help, SSS offers:

- > The latest information on schizophrenia.
- > Trained staff available for one-on-one consultation and public presentations.
- > Support groups for family members.
- > Counsel on how to access mental health services.
- > Guidance concerning the Mental Health Act.

Acknowledgment of lack of knowledge is actually a position of strength. There are many people who do not yet have the knowledge. It is an opportunity to read and learn more about the illness and participate actively in the assessment, planning of treatment, and recovery with your relative’s consent.

How can you look after yourself and other family members?

Maintaining your own personal and emotional health is crucial to helping your ill relative.

1. Be good to yourself

SELF-CARE is very important – even crucial – to every individual, and ultimately helps the functioning of the entire family. Let go of guilt and shame. Remember – poor parenting or poor communication did NOT cause this illness, nor is it the result of any personal failure by the individual.

2. Value your own privacy

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

3. Do not neglect other family members

Brothers and sisters often secretly share the same guilt and fear as their parents. Or they may worry that they might become ill too. When their concerns are neglected, they may feel jealous or resentful of the ill person. Siblings of people with schizophrenia need special attention and support to deal with these issues.

4. GET SUPPORT... Learn From Others Who Have Similar Experience

Check for resources in your community. If you are the parent, spouse, sibling, or child of someone with schizophrenia – it helps to know you are not alone.

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.”*

Knowing where to go and who to see – and how to avoid wasting precious time and energy – can make a world of difference when trying to find good treatment. Continuity of care is also important. Ultimately, this involves ongoing medical, financial, housing, and social support systems. All these services are crucial for recovery – yet they tend to be very poorly coordinated. Support groups can help you start putting the pieces of this puzzle together. They can also advocate for better, more integrated services for people with schizophrenia and their families.

Call the Mental Health Clinic in your community...

Ask about their family education program

Look for family support organizations in your region



JOIN THE SCHIZOPHRENIA SOCIETY OF SASKATCHEWAN!

Note for Aging Parents: Future Plans

Encouraging an adult child to live away from home is a loving positive act, not rejection. For someone with schizophrenia, this can be the first step toward independent living.

Living apart can also mean that the quality of family time spent together is actually better – resulting in less stress for everyone. No one can be on duty 24 hours a day (doing what three hospital shifts do) and also be emotionally involved, without suffering physical and psychological damage.

Remember that schizophrenia does **not** interfere with a person’s intelligence. Believing in the person and their ability to think and do things for themselves is the greatest gift you can give them. If parents continue to “*give their all*” and ultimately burn out, they are of little use to anyone. In addition, the person who is ill ends up unfairly carrying a terrible burden of guilt for such sacrifices.

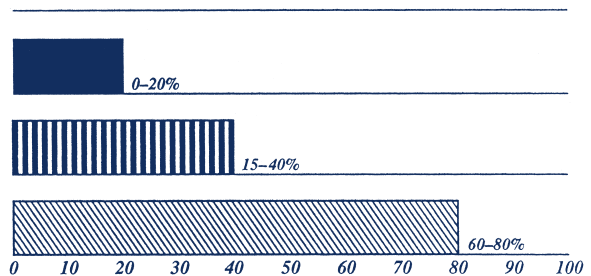
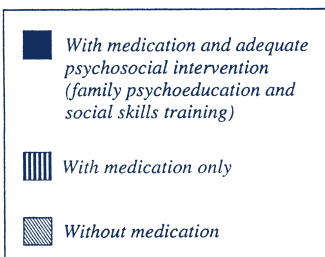
Families must meet their own needs now for the benefit of the ill person in the long run. It is beneficial for all family members to develop their own outside social life – even if it is not large.

It’s always hard to “*let go*”, but to do so **gradually** can be the beginning of a positive move toward adult independence.

Moving away from home is ultimately necessary for all human beings. No matter how loving and capable, parents will become less and less able to provide support as they grow older – and no one lives forever. Thus, it is usually best to establish independent living arrangements at a reasonable age.

It’s a good idea for someone who is ill to try living away from home on an experimental basis at first. If it doesn’t work out, they can return home for a shorter period of time, and then try again. Everyone should be clear that this is just a beginning. That way, if things don’t happen to work out immediately – no one feels the whole exercise was a failure.

Relapse rates and long-term outlook



Relapse rates % at 2 years



How Can Families Obtain Appropriate Help?

“Schizophrenia is not the dreaded disease it was about 30 years ago. Now, with early diagnosis, speedy initiation of treatment, careful monitoring of medication, regular follow-up, proper residential, vocational and rehabilitative support systems in place, the long-term outcome is quite favourable.”

– Psychiatric professional

These two quotes illustrate different “truths” about the present care system for persons with schizophrenia and their families.

Initially, the point of contact for treatment for many will be the medical profession. Another is to call the local mental health clinic and ask to speak to an intake worker.

Many families have difficulty finding a family doctor that has time to assess the onset of symptoms and has an interest in schizophrenia. There is no easy solution to this problem. Quite often the first contact for assistance will be with the intake office at the local mental health clinic, and this person will connect you with a psychiatrist if there is a need to do so!

First of all – schizophrenia can resemble other diseases, so assessment and treatment must involve well-qualified people i.e. psychiatrists and other specially trained persons in mental health. Furthermore, since schizophrenia is a chronic illness, continuing medical care and prescription medications are needed. As prominent psychiatrist Fuller Torrey says, *“There is no avoiding the doctor-finding issue.”*

One way to start is to ask someone in the medical profession who they would go to if someone in their family had schizophrenia. Another way is by talking with other families who have an ill relative. They will often be able to put you in touch with the best resources in your community, and save you a lot of time and frustration. *Sharing this type of information is one of the most valuable assets, and is an important reason to join the Schizophrenia Society of Saskatchewan.*

Besides finding someone who is medically competent, you need to find someone who is interested in the disease, has empathy with its sufferers, and is good at working with other members of the treatment team.

As Dr. Fuller Torrey points out:

“Psychologists, psychiatric nurses, social workers, case managers, rehab specialists and others are all part of the therapeutic process. Doctors who are reluctant to work as team members are not good doctors for treating schizophrenia, no matter how skilled they may be in psychopharmacology.”

Specifically, you need to find a doctor who:

- > Believes schizophrenia is a brain illness;
- > Takes a detailed history;
- > Screens for problems that may be related to other possible illnesses;
- > Is knowledgeable about antipsychotic medications;
- > Involves the patient/person in the treatment plan and maintains regular follow-up;
- > Adjusts the course of treatment when necessary;
- > Reviews medications regularly;
- > Is interested in the patient’s entire welfare, and makes appropriate referrals for aftercare, housing, social support, and financial aid;
- > Explains clearly what is going on;
- > ***Involves the family in the treatment process.***

In order to get enough information to make informed decisions, you will have to ask the doctor some direct questions: *What do you think causes schizophrenia? What has been your experience with the newer medications like Risperidone, Clozapine, Seroquel, or Olanzapine? Is there help available to find a place for my ill relative to live in, be involved in vocational/work programs and social/recreational programs? Can someone help us attain financial assistance for our ill relative?*

If you are uneasy or lack confidence in the medical advice you receive, remember – you do have the right to ask for another opinion, even if this involves travelling to another community.

How Can Family Members Make a Positive Impact?

“... a good family environment can be a major factor in improving the chances of stabilizing the disease and preventing serious relapses.”

– Dr. Ian Fallon, et al.

*“Compassion follows understanding.
It is therefore incumbent on us to understand as best as we can.
The burden of disease will then become lighter for all.”*

- E. Fuller Torrey, MD.

The family can play an important role in all aspects of helping someone with schizophrenia. If you are concerned about schizophrenia in your family, you will want to be aware of some basics.

1. Learn to Recognize Symptoms

When unusual behaviour is experienced or observed, it makes good sense to seek advice from a doctor. An acute episode may happen suddenly, or symptoms may develop over a period of time. The following symptoms are important:

- > Marked change in personality
- > A constant feeling of being watched
- > Difficulty controlling one's thoughts
- > Hearing voices or sounds others don't hear
- > Increasing withdrawal from social contacts
- > Seeing people or things that others don't see
- > Difficulties with language – words do not make sense
- > Sudden excesses, such as extreme religiosity
- > Irrational, angry, or fearful responses to loved ones
- > Sleeplessness and agitation

These symptoms, even in combination, may not be evidence of schizophrenia. They could be the result of brain injury, drug use, or extreme emotional distresses (a death in the family, for example). The crucial factor is the ability to turn off the imagination.

2. Get Proper Medical Help

> ***Take the initiative.***

If symptoms of schizophrenia are occurring, ask your doctor for a mental health/psychiatric assessment or referral. Family members are usually the first to notice symptoms and suggest medical help. Remember, if the ill person accepts hallucinations and delusions as reality, they may resist treatment.

> ***Be persistent. Find a doctor who is familiar with schizophrenia.***

People who are well qualified should do the assessment and treatment of schizophrenia. Choose a physician who has an interest in the illness, who is competent and has empathy with patients and their families. Remember – if you lack confidence in a physician or psychiatrist, you always have the right to seek a second opinion.

> ***Assist the doctor/psychiatrist.***

Patients with schizophrenia may not be able to volunteer much information during an assessment. Talk to the doctor yourself, or write a letter describing your concerns. Be specific. Be persistent. The information you supply can help the physician towards more accurate assessment and treatment.

> ***Other sources of assessment and treatment.***

Saskatchewan Health is the government department responsible for mental health services in Saskatchewan. Assessment and treatment are available through regional mental health centres throughout the province. ***Ask to speak to an intake worker!*** Check your phone book, or call the Schizophrenia Society of Saskatchewan to identify a mental health centre nearest you.

TIPS FOR MAKING FIRST CONTACT

A) Rehearse before you call.

State what you need clearly and briefly.

Make a note of the names of the people you talk to, along with the date and approximate time.

B) If you cannot get the help or information you need ask to speak to the intake worker, a case manager, supervisor, or the person in charge.

C) If you cannot immediately reach the doctor or case manager ask when you may expect a return call, or when the person will be free for you to call back.

3. Making the Most of Treatment

There may be exchanges between doctor and patient that the patient feels are of a highly personal nature and wants to keep confidential. However, ***family members need information related to care and treatment.*** You should be able to discuss the following with the doctor:

- > Signs and symptoms of the illness
- > Expected course of the illness
- > Treatment strategies
- > Signs of possible relapse
- > Suggestions for family to assist in the treatment process

Provide plenty of support and loving care.

Help the person accept their illness. Try to show by your attitude and behaviour that there is hope, that the illness can be managed, and that life can be satisfying and productive.

Help the person with schizophrenia maintain a record of information on:

- > Symptoms that have appeared
- > All medications, including dosages
- > Effects of various types of treatment

4. Learn to Recognize Signs of Relapse

Family and friends should be familiar with signs of “relapse” – where the person may suffer a period of deterioration due to a flare up of symptoms. It helps to know that the same signs of relapse often recur for an individual.

These signs vary from person to person, but the most common signs are:

- > Increased withdrawal from activities
- > Deterioration of basic personal care

You should also know that:

- > Stress and tension make symptoms worse
- > Symptoms often diminish as the person gets older
- > Symptoms can be worsened with the use of street drugs and/or alcohol

5. Managing from Day to Day

Ensure that medical treatment continues after hospitalization.

This means taking medication and going for follow-up treatment, and utilizing community supports and services.

Provide a structured and predictable environment.

The recovering patient will have problems with sensory overload. To reduce stress, keep routines simple, and allow the patient time alone each day. Try to plan non-stressful, low-key regular daily activities, and keep “big events” to a minimum.

Be consistent.

Caregivers should agree on a plan of action and follow it. If you are predictable in the way you handle recurring concerns, you can help reduce confusion and stress for the person who is ill.

Maintain peace and calm at home. Disorganized thoughts are a great problem for many people with schizophrenia. 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 more in the long run. People with schizophrenia 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 illness undermines a person's confidence, initiative, patience, and memory.

Help the ill person set realistic goals. People with schizophrenia 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. If goals are unreasonable, or someone is nagging, the resulting stress can worsen symptoms.

Gradually increase independence. As participation in a variety of tasks and activities increases, so should independence. Set limits on how much abnormal behaviour is acceptable, and consistently apply the consequences. Some relearning is usually necessary for skills such as handling money, cooking, and housekeeping. If outside employment is too difficult, try to help the person plan to use their time constructively.

Learn how to cope with stress together. Anticipate the ups and downs of life and try to prepare accordingly. The person who is ill needs to learn to deal with stress in a socially acceptable manner. Your positive role-modelling can help. Sometimes just recognizing and talking about something in advance that might be stressful can also help.

Encourage your relative to try something new. Offer help in selecting an appropriate activity. If requested, go along the first time for moral support.



How Can Professionals Be Helpful To Families in Distress?

(Psychiatrists, Medical & Community Support Staff)

Professional awareness of family pain, the objective and subjective burden, and stages of coping etc.: will clarify many family reactions and avoid the family being misunderstood. This understanding approach helps make families feel validated and respected.

Be sensitive to these four key factors:

Situational: What is taxing the family's emotional and practical resources?

Personal: What are the family's strengths, resources, skills, and effective ways of coping?

Social Networks: Where can the family find respite, friends, other professional resources and peer support?

Service System Support: What are the needs for crisis intervention, supportive services, housing and financial assistance?

With this assessment in hand, professionals can be much more confident that their interventions and service plans will be “on target” e.g. they will lessen the family burden, meet family needs, and address and solve REAL problems. If these key points are regularly reviewed, this will help families adjust to the long-term demands of serious and persistent mental illness.

(Extract from “What Hurts/What Helps?” NAMI Family- to-Family Education Program)

WITH THE RIGHT SUPPORT COMES HOPE

“I had just received my college degree in English when I was diagnosed with schizophrenia 18 years ago. For a long time I couldn't concentrate enough to read. But with my new medication, I can read again. I play the viola and love the Bach cello suites.”

– Elizabeth MacDonell, B.A. in English Literature

Are There Any Questions Left to Answer?

**PEOPLE HAVE QUESTIONS ABOUT SCHIZOPHRENIA.
NO QUESTION IS TOO SIMPLE - EACH ONE IS WORTH ASKING.**

1. Q. Is there a test for schizophrenia?

A. No. To make a diagnosis of schizophrenia, the doctor must rule out other potential causes with the same symptoms (tumor, trauma to brain, side effects of certain medications, drug/alcohol-induced psychosis, thyroid disease, etc.). Once there is a cluster of negative symptoms for six months with a two-week period of hallucinations and/or delusions, a diagnosis of schizophrenia may be made. Often, it takes a long period of time to make an accurate diagnosis.

2. Q. Can a person with schizophrenia ever recover completely?

A. Yes. There is evidence of people who have completely recovered from this illness with help from medication, psychosocial rehabilitation, psychoeducation, and recovery/empowerment training. At the least, many people can learn to manage their lives well around the illness.

3. Q. Why do some people stop taking their medication?

A. When a person's symptoms improve due to taking medication, or increased awareness of the stigma surrounding the illness may result in stopping the medication.

Some of the side effects of medication are severe. If these side effects interfere greatly with a person's life then he or she may choose to stop taking the medication.

4. Q. I have heard that there are side effects from the antipsychotic medications. Is this true?

A. Yes. These can include movement disorders, weight gain, some sexual dysfunction, drowsiness, loss of appetite or increased appetite, dry mouth, or difficulty sleeping. Each person is individual and will not experience all of these side effects. Different medications can cause different side effects. Discussion with your psychiatrist about each medication would be helpful.

5. Q. Can a person with schizophrenia live on his or her own?

A. Yes. With supported and supportive housing and adequate community supports in place, many people with schizophrenia are living alone in the community. Unfortunately, one of the major roadblocks is the lack of quality, affordable housing for the mentally ill, who often live on disability income.

6. Q. The doctor says that he can't talk with us about our son's case because of confidentiality laws. What are we supposed to do?

- A.** Confidentiality laws do not preclude a doctor from sitting down with the family and answering their general questions about diagnosis, prognosis and his/her philosophy of treatment. The doctor can give you much information which will help you understand what he/she does to treat schizophrenia. The family in return can provide the psychiatrist with pertinent information about their ill relative that will help in the assessment, treatment and recovery of the affected person. (Refer to section on confidentiality for more details.)

7. Q. Why didn't I learn this information earlier on when my daughter was first diagnosed?

- A.** When crises occur, the family may not ask all the pertinent questions or seek the answers they need and deserve. Unfortunately, for a variety of reasons, doctors do not have time to talk with both patients and families. As well, many doctors are remiss in referring families to other resource information such as the Schizophrenia Society.

8. Q. What are the signs of relapse?

- A.** Signs will differ according to each individual, but the most commonly reported signs are: sleeplessness for several nights in a row, the mind "playing tricks" on the person, increased social withdrawal from activities, and deterioration of basic personal care. Stress and tension make the symptoms worse.

9. Q. What are the chances of developing schizophrenia?

- A.** There is no way of knowing exactly who will get schizophrenia. About 1 in 100 persons worldwide will develop the illness. Since schizophrenia tends to run in families, your chances may be higher if someone in your family has the illness.

Risk factors are:

- | | |
|---|-----|
| Parent, brother or sister with schizophrenia | 10% |
| Both parents or an identical twin have schizophrenia | 40% |
| Grandchild, niece, nephew, uncle or aunt with schizophrenia | 3% |

10. Q. Can children develop schizophrenia?

- A.** Yes, but it is very rare. Most people with schizophrenia do not show recognizable symptoms until adolescence or early adulthood.

11. Q. Can schizophrenia be avoided?

- A.** There is evidence from early intervention studies that if you catch the prodromal symptoms early before a psychotic break and treat with medication immediately, that the person may never develop full-blown schizophrenia. This is why early recognition and timely intervention/ treatment are most important. Thus, it is important to educate school guidance counselors, youth workers, parents and general practitioners about early warning signs of schizophrenia.

12.Q. I have schizophrenia. What are the chances of my child developing schizophrenia?

- A. 10% chance. If both you and your partner have schizophrenia then the chance of each child developing the illness increases to 40 per cent.

13.Q. Do street drugs ever cause schizophrenia?

- A. Yes. Any form of cannabis (marijuana), cocaine/crack, LSD, PCP or amphetamines may trigger an episode of schizophrenia if one is genetically or otherwise predisposed to it. One can also develop drug or alcohol induced psychosis which looks like schizophrenia, but is short-term. The best bet is to stay away from street drugs altogether and to use alcohol in moderation.

14.Q. My friend has schizophrenia. How can I help?

- A. We all need friends who stick with us through good times and bad times. People with schizophrenia will value your friendship. They are often discriminated against by those who are ignorant about the illness. Many people with schizophrenia are intelligent worthwhile friends. Unless someone is experiencing symptoms of the illness, there will be nothing especially unusual about their behaviour.

You can be a real friend by trying to understand the illness and by educating yourself and others when the opportunity arises. Let your friends know the facts. Also, if you can, try to get to know the sick person's family. The family might be able to help you understand how your friend may sometimes be overwhelmed and discouraged because of the chronic and persistent nature of the illness. Once you know this, you can help by being supportive and encouraging during rough times.

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

- > People with schizophrenia need to keep to a fairly regular schedule.
- > They need plenty of sleep and rest.
- > Communication should be simple, clear, succinct and often repetitive.
- > Using street drugs and abusing alcohol are very dangerous because they can trigger a return of symptoms (a relapse).

15.Q. I understand communication is very important. Can you give me some principles to use when communicating with my daughter who has schizophrenia?

- A. Many of the communication problems experienced with the person who is ill may be directly linked to his or her symptoms of schizophrenia. Cognitive deficits in such areas as impaired concentration, difficulty reaching conclusions (known as deductive reasoning), and memory are common. Delusions and hallucinations also interfere with communication. Due to the stimulation of hearing voices and distracting sounds, the person may take longer to answer questions or to enter into a conversation.

Negative symptoms may include blunted affect (person's face does not indicate the emotion he or she is feeling) poverty of speech (not having much to say), anhedonia (not being able to experience pleasure), and apathy (not caring about what happens). All these symptoms make it difficult to get an accurate understanding of how the person is thinking and feeling.

Here are some things to remember when communicating:

- > Get to the point. Keep communication brief, direct, focused and on topic.
- > Express your feelings directly and specifically. Subtle, clues (like facial expressions) may be lost.
- > Use praise effectively. The person is painfully aware of their limitations.
- > Listen carefully and be patient. Don't rush the conversation.
- > Speak in a calm voice.
- > Do not speak rapidly.
- > Repeat, repeat and repeat.
- > Ask questions when you don't understand or repeat back what you have heard to check it is correct.
- > Avoid standing too close to the person.
- > Remember you can't out-argue schizophrenia symptoms.

16. Q. What do I need to know about the Mental Health Act in Saskatchewan?

- A. Due to a chemical imbalance that affects the brain, many people who become acutely ill with schizophrenia are unable to recognize their illness. That may mean that they may be unable to access, accept and use voluntarily available treatment – because of the very nature of their disability. The Mental Health Act makes provision for a person to receive needed treatment even when they will not agree voluntarily.

Early treatment and stabilization on medication greatly improves the prognosis for people with schizophrenia. Many people can now, with timely and adequate treatment and support, live satisfactory lives in the community.

Involuntary hospitalization of people who are too ill to care for themselves should never be falsely equated with incarceration in the criminal justice system. To do so not only adds to outmoded stigma and prejudice about people with mental illness – it also deprives them of their fundamental right to proper medical treatment and care. Unfortunately, such confusion is common. As a result, there are already far too many people with severe and chronic brain illnesses such as schizophrenia who have “*fallen through the cracks*” of the system and are abandoned, because they are not well enough to seek treatment for themselves.

It is tragic that people who are severely ill and for whom effective treatment is available if they are unable to access the help they need. Furthermore, suicide rates among this population are alarmingly high. For example, 40% of all people with schizophrenia will attempt to commit suicide – and 10 to 13% will die.

If we do not advocate for the essential right to treatment under the Mental Health Act, this situation will worsen.

“The purpose of the Health Act is to help people who are suffering receive the medical treatment and care they need and deserve so that they can regain health.”

17. Q. What do I do if I come face to face with schizophrenia at school, work, and church or in the community?

A. The answer is simple:

Arm yourself with the facts

Today, many men and women diagnosed with schizophrenia are in school, at work, and are parents and spouses. The winner of the 1994 Nobel Prize for Mathematics, John Nash, has lived with schizophrenia for thirty years. By providing a supportive environment along with treatment, we can enable people who experience the illness to be productive members of our community. Persons with schizophrenia report that consistent support from parents, friends, medical professionals, clergy and teachers is a major factor in their rehabilitation.

Let others know that ignorance hurts

Slang words like “nuts”, “wacko”, “psycho” are dehumanizing affronts to men and women who struggle to cope bravely with symptoms of mental illness.

It is offensive to depersonalize people who have a biologically based disorder. “*He has schizophrenia*” is preferable to “*He’s schizophrenic*”.

It is incorrect to call a situation “*schizophrenic*” or to dub a well person’s behaviour as “*psychotic*”.

Remember a person with schizophrenia is a person with a family, talents, hopes and dreams. They could have the flu- they don’t; they have schizophrenia.

Bring the Illness into the Open

Discuss schizophrenia in class. This will help dispel myths and reduce the stigma and injustice associated with the illness. Provide information on precipitating factors such as drug abuse.

Be Alert to Early Warning Signs

Young people are sometimes apathetic, isolate themselves, have mood swings or experience declines in athletic or academic performance. If these things persist you should talk to the family and help the student receive an appropriate assessment.

Ask for a member of the Schizophrenia Society of Saskatchewan to come to your school, church, workplace, community club or any other setting, to give a talk on all aspects of the illness of schizophrenia. This may help put the illness in perspective and dispel the fears. All presentations are free of charge.

The above information is beneficial for everyone (counselors, employers, guidance and resource teachers, clergy, educators, families, police, community nurses, people working with the general public – the list goes on and on).

Most of all it is beneficial for the men and women suffering from schizophrenia that others have knowledge and understanding about the illness.

*“One night the police pulled me over for expired plates on my car.
It was dark. The lights were flashing. I was terrified and shaking.
I was so scared I couldn’t speak. He accused me of being uncooperative.*

*I managed to say that I had schizophrenia.
He said ‘What does that have to do with anything?’”*

– Elizabeth Anderson. Teacher, married for six years

*“It seems that I am fragile,
As a field of wheat,
And even when I sway,
Heavy in the wind
Because my roots are still there,
I can begin again.”*

- Stephen Yoke 1992



Where Can I Find Resource Material About Schizophrenia?

The Schizophrenia Society of Saskatchewan Inc. has a wide range of current literature in the form of pamphlets, videos and books at the provincial office:

Schizophrenia Society of Saskatchewan
400 Broad Street, P.O Box 305
Regina, Saskatchewan S4P 3A1
Phone: 1-306-584-2620
Fax: 1-306-584-0525
E-mail: sssprov@schizophrenia.sk.ca
Website: www.schizophrenia.sk.ca

SUGGESTED READING (a cross section of books available at SSS Inc.)

Reference Books

“Surviving Schizophrenia: A Manual for Families, Consumers and Providers”. Dr. E. Fuller Torrey, MD. Harper & Row. New York. 2001.

“Brave New Brain”. Nancy C. Andreasen, M.D., Ph.D. Oxford University Press Inc. 2001.

“Madness in the Streets: How Psychiatry and the Law Abandoned the Mentally Ill”. Real Jean Isaac & Virginia C. Aramt. Collier MacMillan, Inc. 1990.

“Out of the Shadows”. Dr. E. Fuller Torrey, MD. John Wiley & Sons Inc., New York. 1997.

Self-Help Books

“I Am Not Sick - I Don't Need Help”. Xavier Amador & Anna-Lisa Johnson. Vida Press. 2000.

“The Secret of the Brain Chip” Marc De Hert, Geerdt Magiels, Erik Thys. EPO. 2002.

“When Madness Comes Home”. Victoria Secunda. Hyperion. New York. 1997.

“When Someone You Love has a Mental Illness: A Handbook for Family, Friends, and Caregivers”. Rebecca Woolis, M.F.C.C. Tarcher/Putnam. 1992.

“Feeling Good”. David Burns, M.D. Avon Books. 1980.

“Schizophrenia: Straight Talk for Families and Friends”. Maryellen Walsh. Warner Books. 1985.

“Living and Working with Schizophrenia”. Jeffries, Plummer, Seeman & Thornton. Revised 1990. University of Toronto.

“Hidden Victims, Hidden Healers”. Julie Tallard Johnson MSW. Doubleday. 1998.

Children's Books

"*Is Dad Crazy*". Jan Liddicut. Buttercup Books Pty Ltd. 1989.

"*Children with Schizophrenia*". Capital Health Glenrose Rehabilitation Hospital. 1995.

"*Catch a Falling Star*" - a tale from *The Iris the Dragon series*. Gayle Grass. Dollco Printing. 2001.

"*Edward the Crazy Man*". Marie Day. Annick Press Ltd. 2002.

"*Someone in My Family has a Mental Illness*". Lyne Brindamour, MSW. The Family Services North Shore. 2000.

"*He Was Still My Daddy*". Laurie Samsel Olson. Ogden House Publishing Co. 1994.

"*The Girl With the Crazy Brother*". Betty Hyland. Franklin Watts. 1987.

Teachers

"*Just Ask*" by Dr. Howard S. Davidson and SSS Inc. 2002.

"*Reaching Out: The Importance of Early Treatment*" by S.S.C. Inc. 2003.

"*Schizophrenia: The Great Disabler of Young People*" by SSS Inc., Partnership Program. 2002.

Personal Stories

"*The Last Taboo*". Scott Simmie M. McLelland and Stewart Ltd. 2001.

"*Beyond Crazy*". Julia Nunes & Scott Simmie. McLelland and Stewart Ltd. 2002.

"*My Crazy Life How I Survived My Family*". Allen Fleming & Kate Scowen. Annick Press. 2002.

"*Beautiful Mind*". Sylvia Nasar. Simon & Schuster. 1998.

"*The Shell People: My Story of Schizophrenia*". Sharon Mercato. 1992.

"*The Quiet Room: A Journey Out of the Torment of Madness*". Lori Schiller & Amanda Bennett. Warner Books. 1994.

"*The Family Face of Schizophrenia*". Patricia Backlar. Tarcher/Putnam. 1994. Nine stories of families and the U.S. mental health system with commentaries by mental health professionals.

"*Tell Me I'm Here*". Anne Deveson. Penguin. 1991. The story of Anne's son Jonathan.

"*I Know This Much Is True*". Wally Lamb. Regan Books/Harper Collins. 1998.

SUGGESTED VIDEOS (available in the Society library)

“Working Together - Things Can Get Better”. Janssen Ortho Inc. 2000.

“The Bonnie Tapes: Recovering from Mental Illness” 27 mins.

“The Bonnie Tapes: My Sister is Mentally Ill” 22 mins.

“The Bonnie Tapes: Mental Illness in the Family” 20 mins.

Mental Illness Education Project. 1997.

“After the Tears: Teens talk About Mental Illness in Their Families”. United Mental Health Inc. 1987.

“Families Coping With Mental Illness”. Mental Illness Education Project.

“First Break” The first episode of mental illness in a person’s life. National Film Board of Canada. 51 min. 1997.

“I Love You Like Crazy”. Mental Illness Education Project. 1999.

“Living With Schizophrenia: A Patient’s Guide to Compliance”. Eli Lilly Inc. 1989.

“Schizophrenia: The Great Disabler of Young People”. SSS Inc. 2002.

“Shattered Dreams”. National Film Board of Canada. 1989.

“Stranger in the House” Heartland Motion Pictures Inc. and SSS Inc. 1992.

“What You Should Know ... Living with Schizophrenia”. Bill McPhee, Editor. Magpie Publishing Inc. 60 mins., 1997.

“It’s Just Different - Childhood Schizophrenia”. Capital Health Glenrose Rehabilitation Hospital. 1997.

“A Journey Through Turbulence: Impact of Schizophrenia on the Family”. Dr. Sylvia Geist., North York, Ontario, 1994.

“DAD”. Chris Triffo. Partners in Motion, Regina, Saskatchewan. 1997.

“Negative Symptoms of Schizophrenia”. Janssen-Ortho Inc. 1995.

“No Place to Go”. National Film Board of Canada. 1989.

“Reaching Out - The Importance of Early Treatment”. SSC. 2003

“Recovery as a Journey of Love”. Schizophrenia Society of Alberta.

“Schizophrenia: Stolen Lives Lost Minds”. Discovery Channel.

“What You Really Need To Know About Schizophrenia”. Medical Audio Visual Communications Inc., Toronto, ON. 1996.

“When Someone You Know has Schizophrenia”. Medical Audio Visual Communications Inc., Toronto, ON. 1996.

NOTE: The library of the Schizophrenia Society of Saskatchewan is updated on an ongoing basis with new books and videos. These resources can be borrowed or purchased through the provincial office or one of the society’s chapters.

What Do Those Words Mean? (Glossary)

This glossary gives brief descriptions of some of the medical terms used in this booklet. It also includes other words that you may hear when talking to members of your treatment team or in reading about mental illness.

Acute Schizophrenia (a-cute skiz-o-fre-ne-ah) – the shortest and most intense period of schizophrenia when the most serious symptoms are found.

Affective Disorder (ah-feck-tiv dis-or-der) – a mental disorder in which the main symptom is an abnormal mood; usually depression or elation.

Affective Flattening – limited range and intensity of emotional expression. A “negative” symptom of schizophrenia.

Agranulocytosis (ah-gran-yu-lo-si-to-sis) – a serious condition in which white blood cells decrease in number or disappear altogether. This can be a side effect of some antipsychotic medications.

Akathisia (ak-ah-thez-e-ah) – the medical word for extreme restlessness. This may include rocking from foot-to-foot, walking in place, pacing, or an inability to sit still.

Akinesia – a state of reduced movement; lack of muscle movement.

Alogia (ah-lo-jee-ah) – lack of fluency and productivity of thought and speech. A “negative” symptom of schizophrenia.

Amenorrhea (a-men-o-re-ah) – absence of menstrual periods. This can be a side effect of antipsychotic medications.

Anhedonia (an-he-do-ne-ah) – an inability to enjoy activities that normally give pleasure.

Anticholinergic (an-te-kol-ih-ner-jik) – blocking the action of acetylcholine, one of the chemicals the body makes to help nerve cells communicate with each other. This describes a group of the most common side effects of psychotropic medications, including dry mouth, blurry vision, palpitations, and constipation.

Antidepressant (an-te-de-pres-ant) – medication used to treat depression.

Antipsychotic (an-te-si-kot-ik) – medication used to treat psychosis. (See psychosis).

Apathy – lack of interest which leads to lack of motivation.

Anxiolytics (ang-ze-o-lit-iks) – medications used to reduce serious anxiety, tension, and agitation. They used to be known as minor tranquilizers.

Avolition (a-vo-lish-un) – inability to initiate or persist in goal-oriented behaviour. A “negative” symptom of schizophrenia.

Bipolar Disorder – an affective disorder characterized by extreme changes in mood ranging from mania to depression. This mood disturbance is also known as manic depression.

Blunting of Affect – Flattening feeling of emotion. The voice may become monotonous and there may be lack of facial expression.

Catatonic Behaviour (kat-a-ton-ik) – unusual motor behaviour which manifests itself in an extreme lack of reactivity to the surrounding environment. Symptoms include psychomotor disturbances with periods of stupor, rigidity, or negativism. A “positive” symptom of schizophrenia.

Catatonic Schizophrenia (kat-a-ton-ik skiz-o-fre-ne-ah) – a marked disturbance in physical activity. This can be a long period of staying very still in a strange position, being mute, or uncontrolled excitement.

Central Nervous System (CNS) – the brain and spinal cord. The CNS is responsible for coordinating the activities of all parts of the brain and spinal cord.

Chronic Schizophrenia (kron-ik skiz-o-fre-ne-ah) – the prolonged period of time, following a period of acute schizophrenia, during which the symptoms are much less serious but still interfering with the persons ability to function. (See acute schizophrenia.)

Cognitive Impairment – difficulty with memory, concentration, decision making etc.

CT Scanning (Computerized Tomography) (to-mog-raf-ee) – a technique using x-rays or ultrasound waves to produce an image of interior parts of the body. For example, within the skull it can be used to view parts of the brain as an aid to diagnosis.

Delusion (de-lu-zhun) – a fixed belief that has no basis in reality, is not affected by rational argument or evidence to the contrary. People suffering delusions are often convinced they are a famous person, are being persecuted, or are capable of extraordinary accomplishments.

Depersonalization (de-per-son-al-ih-za-shun) – a feeling that one is becoming unreal, or that one’s mind is being separated from his/her body.

Depression (de-presh-un) – feelings of sadness, hopelessness, helplessness, and worthlessness. In many cases the affected individual has a lack of energy and motivation. Sometimes physical symptoms such as slow movement and speech are also present.

Disordered Speech – disorganized patterns of speech in which an individual shifts erratically from topic to topic. A “positive” symptom of schizophrenia.

Disorganized Type Schizophrenia – categorized by disorganized speech, disorganized behaviour, and flat or inappropriate affect. Severely disrupts the ability of the individual to perform simple tasks of daily living. Most severe of the schizophrenia subtypes.

Dopamine (do-pah-meen) – neurotransmitter found in high concentrations in the limbic system in the brain. Involved in the regulation of movement, thought, and behaviour.

Dyskinesia (dis-ki-ne-se-ah) – involuntary movements usually of the head, face, neck, or limbs.

Dyspnea (disp-ne-ah) – shortness of breath or difficulty breathing.

Dystonia (dis-to-ne-ah) – an extrapyramidal symptom (EPS) caused by some antipsychotic medicines. The main features are sticking out the tongue, abnormal head position, grimacing, neck spasms and eyes rolling up. (See torticollis.)

Edema (eh-dee-mah) – the build up of watery fluid in parts of the body.

Electroencephalogram (EEG) (e-lek-tro-en-sef-ah-lo-gram) – recording of the electrical activity from various parts of the brain. It is used to study the brain’s electrical activity which may be used to help make a diagnosis.

Electroconvulsive Therapy (ECT) (e-lek-tro-kon-vul-siv) – a treatment that is occasionally used for serious depression, catatonic schizophrenia, and mania. A convulsion is produced by passing an electric current through the patient’s brain while under general anesthesia. ECT is generally limited to cases where medications have not been effective.

Extrapyramidal Symptoms (EPS) (eks-tra-pi-ram-i-dal) – a disturbance of facial or body movements. This can be a side effect of antipsychotic medications. Common symptoms include muscle stiffness, tremors, and lack of arm movement when walking.

Florid Symptoms (flor-id) – pronounced worsening of symptoms.

Galactorrhea (ga-lak-to-re-ah) – an excessive flow of breast milk in men or women. This is sometimes a side effect of antipsychotic medications.

Gradual-Onset Schizophrenia – symptoms develop so slowly that it often takes a long period of time before the illness is obvious to the individual, their family, or their friends. On the average, a person may experience symptoms for two years before they access treatment.

Grossly Disorganized Behaviour – unusual behavior in which the individual acts any number of ways from silly and childlike to angry and aggressive. A “positive” symptom of schizophrenia.

Hallucination (ha-lu-sih-na-shun) – a false perception of something that is not really there. Hallucinations may be seen, heard, touched, tasted, or smelled by the ill individual.

Hyperdopaminergia (hi-per-do-pah-min-er-gee-ah) – neurochemical condition of excess dopamine neurotransmission. Thought to partly underlie the pathophysiology of schizophrenia.

Hypertonicity (hi-per-to-nis-ih-te) – excessive tension of muscles.

Ideas of Reference – the unfounded belief that objects, events, or people are of personal significance. For example, a person may think that a television program he is watching is all about him.

Inappropriate Affect - reacting in an inappropriate manner, such as laughing when hearing bad news.

Limbic System (lim-bik) – group of brain structures composed of the hippocampus and amygdala. Associated with memory storage, the coordination of autonomic functions, and the control of mood and emotion.

Lobotomy (lo-bot-o-me) – a surgical operation on a part of the brain to treat pain or an emotional disorder. This is a very old surgical technique that used to be limited to cases where medications and other treatment methods have not been effective.

Major Depression – a severe mental illness characterized by feelings of hopelessness, helplessness, and worthlessness; often accompanied by inability to sleep, suicidal thoughts and feeling of an inability to move.

Mania (mane-e-ah) – an emotional disorder characterized by euphoria or irritability, rapid speech, fleeting thoughts, insomnia, poor attention span, grandiosity, and poor judgment; usually a symptom of bipolar disorder. Positive symptoms of psychosis may also be present.

Mental Illness – a substantial disorder of thought or mood which significantly impairs judgment, behaviour, capacity to recognize reality, or ability to cope with ordinary demands of life. It may be due to changes in the brain caused by genetic, toxic, infectious, psychosocial, or traumatic influences.

Motor Neuron (mo-tor nur-on) – a nerve cell in the spine that causes action in a muscle.

Negative Symptoms – reflect a diminution or loss of normal functions in individuals with psychosis. Symptoms may include flattening of affect, apathy, and withdrawal.

Neuroleptics (nur-o-lep-tiks) – medications with an antipsychotic effect which are used in the treatment of schizophrenia and other serious mental illnesses. (Also known as antipsychotics.)

Neurotransmitter (nur-o-trans-mit-er) – molecules that carry chemical messages between nerve cells. Neurotransmitters are released from neurons, diffuse across the minute space between cells (synaptic cleft), and bind to receptors located on post-synaptic neuronal surfaces.

Paranoia (par-a-noy-a) – a mental state that includes unreasonable suspicions of people and situations. A person who is paranoid may be suspicious, hostile, feel very important, or may become extremely sensitive to rejection by others.

Paranoid Type Schizophrenia – presence of prominent delusions and auditory hallucinations in an individual whose cognitive functioning is well organized.

Parkinson's Disease – a disease mostly affecting middle-aged and elderly people characterized by tremors and rigid, slow movements.

Parkinsonism (par-kin-son-izm) – a group of symptoms including loss of movement, a lack of facial expression, stiff gait when walking, tremor, or stooped posture. These symptoms are sometimes side effects of older typical antipsychotic medications.

Personality Disorder – a deeply ingrained and maladjusted pattern of behaviour that persists over many years. It is usually well-established in later adolescence or early adulthood. The abnormality of behaviour is serious enough to cause suffering either to the person involved or to other people.

Positron Emission Tomography (PET) (poz-ih-tron e-mish-en toe-mog-ra-fe) – a technique used to evaluate the activity of brain tissues. PET scanning is used as a research tool in schizophrenia, cerebral palsy, and similar types of illnesses.

Positive Symptoms – reflect an excess or distortion of normal functions. Include delusions, hallucinations, disorganized speech, and grossly disorganized or catatonic behaviour.

Postural Hypotension (pos-cher-al hi-po-ten-shun) – also known as orthostatic hypotension, it is characterized by low blood pressure that can cause dizziness and fainting after standing or sitting up quickly. Sometimes an early side effect when starting some psychotropic medicines.

Poverty of Speech – the inability to start or take part in a conversation, particularly “small talk.” This is a very common symptom in schizophrenia and prevents people with this condition from taking part in many social activities.

Prolactin – hormone produced by the pituitary gland in the brain. Stimulates lactation and ovarian function. Excess prolactin release can cause side effects common to many older antipsychotic agents, including abnormal menstrual cycles, abnormal breast milk production, gynecomastia (excessive development of the male mammary glands), and sexual dysfunction.

Psychosis (si-ko-sis) – any major mental disorder which involves changes in personality and loss of contact with reality. This usually includes delusions and/or hallucinations.

Psychotherapy (si-ko-ther-a-pe) – therapy involving psychological instead of medical treatment of mental disorders. It can include sympathetic dialogue and counseling to achieve a thinking-feeling reorganization.

Psychotropics (si-ko-trop-iks) – drugs used in the treatment of mental illnesses.

Rapid or Sudden Onset Schizophrenia – symptoms develop quickly, and the individual experiences dramatic behaviour changes in a matter of a few days or weeks.

Receptor – a protein molecule that resides on the surface or in the nucleus of a cell. Receptors recognize and bind specific molecules of appropriate size, shape, and charge.

Residual Schizophrenia – signs of schizophrenia which may remain in some people after the most serious episode of schizophrenia has passed.

Schizoaffective Disorder (skiz-o-a-feck-tiv) – a condition which includes symptoms of both schizophrenia and affective disorder, but in which psychosis comes first.

Schizophrenia (skiz-o-fre-ne-ah) – the most common of the serious mental disorders. It involves hallucinations and/or delusions, personality changes, withdrawal, and serious thought and speech disturbances.

Schizoid (skiz-oyd) – sometimes used to describe a person who is unusually shy, aloof, sensitive, and withdrawn.

Serotonin-Dopamine Antagonists (SDAs) (ser-o-to-nin do-pah-meen an-tag-o-nists) – also known as “atypical” or newer antipsychotics. Unlike their predecessors, this newer class of medications treats both the positive and negative symptoms of schizophrenia and other serious mental illnesses with fewer side effects. Examples include SERQUEL® (quetiapine fumarate), Clozaril® (clozapine), Zyprexa® (olanzapine), and Risperdal® (risperidone).

Serotonin (ser-o-to-nin) – neurotransmitter that relays impulses between nerve cells (neurons) in the central nervous system. Functions thought to be regulated by nerve cells that utilize serotonin include mood and behaviour, physical coordination, appetite, body temperature, and sleep.

Stereotypical Behaviour (ster-e-o-tip-i-cal) – repeated movements that have no obvious cause and are more complex than a tic. The movement may be repeated in a regular sequence; for example, rocking backwards and forwards or rotating the body.

Stupor (stoo-per) – a condition where a person is immobile, mute, and unresponsive, but appears to be fully conscious because the eyes are open and follow the movement of external objects.

Tardive Dyskinesia (tar-div dis-ki-ne-se-ah) – an occasional reaction to medication, usually after prolonged usage. Characterized by abnormal, spasmodic, involuntary movements of the tongue, jaw, trunk, or limbs (eg, tics).

Thought Alienation (a-le-in-a-shun) – the belief that thoughts have been stolen from one’s mind. This is also known as thought withdrawal.

Thought Broadcasting – the belief that one’s thoughts are being made known to others, usually through the radio or television.

Thought Disorder – the inability to carry through a line of thinking in a way that makes sense to other people.

Thought Insertion – the belief that thoughts are being put into one’s mind.

Topectomy (to-pek-to-me) – surgical removal of a small and specific part of the brain in the treatment of mental illness. Surgery is generally limited to cases where medications and other treatment methods have not been effective.

Torticollis (tor-ti-kol-is) – a contraction of one or more of the neck muscles on one side, resulting in an abnormal position of the head. Also called wry neck. (See dystonia.)

Tranquilizer (tran-kwih-li-zer) – a medicine which produces a calming effect. The so-called major tranquilizers are used to treat serious mental disorders; the minor tranquilizers are often used to treat anxiety.

Typical Antipsychotics – older, first generation medications used to treat serious mental illness. Different from the atypical antipsychotics in that they seldom have an effect upon the “negative” symptoms and often result in greater incidences of EPS in-patients. The most notable example includes haloperidol and chlorpromazine.

Undifferentiated Type Schizophrenia – symptoms of schizophrenia are present, but the individual does not meet criteria for specific schizophrenia types such as paranoid, disorganized, or catatonic.

Ventricles (ven-trih-kals) – in the brain, these are four fluid-filled chambers which form a network with the spinal cord.

Where Should the Schizophrenia Society Go from Here?

The Schizophrenia Society of Saskatchewan Inc. has been supporting families since its inception on August 11, 1982.

Based on the experience of a handful of volunteers and staff over this span of time, the Caring and Sharing support groups have provided families with a very effective climate for sharing experiences and generating hope! This relative success has been earned under trying and often very painful personal circumstances and provided the society with a framework of support and direction for the future! For the foreseeable future, the society must continue to:

1. Provide easily understood information on schizophrenia in an accepting and understanding atmosphere that equips the concerned family with workable options to address the presenting crisis in a more informed, timely and effective manner;
2. Place a more accurate face on Schizophrenia and reduce the stigma through sensitive and creative public education and awareness initiatives that are aimed at the information needs of children, youth, and adults alike;
3. Stress early intervention with the most effective medications and treatment interventions available;
4. Speak on behalf of families when they are unable to do so for themselves;
5. Support research to identify the precise causes and find a cure for schizophrenia; and
6. Raise funds to support these initiatives.

As the society enters the next decade it does so with experience, confidence, determination, as well as a large measure of hope. The momentum of research on schizophrenia in recent years has truly picked up and is making real progress. It is no longer a question as to whether the precise causes and a cure for schizophrenia will be found but rather when!

It is a sad but true admission that while the stigma, myths and stereotypes that surround schizophrenia and those directly affected and their families have been reduced, their painful presence is still evident today. Discrimination in any form cannot be tolerated! There are a large number of families in rural communities and northern Saskatchewan that are still isolated and unsupported. There is still a great deal more to be done if our children and grandchildren are to be better protected from this human tragedy of extraordinary proportions! For their sake alone, we need to capitalize on the inroads we have made in our outreach to children and youth in the school system. Ultimately, we need to find a way to introduce information on schizophrenia (and depression that is often associated with it) directly into the school curriculum. Teachers and other educators would also greatly benefit from a similar injection of awareness on schizophrenia into their respective educational training curriculums. Only then will we have a fighting chance to stop stigma at its point of origin!

Schizophrenia Society of Saskatchewan Inc.

OUR MISSION

“To alleviate the suffering caused by schizophrenia.”

OUR PRIMARY GOAL

“To assist caregiving families to come out of isolation and be heard and believed.

OUR BELIEF

Is that families can improve their effectiveness as a caregiver by taking a more direct role in the assessment, early treatment and recovery of their ill relatives with schizophrenia.

OUR MOST ARDENT HOPE

“That the precise causes of schizophrenia be found leading to the eventual discovery of a cure!”

Outside Saskatchewan

ALBERTA
Schizophrenia Society of Alberta
5th Floor 9942-108 Street
Edmonton, AB T5K 2J5
Tel: (780) 429-7880
Tel: (780) 422-2800
1-800-661-4644 (in Alberta only)

BRITISH COLUMBIA
Schizophrenia Society of British Columbia
201 – 6011 Westminster Hwy.
Richmond, BC V7C 4V4
Tel: (604) 270-7841
Fax: (604) 270-9861

MANITOBA
Manitoba Schizophrenia Society
3-1000 Notre Dame Ave.
Winnipeg, MB R3E 0N3
Tel: (204) 786-1616
Fax: (204) 783-4898

NEW BRUNSWICK
Schizophrenia Society of New Brunswick
PO Box 562
Miramichi, NB E1V 3T7
Tel: (506) 622-1595
Fax: (506) 622-8927

NEWFOUNDLAND & LABRADOR
Schizophrenia Society of Newfoundland & Labrador
205-206 West Block
Waterford Hospital
Waterford Bridge Road
St. John's, NL A1E 4J8
Tel: (709) 777-3335
Fax: (709) 777-3524

NOVA SCOTIA
Schizophrenia Society of Nova Scotia
Nova Scotia Hospital,
Room 408-410, 4th Floor
Dartmouth, NS B2Y 3Z9
Tel: (902) 464-3456
Fax: (902) 464-5479
Toll Free: 1-800-465-2601
(in Nova Scotia only)

ONTARIO
Schizophrenia Society of Ontario
130 Spadina Ave. Suite 302
Toronto, ON M3V 2L4
Tel: (416) 449-6830
Fax: (416) 449-8434
1-800-449-6367 (in Ontario only)

Schizophrenia Society of Canada
50 Acadia Ave., Suite 205
Markham, ON L3R 0B3
Tel: (905) 415-2007
Fax: (905) 415-2337
Toll Free: 1-888-772-4673

PRINCE EDWARD ISLAND
Schizophrenia Society of Prince Edward Island
PO Box 25020, 178 Fitzroy St.
Charlottetown, PEI C1A 9N4
Tel: (902) 566-5573
Fax: (902) 566-9214

QUEBEC
Societe Québécoise de la Schizophrénie
7401 rue Hochelaga
Montréal, Québec H1N 3M5
Tel: (514) 251-4000 ext. 3400
Fax: (514) 251-6347
1-866-888-2323 (in Québec only)

AMI Quebec (Anglophone Association)
5253 Boulevard Decarie, #150
Montreal, Quebec H3W 3C3
Tel: (514) 486-1448
Fax: (514) 486-6157

WORLD SCHIZOPHRENIA FELLOWSHIP
124 - Merton St., Suite 507
Toronto, ON M4S 2Z2
Tel: (416) 961-2855
Fax: (416) 961-1948
E-mail: wsf@inforamp.net
Web site: www.origo.com/wsf

IN THE UNITED STATES
Contact NAMI (National Alliance for the Mentally Ill) at 1-800-950-NAMI. Volunteers staff this toll free Helpline answering questions and providing referrals to local affiliate support groups and information services.



Box 305, Regina, SK, S4P 3A1
Phone 1-306-584-2620
Fax 1-306-584-0525

Email: sssprov@schizophrenia.sk.ca
Website: www.schizophrenia.sk.ca

