



Manitoba Schizophrenia Society Inc.

#### Did You Know?

- People with schizophrenia are men and women, family and friends, neighbors and students.
- 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 very treatable.
- ▼ Schizophrenia costs Canadians nearly \$5 billion per year.
- One out of every five homeless Canadians suffers from chronic mental illness.
- ▼ There is a future with hope for those with schizophrenia.

Please read this booklet.

You can make a difference
by being aware and utilizing
the following information provided
by the Manitoba Schizophrenia Society.

#### The Truth About Schizophrenia

Why You Should Change Your Thinking About Youth's Greatest Disabler.

Edited by

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### Introduction

"Schizophrenia" is a word you've probably heard. 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, 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 end their lives by suicide.

Imagine if you were to go to the hospital for surgery, friends and family will call or visit. If you go to the hospital for a psychiatric reason, friends and even some family members and medical staff are uncomfortable, avoiding you or speaking of you as a "schizophrenic."

Schizophrenia? Yes, spelling it is even difficult. But try living with it. It can be a nightmare.

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.

"My schizophrenia is a painful reality that I live with every day."

- CONSUMER

# What are the Facts About Schizophrenia?

#### First of all, no one is to blame.

"Schizophrenia is a most complex and puzzling illnesses. And now, after 100 years of enigmatic puzzling, I believe we may be on the threshold of an entirely new era of understanding."

Dr. Peter Liddle, Jack Bell Chair in Schizophrenia Research, University of British Columbia.

#### Schizophrenia is a common illness.

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

#### 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.

- $\checkmark$  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 a peak age of 19 years.
- ▼ Generally women between the ages of 25 30 will experience schizophrenia for the first time, with a peak age of 27 years.
- ▼ It is thought that women may be protected for these extra years by estrogen and progesterone produced in their bodies.
- ▼ Each person is very individual and the illness may occur in children as young as 12 years old, though 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 complete suicide.
- ▼ 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.

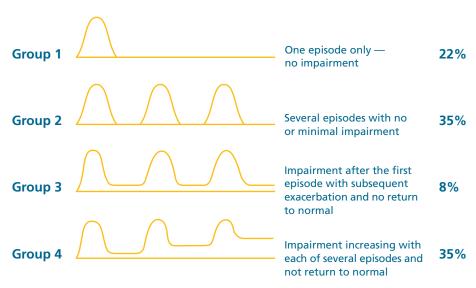
- ▼ The costs to society due to hospitalization, disability payments and lost wages approach 5 billion dollars annually.
- ▼ The cost of losses associated with individual potential, family hardships, shattered personal hopes and dreams are impossible to measure

#### 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.



<sup>&</sup>quot;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.

## What is Schizophrenia?

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 a disease that makes it difficult for the person with the illness 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 often severely affected.

#### **SCHIZOPHRENIA:**

...is a real illness (or group of diseases)
...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.

NOTE: Schizoaffective Disorder (SD) is a transitional stage between schizophrenia and a mood disorder, or a combination of the two.

"RECOVERY IS THE REALIZATION OF THE POTENTIAL WITHIN US DESPITE TRAGEDY, ILLNESS AND OVERWHELMING DARKNESS."

## 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 stress accompanied with an exam, a move, a loss of someone, a difficult relationship etc.

Estimated inherited risk of schizophrenia		
If you are:	Approximate risk	
Part of the general population	I in 100 (1%)	
A brother, sister or child of someone who has schizophrenia	1 in 10 (10%)	
The child of parents who both have schizophrenia	2 in 5 (40%)	
An identical twin of someone who has schizophrenia	2 in 5 (40%)	

#### **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. The infection would affect brain development. As a result, during adolescence schizophrenia would be triggered.

#### **Neurodevelopmental Problems:**

Again, during fetal development 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.

"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.)

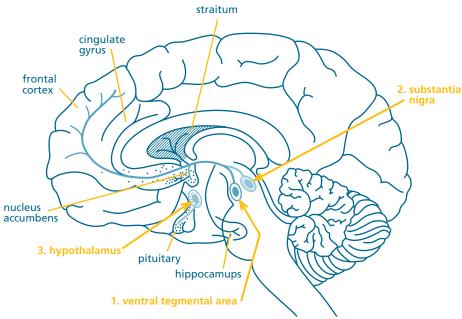
#### **Chemical Brain Imbalance:**

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.
- 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

#### The Transfer of Information: How Nerve Cells Bridge the Gap

Neurons need chemicals to transfer information across the synapse. Those chemicals, which are made by the nerve cells, are called neurotransmitters.

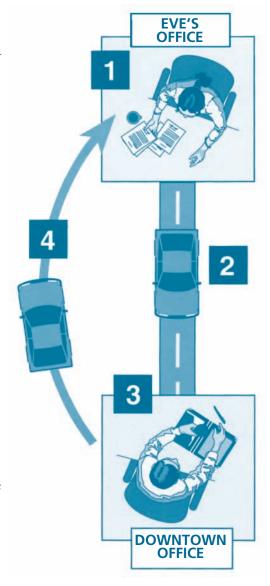
The way in which nerve cells convey their information has a great deal to do with schizophrenia. Thus, to understand schizophrenia, we must examine how nerve cells receive information and pass it on. Since all nerve cells possess those gaps (synapses), we must understand how information jumps across such spaces to discover how communication occurs. Let's use an analogy. Our analogy, which involves a simple four-step document transfer, involves Jim and Eve.

#### AN ANALOGY

(1) Jim's wife, who occupies an office in the accounting branch of a banking company, needs to hand deliver an important document to a person downtown. She puts the document into an envelope and calls her corporation's in house delivery service. Soon a driver appears at her door. After taking the document from Eve, the driver runs down to his car and (2) goes downtown. He arrives at his destination, yet another office building, and goes to the loading/unloading dock (3) There, he delivers the package with the information to the person in office B. With the mission accomplished, the driver returns to his car and drives back to Eve's office building (4).

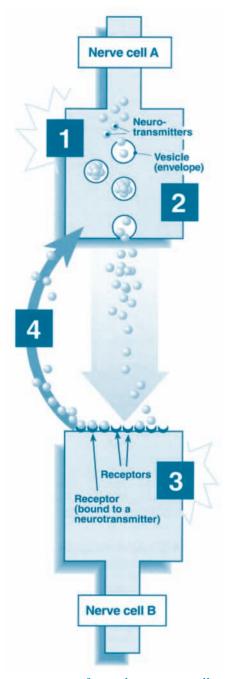
## WHAT DOES THIS HAVE TO DO WITH SCHIZOPHRENIA?

Neurons transfer information across the synapse in a manner reminiscent of the way Eve "hand delivers" important documents to her colleagues. It all involves certain chemicals called neurotransmitter; the chemicals nerve cells use to cross the gaps between them. If nerve cells did not create these chemicals, no information could be transferred. Consider the following four-step, information-transfer process between Nerve cells A and B below.



#### **Bridging the Gap**

- (1) Nerve cell A becomes electrically stimulated, which essentially means it has received information. Its goal is to transfer that information to nerve cell B, which means A has to find a way to electrically stimulate B. This is just like Eve needing to hand deliver a document to the downtown office. Only instead of using a delivery service, the nerve cell uses a neurotransmitter.
- (2) When nerve cell A decides to send information, the neurotransmitters it carries are packaged into "envelopes" we call vesicles, just like Eve packaged her important document into a real envelope. Once packaged, these neurotransmitterladen vesicles are then pushed out of nerve cell A into the synapse, where they travel towards nerve cell B. This pushing is analogous to the driver leaving Eve's building and driving along he road that will take him downtown.
- (3) Once the neurotransmitter has traversed the synapse, it arrives at a "loading/unloading" dock in nerve cell B, just like Eve's driver arrived at a loading dock when he reached the downtown building. On nerve cells, these loading docks are called receptors, though they perform a similar function. The neurotransmitter actually binds to the receptor, and, because of this binding, nerve cell B becomes electrically stimulated. The information has been successfully communicated.



(4) Having accomplished its goal, the neurotransmitter is free to leave nerve cell B and return home to nerve cell A. The neurotransmitter is released from the receptor, and re-crosses the space between the nerves. This process, similar to the driver returning to Eve's building, is called re-uptake. Nerve cell A accepts its returning neurotransmitter and resets itself, waiting for the next electrical

stimulation. The four-step process shown above is how nerve cells transfer information across the gap. As we will see shortly, this transfer sometimes breaks down. If it breaks down in specific regions in the human brain, people can develop a mental illness such as schizophrenia.

Source: John Medina, Ph. D.

Depression: How It Happens, How It's Healed

New Harbinger Publications

"My thoughts get all jumbled up.

I start thinking about something but never quite get there.

The trouble is that I've got too many thoughts constantly coming into my head.

I open my mouth and people say I just talk a load of rubbish."

- Consumer

## 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 contribute approximately 1 to 2 % to the overall incidence of crime in the community. Violence and the illness of schizophrenia are quite independent of each other. However, for those 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. These are the predictors of violence among the small group of people with schizophrenia.

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 react to someone in acute psychosis or "crisis" is very beneficial to both parties)

**Myth:** Schizophrenia is caused by evil spirits or witchcraft.

**Fact:** Regardless of one's religious views, 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.

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. NO GOOD EVIDENCE supports the theory that family environment CAUSES schizophrenia. And very strong evidence 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.

"Our responsibility is to never lose sight of the fundamental sanctity, dignity and sovereignty of another human being no matter what their diagnosis may be; no matter how regressed or poor their prognosis may be, and no matter what their disability may be"



Dr. Patricia E. Deegan PhD.
Director of Training at the
National Empowerment Centre, USA.
Ms. Deegan has suffered from
schizophrenia since childhood.

# 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."

The man or woman with schizophrenia has difficulty in separating what is real from that, which 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 are:

**Positive Symptoms Negative Symptoms** Hallucinations Affective Blunting Delusions Alogia Avolition Disorganized Thought Anhedonia **FUNCTIONING IS AFFECTED Mood Symptoms Cognitive Symptoms** New Learning Insight Memory Demoralization Executive Skills Suicide

"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 ones, which are also symptoms of the acute or (psychotic) phase, are:

- ▼ Hallucinations can affect all five senses. People may see, hear, smell, taste and feel things that are not really there. Most often the hallucination involves hearing voices.
- ▼ Delusions These are fixed beliefs that have no bases 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 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 maybe 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"

# What Is It Like to Have Schizophrenia? A Personal Story

Despite her illness, Janice Jordan has successfully worked as an Engineering and Technical Editor for over 20 years and has completed a book of poetry based on her thoughts and experiences. These are her words:

The schizophrenic experience can be a terrifying journey through a world of madness no one can understand, particularly the person travelling through it. It is a journey through a world that is deranged, empty, and devoid of anchors to reality. You feel very much alone. You find it easier to withdraw than cope with a reality that is incongruent with your fantasy world. You feel tormented by distorted perceptions. You cannot distinguish what is real from what is unreal. Schizophrenia affects all aspects of your life. Your thoughts race and you feel fragmented and so very alone with your "craziness..."

I have suffered from schizophrenia for over 25 years. In fact, I can't think of a time when I wasn't plagued with hallucinations, delusions, and paranoia. At times, I feel like the operator in my brain just doesn't get the message to the right people. It can be very confusing to have to deal with different people in my head. When I become fragmented in my thinking, I start to have my worst problems. I have been hospitalized because of this illness many times, sometimes for as long as 2 to 4 months.

I guess the moment I started recovering was when I asked for help in coping with the schizophrenia. For so long, I refused to accept that I had a serious mental illness. During my adolescence, I thought I was just strange. I was afraid all the time. I had my own fantasy world and spent many days lost in it.

I had one particular friend. I called him the 'Controller.' He was my secret friend. He took on all of my bad feelings. He was the sum total of my negative feelings and my paranoia. I could see him and hear him, but no one else could.

The problems were compounded when I went off to college. Suddenly, the Controller started demanding all my time and energy. He would punish me if I did something he didn't like. He spent a lot of time yelling at me and making me feel wicked. I didn't know how to stop him from screaming at me and ruling my existence. It got to the point where I couldn't decipher reality from what the Controller was screaming. So I withdrew from society and reality. I couldn't tell anyone what was happening because I was so afraid of being labelled as '*crazy*.' I didn't understand what was going on in my head. I really thought that other "normal" people had Controllers too.

While the Controller was the most evident, I was desperately trying to earn my degree. The Controller was preventing me from coping with everyday events. I tried to hide this illness from everyone, particularly my family. How could I tell my family that I had this person inside my head, telling me what to do, think, and say? It was becoming more and more difficult to attend classes and understand the subject matter. I spent most of my time listening to the Controller and his demands. I really don't know how I made it through college...

Since my degree was in education, I got a job teaching third grade. That lasted about 3 months, and then I ended up in a psychiatric hospital for 4 months. I just wasn't functioning in the outside world. I was very delusional and paranoid, and I spent much of my time engrossed with my fantasy world and the Controller.

My first therapist tried to get me to open up, but ... I didn't trust her and couldn't tell her about the Controller. I was still so afraid of being labelled 'crazy.' I really thought that I had done something evil in my life and that was why I had this craziness in my head. I was deathly afraid that I would end up like my three uncles, all of whom had committed suicide.

I didn't trust anyone. I thought perhaps I had a special calling in life, something beyond normal. Even though the Controller spent most of the time yelling his demands, I think I felt blessed in some strange way. I felt 'above normal.' I think I had the most difficulty accepting that the Controller was only in my world and not in everyone else's world. I honestly thought everyone could see and hear him ... I thought the world could read my mind and everything I imagined was being broadcast to the entire world. I walked around paralyzed with fear...

My psychosis was present at all times. At one point, I would look at my co-workers and their faces would become distorted. Their teeth looked like fangs ready to devour me. Most of the time I couldn't trust myself to look at anyone for fear of being swallowed. I had no respite from the illness... I knew something was wrong, and I blamed myself. None of my siblings have this illness, so I believed I was the wicked one.

I felt like I was running around in circles, not going anywhere but down into the abyss of 'craziness.' I couldn't understand why I had been plagued with this illness. Why would God do this to me? Everyone around me was looking to blame someone or something. I blamed myself. I was sure it was my fault because I just knew I was wicked. I could see no other possibilities...

I do know that I could not have made it as far as I have today without the love and support of my family, my therapists, and my friends. It was their faith in my ability to overcome this potentially devastating illness that carried me through this journey.

... So many wonderful medications are now available to help alleviate the symptoms of mental illness. It is up to us, people with schizophrenia, to be patient and to be trusting. We must believe that tomorrow is another day, perhaps one day closer to fully understanding schizophrenia, to know its cause, and to find a cure..."

- Janice C. Jordan. From "Adrift In An Anchorless Reality," Schizophrenia Bulletin, Volume 21, No 3, 1995

#### **Early Warning Signs**

People whose family members 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, although almost everyone mentions "social withdrawal." While the following list is very broad, it is not a checklist, but an attempt to include many variations.

- ▼ Deterioration of personal hygiene
- V Depression
- ▼ Bizarre behaviour
- Irrational statements
- ▼ Sleeping excessively or inability to sleep
- ▼ Social withdrawal, isolation, and reclusiveness
- ▼ Shift in basic personality
- Unexpected hostility
- Deterioration of social relationships
- ▼ 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
- V 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
- ▼ Drug or alcohol abuse
- **▼** Fainting
- ▼ Strange posturing
- ▼ Refusal to touch persons or objects
- ▼ Shaving head or body hair
- ▼ Cutting oneself; threats of selfmutilation
- ▼ Staring without blinking or blinking incessantly
- ▼ Flat, reptile-like gaze
- ▼ 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.

# What is Involved in the Treatment of Schizophrenia? (The Process of Recovery)

Although schizophrenia is not yet a "curable" illness, it is TREATABLE. The proper treatment includes the following four stepping stones to recovery:

- ▼ Medication to lessen symptoms and prevent relapse.
- Psychosocial rehabilitation to help men and women reintegrate into the community and regain social, educational and occupational functioning.
- Psychoeducation for individuals and families to help solve problems, deal with stress and cope with the illness and its complications.
- ▼ Empowerment and Recovery training to deal with loss of sense of self and to deal with the various traumas associated with schizophrenia.

#### A. THE MEDICAL MODEL

Drugs used to treat schizophrenia are called antipsychotic or neuroleptic medications.

There are two categories:

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

The atypical have less severe (though still unpleasant) side effects, and work on negative as well as the positive symptoms. Often, with the older drugs, the person had to take a second drug 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.

"Living your own life, then suddenly you are struck with mental illness. Your whole life then reflects on medications. Medications can be strong and tire you out. As a consumer, I see things different from before.

Some friends that I had before don't associate with me now.

People just shy away from mental illness. I have learned a lot of important life-skills and now work as a proctor and in a library.

Hopefully people will understand better about mental illness in the future and get involved with their own families' members.

The future of mental health is getting brighter."

- Larry Fiddler. Consumer.

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

- E. Fuller Torrey

The following information is given as of date of publication:

**Risperidone:** Use to date has been encouraging. Generally accepted as first-line treatment for newly diagnosed patients. However, side effects can include weight gain, difficulty sleeping, some sexual dysfunction, extreme thirst. When taken for some time, the level of prolactin in the body may be affected. As a result, women may find they are secreting milk and their menstrual cycle may stop or be disrupted.

Olanzapine: To date, shows high rates of efficacy, and is widely used as a first-line treatment. However, side effects can include weight gain, dizziness and a dry mouth. There is rarely an increase in the hormone prolactin and women's menstrual cycles is not usually affected. As this is the case, women may need to consider contraception if they wish to avoid pregnancy.

Clozapine: This drug has been acclaimed because it has been effective with men and women who have treatment-resistant schizophrenia (for those who do not respond to other medication). It is also recommended for people showing signs of tardive dyskinesia (uncontrollable body movements) since it doesn't cause or worsens this condition. Side effects include weight gain, excess salivation (drooling) drowsiness and raised body temperature. Some people have experienced seizures, usually when on a high dose, and may actually lessen its symptoms. The major drawback to taking clozapine is the slight risk (1%) that it will cause reduction of the white blood cells, therefore reducing the person's resistance to infection. People taking clozapine are required to have weekly or bi-weekly blood tests.

Quetiapine: Positive points about this drug are that it does not alter the level of the hormone prolactin, therefore there is no breast secretion in women. It does not usually cause impotence in men, and does not cause women's menstrual cycle to be irregular or stop. As this is the case, women should consider contraception if they want to avoid the risk of unwanted pregnancy. Side effects include weight gain, dry mouth and drowsiness, particularly when first taking the drug.

Always ask your doctor for complete information on all medication.

#### **Reasons for Switching Medication**

The most common reasons for switching from a standard to an "atypical" antipsychotic 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 effects medications
- ▼ Tardive dyskinesia (Abnormal and voluntary movements which may appear after prolong treatment with antipsychotics.)

In most cases, switching medications from standard to "atypical" can be done at any time. The person who is ill should take lots of time to think about it and talk it over with family, friends, and the treatment team. People should also be aware that atypical antipsychotics 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. Patients taking atypical antipsychotics must continue to be monitored for side effects.

"When I started taking a new medication, I regained the will to live. I began working out again. I lost 90 lbs. and now I'm playing as defensive back with the Calgary Colts. All the while my family and friends were there for me."

- Simon Adamson, Spokesperson for the Schizophrenia Society of Canada.

#### A note about sexual functioning:

Antipsychotic medications may interfere with the sex lives of men and women with schizophrenia. One study reported anti-psychotic medication side effects affecting sexual function in 30-60% of persons taking the medications. These effects included decreased libido, male impotence, orgasmic dysfunction and female menstrual irregularities. Such side effects are a major reason why some people discontinue taking their medication, although they may not verbalize this. Whenever sexual side effects are being evaluated, it is important to inquire about sexual dysfunction prior to the onset of the illness as well. Sexual dysfunction is relatively common in the general population, and therefore may be pre-existing and not connected to the antipsychotic medication.

Sex is an important issue for most men and women and there is no reason to think that it should be any different for individuals with schizophrenia. Mentally ill individuals are commonly consigned to an asexual status in our imagination but this is a great mistake. It is important to discuss birth control and pregnancy with your doctor to learn current information.

"I was pregnant when I was diagnosed with schizophrenia.

My friend's parents asked: 'When is the abortion going to take place?'"

Michele Miserelli, Mother

#### **B. THE PSYCHOSOCIAL REHABILITATION MODEL**

Some of the most recent and hopeful news in schizophrenia research is emerging from studies in the field of psychosocial "*rehab*." New studies challenge several long-held myths about the inability of people with schizophrenia to recover from their illness. It now appears that such myths, by maintaining an over-all pessimism about outcomes, may significantly reduce patients' opportunities for improvement and/or recovery.

In fact, the long-term perspective on schizophrenia should give everyone a renewed sense of hope and optimism. According to Dr. G. Gross, author of a 22-year follow-up study of 508 patients with schizophrenia:

"...schizophrenia does not seem to be a disease of slow, progressive deterioration. Even in the second and third decades of illness, there is still potential for full or partial recovery."

Often, after a psychotic episode, there is a loss of social and personal skills. These skills will have to be relearned (caretaking skills, personal grooming habits, catching the bus, shopping, going back to school or work). With the help of proctors, community mental health workers and residential care workers, persons with schizophrenia learn to make choices as they reintegrate back into community living. This is where training in handling stress is important (communication, conflict and stress management). As well, the person will look at issues of self-esteem, vocational goals and what community supports and services they desire. Dr. Courtney Harding of the University of Colorado School of Medicine says, "Rehabilitation should begin on day one," after onset of schizophrenia.

#### C. THE PSYCHOEDUCATION MODEL

It is important for family members and friends to learn as much as they can about schizophrenia and how to relate to and communicate with their loved one. Educating families and friends about living with schizophrenia is called psychoeducation. Relapse can be significantly reduced when families and friends learn specific techniques in relating to the person with schizophrenia.

Clinicians who investigate the long-term course and prognosis of schizophrenia are now presenting a very different picture of the illness from the gloomy scenario painted just a few years ago.

After two decades of empirical study, it is now clear that good rehabilitation programs are an important part of treatment strategy. Furthermore, the importance of family input for treatment and the benefits of appropriate relations between clinicians and families are now well established.

Families need and want education, information, coping and communication skills, emotional support, and to be treated as collaborators. For this reason, knowledgeable clinicians will make a special effort to solicit involvement of family members.

Sometimes this is not easy. Many families were previously hurt by being "blamed" for the illness. This may mean a clinician has to make a special effort to entice some

families into collaboration by acknowledging the difficulties they experienced in the past, and apologizing for the way they were treated by the mental health system. However, once a relationship is established, clinician, patient and family can work together to identify needs and appropriate interventions. Everyone should be able to have realistic yet optimistic expectations about improvement and possible recovery.

#### D. EMPOWERMENT AND RECOVERY TRAINING MODEL

"The capacity for hope is the most significant fact of life. It provides human beings with a sense of destination and the energy to get started."

Norman Cousins, "Anatomy of an Illness."

Up until recently empowerment and recovery principles were not applied to mental illness, though they have become acceptable and standard for those with physical disabilities. Empowerment has to do with making informed choices as a person with a mental illness. Service providers, who have been trained in "caretaking" as opposed to "caregiving," learn how to involve the consumer in decision-making about their treatment and community plans.

When principles of empowerment and recovery are incorporated in service delivery then the service provider will be able to demonstrate the attitude captured in the following words: "Ask not what illness a person has, rather ask what person the illness has."

Recovery is a journey of the heart and mind in which the consumer learns how to live with the mental illness while recovering a quality of life. While not denying the effects of the illness, he or she has come to embrace the illness and to discover the "new person" that has a future with hope. The recovery process is continuous, lifelong and very much an individual journey.

Unfortunately, in the schizophrenia movement, the four models outlined above are still not equally accepted, promoted and utilized. It is well documented that relapse prevention falls significantly to approximately 20% where the four models are used.

A goal of recovery: "To be in control of the illness, rather than the illness being in control of you."

-The BC Early Intervention Study CMHA, BC Division. 1998

#### **Recovery – The Concept**

The concept of recovery, while quite common in the field of physical illness and disability, has heretofore received little attention in both practice and research with people who have a severe and persistent mental illness (Spaniol, 1991). In the field of physical illness and disability "recovery" has a rich and extensive history in both practice and research (Wright, 1983). To recover does not mean that the suffering has disappeared, all the symptoms removed, and/or the functioning completely restored (Harrison, 1984). For example, a person with paraplegia can recover even though the spinal cord has not. Similarly, the person with a mental illness can recover even though the illness is not "cured."

Recovery is a deeply personal process of changing one's attitudes, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful life even with the limitations imposed by illness. It involves developing new meaning and purpose in life as one grows beyond the catastrophic effects of mental illness. It involves much more than recovery from mental illness itself. People with mental illness may have to recover from the stigma they have incorporated into their very being; from the iatrogenic effects of treatment settings; from the lack of recent opportunities for self-determination; from the negative effects of unemployment; from the lack of opportunity to experience adult social roles and from crushed dreams.

Recovery from mental illness involves much more than recovery from the illness itself. People with mental illness may have to recover form the stigma they have incorporated into their very being; from the iatrogenic effects of treatment settings; from lack of recent opportunities for self-determination; from the negative side effects of unemployment; and from crushed dreams. Recovery is often complex, time-consuming process.

Recovery is what people with disabilities do. Clinical services, community support, and rehabilitation are what helpers do to facilitate recovery. Researchers can help both people with the disability and their helpers to manage the recovery process more effectively.

Interestingly, the recovery experience is not an experience which is foreign to services researchers. Recovery transcends illness and the disability field itself. Recovery is a truly unifying human experience. Because all people (services researchers included) experience the catastrophes of life (death of a loved one, divorce, financial reversals), the challenge of recovery must be faced. Successful recovery from a catastrophe does not change the fact that the event has occurred, that its effects are still present, and that one's life has changed forever. Successful recovery does not mean that the person has changed, and that the meaning of these facts to the person has therefore changed. They are no longer the primary focus of one's life. The person moves on to other interests and activities.

Dr. William Anthony, Ph. D. Director of the Center for Psychiatric Rehabilitation, Boston University. Recovery is a common human experience. We will experience recovery at some point in our lives from injury, from illness, or from trauma. Psychiatric disability has a devastating impact on the lives of people who experience it. It is devastating because people with psychiatric disability are left profoundly disconnected from themselves, from others, from their environments, and from meaning or purpose in life. While the illness itself causes people to feel disconnected, stigma (negative personal, professional, and societal values, attitudes and practices) further disconnects people and presents a serious barrier to building new connections.

Recovery is the process by which people with psychiatric disability rebuild and further develop these important personal, social, environmental and spiritual connections, and, confront the devastating effects of stigma through personal empowerment. Recovery is a process of adjusting one's attitudes, feelings, perceptions, beliefs, roles and goals in life. It is a process of self-discovery, self-renewal, and transformation. Recovery is a deeply emotional process. Recovery involves creating a new personal vision for oneself. Recovering from the illness and from stigma can be very stressful. We have written a workbook as a resource for people with psychiatric disability to help them in their recovery process and to help them to prevent, eliminate or cope with the stressors in their lives. We believe that it is never too late to begin the recovery process. Understanding the recovery process and our own recovery experience are important first steps in returning to a life that is fulfilling for ourselves and contributing to others.

- Centre for Psychiatric Rehabilitation, Boston University

"The rehabilitation view of recovery is that people can regain some social functioning, despite having symptoms, limitations, medication, and remaining mentally ill...

To say that the person's mental illness is a permanent condition is to forever ostracize the person from society and say that they will never be able to regain a major social role."

- D. Fisher (1999)

"Many of us who have been psychiatrically labeled have received powerful messages from professionals who in effect tell us by virtue of our diagnosis our futures are already sealed."

- P. Deegan (1995)

#### **Three Phases of Recovery**

- 1. "Overcoming Stuckness."
  - a) Acknowledging and accepting illness.
  - b) Having desire and motivation to change.
  - c) Finding/having source of hope and inspiration.

#### 2. Regaining what was lost and moving forward.

- d) Recovery as a process of learning and self-empowerment.
- e) Recovery as a process of learning and redefinition.
- f) Recovery as a process of returning to basic functioning.

#### 3. Improving Quality of Life.

- g) Recovery involves striving to attain an overall sense of wellbeing.
- h) Recovery involves striving to reach new potentials of higher functioning.

\*Young, S. L. Ensing, D. S. (1999).

Exploring Recovery from the perspective of people with the Psychiatric Disabilities. Psychiatric Rehabilitation Journal. 22(3). 219-231.



If the flower represents a person with a mental illness, where on the flower do we put the mental illness?

(adapted from Pat Deegan)

NOTE: (What about alternative medicine and approaches? Today even medical schools such as Harvard University and Johns Hopkins University are including courses on alternative or adjunctive medicine. Some consumers find comfort in utilizing relaxation therapy, massage therapy, music therapy, spiritual therapy and vitamin therapy in dealing with stress. But these should never be a substitute for medication when such is required.)

## 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 EPS 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.
- ▼ 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 (EPS).

#### **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:

- V 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.

The newer antipsychotics have far fewer problems with EPS. As these medications become more common in the treatment of psychosis, EPS may become a less frequent problem.

Another possible side effect involving the extrapyramidal system is called tardive dyskinesia (TD). This is much more rare than the EPS symptoms discussed above. It is not yet known whether the newer atypical products have a lower potential to cause TD. However, there is some research that suggests this may be the case.

#### **Other Side Effects**

A rare but serious side effect is neuroleptic malignant syndrome. 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.

# 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? MSS Executive Director, Chris Summerville tells audiences in his presentations on schizophrenia that the formula is a simple one:

Lack of understanding (Ignorance)

Lack of exposure to people with schizophrenia

X Fear

STIGMA

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 always 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.

#### 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 as a disease 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 lessons 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. It's 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 psychiatric hospitals.
- ▼ "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. It generally does not respond to anti-psychotic medication.
- ▼ It is offensive to depersonalize people who have 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

# **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 ("My relationship with my husband became cold. I felt dead inside.")
- ▼ 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.")

- ▼ Excessive searching for possible explanations ("Was it something we did to him?")
- ▼ 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 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 Manitoba Schizophrenia Society will endeavour to help you all they can, and will also be there to talk when you have questions. Recognized as a source of help, MSS offers:

- ▼ The latest information on schizophrenia.
- ▼ Trained staff available for one-on-one consultation and public presentations.
- ▼ Support groups for both family members and consumers.
- ▼ 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 planning of treatment, with your relative's consent.

A fundamental principle families must live by is, "You cannot impart what you don't possess." Maintaining your own personal and emotional health is crucial to helping your ill relative.

## How can you look after yourself and other family members?

- 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 MANITOBA SCHIZOPHRENIA SOCIETY – CALL 1-800-263-5545

### A Note for Aging Parents: Future Plans

Encouraging an adult child to live away from home is a loving positive act, not a 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. 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.

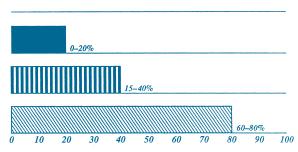
Moving away from home is ultimately necessary for all human beings. No matter how loving and capable, parents will become less and less able to provide support as they grow older – and no one lives forever. Thus, it is usually best to establish independent living arrangements at a reasonable age.

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

"Health professionals talk about how things could be or should be. The way things are is that many crucial support systems do not exist. As a result, schizophrenia becomes a living hell for the sufferer and his family."

- Parent of a young man with schizophrenia

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.

Many families are shocked when they try to find a doctor for a relative with schizophrenia. It seems that few doctors either know about, or have any interest in, schizophrenia. There is no easy solution to this problem.

First of all – schizophrenia can resemble other diseases, so assessment and treatment must involve well-qualified people. 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 organization of your local Manitoba Schizophrenia Society branch.

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 disease
- ▼ Takes a detailed history
- ▼ Screens for problems that may be related to other possible illnesses
- ▼ Is knowledgeable about antipsychotic medications
- ▼ Follows up thoroughly
- ▼ 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, or olanzapine? How important is psychotherapy in treating schizophrenia? What about rehabilitation?

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 odd 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 an 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. The Ministry of Health is the government department responsible for mental health services in Manitoba. Assessment and treatment are available through regional Mental Health centres throughout the province. Check your phone book, or call the Manitoba Schizophrenia Society to find the one 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 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
- Other related information

**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 disease 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 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.

#### 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 person 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 and Community Support Staff, Etc.)

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 brain disorders. (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

# What About the Use of Alcohol and Drugs?

Alcohol and certain drugs can trigger mental health problems, particularly in young people and those who already have or have had a mental illness in the past. Many drugs, including those legitimately prescribed to treat other conditions, may interact with the drugs used to treat mental illness, making them less effective and perhaps precipitating a crisis. It is crucial when recieving prescription drugs that both you and your carers make your doctor aware of your history of mental illness and any psychiatric drugs currently being taken.

However, a far greater risk comes from "street" drugs purchased illegally and without control. Not a great deal is known about the extent of drug misuse and statistics have to be built from various sources including the number of drug offences and thefts from chemist's shops as well as the number of addicts who visit doctors.

Rates of drug abuse are high in disadvantaged inner-city areas, particularly among children of school-leaving age. Many of these young people are unemployed and lead lives with few stable relationships. Some will be suffering from a mental illness or its precursor, but it is known whether those who are or are becoming mentally ill are particularly vulnerable to drug abuse.

#### HOW PEOPLE BECOME DEPENDENT

Three factors seem to be important. The first is the availability of drugs. In the past, many people were introduced to and became dependent on drugs as a result of careless and over-prescription by the medical profession. That was true, for example of opiates, the barbiturates and, later, the amphetamines which were greatly over-prescribed. In 1966, there were 16 million prescriptions written for barbiturates compared with only 1 million in 1988. The most recent example of over-prescription in the past 20 years has been seen with benzodiazepine, anxiety drugs and sleeping pills. The result has been widespread dependence.

Others acquired their addiction from drugs contained in commonly available purchases of the time. For example, until 1904, Coca-Cola contained a little cocaine. Many familiar remedies, especially cough medicines, were laced with morphine. And the ready availability of alcoholic drinks and tobacco is responsible for the widespread dependence on alcohol and nicotine. The second factor seems to be vulnerability. This is dependent upon the personality of the user and on the setting in which he or she is first introduced to drugs. The third factor is the social pressure exerted by peers who force the young person to abuse drugs to mark status, camaraderie or adulthood.

#### What is a Co-occuring Disorder?

A co-occuring disorder occurs when an individual is affected by both an emotional or psychiatric illness and chemical dependency. Psychiatric illness and chemical dependency both effect an individual physically, psychologically, socially, and spiritually. Although the two illnesses are separate and independent, they do interact in ways that make diagnosis, treatment and recovery more complex.

#### What Causes a Co-occuring Disorder?

The specific causes of psychiatric illness and chemical dependency are not fully understood at this time. Family history, genetics, brain chemistry, and environmental factors all appear to play important roles in the development of both psychiatric illness and chemical dependency.

### What Problems are Associated with Co-occuring Disorders?

- **▼** family problems
- ▼ employment or school problems
- ▼ high risk behavior on the highways (DUI)
- ▼ multiple admissions for chemical dependency due to relapse
- multiple admissions for psychiatric care due to reoccurrence of psychiatric symptoms
- ▼ increased emergency room admissions
- ▼ increased need for acute health care services
- ▼ legal problems and incarceration

# Are Co-occuring Disorders Common?

During the past ten years, researchers and mental health and chemical dependency treatment providers have found that co-occuring disorders do occur with regular frequency. The National Institute of Mental Health sponsored two large-scale research studies. The studies provided significant information about dual disorders.

- ▼ 56% of individuals with a bipolar disorder, (Manic depressive illness) abuse substances
- ▼ 47% of individuals with a schizophrenia disorder, abuse substances
- ▼ 32% of individuals with a mood disorder other than bipolar, abuse substances
- ▼ 27% of individuals with an anxiety disorder, abuse substances

Other researchers looked at individuals who were in treatment and experienced a severe mental illness. They found that 40-60% of the patients also had a co-existing substance abuse disorder.

Investigators who looked at individuals in treatment and for substance abuse found them to have co-existing mental disorders in rates of over 60%.

Clearly, there are a substantial number of men and women who experience co-occuring disorders each year.

Research and clinical findings illustrate that it is not a rare occurance, but rather a problem that occurs with consistant frequency. Therefore, it is important that specialized programs and ongoing community based support groups be available for men and women who experience dual disorders.

## Is There a Single Type of Co-occuring Disorder?

There is no single type of co-occuring disorder. This is due to the fact that there are many forms of emotional or psychiatric illness. Some forms of psychiatric illness can severely impair an individual's ability to function effectively and relate well to others. Creating a need for ongoing case management and a variety of other supportive services. Others may be impaired during ongoing periodic episodes or cycles. The degree of impairment due to psychiatric illness may vary greatly from mild or moderate to severe, or it may occur in mixed patterns.

The nature of co-occuring disorders becomes even more complex when alcohol and drug use is considered. For example, there are many types of intoxicating chemicals that people can choose from today. Some people may choose to use a single type of drug while another person may use many different types of drugs. Some people use large amounts for the effects while other people use smaller amounts. Some people use daily, while others use on periodic binges. It becomes evident that there are many different forms of dual diagnosis when the different types of psychiatric illnesses and different patterns of alcohol and drug use are all taken into account. However, in terms of dual recovery, they do share one thing in common: an individual will need to focus their recovery efforts on both their emotional or psychiatric illness and their chemical dependency within a comprehensive personal program of recovery.

## What are the Goals for Co-occuring Recovery?

There are three basic goals for co-occuring recovery:

- ▼ Develop a lifestyle that is free of alcohol and other intoxicating drugs and prevent relapse.
- ▼ Learn ways to manage the symptoms of emotional or psychiatric illness in a healthy and constructive way.
- ▼ Learn ways to improve the quality of life.

Some people may require medical care to safely withdraw from alcohol or street drugs. They may also need medical care to stabilize their acute

psychiatric symptoms. Many people may want to participate in self-help programs such as Dual Recovery Anonymous (DRA) where they can feel accepted when discussing recovering issues that are related to both their psychiatric illness and their chemical dependency.

# If a Person Does Have Both an Alcohol/Drug Problem and an Emotional Problem, Which Should Be Treated First?

Ideally, both problems should be treated simultaneously. For any substance abuser, however, the first step in treatment must be detoxification - a period of time during which the body is allowed to cleanse itself of alcohol or drugs. Ideally, detoxification should take place under medical supervision. It can take a few days to a week or more, depending on what substances the person abused and for how long.

Until recently, alcoholics and drug addicts dreaded detoxification because it meant a painful and sometimes life-threatening "cold turkey" with-drawl. Now, doctors are able to give hospitalized substance abusers carefully choosen medications which can substantially ease withdrawl symptoms. Thus, when detoxification is done under medical supervision, it's safer and less traumatic.

#### What Is Next After Detoxification?

Once detoxification is complete, it's time for dual treatment; rehabilitation for the alcohol or drug problem and treatment for the psychiatric problem.

Rehabilitation for a substance abuse problem usually involves individual and group psychotherapy, education about alcohol and drugs, exercise, proper nutrition, and participation in a 12-step recovery program such as Alcoholics Anonymous. The idea is not just to stay off booze and drugs, but to learn to enjoy life without these "crutches."

Treatment for a psychiatric problem depends upon the diagnosis. For most disorders, individual and group therapy as well as medications are recommended. Expressive therapies and education about the particular psychiatric condition are often useful adjuncts. A support group of other people who are recovering from the same condition may also prove highly beneficial. Adjunct treatment, such as occupational or expressive therapy, can help individuals better understand and communicate their feelings or develop better problem-solving or decision-making skills.

## Must a Co-occuring Disorder Patient Be Treated in a Hospital?

Not neccessarily. The nature and severity of the illness, the associated risks or complications, and the person's treatment history are some of the facts considered in determining the appropriate level of care. There are several different levels or intensities of care including full hospitalization or inpatient treatment, partial hospitalization, and outpatient treatment.

#### What is the Role of the Patient's Family in Treatment?

With both rehabilitation for substance abuse and treatment for a psychiatric problem, education, counseling sessions, and support groups for the patient's family are important aspects of overall care. The greater the family's understanding of the problems, the higher the chances the patient will have a lasting recovery.

# How Can Family and Friends Help with Recovery from the Substance Abuse?

They need to learn to stop enabling. Enabling is acting in ways that essentially help or encourage the person to maintain their habit of drinking or getting high. For instance, a woman whose husband routinely drinks too much, might call in sick for him when he is too drunk to go to work. That's enabling. Likewise, family members or friends might give an addict money which is used to buy drugs, because they're either sorry for him or affraid of him. that's enabling also.

When family and friends participate in the recovery program, they learn how to stop enabling. If they act on what they've learned, the recovering substance abuser is much less likely to relapse into drinking or taking drugs.

# How Can Family and Friends Help with Recovery from a Psychiatric Conditions?

They should be calm and understanding, rather than frightened or critical. They should be warm and open, rather than cool or cautious. Although it is fine to ask the person matter-of-factly about the psychiatric treatment, that shouldn't be the only focus of conversion.

# If Someone I Know Appears to have A Substance Abuse Problem and the Symptoms Of A Psychiatric Disorder, How Can I Help?

Encourage the person to acknowledge the problems and seek help for themselves. Suggest a professional evaluation with a licensed physician, preferably at a medical center that's equipped to treat addiction problems and psychiatric conditions. If the person is reluctant, do the legwork yourself - find the facility, make the appointment, offer to go with the person. A little encouragement may be all it takes. If you talk to the physician first, be honest and candid about the troubling behaviour. Your input may give the doctor valuable diagnostic clues.

#### There Is Hope

As a relative or friend, you can play an important role in encouraging a person to seek professional diagnosis and treatment. By learning about dual diagnosis, you can help this person find and stick with an effective recovery program.

The more you know about co-occuring disorders, the more you will see how substance abuse can go hand-in-hand with another psychiatric condition. As with any illness, a person with co-occuring disorder can improve once proper care is given. By seeking out information, you can learn to recognize the signs and symptoms of dual diagnosis - and help someone live a healthier or more fulfilling life.

For more Information regarding Dual Diagnosis visit Dual Diagnosis Recovery Network's website http://dualdiagnosis.org

(The material for this chapter comes from the National Mental Health Association and the Dual Diagnosis Recovery Network)

# Are There Any Questions Left To Answer?

# MANY PEOPLE HAVE MANY 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 or/and 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. Recovery is possible for everyone living with schizophrenia!

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

A. When a person's symptoms improve due to taking medication, 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 suppose 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 the physician's philosophy of treatment. As long as the doctor does not mention your child's name and the specifics of his treatment, the doctor can give you much information which will help you understand what the doctor does to treat schizophrenia.

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

A. Unfortunately, for a variety of reasons, doctors do not spend a lot of time talking with both patients and families. As well, many doctors are remiss in referring families to resource centres 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. No. But one can develop drug or alcohol induced psychosis which looks like schizophrenia, but is short-term. However, abuse of drugs and alcohol can *trigger* schizophrenia. This would be due to an existing vulnerability predisposing factors. Any form of cannabis (marijuana), cocaine/crack, LSD, PCP or amphetamines may trigger an episode of schizophrenia. 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:

- Maintain good eye contact.
- ▼ 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 Manitoba Mental Health Act?

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 means they are unable to access, accept and use voluntarily available treatment – because of the very nature of their disability. The Manitoba Mental Health Act is about the care and protection of our citizens who are victims of such illnesses.

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 diseases 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 are literally dying in our streets from neglect. 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 succeed.

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

"The purpose of the Manitoba 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 THAT 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, 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 Manitoba Schizophrenia Society 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 Manitoba Schizophrenia Society, Inc. has a wide range of current literature in the form of pamphlets, videos and books at the provincial office in Winnipeg.

Manitoba Schizophrenia Society, Inc. 3 – 1000 Notre Dame Avenue, Winnipeg, Manitoba R3E 0N3 Phone: 1-(204)-786-1616

Toll-Free: 1-800-263-5545 Fax: 1-(204)-783-4898 Website: www.mss.mb.ca E-mail: info@mss.mb.ca

Or you may contact one of the eight regional offices throughout Manitoba.

### **SUGGESTED READING (available in the Society Library)**

Hidden Victims, Hidden Healers by Julie Tallard Johnson MSW. Published by Doubleday.

Troubled Journey by Diane Marsh. Published by Putnam.

Helping Someone with Mental Illness by Rosalyn Carter. Published by Random House, Times Books.

Psychological and Social Aspects of Psychiatric Disability, edited by LeRoy Spaniol, Cheryl Gagne & Martin Koehler. Published by the Centre for Psychiatric Rehabilition, Boston University. (Reader friendly)

*Uninvited Guest* by Jenny Robertson. A family's journey into Schizophrenia. Published by Triangle SPCK . (England)

*Schizophrenia – the Facts* (2nd edition) by Ming T. Tsuang & Stephen Faraone. Published by Oxford Medical Publications.

Mental Illness in the Family - Issues and Trends, edited by Beverly Abosh & April Collins. Published by University of Toronto Press.

Working with Schizophrenia – A Needs Based Approach, by Gwen Howe. Published by Jessica Kingsley Publishers

*Surviving Schizophrenia − A Family Manual*, by E. Fuller Torrey, MD. Published by Harper & Ros, New York.

*Out of the Shadows* by E. Fuller Torrey, MD. Published by John Wiley & Sons Inc., New York,

Coping with Schizophrenia (a guide for families) by Kim Mueseer, PhD & Susan Gingerich, MSW. Published by New Harbinger Publications Inc.

The Manitoba Schizophrenia Society library is updated on an ongoing basis with new books added whenever possible. Books and videos may be borrowed from the library free for members of the Society or with a \$5 deposit for non-members.

## **SUGGESTED VIDEOS** (available in the Society library)

"Uncertain Journey – Families Coping with Serious Mental Illness" by Duke University Medical Centre. 45 mins in length.

"Recovery as a Journey of the Heart" by Pat Deegan PhD. 54 mins.

"Living with Schizophrenia – a Personal Account" by Bill McPhee, Editor of Schizophrenia Digest. 60 mins.

"First Break" The first episode of mental illness in a person's life by the National Film Board of Canada. 51 mins.

"Understanding and Communicating with a Person Who is Hallucinating" by Mary D. Moller Series. 60 mins.

"Understanding and Communicating with a Person Who has Delusions" by Mary D. Moller Series. 60 mins.

"Understanding and Communicating with a Person Who is Experiencing Mania" by Mary D. Moller Series. 60 mins.

"Understanding Relapse – Managing Symptoms of Schizophrenia" by Mary Moller Series. 60 mins.

The Bonnie Tapes- "Recovering from Mental Illness" 27 mins.

"My Sister is Mentally Ill" 22 mins.

"Mental Illness in the Family"  $20\ mins.$ 

"I'm Still Here – the Truth about Schizophrenia," Narsad & Janssen , 1997.

"Until a Cure is Found": Neuroleptic Medication in the Management of Schizophrenia." A guide for patients and their families. 15 mins.

"A Mind Worth Saving" by the Manitoba Schizophrenia Society. 16 mins.

# 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 an anitpsychotic medication called clozapine (brand name Clozaril).

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.

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** – lack of emotion. The voice may become monotonous and the expression on the fact may not change.

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, which include 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 long period of time, following a period of acute schizophrenia, during which the symptoms are much less serious. (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; also known as derealization.

**Depression** (de-presh-un) – feelings of sadness, hopelessness, helplessness, and worthlessnesss. 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 flate or inappropriate affect. Severely disrupts the ability of the individual to perform simple tasks of daily living. Most severe of the schizophernia 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 if often takes a long period of time before the illness is obvious to the individual, their family, or their friends.

**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. Surgery is generally 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 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. Neurotransmittors 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. Least severe of the schizophrenia subtypes.

**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 brain damage.

**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 know as orthostatic hyptoension, 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 schizophrenic episode 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 SEROQUEL® (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 chlopromazine.

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.

# What is the Manitoba Schizophrenia Society All About?

While Canadians have a national Society to provide public education and to support research into schizophrenia, people dealing with the disease usually find it is more beneficial to them, and critical to their needs, if they can connect with a local organization.

The Manitoba Schizophrenia Society (MSS), formed in 1979, is one of several provincial societies across Canada. MSS's mission is to be a consumer focused, family sensitive mental health self help organization dedicated to the improvement of quality of life for all those who are affected by schizophrenia and co-occuring disorders through education, peer support and advocacy by working in partnership with consumers, families and service providers.

MSS is committed to working in a collaborative fashion with governments, hospitals, community mental health services and consumers, in keeping mental health central within the health care system. In particular, MSS is dedicated specifically to those who live with schizophrenia, to ensure they are not "lost, or forgotten in the shuffle" caused by cutbacks and regionalization.

Once people make contact with MSS, a great deal of isolation and fearfulness is quelled, if for no other reason, than they know such a resource is available. In Manitoba, the Society offers such things as a lending library, peer support, referral services to mental health organizations and services, telephone support and in-person consultation. This is done through nine outreach offices in Manitoba.

Given that the majority of people afflicted with schizophrenia live at home, the need for education and family support groups has never been greater. In Manitoba, there are approximately 25 such groups, which hold monthly and weekly meetings. Staff provides telephone support and educational presentations in the community; all designed to assist consumers and caregivers. There are support groups for consumers and family members, along with "Eight Stages of Healing" groups and workshops on empowerment and recovery; which are held regularly. As well, MSS is involved in peer counseling at PsychHealth and Grace Hospital, a Family Issues series addressing the concerns of family members, and partnership with the STEP Program in educating families and friends. There also is a program designed especially for women with schizophrenia that addresses their unique needs in dealing with the illness.

MSS outreach workers devote long hours to supporting families, consumers and service providers. They work hand-in-hand with local members and those involved with Manitoba's mental health system. A major part of their work is to navigate the health and social service systems in order to help people access the best possible services available in their region.

Along with constantly seeking to widen public and professional awareness of schizophrenia, MSS also supports and promotes research to determine the causes and improve the treatment of the illness; helps raise funds to finance these activities; and, works in partnership with other agencies,

organizations and government departments to achieve these goals. The MSS also acts as an advocate at government and regional health authority levels through networking and collaborating with the mental health community in addressing the needs of those with schizophrenia.

# Manitoba Schizophrenia Society Inc.

#### **OUR MISSION**

"A consumer focused, family sensitive mental health self help organization dedicated to the improvement of quality of life for all those who are affected by schizophrenia and co-occuring disorders through education, peer support and advocacy by working in partnership with consumers, families and service providers.."

#### **OUR VISION**

"Promoting a dignified, non-discriminatory quality of life for sufferers while seeking a cure for schizophrenia."

#### **OUR PASSION**

Giving people who struggle with, and are affected by schizophrenia, a future with hope."

#### **OUR BELIEF**

About Intervention

"Recovery is possible
through timely and
adequate medical treatment
and management,
psychosocial rehabilitation,
education, community
supports and personal
empowerment."

#### **OUR CORE VALUES**

Authenticity

Integrity

Respect

Support

Access and availability to treatment, support and services

Financial accountability as a non-profit organization.

#### **Outside Manitoba**

#### ALBERTA

Schizophrenia Society of Alberta 5th Floor 9942-108 Street Edmonton, Alberta T5K 2J5 Tel: (780) 429-7880 Fax: (780) 422-2800

#### **BRITISH COLUMBIA**

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

#### **NEW BRUNSWICK**

Schizophrenia Society of New Brunswick PO Box 562 Miramichi NB E1V 3T7 Tel: (506) 363-5886 Fax: (506) 363-8108

#### NEWFOUNDLAND & LABRADOR

Schizophrenia Society of Newfoundland & Labrador 205-206 W. Block St. John's, NF A1E 4S8 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

#### **ONTARIO**

Schizophrenia Society of Ontario 30 Spadina Ave., Suite 302 Toronto, ON M5V 2L4 Tel: (416) 449-6830 Fax: (416) 449-8434

Schizophrenia Society of Canada 50 Acadia Avenue, 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 Charlottetown, PEI C1A 9N4 Tel: (902) 566-5573 Fax: (902) 566-9214

#### SASKATCHEWAN

Schizophrenia Society of Saskatchewan PO Box 305 Regina, SK S4P 3A1 Tel: (306) 584-2620 Fax: (306) 584-0525

#### **QUEBEC**

Association Québécoise de la Schizophrénie 7401 rue Hochelaga Montréal, Québec H1N 3M5 Tel: (514) 251-4000 ext. 3400 Fax: (514) 251-6347

#### AMI Quebec

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

#### WORLD SCHIZOPHRENIA FELLOWSHIP

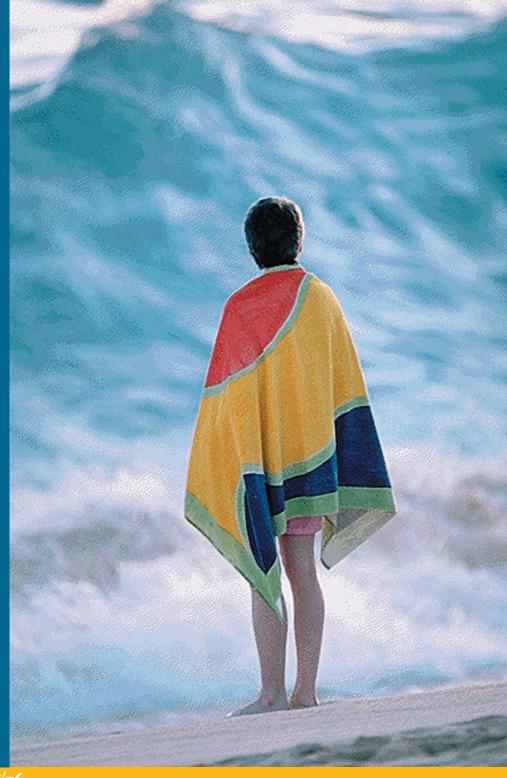
238 Davenport Road, Suite 118 Toronto, ON M5R 1J6 Tel: (416) 960-1808 Fax: (416) 944-3183 E-mail: wsf@inforamp.net Web site: www.origo.com/wsf

#### 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.



For information in Manitoba about our service, call 1-800-263-5545





# Manitoba Schizophrenia Society Inc.

3 – 1000 Notre Dame Avenue, Winnipeg, Manitoba R3E 0N3 Phone (204) 786-1616 Fax (204) 783-4898 Toll Free 1-800-263-5545