











# Strengthening Families in Durham Region

Get what you need to know...!

Learn ways to cope with Mental Health in 'Your Family'



# **Strengthening Families Together**

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**Strengthening Families Together** grew out of the strong belief that Canadian families have a right to consistent educational information on serious mental illnesses, regardless of where they reside.

This 10-session education program for family members and friends of individuals with serious and persistent mental illnesses aims at increasing accessibility to Canadian-based information on the topics associated with living daily with a mental illness.

**Strengthening Families Together** is about more than education; it is about **strengthening** family members and friends of individuals with a serious mental illness by providing **support**, **awareness**, and **tools**.

#### Support

Families have an opportunity to discuss the daily challenges they face and learn how to connect with others through membership in their local provincial society and chapter/branch.

#### **Awareness**

Families get the real scoop about mental illness, treatment options, causes, research, and mental health services available, in the hopes of diminishing the stigma attached to diagnosis.

#### **Tools**

Families are equipped with problem solving, coping, and advocacy and communication skills, and the know-how to develop their own local support group.

# **Participation Guidelines**

As a participant in the group, we ask that you keep the following guidelines in mind:

- ✓ Include everyone!
- ✓ Encourage the others and listen well.
- ✓ Challenge ideas instead of criticizing people.
- ✓ Share ideas and feelings freely!
- ✓ Be prepared to explain your answers.
- ✓ Ask probing questions.
- ✓ Be respectful of each person's privacy. Any *personal information* that is discusses in the sessions should be considered confidential and private.

You may find that medical professionals and others use words you are not familiar with. This is a short glossary of some of the most commonly-used terms.

#### 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)

Also know as Mood Disorder. A mental illness characterized by greatly exaggerated emotional reactions and mood swings from high elation to deep depression. Commonly used terms are manic depression (or bipolar disorder) and depression—although some people experience only mania and others only depression. These extreme mood changes are unrelated to changes in the person's environment.

#### **Affective Flattening**

Limited range and intensity of emotional expression. A negative symptom of schizophrenia. Also referred to as emotional blunting.

#### 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 antipsychotic medication called clozapine (brand name Clozaril).

#### Akatisia (ak-ah-thez-e-ah)

The medical word for extreme restlessness. This may include rocking from foot to foot or back and forth, walking in place, pacing, or an inability to sit still. An extremely confused mental state generally accompanies akatisia.

#### Akinesia (ak-in-kneez-e-ah)

A state of reduced movement; lack of muscle movement.

#### Alogia (ah-lo-jee-ah)

The loss of ability to speak or understand spoken or written language due to disease or injury of the brain. A negative symptom of schizophrenia.

#### Anxiolytics (ang-ze-o-lit-iks)

Medications used to reduce serious anxiety, tension,

#### 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)

A lack of pleasure or interest in activities that were previously enjoyed.

#### Anosognosia (ah-nah-sog-no-see-ya)

A symptom of several brain disorders. Anosognosia is a very severe lack of awareness. It is not simply denial of illness, but a lack of awareness of the illness. The individual cannot understand that he/she is ill.

#### 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, & constipation.

#### Antidepressant (an-te-kol-ih-ner-jik)

Medications used to treat depression. (See Medications.)

#### Antipsychotic (an-ti-si-cot-tic)

A group of medications used to treat psychosis. There are 2 types of antipsychotic medications: neuroleptics (also called standard or typical antipsychotics) and atypicals. Neuroleptics are older, first generation medications used to treat serious mental illness. Neuroleptics have a tendency to cause neurological side effects (see extrapyramidal symptoms) such as akinesia (slowed movement), akatisia (restless limbs), and tadive dyskinesia (permanent, irreversible movement disorders). See Medications, Neuroleptics.

#### **Central Nervous System (CNS)**

The brain & spinal cord. The CNS is responsible for coordinating the activities of all parts of the brain & spinal cord.

#### Chronic Schizophrenia (Kron-ik skiz-o-fre-ne-ah)

The long period time, following a period of acute schizophrenia, during which the symptoms are much

& agitation. They used to be known as minor tranquilizers.

#### **Apathy**

A lack of interest.

#### **Atypical Antipsychotics (ay-tip-ih-cal)**

See Antipsychotic, Medications.

#### Avolition (a-vo-lish-un)

The individual lacks energy, spontaneity, & initiative. There is a loss of drive and interest. It's very difficult to begin a new task or to finish any assignment. A negative symptom of schizophrenia.

#### **Bipolar Disorder**

A serious affective disorder characterized by extreme changes in mood ranging from high elation to deep depression. An individual with Bipolar Disorder may feel extremely excited with boundless energy, & then suddenly feel very sad & depressed. Previously called Manic Depression.

#### **Blunted Affect/Blunted Emotions**

An apparent lack of emotion. The voice may become monotonous and the facial expression may not change. This does not mean that the individual cannot feel emotions, but that he/she appears emotionless.

#### Catatonic Behaviour (Kat-a-ton-ik)

Unusual motor (physical) behaviour, which shows an extreme lack of reactivity to the surrounding environment. Symptoms include stupor, muscular rigidity, or excitement. A positive symptom of schizophrenia.

#### Catatonic Schizophrenia (Kat-a-ton-ik skiz-o-fre-ne-ah)

Categorized by 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. This is one of the schizophrenia subtypes.

#### 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,

less serious.

#### **Concurrent Diagnosis**

A concurrent diagnosis is made when an individual shows symptoms of both a mental illness & substance or alcohol abuse. The term is also used when a person is diagnosed with two or more mental disorders. (Also called Dual Diagnosis or Co-occurring disorders)

#### Cognitive Impairment (cog-ne-tiv)

Cognitive abilities include knowing, thinking, learning, & judging. Cognitive impairment means the individual is experiencing difficulty with memory, concentration, & decision-making. (These are also called Executive Skills)

# 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 symptom of many mental illnesses, a delusion is a fixed belief that has no basis in reality. This belief is strongly held even in the face of evidence that it is false. Individuals suffering from this type of thought disorder are often convinced they are famous people, are being persecuted, or are capable of extraordinary accomplishments.

#### 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-ma)

The build up of watery fluid in parts of the body.

# Electroencephalogram (EEG) (e-lek-tro-en-sef-ah-logram)

A 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-ro-kon-vul-siv)

A treatment that is occasionally used for serious depression, catatonic schizophrenia, & mania. A convulsion is produced by passing an electric current through the patient's brain while under general anesthesia. ECT is used primarily for patients suffering from extreme depression for long periods, who are

&worthlessness. In many cases the affected individual has a lack of energy & motivation. Sometimes physical symptoms such as slow movement & speech are also present.

#### **Diagnosis**

Classification of a disease by studying its signs and symptoms. Schizophrenia is one of many possible diagnostic categories used in psychiatry.

#### **Disordered Speech**

Also know as disorganized speech. Disorganized patterns of speech in which an individual shifts erratically from topic to topic. A positive symptom of schizophrenia.

#### **Disorganized Type Schizophrenia**

Categorized by disorganized speech, disorganized behaviour, and flat or inappropriate affect. Severely disrupts the ability of the individual to perform simple tasks of daily living. This is one of the schizophrenia subtypes.

#### Dopamine (do-pah-meen)

A neurotransmitter found in high concentrations in the limbic system in the brain. Involved in the regulation of movement, thought, and behaviour.

#### **Dual Diagnosis**

See Concurrent Diagnosis.

#### 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.

#### Galactorrhea (ga-lak-to-re-ah)

An excessive flow of breast milk in men or women. This is sometimes a side effect of antipsychotic medications.

#### **Gradual-Onset Schizophrenia**

Symptoms develop so slowly that it often takes a long period of time before the illness is obvious to the individual, his/her family, or his/her friends.

#### **Grossly Disorganized Behaviour**

This term describes unusual behaviour in which the individual may act in any number of ways, from silly

suicidal, & who do not respond to medication or to changes in circumstances.

#### Extrapyramidal Symptoms (EPS) (eks-tra-pi-ram-i-dal)

The medical term for neurological side effects: 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. (See Medications, Neuroleptics, Side Effects.)

#### **Flight of Ideas**

Flight of ideas refers to a period where the individual's thoughts become very accelerated.

#### Florid Symptoms (flor-id)

The symptoms are obviously worsening.

#### **Involuntary Admission**

\*The process of entering a hospital is called admission. Voluntary admission means the patient requests treatment, and is free to leave the hospital whenever he or she wishes. People who are very ill may be admitted to a mental health facility against their will, or involuntarily:

- Under medical admission certificate or renewal certificate:
- under special court order when they have been charged or convicted with a criminal offence. In this case, they may be held in a forensic facility.

Before someone can be admitted involuntarily, a physician must certify that the person is:

- suffering from a mental disorder and requiring care, protection, and medical treatment in hospital;
- likely to cause harm to self or others or to suffer substantial mental or physical deterioration if not hospitalized.

\*This procedure varies from province to province. Contact your provincial health authorities or local mental health organization for more specific details.

#### Labile Mood (lay-buy-el)

An individual in a labile mood has alternating euphoria and irritability.

#### Limbic System (lim-bik)

Group of brain structures composed of the hippocampus and amygdale. Associated with memory storage, the coordination of autonomic function, and the control of and child like to angry and aggressive. A positive symptom of schizophrenia.

#### Hallucination (ha-li-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)

A neurochemical condition of excess dopamine neurotransmission. This is thought to partly underlie the pathophysiology of schizophrenia.

#### Hypertonicity (hi-per-to-nis-ih-te)

Excessive tension of muscle.

#### **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.

Antipsychotics: These reduce agitation, diminish hallucinations and destructive behaviour, and may bring about some correction of other thought disorders. Side effects include changes in the central nervous system affecting speech and movement, and reactions affecting blood, skin, liver, and eyes. Periodic monitoring of blood and liver functions is advisable. See Antipsychotic.

Antidepressants: These are normally slow-acting drugs, but if no improvement is experienced after 6 weeks, they may not be effective at all. Some side effects may occur such as dry mouth, drowsiness, or headaches.

Mood Stabilizers: e.g., Lithium Carbonate, used in manic and manic-depressive states to help stabilize the wide mood swings that are part of the condition. Regular blood checks are necessary to ensure proper medication levels. There may be some side effects such as thirst and burning sensations. (Also call Mood Normalizers.)

*Tranquilizers:* Generally referred to as benzodiazapines. These medications can help calm agitation and anxiety. Examples include: valium, Librium, Ativan, Xanax, and Rivotril.

mood and emotion.

#### Medications

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

#### **Mental Disorder/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. A mental illness usually involves a change in ability and personality.

#### **Mental Health**

Describes an appropriate balance between the individual, his or her social group, and the larger environment. These 3 components combine to promote psychological and social harmony, a sense of well-being, self-actualization, and environmental mastery.

#### **Mental Health Act**

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

#### Multifactorial

A term used by doctors in describing the causes for an illness. Basically the term means "multiple factors."

#### **Multiple Personality Disorder**

A personality disorder categorized by the appearance of 2 or more distinct and separate personalities in one person. In popular public opinion, this is often the mistaken belief about schizophrenia.

#### **Negative Symptoms**

These are symptoms that are considered missing from the individual and should be present. These symptoms may include blunted affect (blunted emotions), apathy, a lack of energy or motivation, and emotional or social withdrawal.

#### Parkinson's Disease

A disease mostly affecting middle-aged and elderly

#### **Major Depression**

A severe mental illness characterized by feelings of hopelessness, helplessness, and worthlessness; often accompanied by a loss of energy or motivation. Some individuals also experience suicidal thoughts.

#### 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.

#### **Motor Neuron (mo-tor-nur-on)**

A nerve cell in the spine that causes action in a muscle.

#### **Neuroleptics (nur-o-lep-tiks)**

A group of medications used in the treatment of schizophrenia and other serious mental illnesses with psychosis. (See Antipsychotics, Medications.)

#### **Neurotransmitter (nur-o-trans-mit-er)**

Molecules that carry chemical messages between nerve cells. Neurotransmitters are released from neurons, diffuse across the minute space between cells (synaptic cleft), and bind to receptors located on post-synaptic surfaces.

#### Non-Compliant (nah-n come-ply-ant)

This means that the ill individual is not taking his or her medication or following the treatment plan. There are various reasons for non-compliance, including inability to remember to take medication, unpleasant side effects, or a lack of awareness about being ill. (See Anosognosia.)

#### **Obsessive Compulsive Disorder**

An anxiety disorder in which individuals become trapped in repetitive patterns of thoughts (obsessions) and behaviours (compulsions) that are potentially disabling, senseless, and extremely hard to overcome.

#### **Out-patient**

An individual who come to the hospital for medical or surgical care but does not need to remain in the hospital afterwards as an in-patient.

#### Paranoia (par-a-noy-a)

A mental state that includes unreasonable suspicions of people and situations. A person who is paranoid

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 antipsychotics.)

#### **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 type of brain damage.

#### **Positive Symptoms**

These are symptoms that are added to the individual's behaviour that should not be present. These symptoms may include delusions, hallucinations, disorganized speech, and grossly disorganized or catatonic behaviour.

#### Postural Hypotension (pos-cher-al hi-po-ten-shun)

Also known as orthostatic hypotension, it is characterized by low blood pressure that can cause dizziness and fainting after standing or sitting up quickly. This is sometimes an early side effect when starting some psychotropic medicines.

#### 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

This refers to signs of schizophrenia which may remain in some people after the most serious schizophrenic episode has passed.

#### Schizoaffective Disorder (skiz-o-a-feck-tiv)

The diagnosis of this illness is made when the clinical picture is not "typical" of either schizophrenia or a mood disorder, but the person shows symptoms of both illnesses (psychosis and severe mood swings). Treatment

may be suspicious, hostile, feel very important, or may become extremely sensitive to rejection by others. Paranoia falls within the category of delusional thinking.

#### Paranoid Type Schizophrenia

Categorized by the presence of prominent delusions and auditory hallucinations in an individual whose cognitive functioning is well organized. This is one of the schizophrenia subtypes.

#### **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**

A 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)

A group of symptoms of several major mental disorders. These symptoms include loss of contact with reality, breakdown of normal social functioning, and extreme personality changes. People affected with this condition usually experience delusions and/or hallucinations.

#### Psychotherapy (si-ko-ther-a-pe)

Basically "talk" therapy. Psychotherapy is a form of treatment involving discussions between the patient and the mental health professional, and is often combined with prescribed medications. There are many different types of psychotherapy with different aims and approaches.

#### Psychotropics (si-ko-trop-iks)

Drugs used in the treatment of mental illnesses. (See Antipsychotic, Medications.)

#### Rapid or Sudden Onset Schizophrenia

The symptoms develop quickly, and the individual

usually consists of a combination of antipsychotic medications, antidepressants, and/or mood stabilizers.

#### **Prodromal Phase**

The 1<sup>st</sup> or early stage of an illness, before the onset of the full-blown illness.

#### Schizoid (skiz-oyd)

A term sometimes used to describe a person who is unusually shy, aloof, sensitive, and withdrawn.

#### Schizophrenia (skiz-o-fre-ne-ah)

Schizophrenia is a severe and often chronic brain disease. Common symptoms include personality changes, withdrawal, severe thought and speech disturbances, hallucinations, delusions, bizarre behaviours.

#### **Side Effects**

Side effects occur when there is drug reaction that goes beyond or is unrelated to the drug's therapeutic effect. Some side effects are tolerable, but some are so disturbing that the medication must be stopped. Less severe side effects include dry mouth, restlessness, stiffness, and constipation. More severe side effects include blurred vision, excess salivation, body tremors, nervousness, sleeplessness, tardive dyskinesia, and blood disorders. Some drugs are available to control side effects. Learning to recognize side effects is important because they are sometimes confused with symptoms of the illness. A doctor, pharmacist, or mental health worker can explain the difference between symptoms of the illness and side effects due to medication. (See Antipsychotics, Extrapyramidal Symptoms, Medications, Neuroleptics.)

#### 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. (See Catatonic Behaviour.)

#### 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. (See Extrapyramidal Symptoms.)

#### Thought Alienation (a-le-in-a-shun)

This term refers to the belief that thoughts are being made known to others, usually through the radio or television. experiences dramatic behaviour changes in a matter of a few days or weeks.

#### **Treatment**

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

# 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), & RISPERDAL® (risperidone). (See Antipsychotics, Medications.)

#### Serotonin (ser-o-to-nin)

A neurotransmitter that relays impulses between nerve cells (neurons) in the central nervous system. Functions thought to be regulated by nerve cells that use serotonin include mood and behaviour, physical coordination, appetite, body temperature, and sleep.

#### Stereotypical Behaviour (ster-e-o-tip-i-cal)

A description of 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.

#### 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.)

#### **Standard Antipsychotics/Typical Antipsychotics**

Older, 1<sup>st</sup> generation medications used to treat serious mental illness. Standard antipsychotics differ 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 examples include haloperidol and chlorpromazine. (See Antipsychotics, Medications.)

#### **Thought Disorder**

A symptom of severe mental illnesses. Thoughts may be slow to form, or come extra fast, or not at all. The person may jump from topic to topic, seem confused, or have difficulty making simple decisions. Thinking may be coloured by delusions—false beliefs that have no logical basis. Some people also feel they are being persecuted—convinced they are being spied on or plotted against. They may have grandiose delusions or think they are all powerful, capable of anything, and invulnerable to danger. They may also have a strong religious drive, or believe they have a personal mission to right the wrongs of the world. (See delusions.)

#### **Thought Insertion**

This term refers to the belief that thoughts are being put into one's mind.

#### **Topectomy (to-pek-to-me)**

A procedure where there is a surgical removal of a small and specific part of the brain in the treatment of mental illness. Surgery is generally limited to cases where medication and other treatment methods have not been effective.

#### Tranquilizer (tran-kwih-li-zer)

A medicine which produces a calming effect. The socalled major tranquilizers are often used to treat anxiety.

#### **Undifferentiated Type Schizophrenia**

Categorized by the fact that symptoms of schizophrenia are present, but the individual does not meet criteria for specific schizophrenia types such as paranoid, disorganized, or catatonic. This is a subtype of schizophrenia.

#### Ventricles (ven-trih-kals)

These are 4 fluid-filled chambers in the brain which form a network with the spinal cord.

Sources:

Basic Facts About Schizophrenia: Youth's Greatest Disabler, British Columbia Schizophrenia Society, April 2000.

<u>The Truth about Schizophrenia: Why You Should Change Your</u>
<u>Thinking about Youth's Greatest Disable, Manitoba Schizophrenia Society,</u>
(Jane Burpee & Chris Summerville, eds.), March 2000.

Schizophrenia Digest Magazine, Spring 2002 Edition.

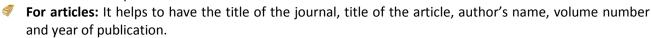
This is a list of books and articles on the subject of mental illness and family recovery. You can find most of these publications at your local library, or you can order them from a bookstore.

While most of these publications are authored by professionals, some are written by those afflicted with mental illness or their family members and offer very personal points of view that may help you feel less alone.

When you are searching for these publications, keep in mind the following:



For books: It helps to have BOTH the title of the book and the author's name.



Some mental health organizations have small libraries where you can borrow books. You may be asked for a small deposit, which is refunded when the books are returned.

If you are searching for a book at a bookstore, it helps to have the ISBN, the International Standard Book Number. Every book has one, and it is the most specific way for bookstores to help you find the exact book.

#### REFERENCE BOOKS

Beyond Crazy: Journeys Through Mental Illness



by Scott Simmie & Julia Nunes (Toronto: M&S, 2002) ISBN: 0771080689

Brave New Brain: Conquering Mental Illness in the Era of the Genome

by Nancy Andreasen (Toronto: John Wiley & Sons, 2001) ISBN: 0195145097

Breakthroughs in Antipsychotic Medications: A Guide for Consumers, Families, and Clinicians

Edited by Peter J. Wieden (NY: W.W. Norton &Co, 1999) IBSN: 0393703037

The Broken Brain: The Biological Revolution in Psychiatry

by Nancy Andreasen(New York: Harper & Row, 1984) IBSN: 0060912723



The Burden of Sympathy: How Families Cope with Mental Illness

by David A. Karp (NY: Oxford University Press, 2001) IBSN 0195123158

Family Caregiving in Mental Illness

by Dr. Harriet P. Lefley (Sage Publication, 1996) IBSN: 0803957203

Grieving Mental Illness: A Guide for Patients and Their Caregivers

by Virginia Lafond (Toronto, U. of T. Press, 1994) ISBN: 0802006140

Helping Someone with Mental Illness

by R. Carter with S.K. Gohant (NY: Time Books, 1998) IBSN: 012928997

Hidden Victims: An Eight-stage Healing Process for Families and Friends of the Mentally III

ByJulie Taillard Johnson(NY: Doubleday, 1988) ISBN: 038242123

How to Cope with Mental Illness in your Family: A Self-Care Guide for Siblings, offspring and Parents by Diane T. Marsh & Rex M. Dickens (NY: J.P. Tarcher/Putnam, 1998) IBSN: 0874779235

<u>How to Live with Mentally III Person: A Handbook of Day-to-Day strategies</u> by Christine Adamec (NY: John Wiley & Sons, 1996) IBSN: 0471114200

I Am Not Sick, I Don't Need Help

By X. Amador with A Johanson (NY: Times Books, 1996) ISBN: 0967718902

<u>It's Nobody's Fault: New Hope and Help for Difficult Children and Their Parents</u> by Harold Koplewicz (NY: Free Press, 1990) ISBN: 0812924738

The Last Taboo: A Survival Guide to Mental Health Care in Canada by Scott Simmie and Julia Nunes (Toronto: M&S, 2001) ISBN: 077108062x

Madness in the Streets: How Psychiatry and the Law Abandoned the Mentally III By R.J. Isaac & V.C. Armat (NY: Free Press, 1990 ) ISBN: 0029153808

Mapping the Mind

by Rita Carter (Berkeley: University of California Press, 1998) ISBN: 0520219376

Nothing to be Ashamed of: Growing up with Mental Illness in Your Family by Rita Carter (Berkeley: University of California Press, 1998) ISBN: 0688084931

Out of the Shadows: Confronting the American Mental Illness Crisis by E. Fuller Torrey (NY: J. Wiley & Sons, 1997) ISBN: 0471161616

<u>Surviving Mental Illness: Stress, Coping & Adaptation</u> by Agnes B. Hatfield & Harriet P. Lefley (NY. Guildford Press, 1993) ISBN: 0898620228

<u>Telling Is Risky Business: The Experience of Mental Illness Stigma</u> by Otto F. Wahl (Rutgers University Press, 1999) ISBN: 0813527244

<u>Transforming Madness: New Lives for People Living with Mental Illness</u> by Jay Neugeboren (CA: University of California Press, 2001) ISBN: 0520228758

<u>Understanding & Treating Mental Illness: The Strength & Limits of Modern Psychiatry</u> by John Cleghorn with Betty Low Lee (Toronto: Hogrefe & Huber, 1991) ISBN: 0920887201

When Madness Comes Home: Help & Hope for the Families of the Mentally III by Victoria Secunda (NY: Hyperion, 1997) ISBN: 0786861711
When Someone You Love Has a Mental Illness: A Handbook for Family, friends & Caregivers by Rebecca Woolis (NY: J.P. Tarcher, 1992) ISBN: 084776953

#### **BIPOLAR DISORDER/DEPRESSION**

A Map for The Journey: Living Meaningfully with Recurring Depression by Nan Dickie (Baltimore: America House Book Publisher, 2001) ISBN: 1588511073

A Mood Apart: Depression, Mania & Other Afflictions of the Self

by Peter C. Whybrow (NY: Harper Perennial, 1997) ISBN: 0465047254

Anti-Depressant Survival Program: How to Beat the Side Effects & Enhance the Benefits of You Medication

by Dr. R. J. Hedaya (NY: Crown Pub, 2000) ISBN: 0609604651

Bipolar Disorder: A Guide for Patients and Families

by Francis Mark Mondimore (Baltimore: John Hopkins Press 1999) ISBN: 0801861179

How to Heal Depression

by H. Bloomfield & P. McWilliams (LA: Prelude Press, 1994) ISBN: 0931580390

On an Even Keel: Understanding Bipolar Mood Disorder

by C. Thériault, LC. Thériault & P. Richard (Beresford NB; Publik-Art Ltd., 1992) ISBN: 0969659504

Riding the Roller Coaster: Living with Mood Disorder

by Marja Bergen (Kelowna: Northstone Pub, 1999) ISBN: 1896836313

Surviving Manic Depression: A Manual For Patients, Families and Providers

by E. Fuller Torrey & M.B. Knable (NY: Basic Books, 2002) ISBN: 0465086632

The Depression Workbook: A Guide for Living with Depression & Manic-Depression

by Mary Ellen Copeland (Oakland, CA: New Harbinger Publications, Inc. 1992) ISBN: 1879237326

The Tormented Mind: A True Story of Manic Depression

By Caroline Fei-Yeng Kwok (Toronto: C&R Publisher, 2000) ISBN: 0968674208 Order direct from;

http://www.thetormentedmind.com

<u>Understanding Depression: A Complete Guide to its Diagnosis and Treatment</u>

By Donald F. Klein & Paul H. Wender. (NY: Oxford University Press, 1993) ISBN: 0195072790

We Cry, We Fly: Our Lives with Manic Depression

by Betty Anne Sakals (Vernon: Lazuli Press, 2001) ISBN: 0968861903

When Someone You Love is Depressed: How to Help Your Loved One Without Losing Yourself

By L, E, Rosen & X.F. Amodor (NY: The Free Press, 1996) ISBN: 0684824078

You Mean I Don't Have to Fell This Way?

by Collette Dowling (NY: Scribner, 1991) ISBN: 0684192578

#### **SCHIZOPHRENIA**

Coping with Schizophrenia: A Guide for Families

by Evelyn B. Kelly (NY: Rosen Pub, 2001) ISBN: 0823928535

Diagnosis Schizophrenia: A Comprehensive Resource for Patients, Families and Helping Professional

by R. Miller & S.E. Mason (NY. Columbia University Press 2002) ISBN: 02311265255

Family Care of Schizophrenia: A Problem Solving Approach in the Treatment of Mental Illness

by Ian Falloon et al. (NY.Guildwood Press, 1984) ISBN: 08962049X

Getting Your Life Back Together When You Have Schizophrenia

by Roberta Temes, Ph.D. (Oakland: New Harbinger Pub, 2002) ISBN: 1572242736

The Family Face of Schizophrenia: True Stories of Mental Illness with Practical Counsel from America's Leading

Experts

by Patricia Backlar (NY: Putnam, 1995) ISBN: 0874777909

Inside Schizophrenia

by Gwynneth Hemmings (London: Sedgewick & Jackson, 1989) ISBN: 0283999349

Living and Working With Schizophrenia

by Joel J. Jeffries (Toronto: University of Toronto Press, 1990) ISBN: 0920490697

<u>Living with Schizophrenia: A Positive Guide for Sufferers and Carers</u>

by B. Linter (London: Vermillion 1996) ISBN: 0091813409

Schizophrenia at Home: A Guide to Helping the Family

by Jacqueline Atkinson (London: Croom Helm, 1986) ISBN: 0709905652

Schizophrenia: Straight Talk for Families and Friends

by Maryellen Walsh (NY: Morrow, 1985) ISBN: 0688041787

Surviving Schizophrenia—A Manjual for Families, Consumers and Providers

by Dr. E. Fuller Torrey (NY: Perrenial Library, 1988) ISBN: 0060962496

<u>Understanding Schizophrenia: A Guide to New Research on Causes and Treatment</u>

by Richard S. Keefe & Philip D. Harvey (NY: Free Press, 1994) ISBN: 0029172470

#### **OBSESSIVE COMPULSIVE DISORDER**

The Boy Who Couldn't Stop Washing: The Experience & Treatment of Obsessive-Compulsive Disorder

by Dr. Judith Rapoport (NY: Dutton 1989) ISBN: 0525247084

Brain Lock; Free Yourself from Obsessive-Compulsive Behaviour

by J. Schwartz with B. Beyette (NY: Reganbooks, 1996) ISBN: 0060391669

OCD New Help for the Family

by H.L. Gravitz (CA: Healing Visons Press, 1999) ISBN: 0966110447

When Once is Not Enough: Help for Obsessive-Compulsives by Gail Steketee & Kerrin White (Oakland, CA: New

Harbinger Publications, 1990) ISBN: 0934086878

When Going Through Hell...Don't Stop: A Survivor's Guide to Overcoming Anxiety and Clinical Depression

by Douglas Block (Portland: Pallas Communication, 2000) ISBN: 0929671023

Over and Over Again: Understanding Obsessive-Compulsive Disorder

by Fugen Neziroglu and Jose A. Yarura-Tobias (San Francisco, CA: Jossey-Bass Publications, 1997)

ISBN: 0600355349

#### **PERSONAL STORIES**

A Brilliant Madness: Living with Manic-Depressive Illness

by Patty Duke and Gloria Hochman (NY: Bantam Books, 1992) ISBN: 055030072560

Angelhead: My Brother's Descent into Madness

by Greg Bottoms (NY: Crown Pub., 2000) ISBN: 0609807145

An Unquiet Mind: A Memoir of Moods and Madness

By Dr. Kay Jamison (NY: A.A. Knopf, 1995) ISBN: 067102437x

The Beast: A Reckoning with Depression

by Tracy Thompson (NY: G.P. Putnam's Sons, 1995) ISBN: 0399140778

Call Me Crazy: Stories From the Mad Movement

Ed. by Irit Shimrat (Vancouver: Press Gang Publisher, 1997) ISBN: 0889740704

Conquering Schizophrenia: A Father, his Son, and a Medical Breakthrough

by Peter Wyden (NY: Knopf, 1997) ISBN: 0679446710

**Darkness Visible: A Memoir of Madness** 

by William Styron (NY: Farrar, Straus and Giroux, 1979) ISBN: 0376135029

Daughter of the Queen of Sheba

by Jacki Lyden (Boston: Houghton Mifflin, 1997) ISBN: 0395675

The Four of Us

by Elizabeth Swados (NY: Plume, 1993) ISBN: 04562269601

The Ghosts Behind Him

by Doris Ray (Prince George: Caitlin Press, 1999) ISBN: 92057677

In the Jaws of the Black Dogs

by John Bentley Mays (Toronto: Viking, 1995) ISBN: 0670861138

Imagining Robert, My Brother, Madness and Survival

by Jay Neugeboren (NY: Morrow, 1997) ISBN: 0688149685

Just A Mom

by Paula West (Meunster: Patio Pub, 2001) ISBN: 0968957005

Order direct from http://www.justamom.ca

Just Checking: Scenes from the Life of an Obsessive-Compulsive

by Emily Colas (NY: Doubleday, 1997) ISBN: 0385478526

Mad House: Growing Up in the Shadow of a Mentally III Sibling

by Tara Elgin Holley & Joe Holley (NY: W. Morrow, 1997) ISBN: 0688133681

My Mother's Keeper: A Daughter's Memoir of Growing up in the Shadow of Schizophrenia

by Kathy Cronkite (NY: Doubleday, 1994) ISBN: 038542194X

Passing for Normal: A Memoir of Compulsion

by Amy S. Wilensky (NY: Broadway Books, 1999) IBSN: 0767901851

Tell Me I'm Here

by Anne Deveson (Australia: Penguin Books, 1998) ISBN: 0140272577

The Outsider, A Journey into My Father's Struggle with Madness

by Nathaniel Lachenmeyer (NY: Broadway Books, 2000) ISBN: 076790190

The Quiet Room: A Journey Out of the Torment of Madness by Lori Schiller (NY: Warner Books, 1994) ISBN: 0446517771

Undercurrents: A Therapist's Reckoning with her own Depression

by Martha Manning (New York: Harper Collins, 1994) ISBN: 0062511831

Upstairs in the Crazy House: The life of a Psychiatric Survivor by Pat Capponi (Toronto: Penguin Books, 1992) ISBN: 0670838985

#### **FOR CHILDREN**

Can I Catch it Like a Cold? A story to Help Children Understand a Parent's Depression by Gretchen Kelbaugh (Toronto: CAMH, 2002) Order direct from the Centre for Addiction & Mental Health at: http://www.camh.net

Catch a Falling Star: A Tale from the Iris the Dragon Series

By Gayle Grass Order direct from : Iris the Dragon Inc., Otter Creek, 667 Highway 15, Lombardy, ON KOG 1L0

Fax: 613-283-9507

Edward the "Crazy Man"

By Marie Day (Toronto: Annick Press, 2002) ISBN: 1550377205

Kids Speak Up: Shining Light On Mental Illness

Order direct from: Canadian Mental Health Association, Calgary, Alberta

Phone: 403-297-1700; Fax: 403-270-3066

My Crazy Life: How I Survived My Family

Ed. Allen Flaming & Kate Scowen (Toronto: Annick Press, 2002) ISBN: 1550377329

Someone in My Family has a Mental Illness

by Lyne Brindamour, MSW (Vancouver: The Family Service of the North Shore, 2000)

Order direct from: 101-255 West 1<sup>st</sup> Street, North Vancouver BC V7M 3G8

Phone: 604-988-5281; Fax: 604-988-3961

Something is Bugging Me: Why Did Mom Get Sick? A booklet for children with a parent hospitalized in psychiatry \*

By Sharon Stern, M.S.W, R.S.W. (Ottawa: printed by Ottawa Hospital, General Campus, August 2000)

#### When Things Are Sad and Gloomy: Understanding Mental Illness in Your Family for Children who have a Parent

with Depression \*\*

By Nicole Chovil Order direct from: British Columbia Schizophrenia Society

Phone: 604-270-7841; Email: bcss.prov@telus.net

When Moods Go Up and Down: Understanding mental Illness in Your Family for Children who Have a Parent

with Bipolar Disorder 🔫

By Nicole Chovil Order direct from: British Columbia Schizophrenia Society

Phone: 604-270-7841; Email: bcss.prov@telus.net

When Things Get Really Weird: Understanding mental Illness in Your Family for Children who have a Parent with

Schizophrenia 🌹

By Nicole Chovil Order direct from: British Columbia Schizophrenia Society

Phone: 604-270-7841; Email: bcss.prov@telus.net

Why Are You So Sad? A Child's Book about Parental Depression

(American Psychological Association, 2002) ISBN: 1557988366

#### **MAGAZINES**

Some journals and magazines are available at the library, or you may subscribe to receive them at your home.

#### SCHIZOPHRENIA DIGEST 🌞



176 Catherine Street Fort Erie, ON L2A 2J5

Phone: 905-994-0302 Toll Free: 888-834-5537 Fax: 905-994-0304

Email: publisher@schizophreniadigest.com Website: http://www.schizophreniadigest.com

#### SOURCES:

The Truth about Schizophrenia: Why You Should Change Your Thinking about Youth's Greatest Disabler Manitoba Schizophrenia Society (Jane Burpee & Chris Summerville, Eds.) March 2000 (http://www.mss.mb.ca) British Columbia Schizophrenia Society (<a href="http://www.bcss.org">http://www.bcss.org</a>)

Schizophrenia Society of Nova Scotia (http://www3.ns.sympatico.ca/ssns)

AMI Quebec - Alliance for Mentally III (http://www.amiquebec.org)

#### **Session 1>** Recommended Websites

The Internet offers a lot of information, but there are some sites that may be misleading or have incorrect information. When searching sites, it is a good idea to consider the following:

- When was the site created and updated?
- Who wrote the information available on the site?
- Where does the site's information come from?
- Is the information consistent with other published material on the topic?
- Can the information be checked in books, periodicals, or other sources?
- Does the information seem biased in any way?

These are just a few recommended websites. Many sites have links to other sources of information

#### **AXIETY DISORDERS**

<a href="http://www.anxietybc.com">http://www.anxietybc.com</a>
 <a href="http://www.adam.mb.ca">http://www.adam.mb.ca</a>
 <a href="http://www.anxietyontario.com">http://www.anxietyontario.com</a>
 Anxiety Disorders Association of Manitoba
 Anxiety Disorders Association of Ontario

<a href="http://www.anxietynetwork.com">http://www.anxietynetwork.com</a>
 The Anxiety Network

http://www.adaa.org
 Anxiety Disorders Association of America

http://www.oocdn.org
 Ontario Obsessive Compulsive Disorder Network

http://www.amiguebec.org Alliance for the Mentally III in Quebec

http://www.bpkids.org Website of the Child and Adolescent Bipolar Foundation

http://www.bpso.org Bipolar Significant Others. An internet mailing list providing support and

information about Bipolar Disorder.

http://www.chovil.com An excellent consumer site, with unique and interesting information

about schizophrenia.

http://www.canadian-health-network.ca Public Health Agency of Canada

http://www.camh.net The Centre for Addiction and Mental Health

http://www.cmha.ca Canadian Mental Health Association

http://www.cami.org Canadian Alliance for the Mentally Ill

http://www.canmat.org The Canadian Network for Mood and Anxiety

http://www.depression.org National Foundation for Depressive Illness (American)

http://www.eufami.org Eurpean Federation of Family Associated of People with Mental Illness. Headquartered in Belgium, they are affiliated with 16 mental illness support organizations throughout Europe.

http://www.familyaware.org Families for depression awareness

http://www.kaiserfoundation.ca Information on concurrent disorders

by mental illness.

http://www.mentalhealth.com An award-winning site with an encyclopedic wealth of mental health

information, including online diagnosis. Designed by well-known Canadian psychiatrist, Dr. Phillip Long, and programmed by his

colleague, Brian Chow.

http://www.mcmanweb.com McMan's Depression and Bipolar Web. A site devoted to depression and

bipolar disorder.

http://www.mind.org.uk The leading mental health charity in the UK. Excellent fact sheets and

booklets available.

http://www.mhsanctuary.com/bipolar Mental Health Sanctuary

http://www.mhsource.com Mental Health Information Source

http://www.mentalwellness.com

information.

An online resource for schizophrenia and other mental health

#### MOOD DISORDERS

Some provinces do not yet have Mood Disorders Associations. The National website has useful links for various regions in Canada.

National <a href="http://www.mooddisorderscanada.ca">http://www.mooddisorderscanada.ca</a>

Alberta <a href="http://www.obad.ca">http://www.obad.ca</a>British Columbia <a href="http://www.mdabc.ca">http://www.mdabc.ca</a>

Manitoba <a href="http://www.depression.mb.ca">http://www.depression.mb.ca</a>
 Ontario <a href="http://www.amiguebec.org">http://www.amiguebec.org</a>
 Automodisorders.on.ca
 http://www.amiguebec.org

http://www.nami.org National Alliance for the Mentally III (American)

http://www.narsad.org National Alliance for Research on Schizophrenia and Depression

(American)

http://www.nisad.org.au Neuroscience Institute of Schizophrenia and Allied Disorders

(Australian)

http://www.nmba.org National Mental Health Association

http://www.openthedoors.com A site created by the World Psychiatric Association especially for teens

to dispel the stigma of mental illness.

http://www.pendulum.org Information about mood disorders.

http://www.psychcentral.com An index for psychology, support, resources, and mental health issues.

#### **SCHIZOPHRENIA**

Schizophrenia Society of Canada <a href="http://www.schizophrenia.ca">http://www.schizophrenia.ca</a> This site has links to branches across Canada.

• Alberta <a href="http://www.schizophrenia.ab.ca">http://www.schizophrenia.ab.ca</a>

British Columbia <a href="http://www.bcss.org">http://www.bcss.org</a>Manitoba <a href="http://www.mss.mb.ca">http://www.mss.mb.ca</a>

New Brunswick <a href="http://www.schizophrenia.ca/ssnb">http://www.schizophrenia.ca/ssnb</a>

Newfoundland & Labrador <a href="http://www.ssnl.org">http://www.ssnl.org</a>
 Nova Scotia <a href="http://www.ssns.ca">http://www.ssns.ca</a>

Ontario <a href="http://www.schizophrenia.on.ca">http://www.schizophrenia.on.ca</a>
 Prince Edward Island email:schizophreniapei@pei.aibn.com

• Saskatchewan <a href="http://schizophrenia.sk.ca">http://schizophrenia.sk.ca</a>

Quebec <a href="http://www.schizophrenie.qc.ca">http://www.schizophrenie.qc.ca</a>

<u>http://www.schizophrenia.com</u> A site created and maintained by Brian Chiko in memory of his brother, John. Forums for consumers, families, and professionals. Lots of up-to-date information, chat rooms, great links--plus an excellent search engine.

http://www.schizophreniadigest.com
The website for the Canadian magazine started by Bill MacPhee.
Inspiration and information online.

http://www.world-schizophrenia.org World Fellowship for Schizophrenia and Allied Disorders.

# Activity Getting to Know You

The goal of this activity is to provide an opportunity for you to share a bit about yourself and learn about the other participants in the group.

#### **Activity Steps**

- 1. Please turn to the person sitting to your right. If you do not already know this person, he/she is now your partner for this activity.
- 2. Take turns asking each other the interview questions below, taking a few minutes each to answer.
- 3. Once everyone has completed their interviews, you will be asked to introduce your partner to the rest of the group.

#### **Interview questions**

Ask your partner the following:

- 1. What is your first name?
- 2. Where are you from?
- 3. What is the first name of your relative/friend and his or her illness?
- 4. What are you hoping to learn from Strengthening Families Together?
- 5. Compare yourself to an animal, a dessert, or a type of weather condition that explains a personality trait or your current life situation.

#### Here are son examples to give you an idea:

ANIMAL: Cat – independent, Dog – loyal, Ox – strong, Horse – majestic DESSERT: Strawberry Rhubarb Pie – sweet and tart, Fudge – decadent WEATHER: Sunny – happy, Fog – confused, Tornado – very busy!

## Facts about > Mental Illness in Canada

The following quote accurately describes the dilemma in dealing with this topic:

Ask a hundred Canadians this question — what is mental disorder? — and you'll likely get a hundred different answers. And a lot of them will be just plain wrong. A character flaw, laziness, lack of discipline, the devil at work; such answers still pop up in public surveys.

This quote is from the book 'The Last Taboo: A Survival Guide to Mental Health Care in Canada'. This book is on your reading list and is highly recommended as a valuable resource. As you can also tell from this quote, often the terms 'mental illness' and 'mental disorder' are used interchangeably. We will be using them in this capacity throughout the sessions and handouts.

Many of you are participating in this group because your life has been affected by a mental disorder. You may be a family member, a person with a mental illness, or a professional working in their field of mental health. You may not have discussed this subject with many people. Most people are surprised to learn how common mental illness is.

First let's start with some definitions.

#### **Severe Mental Illnesses ARE:**

- Biological brain disorders that interfere with normal brain chemistry.
- More prevalent than most people realize. Nearly 6 million Canadians are likely to experience a diagnosable mental illness; 3% of Canadian are likely to have to live with a serious mental illness.
- Equal opportunity diseases, striking families from all walks of life, regardless of age, race, income, religion, or education.
- Devastating to ill persons and their families. One's thinking, felling, and relating are disrupted. All family members are affected.
- Treatable! Appropriate medical care and rehabilitation enable many people to recover enough to live productive lives.

#### **Severe Mental Illnesses Are NOT:**

- Anybody's fault. They are not caused by poor parenting or weak character.
- Completely preventable or curable at this time. Great advances have been made in understanding brain functioning, but not enough is yet known to prevent or cure serious brain disorders (mental illnesses).
- Hopeless. These illnesses present difficult challenges, but help is available. Support, education, and a community of friends who understand can make family life satisfying and meaningful again.

To fully appreciate the magnitude of these illnesses, we have some mental illness facts and figures to share with you.

# Did you Know?

#### Of the 10 leading causes of disability world wide, 5 are mental disorders:

- major depression
- schizophrenia
- bipolar disorder
- substance abuse disorder
- obsessive-compulsive disorder

The economic cost of mental illnesses in Canada was estimated to be at least **\$7.331 billion** in 1993.

**Less than 4%** of medical research funding goes to mental illness research.

# Facts about: Schizophrenia

- Schizophrenia is found all over the world, in all races, in all cultures, and in all social classes.
- It affects 1 in 100 people worldwide; that's approximately 290,000 Canadians.
- Persons with schizophrenia occupy more hospital beds in Canada (8%) than those with any other illness, except cardiovascular disease. One out of every 5 hospital beds in Canada is being used by someone suffering from schizophrenia.
- Schizophrenia costs Canadians more than \$2.3 billion in direct health care costs (hospitalization, disability payments) and an additional \$2 billion in support costs such as welfare, family benefits, and community support services, for a total of \$4.3 billion annually.
- Other costs, such as loss of individual potential, personal anguish, and family hardships, are impossible to measure.

#### **Facts about:**

#### **Moods Disorders**

- They can occur at any age. Approximately 1 in 4 of all women, and 1 in 8 of all men in Canada will have a serious mood disorder at some point in their lives.
- At any given time, almost 3 million Canadians have serious depression, but less than a third seek help due to the stigma.
- Bipolar Disorder affects 1-2 % of men and 10-25 % of women will have at least one episode of major depressive disorder.
- Thoughts about suicide are so common in mood disorders that they are considered a symptom of the illness.
- by 2020, it is estimated that depressive illnesses will become the second leading cause of disease burden worldwide, and the leading cause in developed countries like Canada.

#### **Facts about:**

# **Obsessive-Compulsive Disorder**

- Approximately 2% of the population has OCD
- Anxiety and depression account for 79% of all psychiatric diagnoses.

## **How Common Are Mental illnesses in Canada?**

It is estimated that nearly 1 in 5 Canadian adults will personally experience a mental illness during a 1-year period. The following chart summarizes estimates of the prevalence of the major mental illnesses among adults in Canada.

# Estimated One-Year Prevalence\* of Mental Illness among Adults in Canada

Mental Illness	Estimates of One-Year Prevalence
Mood Disorders	
Major (Unipolar) Depression	4.1-4.6 %
Bipolar Disorder	0.2-0.6 %
Dysthymia	0.8-3.1 %
Schizophrenia	0.3 %
Anxiety Disorders	12.2 %

<sup>\*</sup>Estimated percentage of the population who have the disorder during any 1 year period.

# The following are the estimated rates of mental illness in Canada according to the Canadian Health Network:

- Schizophrenia affects about 1 % of Canadians
- Mood disorders affect about 10 %
- Anxiety disorders affect about 12 %

## **Mental Illness is a Physical Disease**

Illness	Organ Affected	Signs & Symptoms	Treatment
*Diabetes	Pancreas	<ul> <li>Unusual Thirst</li> <li>Frequent urination</li> <li>Blurred vision</li> <li>Lack of energy, fatigue</li> <li>Unusual weight loss</li> <li>Frequent infections</li> <li>Numbness in hands or feet</li> </ul>	<ul><li>Insulin</li><li>Diet changes</li><li>Healthy lifestyle</li></ul>
*Cancer	Lungs	<ul> <li>Chronic fatigue</li> <li>Constant chest ache</li> <li>Persistent cough</li> <li>Persistent lung congestion</li> <li>Enlarged lymph nodes in neck</li> </ul>	<ul><li>Surgery</li><li>Chemotherapy</li><li>Radiotherapy</li><li>Healthy lifestyle</li></ul>
*Mental Illness	Brain	<ul> <li>Changes in personality</li> <li>Changes in behaviour</li> <li>Changes in perception</li> <li>Changes in mood</li> <li>Changes in thinking</li> </ul>	<ul><li>Medication</li><li>Psychotherapy</li><li>Support systems</li><li>Healthy lifestyle</li></ul>

<sup>\*</sup>Heredity may be a factor in mental illness, as it is in diabetes and cancer.

For more statistical facts, access health Canada's document A Report on Mental Illnesses in Canada online at: <a href="http://www.hc-sc.gc.ca">http://www.hc-sc.gc.ca</a>.

- I. Mental Illness Awareness Week Guidebook 2001, Canadian Psychiatric Association (http://www.cpa-apc.org/MIAW/guidebook/facts.asp)
- II. Ibid
- III. Basic Facts About Schizophrenia, Schizophrenia Society of PEI (http://www.schizophrenia.bcss.org)
- IV. Youth's Greatest Disabler, Schizophrenia Society of Canada (http://www.schizophrenia.ca/info.html)
- V. TenFacts You Should Know about Schizophrenia, Schizophrenia Society of PEI(http://www.schizophreniapei.pe.ca/QuickFacts.html)
- VI. Mood Disorders Association of Manitoba (http://www.depression.mb.ca/facts.htm)
- VII. Centre for Addiction and Mental Health (http://www.camh.net/depression/understanding\_depstats.html)
- VIII. Ibid
- IX. Centre for Addiction and Mental Health (<a href="http://www.camh.net/depression/understanding">http://www.camh.net/depression/understanding</a> depstats.html)
- X. Mood Disorder Association of Manitoba (<a href="http://www.depression.mb.ca/facts.htm">http://www.depression.mb.ca/facts.htm</a>)
- XI. Mental Illness Awareness Week Guidebook 2001, Canadian Psychiatric Association
- XII. The Last Taboo, Simmie, Scott & Nunes, Julia, Toronto: Mclelland & Stewart, 2001 (p.122)
- XIII. Centre for Addiction and Mental Health (http://www.camh.net/depression/understanding\_depstats.html)
- XIV. <u>A Report on Mental Illnesses in Canada, Chart Health Canada. Ottawa, Canada. October 2002. (http://www.hc-sc.gc.ca/pphbdgspsp/pubicat/miic-mmac)</u>

### Facts about> How is Mental Illness diagnosed?

Even though serious mental illnesses are physical diseases, there are no blood tests or x-rays that can easily detect the presence of a mental disorder. Typically, a diagnosis is made after a careful review of symptoms by a medical doctor, generally a psychiatrist.

Initially it is family members and friends who notice the symptoms. Family and friends often comment that the person is "not the same." The person who is ill usually becomes distant. The change in behavior is noticed in areas where there is a loss in ability: work or academic activities, relationships with others, and personal care and hygiene.

Since some symptoms may be common to more than one disorder, it may take some time to determine the specific illness that is affecting the individual.

Diagnosis is made on the basis of the symptoms that appear. This process involves ruling out other diagnoses. Diagnosing is not a precise art, and because a number of mental disorders share common symptoms, arriving at the right diagnosis can be a trial and error process. For some individuals, it can take a number of years before a correct diagnosis is made.

In making the diagnosis, doctors use the *Diagnostic and Statistical Manual of Mental Disorders*, also called DSM, which contains descriptions of the symptoms of psychiatric disorders and notes the different criteria necessary to diagnose each one.

The DSM is updated and revised by the American Psychiatric Association (APA) to include new diagnoses or criteria based on research. The DSM is currently in its 4<sup>th</sup> edition, and additions and revisions have been recently added to the text (2002) to ensure the manual remains current and relevant. Clinicians, researchers, psychiatrists, psychologists, social workers, nurses, and other health and mental health professionals use DSM-IV-TR.

#### The Diagnostic Process:

- An initial assessment to determine whether an individual has developed a brain disorder and the severity of the symptoms is scheduled with a psychiatrist, usually through a referral by a family doctor. This assessment includes both a physical examination and a clinical investigation.
- During the assessment, the individual's symptoms, functioning, cognitive ability, and family and medical history are reviewed and analyzed.
- Collateral information is also collected from every available source, including family members, social workers, school, police, or other authorities.

During the assessment phase, a psychiatrist usually makes specific inquiries related to the following:

- Positive and negative symptoms and signs, and changes in functioning;
- When the psychotic symptoms began and possible precipitating factors (e.g., substance use/abuse);
- Substance use/abuse;
- Any history of suicidal thinking and behaviour;
- Any history of violence, verbal or physical;
- The patient's general medical history;
- Any family history of schizophrenia and other psychotic disorders (including treatment received), other
  psychiatric disorders (including addictions and suicidal behaviour), and inherited medical illnesses;

- The current lifestyle of the patient, including housing environment, finances, social network and activities, work environment, and general functionality in the community;
- A developmental history, including social and academic functioning, both in childhood and adolescence.

The answers to these questions give the psychiatrist clues to the potential outcome of treatment. After the initial assessment, the individual should continue to receive assessments and further medical assistance in dealing with his or her brain disorder.

# What is>Biopsychosocial

Serious mental illnesses are complex illnesses that are defined by their symptoms. In considering the cause of these symptoms, doctors are concerned with the individual's *biology*, *psychology*, and *sociology*. Each of these areas may contribute factors to the cause of mental illness, and each is also considered important in the treatment process. The word is *BIOPSYCHOSOCIAL*.

This deals with the individual's environment, including cultural background and stressful events. Treatment would involve support systems set up with the individual.

BIO=	BIOLOGY	This deal with the individual's physical brain structure, chemicals in the brain, and genetic predisposition (a family history of mental illness). Treatment of this element would be medication.
beliefs therap		This involves the individual's personality, experiences, and personal beliefs. Treatment of this element would be psychotherapy (talk therapy). The individual would be taught healthy coping habits and given skills to help deal with the illness.
SOCIAL=	SOCIOLOGY	This deals with the individual's environment, including cultural background and stressful events. Treatment would involve support systems set up with the individual.

Biological factors that may contribute to mental illness include chemical imbalances in the brain, pre-natal trauma, birth trauma, and/or genetic vulnerability. Psychological and social factors may include lack of support from others, family violence, an abusive childhood, or major life changes like divorce or unemployment.

It is important to note that the exact causes of serious mental illnesses remain unknown. And it is also important to remember that mental illness is a physical disease; it is not just in someone's head or willful stubbornness.

# Facts about > Psychosis

Psychosis is a medical condition that affects the brain, causing a loss of contact with reality. Psychosis can lead to changes in mood, thinking, and abnormal ideas, and involves a change in ability and personality. When someone experiences or develops symptoms of psychosis, it is referred to as a 'psychotic episode.'

First-episode psychosis or 'first break' refers to the first time someone experiences psychotic symptoms. People experiencing a first-episode psychosis may not understand what is happening. Symptoms are highly disturbing and unfamiliar, leaving the person confused and distressed. The individual experiencing psychosis is no longer able to tell what is real from what is not real.

Psychotic episodes can occur with:

- ✓ Bipolar disorder
- ✓ Clinical depression
- ✓ Schizophrenia
- ✓ Schizoaffective disorder
- ✓ Schizophreniform disorder
- ✓ Some physical illnesses, such as : thyroid problems, Alzheimer's, and brain tumors or trauma to the brain.

With mood disorders such as bipolar disorder and clinical depression, the psychotic symptoms tend to fit with the person's mood. For example, if the person is unusually excited or happy (manic), the person may believe he/she is special and can perform amazing feats. If the person is depressed, the person may hear voices telling him/her to commit suicide.

#### WHAT CAUSES PSYCHOSIS?

While there are several theories about the causes of psychosis, the exact cause remains unknown. Psychosis may be caused by a combination of biological factors -- which are not clearly understood at this time – that create vulnerability, changes in the brain, or a dysfunction in neurotransmitters in the brain.

Psychotic symptoms may emerge in response to stress or drug abuse, or emerge as a result of maturation (puberty). Some psychoses appear to be a response to stress, for example Brief Reactive Psychosis. And some drugs can induce psychosis. This is referred to as drug – induced or drug – assisted psychosis. Drugs can also induce a psychotic episode in someone developing schizophrenia.

#### THE PHASES OF PSYCHOSIS

A psychotic episode occurs in 4 phases. The length of each phase varies from person to person.

#### 1. The Premorbid phase

This is the period of time before the onset of symptoms.

#### 2. The Prodrome phase

During this phase, the early signs are vague and hardly noticeable. There may be changes in the way people describe their feelings, thoughts, and perceptions. The individual may withdraw socially and may begin to display signs of poor personal hygiene (not bathing regularly, brushing teeth, or combing hair). Often the changes in behaviour seen during this phase are dismissed as "teenage angst."

Awareness of the early warning signs is very important at this stage. The most noticeable symptom is withdrawal from friends and social activities. One mother noted that her son became antisocial, hostile, and angry. "He would give me these 'drop dead looks' in response to some of my requests. They were cold, reptilian, "lizard-like" look which gave one the shivers. Only later, in hindsight, did I learn those looks were indicators of the disease."

#### 3. The Acute phase

During the acute passé, psychotic symptoms are experienced, such as disorganized thinking, hallucinations, or delusion. The individual may heighten or blunted senses. The writer Anne Deveson noted this sensory distortion in her book, *Tell Me, I'm Here:* "Sounds may seem louder or sharper, colours brighter, touch unexpected, smells more pungent. Sometimes objects become distorted and frightening. The steering wheel of a car might turn into a snake. There might be a growing sensation that everyone is watching you. Noises might follow you. Time can seem to disappear, slow down or speed up."

#### 4. The Recovery phase

Psychosis is treatable, and most people recover. The pattern of recovery varies from person to person. People have also recovered from first-episode psychosis and not experienced another psychotic episode again.

#### **TYPES OF PSYCHOSIS**

When someone has a psychosis of a particular psychotic illness is usually given. Diagnosis means identification of an illness by symptoms, so the diagnosis will depend on what symptoms are present, what brought on the illness, and how long the symptoms last.

When someone is experiencing psychosis first time, it can be difficult to make an exact diagnosis because many of the factors about the illness may remain unclear.

The following are some of the diagnostic labels you might hear.

#### **Drug-induced psychosis**

Using or withdrawing from drugs and alcohol can sometimes cause psychotic symptoms. Often these symptoms will rapidly disappear as the substance wears off. In other cases, the illness may persist after beginning with

drug-induced psychosis. This occurs when the individual has a genetic vulnerability to an illness and the drugs set off the psychosis.

#### **Organic Psychosis**

Psychotic symptoms may appear as a result of head injury or a physical illness that disrupts brain functioning, such as encephalitis, AIDS, Alzheimer's disease, or a tumor. There are usually other symptoms present, such as memory problems or confusion.

#### **Brief Reactive Psychosis**

Psychotic symptoms may appear quickly in response to a major stress in someone's life, such as a death in the family, divorce, or other important change of circumstances like being laid off. symptoms can be severe, but the person usually makes a quick recovery in only a few days.

#### Schizophrenia

Schizophrenia refers to an illness in which the psychotic symptoms have been present for a period of at least 6 months. Again, symptoms, severity, and length of illness vary from person to person. There is significant loss of ability in a social and/or occupational setting.

#### **Schizophreniform Disorder**

This diagnosis is usually given when symptoms have lasted for less than six months.

#### **Bipolar Disorder (Manic Depression)**

Since bipolar disorder is a mood disorder, psychosis appears as part of a more general disturbance in mood. The mood disturbance is characterized by extreme highs (mania) and lows (depression). Psychotic symptoms tend to fit in with the person's mood. If they are unusually excited or happy, they may believe they are special and can perform amazing feats. If they are depressed, they may hear voices telling them to commit suicide.

#### **Clinical Depression**

Clinical or major depression, as it is also called, is also a mood disorder. This is a severe depression. Psychotic symptoms like auditory hallucinations can occur with depression. As we mentioned earlier, the psychotic symptoms usually suit the mood – so people with clinical depression may hear voices telling them that they are ruined, or that they are worthless individuals with nothing to contribute.

#### **Schizoaffective Disorder**

This diagnosis is made when the clinical picture is not typical of either a mood disorder or schizophrenia; the person has concurrent or consecutive symptoms of both illnesses. This means the individual has schizophrenia with a mood component.

Facts about > Psychosis

#### SYMPTOMS OF PSYCHOSIS

It is difficult to understand the experience of psychosis. The following are some of the more characteristic symptoms of psychosis.

#### **Disorganized Thinking**

Everyday thoughts become confused or do not connect properly. Ideas are unclear or don't make sense. A person may have difficulty concentrating, following a conversation, or remembering things. Thoughts seem speeded up or slowed down. Often there is an inability to plan or make decisions. If the individual is having difficulty communicating thoughts or is verbally expressing unusual ideas, the person may be experiencing disorganized thinking.

#### **Hallucinations**

In psychosis, the person sees, hears, feels, smells, or tastes things that are not actually there. For example, they may see things or hear voices that aren't there. These voices are referred to as auditory hallucination. Hallucinations are very difficult to understand for those who have not experienced them.

Hallucinations occur more frequently during the acute phase. During this phase, some individuals also experience heightened senses. This is not the same as a hallucination. In this case, sense can become so acute that the individual experiences great discomfort.

#### **Delusions (False Beliefs)**

It is common for a person experiencing a psychotic episode to hold false beliefs, known as delusions. They are so convinced of their delusion that even the most logical argument cannot make them change their mind. For example, someone may be convinced that the cars parked outside his or her house indicate that the police are watching him or her. It is important to never argue with someone's delusion. The delusion is extremely powerful and arguing with the person will only increase his or her stress level.

#### **Changed Feelings**

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

#### **Changed Behaviour**

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

Behavioural changes are often associated with these symptoms. For example, a person may call the police or be too scared to sleep because of what the person believes he/she has seen or heard. They may stop eating if they think their food is poisoned. Someone who believes he is Jesus Christ may spend all day preaching in the streets. Symptoms vary from person to person and can change over time.

Someone who is experiencing such frightening changes will often try to keep them a secret. There is often a strong need to deny what is happening, and attempts are made to avoid other people and situations where the fact that one is different might be discovered. These intense misperceptions of reality can cause feelings of dread, panic, fear, and anxiety – all natural reactions to such terrifying experiences. The distress is intense, but often the individual may try to keep it hidden due to a strong sense of denial or fear.

# Facts about > Stigma – Misunderstanding Mental Illness

Why do people find mental illness so unacceptable? Can you think of many other illnesses that are not discussed openly? Years ago, cancer was not a topic that anyone discussed in an open and frank manner, yet as more information about cancer became available, pamphlets and health warnings became more visible. Even AIDS, a once severely taboo topic, has lost its stigma today.

#### **Public Perception of Mental Illness**

The following questions may help illuminate this subject. It is a multiple-choice question, and you may have multiple answers.

- 1. How many movies have you seen with characters that had a mental illness?
- 2. How many of those characters were:
  - A. Quiet, unassuming neighbours
  - B. Hardworking, struggling artists
  - C. Dangerous, violent individuals with no friends
  - D. University (or college) professors who won the Nobel Prize

This question is not meant to be as casual as it may appear. For many people, the images they have of mental illness have come from television, movies, or newspapers.

In the case of the latter, has anyone ever seen a front-page headline that reads: "Woman who suffers with schizophrenia receives Volunteer of the Year Award", or how about "Father with bipolar disorder: An incredible role model for his community"?

It is more likely that you will read a story about mental illness when a crime has been committed and the newspapers want to sensationalize the story in an effort to sell more papers.

In addition, people with mental disorders are rarely portrayed accurately or realistically in movies. Often, a character with a mental illness is portrayed negatively or else inaccurately (for example, *The Snake Pit; The Cell; Me, Myself & Irene*). The media often shows people with a mental illness as dangerous individuals. Fortunately, film portrayals and media reporting have gotten much better over the years, but often it just takes one negative image to set back the clock on all the positive progress and education.

This societal stigma creates a tremendous burden for people with mental disorders, and leaves them vulnerable to becoming isolated.

As Jane E. Kenny notes in her article on stigma, the term "mental illness" has been linked to images of people who are unpredictable, unreliable, unlikable, incompetent, and bizarre.

To be fair, this stigma existed before the invention of television or motion pictures. People with mental illness have been discriminated against for centuries. They were the "rarely spoken about" relatives, shunted away in mental asylums. But in our modern society, this is an unacceptable reality.

Society's understanding about serious mental illnesses lags way behind the facts. People with mental illness are discriminated against due to this general ignorance. This is, in effect, a double burden. First, they have an incurable, chronic brain illness that they must learn to live with as best they can. Then, due to their illness, they are also discriminated against and have to live with that as well.

Professor James Fox says:

"If people would realize that with mental illness there is often something wrong with the structure or function of the brain, just like a pancreas or a kidney sometimes doesn't form or function properly, there would be fewer stigmas attached to it."

Many people with mental illness say one of the biggest problems is that others do not accept them. Once they have learned to manage their symptoms, they still have to face overwhelming difficulties with friends, housing and work. They feel the sting of discrimination in almost everything they do. Old friends, and sometimes family members, find it difficult and are uncomfortable in their presence. People with mental illnesses then become isolated and cut off from society.

Is it any wonder that many people with a mental disorder feel they don't belong; that they are "different"; that they are not respected or valued? Is it any wonder that someone who is becoming ill may delay getting help? This widespread, hurtful ignorance leads to the terrible social isolation and loneliness that can become the most disabling feature of the illness.

Why does the stigma persist after all the advances made in research about mental illness being a physical illness like diabetes or a heart condition? Because the myths still persist.

# The Myths about Mental Illness

There are many, many myths about mental illness. These myths have contributed to creating this stigma, which has been around for centuries. The stigma is really a result of fear and ignorance.

# **Commonly Held Fears**

#### The Fear of Danger

Many people are afraid that people who have a mental illness are dangerous, unpredictable, and aggressive. In reality, people with a mental illness are usually anxious, fearful of others, and passive. The myth of danger is largely based on inaccurate and outdated cultural myths that always portrayed people with mental illness as

violent, and media sensationalist stories about the few mentally ill people who do commit violent acts. (For example, the 1995 death of sports television reporter Brian Smith in Ottawa.)

#### Fear of the Unknown

People often fear what they do not understand. In the past, there was extremely limited understanding about mental illness. Wild guesses were the norm for diagnosis. Some cultures believed mental illness was the work of evil spirits, while others believed bad blood, poisons or lack of moral integrity caused it. As people learn more about the real nature of mental illness, many of these harmful beliefs will hopefully fade.

#### **Fear of Violence**

This is an illusion, reinforced by the fact that you always hear about the criminal acts perpetrated by individuals who are ill in a sensational manner – on the front page, with big bold type to emphasize or really exaggerate the issue. People with mental disorders are no more likely to commit crimes than the general population.

However individuals with untreated mental illness do have a higher rate of violence than the general population. also, these individuals generally have a previous history of violent behaviour.

The three primary predictors of violence include:

- History of past violence, whether or not a person has a serious brain disorder;
- Drug and alcohol abuse, whether or not a person has a serious brain disorder; and
- Failure to take medication when experiencing command hallucinations or paranoid delusions.

Also, if mental illness is left untreated and allowed to become progressively more severe, people who are acutely ill may inadvertently end up in jail. Most of these individuals end up in jail for committing minor or so called "nuisance crimes" (e.g., shoplifting, disturbing the peace, public drunkenness). Due to this situation, prisons have become the "new asylums of the 20<sup>th</sup> century" for some individuals.

#### **General Aversion to Illness**

After hundreds of years, mental illness has finally been identified as an illness, just like epilepsy, Parkinsonism, or diabetes. This change from the realm of the witch doctor to the medical doctor doesn't erase all the negative feelings; it only lessens them somewhat. The public still has a very strong aversion to hospitals, illness, and doctors.

An individual who may have been absent from work due to lung cancer treatment receives more sympathy and understanding than someone who develops a mental illness, even if the cancer patient has spent a lifetime smoking. This is not to say that people who develop cancer as a result of smoking for years do not deserve sympathy; of course they do. Smoking is addictive. But people who develop mental illnesses also require compassion, patience, and understanding. As one individual stated, "Have a look around the average psychiatric ward of a hospital and not the almost total absence of 'Get Well Soon' floral and balloon bouquets."

### Reducing Stigma: What Can You Do To Help?

Sharing the knowledge you have gained with others is an effective tool in battling stigma. Using terms like *brain disorder* or *biological chemical imbalance in the brain* may help. The words schizophrenia and mental illness are surrounded by misconceptions.

Dr. Fred Frese, a prominent American psychiatrist who has schizophrenia, believes that the best thing anyone can do in fighting stigma is to stop using pejorative language. Words like crazy, nuts, or psycho offends people with mental health problems and reinforce the stigma of mental illness. Dr. Frese talks about his patients' troubled responses to offensive signs and t-shirts that say, "You don't have to be crazy to work here but it helps" or "Gone crazy....back in 5 minutes."

Expression like "I must have been crazy" or "What, are you nuts?" are not helpful, even in casual conversation. You could easily say, "I was not thinking clearly" or "That's an odd suggestion."

What if you heard someone say, "That guy's a psycho." You probably have heard someone say something like this, or similar. Your response could be "He seems to be acting strange; perhaps we should try to help by

understanding what difficulties he may be going through." You can also say, in your most polite voice, "Your language is reinforcing a negative image that hurts people who are mentally ill." or, "Your language is offensive; would you call a person 'Canceric'?" Eventually, people will get the idea.

On a larger scale, when you see offensive advertising campaigns, write or phone your local mental health organization as well as the company behind the campaign. By doing this, you can inform the company about the disturbing nature of their lack of knowledge, and the problem that their ignorance has caused. This type of misunderstanding usually occurs

out of ignorance, not malice. In some provinces, mental health associations have started a media stigma awareness campaign and provide web addresses where you can submit information.

# **Resources** > Where Can You Go for Help?

### You are not alone.

You and your family are not alone in helping someone with a serious mental illness.

Today, there is information available and there are many organizations and professionals that can assist you in dealing with the challenges you face.

Some of the professionals you can find in your community include:

- + Family doctors
- + Nurses
- + Psychiatrists
- + Counsellors
- + Social workers
- + Psychologists

You may also receive advice and much needed support from other families, friends, self-help groups, and associations.

The Schizophrenia Society of Canada, the 10 provincial societies, and the over 100 community-based chapters are there to help individuals with schizophrenia and their families have a better quality of life.

#### Where can you go for help in your neighbourhood?

Contact your provincial society today for an answer.

### SCHIZOPHRENIA SOCIETY OF CANADA

### Who are we?

SSC is a national registered charity that has been in operation since 1979. Our mission is to alleviate the suffering caused by schizophrenia and related mental disorders.

Using a federation model, we work with 10 provincial societies and their over 100 chapters and branches to help individuals with schizophrenia and their families have a better quality of life while we search for a cure. At SSC, we are committed to:

- Raising awareness and educating the public to help reduce stigma and discrimination;
- Supporting families and individuals;
- Advocating for legislative change and improved treatment and services; and
- Supporting research through the SSC Foundation and other independent efforts.

### What is our mission?

The SSC's mission is to alleviate the suffering caused by schizophrenia and related mental disorders.

### What do we believe?

SSC's philosophy is based on the following core values:

- Persons with schizophrenia and their families are not to blame for this biological brain disorder;
- The basis of effective treatment is early detection and intervention, including access to the most effective medications and efficient multidisciplinary and intergraded community support systems;
- Individuals and families that live with schizophrenia and other mental illnesses should be included in determining their treatment and care process; and
- Persons who live with schizophrenia and other mental illnesses should be treated with compassion. Stigma is one of the greatest barriers to accessing treatment.

For more information on our national, provincial, and community operations, please call toll free in Canada at 1-888-SSC-HOPE (1-888-772-4673) or visit our website at <a href="http://www.schizophrenia.ca">http://www.schizophrenia.ca</a>

# Getinvolved

### How can I help?

You can become a member, a volunteer and/or a donor. All three are needed at the national, provincial, and community levels to help alleviate the suffering caused by schizophrenia.

#### Member?

As a member, you will be connected with people who understand and share similar concerns for loved ones suffering from schizophrenia. You will help strengthen an effective voice that advocates on behalf of individuals and families living with schizophrenia and related mental disorders. You will also receive national, provincial, and local newsletters, which will provide updates on the latest developments and activities.

#### Volunteer?

As a volunteer, you will work with people committed to making a difference to those living with schizophrenia. You will gain valuable experience by working in a variety of areas, such as public awareness and education, fund raising family support, and advocacy at the national, provincial, and community levels.

#### Donor?

As a donor, it is our hope that your financial donation will improve the quality of life today for those who suffer from schizophrenia, and provide hope for a cure. your financial support can go toward programs and initiatives required to keep our organizations, at various levels, running.

### **SSC Provincial Affiliates**

#### **BRITISH COLUMBIA**

### **British Columbia Schizophrenia Society**

#201, 6011 Westminster Highway

Richmond, BC V7C 4V4 Tel: (604)270-9861

Email: <a href="mailto:bcss.prov@telus.net">bcss.prov@telus.net</a> Website: <a href="mailto:www.bcss.org">www.bcss.org</a>

#### **ALBERTA**

#### Schizophrenia Society of Alberta

5<sup>th</sup> Floor, 9942-108 Street Edmonton, Alberta T5K 2J5

Tel: (780)429-7880 Fax: (780)422-2800 Toll Free in Alberta: 1-800-661-4644 Email: infor@schizophrenia.ab.ca Website: www.schizophrenia.ab.ca

#### **SASKATCHEWAN**

#### Schizophrenia Society of Saskatchewan

PO Box 305, Station Main Regina, SK S4P 3A1

Tel: (306)584-2620, Fax (306)584-0525

Email: sssprov@asktel.net

Website: www.schizophrenia.sk.ca

#### **MANITOBA**

#### Manitoba Schizophrenia Society

3-1000 Notre Dame Avenue Winnipeg, MB R3E 0N3 Tel: (204)786-1616

Toll free in Manitoba: 1-800-263-5545

Email: <a href="mailto:info@mss.mb.ca">info@mss.mb.ca</a>
Website: <a href="mailto:www.mss.mb.ca">www.mss.mb.ca</a>

#### **ONTARIO**

### **Schizophrenia Society of Ontario**

130 Spadina Avenue, Suite 302 Toronto, Ontario M5V 2L4

Tel: (416)449-6830 Fax: (416)449-6830 Toll Free in Ontario 1-800-449-6367 Email: <a href="mailto:sso@schizophrenia.on.ca">sso@schizophrenia.on.ca</a> Website: <a href="mailto:www.schizophrenia.on.ca">www.schizophrenia.on.ca</a>

#### **QUEBEC**

#### Societe quebecoisse dela schizophrenie

741 Rue Hochelaga

Montreal, Quebec H1N 3M5 Tel: (514)241-4000 ext. 3400

Toll Free in Quebec: 1-866-888-2323

Fax:(514)251-6347 Email: info@schizophrenie.gc.ca

Website: www.schizophrenie.qc.ca

#### **NEW BRUNSWICK**

### **Schizophrenia Society of New Brunswick**

Victoria Health Centre 65 Brunswick St., Rm G54

Fredericton, NB E3B 5G6 Tel: (506)451-7770

Email: <a href="mailto:ssnb@nb.aibn.com">ssnb@nb.aibn.com</a>

Website: www.schizophrenia.ca/ssnb

#### **PRINCE EDWARD ISLAND**

### Schizophrenia Society of Prince Edward Island

P.O. Box 25020,

Charlottetown, PEI, C1A 9N4

Tel: (902)368-5850, Fax: (902)368-5467 Email: <a href="mailto:schizophreniapei@pei.aibn.com">schizophreniapei@pei.aibn.com</a>

#### **NOVA SCOTIA**

### **Schizophrenia Society of Nova Scotia**

Nova Scotia Hospital Rm 401- 410, Fourth Floor P.O. Box 1004, Simpson Hall Dartmouth, NS B2Y 3Z9 Tel: (902)465-2601

Toll Free in Nova Scotia: 1-800-465-2601

Email: <a href="mailto:ssns@ns.sympatic.ca">ssns@ns.sympatic.ca</a>
Website: <a href="mailto:www.ssns.ca">www.ssns.ca</a>

#### **NEWFOUNDLAND & LABRADOR**

#### Schizophrenia Society of Newfoundland & Labrador

205-206 West Block, Waterford Hospital

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# **Session 1** > Voices from the Shadows

Voices from the shadow; they show up as a single line in a patient's file: "auditory hallucinations." But these hallucinations or voices can mean a lifetime of feeling that someone is following you around, humiliating you at every turn.

I've got a little job to do at Mountain Plaza Mall. I need to find a framed photo of the Team Canada players who beat the Soviets in 1972.

But I'm having a hard time getting the errand done. Somebody's yelling at me and I can't make him go away.

"Hey pig, pig, pig. You smell. You're filthy.""You swine. You're disgusting. Stop it. Don't touch it. Hey you,pigbreath. They smell you. Everyone smells you."

I notice the young clerk at the entrance to The Fashionable. I think she's looking at me. I think she can hear this guy yelling at me.

There's another sound. Whispers. Whimpers. I can't quite make them out. Now a soft woman's voice.

"You are the one. We chose you. You know I came for you. Just you."

I move past Hortons. The sounds are going away. I'm getting tired. I'm having a hard time remembering what I'm supposed to be doing. Oh yes, the picture.

At the far end of the mall I find Art & Carpet. They've got hockey pictures here. Maybe they've got the '72 team.

"You're pathetic. Everyone knows about you and you're disgusting."

The voices have started again.

I'm supposed to get that picture. A man and woman are talking in the store.

I wait until they're finished, while the guy keeps taunting me. "Loser, loser. Go ahead and try to do something right. You can't."

Then I walk over him, to the man in the store. He doesn't have that picture. He says he can order it for me. I say no thanks. I just want to get out of here.

I can't even walk properly. I feel I'm leaning to my right. My balance is gone. I'm exhausted.

I don't want to, but I go into Tally's Sports & Cards. There's the picture. I note that it's \$29.95 and leave the store.

It starts up again. "Hey, they smell you. You better get inside. Get out of sight."

More whimpering, titters, cries. Then nothing. I brace for more.

This time, though, in front of *Caliga Shoes*, the silence is broken by the clear, calm voice of Patricia Deegan, PhD, Director of training for the National Empowerment Centre in Lawrence, Mass.

"Congratulations. You're one of the lucky ones. You can turn your voices off. The simulation is over."

For about 45 minutes, I had ataste of what many people with schizophrenia experience all the time. I heard voices.

The session was held the other day at the St. Joseph's Centre for Mountain Health Services, site of the old Hamilton Psychiatric Hospital.

There were several dozen of us. Workers with Mission Services, Good Shepherd, therapists, cops.

First we watched a video address from Deegan, who has spoken the world over on *Hearing Voices That Are Distressing*. She hears them herself, nearly every day.

She explained that little attention has been paid to the voices. They show up as a single line on a patient's file: "Auditory hallucinations. At times, voices are persecutory in nature."

Health workers whose clients can't walk say that spending 24hours in a wheelchair gives them an understanding that no classroom lecture can. So Deegan and colleagues, other "experienced voice hearers," produced a tape and an assignment.

Mary Griffiths, a nurse who helps integrate people with schizophrenia back into the community, handed each of us a tape and an assignment.

Mine was to find that team photo. Others had to count shampoo at the drug store or check out shoes or vitamins.

Before we switched on our Walkmans and pulled on the headphones, she told us to be careful on that walk to the mall.

I went alone along Brantdale. There were 2 people not far ahead of me.

I could see them talking. Then I saw the woman stop and pull off her headphones. "I can't do this," she told me, and headed back to the hospital.

We listened to those voices, knowing it was just an exercise, knowing we could just hit the off button. Even with medication, a great number of people with schizophrenia can never make the voices go away.

Schizophrenia is more prevalent that Alzheimer's disease or multiple sclerosis. About one in 10 people with schizophrenia commits suicide.

The idea here is to start finding out more about the voices, to ask the right questions, to case that person's torment and isolation.

In the words of one worker after a session with the tape: "Never again will I say to someone: "Just block it out."

# Mental Illness > Chinese Style

Social Stigma towards mental illness exists in every society, including Canada and the United States of America. Yet the extent of such stigma varies according to the cultural and sociological backgrounds of each society. The purpose of this article is an attempt to examine the specific factors which lead to the social stigma towards mental illness in the Chinese community at large.

Culturally, most Chinese tend to hide their feelings in comparison to their western counterparts. Indeed, there is a famous Chinese saying which said that "family shame should be kept inside the house." The loss of face is important to many Chinese. It is a social phenomenon that mental illness is a shame. This ill-conceived notion has to do with their ignorance of 'mental illness." According to Lin Chiu, a veteran pharmacist at the Castle Peak Mental Asylum in Hong Kong, "Many Chinese have a very vague idea as to what mental illness is. To a lot of them, they tend to relate mental illness to violence, with kittle knowledge that there are various degrees and types of mental illness." Dr. Ted Lo, a Chinese-speaking psychiatrist in Toronto and the founder of the HONG FOOK MENTAL HEALTH ASSOCIATION in Toronto, echoes with Chiu's opinion. He emphasizes that there is a lack of education among the Chinese towards mental illness and most tend not to admit that they are afflicted with the illness. This unwillingness to be "associated with mental illness" is understandable when there is so much social stigma within the community towards mental illness.

To the mind, the Chinese media plays an important role in stereotyping mental illness. Dr.Ted lo also agrees with this view. In my own experience of reading Chinese newspapers, I hardly find any editorials which pay attention to analyzing the causes of mental illness. On the other hand, they tend to use sensational headline in their reports of the "mentally ill" cases. For instance, big headline such as 'MENTALLY-ILL MAN TRIED TO KILL A TRANGER." In a recent incident in which a homicide occurred as a result of some family matters, the reporter just mentioned very briefly that the father is believed to have mental problems. In fact, according to a survey done in Hong Kong, only 1.4% of those who committed violent crimes are related to the so-called "mentally-ill" while 98.6% who committed violent crimes are considered 'normal.' Thus, such negative reports from the mass media undoubtedly increase the social stigma of the Chinese community towards mental illness. And of course, there is a popular local slang, which adds to the existing social stigma. Phrases such as "you want to go to Castle Peak Asylum?" or "you must be CRAZY!" are often heard in the streets and in movies. Thus, under such a negative cultural environment towards mental illness, it is understandable that many potential mentally ill people refuse to seek help.

Hong Kong, a small island, is crowded with over 6 million people, with a big contrast between the rich and the poor. With such a discriminatory attitude towards mental illness, it seems that there would be little hope for employment if the employer finds out that the employee has a psychiatric history,. Dr. Lo said that when he left Hong Kong about 24 years ago, there were the Pro-Life Rehabilitation Program and the Hong Kong Mental Health Association who tried to line up jobs for the ex-psychiatric patients. But he also pointed out that to what extent is it successful, he does not know. Dr. Lo, who also knows about the psychiatric system in China, said that in China, little attention is paid to mental illness and that the social stigma exists even more so.

According to the Canadian Mental Health System, there are about one in four Canadians who suffer one kind of mental illness or another. However, in Toronto alone, there are about 380,000 Chinese-Canadians, yet there are only a few who seek help at the Hong Fook Mental Health Association. Does it mean that the Chinese immigrants are healthier mentally that the Canadians? Or that they are afraid of being "labeled?" Or is it to do with the lack of language skills. Dr. Lo again emphasizes the lack of education among the Chinese as well as the lack of services and funding from the Government. There are workshops being offered by Honk Fook Mental Health Association, yet the number of people who show up at these workshops is another matter. He agrees

that the lack of language skills can hamper new immigrants to seek help, especially when a number of them do not know the hospital system here in Toronto. He sees that there are changes which have happed within the Chinese community, but that it is gradual and slow.

To conclude, it is important that the Chinese at large have to change their deep-rooted bias toward mental illness, to accept those afflicted with the illness without prejudice, before major changes can be done. Just like Dr. Lo said, "There is hope but it is gradual."

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### **About the Author:**

Caroline Fei-Yeng Kwok, B.A., M.Ed. Live in Toronto. She is the author of The Tormented Mind and numerous articles on mental illness in the Chinese-Canadian community. She completed her memoir as a student at Yale University. Information on purchasing her book can be found at <a href="www.thetormentedmind.com">www.thetormentedmind.com</a> She is the recipients of the 2001 Courage-To-Come-Back Award sponsored by the Centre for Addiction and Mental Health in Toronto, Canada.

# Facts About> Schizophrenia

# What is Schizophrenia?

Schizophrenia is a biological illness that affects the brain; it is a brain disorder. This disorder distorts the sense. making it very difficult for the individual to distinguish what is real from what is not real. Schizophrenia has specific symptoms due to the physical and biochemical changes in the brain.

The word Schizophrenia comes from the Greek and means split (schizo) and mind (phrenia)—3 mind split from reality, or a splitting of the various parts of the though process.

Schizophrenia is diagnosed after specific symptoms are present for a period of at least 6 months. Symptoms are not present all the time; the illness can involve repeated episodes throughout the individual's lifetime.

The risk of suicide for people with schizophrenia is much higher than that found in the general population. Forty to fifty per cent of people with schizophrenia will attempt suicide at some point, and approximately 10% of individuals with schizophrenia commit suicide.

Some researchers believe schizophrenia is really a group of related illnesses that fall within the same category. This would mean that schizophrenia is a name for an illness that includes a variety of disorders. This may be a confusing concept, which doesn't help you when dealing with an illness that is already difficult to understand. To make this easier to follow, we can compare schizophrenia to cancer. There are many different types of cancer such as leukemia, breast cancer, and lung cancer. A diagnosis of "cancer" alone is not specific enough, as cancer is the umbrella name of many different forms of the illness; and the same may be true of schizophrenia. With schizophrenia, the specifics are still being researched.

There are two illnesses that sound similar to schizophrenia and carry specific schizophrenia-like symptoms., these are person exhibits symptoms of both schizophrenia and a mood disorder (either bipolar disorder or clinical depression).

Schizophreniform disorder is similar to schizophrenia in that 2 or more of the same symptoms seen in schizophrenia must be present, but the length of time an individual is ill is different. Schizophreniform disorder lasts between one to six months.

Schizophrenia is a physical illness—just like cancer, diabetes, or heart illness. As the American psychotherapist and writer Julie T. Johnson noted: *Psychiatric disorders* [such as schizophrenia] are the #1 reason for hospital admission in this country and are more common than cancer, diabetes, heart illness, and arthritis combined. In Canada, 86% of hospitalizations for mental illness occur in general hospitals.

The Schizophrenia Society of Canada has found that individuals with schizophrenia occupy more hospital beds (8%) than those with any other illness, except cardiovascular illness. In Canada, someone suffering from schizophrenia is using 1 out every 12 hospital beds.

### **Ten Facts You Should Know About Schizophrenia**

- 1. **Schizophrenia** is a biochemical brain illness which results in disordered thinking, delusions, hallucinations, and a lack of energy and motivation.
- 2. **Schizophrenia** typically strikes people in their late teens or twenties.
- 3. **Schizophrenia** strikes one in every 100 people. That adds up to 280,000 individuals who have or will have schizophrenia in Canada in their life time.
- 4. **Schizophrenia** patients occupy 1 in every 12 hospital beds in Canada—more beds than are needed for any other single illness, except cardiovascular illness.
- 5. **Schizophrenia** costs us more than \$2.3 billion in direct health care costs in Canada, and an additional \$2 billion in indirect costs such as welfare, family benefits, community support, etc. (1996)
- 6. **Schizophrenia** has no cure, yet.
- 7. **Schizophrenia** drastically affects people's quality of life. Many people in prison have the illness, as do about one-third of the homeless. 40% of the people with schizophrenia try to commit suicide; 10% succeed.
- 8. Living with schizophrenia is a major burden for the individual and his/her family. There is a stigma attached to the illness; families often come under enormous stress from trying to cope with schizophrenia.
- 9. **Schizophrenia** research in Canada is funded at about one-tenth of the rate of other major illnesses, if you measure against the total health care costs for each illness.
- 10. **Schizophrenia** suffers from very low public awareness. As a consequence, people with schizophrenia and their families suffer because of too little research, and too little understanding.

# **Causes of Schizophrenia**

Sometimes schizophrenia-like symptoms may occur with other diseases, such as Huntington's disease, phenylkeronuria, Wilson's disease, epilepsy, tumor, encephalitis, meningitis, multiple sclerosis, and numerous other diseases. The real schizophrenia is diagnosed when these other conditions are excluded as the source psychotic symptoms.

The precise cause of schizophrenia remains unknown. Changes in key brain functions, such as perception, emotions, and behaviour, indicate that the brain is the biological site of schizophrenia. Some researchers suspect neurotransmitters

(the substances through which cells communicate) may be involved.

There may be changes in dopamine, serotonin, or other neurotransmitters. The limbic system (an area of the brain involved emotion), the thalamus (which coordinates outgoing messages), and several other brain regions may also be affected

#### **SCHIZOPHRENIA DEFINITELY IS:**

**NOT** caused by childhood experiences

**NOT** caused by poverty

**NOT** caused by domineering mother/passive fathers

NOT caused by parental negligence, and

**NOT** caused by guilt, failure, or misbehavior

- Adapated from TEN FACTS YOU SHOULD KNOW ABOUT SCHIZOPHRENIA Schizophrenia Society of Prince Edward Island
- (http://:www.schizophreniapei.pe.ca/QuickFacts.html)

From LEARNING ABOUT SCHIZOPHRENIA: RAYS OF HOPE (3<sup>RD</sup> Revised Edition) Schizophrenia Society of Canada

# Facts About > The Symptoms and Types of Schizophrenia

Schizophrenia is an extremely complex mental illness. People with the illness will have various symptoms to varying degrees. The following chart lists the different symptom of schizophrenia and their different elements.

**Symptoms** of schizophrenia are generally divided into 3 categories:**POSITIVE** symptoms, **NEGATIVE** symptoms, and **COGNITIVE** symptoms.

#### **POSITIVE SYMPTOMS**

"Positive" as used here does not mean "good." It refers to having symptoms that ordinarily should not be there.

Positive symptoms are sometimes called "Psychotic" symptoms, since the patient has lost touch with reality in certain important ways.

Hallucinations: People with Schizophrenia hear, see, or less commonly, taste, smell, or feel things that are not there.

Delusions: Ideas that are strange and out of touch with reality, often under the categories of

Paranoia – Belief that others can read your thoughts, are plotting against you, or secretly monitoring your activities.

Grandiosity – Belief that you can control other people's minds, or that you are a well-known historical or media figure, or an important and influential personage (writer, artist, musician, inventor, politician, police or military personnel, religious figure, etc.)

#### **NEGATIVE SYMPTOMS**

These symptoms refer to elements that are taken away from a person.

Affective Flattening: Marked by diminished emotional responsiveness, including: few expressive gestures; changes in facial expression; stilted, forced, or artificial gestures; poor eye contact; lack of vocal inflection; decreased spontaneous movements.

**Alogia**: Poverty of speech and of its content; lack of spontaneity and flow of conversation; inability to communicate.

**Avolition:**(Apathy) Associated with social withdrawal: physical anergia; impaired grooming and hygiene; lack of persistence in performing activities.

Anhedonia: (Asociality) Few recreational interests/activities; impaired personal and sexual relationships; uncommunicative, detached, distant.

Inattention:Impaired concentration; social inattentiveness; inattentiveness during conversation/interview; poor rapport.

#### **COGNITIVE SYMPTOMS**

Disorganized Perceptions: People with schizophrenia often have a hard time making sense of everyday sights, sounds, and feelings. Perceptions of what is going on may be distorted so ordinary things seem distracting or frightening. They may exhibit extra sensitivity to background noises, colours, and shapes.

#### **Disorganized Thinking & Speech:**

Trouble understanding language, communicating in coherent sentences, or carrying on a conversation. Odd word association; "word salad."

#### **Disorganized Behaviour**

Loss of short-term memory & organizational skills make planning, prioritizing, and decision-making tasks very difficult, if not impossible.

Schizophrenia may also cause people to move slowly, repeat rhythmic gestures, or make ritualistic movements. In severe cases, the illness can cause people to become catatonic—to stop speaking or moving completely and hold a fixed position for long periods of time.

# **Specific Types of Schizophrenia**

While there are several forms of the illness, the following 2 types occur outside the usual age of onset and can provide certain treatment opportunities and challenges.

#### CHILDHOOD SCHIZOPHRENIA

Schizophrenia in children is rate, affecting about 1 in 40,000 compared to the 1 in 100 in adults. In the past, some children may have been misdiagnosed with schizophrenia because a few of the symptoms are similar to autism or other developmental disabilities. Children with schizophrenia experience the same symptoms as adults: hallucinations, delusions, social withdrawal, flattened emotions, and loss of social and personal care skills. As in adults, antipsychotic medications and other treatment/rehabilitation services are used to treat schizophrenia in children.

#### **LATE-ONSET SCHIZOPHRENIA**

Late onset schizophrenia (schizophrenia that develops after age 35) is more common among women than men. Researchers are currently studying whether there is a connection between estrogen levels, menopause, and the development of late-onset schizophrenia later in life often allows the individual to draw on a strong support system and previously learned life skills.

<sup>\*</sup>SOURCES: Adapted from the Schizophrenia Fact Sheet from the British Columbia Schizophrenia Society

# What are > the Phases of Schizophrenia?

Like other physical illnesses, schizophrenia occurs in stages. These are referred to as the phases of illness. Schizophrenia has 4 phases: the Prodromal phase, the relapse or active phase, the residual phase, & the recovery phase.

**IT IS IMPORTANT TO REMEMBER:** schizophrenia is episodic & recurrent; it is not a "linear" disease as these phases might suggest.

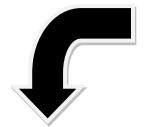
#### **PRODROMAL PHASE**

The Prodromal phase refers to the early stages of the illness.

There are changes in the behaviour, mood, & thinking of the individual.

There may also be changes in eating & sleeping habits. Features of this phase include: reduces concentration, reduced motivation, lack of energy, depressed mood, anxiety, social withdrawal, irritability, suspiciousness, & a deterioration in functioning.



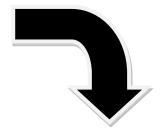


#### **RELAPSE/ACTIVE PHASE**

As the name of the phase would indicate, the relapse or active phase is the phase where the illness is most obvious. During this phase the "positive" symptoms begin to appear. These symptoms are most effectively treated with medication. The individual may even be hospitalized at this point. The featured symptoms of this phase are: delusions, hallucination, disordered thinking and agitated or bizarre behaviour.

### **RESIDUAL PHASE**

During the residual phase, the "negative" symptoms of schizophrenia are more apparent. These include: social withdrawal, blunted emotions, reduced motivation, reduced social functioning, poor speech or thought, and possibly poor hygiene.



#### **RECOVERY**

During the recovery phase, the illness becomes more able to stable. The ill individual's ability to function will increase at this phase. The individual may be consider increasing his/her level of functioning by returning to school, work, or a life skills training program.

# Facts About > Treating Schizophrenia

### What treatments are available for schizophrenia?

There is no instant cure for schizophrenia, but people can and do recover. The experience of schizophrenia is unique to each person, and as a result, each person's experience of recovery is unique—what might work well for one person may not work so well for another. It's therefore vital for people with schizophrenia to learn about all the different treatment options available so they can play an active role in their recovery.

### Medication

The medications used to treat schizophrenia, commonly referred to as "antipsychotics," are generally an effective method for decreasing the psychotic (or active) symptoms of schizophrenia, such as delusions and hallucinations. The newer antipsychotics can also help relieve some of the passive symptoms (such as confusion, withdrawal, suicidal thoughts, and lack of concentration). For many people with schizophrenia, medication will also be needed during stable phases (also called "maintenance" or "recovery" phases).

Determining the type and dosage of medication needs to be individually assessed and may need to be altered until the right combination is achieved. Remember: although medication is almost always necessary, it should not be considered the sole treatment for schizophrenia. Rather, it should be used in addition to other therapies described later in this section.

### Additional pathways to recovery

Although medication is almost always necessary in the treatment of schizophrenia, it is not usually enough by itself. It is important to seek out additional resources, such as talking therapies, social and employment rehabilitation services, and living arrangements that may be helpful at various stages of recovery. It is also extremely important for individuals, family members, and health care providers to make decisions together about treatment plans and goals to work toward. Below are some forms of activities that may be useful in the recovery process.

## **Psychosocial Interventions**

**Education:** Education about schizophrenia for the individual & the family is essential. Providing education & information enables the family as well as the person with schizophrenia to take an active role in the recovery & rehabilitation process, & to do so from an empowered position.

#### Social & living skills training:

Social & living skills training is an effective means of enabling individuals with schizophrenia to re-learn a variety of skills necessary for living independently. Social & living skills training can be used with individuals & with groups. This training provides opportunities for people to: acquire skills they have not been able to develop due to particular life circumstances; re-learn skills which were lost or reduced due to the disabling effects of schizophrenia or particular life circumstances: and enhance existing skis to enable more effective functioning.

**Vocational Training & Rehabilitation:** Work has the potential to be a "normalizing" experience & to provide benefits such as enhanced personal satisfaction, increased self-esteem, additional income, financial independence, social interaction, & recreations & companionship opportunities. Most importantly, it is frequently identified as a goal of people with schizophrenia. Any person with schizophrenia who expresses an interest in gaining employment, or who may benefit from employment, should receive vocational services.

Facts About > Treating Schizophrenia

# **Talking Therapies**

There are several different talking therapies to choose from. They range in their approaches, from aiming to ease distress and improve coping skills, though to seeking to help people understand their own thoughts, feelings, and patterns of behaviour. Some of these talking therapies are listed below.

**COUNSELLING:** Counsellors listen without judgment and help individuals to explore issues which are important in the recovery process. Counsellors do not give advice, but should act as a guide for individuals in working things out for themselves. Attending regular counselling can be extremely beneficial to both the individual with schizophrenia and the family members.

**PSYCHOTHERAPY:** Psychotherapy is a learning process that is accomplished largely by the exchange of verbal communication. Psychotherapy has many different orientations, but can generally be categorized into 3 broad groups: psychodynamic (which is based on the teachings of Freud), behavioural (which aims to modify behaviour), and humanistic (which aims to increase self-understanding). While behaviour modification can be very helpful for some people, research into the use of psychodynamic therapy for people with schizophrenia has consistently failed to support its effectiveness. Furthermore, there is some evidence to suggest that psychodynamic therapy is harmful and therefore is not recommended.

**Cognitive Therapy:** Cognitive therapy is also known as cognitive behavioural therapy (CBT). Cognitive behavioural therapy is concerned with the influence of beliefs, thoughts, and self-statements on behaviour. CBT for the symptoms of schizophrenia aims to heighten awareness of the inconsistency of delusions and to develop practical coping mechanisms for persistent symptoms.

**Self-Help Groups:** Some people find it helpful to talk about their experiences with others who can empathize because they have been through similar situations themselves. People can get practical help by working through their problems with others, and develop strong support networks among peers. Self-help groups are often run by local organizations.

# **Alternative Therapies**

Alternative therapies have been used by people for thousands of years, & some people find them very helpful in the recovery process. Some of these therapies include: meditation (a special form of relaxation), aromatherapy (the use of essential oils), reflexology (the manipulation of pressure points on the feet), acupuncture (an ancient Chinese remedy using needles and herbs), massage, t'ai chi (meditation in movement), and yoga (exercise which concentrates on breathing and stretching). some creative therapies include art, drama, music, writing, and performing. It is very important to remember, however, that these therapies should be used in addition to medication and psychosocial therapies (listed above), not instead of them.

## **Family Interventions**

The family is considered to be an essential part of the assessment, treatment, and recovery process for people with schizophrenia. For families to be effective in this role, without becoming overburdened or exhausted, they need information, support, sufficient time for professional consultation, and respite mental health services. See the fact sheet for relatives in this pack for more information on services specifically for families.

Source: Adapted from What Treatments are Available for Schizophrenia? and Medication Fact Sheet from Schizophrenia of NSW Inc. http://www.sfnsw.org.au/consumers/recovery.htm

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Source: Adapted from What Treatments are Available for Schizophrenia? and Medication Fact Sheet from Schizophrenia of NSW Inc; <a href="http://www.sfnsw.org.au/consumers/recovery.htm">http://www.sfnsw.org.au/consumers/recovery.htm</a>

# **Activity** > The Voices

This exercise is designed to help you understand the impact of auditory hallucinations on people with schizophrenia.

### Instructions for "The Voices" Activity

For this activity, you will need 4 volunteer readers. Give everyone else a blank sheet of paper and pen, and tell them to write numbers 1 to 22 on their sheet of paper. Have the first volunteer begin reading sheet # 1 for about 10 seconds (that will allow the participants to get the first answer (\$100). Then a second reader reads sheet #2, then the third reads sheet #3 after 15 more seconds, then the final reader begins sheet #4 after another 15 seconds. In this way shortly after all the volunteers have begun reading, they will all be speaking at the same time.

The facilitator will start asking the questions after all the readers have begun reading—again, roughly 15 seconds after.

1. Whatever the interpretation, Robert Rhodes is out almost \$100 and is left with a very bad feeling towards the Burnaby SPCA after a run-in with the civic pound patrol this week.

Rhodes and Maddy, his three-and-a-half-year-old golden retriever, were doing their usual afternoon walk from the corner grocer 'Wednesday when the Burnaby pet patrol noticed something amiss. Rhode's leash was attached to Maddy, but not to Rhodes' hand—it was left to dangle behind the dog. The pound patrol recognized the man and dog from previous encounter, and moved to find out what was going on.

Rhodes scooped up the leash and continued walking, ignoring the SPCA officers. Undaunted, the pet patrol took up the pursuit and began asking questions such as, "Is this dog licensed?" and "Why were you walking without holding the leash?"

Rhodes kept walking, and the game of questions being asked and going unanswered continued until the SPCA called in the heavy artillery—the RCMP. Not surprisingly, Rhodes' retriever was eventually impounded and he was forced to pay \$98.65 'ransom' to get his dog back.

"There's got to be more productive things for them to do," Rhodes said.

|They called in 2 SPCA vans, 2 SPCA people, 2 police cars and 2 officers." Rhodes believes he and Maddy were following the letter of the law. "it says all dogs must be on leash no longer than 2 meters—well, I could qualify. I do have the dog on the leash all the time—it's just I'm not always on the other end of it."

But the story generated very little sympathy from Carson Wilson, the superintendent of the Burnaby SPCA shelter.

 $oldsymbol{2}$  In 1995 my family moved to Whitehorse in the Yukon. We stayed 2 years.

Brr! Our first January, the temperature dropped to minus 48 degrees for 3 weeks. Our car wouldn't start. We wore lots of winter gear to go outside and we were still cold.

I didn't like the 10 or 15 minute walks to school because I got so cold.

It was so cold the front door was stuck for about 2 weeks. So when we wanted to go outside, we had to go through the back door.

We made an ice rink in our back yard. It was great to put on ice skates in our living room and walk out the door to the ice rink.

I also took cross-country skiing lessons. The cut-off temperature for skiing was minus 20. Otherwise it's too cold. There were lots of fun things to do in the cold. We liked to make snowmen. We had snowball fights.

My dad would walk my brother Tom to preschool and Tom would stop to play even when it was 48 degrees below zero!

**3** I've lived all my life in a very old neighbourhood called Glenbrook in New Westminster. I'm interested in the changes that have happened over the years.

This helps me understand how my neighbourhood developed the way it did.

Glenbrook was named after a creek that ran through the neighbourhood. This creek has long since been covered over.

The old street named after a creek that ran through the neighbourhood. This creek has long since been covered over.

The old street names were given by Colonel Clement Moody. For example, 6<sup>th</sup> Street was called Mary, after his wife. The original names were changed in the late 1890's and early 1900's.

In 1913, there were only 13 houses on my street. Now it has 46. The reason for the development of the area was the construction of the Westminster Street Railway in 1891, which ran up 6<sup>th</sup> Street into Burnaby.

This allowed people to travel to work or shop more easily. The fare was five cents.

**4**I am a piano and my name is Lillian. I was just wondering what life is like outside. I've never been outside because I'm still little. My Mom says I will just have to wait.

She's been telling lots of stories about the world. My mom is a grand piano.

She doesn't take care of me anymore because she has to go all around the world to be a famous piano.

Willy, my friend, takes care of me now. He acts like my grandpa because he is old and kind.

Willy is a human being but I don't really mind because he knows my Mom from when he was young.

One day something wonderful happened to me. A girl and her family came to the store I lived in and they hugged each other. I found out the girl is Marian and she is 8 years old. I like her a lot and I didn't care if I wasn't famous. I was happy!

# **Questions For the Voices Activity**

- How much money did Robert Rhodes lose?
- How old is the dog?
- When did they move to Whitehorse?
- What is the name of the neighbourhood?
- Who is Lillian?
- Did the dog have a leash on her?
- How cold was it?
- What was Glenbrook named after?
- Who is Lillian's mother?
- What did Rhodes say to the SPCA officers?
- How long did it take to walk to school?
- What was the original name of 6<sup>th</sup> Street?
- Who takes care of Lillian?
- Who called the RCMP?
- Which door was stuck?
- How many houses were there in 1913?
- Who did Willy know?
- How many police cars were on the scene?
- Where was the ice rink?
- What cost five cents?
- How old is Miriam?

Last week my father had a heart attack while at a church camp near Lacombe, Alberta. I live in Edmonton,

which is about an hour's drive north of Lacombe. When I was told that he was ill and in hospital, I wasn't able to immediately leave because of a bureaucratic delay involving my Albert Assured Income for Severely Handicapped (AISH) card. The card, issued by my provincial government, hadn't arrived in the mail yet and without this card I cannot be guaranteed medical coverage for things like medication.

My family, meanwhile, said I should stay home. Why? I have schizophrenia. And although I have a university education and I work, I am susceptible to the effects of stress. My family, knowing stress can trigger hallucinations and paranoia in me, was worried over how the stress of my father's hospitalization would affect me.

The previous month I had been traveling and I ran out of my secondary medication for three days. It took me 3 weeks to recover from the effects of missing that medication.

When my family said they did not want me to visit, it reminded me of when my father had emergency heart bypass surgery several years ago. My family did not want me to visit then, too.

My father was transferred from the hospital near Lacombe to another hospital in Red Deer, then to a hospital in Calgary, Alberta. My AISH card arrived and I decided to travel to Red Deer to accompany my mother to Calgary.

I began to experience voices and paranoia. It was especially serious when I was in the Greyhound bus depot in Edmonton, waiting to catch the midnight bus to Red Deer. I thought that people were talking about me and that my name was being continually being called.

Life still happens to those that have schizophrenia. Life, death and illness do not avoid the person or family that lives with schizophrenia.

After I arrived in Red Deer, my sister had to return to Edmonton because of job commitments and I was left with

my parents. My father was discharged from the Calgary hospital and we stayed overnight in a hotel, intending to return to Lethbridge, the city where my parents lived.

The next day, however, we had to go back to the hospital emergency department because my father's water works did not work. I told the emergency room doctor that he was in no condition to go back to Lethbridge by Greyhound bus, so they arranged for him to get shuttled back to Lethbridge in an ambulance. I did not have any symptoms until I

"Though I might get sick, like anyone with schizophrenia we still need to be a full member of the family—though we have an illness that affects our ability to socialize."

was back in Lethbridge with my parents, when I started to think people were talking about me behind my back.

We as people with schizophrenia should not be sheltered from life's vicissitudes by our families. Life does involved pain and hardship. It is not always honey and sweetness. As human beings we should be allowed to have the full spectrum of experiences even though they hurt and cause us distress. If my father had died last week, with me being unable to say my lost goodbye, I would have been devastated. My 'well' sister would have seen him, as would have my mother, but not his only son.

My family was trying to protect me from the stress, but I would say that even though the stress might put me in hospital I should be able to be a full part of the family.

My father made it through, my mother made it through, the rest of the family came through and I made it through even though even at this moment I am a bit stressed out.

Life at its essence means getting a few bumps and scratches, experiencing the good and the bad. That is how character is built. We as people with schizophrenia still need to experience the difficult times and part of our families, not be shunned under the pretext that we are too emotionally weak.

As one character in a Canadian movie says at the end of the film: "Life ain't no candy mountain."

#### About the Author:

Austin Mardon was awarded the Schizophrenia Society of Canada's 2001 National Flag of Hope awarded for his strong determination and many voluntary contributions. In 1999 he received the Governor General's Caring Canadian Award.

He has authored over 100 scholarly communications and 22 books, on topics as diverse as space science, historical geography, political history and psychosocial rehabilitation. He was also a member of the 1986-87 Antarctic Meteorite Recovery Expedition.

<sup>\*</sup>Schizophrenia Digest Magazine, Summer 2002 Edition

This article is part of the *Schizophrenia Bulletin's* ongoing *First Person Account* series. We hope that mental health professionals—the *Bulletin's* primary audience-will take this opportunity to learn about the issues and difficulties confronted by consumers of mental health care. In addition, we hope that these accounts will give patients and families a better sense of not being alone in confronting the problems that can be anticipated by persons with serious emotional difficulties. We welcome other contributions from patients, ex-patients, or family members. Our major editorial requirement is that such contributions be clearly written and organized, and that a navel or unique aspect of schizophrenia be described, with special emphasis on points that will be important for professionals. Clinicians who see articulate patients with experiences they believe should be shared might encourage these patients to submit their

### First Person's Account >Susan's Cello

use to play a lot of music. I played piano beginning at age 5. I eventually taught it to pay for college and university. I never really wanted to become a professional musician, even if I admired talented people who make music for a living. I decided to become a pharmacist. Through music, I met extraordinary people with exceptional talent. I will always consider music a gift and treasure the chance I had to learn it and to be able to share its magic by playing with others. Susan is one of these others. In fact, she is the one. We used to go to high school together. I played piano. She played cello. She is a true artist. She has this extra thing that makes you feel you are with someone with a special gift, someone who will become famous and have a great career. I felt lucky to play with her. I always will. She was so strong, so affirmative, and so able. Every single day, she went to school, then went to the conservatory for her music lessons and practiced overnight to perform her best. She was very disciplined, very demanding of herself and of others, like me, who played with her. She was beautiful and healthy, with a natural blush on her cheeks and large blue eyes, making her look like a pretty doll.

She was cherished by all of us. In fact, I think that lots of us admired her. She had it all. In 1985, our last year of high school, we were preparing for our annual school concert of chamber music. We were putting a lot of efforts in accompanying singers and several musical instrument players. Susan was the leader, the most talented among us. That night, she played a Concerto of Saint Sadus with rare emotion and virtuosity. The audience was captive under her charm. At the end of this concert, she received an award for her accomplishment at school and was ready to start a musical career. She also received a grant from the conservatory to go to Europe to study cello with a well-known musician in Strasbourg. I left school that year with the strong conviction that I would hear from Susan in the next few years, and I admired the courage she had to choose the road of music.

Fifteen years later, I work as a pharmacist in an out-patient psychiatric clinic. People attending our clinic are first-episode psychotic patients. Our team has put in place a multidisciplinary program to help patients, with the hope that early intervention will make a difference.

At first, I couldn't believe it was her. She was so devastated. She had just left the hospital. She was hospitalized without her consent because she had threatened a dishwasher repairman with a knife, convinced he had come to her mother's house to hurt her. Her beautiful hair was a mess. She had pulled out a tuft of hair, leaving a big spot on the bottom of her scalp. She had several cutaneous lesions she had inflicted to herself on her face and arms. She had acne and hirsutism and had gained weight. She was frankly psychotic, with grandiose preoccupations, talking about NASA, about other worlds. She had absolutely no insight into her condition and was convinced she was in the middle of a plot. She nevertheless recognized me easily. She even helped me to deal with this strange and painful situation by not letting me ask her too many questions. She minimized her condition or, at least, never fully described it to me. She talked very fast, referring to the past and our successes together. It was like her life had stopped there. For me, it was the beginning of a series of accomplishments. For her, it was the beginning of her deterioration. I was shocked. I felt immensely sad. I felt like I had witnessed her apotheosis and now was the witness of her decline. My colleagues evaluated her and planned pharmacological and psychosocial therapeutic interventions.

Susan had her first symptoms in Strasbourg, where she was hospitalized and given haloperidol. This experience was very stressful for her; she went through a painful dystonic reaction that finally led her to leave the hospital without consent. She managed to come back to her mother's house. She was hospitalized twice and then disappeared. From what we learned after, she left for another city and lived as an itinerant for one year, untreated, alone, unable to get even social assistance. Her living conditions were extremely harsh. Finally, her mother got her back home and managed to bring her to our clinic for a first evaluation, pretending it was not a psychiatric clinic because Susan would have refused to come. Then she had to be hospitalized without her consent when the repairman incident happened.

At first, she was treated with risperidone. She responded very well in terms of positive symptoms reduction. She rapidly became free of any hallucinations or aggressive behaviour. However, she still had no insight and had persistent negative symptoms, particularly sadness, avolition, and lack of interest. Anxiety was also present. An antidepressant was added and helped her mood. She reported amenorrhea. Her mother also noted light galactorrhea. A pregnancy test was performed and proved negative. Marked weight gain was also present. The risperidone dosage was reduced and laboratory tests were performed. Considering all these side effects, it was decided to stop risperidone and start olanzapine.

It has now been three months since this new treatment was begun. Susan remains fragile, with no insight, marked apathy, and a tremendous need to be taken care of. Her menses have returned, and galactorrhea is no longer present. The recent neurocognitive assessment reveals an average intellectual capacity, inferior to what would be expected of someone with her education level. Deficits of executive functioning, particularly in planning tasks and elaboration of complex strategies, are observed.

Susan still lives with her mother. She does not play the cello anymore and is very anxious about her future. Every time I see her, it hurts. I cannot accept what the illness has done to her. Life is now so hard on her. I can see the harsh and devastating impact of a severe psychiatric illness left untreated for too long, with undeniable sequelae.

As a professional, this experience gave me a new understanding of patient and family grief about the loss of a hoped-for successful life. Learning to deal with a new life perspective is a painful aspect of the illness and one important step of the remission process. Obviously, I also learned that I cannot be a health care professional and a good friend at the same time. My clinical judgment is biased. It had been decided early on that I wouldn't be professionally involved in Susan's case. But this experience has changed my practice. Recently, I went to a meeting of families where, as a pharmacist, I shared some notions on medication and on side effects. I felt more touched by the questions, the fears, the anxiety of these people than I ever had before. I felt their hope and their fear, and I shared their outrage at not being able to cure this disease.

As a friend, I learned that, as life goes on, challenges you would not have expected come along. it brings you back to simple things: family, love, health. I still grieve and hope optimal treatment can offer Susan a new freedom to be herself again, a new self, different from what I knew, but hopefully still inhabited by this unique flame that is her essence. I hope to play music again with Susan one day. I hope this day is not so far off. Most of all, I hope she and I will regain the joy of sharing simple things, simple thoughts, simple notes.

#### **EPILOGUE**

More than 2 years have passed since this paper was first written.

In July 2001, Susan committed suicide. That night, she amazed everybody with her joy and serenity, playing music and singing at a family reunion, something she had not done for a long time.

I have to admit the pharmacological treatments did not reach her level of expectation: Susan never really had a full remission and experienced unacceptable side effects all along. Because of her apparent lack of insight, it was sometimes thought that her suffering was limited and that she was, consequently, protected from the crude reality of her life. I never really believed that and, in a way, I am not surprised by her decision, even though it is hurtful.

Her fight has touched us profoundly. Her quest contributed greatly to further push our goals in research. Our team is about to start an important research project on metabolic and endocrinologic side effects induced by atypical antipsychotics and Susan was our initial inspiration. She is constantly a part of my motivation as a clinician, as a researcher, and as a woman who cherishes a unique friendship. I will forever treasure her talent, her courage, and her willingness.

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#### **About the Author:**

Marie-France Demers is a clinical pharmacist working at the Clinique Notre-Dame des Victoires from le Centre Hospitalier Roberi-Giffard, an outpatient psychiatric clinic specializing in first psychotic episodes, in Quebec.

# What is > Clinical Depression

# What is Clinical Depression?

Everyone has experience with feeling sad or lonely, especially after a personal disappointment or the loss of a loved one. Sadness is a normal reaction when the inevitable losses and frustrations of daily life occur. However, clinical or major depression differs from a normal sad reaction in severity, duration, and the degree of disability it causes in one's daily life. In fact, in depression, we lose the ability to feel any emotion strongly. The true opposite of depression is vitality – the ability to feel a full range of emotions, including happiness, joy, pride, but also including sadness and grief.

### **FACTS & STATS:**

Clinical depression is the most common form of mental illness and can occur at any age or stage of life. Approximately 8% of adults will experience a major depression at some point in their lives.

Women are diagnosed with clinical depression twice as often as men, but this increase may be due to the fact that men are less likely to seek help for the illness. Physical and hormonal factors, as well as pregnancy, postpartum, and menopause may also contribute to this increase for women.

Approximately 10—15% of individuals with this illness commit suicide. This is a higher mortality rate than that of cancer or heart disease.

The symptoms of depression include:

Changes in appetite or weight – usually a decrease; a few individuals gain weight, and this is referred to as atypical depression

- Changes in appetite or weight-usually a decrease; a few individuals gain weight, and this is referred to as atypical depression
- Changes in sleep, either not sleeping at all (insomnia) or excessive oversleeping (hypersomnia)
- Change in productivity
- Persistent sadness or despair
- Lack of energy or motivation
- Fatigue
- Difficulty in thinking or concentrating
- Difficulty making decisions
- Inability to feel pleasure in previously enjoyed activities (anhedonia)

- Apathy
- Excessive crying
- Unexplained aches or pains, especially headaches
- Social withdrawal
- Pessimism
- Feelings of hopelessness, guilt, self-blame
- Feeling worthless
- Feeling anxious or irritable
- Pacing and fidgeting
- Persistent thoughts of suicide

Some of these symptoms may occur due to stressful life events. In the case of clinical depression, these symptoms will interfere with the individual's everyday life. It's important to note that there are many different types of depression, ranging from mild to severe. Clinical depression is considered severe due to the interference it causes which drastically reduces the quality of the individual's daily life.

# **TYPES OF DEPRESSION**

Dsythymic Disorder	Dsythymic disorder is a common milder form of depression. An individual with this disorder can continue to function, but is not capable of feeling good or fully enjoying life. This disorder lasts for at least 2 years
Post-Partum Depression	Post-Partum depression is experienced by new mothers after giving birth and may be due to hormonal changes. Post-partum depression can last anywhere from a few weeks after delivery to a few months. A small percentage of these women (10%) may develop more severe symptoms of clinical depression.
Seasonal Affective Disorder (SAD)	This disorder is also called the "winter blues" and is commonly associated with reduced daylight hours. Many people notice a change in energy or mood as winter approaches. It becomes harder to get up in the morning when it's still dark outside, and there may be some weight gain as the level of exercise drops. (This can be especially true in a northern climate!) For some people, the depression and lack of energy become disabling and affect their jobs and relationships.
Situational Depression (Reactive Depression)	A situational depression is just what it sounds like—the person is depressed in response to something that has happened. This could include dealing with severe stress on the job or in personal relationships, or from the loss of a loved one.

Even though these types of depression are less severe than clinical depression, it is important to monitor and maintain good mental health. If someone you know is experiencing symptoms of any of these illnesses, or if you are experiencing them yourself it is important to seek support.

remember...



**NOT**a character flaw **NOT**a sign of weak character **NOT**contagious

# **How is Clinical Depression Treated?**

Treatment for clinical depression involves a combination or medication (antidepressants), psychotherapy (talk therapy), education, and support groups.

**Counselling and psychotherapy** are considered extremely helpful for this illness. During psychotherapy, and individual may discuss experiences, relationships, events, and feelings with a therapist in an attempt to identify and resolve areas of difficulty in his/her life. Working together with a good therapist can help the individual find better coping skills for stressful situations.

For cases of severe depression, *medication* is an important part of the treatment plan. The most commonly prescribed medications for depression today are called selective serotonin re-uptake inhibitors (SSRI's). SSRI's block the serotonin from being reabsorbed by the "sender" neuron; this in turn increases the serotonin levels in the brain. Researchers believe that low levels of serotonin, among other factors, may result in depression.

When medication is not a viable option, when medication is not a viable option, when medications are not effective, or in cases of debilitation or high risk of suicide, *electroconvulsive therapy (ECT)* may be used to relieve symptoms of depression. Although ECT has been in use for more than 45 years, there is continuing controversy concerning the mental illnesses for which ECT is indicated. The efficacy of the treatment, the optimal methods of administration, possible complications, and the extent of its usage in various settings are issues that have contributed to concerns about the potential for misuse and abuse of ECT and to desires to ensure the protection of patient's rights. At the same time, there is concern that the curtailment of ECT use in response to public opinion and regulation may deprive certain patients of a potentially effective treatment.

There is also some concern about the side-effects generally reported after treatment. Almost all people who are treated with ECT experience some memory loss of what happened immediately before or during the treatment. In some cases, clients lose the memory of significant periods in their lives. Like other treatments for mental health problems, it is important to get all the facts about ECT and the potential side effects before deciding which treatment is right.

# **What Causes Clinical Depression?**

Many things can contribute to clinical depression. For some people, a number of factors seem to be involved, while for others a single factor can cause the illness. Oftentimes, people become depressed for no apparent reason.

- Biological—People with depression typically have too little or too much of certain brain chemicals, called "neurotransmitters." Changes in these brain chemicals may cause or contribute to clinical depression.
- Cognitive—People with negative thinking patterns and low self-esteem are more likely to develop clinical depression.
- Gender—Women experience clinical depression at a rate that is nearly twice that of men. While the
  reasons for this are still unclear, they may include the hormonal changes women go through during
  menstruation, pregnancy, childbirth, and menopause. Other reasons may include the stress caused by
  the multiple responsibilities that women have.
- **Co-occurrence**—Clinical depression is more likely to occur along with certain illnesses, such as heart disease, cancer, Parkinson's disease, diabetes, Alzheimer's disease, and hormonal disorders.
- **Medications**—Side effects of some medications can bring about depression.
- Genetic—A family history of clinical depression increases the risk for developing the illness.
- **Situational**—Difficult life events, including divorce, financial problems, or the death of a loved one can contribute to clinical depression.

<sup>\*</sup>Adapted from the information sheet on depression by the National Mental Health Association, 2005

# What is > Bipolar Disorder?

Like clinical depression, bipolar disorder is a mood disorder. The mood of the individual is affected, and the illness causes unusual shifts in a person's energy and ability to function. A person with bipolar disorder usually experiences both episodes of depression (feeling low) and episodes of mania (feeling high).

### The symptoms of bipolar disorder include:

### Mania

- Full of energy
- Persistent elevated and euphoric mood
- Excessive talking
- · Talking too fast or too loud
- Excessive spending
- Lack of sleep
- Easily irritated
- Easily distracted

- Feeling grandiose (inappropriately high self esteem)
- Aggressive behaviour (pushy behaviour)
- Racing thoughts
- Poor judgment
- Loss of ability to control impulses
- Unusual sexual behaviour

# **Depression**

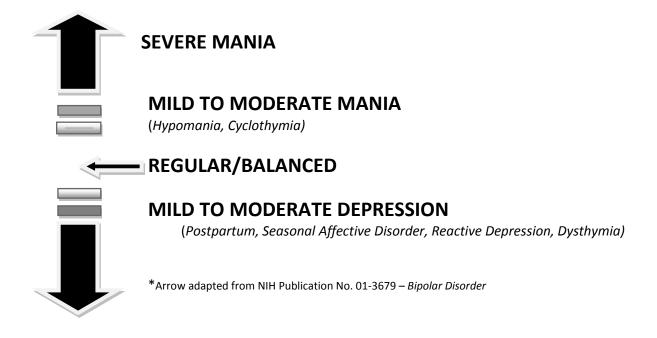
The symptoms are the same as clinical depression.

### **Mixed States**

Mixed states or episodes can include any combination of mania and depression, and last for varying lengths of time. Some examples of mixed states would be dysphoric mania (mania with depressed mood and/or thoughts) and agitated depression (depression with restlessness and anxiety).

### THE RANGE OF MOOD STATES IN BIPOLAR DISORDER

There is a wide scope of mood states in bipolar disorder. It may be helpful to view the various mood states in the illness as a continuous range. At one end there is severe depression, and at the opposite end there is severe mania. For some people, the symptoms of mania and depression occur together, which is called *mixed states* or *mixed episodes*.



During the mania phase, the individual's mood becomes extremely high and he/she may act recklessly. The symptoms of mania can be different for each person. If the mania phase is extremely high (severe mania) it is referred to as a *manic episode*.

Before the onset of mania, the individual will experience a phase called *hypomania*. During this hypomanic period, the individual feels energized and excited, and may continue to function at work. A hypomanic phase is milder than a manic episode. Without proper treatment, however, hypomania can develop into sever mania in some people.

Previously, people with bipolar disorder may have been misdiagnosed with schizophrenia, due to thesimilarities when psychosis is present. Unlike people with schizophrenia, people with bipolar disorder may have long periods of stability between episodes.

# **Types of Bipolar Disorder**

Bipolar 1	Bipolar 1 is occasionally referred to as the "classic" form of the illness. The individual has experienced at least one manic episode and has also experienced depression. Usually these are recurring episodes. The individual may have experienced psychotic symptoms such as delusions or hallucinations during either a manic or depressive episode.
Bipolar 2	The individual experiences depression and hypomania, which is milder than mania. Individuals with bipolar 2 do not experience psychotic symptoms.
Cyclothymic Disorder	This illness is considered a chronic, milder version of bipolar disorder and lasts for at least 2 years. The individual experiences both mild lows and mild highs. Episodes last for a few days as opposed to weeks, and the Cycles of depression and mania are shorter and less intense.
Rapid Cycler	The individual experiences 4 or more episodes of depression, mania, mixed states, or hypomania in one year (this means that they alternate between the lows and highs within a very short period of time). People who are rapid cyclers need special attention as some <i>antidepressants may contribute to the cause of this condition</i> . As in every case of illness, a correct diagnosis will ensure proper treatment.
Mixed State	The symptoms involve both mania and depression occurring at the same time or alternating frequently during the day. Due to the combination of high energy and depression, mixed state presents the greatest risk of suicide.

# What Causes Bipolar Disorder?

The exact cause of bipolar disorder remains unknown. Similar to other mental illnesses discussed so far, bipolar disorder is most likely caused by a combination of biological and psychological factors.,

Bipolar disorder usually begins in early adulthood, with the average age of onset around 18-24 years, although it can sometimes start in childhood or as late as the 40s or 50s. Bipolar disorder affects approximately 1.2% of the adult population. Men and women are equally affected.

# **How is Bipolar Disorder Treated?**

On average, people with bipolar disorder will see 3 to 4 doctors and spend over 8 years seeking treatment before they receive a correct diagnosis. Early diagnosis, proper treatment, and finding the right medication are important, as they can lessen the effect of the disorder on the individual.

Treatment for bipolar disorder involves a combination of medication and psychosocial treatments. The medications used to treat bipolar disorder are known as *mood stabilizers*.

Psychosocial treatments could involve psychotherapy (talk therapy), education (learning about symptoms and what makes them better or worse), and support groups. The treatment for bipolar disorder needs to be continuous, even though there may be long periods of stability between episodes.

An effective tool in the treatment of bipolar disorder includes keeping a chart of daily mood symptoms, as well as documenting sleep patterns, life events, and medication or treatment plan changes. This chart can help the individual take an active part in their mental health, and includes the side benefit of allowing the doctor to track and treat the illness more effectively.

Adapted from What is Bipolar Disorder from Mood Disorders Canada Same as above.

# Review Questions about > Depression and Bipolar Disorder

Test what you've learned about clinical depression and bipolar disorder so far by answering **True or False**to the following questions.

#### **QUESTIONS**

- 1. Clinical depression is the most common form of mental illness
- 2. SSRI's are newer medications used to treat depression.
- 3. One symptom of depression is an increase in energy.
- 4. Women are at a greater risk to develop depression and bipolar disorder.
- 5. Bipolar disorder and manic-depressive illness are 2 distinct mental illnesses.
- 6. A diagnosis of "atypical depression" means the individual has an odd personality.
- 7. It's normal for teens to be moody; teens don't suffer from "real" depression.
- 8. Inappropriately high self-esteem is a symptom of mania.
- 9. As yet, the causes of clinical depression and bipolar disorder remain unknown.
- 10. Both clinical depression and bipolar disorder are treatable.

# What is > Anxiety Disorder?

## **Quick facts**

- » Anxiety disorders/conditions are the most common mental health concern in Canada.
- At any time, one in every 10 adults is experiencing and anxiety disorder. Over the course of a lifetime, one in 4 individuals will be affected.
- » Anxiety disorders/conditions tend to start early in life (during childhood or adolescence) and often persist for many years.
- **»** For many people, these problems limit progress in education and employment and interfere with the enjoyment of family and social life.
- **»** The presence of an untreated anxiety disorder is a risk factor for the development of other serious mental health problems, such as major depression.

# The main symptoms of anxiety disorders include:

¤	Perspiration	¤	Apprehension
¤	Dizziness, light-headedness	¤	Nervousness
¤	Shortness of breath	¤	Feeling a loss of control
¤	Shakiness or trembling	¤	Feeling of choking
¤	Restlessness	¤	Fear of dying
¤	Dry mouth	¤	Chest pain or discomfort
¤	Fatigue	¤	De-realization (Feeling of not being real)
¤	Irritability		Or
¤	Rapid heartbeat	¤	To personalization (Feeling decidence 3.5)
¤	Muscle tension/aches	one's body or mental process. An example of this would be feeling like one is in a dream.)	

# **Types of Anxiety Disorders**

**Generalized Anxiety Disorder (GAD)**--GAD is characterized by excessive, unrealistic worry that lasts 6 months or more; in adults, the anxiety may focus on issues such as health, money, or career. In addition to chronic worry, GAD symptoms include trembling, muscular aches, insomnia, abdominal upsets, dizziness, and irritability.

**Obsessive-Compulsive Disorder (OCD)**—In OCD, individuals are plagued by persistent, recurring thoughts (obsessions) that reflect exaggerated anxiety or fears; typical obsessions include worry about being contaminated or fears of behaving improperly or acting violently. The obsessions may lead an individual to perform a ritual or routine (compulsions)—such as washing hands, repeating phrases, or hoarding—to relieve the anxiety caused by the obsession.

**Panic Disorder**—People with panic disorder suffer severe attacks of panic—which may make them feel like they are having a heart attack or are going crazy—for no apparent reason. Symptoms include heart palpitations, chest pain or discomfort, sweating, trembling, tingling sensations, feeling of choking, fear of dying, fear of losing control, and feelings of unreality. Panic disorder often occurs with agoraphobia, in which people are afraid of having a panic attack in a place from which escape would be difficult, so they avoid these places.

**Post-Traumatic Stress Disorder (PTSD)**—PTSD can follow an exposure to a traumatic event such as a sexual or physical assault, witnessing a death, the unexpected death of a loved one, or a natural disaster. There are three main symptoms associated with PTSD: "reliving" of the traumatic event (such as flashbacks and nightmares); avoidance behaviours (such as avoiding places related to the trauma) and emotional numbing (detachment from others); and physiological arousal such difficulty sleeping, irritability, or poor concentration.

**Social Anxiety Disorder/Social Phobia (SAD)**—SAD is characterized by extreme anxiety about being judged by others, or behaving in a way that might cause embarrassment or ridicule. This intense anxiety may lead to avoidance behaviour. Physical symptoms associated with this disorder include heart palpitation, faintness, blushing, and profuse sweating.

**Specific Phobias**—People with specific phobias suffer from an intense fear reaction to a specific object or situation (such as spiders, dogs, or heights). The level of fear is usually inappropriate to the situation, and is recognized by the sufferer as being irrational. This inordinate fear can lead to the avoidance of common, everyday situations.

# What Causes Anxiety Disorder?

Experts believe that anxiety disorders are caused by a combination of biological and environmental factors, such as brain chemistry, life events, personality, and genetic predisposition. This makes an anxiety disorder much like other physical and mental disorders.

### **How are Anxiety Disorders Treated?**

- Anxiety disorders are highly treatable with psychosocial therapies, medication, or both.
- Psycho-social treatments used in the treatment of anxiety disorders include cognitive-behavioural therapy (CBT), exposure therapy, anxiety management and relaxation therapies, and psychotherapy.
- Drugs used to treat anxiety disorders include selective serotonin re-uptake inhibitors (SSRI's), tricyclic antidepressants, benzodiazepines, beta blockers, and monoamine oxidase inhibitors (MAOI's).
- Combination therapies are often used.

# What is > Obsessive Compulsive Disorder?

Everyone has worries or thoughts that preoccupy them. Everyone has experienced the anxiety caused by thinking, "Did I leave the oven on?" Or "Is my building earthquake safe?" Many individuals have superstitious beliefs or rituals that they follow, such as buying lottery tickets with the same numbers every week or cleaning the house every Sunday morning.

When these behaviours or thoughts become excessive, the individual may be diagnosed with obsessive-compulsive disorder (OCD). OCD is a type of anxiety disorder which can include both obsessions and/or compulsions. These obsessive thoughts and compulsive behaviours can occupy many hours of the day, making it very difficult for the individual to accomplish many tasks or enjoy his/her life.

#### **Obsessions**



are unwelcome thoughts, images, or impulses that occur over and over again. These obsessions are disturbing and invasive. A person with OCD generally recognizes that the obsessions don't really make sense, yet he/she is still compelled to respond to them. Obsessions are accompanied by feelings of fear, doubt, uneasiness, and disgust.

#### Compulsions

are behaviours or acts performed by the individual over and over again. People with OCD perform compulsions according to certain rules in an attempt to try to make their obsessions go away. Compulsions do not give the person any pleasure. Compulsions are performed to obtain temporary relief from the corresponding obsession. Someone who is excessively afraid of dirt and germs would wash constantly, to the point of causing his/her skin to become raw, cracked, and painful. If the obsession is about losing things, the corresponding compulsion could de counting over and over again.

# **Types of OCD**

The types of OCD symptoms can vary from person to person. The following are the most typical personality profiles of

those suffering with OCD. It is also common for people to experience a combination of the following traits.

**Checkers** – Checkers feel compelled to check objects such as door locks and "off" settings on household appliances.

They live with an excessive, irrational fear that harm will be brought to themselves or others because of a failure to

check and recheck things. They often visualize horrific catastrophes in which they are to blame for a lack of responsibility. Checkers often develop elaborate checking rituals that make it difficult for them to complete daily tasks.

**Washer and Cleaners**—Washer & cleaners have an irrational fear of contamination. They compulsively avoid potential

contaminants. They have obsessions regarding disease spread by dirt, germs, viruses, and foreign substances.

They live

with the constant dread of becoming contaminated or contaminating other. Washers and cleaner often wash and clean

their hands, clothes, and houses countless times a day, though they never feel clean or "safe" from contaminants.

**Orderers** – Orderers are focused on arranging things in the "right" way. Often, they must organize things in an exact, particular, or "perfect" way before beginning daily tasks. They become extremely distressed if their things are moved, touched, or rearranged.

**Obsessionals**—Obsessionals experience unwanted, intrusive, and horrific thoughts and images of causing harm to

others. Many obsessionals engage in repetitive thoughts, such as praying, counting, or repeating certain word, to

counteract their disturbing thoughts.

**Hoarders**—Hoarders collect insignificant items and have difficulty throwing away things most people would consider

to be of no value. Hoarders often have chaotic living environments as a result of their extensive collections.

# What Causes Obsessive Compulsive Disorder?

Research shows that OCD tends to run in families, so it is likely that there is a genetic predisposition that makes an individual vulnerable to the illness. Stress does not cause the disorder, but a stressful event can trigger the onset of the illness.

The exact cause of OCD remains unknown, yet due to the fact that the illness may appear after a stressful event, it seems likely that obsessive-compulsive disorder is a combination of the individual's environment (psychological) and genetics (biological). People with OCD appear to have abnormal functioning of a neurotransmitter (serotonin) in their brain.

#### How is OCD Treated?

There is currently no "cure" for obsessive-compulsive disorder, but treatment does offer many people relief from their symptoms. OCD can be treated effectively with medication (antidepressants) and Cognitive Behavioural Therapy (CBT).

Medication is used to treat the obsessive thoughts. People with obsessive-compulsive disorder may have recurring symptoms, so it is important for them to continue taking medication and monitoring the effect. The antidepressants affect the individual's serotonin levels.

Cognitive Behavioural Therapy (CBT) is used to treat the compulsions. The technique used in this therapy is referred to as ERP: Exposure and /response Prevention. This involves exposing the individual to the object or situation that is at the root of the obsession, and then preventing the ritual response (compulsion) that is normally done to ease the obsession. This is an effective psychological treatment that allows the patient to both practice coping exercises and to confront the belief that the compulsive behaviour can prevent a disaster.

# **Step 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 especially important to note:

- 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

Learn to recognize the signs of relapse and the early warning signs. Keep a journal of your relative's behaviour. This will help you and your relative determine clearly what is happening and, with the help of a health care professional, you can both determine what the best course of action may be. This course of action may be as simple as a change in medication or dosage.

Each individual has his/her own set of relapse signs, but the most common signs are:

- Increased withdrawal from activities
- Deterioration of basic personal care

It is also important to note that stress and tension can make symptoms worse or bring on other symptoms.

# Step 2: get proper help

You need to take the initiative—If symptoms of mental illness are occurring, ask your doctor or other health care professional for an assessment or referral. Family members are usually the first to notice symptoms and suggest help.

You need to be persistent—If your health care professional is not familiar with your relative's illness, you may want to provide him/her with literature and information. The assessment and treatment of any mental illness should be done by people who are well qualified. Use referrals to find someone who has an interest in the illness, who is competent, and who has empathy with clients and their families.

You can assist the health care professional—Patients with mental illness may not be able to volunteer much information during their visit. Talk to the health care professional yourself, or write a letter describing your concerns and documenting the behaviours you have noticed. Be specific. Use your notes for details. Be persistent. The information you supply can help them toward a more accurate assessment and treatment.

In order to get enough information to make informed decisions, you will have to ask the health care professional some direct questions.

**Contact other mental health services**—Treatment and other services are available through mental health centers throughout the country. Check your phone book, or contact your provincial Schizophrenia Society to find the centre nearest you.

# **Step 3: Make The Most of The Treatment**

There may be exchanges between a health care professional and client that are of a highly personal nature and confidential. Confidentiality is an integral part of the therapeutic process and needs to be respected. However, family members do need information related to the care and treatment of their loved one. Within the parameters of confidentiality, you should be able to discuss the following with the various health care professionals involved in the patient's care:

- Signs and symptoms of the illness and early warning signs
- Expected course of the illness
- Treatment strategies

You may also ask them about the role you can play in supporting the patient's treatment plan. By your attitude and behaviour, try to show that there is hope, that the illness can be managed, and that life can be satisfying and productive.

- It's a good strategy to help the person maintain a record of information on:
- Symptoms that have appeared
- All medications, including dosages
- All treatment plans and coping strategies
- A schedule of appointments and contact information

Keeping a daily record of the above can help you keep track of this information. it is an effective way for everyone to be involved in the process of the person getting well.

# **Step 4: Manage The Day To Day**

Any illness will cause increased levels of stress in your daily life, and this is particularly true of mental illness. The following suggestions may help combat the amount of stress brought on by the illness.

**Ensure that treatment continues after hospitalization**—This means taking medication and going for follow-up appointments with the various health care professionals involved in his/her treatment (e.g., psychiatrist, social worker, case manager, occupational therapist).

**Provide a structured and predictable environment**—The recovering patient may 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. Do not be upset if the patient isn't able to attend family functions.

**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**—Thought disorder is a great problem for people with mental illness, particularly 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, especially about delusions (false beliefs).

**Be positive and supportive**—Being positive instead of critical will help the person more in the long run. People with mental illness 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 individual set realistic goals**—People living with mental illness 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 stress level will increase, and the symptoms could become worse as a result.

**Gradually increase independence**—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 his/her time constructively. Participating in various tasks and activities helps to increase independence. It is important to set limits on how much the family will tolerate certain behaviours (e.g., excessive smoking or sleeping in).

**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. Be a positive role model. Sometimes just recognizing and talking about something in advance that might be stressful can also help.

**Encourage your relative to try something new**—You can offer help selecting an appropriate activity. If requested, go along the first time for moral support.

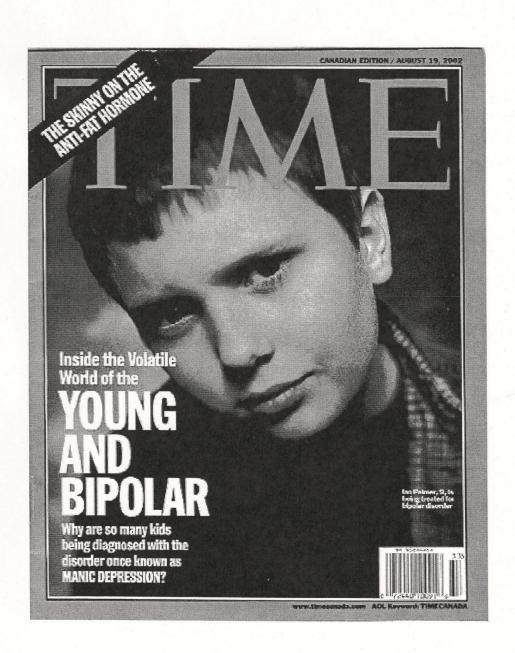
# **Step 5: Look After Yourself And Other Family Members**

Remember to 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 what you have learned here: poor parenting or poor communication did not cause this illness, nor is it the result of any personal failure by the individual. However, poor family communication and a stressful home environment can trigger a relapse in your relative and compromise your own emotional and physical health.

**Value your own privacy**—Keep up your friendships and outside interests. Try not to neglect the other members of your family. In many families, when one member becomes ill, the others may be neglected. (This is true of all illnesses, not just mental illness). It is important to give the appropriate attention to the ill individual and to also attend to the needs of the whole family. As Julie T Johnson notes: "*Mental Illness often disable the entire family.*" Siblings, children, spouses, or parents of people with schizophrenia need special attention and support to deal with these issues.

**Get Support**—Learn from others who have similar experience. If you are the parent, spouse, sibling, or child of someone with a mental illness, 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." 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 mental illness and their families.

# Article 1 > Inside The Volatile World of the Young and Bipolar



#### **YOUNG & BIPOLAR**

# Once called manic depression, the disorder afflicted adults. Now it's stoking kids. Why?

By Jeffrey Kluger with Sora Song Photographs for TIME by Steve Liss

It wasn't every day that Patricia Torres raced down the street of Miami at 110 k.p.h. But then it wasn't every day that her daughter Nicole Cabezas hallucinated wildly, trying to jump out of the car, pulling off her clothes and ranting that people were following her, so this seemed like a pretty good time to hurry. Nicole, 16, had been having problems for a while now – ever since she was 14 and began closeting herself in her bedroom, incapable of socializing or doing her schoolwork, and contemplating suicide.

The past few months had been different though, with the depression lifting and an odd state of high energy taking its place. Nicole's thoughts raced; her speech was fragmented. She went without sleep for days at a time and felt none the worse for it. She began to suspect that her friends were using her, but that was understandable, she guessed, since they no doubt envied her profound gifts. "I was the center of the universe, "she says quietly today. I was the chosen one."

Finally, when the chosen one was struck by violent delusions – the belief that she had telekinetic powers that she could change the colours of objects at will – Torres decided it was time to take Nicole to the hospital. Emergency-room doctors took one look at the thrashing teenager, strapped her to a gurney and began administering sedatives. She spent 2 weeks in the hospital as the doctors monitored her shifting moods, adjusted her meds and talked to her and her parents about her descent into madness. Finally, she was released with a therapy plan and a cocktail of drugs. Six months later, doctors at last reached a diagnosis: she was suffering from bipolar disorder.

While emotional turmoil is part of being a teenager, Nicole Cabezas is among a growing cohort of kids whose unsteady psyches do not simply rise and fall now and then but whipsaw violently from one extreme to another. Bipolar disorder once known as manic depression, always known as a ferocious mental illness, seems to be showing up in children at an increasing rate, and that has taken a lot of mental-health professionals by surprise. The illness until recently was thought of as the rare province of luckless adults—the overachieving businessman given to sullen lows and impulsive highs; the underachieving uncle with the mysterious moods and the drinking problem; the tireless supermom who suddenly takes to her room, pulls the shades and weeps in shadows for months at a time.

But bipolar disorder isn't nearly so selective. AS doctors look deeper into the condition and begin to understand its underlying causes, they are coming to the unsettling conclusion that large numbers of U.S. teens and children are suffering from it as well. The National Depressive and Manic-Depressive Association gathered in Orlando, Florida, last week for its annual meeting, as doctors and therapists face a daunting task. Although the official tally of Americans suffering from bipolar disorder seems to be holding steady – at about 2.3 million, striking men and women equally—the average age of onset has fallen in a single generation from the early 30s to the late teens.

And that number doesn't include kids, under 18. Diagnosing the condition at very young ages is new and controversial, but experts estimate that an additional 1 million preteens and children in the U.S. may suffer from the early stages of bipolar disorder. Moreover, when adult bipolar are interviewed, nearly half report that their first manic episode occurred before age 21; 1 in 5 says it occurred in childhood.

"We don't have the exact number yet," says Dr. Robert Hirtschfeld, head of the psychiatry department at the University of Texas in Galveston, "except we know it's there, and it's underdiagnosed."

If he's right, it's an important warning sign for parents and doctors, since bipolar disorder is not an illness that can be allowed to go untreated. Victims have alcoholism and drug-abuse rate triple that of the rest of the population and a suicide rate that may approach 20%. They often suffer for a decade before their condition is diagnosed, for years more before it is properly treated. "If you don't catch it early on," says Dr. Demitri Papolos, research director of the juvenile Bipolar Research Foundation and co-author of *The Bipolar Child*, " it gets worse, like a tumor." Heaping this torment on an adult is bad enough; loading it on a child is tragic.

Determining why the age-of-onset figures are in free fall is attracting a lot of research attention. Some experts believe that kids are being tipped into bipolar disorder by family and school stress, recreational drug use and perhaps even a collection of genes that express themselves more aggressively in each generation. Other argue that the actual number of sick kids hasn't changed at all; instead, we've just got better at diagnosing the illness. If that's the case, it's still significant, because it means that those children have gone for years without receiving treatment for their illness, or worse, have been medicated for the wrong illness. Regardless of the cause, plenty of kids are suffering needlessly. "At least half the people who have this disorder don't get treated," says Dr. Terrence Ketter, director of the bipolar disorder clinic at Stanford University.

Yet scientists are making progress against the disease. Genetic researchers are combing through gene after gene on chromosomes that appear to be related to the condition and may offer targets for drug development. Pharmacologists are perfecting combinations of new drugs that are increasingly capable of leveling the manic peaks and lifting the disabling lows.

Behavioural and cognitive psychologists are developing new therapies and family-based programs that get the derailed brain back on track and keep it there. "We did a good job for a long time of putting a lid on [the disorder], "says Dr. Paul Keck, vice chairman of research at the University of Cincinnati College of Medicine. "Now the goal is to completely eradicate the symptoms."

For Lynne Broman, 37, of Los Angeles, just taming the disorder would be more than enough,. A single mom, she is raising 3 children, 2 of whom—Kyle,5, and Mary Emily, 2—are bipolar.

At the moment it's Kyle who is causing the most trouble. He has been expelled from 6 preschools and two day-care centers in his short academic career and has made a shambles of their once tidy home. Kyle was hospitalized for violent outbursts at age 4 and still has periods when he goes almost completely feral. He once threw a butcher knife at his mother, nearly striking her before she ducked out of the way. "that day started out fine, "Broman says, "but he turned on me like a rabid dog."

Until quite recently, a child who behaved like this would have been presumed to have either attention-deficit/hyperactivity disorder (ADHD) or oppositional defiant disorder. Bipolar would not even have been considered. And with good reason: the classic bipolar profile, at least as it appears in adults, is almost never seen in kids.

Most bipolar adults move back and forth between depressions and highs in cycles that can stretch over months. During the depressive phase, they experience hopelessness, loss of interest in work and family, and loss of libido—the same symptoms as in major (or Unipolar) depression, with which bipolar is often confused. The depressive curtain can descend with no apparent cause or can be triggered by a traumatic event such as an accident, illness or the loss of a job.

But in bipolar disorder, there is also a manic phase. It usually begins with a sort of caffeinated, can-so buzz. "Sometimes the patients find the highs pleasant," says Dr. Joseph Calabrese, director of the mood disorders program at Case Western University in Cleveland. As the emotional engine revs, higher, however, that energy can become too much. Bipolars quickly grow aggressive and impulsive. They become grandiose, picking fights, driving too fast, engaging in indiscriminate sex, spending money wildly. They may ultimately become delusionally mad.

With kids, things aren't nearly so clear. Most children with the condition are ultra-rapid cyclers, flitting back and forth among mood states several times a day. Papolos, who co-wrote The Bipolar Child, studied 300 bipolar kids ages 4 through 18, and he believes he has spotted a characteristic pattern. In the morning, bipolar children are more difficult to rouse than the average child. They resist getting up, getting dressed, heading to school. They are either irritable, with a tendency to snap and gripe, or sullen and withdrawn.

By midday, the darkness lifts, and bipolar children enjoy a few clear hours, enabling them to focus and take part in school. But by 3 or 4 p.m., Papolos warns, "the rocket thrusters go off," and the kids become wild, wired, euphoric in a giddy and strained way. They laugh too loudly when they find something funny and go on long after the joke is over. Their play has a flailing, aggressive quality to it. They may make up stories or insist they have superhuman abilities. They resist all efforts to settle them and throw tantrums if their needs are denied. Such wildness often continues deep into the night—which accounts in part for the difficulty they have waking up in the morning. "They're like Dr. Jekyll and Mr. Hyde," says Papolos, "which is how their parents describe them."

Preverbal toddlers & infants cannot manifest the disorder so clearly, & there is no agreement about whether they exhibit any symptoms at all. However, many parents of a bipolar say they noticed something off about their baby almost from birth, reporting that he or she was unusually fidgety or difficult to soothe. Broman insists she knew her son Kyle was bipolar even when he was in the womb. "This child never slept inside," she says. "He was active 24 hours a day."

For Broman, making that diagnosis may not have been hard since the condition, as Ketter puts it, "is hugely familiar." Broman herself is bipolar, though her illness was not diagnosed until adulthood. Children with one bipolar parent have a 10% to 30% chance of developing the condition; a bipolar of bipolars have at least one close relative with a mood disorder.

For all that, when the disorder does appear in a child, the diagnosis is often wrong. ADHD is the likeliest first call, if only because some of the manic symptoms fit. The treatment of choice for ADHD is Ritalin, a stimulant that has the paradoxical ability to calm overactive kids. But giving Ritalin to a bipolar child can deepen an existing cycle or trigger one anew. Brandon Kent, a 9-year-old from La Vernia, Texas, in whom ADHD was diagnosed in kindergarten (they did not yet know he was bipolar), took Ritalin and paid the price. "It sent him into depression," says his mother Debbie Kent. "Within a couple of months, he was flat on the couch and wouldn't move." By some estimates, up to 15% of children thought to have ADHD may actually be bipolar.

Similar misdiagnoses are made when parents and doctors observe symptoms of the low phase of the bipolar cycle and conclude that the kid is suffering from simple depression. Treat such a child with antidepressants like Prozac, however, and the rejiggering of brain chemistry may trigger mania. some researchers believe that nearly half of all children thought to be depressed may really be bipolar.

For most kids, the consequences of not identifying the illness can be severe, since the bipolar steamroller gets worse as a children get older. Though they tend to be verbally skilled and are often creative, bipolars find school difficult because the background noise of the disorder makes it hard for them to master such executive functions as organizing, planning and thinking problems through.

Now it's stoking kids. Why?....continued

The most serious symptoms may appear when kids reach age 8, just when the academic challenge of grade school start to be felt. "They're being asked to do things that they're very poor at," Papolos says, "and it's a blow to their self-esteem." If school doesn't kick the disorder into overdrive, puberty often does, with its rush of hormones that rattle even the steadiest preteen mind.

Still, all these natural stressors and the new awareness of the disorder may not be enough to account for the explosion of juvenile bipolar cases. Some scientists fear that there may be something in the environment or in modern lifestyles that are driving into a bipolar state children and teens who might otherwise escape the condition.

One of the biggest risk factors is drugs. People with a genetic predisposition to bipolar disorders live on an unstable emotional fault line. Jar things too much with a lot of recreational chemistry, and the whole foundation can break away, especially when the drugs of choice are cocaine, amphetamines or other stimulants. "We do think that use of stimulating drugs is playing a part in lowering the age of onset." says Hischfeld.

Stress too can light the bipolar fuse. Many latent emotional disorders, from depression to alcoholism to anxiety conditions, are precipitated by life events such as divorce or death or even a happy rite of passage like starting college. And bipolar disorder can also be set off this way. "Most of us do not think environmental stress causes the disorder," says Dr. Michael Gitlin, head of the mood-disorders clinic at UCLA. "But it can trigger it in people who are already vulnerable."

A decidedly more complicated explanation may be gene penetrance; not every generation of a family susceptible to an illness develops it in the same way. Often, later generations suffer worse than earlier ones because of a genetic mechanism known as trinucleotide repeat expansion.

Defective sequences of genes may grow longer each time they are inherited, making it likelier that descendants will come down with the illness. This phenomenon plays a role in Huntington's disease and could be involved in bipolar. "There's a stepwise genetic dose that can increase the risk," theorizes Ketter.

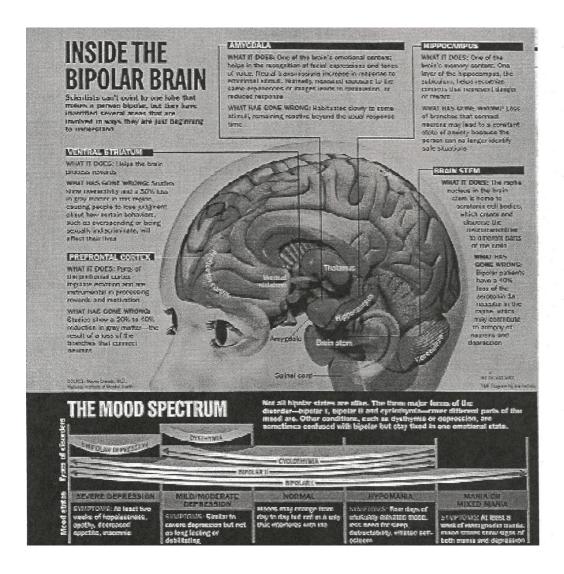
The first part of determining how those genes work is figuring out where they are hiding, and the National Institute of Mental Health is looking hard. Investigators at eight research centers around the U.S., working under an NIMH grant, are studying the genomes of 500 families with a bipolar history to see what genetic quirks they share. So far, at least 10 of the 46 human chromosomes have shown irregularities that may be linked with the condition. The most interesting is chromosome 22, which has been implicated not only in bipolar disorder but also in schizophrenia and a little-known condition called velo-cardiofacial syndrome, which has schizophrenia links as well. The seeming relatedness of disorder that so prominently feature delusions has not been lost on researchers, though with so much still unknown about chromosome 22—to say nothing of the other nine tentatively linked with bipolar—no one is ready to draw any conclusions. "There are probably genetic variants that across multiple systems in the brain," says Dr. John Kelsoe, psychiatric geneticist at the University of California, San Diego.

While this wealth of chromosomal clues makes fascinating work for geneticists, it promises little for bipolar sufferers, at least for the moment. What they want is relief—and fast. Thanks to rapid advances in pharmacology, they are finally getting it. In fact, children on a properly balanced drug regimen supplemented with the right kind of therapy can probably go on to lead normal lives.

For decades, the only drug for bipolar patients—and one that is still an important part of the pharmacological arsenal—was lithium. It works by regulating a number of neurotransmitters, including dopamine and

norepinephrine, as well as protein kinase C, a family of chemicals that help determine the neurotransmitter amounts that nerve cells release. With its hands on so many of the brain's chemical levers, lithium can help bring bipolars back to equilibrium. For 30% of sufferers, however, it has no effect at all; for others, the side effects are intolerable. "It's still a miraculous drug," says Keck. "But some people simply don't respond to it enough."

New drugs are stepping into the breach. Rather than rely on the imprecise relief that a single drug like lithium provides, contemporary chemists are investigating a battery of other medications.



Depakote, an anticonvulsant developed to calm the storms of epilepsy, was found to have a similarly soothing effect on bipolar cycling, and it was approved in 1995 to treat that condition too. The success of one anticonvulsant prompted researchers to look at others, and in the past 5 years several—including Lamictal, Tegretol and Topamax—have been put to use.

Anticonvulsants are not the only drugs being reformulated. Also showing promise are the atypical antipsychotics. The best known antipsychotic, Thorazine, is a comparatively crude preparation that controls delusions by blocking dopamine receptors. In the process, it also causes weight gain, mood flattening and other

side effects. Atypical antipsychotics work more precisely, manipulating both dopamine and serotonin and suppressing symptoms without causing so many associated problems. There are numerous atypical antipsychotics out there, including Zyprexa, Risperdal and Haldol, and many are being used to good effect on bipolar patients.

For any bipolar, the sheer number of drug options is a real boon, as what works for one patient will not necessarily work for another. When Brandon Kent, the 9-year-old Texas boy, started taking Depakote and Risperdal, his body began to swell. Then he switched to Topamax, which made him lethargic. Eventually he was put on a mix of Tegretol and Risperdal, which have stabilized him with few side effects. Kyle Broman in Los Angeles is having a harder time but has grown calmer on a combination of Risperdal and Celexa, an antidepressant that for now at least does not appear to be flipping him into mania.

But drugs go only so far. Just as important is what comes after medication: therapies and home regimens designed to help patients and their families cope with the disorder. Early last year the National Institute of Mental Health launched a five-year, \$22 million study, the Systematic Treatment Enhancement Program for Bipolar Disorder (STEP-BD) to refine bipolar therapies. Some 2,300 volunteers are participating in the program, and enrollment is expected to reach 5,000. Of all the treatments the STEP-BD doctors are studying, the most basic and perhaps the most important one for children and teen involves lifestyle management.

From infancy, kids can easily be unsettled by disruptions in their circadian cycles, as parents of newborns and toddlers learn whenever they try to change nap times. Bipolars, regardless of age, are also reactive to fluctuating schedules; many things can destabilize patients, but Keck believes that sleep deprivation and time zone changes are the most upsetting.

For this reason, parents of bipolar kids are urged to enforce sleep schedules firmly and consistently Bedtime must mean bedtime, and morning must mean morning. While that can be hard when an actively manic child is still throwing a tantrum 2 hours after lights-out, a combination of mood stabilizing drugs and an enforced routine may even bring some of the most symptomatic kids into line. Teens, who are expected to do a lot more self-policing than younger children, must take more of this responsibility on themselves, even if that means a no-excuses adherence to a no-exceptions curfew.

Also important is diet. Caffeine can be a mania trigger for bipolars, so teens are advised to stay away from coffee and tea. Bipolar kids of all ages must also be careful with less conspicuously caffeinated foods such as sodas and chocolate. And for adolescents and teens, staying free of alcohol and drugs is critical. Not only is the risk of addiction high, but treatment of the underlying bipolar problem is much more difficult if the patient's mind is clouded by recreational chemicals.

For children old enough to benefit, the second leg of treatment is individual therapy, which includes social-rhythms work, learning to balance meals, sleep, studies and recreation. If a triggering incident such as a divorce or death kicked the condition off, the doctor can help the child process that too.

The last perhaps hardest element of treatment is family therapy. Bipolar disorder, like schizophrenia, depression and certain anxiety conditions, is powerfully influenced by surroundings. When an identical twin suffers from bipolar, the other twin has only a 65% chance of developing it too. Conversely, adopted children with no genetic legacy for bipolar have a 2% chance of coming down with the condition if they are raised in a home with one nonbiological bipolar parent. Clearly, something is in play besides mere genes, and that something is environment. Raise a child in a steady and stable home, and you reduce the odds that the illness will gain a toehold, which is why Counsellors work hard to teach parents and kids how to minimize family discord.

# Once called manic depression, the disorder afflicted adults. Now it's stoking kids. Why?....continued

One strategy is to avoid too much negatively expressed emotion. Tough love, for example, is a good idea in principle, but in some situations it can do more harm than good, especially if it makes kids who can't control their behaviour feel worse about themselves. When family arguments do break out, they need to be conducted in a controlled way. Psychology professor David Milkowitz of the University of Colorado encourages families to avoid what he calls the "three volley," a provocation followed by a rejoinder, then a rebuttal. Hold the volleys to just one or two, and you'll avoid some domestic breakdowns.

The most important thing parents and siblings can do is simply to serve as the eyes and ears of the bipolar child. A teen in a depression can't see the hope beyond the gloom. A child in a manic cycle can't see the quiet reality behind the giddiness. It's up to people whose compasses are more reliably functioning to step in and point the way. Says Dr. Gary Sachs, director of the Bipolar Treatment Center at Boston's Massachusetts General Hospital and principal investigator for the STEP-BD project: "Treatment is modeled on Homer's Odyssey. When Odysseus gets blown off course, he asks the In the future, kids should be getting yet more assistance as they sail. At the Stanley Research Center, in Massachusetts General Hospital, investigators are beginning a yearlong study of at least 10 bipolar drugs, comparing the merits of each and the ways they can best be combined. Others are looking at such unconventional treatments as omega-3 fatty acids, found in fish oil, which may inhibit the same brain receptors that lithium affects. Elsewhere, researchers are running brain scans to determine which lobes and regions are involved in bipolar disorder and how to target them more accurately with drugs. Investigators also hope to develop a blood test that will allow bipolar disorder to be spotted as simply as, say, high cholesterol, eliminating years of incorrect diagnoses and misguided treatments.

Getting all this work done right—and getting the treatments to the kids who need it—is one of the newest and most challenging goals of the mental-health community. Doctors who recognize bipolar disorder and know how to handle it are in critically short supply. Growing up is hard enough for children who are bipolar. The last thing they need is a misdiagnosis and treatment for something they don't have.

#### **Manic Genius**

Lord Byron



Edgar Allan Poe



Robert Schumann



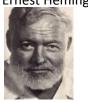
Vincent Van Gogh



Virginia Woolf



**Ernest Hemingway** 







## IF SO...

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**ANTICONVULSANT DRUGS** First used for epilepsy, such medications as Depakote and Lamictal calm manic storms.

**ATYPICAL** ANTIPSYCHOTICS Drugs designed to help schizophrenics' battle delusions, including Zyprexa and Risperdal, can do the same for bipolars.

ANTIDEPRESSANTS Risky, since they can trigger bipolar cycling, but drugs such as Prozac may be part of the mix

LIFESTYLE Schedules are key, with fixed bed and wake-up times. Foods with caffeine should be limited. Teens should avoid drugs and alcohol.

**INDIVIDUAL THERAPY** Kids need counselling to help them balance sleep, meals, work and play. They also must talk about problems at home & resolve crises that can trigger disorder.

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Reported by Dan Cray and Jeffrey Ressner Los Angeles, Jeanne DeQuine Miami, Melissa Sattley Texas, Cristina Scalet New York and Maggie Sieger Chicago Source: <u>TIME</u> magazine, AUGUST 19, 2002 edition; used with permission

## Article 2 > Don't Panic\*

By Nan Dickie

You wake up. You're not feeling quite right. Perhaps you're gloomy, or exhausted, or can't remember what you're supposed to do even though you planned today's activities yesterday. Things have been going along so smoothly for so long; you'd almost forgotten you ever get depressed. But this morning is different.

When you get to work, you're edgy and self-critical, and you want to avoid your colleagues.

What's going on? What do you do?

Your instinct may be to panic. Oh, my God, I'm going into an episode!

You ask yourself what you've done to deserve an episode now. Or you ask yourself what you should've done that you haven't. If this is an episode, I've brought it on myself. It's all my fault.

You've fallen in the trap. You want to turn back the clock & start the day again, this time without the nightmare. Notpossible.

How do you escape this mess? You try to calm yourself, but the memories of earlier down times gush into your mind and take over. You lose all perspective of where your life was going before this morning.

Whoa! Rather than panicking & sinking deeper into this mire, ask yourself some important questions.

Quiet questioning may help you determine whether this is an episode coming on, or not. Your answers may indicatewhat has precipitated this bad morning. Of course, there may not have been a precipitator; you may have just gotten out of bed on the wrong side. It's happened before. In any case, it's best not to immediately jump to the conclusionthat your next episode is inescapably descending on you.

The act of questioning, the orderly process of asking & answering, is in itself therapeutic. It can help you to settle down for a bit & and allow you to make more rational decisions about whatever it is you are facing.

# **Common reasons for normal depression:**

Ask Yourself	Why The Question is Relevant	
Have you been exercising more than usual? Are you suffering from a recent painful injury or illness?	If you ask your body to do more than it's used to, you may be more tired than usual. Pain can cause one to feel frustrated and dispirited.	
Have you recently had, or do you have the flu, or other sickness?	Any illness that causes loss of energy can masquerade as depression.	
For women: Could this be premenstrual syndrome (PMS), or are you going through menopause?	Some women feel low before their periods, & many women experience depression at some point during menopause.	
Are you using over the counter medication (antihistamines, decongestants, Aspirin, Tylenol, etc.) as well as medication prescribed for depression?	Over-the-counter medication may interact badly with prescribed medication. Check with your doctor before using over the counter drugs.	

# Could be an episode, or not:

Ask yourself	Why the question is relevant
Has a traumatic event happened recently in your life? Have you lost your job? Has a loved one died recently?	Some people think that personal traumas can make one more vulnerable to an episode. In any case, they can make one feel despondent.
Have you had an argument with someone close to you?	A personal upset may seem to, but rarely does, precipitate an episode.
Have you just finished a job, or term at school?	One can experience a let-down after sustained or arduous activity.
Has your best friend recently left town? Have you recently moved? Are you anxiously awaiting important news?	Loneliness, upheaval, & anxiety cause many of us to feel somewhat depressed. But feeling low does not necessarily mean an episode is imminent.
Is a long weekend looming & you hate long weekends? Is it December, & you have always dreaded Christmas?	Distress associated with a dreaded event may seem like a symptom of depression.
Has the weather been grey & rainy, or hot & sticky for the past month or so?	Many weeks of the same weather, be it good or bad, can get anyone down.
Do you have something difficult to do or decide that you don't want to face?	People do get sick to avoid things they fear or dread. They don't get sick on purpose. it just happens. They may end up feeling gloomy and ill-tempered for some time.

# Possible episode indicators:

Ask yourself	Why the question is relevant:	
Have you been taking the prescribed amount of your medication(s) in the past few days, weeks?	If you are taking less medication than you should, your body may not be getting what it needs.	
Has your doctor increased or decreased the dosage of one of your medications in the past 6 weeks, or are you in the process of switching from one medication to another?	In the midst of changing types of dosages of medication, it is not uncommon for one to experience symptoms of depressive illness while the body adjusts.	
Have you been keeping your medication(s) in a cool, dry place, out of sunlight?	Medications stored in warm, humid, bright places may not work as intended.	
Do you think it is time for you to have an episode? Do you usually have episodes at regular intervals & now your time is up?	Some of us have episodes "like clockwork." But cycles may change. You may be spared for another month or year.	
Have you been diagnosed with Seasonal Affective Disorder (SAD), and winter is coming on?	People who have SAD are more vulnerable to an episode when there are fewer daylight hours.	

This list may raise additional questions for you, or give you an idea of why you feel low today. If possible, discuss your concern with someone who has seen you through at least one episode. He or she may be able to help pinpoint the cause or ease the fear.

If you are still unsure, phone your doctor & discuss your situation. Have your answers to the above questions at hand. Follow your doctor's instructions. Do not alter the amount of medication you take unless your doctor instructs you to do so.

Be aware of mood shifts over the next few days. Soon you will know whether or not this is going to be a real episode.

\*Nan Dickie, <u>A Map for the Journey: Living Meaningfully with Recurring Depression</u> (Baltimore, Maryland: America House Book Publisher, 2001);

web site: <a href="http://www.publishamerica.com">http://www.publishamerica.com</a>

The SSC Education Program has received the author's permission to reprint this article.

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# "Twenty-hour days were not uncommon. In the meantime my dress had become slightly eccentric..."

This is the conclusion of 5 articles that chronicle my lifelong struggles with depression and mania:

Few of you have ever had the experience of waking up from a drunken stupor in a strange city in a strange country, jobless and friendless and nearly penniless. You don't really want to be sober, for aside from the unwelcome intrusion of reality, you also find your psyche playing host to the type of cold fusion nuclear reaction that demands instant release.

Rage, goddess, sing the Rage—a line from Homer. The shrinks have no adequate description for it—agitated depression, dysphoric mania, a mixed state, mania and depression fused into an explosive kinetic ball of emotional kilotonnage, one that makes the very act of living totally unbearable. It was simply a matter of following through.

Meanwhile, as I lay sprawled on the floor of an apartment that I could ill afford to pay the rent on, it was a beautiful summer day in Melbourne, Australia. Outside my window the eucalyptus trees that lined my street created the impression of an urbanized Eden, while kookaburras' shrill laughter in the distance sounded forth a Midsummer Night's Dreamscape of fairy land gaiety.

But the rumbling of the tramways around the corner represented my one-way ticket out this life, out of my private little hell. I only had to change trams maybe once or twice to put me within walking distance of the suspension bridge that spanned the harbor.

Only 7 months before I had been on a plane to Melbourne bound for a bright new life. I had sent out my resume to the major Australian newspapers and business magazines, and 4 editors had made me an offer. Oddly enough, I snapped at the one that offered the least money, lured by the idea of making my mark on a paper going through the kind of changes I reveled in.

This had been my modus operandi in New Zealand, taking over stodgy publications and giving them the old razzamatazz. I had done this on a law journal, an accountant's journal, a finance journal, and the business pages of a national Sunday newspaper. My average tenure lasted about a year. My longest stay was 3 years. On my last job, they integrated the Sunday paper into the daily one, and I had been left out in the cold. Looking back, my downsizing only served to delay my ultimate crash and burn.

The motor had been running hard back in New Zealand. The new Labour Government there had surprised everyone by becoming more right-wing that the right-wingers had ever been, and a whole new wildwest economy had been born, dominated by capitalist cowboys with paper fortunes who had Parliament at their beck and call. Suddenly, instead of operating on the fringes of journalism, we business/finance journalists were front stage center, smugly looking down our noses at our less-knowing brethren in the Parliamentary gallery.

Fifteen-hour days were par for the course, and 24 hour days were not uncommon. In the meantime my dress had become slightly eccentric, featuring brightly coloured socks and ties and a collection of broad-brimmed Humphrey Bogart fedoras. The thing I am most proud of during all that time was that, unlike many of my colleagues, I never glorified any of these capitalist cowboys. It would have been easy to fill up space with material put out by their PR flaks, but I resisted pressure from a lot of quarters and put my readers first.

It took me a little while to find my rhythm in Australia, but by September my old habits were returning. Then came the stockmarket crash of October 1987, and—thanks to all those paper fortunes going up in smoke—nowhere in the world did it hit harder than in Australia and New Zealand. By then, I had found my niche as the paper's stay, not to mention New Zealand, always on short notice, usually not knowing for sure when I would return.

Often I literally composed the stories in my head, dictating them over the phone to someone at the other end in hopes of making it into the next edition. On one occasion, I actually found myself reviewing a Frank Sinatra concert, which got major play on the paper's entertainment pages, together with about 3 or 4 pieces of mine that appeared on the business pages that same day.

An acquaintance from New Zealand then living in Melbourne called me up & commented on my output, for which I had a ready answer: "Yeh, well it was my turn to write the paper that day."

Oh, I had the one-liners coming. I was floating on air. On a return visit to New Zealand I was even nice to my exwife & her boyfriend. Somewhere, I found the time to fit in a brief fling with someone who had just left her husband.

But the high was beginning to turn on me. Sometimes I found myself snapping at people, which was very uncharacteristic of me. Once, on the tram, on my way to work in the early morning, I found myself on the brink of physically attacking some wise-assed teenager. I actually got up out of my seat & went for his neck before I caught. And then there was the issue of my 6 months' salary review.

Based on my performance, I was certainly entitled to a substantial raise. No, it was not delusional. The delusional part came in thinking I couldn't be replaced. When the editor failed to make me a decent offer I quit in a huff, bitterly resentful over his treatment of me. Furious, in fact, in a blind rage. I told my colleagues what had happened & they look at me like I was crazy. Didn't anyone understand?

Hell with them, I thought. I'll just apply for another job. But this time there were no takers. no one would touch me with a ten-foot pole. I happened to encounter one of the paper's big name journalists in a nearby pub, and he literally turned his back on me, pointedly refusing to acknowledge my existence. I was nothing, non-person, a pariah.

Meanwhile, I would walk for hours—occasionally breaking out into a run—feeling the cold fusing inside my psyche pulsing and surging and desperately seeking a fast way out. Going to sleep was like the 4<sup>th</sup> of July. All I had to do was close my eyes to experience the fireworks flashing onto my retinal screen. I would open my eyes only to find shadows & objects merging in the dark into an ominous new hellscape. I was on the brink of breaking out into full-scale hallucinations, and I knew that fairly soon I would be going mad.

I'M NORMAL! I wanted to shout. I've always been normal. This was just—stress—that was it. New location, crazy working hours. I just needed to slow down, that was all.

But no, that wasn't it, I decided in a Damascus Road flash of insight. I needed a religious experience, a spiritual transformation, a zen moment, a cosmic turbocharge. Then everything would be fine, better than fine, in fact. Perfect—I could walk the earth as an enlightened being. I'm ready! I let God know. Plug me in.

I found myself prowling the bookshops, spending my dwindling supply of funds on books about Tibet and eastern religions and white magic. I tried to float out of my body and talk to spirits and will my hair to grow in

and move objects by thought, knowing the only thing holding me back was my lack of ability to change my vibrations and concentrate my mind.

But it was only a matter of time.

But how there was the small matter of me on the floor emerging from a drunken stupor in a strange new country with no job, no friends, almost no money, and no hope of finding work. But just when the idea of jumping off a bridge seemed my only alternative, another option presented itself:

I'll write a book, I thought. On the stock market crash. The idea had actually crossed my mind much earlier, while still at work, but now there was a certain desperate quality to the proposition. That day I grabbed hold of a typewriter and began pounding on the keys:

"A stock market crash has no setting," I wrote. "It occurs in people's minds, a collective will that determines what is valuable and what is worthless, from day to day, minute to minute. To understand finance has nothing to do with economics or accounting. Instead, it is a philosophical discipline, of the mind determining reality, the natural territory of Kant & Plato and the rest."

In nothing flat I filled up a page, then another and another, all rushing out in a frothy stream requiring very little rewriting. Paradoxically, this new state of productive mania pulled me away from my more destructive old state. As the days went on, I began to enjoy my new life working from my apartment. I would pour a glass of wine or make myself a cup of tea, and put on Duke Ellington or Beethoven or any number of composers in between, and settle in for a pleasant round at the keyboard. Later I would go out for a walk in my urbanized Eden.

The creative afterburners were running white hot by the time I put sheet number two hundred in my typewriter: "One would never know there'd been a crash," I banged out. "It was a different sort of disaster in a new world of intangibles—far more subtle than a nuclear bomb—one that could practically be willed away in a Berkelian-Kantian outburst of subjective idealism—or was it the other way around?"

I finished my book in 5 weeks, and very soon after I found an agent and a publisher. Lest I be seen to be giving my manic phase all the credit, let me make it clear that I did not write that book so much as retrieve it. The book was actually the product of 6 years of immersion in the world of business and finance, and several years before that in law and many more years working at my craft as a writer, plus a whole lifetime of reading and learning. By the time I came to sit down at the keyboard, my brain knew exactly what to do. Mania may have been a part of the process, but only as an accessory to the deed.

Once I had a publisher lined up, the inevitable letdown occurred. I literally didn't get out of my bed for weeks. Meanwhile, my depression was punctuated by the kind of rages that could very easily be mistaken for mania. In fact, mania may have intruded into my depression. These "mixed" states, by the way, continue to perplex the psychiatric profession, who can't seem to agree amongst themselves.

Over time my depression eased and I took on another major writing assignment. As for my Damascus Road experiences, there was no turning back. I now began to explore my innate spirituality in a far less delusional fashion, and experienced several immediate benefits. The meditation and yoga I began practicing brought me back from the edge, and gave me a sense of hope. I also found that after years in the singe-minded world of business and finance, my thinking became far more three-dimensional.

But my miraculous "recovery" prevented me from seeking real help. My minor successes only served to fuel grandiose ideas, and my resurrection back into the real world gave way to the intoxication of mild mania. In time

I would be felled by a cascading series of killer depression. it was only when I had an irresistible vision of myself swinging from the balcony of my bedroom that I finally called out.

Fortunately I was back in the States with my family able to help.

It has taken me 6 months to claw my way back to a state where I actually had an experience of feeling happy without being in a state of mania or hypomania. All my life I have always wanted to be normal & fit in, even though I knew from day one almost that I was different. But now normal has taken on a new meaning. Normal is what is normal for me.

These days, thanks to medications and talking therapy and a strict diet and exercise and sleeping regime, I have declared an uneasy truce with my disorder. I have learned to live with this beast inside me, even with the knowledge that it could very well bring me down at a moment's notice and show me no mercy. it has taken me into faraway places and endowed me with near-mystical qualities and insights plus real-world wisdom and skills. It has brought me closer to God and myself and my fellow human beings. But it has also reduced me to nothing and taken away everything I had. It has left me for dead, powerless to fight, feeling abandoned by both God and man.

And so I must accept what I am, the bad as well as the good, the ridiculous as well as the sublime. Maybe then, in my own way that is unique to me, I can feel as though I fit in. Maybe then, after nearly a lifetime of feeling different, I can say for the first time—and say it like I really mean it—that I am truly normal.

\*This story first appeared on **Suite 101.com** – Depression: http://www.suite101.com/welcome.cfm/depression

#### **About the Author:**

John McManamy publishes a weekly online depression and bipolar newsletter. For further information: http://www.mcmanweb.com

# Article 4> It's Just a Thought

By Rick Cropp, Author and Newspaper Columnist\*



t one time, I thought I was going insane—a common theme I learned later. Over a hundred times a day I would catch myself daydreaming about fearsome catastrophes—my car going off the road at high speed, criminals breaking into my house and killing me or a loved one, gunfights, knife fights, war, disease, divorce, jail—anything catastrophic, in my head, I gravitated to it.

I would begin to sweat, my heart would rattle out of my chest and I sometimes had so much adrenaline rushing around in my body I shook. I would find myself completely stopped, hands and face clenched as I watched all these things unfold on my internal movie screen. by the end of every day I was exhausted.

I slowly stopped going out with friends, (They said I was too preoccupied. An understatement.), and stopped going to certain places afraid that these waves of mayhem would start again. I couldn't watch TV programs with violence in them because it triggered these fantasies (Besides, it was boring. What went on in my head was far gorier, far more Technicolor vivid than any TV show.). I was cranky and tired all the time from the internal struggle and being hyped on adrenaline.

I tried everything to make the thoughts go away. I stopped watching the news, stopped drinking coffee, exercised more and quit a stressful job. I told myself to get a grip and stop being weak, tried pills, tried everything, all the while realizing that my peace of mind and possibly my sanity was disappearing. All I wanted was for it to stop.

I had no idea where this all came from or why it was happening but I knew it was getting worse. More than once I stood at the end of the Second Narrows Bridge wondering if jumping wasn't the only way I was going to rid myself of this horror. Fortunately, when I got right down to it, the trade off for this kind of successful "cure" seemed a little steep.

I was so embarrassed by my inability to control my thoughts that I lied to my wife (What would she think of this monster who thought such horrendous things?) and my doctor. When I finally confessed to my doctor, he sent me to a psychiatrist who said "everyone has rotten thoughts sometimes and it doesn't mean anything. Take these pills whenever you have these thoughts. "Which I did. The pills didn't stop the thoughts but they didn't seem quite so terrifying, at least for a while. Eventually I got tired of moving through life like a zombie (I did catch up on my sleep.) and trashed the medication.

#### Back came the terrors.

The strange thing is that I still functioned. My career did well enough but it was stressful hiding the problem, praying that I wouldn't have to go to lunch with a client when the demons raged at their worst or give a talk at work after not sleeping all night. Friends just thought I was moody. Some people commented on the number of colds I got every year (My number one excuse for avoiding a commitment when I was overwhelmed by the gore in my head.) but other than that, I look "normal." Amazingly, I fooled them all. I married well, made a bit of money, carved out a terrific life for myself as a successful writer (travel not horror)—except for this one overwhelming "problem."

Eventually I realized that I could do no more. I had tried to be self-reliant but it was time for the cavalry if this life was going to be saved. I read about other people who seemed to have somewhat similar problems but with some crucial differences. The condition was called obsessive-compulsive disorder (OCD), part of a complex of conditions called anxiety disorders. The classic case was Jack Nicholson in the movie *As Good As it Gets* who feared contamination and washed his hands constantly. I didn't do that or any other visible things. What took place was all in my head. Still, there were unmistakable similarities between what was happening to me and what I read. (I did yelp or grimace occasionally when these thoughts were particularly horrid. I assumed this was evidence that I was teetering on the edge of a total breakdown that would find me full time on the streets in the rain mumbling from a dumpster.)

I made an appointment with a psychiatrist doing a research project on OCD at St Paul's Hospital who gave me a battery of tests which confirmed that this was a classic case of obsessive compulsive disorder. Hey, we were making progress. he said it was fairly common and there was treatment that worked fairly well. Great, I am all yours. Cure me.

Then came a brutal shock. He couldn't treat me. No one in ST Paul's could, in fact. He referred me to the UBC Anxiety Clinic. They had a small program but it was full and the waiting list was closed. I tried other hospitals, private psychologist (the government does not pay for this) and finally, in disgust at the lack of qualified help, laid siege to the UBC Clinic until I had a slot on the wait list. Two years after the initial diagnosis and more than a dozen years after I had first started to try to do something about it I finally made real progress.

The psychologist at the UBC Anxiety Disorders Clinic gave me a battery of tests and asked hundreds of questions. I answered truthfully expecting dramatic disgusted responses to some of the horrid things I told them about. No one seemed surprised. This seemed to be pretty easy stuff to them. During the interview process, as I got a little braver, I asked some of the urgent questions that plagued me. First the simple ones: Are there other people who have these kinds of thoughts? Oh, yes, quite common. Does it get worse? There are ups and downs but with moderated cases like yours, it would be unlikely. Can it be treated? Simple, they said. 10 weeks and there is an 80% chance you'll see improvement.

Then the harder, more important, question: Will I go insane? NO. NOT A CHANCE. Will I hurt someone because of these thoughts—mistake a dream for reality? They asked me, 'Have you ever hurt someone before?' Nope. Then no. You're sure? Positively, it will never happen.

In my care after the interview I cried with relief. There was a possibility of a normal life, I was not alone and I wasn't going to go insane.

The treatment lasted a bit longer than 10 weeks. At some point I had had enough to satisfy me that it was under control and that I had a new skill set to really manage the problem.

Most of all I accepted the fact that this is a part of me, that I had to make a few allowances for it the same way someone who tires quickly might adjust their life by taking it a little easier or getting a little more sleep. Or the way one adjusts to the fact that they are not a great athlete but decide to play the game anyway. You adjust and get on with it.

It gets uncomfortable still sometimes but it is clear to me that the thoughts are not what they seem—there is not life threatening emergency going on. Part of my mind is just playing tricks on me. I have even come to appreciate just how inventive I can be. If I could just market some of these fantasies as movie scripts, move over Steven King.

The best part is that I do not think of myself as weird anymore. I am so attuned to the start of one of these episodes now that I can feel normal, carry on daily tasks while this whole dreadful movie flickers just behind my eyes. It's like having a bad horror show on TV playing low in the background while I do the dishes or write a column. Mostly I ignore the background static.

If there is anything I want to tell you, it is that it seems to be part of the symptoms that it is nearly impossible for you to tell anyone what is going on. You become terrific at making your way in the world without letting on that you are on the edge of a precipice. Because you can hide a lot of it, you can go for years, desperate and silent.

It truly does not have to be that way. Although treatment is not easy to get—many doctors misdiagnose the problem through ignorance or because they never get a complete picture from the tight lipped sufferers—perseverance can bring you back to health. The treatment entails a lot of homework but it does work miracles.

If you suspect that you may have an anxiety disorder, (take the test on this website: <a href="http://www.anxietybc.com">http://www.anxietybc.com</a> please takes control of your own treatment, go to the library and read, ask different docs, go see a psychologist but persevere. It is worth the effort. Life with an untreated anxiety disorder is a plague. With it under control, it is unbelievably sweet.

#### **About the Author:**

Rick now happily lives in a tall green house in Vancouver with his wife and the neighbour's cat. He still has OCD, but no longer suffers with the head garbage his mind generates.

<sup>\*</sup>This article first appeared at; <a href="http://anxietybc.com">http://anxietybc.com</a>

# **Supplement 1** > Expert Consensus Treatment Guidelines for Obsessive-Compulsive Disorder

#### A Guide for Patients and Families

If you or someone you care about has been diagnosed with obsessive-compulsive disorder (OCD), you may feel you are the only person facing the difficulties of this illness. But you are not alone. In Canada, roughly 2% of the population has OCD.\* Fortunately, very effective treatments for OCD are now available to help you regain a more satisfying life. Here are answers to the most commonly asked questions about OCD.

## What is obsessive-compulsive disorder?

Worries, doubts, superstitious beliefs—all are common in everyday life. However, when they become so excessive—such as hours of hand washing—or make no sense at all—such as driving around and around the block to check that an accident didn't occur—then a diagnosis of OCD is made. OCD, it is as though the brain gets stuck on a particular thought or urge and just can't let go. People with OCD often say the symptoms feel like a case of mental hiccups that won't go away. OCD is a medical brain disorder that causes problems in information processing. It is not your fault or the result of a "weak" or unstable personality. Before the arrival of modern medications and cognitive behaviour therapy, OCD was generally thought to be untreatable. Most people with OCD continued to suffer, despite years of ineffective psychotherapy. Today, luckily, treatment can help most people with OCD. Although OCD is usually completely curable only in some individuals, most people achieve meaningful symptom relief with comprehensive treatment. The successful treatment of OCD, just like that of other medical disorders, requires certain changes in behaviour and sometimes medication.

# What are the symptoms of obsessive-compulsive disorder?

OCD usually involves having both obsessions and compulsions, though a person with OCD may sometimes have only one or the other. Table 1 lists some common obsessions and compulsions. OCD symptoms can occur in people of all ages. No all obsessive-compulsive behaviours represent an illness. Some rituals (e.g., bedtime songs, religious practices) are a welcome part of daily life. Normal worries, such as contamination fears, may increase during times of stress, such as when someone in the family is sick or dying. Only when symptoms persist, make no sense, cause much distress, or interfere with functioning do they need clinical attention.

<sup>\*</sup>Health Canada: A Report on Mental Illness in Canada. Ottawa, Canada 2002 (p.61)

# **Table 1: Typical OCD Symptoms**

#### **Common Obsessions**

- Contamination fears of germs, dirt, etc.
- Imagining having harmed self or others
- Intrusive sexual thoughts or urges
- Excessive religious or moral doubt
- Forbidden thoughts
- A need to have things "just so"
- A need to ell, ask, confess

# **Common Compulsions**

- Washing
- Repeating
- Checking
- Touching
- Ordering/arranging
- Hoarding
- Praying

# **Supplement 1**> Expert Consensus Treatment Guidelines for Obsessive-Compulsive Disorder

**Obsessions** Obsessions are thoughts, images, or impulses that occur over and over again and feel out of your control. The person does not want to have these ideas, finds them disturbing and intrusive, and usually recognizes that they don't really make sense. People with OCD may worry excessively about dirt and germs and be obsessed with the idea that they are contaminated or may contaminate others. Or they may have obsessive fears of having inadvertently harmed someone else (perhaps while pulling the car out of the driveway), even though they usually know this is not realistic. Obsessions are accompanied by uncomfortable feelings, such as fear, disgust, doubt, or a sensation that things have to be done in a way that is "just so."

**Compulsions** People with OCD typically try to make their obsessions go away by performing compulsions. Compulsions are the acts the person performs over and over again, often according to certain "rules." People with an obsession about contamination may wash constantly to the point that their hands become raw and inflamed. A person may repeatedly check that she has turned off the stove or iron because of an obsessive fear of burning the house down. She may have to count certain objects over and over because of an obsession about losing them. Unlike compulsive drinking or gambling, OCD compulsions do not give the person pleasure. Rather, the rituals are performed to obtain relief from the discomfort caused by the obsessions.

### Other features of obsessive-compulsive disorder

OCD symptoms cause distress, take up a lot of time (more than an hour a day), or significantly interfere with the person's work, social life, or relationships.

Most individuals with OCD recognize at some pointy that their obsessions are coming from within their own minds and are not just excessive worries about real problems, and that the compulsions they perform are excessive or unreasonable. When someone with OCD does not recognize that their beliefs and actions are unreasonable, this is called OCD with poor insight.

OCD symptoms tend to wax and wane over time. Some may be little more than background noise; other may produce extremely severe distress.

# When does obsessive-compulsive disorder begin?

OCD can start at any time from preschool age to adulthood (usually by age 40). One-third to one-half of adults with OCD report that it started during childhood. Unfortunately, OCD often goes unrecognized. On average, people with OCD see three to four doctors and spend over 9 years seeking treatment before they receive a correct diagnosis. Studies have also found that it takes an average of 17 years from the time OCD begins for people to obtain appropriate treatment. OCD tends to be under-diagnosed and under-treated for a number of reasons. People with OCD may be secretive about their symptoms or lack insight about their illness. Many Health care providers are not familiar with the symptoms or are not rained in providing the appropriate treatments. Some people may not have access to treatment resources. This unfortunate since earlier diagnosis and proper treatment, including finding the right medications, can help people avoid the suffering associated with OCD and lessen the risk of developing other problems, such as depression or marital and work problems.

## Is obsessive-compulsive disorder inherited?

No specific genes for OCD have yet been identified, but research suggests that genes do play a role in the development of the disorder in some cases. Childhood-onset OCD tends to run in families (sometimes in association with tic disorders). When a parent has OCD, there is a slightly increased risk that a child will develop OCD, although the risk is still low. When OCD runs in families, it is the general nature of OCD that seems to be inherited, not specific symptoms. Thus a child may have checking rituals, while his mother washes compulsively.

## What causes obsessive-compulsive disorder?

There is no single, proven cause of OCD. Research suggests that OCD involves problems in communication between the front part of the brain (the orbital cortex) and deeper structures (the basal ganglia). These brain structures use the chemical messenger serotonin. It is believed that insufficient levels of serotonin are prominently involved with OCD. Drugs that increase the brain concentration of serotonin often help improve OCD symptoms. Pictures of the brain at work also show that the brain circuits involved in OCD return toward normal in those who improve after taking a serotonin medication or receiving cognitive-behavioural psychotherapy. Although it seems clear that reduced levels of serotonin play a role in OCD, there is no laboratory test for OCD. Rather, the diagnosis is made based on an assessment of the person's symptoms. When OCD starts suddenly in childhood in association with strep throat, an autoimmune mechanism may be involved, and treatment with an antibiotic may prove helpful.

## What other problems are sometimes confused with OCD?

Some disorders that closely resemble OCD and may respond to some of the same treatments are trichotillomania (compulsive hair pulling), body dysmorphic disorder (imagined ugliness), and habit disorders, such as nail biting or skin picking. While they share superficial similarities, impulse control problems, such as substance abuse, pathological gambling, or compulsive sexual activity are probably not related to OCD in any substantial way.

The most common conditions that resemble OCD are the tic disorders (Disorder and other motor and vocal tic disorders). Tics are involuntary motor behaviours (such as facial grimacing) or vocal behaviours (such as snorting) that often occur in response to a feeling of discomfort. More complex tics, like touching or tapping tics, may closely resemble compulsions. Tics and OCD occur together much more often when the OCD or tics begin during childhood.

Depression and OCD often occur together in adults and, less commonly, in children and adolescents. However, unless depression is also present, people with OCD are not generally sad or lacking in pleasure, and people who are depressed but do not have OCD rarely have the kinds of intrusive thoughts that are characteristic of OCD.

Although stress can make OCD worse, most people with OCD report that the symptoms can come and go on their own. OCD is easy to distinguish from a condition called posttraumatic stress disorder, because OCD is not caused by a terrible event.

Schizophrenia, delusional disorders, and other psychotic conditions are usually easy to distinguish from OCD. Unlike psychotic individuals, people with OCD continue to have a clear idea of what is real and what is not.

# **Supplement 1**> Expert Consensus Treatment Guidelines for Obsessive-Compulsive Disorder

In children and adolescents, OCD may worsen or cause disruptive behaviours, exaggerate a pre-existing learning disorder, cause problems with attention and concentration, or interfere with learning at school. In many children with OCD, these disruptive behaviours are related to the OCD and will go away when the OCD is successfully treated.

Individuals with OCD may have substance-abuse problems, sometimes as a result of attempts to self-medicate. Specific treatment for the substance abuse is usually also needed.

Children and adults with pervasive developmental disorders (autism, Asperger's disorder) are extremely rigid and compulsive, with stereotyped behaviours that somewhat resemble very severe OCD. However, those with pervasive developmental disorders have extremely severe problems relating to and communicating with other people, which do not occur in OCD.

Only a small number of those with OCD have the collection of personality traits called obsessive-compulsive personality disorder (OCPD). Despite its similar name, OCPD does not involve obsessions and compulsions, but rather is a personality pattern that involves a preoccupation with rules, schedules, and lists and characteristic traits such as perfectionism, an excessive devotion to work, rigidity, and inflexibility. However, when people have both OCPD and OCD, the successful treatment of the OCD often causes a favourable change in the person's personality.

## How is obsessive-compulsive disorder treated?

The first step in treating OCD is educating the patient and family about OCD and its treatment as a medical illness. During the last 20 years, two effective treatments for OCD have been developed: cognitive-behavioural psychotherapy (CBT) and medication with a selective serotonin reuptake inhibitor (SSRI).

## **Stages of Treatment**

Acute treatment phase: Treatment is aimed at ending the current episode of OCD.

Maintenance treatment: Treatment is aimed at preventing future episodes of OCD.

## **Components of Treatment**

Education: Crucial in helping patients and families learn how best to manage OCD

and prevent its complications.

Psychotherapy: Cognitive-behavioural psychotherapy (CBT) is the key element of

treatment for most patients with OCD.

Medication: Medication with a selective serotonin re-uptake inhibitor is helpful for

many patients.

#### **EDUCATION**

## Is there anything I can do to help my disorder?

Absolutely yes. You need to become an expert on your illness. Since OCD can come and go many times during your

life, you and your family or others close to you need to learn all about OCD and its treatment. This will help you get the

best treatment and keep the illness under control. Read books, attend lectures, talk to our doctor or therapist, and

consider joining the Obsessive-compulsive Foundation. A list of recommended readings and information resources is

given at the end of this handout. Being an informed patient is the surest path to success.

## How often should I talk with my clinician?

When beginning treatment, most people talk to their clinician at least once a week to develop a CBT treatment plan and

to monitor symptoms, medication doses, and side effects. As you get better, you see your clinician less often.

Once you

are well, you might see your clinician only once a year.

Regardless of scheduled appointments or blood tests, call you clinician if you have:

- ✓ Recurrent severe OCD symptoms that come out of nowhere
- ✓ Worsening OCD symptoms that don't respond to strategies you learned in CBT.
- ✓ Changes in medication side effects
- √ New symptoms of another disorder (e.g., panic or depression)
- ✓ A crisis (e.g., a job change) that might worsen your OCD

## What should I so if I feel like quitting treatment?

It is normal to have occasional doubts and discomfort with your treatment. Discuss your concerns and any discomforts with your doctor, therapist, and family. If you feel a medication is not working or is causing unpleasant side effects, tell your doctor. Don't stop or adjust your medication on your own. You and your doctor can work together to find the best and most comfortable medicine for you. Also, don't be shy about asking for a second opinion from another clinician, especially about the wisdom of cognitive-behaviour therapy. Consultations with an expert on medication or behavioural psychotherapy can be a great help. Remember, it is harder to get OCD under control than to keep it there, so don't risk a relapse by stopping your treatment without first talking to your clinician.

## What can families and friends do to help?

Many family members feel frustrated and confused by the symptoms of OCD. They don't know how to help their loved one. If you are a family member or friend of someone with OCD, your first and most important task is to learn as much as you can about the disorder, its causes, and its treatment. At the same time, you must be sure the person with OCD has access to information about the disorder. We highly recommend the booklet, *Learning to Live with Obsessive Compulsive Disorder* by Van Noppen et al. (Information on obtaining this and other educational resources is given at the end of this handout.) This booklet gives good advice and practical tips to help family members help their loved ones and learn to cope with OCD. Helping the person to understand that there are treatments that can help is a big step toward getting the person into treatment; this can be very difficult for family members. Continue to offer educational materials to the person. In some cases, it may help to hold a family meeting to discuss the problem, in a similar manner to what is often done when someone with alcohol problems is in denial.

Family problems don't cause OCD, but the way families react to the symptoms can affect the disorder, just as the symptoms can cause a great deal of disruption and many problems for the family. OCD rituals can tangle up family members unmercifully, and it is sometimes necessary for the family to go through therapy with the patient. The therapist can help family members learn how to become gradually disentangled from the rituals in small steps and with the patient's agreement. Abruptly stopping your participation in OCD rituals without the patient's consent is rarely helpful since you and the patient will not know how to manage the distress that results. Your refusal to participate will not help with those symptoms that are hidden and, most important, will not help the patients learn a lifelong strategy for coping with OCD symptoms.

Negative comments or criticism from family members often make OCD worse, while a calm, supportive family can help improve the outcome of treatment. If the person views your help as interference, remember it is the illness talking. Try to be as kind and patient as possible since this is the best way to help get rid of the OCD symptoms. Telling someone with OCD to simply stop their compulsive behaviours usually doesn't help and can make the person feel wowrse, since he or she is not able to comply. Instead, praise any successful attempts to resist OCD, while focusing your attention on positive elements in the person's life. You must avoid expecting too much or too little. Don't push too hard. Remember that nobody hates OCD more than the person who has the disorder. Treat people normally once they have recovered, but be alert for telltale signs of relapse. If the illness is starting to come back, you may notice it before the person does. Point out the early symptoms in a caring manner and suggest a discussion with the doctor. Learn to tell the difference between a bad day and IOCD, however. It is important not to attribute everything that goes poorly to OCD.

Family members can help the clinician treat the patient. When your family member is in treatment, talk with the clinician if possible. You could offer to visit the clinician with the person to share your observations about how the treatment is going. Encourage the patient to stick with medications and/or CBT. However, if the patient has been on a certain treatment for fairly long time with little improvement in symptoms or has troubling side effects, encourage the person to ask the doctor about other treatments or about getting a second opinion.

When children or adolescents have OCD, it is important for parents to work with schools and teachers to be sure that they understand the disorder. Just as with any child with an illness, parents still need to set consistent limits and let the child or adolescent know what is expected of him or her.

# **Supplement 1**> Expert Consensus Treatment Guidelines for Obsessive-Compulsive Disorder

Take advantage of the help available from support groups (for addresses and phone numbers, see the end of this handout). Sharing your worries and experiences with others who have gone through the same things can be a big help. Support groups are a good way to feel less alone and to learn new strategies for coping and helping the person with OCD.

Be sure to make time for yourself and your own life. If you are helping to care for someone with severe OCD at home, try to take turns "checking in" on the person so that no one family member or friend bears too much of the burden. It is important to continue to lead your own life and not let yourself become a prisoner of your loved one's rituals. You will then be better able to pride support for your loved one.

## **Psychotherapy**

Cognitive behavioural psychotherapy (C BT) is the psychotherapeutic treatment of choice for children, adolescents, and adults with OCD. In CBT, there is a logically consistent and compelling relationship between the disorder, the treatment, and the desired outcome. CBT helps the patient internalize a strategy for resisting OCD that will be of lifelong benefit.

#### What is CBT?

The BT in CBT stands for behaviour therapy. Behaviour therapy helps people learn to change their thoughts and feelings by first changing their behaviour. Behaviour therapy for OCD involves **exposure** and **response prevention** (E/RP).

**Exposure** is based on the fact that anxiety usually goes down after long enough contact with something feared. Thus people with obsessions about germs are told to stay in contact with "germy" objects (e.g., handling money)until their anxiety is extinguished. The person's anxiety tends to decrease after repeated exposure until he no longer fears the contact.

For exposure to be of the most help, it needs to be combined with **response or ritual prevention (RP)**. In RP, the person's rituals or avoidance behaviours are blocked. For example, those with excessive worries about germs must not only stay in contact with "germy things," but must also refrain from ritualized washing.

Exposure is generally more helpful in decreasing anxiety and obsessions, while response prevention is more helpful in decreasing compulsive behaviours. Despite years of struggling with OCD symptoms, many people have surprisingly little difficulty tolerating E/RP once they get started.

Cognitive therapy (CT) is the other component in CBT. CT is often added to E/RP to help reduce the catastrophic thinking and exaggerated sense of responsibility often seen in those with OCDE. For example, a teenager with OCD may believe that his failure to remind his mother to wear a seat belt will cause her to die that day in a car accident. CT can help him challenge the faulty assumptions in this obsession. Armed with this proof, he will be better able to engage in E/RP, for example, by not calling her at work to make sure she arrived safely.

Other techniques, such as thought stopping and distraction (suppressing or "switching off" OCD symptoms), satiation (prolonged listening to an obsession usually using a closed-loop audiotape), habit reversal (replacing an

OCD ritual with a similar but non-OCD behaviour), and contingency management (using rewards and costs as incentives for ritual prevention) may sometimes be helpful but are generally less effective than standard CBT.

People react differently to psychotherapy, just as they do to medicine. CBT is relatively free of side effects, but all patients will have some anxiety during treatment. CBT can be individual (you and your doctor), group (with other people, or family. A physician may provide both CBT and medication, or a psychologist or social worker may provide CBT, while a physician manages your medications. Regardless of their specialties, those treating you should be knowledgeable about the treatment of OCD and willing to cooperate in providing your care.

#### How to get the most out of psychotherapy

- Keep your appointments.
- Be honest and open.
- Do the homework assigned to you as part of your therapy.
- Give the therapist feedback on how the treatment is working.

## **Commonly Asked Questions about CBT**

#### How successful is CBT?

While as many as 25% of patients refuse CBT, those who complete CBT report a 50%-80% reduction in OCD symptoms after 12-20 sessions. Just as important, people with OCD who respond to CBT stay well for years to come. When someone is being treated with medication, using CBT with the medication may help prevent relapse when the medication is stopped.

### How long does CBT take to work?

When administered on a weekly basis, CBT may take 2 months or more to show its full effects. Intensive CBT, which involves 2-3 hours of therapist-assisted E/RP daily for 3 weeks, is the fastest treatment available for OCD.

#### What is the best setting for CBT?

Most patients do well with gradual weekly CBT, in which they practice in the office with the therapist once a week and then do daily E/RP homework is necessary because the situations or objects that trigger OCD are unique to the individual's environment and often cannot be reproduced in the therapist's office. In intensive CBT, the therapist may come to the patient's home or workplace to conduct E/RP sessions. On occasion, the therapist may also do this in gradual CBT. In very rare cases, when OCD is particularly severe, CBT is best conducted in a hospital setting.

## How can I find a behaviour therapist in my area?

Depending on where you live, finding a trained cognitive-behavioural psychotherapist may be difficult, especially one trained to work with children and adolescents. To locate a therapist skilled in CBT for OCD, you may want to ask your physician or other health care provider, an academic psychiatry or psychology department, your local OCD support group, or the Obsessive Compulsive Foundation, the Anxiety Disorders Association of America, or

the Association for the Advancement of Behavioural Therapy (addresses and phone numbers are given at the end of this handout). In some cases, you may find that a local cognitive-behavioural psychotherapist has experience with depression or other anxiety disorders, but not with OCD. However, using one of the excellent treatment manuals now available, it is relatively easy to translate CBT skills from another disorder to OCD. So if there is no one immediately available, look for a skilled psychologist or psychiatrist who is willing to learn. Remember though if you are not getting real CBT, which involves exposure and response prevention using a list of OCD symptoms that are ranked from most difficult to easiest to resist, you are probably not getting the treatment you need. Don't be afraid to ask for a second opinion where necessary. In rare cases, traveling to a specialized center where intensive CBT is available on an outpatient or inpatient basis may be the most practical solution.

## Medication

#### What medications are used to treat obsessive-compulsive disorder?

Research clearly shows that the selective serotonin re-uptake inhibitors (SSRIs) are uniquely effective treatments for OCD. These medications increase the concentration of serotonin, a chemical messenger in the brain. The following SSRIs are currently prescribed for treatment of OCD in Canada:

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- ☑ Anafranil (generic name Clomipramine)
- ✓ Prozac (generic name Fluoxetine)
- ✓ Luvox (generic name Fluvoxamine)
- ✓ Paxil (generic name Paroxetine)
- ☑ Zoloft (generic name Sertraline)

Prozac, Luvox, Paxil, and Zoloft are called selective serotonin re-uptake inhibitors (SSRIs) because they primarily affect only serotonin. Anafranil is a tricyclic, which means that it affects many other neurotransmitters besides serotonin.

#### How well do medications work?

When patients are asked about how well they are doing compared to before starting treatment, they report marked to moderate improvement after 8-10 weeks on a selective serotonin re-uptake inhibitor (SSRIs). Unfortunately, fewer than 20% of those treated with medication alone end up with no OCD symptoms. This is why medication is often combined with CBT to get more complete and lasting results. About 20% don't experience much improvement with the first SSRI and need to try another SSRI.

#### Which medication should I choose first?

Studies show that all the SSRIs are about equally effective. However, to reduce the chance of side effects, most experts recommend beginning treatment with one of the selective serotonin re-uptake inhibitors (SSRIs). If you or someone in your family did well or poorly with a medication in the past, this may influence the choice. If you have medical problems (e.g., an irritable stomach, problems sleeping) or are taking another medication, these

factors may cause your doctor to recommend one or another medication to minimize side effects or to avoid possible drug interactions.

#### What if the first medication doesn't work?

First, it is important to remember that these medications don't work right away. Most patients notice some benefit after 3 to 4 weeks, while maximum benefit should occur after 10-12 weeks of treatment at an adequate dose of medication. When it is clear that a medication is not working well enough, most experts recommend switching to another SSRI. While most patients do equally well on any of the SSRIs, some will do better on one than another, so it is important to keep trying until you find the medication and dosage schedule that is right for you.

#### What are the side effects of these medications?

In general, the SSRIs are well tolerated by most people with OCD. The four SSRIs (fluoxetine, fluvoxamine, paroxetine, and sertraline) have similar side effects. These include nervousness, insomnia, restlessness, nausea, and diarrhea. The most common side effects of clomipramine are dry mouth, sedation, dizziness, and weight gain. While all 5 drugs can cause sexual problems, on average these are a bit more common with clomipramine. Clomipramine is also more likely to cause problems with blood pressure and irregular heartbeats, so that children and adolescents and patients with preexisting heart disease who are treated with clomipramine must have electrocardiograms before beginning treatment and at regular intervals during treatment. Remember that all side effects depend on the dose of medication and on how long you have been taking it. If side effects are a big issue, it is important to start with a low dose and increase the dose slowly. More severe side effects are associated with larger doses and a rapid increase in the dose. Tolerance to side effects may be more likely to develop with the SSRIs than with clomipramine, so that many patients are better able to tolerate the SSRIs than clomipramine over the long term. All SSRIs except fluoxetine should be tapered and stopped slowly because of the possibility of the return of symptoms and withdrawal reactions.

#### Tell your doctor right away about any side affects you have.

Some people have different side effects than others and one person's side effect (for example, unpleasant sleepiness) may actually help another person (someone with insomnia). The side affects you may get from medication depend on:

- The type and amount of medicine you take
- Your body chemistry
- Your age
- Other medicines you are taking
- Other medical conditions you have

If side effects are a problem for you, your doctor can try a number of things to help:

- Reducing the amount of medicine the doctor may gradually lower the dose to try to achieve a dose low enough to reduce side effects but not low enough to cause a relapse.
- Adding another medication may be helpful for some side effects, such as trouble sleeping or sexual problems.

Trying a different medicine to see if there are fewer or less bothersome side effects - Even when a medication is clearly helping, side effects sometimes make it intolerable. In such a case, trying another SRI is a reasonable strategy.

Remember: Changing medicine is a complicated, potentially risky decision. Don't stop your medicine or change the does on your own. Discuss any medication problems you are having with your doctor.

## Does it help to add CBT or another medication to a SRI?

When medication has produces only a little benefit after 6 weeks, adding CBT or another medication to the SSRI is also sometimes useful.

Many experts believe that CBT is the most helpful treatment to add when someone with OCD is not responding well to medication alone. When people continue to avoid the things that make them anxious or continue to do rituals, this blocks the effects of the medication. For the medication is helpful because it teaches those with OCD to expose themselves to the triggers that make them anxious and then to resist performing rituals.

It may also be helpful to add one of the following types of medications to an SSRI:

- An anxiety-reducing medication, such as clonazepam or alprazolam, in patients with high levels of anxiety
- A high potency neuroleptic, such as haloperidol or risperidone, when tics or thought-disorder symptoms are present.

These complex medication strategies are best reserved for those who have not done well with a combination of SSRI and CBT.

### What if nothing seems to work?

Before deciding that a treatment has failed, your therapist needs to be sure that the treatment has been given in a large enough dose for a sufficient period of time. There is little consensus among the OCD experts on what to do next when someone with OCD fails to respond to expert CBT plus well-delivered, sequential SSRI trials. Switching from an SSRI to clomipramine may improve the chances that a previously non-responsive patient may have a good response. Most experts recommend considering a trial of clomipramine after 2 or 3 failed SSRI trials. Occasionally, a doctor may wish to combine an SSRI with clomipramine either to reduce side effects or to increase the potential benefits of medication. In the adult with extremely severe and unremitting OCD, neurosurgical treatment to interrupt specific brain circuits that are malfunctioning can be very helpful. In patients who have severe OCD and depression, electroconvulsive therapy (ECT) may be of benefit.

## Answers to other questions about medications

If you think you might be pregnant or are planning to become pregnant, most experts prefer to treat OCD with CBT alone. However, if medications are necessary (and they may be since OCD commonly gets worse during pregnancy), it is better to use them sparingly and to select and SSRI rather than clomipramine.

The SSRIs are preferred in patients with renal failure or coexisting heart disease who require medication.

When another psychiatric disorder is present, your doctor will likely mix and match treatment for the other conditions with treatment for OCD. Sometimes, the same medication can be used for two disorders (e.g., an SSRI for OCD and panic disorder). In other cases, such as concurrent mania and OCD, more than one medication will be necessary (e.g., a mood stabilizer and an SSRI).

Laboratory tests are necessary before and during treatment with clomipramine, but not with the SSRIs.

The SSRIs are not addictive, but it is a good idea to stop them gradually.

#### Is hospitalization an option?

People with OCD can almost always be treated as outpatients. In very rare cases in which the OCD involves severe depression or aggressive impulses, hospitalization may be necessary for safety. When a person has very severe OCD or the OCD is complicated by a medical or neuropsychiatric illness, hospitalization can sometimes be a useful way to give intensive CBT.

#### Do I have to choose between CBT and medication?

No single approach works bests for everyone with OCD, although most people probably do best with CBT alone or CBT plus an SSRI. The treatment choice will of course depend on the patient's preference. Some people prefer to start with medication to avoid the time and trouble associated with CBT; others prefer to begin with CBT to avoid medication side effects. Many, if not most, people seem to prefer combination treatment.

The need for medication depends on the severity of the OCD and the age of the person. In milder OCD, CBT alone3 is often the initial choice, but medication may also be needed if CBT is not effective enough. Individuals with severe OCD or complicating conditions that may interfere with CBT (e.g., panic disorder, depression) often need to start with medication, adding CBT once the medicine has provided some relief. In younger patients, clinicians are more likely to use CBT alone. However, trained cognitive-behavioural psychotherapists are in short supply. Thus, when CBT is not available, medication may become the treatment of choice. Consequently, it is likely that many more people with OCD receive medication than CBT.

Before deciding on a treatment approach, you and your clinician will need to assess your OCD symptoms, other disorders you have, the availability of CBT, and your wishes and desires about what treatment you want. Try to find a clinician who will talk to you about these possibilities so that you can make your own best choice among the options available to you.

#### **Maintenance Treatment**

Once OCD symptoms are eliminated or much reduced—a goal which is practical for the majority of those with OCD—then maintenance of treatment gains becomes the goal.

#### Maintaining treatment gains

When patients have completed a successful course of treatment for OCD, most experts recommend monthly follow-up visits for at least 6 months and continued treatment for at least 1 year before trying to stop medications or CBT.

Relapse is very common when medication is withdrawn, particularly if the person has not had the benefit of CBT. Therefore, many experts recommend that patients continue medication if they do not have access to CBT.

Individuals who have repeated episodes of OCD may need to receive long-term or even lifelong prophylactic medication. The experts recommend such long-term treatment after 2 to 4 severe relapses or 3 to 4 milder relapses.

#### **Discontinuing treatment**

When someone has done well with maintenance treatment and does not need long-term medication, most experts suggest discontinuing medication only very gradually, while giving CBT booster sessions to prevent relapse. Gradual

medication withdrawal usually involves lowering the dose by 25% and then waiting 2 months before lowering it again, depending on how the person responds.

Because OCD is a lifetime waxing and waning condition, you should always feel comfortable returning to your clinician if your OCD symptoms come back.

## **Support Groups**

Support groups are an invaluable part of treatment. These groups provide a forum for mutual acceptance, understanding, and self-discovery. Participants develop a sense of camaraderie with other attendees because they have all lived with OCD. People new to OCD can talk to others who have learned successful strategies for coping with the illness.

Contact your local mental health center to see if there are support groups available for people with OCD.

SOURCE: *March, J.S., Frances, A., Kahn, D.A., Carpenter, D.* Eds. <u>The Expert Consensus Guideline Series: Treatment of Obsessive-Compulsive Disorder.</u> Journal of Clinical Psychiatry 1997:58 f (suppl4) (<a href="https://www.psychguides.com/index.html">https://www.psychguides.com/index.html</a>)

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## Session 3> Anxiety Disorder Associations in Canada

## **Anxiety Disorder Associations in Canada**

At this time, there is not national anxiety disorder organization, and there are only three provincial associations. More information on specialized anxiety treatment services in Canada can be found at: <a href="http://www.macanxiety.com/satsc.htm">http://www.macanxiety.com/satsc.htm</a> or at the Canadian Network for Mood and Anxiety Disorders: <a href="http://www.canmat.org">http://www.canmat.org</a>

#### **BRITISH COLUMBIA**

#### **Anxiety Disorders Association of British Columbia (ADABC)**

4438 W. 10<sup>th</sup> Ave., Suite # 119 Vancouver, B.C., V7R 4R8

Phone: (604)681-3400 E-mail: (information): info@anxietybc.com

E-mail: (membership): membership@anxietybc.com

Website: <a href="http://www.anxietybc.com">http://www.anxietybc.com</a>

#### **MANITOBA**

#### **Anxiety Disorders Association of Manitoba (ADAM)**

206-309 Hargrave Street Winnipeg, Manitoba, R3B 2J8

Phone: (204) 925-0600 Fax: (204) 925-0609

E-mail: <a href="mailto:adam@adam.mb.ca">adam@adam.mb.ca</a>
Website: <a href="mailto:http://www.adam.mb.ca">http://www.adam.mb.ca</a>

#### **ONTARIO**

#### **Anxiety Disorders Association of Ontario (ADAO)**

797Somerset Street West, Suite 14

Ottawa, Ontario, K1R 6R3 Phone: 1-613-729-6761

Toll Free in Canada: 1-877-308-3848
E-mail: contactus@anxietyontario.com
Website: http://www.anxietyontario.com

#### **Mood Disorder Associations in Canada**

Some provinces do not have mood disorder associations. For more information, contact the Mood Disorders Association of Canada: <a href="http://mooddisorderscanada.ca">http://mooddisorderscanada.ca</a>, or the provincial branch of the Canadian Mental Health Association <a href="http://www.cmha.ca">http://www.cmha.ca</a>

#### **MOOD DISORDERS SOCIETY OF CANADA**

Suite 763, 3-304 Stone Road West Guelph, Ontario, N1G 4W4

Phone: (519) 824-5565 Fax: (519) 824-9569

E-mail: info@mooddisordersCanada.ca

Website: <a href="http://www.mooddisorderscanada.ca">http://www.mooddisorderscanada.ca</a>

#### **BRITISH COLUMBIA**

#### Mood Disorders Association of BC (MDABC)

2730 Commercial Drive, #201 Vancouver, B.C. V5N 5P4 Phone: (604) 873-0103 Fax: (604) 873-3095

E-mail: <a href="mailto:mdabc@telus.net">mdabc@telus.net</a>
Website: <a href="http://www.mdabc.ca">http://www.mdabc.ca</a>

#### **ALBERTA**

# The Organization For Bipolar Affective Disorders (OBAD)

1019-7<sup>th</sup> Ave. SW

Calgary, Alberta, T2P 1A8
Phone: (403) 263-7408
Phone: 1-866-263-7408
Fax: (403) 266-2478
E-mail: obad@obad.ca

Website: http://www.obad.ca

#### **MANITOBA**

#### Mood Disorders Association of Manitoba (MDAM)

4-1000 Notre Dame Avenue, Winnipeg, Manitoba R3E 0N3

Phone: (204) 786-0987 Fax: (204) 786-1906 Toll Free: 1-800-263-1460

E-mail: sdmdm@depression.mb.ca

#### **ONTARIO**

#### The Mood Disorders Association of Ontario (MDAO)

40 Orchard View Blvd., Suite 222 Toronto, Ontario M4R 1B9 Phone: (416) 486-8046

Toll free: 1-888-486-8236 Fax: (416) 486-8127

E-mail: info@mooddisorders.on.ca

Website: http://www.mooddisorders.on.ca

#### QUEBEC (FRENCH)

#### Association Canadienne de la santé mentale

911 rue Jean-Talon Est, bureau 500

Montreal, PQ, H2R 1V5 Tel: (514) 849-3921 Fax: (514) 849-8372

Courriel electronique: <a href="mailto:acsm@cam.org">acsm@cam.org</a> Site web: <a href="http://www.cam.org/acsm">http://www.cam.org/acsm</a>

#### **QUEBEC (FRENCH) REVIVRE**

Association quebecoise de soutiens aux personnes souffrant de troubles anxieux, depressifs et bipolaires

801 rue Sherbrooke Est, bureau 500

Montreal, PQ, H2L 1K7 Tel: (514) 738-4873 1-888-738-4873

#### QUEBEC (English) Alliance for the Mentally ill

5253 Decarie, Suite 150 Montreal, Quebec H3W 3C3 Phone: (514) 486-1448 Fax: (514) 486-6157

E-mail: <a href="mailto:amique@amiquebec.org">amique@amiquebec.org</a>
Website: <a href="mailto:http://www.amiquebec.org">http://www.amiquebec.org</a>

## Facts About> The Challenges and Needs Facing Family Members

In families with mental illness, each family member faces unique challenges and has different needs. The following list will help you understand and identify what each member may experience.

## The ill family member **CHALLENGES:** Complying with medication Establishing trusting relationships with others Seeking out professional assistance Finding a support group o Coping with symptoms, lost skills, and a changed future **FEELINGS & NEEDS:** For the family member with the illness, there are many needs and challenges to be met. People with mental illness may experience loss of relationships, educational opportunities, jobs, earning potential, money, and hope and dreams for the future. The needs of people with a serious mental illness are often among the most fundamental, and include a job, a home, and a friend. A person with a serious mental illness will require patience, understanding, support, care, and medical attention. Children (& adult children) For children who have a parent with a serious mental illness, the experiences will vary depending on the age of the child at the onset of the illness. If the child was very young, he/she may not remember a time when the parent was healthy; if the child was older, the child's memory of his/her parent will include a time before the onset of the illness. This memory may **CHALLENGES** contribute to the feelings of loss. Having to grow up very quickly Loss of a role model

Loss of love, comfort, guidance Alienated by their peer group

Growing up in an atmosphere of secrecy and

Carrying the stigma of growing up in the

Possible loss of "well" parent, if the parent is less available to meet the needs of the offspring due to the fact that he/she is overwhelmed by the loss of his/her spouse.

Neglected needs

"weird" house

shame

**FEELINGS & NEEDS:** Feelings experienced by offspring may include: guilt; fear of also becoming ill, of the ill relative, of having children, and of telling others about mental illness in their family; grief that "never ends"; feelings of depression, anxiety, hopelessness, and isolation; and a skewed sense of "normal." Offspring may need to find validation from another adult source. Receiving guidance from a respected role model will help foster resiliency and most likely offer the opportunity to learn coping skills. Some children may need to be reminded that they need not shoulder the responsibility for the situation. **Siblings** Families with 2 or more siblings often find there are widely mixed feelings based on the individual sibling's experiences with his/her brother/sister. As with children, a sibling's experiences will depend on his/her birth order and age relative to the ill brother/sister. **CHALLENGES:** \* Having to grow up very quickly \* Loss of a sibling support and companionship \* Alienated by their peer group \* Attempting to compensate with parents for loss of sibling to mental illness \* Growing up in an atmosphere of secrecy and shame ★ Neglected needs \* Siblings may also experience a parental loss, if the parents are consumed by grief or caregiving for the ill family member **FEELINGS & NEEDS** Feelings experienced by siblings may include: survivor's guilt; fear of also becoming ill, of the ill relative, of having children who may become ill, and of telling others about mental illness in their family; grief that "never ends"; feelings of anger, sadness, anxiety, and isolation; and a skewed sense of "normal." Siblings may also feel angry with parents for a lack of attention. Siblings will require assistance and validation from an adult source much like offsprings do. Siblings may attempt to shoulder too much responsibility as well, or may try to "fill the void" they think has been created by the illness. Both siblings and offspring may need to be reminded of their roles, and not to take on more **Spouses** responsibility. When a spouse becomes ill, from either a mental or physical illness, the impact on the relationship can be devastating.

Spouses are often the caregivers and sotheir

	needs are often set aside in their efforts to support the ill partner.
CHALLENGES	<ul> <li>Loss of intimacy</li> <li>Loss of income</li> <li>Coping with ill spouse's withdrawal</li> <li>Coping with disturbed sleep patterns</li> <li>Coping with financial difficulties (due to income loss or financial mismanagement)</li> <li>Coping with being the primary caregiver and possibly "single-parent" (feeling caught between the needs of the spouse and the needs of the children)</li> <li>Coping with shouldering the plans for the future alone (e.g. financial worries)</li> <li>Finding a balance between personal needs and the needs of the spouse</li> <li>Lack of peer support and social life</li> </ul>
FEELINGS & NEEDS	A spouse may experience feelings of loss, grief, sadness, shame, fear and anger. Like all family members, spouses could benefit from a peer support group. Spouses will need to find activities that they enjoy that help alleviate their personal stress and together the couple may pursue counseling to resolve emerging issues.
Parents	Parents often play a central role in the care and treatment of their son/daughter's illness. They often seek out services regardless of their child's age. The role of caregiver is one that can be more or less intense and last for a short or long period of time, depending on their son/daughter's network of support and treatment progress.
CHALLENGES	<ul> <li>Becoming primary caregivers</li> <li>Coping with marital discord as a result of the stress</li> <li>Balancing their own needs as well as those of other family members</li> <li>Coping with feelings of stress, anxiety, and fear while care-giving</li> <li>Coping with feelings of guilt</li> <li>Coping with an "unimagined future"</li> <li>Lack of peer support</li> </ul>
FEELINGS & NEEDS	Some feelings experienced by parents may include: guilt, blame, sadness and loss; bitterness; and fear of the ill relative, of the future, and of telling others about mental

#### **Multigenerational Family Member**

illness in their family (isolating/withdrawing from a social life). Parents need to be aware that every member of the family will be affected differently by the situation, and every member needs to develop different coping strategies. Parents, like all family members, can benefit enormously from support groups.

This term usually applies to family members who have both a sibling and a parent with a mental illness, or spouses with partners and offspring with a brain disorder. This process of dual loss can be emotionally draining an overwhelming for the family. This multigenerational family member has challenges and experiences in common with those listed for their particular role and relationship to the ill relative.

#### Needs all family members and friends share:

- The need for information & education
- The need for support
- The need for certain skills that will increase coping ability
- ♣ The need for hope that recovery can occur

It is important for all members of the support network to learn everything they can about the illness, and to educate themselves about the services and resources available to them in their community. A support system is vital and can be comprised of other family members, friends, coworkers, professionals, and advocacy groups such as the Schizophrenia Society of Canada, Mood Disorders Association of Canada, and/or the Canadian Mental health Association—just to name a few. Skills that family members need include: coping skills, communication skills, stress management skills, and problem-solving skills.

**PARENTS** need to be aware that every member of the family will be affected differently by the situation and will develop various coping strategies. Parents cannot control how other family members will react, but they can provide an environment where it is safe to discuss the impact of the illness. It is helpful for parents to reach out to others through support groups with other parents dealing with mental illness (e.g. church, friends, and extended family).

**SPOUSES**, like all family members, could benefit profoundly from a peer support group. Spouses need to find activities they enjoy that help alleviate their personal stress. Spouses can also engage other family members to provide a supportive and open environment.

**CHILDREN (& ADULT CHILDREN)** need to find validation from a healthy adult source. Receiving guidance from a respected role model will help foster resiliency and offer the offspring opportunities to learn much needed coping skills. Some offspring will need to be reminded that they need not shoulder the responsibility for the situation. A guiding influence would alleviate some of the emotions the offspring may feel toward their ill parent.

**SIBLINGS** also require assistance and validation from a healthy adult source, much like offspring do. Siblings may attempt to shoulder too much responsibility as well, or they may try to fill the void they think has been created by the illness. Siblings may feel left out and experience resentment if the situation is not treated as openly as possible.

Both siblings and offspring may need to be reminded of their roles. The various responsibilities of family members should always reflect their particular role, ages, and concerns. In this way, young family members can be given information and assistance that is age appropriate.

## Facts about > Loss and Grief

In the book *Grieving Mental Illness:* A *Guide for Patients and Their Caregivers* by Virginia Lafond, grieving is explained as beginning "with the loss of health that mental illness is of itself, and goes on to include other major losses that can touch every aspect of life, both for those who suffer mental illness first hand and for those who give care." Grief is the emotional reaction to that loss, and it can be particularly acute for families where a loved one has a mental illness. This illness impairs the person's ability to function and participate in the normal activities of daily life, and that impairment can be ongoing. Families, and the ill person, struggle with accepting the realities of an illness that is treatable, but not curable.

The stages of the grieving process in Virginia Lafond's book explore grief from both the perspective of those with the illness and their caregivers (family members). Lafond stresses, to both individuals with the illness and the people who care about them, that before the grieving process can begin, there is a need to acknowledge the loss.

**Acknowledging the loss** involves recognizing our experience with mental illness as a loss to be grieved. This requires everyone touched by mental illness to look at what the illness has done and is doing to bring unwanted and unanticipated changes in his/her life.

Once the loss has been recognized, then the stages of grief begin. Lafond describes the stages as: denial, sadness, anger, taming fear, and, finally, acceptance.

**Denial:** Denial, like the other grief stages, is not something we choose to experience. It happens spontaneously to help us cope with the reality of mental illness. It is normal and healthy, and like the other stages, can become unhealthy only if it lasts too long. Denial protects us from being overwhelmed by the reality of our loss and provides us with an opportunity to prepare ourselves for the journey of acceptance.

**Sadness:** At some point after the onset of psychiatric illness and before the resolution stage of recovery (acceptance), feelings of sadness come both to those living with the illness and to their caregivers. However, sadness is not always immediately addressed, giving way to the stronger feelings of fear and anger. Moving forward requires becoming aware of and working with the sadness you feel.

Anger: This step involves becoming rightfully and appropriately angry about the impact of mental illness in our lives. This begins by looking at common ideas about anger that block its healthy, constructive expression. Given the unhealthy and unhelpful messages we receive about anger, it can be a challenge to find healthy ways of expressing it. Like the conscious processing of any grieving emotion, anger deserves to be dealt with thoroughly and respectfully, one step at a time.

**Fear:** Fear has a way of weaving itself throughout the grieving process as it relates to mental illness. Often masked by other emotions of denial, sadness, and anger, it can be difficult to pinpoint the exact source of our fears. Some of the initial fears reflect the stigma associated with mental illness. They may be a fear of rejection or misunderstanding. The key is to clearly focus on what we fear and develop ways of coping.

**Acceptance:** Acceptance means facing the realities brought about by the presence of mental illness, and then building and practicing coping skills so that recovery can be achieved and maintained. Signs of acceptance include giving ourselves permission to get in touch with our feelings of grief and regain a sense of control in our lives, and changing our expectations (hopes/dreams/goals) in light of knowledge about the illness and its impact on ourselves and our loved one. Acceptance is not a passive state, but an engagement in activities such as the ongoing pursuits of information about mental illness and the furthering of coping skills.

## Facts about > Caregiving

#### What is a Caregiver?

Caregivers are individuals who provide or intend to provide practical and emotional support to someone with a mental illness. You may or may not live with the person you care for. You may be a relative, partner, friend, or neighbor. You may be a young person, but you now find yourself in the position of needing to support a person who is ill or in recovery.

The role of a caregiver can be both challenging and rewarding. According to the VON (Victoria Order of Nurses) Caregiver Best Practice Guidelines, caregivers generally identify with one or several of the Seven Meanings for Caregivers:

- Satisfaction and gratification
- Family responsibility and reciprocity
- Friendship and company
- Doing what needs to be done
- Caring personality
- Personal growth
- Improved relationships

Despite these motivating factors encouraging family members to step in and assume the caregiving role, they can feel cut off and disconnected from the system and the professionals involved in the care of their loved one.

In Canada, there are some coalitions and associations working for the rights of caregivers.

#### These include:

- The Canadian Caregiver Coalition
- VON Canada
- The Schizophrenia Society of Canada, its provincial affiliates, and local chapters/branches

Helping caregivers to feel a part of their loved one's treatment process does not require the disclosure of confidential information about the individual receiving care. Caregiver organizations suggest some information can and should be shared without breaching confidentiality. Mental health professionals generally agree that informal caregivers are "coping, grieving, and positive treatment resources." What is required is additional information and tools to support the role of the family caregiver and assist them to maneuvers the complex mental health system.

## **Caregivers Bill of Rights**

## I have the right:\*

- ▼ To take care of myself. This is not an act of selfishness. It will give me the capability of taking better care of my loved one.
- ▼ To seek help from others, even though my loved one may object. I recognize the limits of my own endurance and strength.
- ▼ To maintain facets of my own life that do not include the person I provide care for, just as I would if he or she were healthy. I know that I do everything I reasonably can for this person and I have the right to do some things just for myself.
- ♥ To get angry, be depressed, and express other difficult feelings occasionally.
- ▼ To reject any attempt by my loved one [either conscious or unconscious] to manipulate me through guilt, anger, or depression.
- ♥ To receive consideration, affection, forgiveness, and acceptance for what I do for my loved one for as long as I offer these qualities in return.
- ▼ To take pride in what I am accomplishing and to applaud the courage it has sometimes taken to meet the needs of my loved one.
- ▼ To protect my individuality and my right to make a life for myself that will sustain me in the time when my loved one no longer needs my full-time help.
- ▼ To expect and demand that, as new strides are made in finding resources to aid persons living with mental illness in our country, similar strides will be made toward aiding and supporting caregivers.

<sup>\*</sup>Adapted from The Alberta Caregivers Association

## **Tools** > Caregiver Burnout

## Check any that apply to you:

You feel fatigued, as if you have less energy than usual
Lately, everything feels like it takes tremendous effort
You are having difficulty getting a good night's sleep
You wake up feeling tired or exhausted
You are more susceptible to colds, flues, or headaches than before
You are feeling frustrated, sad, and impatient most of the time
You are feeling anger and resentment
You are experiencing more mood swings or crying spells
You feel overwhelmed and are worrying about the future a lot
You feel more disjointed and disorganized than usual
You notice you have withdrawn from social events and have no desire for social contact
You feel as though you've lost your sense of humour or your ability to enjoy life
You feel unsatisfied (more than usual)
You are ignoring your own needs and avoiding setting aside time for yourself
You feel very self-critical and are blaming yourself for everything

## Facts about > Stress in the Caregiving Family

The responsibilities of caregiving, added to the routine pressures of maintaining a family and professional life, can naturally lead to stress. Stress, in turn, creates a ripple effect on the health and well-being of not only the caregiver, but everyone from family members to friends and co-workers.

#### **Bearing Extra Burdens\***

Living with a chronic illness—and caring for a person with a chronic illness—can lead to physical and emotional stresses. The symptoms of this stress may look remarkably similar in both the person dealing with the illness and the caregiver. They include:

- Anger, sometimes leading to physical violence
- Anxiety
- Denial
- Depression
- Dissatisfaction with life
- Exhaustion
- ➢ Guilt
- Irritability
- Stress-related physical conditions

For caregivers who offer a wide range of help, both physical and emotional, stressors also vary depending on the intensity of their involvement and their relationship to the person in need. These stressors often include:

- Extra demands on time and energy
- Changes in family roles and responsibilities
- Changes in ability to perform work and professional responsibilities
- Pressure of sustaining a life independent of caregiving

"Caregivers are most likely to feel stressed in terms of their emotional health, but also experience problems with their finances and physical health."

According to a Health Canada report titled National Profile of Family Caregivers in Canada – 2002, the groups most likely to say that caregiving has created significant or some difficulties in terms of their own emotional health included women (32%), younger caregivers (36%), those caring for family members under 45 (39%), and those caring for someone with a mental disability (47%).

#### **LEARNING TO HANDLE STRESS**

#### STRESS BUSTERS – Things to keep in Mind

- Stress may increase depression and make everything seem worse. Learning to handle stress will help with recovery
- Learn effective coping skills. Develop a self-care plan, including activities you enjoy doing. Refer to the plan whenever you are stressed
- Do not blame yourself for the illness.
- Separate the illness from the individual.
- Do not take the illness personally. Most people who don't take it personally find it easier to cope.
- Forgive yourself for any mistakes you feel you might have made. Be kind to yourself.
- Don't dwell on what might have been. Many people live in the nostalgia of the past or in fear of the future. By focusing on the past and the future you will never be able to handle the present.
- Set boundaries and clear limits for what you feel you are capable of, and stick to them.
- Getting the right amount of sleep is very important. When you are tired from lack of sleep or groggy from oversleeping, things can seem worse.
- Develop better eating habits. Good food can give you more energy to face the day.
- Learn to take some time to relax. It will help you relieve unwanted stress. Set aside some personal time for yourself. Treat yourself well—you're worth it!

<sup>\*</sup>Source: Caregiver Stress: The Impact of Chronic Disease on the Family by Elisa Sonnenberg, MS Ed, Swedish Medical Centre

### **Tools:** > Tense-O-Meter

Let's begin by getting comfortable in your chair. It helps if you keep your eyes closed, but it's not necessary if you don't feel comfortable. You can put your head down on the table or slouch over in your chair. Posture isn't important, but comfort is. Don't worry if you're shifting and moving around, it's important that you are comfortable. Don't let yourself get stressed out by the idea that you have to be perfectly relaxed; there is no such thing, especially not with the **TENSE-O-METER**.

How we can begin.

First take a deep breath. **HOLD IT FOR 3 SECONDS** and exhale. Now let's take a slower breath. HOLD, and exhale. Continue breathing at a pace that is comfortable for you... When we are stressed, we can often become shallow breathers, or unfortunately, hold our breath in anticipation and apprehension. Breathing at a regular pace is an important part of relaxing and being able to focus. Many relaxation-focused and centering exercises like Yoga or Tai Chi require people to breathe at a steady pace. Notice if there's any tension in your breathing or in your throat when you breathe in. You don't need to worry about it, just notice it and remember it for later.

Now, let's focus on the different parts of our bodies, starting with our feet. Take another breath, then slowly and carefully, tense up your right foot and release it. Now do the same to your left foot and release it. Are you carrying any tension in your feet? Did you notice where that tension was? Was it in your big toe? Was it in your arch? Our feet maintain our whole body's balance the entire time we are standing. This can also be a cause of a great deal of physical tension. Wherever you notice tension, imagine you are breathing new life into that area. Like a deflated balloon, you can breathe in new energy to the different parts of your body. Breathe and exhale at your own pace.

Now check in with your legs. Slowly and carefully, tense your right leg and release it. Now do the same with your left leg, and release it. Like our feet, our legs have important body responsibilities. Our legs support us, and carry us forward in movement. Did your legs feel tense or sore? If you work at a job where you're on your feet all day, your legs will also carry a lot of that tension, and you need to attend to them. Breathe and exhale at your own pace.

Now check in with your hips. Does one side feel sorer than the other? Do you tend to lean in certain directions posture-wise? Slowly and carefully, take a moment to tense up your seat muscles. Now do it again, and then again. Notice your hips now: are you still holding tension? Breathe and exhale at your own pace.

Now notice your stomach. Are you holding it in? If so let it out. Take a few deep breaths and see if you can release some of the tension you may be holding there.

Now it's time to check out your back. Many people notice they carry tension in their backs. Often this can also result in mid aches. Breathe in allowing the air to circulate throughout your back, again as if it was a deflated balloon. Breathe into each part of your back, noticing where you may be carrying tension. Breathe and exhale at your own pace.

Now we come to the shoulders. For some, this is the goldmine reserve of tension. Slowly and carefully, tense up your right shoulder, moving it towards your ear, and release it. If you carry a lot of tension here, notice what happens when you release your shoulder. Slowly and carefully, tense up your left shoulder, and release it. Some people carry so much tension that the distance between their shoulders and their ears is very short. Now slowly and carefully, tense up both your shoulders, and release them. Breathe and tense up your shoulders again. Breathe and exhale and your own pace.

Now slowly and carefully, as always, tilt your head to your right shoulder. Don't strain, be gentle, being careful not to push yourself farther than you can go. Breathe with your head in this position, and release your head back to the middle. Slowly and carefully, tilt your head to your left shoulder; again, don't strain, be gentle, and don't push yourself farther than you can go. Breathe here, and release your head back to the middle. Was one side easier than the other? If so, you may be favoring one side of your body in storing all your stress. Notice also what is happening with your jaw, your neck, and your forehead. Many people carry tension in those areas.

Now slowly open your eyes, remembering what you learned about the tension in your body.

#### **Tension Identification**

This exercise is to help you notice where you physically hold your stress. For some people, tension is the glue that holds their bodies together. In the modern world, we may be more accustomed to being constantly stressed. As people coping with an illness or the illness of a loved one, or caregivers, there are many opportunities for situational stress.

Take a moment to notice and record areas in your body that you feel get strained or tense when you are overstressed.

**HEAD & NECK:** (jaw? Face? Ears? Eyes?)

**SHOULDERS & ARMS:** 

**BACK:** (what parts specifically?)

WAIST/HIPS/REAR:

**LEGS:** (thighs? Knees? Calves?)

FEET:

## **Article 1** > Confronting The Dark\*

By Jennie Emmott

As a 17 year old girl, I was terrified of ghost stories. The odd, the creepy and the unexplained were fuel for my imagination. My response to "Who's Afraid of the Dark?" a popular television program at that time, was "I am!"

My older brother took full advantage of my frightful nature, tormenting me with scary remarks that often kept me awake at night. I have to admit he was pretty good at 'getting under my skin'. But, as good as my brother was, he didn't have the bone chilling skill of my Aunt Joan.

Aunt Joan can tell fascinating stories; terrifying stories. To this day, when I think about the kind of things my aunt would talk about, I shiver. Like the story of her packing her suitcase the night before a trip to visit us. She had heard whispers. Then, in the morning, she found her suitcase unpacked, with its contents back in the closets and drawers. I was spellbound. "Really, Aunt Joan?" I would ask "Oh yes, Jennie!" And she wasn't teasing. Because like the best salespeople, the best story tellers are those who actually believe what they are saying.

Joan grew up in a loving home, along with her brother, sister and parents. They lived in Quebec City. Joan was a gorgeous teenager with error free skin, blonde hair and piercing blue eyes. She was an average student but did an exceptional job of holding her grades up. Although she was shy, Joan had a florescent social life. Besides being a cheerleader, she always had a boyfriend.

After high school, Joan explored living away from home. Within the year she was attending college near her parents' home. She had an active social life with many friends. With her college certificate, she found employment in Quebec City, and lived alone in her own apartment.

Outwardly, Joan was entering her adult live just like everyone else. Her family and friends may have noticed her tendency to avoid stress, or deal with stress in mildly inappropriate ways, but it was never enough to question in terms of her health. It wasn't until she was in her late twenties that my aunt's condition would get terribly worse. By this time, her imagination was making up detailed stories about ghosts and devils. She was helpless; her mind was her worst enemy. My aunt felt no one could help her. One day she decided to call 911 for an ambulance to take her mind away. My aunt was in a state where only the doctors of the psychiatric ward could help.

It took several years, with initial visits to the family doctor leading to other medical specialists. There was suspicion that it could be a mental illness. There was denial—from herself and those close to her as well. For many years, Aunt Joan lived a life of trial and error with different medications. Finally, after a long period of frustration, guilt and fear, my Aunt Joan's diagnosis was verified, and just as importantly, accepted, to be a mental condition known as schizophrenia.

As defined in the "American Medical Association Family Medical Guide" schizophrenia is a disorganization of normal thought and feeling. Symptoms usually appear in the late adolescence, and extreme mental stress almost always triggers them.

There is a certain stigma attached to mental illness. Mental illness in a way is a kind of ghost story. People don't like discussing it because it sounds crazy and eerie. It takes a special courage to confront mental illness. My aunt has that kind of courage; my aunt has done a fabulous job handling her illness. She lives alone in a homey apartment and leads a daily routine. She volunteers at a local care centre preparing food.

My aunt is a beautiful person and I'm so proud to be her niece. She inspires me to take chances, make mistakes, and to never be ashamed of the person I am. Through her I've learned to confront some of my own fears. Now I'm not so afraid of the dark.

<sup>\*</sup>Confronting the Dark won second prize in the Junior Category of the 2002 YWCA Real Story Competition. Jennie Emmott is a grade 10 student from Delta, British Columbia. She enjoys writing, dancing, and spending time with friends and family.

## Article 2 > Personal Demons\*

By Alice N.

speak with my older sister via telephone very few weeks. It's usually I who would call her, not the other way around. This time she had made the call to me. My husband answered it as I lazily rolled over in our bed—not time to get up quite yet, it was early Saturday morning. He walked toward me with the cordless, listening and I could tell something was up just by the look on his face.

"It's Anna" his expression was now blank as he passed the phone to me.

"Get ready for this," she warned and I sat up straight. "You're not going to believe what he's done now."

I knew exactly whom "he" was that Anna was referring to. Just a year earlier my siblings and I had settled the affairs of our father's estate, selling his house that we all grew up in, dividing his assets between us and finally, with a sigh of relief, putting the last few years of tension, pain and indignation behind us. My brother had been the instigator of much of the pandemonium during that very difficult time, and now it was him she was calling me about. Carl can be a master manipulator, a skilled liar who has no guilt, no remorse. I think he takes delight in creating chaos within the lives of his 3 sisters. My sisters and I had, once again, estranged ourselves from him and it had been awhile since I had heard anything about him.

"Carl has been arrested. He set his apartment on fire." I paled. I had spent a week at Carl's apartment to keep him company when my father passed away. He lived alone on the 20<sup>th</sup> floor.

"They have him in the psychiatric ward at Toronto General for observation. He is in really bad shape" she told me.

He had narrowly escaped with his life by climbing down from his balcony to the apartment below and actually called the police and fire department himself. He insisted that while he was out jogging that morning, he had been followed and he was certain "they" were going to kill him. He was having a psychotic episode. The first we were ever aware of. Had anyone been hurt? Was he going to be ok? Why did this happen now? So many question, yet I couldn't speak. I was stunned.

My brother is a stress analyst engineer in the construction of military aircraft. He went to university for 7 years. He was always withdrawn, quiet and extremely shy. I don't believe I ever had a civil conversation with him until the break-up of my first marriage when I was 32 years old. He had called to see how I was doing. After that I would receive the occasional birthday card and Christmas card, and then he actually started to call more often. I forgot about and forgave the torments he inflicted upon me in our youth. I needed to have a normal relationship with my brother after so many years of estrangement, but I wouldn't last.

Carl was different, difficult, nothing like any guy I had ever met before. I believed he was that way because he was like my father. Like father, like son. The reality of it was my father could be even worse at times. He never tried to set the family home on fire. I don't know if he ever had hallucinations, but I do know he was angry and paranoid. He was so mean to all of us and he yelled and cursed, dumping his personal pain on his family. I didn't know what was causing him to be so angry and I didn't think much about it either. It was just the way it was. Was I that much trouble? I don't think so, yet he blamed me for all his woes. His abuse damaged me but he didn't break my spirit. I know now that he was a paranoid schizophrenic just like my brother, and I can't be blamed for that. After my mother died from a cancerous brain tumor, I moved away for good. I was nineteen, old enough and not afraid.

To be on my own. Anything would be better than to be in the same house with my father and brother as they grieved the loss of my mother. I thought she was the lucky one; she escaped. I know my mother had been warned to get my father help, and I knew she was too afraid to do anything about it.

There was a code of silence within my family. If it was the least bit difficult to face, whatever it was, was never discussed. In fact we hardly talked at all about anything. Day by day passed and we all seemed to keep apart as much as we could. Hiding out, getting out of the way, and keeping our thoughts to ourselves, always. The neighbours talked, they knew something wasn't right at our house. My father fought with them if they came near and he kept my mother isolated and away from her friends when he could. Did anybody ever guess the truth? If they did, no one ever said so.

Yet, I did love him. He was the only Dad I knew.

Shortly after the incident with my brother, the movie A Beautiful Mind came out and I saw in that film the behaviour of my brother.

Now my two sisters and I know the truth and it is not our fault. It's not their fault either, though. They desperately needed help and didn't know it. It was just the way they were and they saw nothing wrong.

I saw my brother a month ago when I flew back east for a short visit. It saddened me to see him so broken down. I told him how sorry I was that this had happened to him and I meant it with all my heart. He was medicated and somewhat depressed. His fate has landed him in a sort of home for mental patients where his behaviour and his medication are monitored for the courts by a sweet, kind, old black lady named Pearl. He has put his life in the hands of this brave woman. He will probably get off with probation. I hope he will stay on his medication.

Today I will start to learn all I can about this disease of the mind. In doing so I will make my peace with my brother and my father and I will help if I can. I will be what I needed them to be for me—loving, understanding, supportive—and I will be happy. I will not turn my back and do nothing. I will not be silent and I will try to make a difference.

I hope I will never get this disease.

<sup>\*</sup>I live with my husband in Port Moody BC at the end of the Burrard Inlet. I have no children. I have travelled extensively for a person of my means. I love to hike and run to keep fit. I go to the movies a lot and the theatre now and then. I moved away from my brother and sisters and Father over 20 years ago and believe that is what has saved me and started me on my own journey of recovery. Today I am content, satisfied, happy, and at peace with my demons. Alice N.



## Leave my stuff alone!

-a story for young teen siblings

#### WORLD FELLOWHSIP FOR SCHIZOPHRENIA AND ALLIED DISORDERS

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Our grateful thanks to the

#### **Skoll Community Fund**

For making the publication of this educational material possible

"Leave my stuff alone! Don't go into my room!"

That was the greeting Joan got when she came in the door from school. She had hardly put her books down before he started again, "You've been spying on me."

Joan didn't know what to say or do. She stood there with her mouth open. Tim's outburst completely confused her. He was her brother—five years older than her—and they had always had such fun together. Now he always seemed irritated, upset or just plain glum.

Picking up her books she turned and went into the kitchen. She phoned Barb to ask if she could go over. They could chat and maybe do their homework together.



She told Barb what had happened and Barb thought maybe Tim's school work was the problem. He would be working hard to make sure he got his Certificate and maybe that was what was making him bad tempered.

When Joan went home she felt nervous in case Tim was still mad, but he was nowhere to be seen.

Mum was home. She was preparing a rice dish for dinner. Tim didn't come down to dinner although Mum called him. He stayed in his room working.

The next day he didn't go to school and he still didn't come out of his room. There had been a lot of odd little things like this happening and you could see that everyone was getting a bit jittery and tense at home.

At last Mum went into his room and found him asleep curled up in a blanket. All around the room there were bits of paper filled with writing. She thought at first these were school work, but when she began to read she could see that this was no ordinary kind of writing—it didn't make much sense and went on sentence after sentence. She knew that something was terribly wrong.

That night when they were all in bed, Joan woke up and could hear Tim walking around the house muttering to himself. She stayed in bed as this made her nervous again, but in the morning she heard Tim telling Mum that people were taking to him all night long. Mum didn't seem to want to talk to Joan about it but Joan finally said: "I know something is wrong and I would rather know than have everything a sort of mystery."

It was about 2 weeks later that Mum took Tim to the family doctor because Tim had not been sleeping at night and he seemed to be having strange ideas about his family. Tim said his thoughts were all jumbled up and wouldn't let him sleep. The doctor wasn't sure whether Tim was anxious because of his exams. He said Tim should make sure to get a good night's sleep and suggested that he exercise more to make sure he was really tired—maybe get more involved in sports.

Several weeks later the doctor suggested that Tim see a specialist and get treatment for his jumbled thinking. Tim agreed though he felt embarrassed at having to tell people about what was going on. But after seeing the specialist he began to take some medication that the doctor hoped would help him.

"Come and look at the new poster I got from John's Dad." It was Tim calling to Joan from his room. She had just come in the door from school. Tim was holding up a brightly coloured picture of one of the local soccer heroes. He seemed much better in the last few days. Joan was happy that Tim was more like his old self.

From this little story, we do hope that Tim was getting better. However, very often people of Tim's age (late teens or twenties) who "hear people talking" and get "jumbled thoughts" are suffering from a psychotic illness and need treatment to get better. When you have a psychotic illness it means that you are unable to tell the difference between reality and fantasy. Sometimes the fantasy world seems to take over the person's thoughts and becomes entirely real. In Tim's case, believing his sister was spying on him was one example of this.

The specialist Tim saw was a psychiatrist, a doctor who specializes in illnesses that affect the mind and the brain.

It is very important that people go to the doctor when they have unusual experiences like Tim had, because getting treatment as early as possible is very important. Tim felt embarrassed and possibly ashamed about his symptoms, but mental illness is no more shameful than any other illness that you might get. People are not ashamed of having diabetes or arthritis, so why should they be ashamed of having a mental illness?

There are several illnesses in which people are unable to tell the difference between fantasy and reality. Sometimes the fantasy world becomes so real that they believe it is the real world and cannot be persuaded otherwise.

One of these illnesses is called schizophrenia. Schizophrenia can be treated, but quite often people cannot believe that this is happening to them. Fear, disbelief and sometimes the illness itself makes them believe that nothing is wrong.

The brothers and sisters of people who develop schizophrenia often feel guilty that in some way they have done something that has made their brother or sister ill. But this is not true. Schizophrenia is an illness like any other. We do not know why some people get diabetes or arthritis and the same goes for schizophrenia. Just like diabetes or arthritis, we do not know what causes it and how to cure it, but we do have treatments that help to reduce the symptoms. So don't blame yourself.

Another thing that sometimes happens is that the family tries to protect younger brothers and sisters from knowing about the illness. This is not a good idea because you need to learn and understand why things have changed at home.

Signs of illness are called symptoms. Here's what to expect when someone has a psychotic illness like schizophrenia, but remember that not everyone with schizophrenia will have all these symptoms.

#### People may:

- ☑ Believe strange things that are not true
- ☑ Feel that their friends and family are against them
- ☐ Hear strange sounds or voices which seem to come from the outside world, or see, hear or taste things that are not there
- ☑ Have muddled thoughts which confuse them
- ☑ Be unable to concentrate or make decisions
- ☑ Have mixed up emotions
- ☑ Begin to believe they are famous peoples

Imagine how you might feel if this happened to you. Think how you might react to friends and family. So, remember to be helpful and to try to be as understanding as possible.

No doubt you will feel nervous or upset or worried by the events that are overtaking your family. If your brother or sister who appears to be ill is rude to you, try not to take the unpleasant comments as a personal attack, since they are the result of illness, not the true opinion of the person saying them.

The earlier that schizophrenia is treated, the more likely the person will recover. The longer that schizophrenia is left, the less likely it is that full recovery will be possible. So remember, "Psychotic episodes are bad for your health"? and do your best to get the person to see a doctor.

\*Ian Chovil – in his educational program for schools

This pamphlet was written by Diane Froggatt and illustrated by Kate Ham.

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Other pamphlets by WFSAD - Principles for Working with Families - Schizophrenia: How Should One Behave?

My Brother, My Sister-Maintaining Your Own Health-for Family & Friend

To obtain a full list go to our website: www.world-schizophrenia.org

Or write to: 124 Merton Street, Suite 507, Toronto, Ontario, Canada M4S 2Z2

Pamphlet was reformatted for use in the Canadian Family Education Program (Schizophrenia Society of Canada)

## Facts about > Self Care

#### What is Self Care\*

Self-care has been defined as "the right and responsibility to take care of your physical, emotional and spiritual well-being" (Salvucci, 2001). Self-care may also be thought of as anything that contributes to our emotional, spiritual, physical, and/or social rejuvenation, enabling us to create balance in our lives while providing care for our family member or friend with a mental illness.

## What can stop us from expressing our needs and caring for ourselves?\*

#### **Discomfort:**

- You may feel awkward or uncomfortable in asking for what you want.
- In stating your need, you become vulnerable to the possibility that the listener may say no.

#### Fear of being selfish:

- You may be uncertain if your request is "reasonable." You may convince yourself that your needs are somehow less important than those of your family member.
- You may be tempted to give all of your energy (resources, time, money, etc.) to the family member. In so doing, you can lose yourself, and that strategy will eventually backfire. You may even forget that you have personal needs that you are neglecting.

#### Guilt can drive you to ignore your own needs:

The consequences of ignoring your own needs over time usually are anger and resentment. These emotions can be expressed in one or more of the following manners:

- Displaced onto the children, co-workers, other family members, the family dog, etc.
- Directly expressed to your ill relative
- Passive-aggressively expressed to the family member you are struggling with (e.g., coming home late with no explanation; making meals that you know he/she dislikes)
- Turned inward on yourself, which can result in depression or self-destructive behaviour

## **Developing a Self-Care Plan**

#### Step 1: Begin with a "taking stock" exercise

List your current caregiving activities and your other responsibilities, and then list your current self-care activities.

Caregiving Activities/Responsibilities	Self-Care Activities

The key is to try to achieve a balance between your responsibilities and stresses on the one hand, and those things that help you to "recharge" and maintain your health and quality of life on the other hand. Both sides of this scale will look different for each of us. They will also likely change over time as your caregiving situation and/or other parts of your life change.

How are you doing? If your current responsibilities significantly outweigh your self-care activities, think about ways that you could achieve a better balance and go to Step 2.

#### Step 2: Drafting a self-care plan

Your self-care plan can be developed by...

- **Continuing to do...**those things that you are already doing that rejuvenate you and positively contribute to your health and quality of life.
- **Start doing...**new activities or accessing services that will enable you to recharge and achieve better balance in your life.
- **Stop doing...**those things which are optional and add to your current responsibilities and stresses, and/or those things for which you can enlist the help of others to lighten your load.

Take a few minutes and identify activities and lifestyle choices that can help you improve your emotional, spiritual, physical, social, and intellectual aspects of life. Also note those responsibilities and stresses which you can stop doing on your own or altogether.

	Continue to do	Start doing	Stop doing
emotional			
Spiritual			
Physical			
Social			
Intellectual			

The following are some suggestions that other caregivers have included in their self-care plan:

#### Emotional

- Participate in a caregiver self-help group or one-on-one peer support with another caregiver for practical information-sharing and emotional support
- Seek emotional support for yourself from family and friends and/or from professional counselors

#### Spiritual

- Take time for regular spiritual rituals that are important to you (e.g., meditation, attending organized religious services)
- Take time to enjoy nature

#### Physical

- Maintain good nutrition
- Exercise regularly
- Seek services to relieve you of some physical caregiving tasks (e.g., home and yard maintenance and cleaning services)

#### Social

- Take time to maintain regular contact with other family members and friends to maintain these

important relationships

- Take time for regular participation in your favourite recreational activities

#### Intellectual

 "Knowledge is power" – Seek out information about mental illness, available resources, etc., so that you are well-equipped to deal with the challenges of supporting someone living with a mental illness

Obviously, this is not an exhaustive list, so think creatively about your own situation and what would make a difference for you.

<sup>\*</sup>Source: MS Society of Canada <u>Taking Care: A travel Guide for Your MS Caregiver Journey</u>

<sup>\*</sup>Source: SAFE Program, Oklahoma City Veterans Affairs Medical Center

# Facts about > Support Systems & Respite

# **Support System:**

Each member of the family will need a **support system** and **healthy coping skills.** The following list outlines what a support system can include. Take a moment to think about how many of these support systems are in place for you and your family. If you feel you don't have a strong support system, make it a priority to create one. Remember there are others who will be searching for a support system as well.

✓	A self-help/support group that focuses on coping with problems and learning to problem-solve rather than just telling/retelling traumatic events
	Friends who can empathize
Ø	Friends who do not need to drink or use mood-altering substances for entertainment
	A professional counsellor (this relationship can be temporary, but you should feel that you can rely on it during difficult transition periods)
V	Recreation time with others at least once a week
V	Involvement in a group or activity that caters to your personal interests, such as volunteering or adult education classes

With support, you can ensure that you do not deplete your "emotional bank account." It is essential to your health that you nurture your needs.

### **Respite:**

A broad definition of *respite* simply means a break or reprieve. *Respite care* is defined as temporary, short-term care designed to give relief or support to a primary unpaid caregiver who has accepted responsibility for the ongoing care and supervision of an individual. Most respite care services offer periodic breaks from caregiving through planned outings or through planned outings or through home visits to the ill person.

#### Some reasons for using respite services include:

- Respite can alleviate tension that builds up in the home
- Without the use of respite, many caregivers have no one to help share the burden of responsibility
- Some families are never able to take a vacation because they are too worried about their ill family member
- Respite can allow the care receiver as well as the caregiver the opportunity to feel independent again
- Respite provides professional staff trained in mental health services
- Respite can help families refuel the energy required to care for someone who suffers from a mental illness
- Respite provides caregivers with an opportunity to attend to their own personal needs
- Respite has been proven to be beneficial to both caregivers and care receivers
- Using respite services can actually improve the well-being of the family unit
- Without respite, some families are overwhelmed by the stress of caregiving

# An example of a respite arrangement could be:

- An escort for outings (walking, swimming, going for coffee or lunch, going for a drive)
- A person who is willing to stay/visit with the ill family member (depending on the extent of the disability) while primary caregiver goes away for a vacation
- An escort for doctor's appointments or to groups offering social or community service

#### Group activities can include:

- Community meals, outings to restaurants
- Cultural or leisure activities (museums, theatre, nature centers, movies)
- Day or weekend camps
- Special events

Respite can help families cope by providing relief from physical, mental, and emotional exhaustion that can accompany caring for someone with a mental illness.

In Canada, most jurisdictions do not have designated respite services for family caregivers of those living with a mental illness. To find out if respite services are available in your community, contact the following organizations:

- VON Canada (National)
- Canada Red Cross (National)
- Some schizophrenia societies, such as British Columbia, offer respite services. Please contact your provincial society for respite services in your community.

# **Tools**> Effective Communication Skills

Effective communication is a necessary skill for families to cope with the ups and downs of a mental illness, because sometimes it's not **what** you say but **how** you say it that is important. Everyone can feel alienated by remarks that can be interpreted as blaming, belittling, accusing, or ridiculing. Developing effective communication skills means finding ways to express yourself and your needs in a clear and respectful manner.

#### **COMMUNICATION DO'S & DON'TS**

# DO ☑ Be respectful

- ☑ Be straightforward and brief
- ☑ Stay calm
- ☑ Listen carefully
- ☑ Minimize other distractions (turn off the TV or radio)
- ☑ Acknowledge what is being said
- ☑ Stick to one topic at a time (the current issue, not an old one)
- ☑ Repeat questions or statements when necessary (do not rephrase the question in the hope that it will be clearer)
- ☑ Empathize ("that must be very difficult for you")
- ☑ Use "I" messages to communicate your feelings
- ☑ Keep your statements brief; saying too much at a time makes it challenging to respond

#### DON'T

- DON'T criticize
- DON'T argue about past events
- DON'T take anything personally
- ☑ DON'T interrupt
- AVOID name-calling
- AVOID being judgmental
- **☑** DON'T tease your family member about their symptoms
- DON'T raise your voice; yelling or shouting will never help you communicate
- DON'T generalize—be specific; words like 'always' or 'never' are loaded and unhelpful (for example: "You never lift a finger around here")
- AVOID patronizing authoritative statements such as "You're acting like a child" or "You'll do as I say, young lady"

When communicating your needs, you want to be assertive. Being assertive allows you to act in your own best interests, while also considering the needs of others.

### **Communication Skills:**

### LISTENING IS TO:

Listen attentively to the words (verbal) and expressions (non-verbal)

Involve yourself-be interested in what is said

**Showrespect**—treat adults as adults

Take time to reflect on what is said

**E m p a t h li z e**—respect how others feel

Never accuse, blame, or belittle

### **SPEAKING IS TO:**

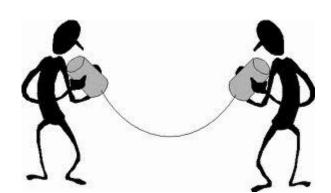
**Share** your feelings honestly by using "I" messages

Present issues and concerns, not past

**Express** your thoughts and concerns, both negative and positive

Acknowledge the other person's feeling

Keep it simple and clear



# "I" messages

One simple method of communicating your needs assertively is called the "I message" tool. The "I message" is a basic communication tool that can be used to make a request or express negative feelings.

The "I message	" works like this:		
	I feel	_, when you	•
Some examples	3:		
	I feel irritated, when you criticize	me.	
	I feel relieved, when you take you	r medication.	
	I get scared, when you raise your	voice	
	I worry, when you come home lat	e.	

# **Expressing Negative Feeling\***

The situation that seems to challenge one's communication skills the most is when negative feelings need to be expressed. It can create additional anxiety and nervousness and cloud our best intentions to deliver the message in a clear and respectful manner.

The following are some tips to help you expr4ess negative feelings effectively:

- ☑ Express yourself when the problem behaviour occurs. Don't wait until later unless it is impossible to be reasonably calm and clear at the moment.
- ☑ State specifically, using "I" messages, what the other person has done or said that is producing the negative feeling in you.
- ☑ Tell the other person how their behaviour is affecting you by stating the feeling you are experiencing. Be direct and honest.
- ☑ Request a change in behaviour or ask the person to help you solve the problem by offering up an alternative solution.
- ☑ Look at the other person when you are expressing your negative feelings.
- ☑ Take note of your non-verbal language: leaning towards them or coming close makes the expression more direct and clear; have a serious expression on your face to match the seriousness of your discussion.
- ☑ Use a firm tone of voice consistent with the feelings you are expressing.

# Making Positive Requests\*\*

To make a positive request:

- ☑ Look at and lean toward the other person.
- ☑ Smile or have a pleasant facial expression.
- ☑ Use a warm tone of voice, accentuating positive feelings.
- ☑ Specify and clarify exactly what would you like the other person to do or say.
- ☑ Let them know how you would feel if your request was granted, accentuating positive feelings.

Topics that might be dealt with using positive requests include asking the ill person to:

- Take medication regularly
- Engage in a particular activity
- Do a favour
- Engage in conversation
- Provide some help in solving a problem

# Communicating with a Person with a Mental Illness\*\*\*

People who have a mental illness have symptoms and characteristics that require adaptations in the way you communicate to increase your chances of being understood. The following table shows symptoms of mental illness and corresponding adaptations.

adaptations.	
Symptoms or Characteristic	Adaptation
Confusion about what is real	Be simple and straightforward
Difficulty in concentrating	Be brief; repeat
Overstimulation	Limit input; don't force discussion
Poor judgment	Don't expect rational discussion
Preoccupation with internal world	Get attention first
Agitation	Recognize agitation and allow the person an exit
Fluctuating emotions	Don't take words or actions personally
Fluctuating plans	Stick to one plan
Little empathy for others	Recognize as a symptom
Withdrawal	Initiate conversation
Belief in delusions	Don't argue
Fear	Stay calm
Insecurity	Be loving and accepting
Low self-esteem	Stay positive and respectful

<sup>\*</sup>Adapted from: When Someone You Love Has a Mental Illness by Rebecca Woolis, MFCC, 1992

<sup>\*\*</sup>Source same as above \*\*\*Source same as above

# Tools> "I" Messages Practice Sheet

### "I" messages

One simple method of communicating your needs assertively is called the "I message" tool. The "I message" is a basic communication tool that can be used to make a request or express negative feelings.

The "I message" works like this	The '	"I mes	sage"	works	like	this
---------------------------------	-------	--------	-------	-------	------	------

	I feel	, when
you		
Some exan	nples:	

I feel irritated, when you criticize me.
I feel relieved, when you take your medication.
I get scared, when you raise your voice.
I worry, when you come home late.

Identify the corresponding feeling to the behaviours listed below.

I feel	, when you miss your appointment at the doctor's office.
I feel	, when you forget to mow the lawn like you had agreed to.
I feel	, when you make your bed and clean up your room.
I feel	, when you ignore me when I am trying to talk to you.
I feel	, when you make dinner for me.
I feel	,when you yell at me.
I feel	, when you go out and never tell me where you are.
I feel	, when you take care of yourself by following your treatment plan
I feel	, when you are rude to me in front of my friends.
I feel	,when you thank me for helping you.

# Facts about > Talking about Mental Illness

# Dealing with other family members and friends

Awkward, challenging moments can arise in interactions with other family members and friends. Especially when caught off guard, you may struggle with knowing what to say. Keep in mind that you only need to tell other what you feel comfortable telling them.

In order to be most helpful, you may choose to discuss in advance with your family member how the two of you would like to respond to inquiries. Communication and planning can reduce the potential for hurt feelings later.

Different situations call for diverse responses from caregivers. The context and individuals involve may influence your response. For example, if your loved one acts bizarrely in public (e.g., starts talking about the special messages he's receiving from the television program), you have several choices:

- If the listeners are not important to you (e.g., waitress, gas station attendant) or if the timing is bad, you can ignore the bizarre behaviour or not say anything at all. You can also simply say that your relative is having a hard time and you don't wish to discuss it. You don't owe strangers an explanation.
- If the listener is important to you, you can choose to educate them. You can share a limited amount or
  disclose more, depending on the situation. The key is to always be respectful and to determine in
  advance what works best for your family.

# What Should We Tell Family Members and Friends?

If you want others to better understand mental illness, the following pieces of information can be helpful:

- 1. Although the exact causes of mental illness are not yet known, many illnesses have a strong biological/genetic component.
- Mental illness is very common! Over 6 million Americans suffer from mental illness, and psychiatric patients take up more hospital beds than patients with cancer, diabetes, arthritis, and heart disease combined.
- 3. Mental illness affects thinking, behaviour, feeling, and judgment.
- 4. The course of mental illness is often unpredictable, as symptoms can come and go for no apparent reason.
- 5. There are no known cures or easy ways to prevent mental illness—but doctors can help some of the symptoms with medications and therapies. The side effects of some medications can be unpleasant.
- 6. Mental illnesses can be quite severe and chronic. They often have a strong impact, both emotionally and financially, on the ill person and those close to them. Therefore, these people need a great deal of support and understanding.

- 7. Mental illness is not contagious.
- 8. Individuals with mental illness are rarely dangerous; rather, they generally tend to fear people and be quite introverted.

### What Should We Tell the Children?

- 1. You are not to blame—you didn't do anything wrong!
- 2. We don't have all of the answers, but we can deal with this situation together. You can be helpful to your parent, and here's how...(Give specific behaviours children can do).
- 3. Both parents love you and will be here for you to the best of our abilities.
- 4. It's ok to ask questions.
- 5. Please tell us how you feel.
- 6. Provide information (at an age-appropriate level) about the illness, such as: What is it? Will I get it? Will my parent get better? What are the risks that my children may get it someday?
- 7. Foster supportive relationships for the child with people outside the immediate family. It's important for a child to have a good support system of friends and other activities outside the family.
- 8. Children should not be promised that the parent will get well and stay well forever.

Source: Parts adapted from When someone you love has a mental illness by R. Woolis (1992).

# **Tools> Problem Solving**

In our everyday life, we will encounter many challenges and problems that we will need to solve. Research indicates that people who cope effectively do the following when faced with problems:

- 1. Work on one problem at a time
- 2. Try new approaches to the problem
- 3. Stay open to suggestions from others
- 4. Use flexible and creative thinking

When you are confronted with a problem, try the "IDEAL" Problem Solving technique:

I	D	E	Α	L
IDENTIFY: Define the problem before trying to tackle it. Start with the most urgent or the simplest problem—focus on that problem	DESCRIBE: List everything you might try to solve the problem.	EVALUATE: Once you have a list, evaluate each option. Consider the consequences (both positive and negative) of each option.	ACT: Once you have selected the best solution, take action.	LEARN: Learn from the choices you have made.

Remember... When the problem seems too difficult to manage, use your support system and get help.

# **Problem Example**

#### One daughter describes her problem as this:

"My mother is always angry. She doesn't like being told she's sick and that she has to take her medication. She thinks I'm bossing her around—but she doesn't know what's best for her, that's how sick she is! She's been in a few car accidents and now she wants to buy a new car with the insurance from her last accident. I'm worried she'll either get hurt—or hurt someone else."

**IDENTIFY** the problem: There are many, but the most urgent is the fact that the mother wants to drive and this could end up causing a great deal of harm. There is also the issue of stopping medication, the mother's anger, and the resulting frustration felt by the daughter.

#### **DESCRIBE** possible solutions:

- 1. The daughter could try to reason with her mother when they are both less upset. Perhaps the daughter's tone has been "bossy"—She could try being more empathetic.
- 2. In the past, the daughter would borrow the new car, giving her mother less opportunity to use it, or she would hide the car keys.
- 3. The daughter could talk to the mother's doctor and social worker about her fears and enlist their aid.
- 4. The daughter could encourage her mother to find other activities or hobbies she enjoys.
- 5. The daughter could request legal advice from a lawyer or help from the RCMP.
- 6. The daughter could also request assistance from support groups and organizations to find out what others have done in similar situations.

**EVALUATE** the possibilities: In the past, this problem was dealt with ineffectively. Arguing about the car or hiding the keys only exacerbated the stress levels of both individuals involved. The best possibilities so far are #3 and #6. Number five could be a backup plan.

**ACT:** At this point, the daughter will need to enlist the aid of friends and other family members who can help. These individuals may also be involved in the problem solving before it's time to take action. It is imperative that everyone agrees about the course of action (or comes to a compromise) before the ill relative is unnecessarily stressed.

**LEARN** from your actions: The daughter needed to get help in this situation. She had determined that it was dangerous for her mother to drive and she enlisted the aid of others. This was not a betrayal of her mother, but a serious attempt to protect her mother from hurting herself.

# IDEAL Problem Solving Worksheet

ı	<b>IDENTIFY:</b> Define the problem before trying to tackle it. Start with the most urgent or the simplest problem – focus on that problem. <i>List the problem(s) being raised by the situation.</i>
D	<b>DESCRIBE:</b> List everything you might try to solve the problem. What are some potential solutions? Brainstorm a list, being as creative as possible.
E	<b>EVALUATE:</b> Once you have a list – evaluate each option. Consider the consequences (both positive and negative) of each option. <i>Review the list above and write down your top choices</i> .
A	<b>ACT:</b> Once you have selected the best solution, take action. Choosing the most effective option, describe what you will do and say. Remember to use "I" messages.
L	<b>LEARN:</b> Learn from the choices you have made. What could you do in the future to avoid this problem or minimize it?

# **Activity**> Problem Solving Scenarios

## The Story of Jack

Your husband Jack was diagnosed 15 years ago with a mood disorder. For the past 5 years, his treatment plan has included regular appointments with a clinical therapist and medication, which is prescribed by his psychiatrist. You know that one of Jack's triggers is exhaustion and lately life has been very hectic. He recently took on some additional responsibilities at work, and you have both been busy with some household renovations. You've noticed how withdrawn and uncommunicative he's been lately. Your children and friends have also noted his lack of involvement in activities and have come to you with their concerns. You have tried to delicately bring up the subject, but each time Jack has made an excuse and left the room. Your concern is growing, as is your frustration with his unwillingness to address the problem.

# The Story of Erica

Although you love your daughter Erica very much and are aware of her struggles with schizophrenia, she's really been getting on your nerves lately. She hasn't showered for over 4 days and has begun smoking cigarettes in the house again, which really annoys you. To top it off, she's now saying she doesn't want to go to her rehabilitation group appointments anymore or talk to her case worker. Her refusal to attend her appointments jeopardizes the living agreement the two of you set up when she moved in a year ago. You want to share your concerns with Erica but aren't sure how to approach her without sounding angry and bossy.

## The Story of Peter

Your younger brother Peter and you have always been close. When you were married a few months ago, he was thrilled to be in your wedding party. Peter was diagnosed with schizophrenia when he was 18 years old and it took some time for this illness to be stabilized. While medication is something that is very helpful, helping Peter find meaning in his life has made an even bigger difference. Something Peter loves is his involvement in a bicycle club. A few weeks ago the club was disbanded when the founding members moved away. Peter was understandably upset and angry at the news. While visiting with Peter at his apartment, you notice some bizarre behaviour and a general lack of self-care. He says he's feeling really lonely and wants to move in with you. Uncertain what to do, you say you'll think about it and talk to him later. How can you tell him no?

# The Story of Jane

You and Jane have been friends forever. You grew up in the same neighbourhood, went to the same school, and continued to stay connected long after each of you had married and she had moved away. Jane had always been branded "a free spirit" and known for her wild antics and slightly erratic moods. A few years ago, after the death of Jane's husband, she developed a very serious depression and was hospitalized. While in hospital, Jane was diagnosed with a mood disorder. You have provided as much support as you can to help Jane get back on her feet. She recently moved back to the old neighbourhood, and you try to visit her on a regular basis and invite her to Sunday dinner with your husband and children. Over the past few months, Jane has started calling you whenever she is in crisis. You try to help her, but she generally refuses to listen to your suggestions, gets angry, threatens to harm herself, and then hangs up. These calls generally leave you feeling worried and upset and completely powerless.

# The Story of Adam

Your 25-year old son Adam has an obsessive-compulsive disorder and often experiences severe bouts of depression. A few years ago, Adam sought treatment for his illness and found relief from many of the symptoms through medication.

and psychosocial rehabilitation programs. He recently got a job working at a local grocery store and has been putting in a lot of hours. He's also started dating someone new and things seem to be getting pretty serious. The other day you noticed that Adam left for work without taking his medication. When he returned home after work, you reminded him of this and he said he didn't think he needed to take it anymore. Adam feels that his symptoms are gone and so has decided to take a break for a while. You are very concerned that this "break" may lead to a relapse and worsen his condition.

#### FAMILES WORRY WHAT WILL HAPPEN TO ILL CHILDREN WHEN PARENTS ARE GONE\*

By all account, Gordon Thompson has covered all the bases. The Edmonton, Alberta man has painstakingly completed a will in which a discretionary trust has been set up for this daughter, Sherry. He's completed the legalities clearing the way for his other children to act as trustees for the fund. And Sherry, who was diagnosed with schizoaffective disorder at age 12, live relatively independently in a group home with a dedicated, caring staff and a growing circle of friends. It would seem everything's been taken care of.

And yet Gordon worries. What if the government changes trust fund rules? If Sherry loses her placement at the group home, where will she go? Who will be there to stick up for his vulnerable child when he and his 69-year old wife Evelyn are gone?

"Nobody can tell what's in the future," says the 67-year-old retired chemist. "There are all sorts of worries that go through your mind."

As for Sherry, she figures life is going pretty good right now.

Staff in the group home where she lives treats her with respect and dignity. On weekdays she takes part in a day program, travelling downtown for cooking classes, art activities and other activities. She has developed friendships with two people with schizophrenia, and her dad visits several times every week, taking her out for snacks or window shopping—the "little things," as he calls them.

"I'm very happy with the way my life is going (now)" says Sherry.

But both father and daughter remember how bad it can be. Psychotic visions that began as early as age 5—of seeing dead bodies fall out of her school locker, of seeing snakes and lizards writhing on her plate at supper time—made Sherry an outcast with other kids. Through the bouts of hospitalization and the roughest times, Sherry had to rely on her parents to be her rock and foundation.

"There's always the worry," Gordon concedes, "if something were to happen to me, would it all come crashing to a halt?"

Today, stable for the past several years after being discharged fr4om hospital, Sherry has developed a small circle of friends. She tries not to fret too much about what the future holds for her when her parents are gone.

"If I were to worry and worry, I wouldn't have much of a life, would?" Yet she quickly points out that her two brothers "have lives of their own," and that her big sister Kathleen lives far away in Regina, Saskatchewan.

"I'm afraid, to be quite honest." The Thompson's aren't alone. Across Canada and the U.S., tens of thousands of families worry what fate awaits their adult family members with schizophrenia. Although many of this group lives productive, enjoyable lives, the support of parents—for financial mentoring, for ensuring antipsychotic medication is taken, for social interaction—plays a vital role in maintaining consumer's quality of life and independence.

Parents and their children alike worry about who will be there to act as support in times of crisis. Will their children stop taking their medication and relapse into psychosis? Will they end up homeless, penniless, in jail?

North America's huge Baby Boomer population, those born between the end of the Second World War and the mid 1960's, is aging: the leading edge of the generation that accounts for roughly a third of Canada's population is now in their 50s, and their parents are senior citizens.

With about one in 100 people affected by schizophrenia and Canada's Baby Boom population pegged at 9.9 million, that translates into nearly 100,000 people from that generation suffering from the debilitating brain disorder.

Parents of Baby Boomers have played a much larger role in the care of their children with schizophrenia than previous generations. The deinstitutionalization of psychiatric populations in the 1960s and 1970s meant that parents of children with mental illness became the primary support givers.

In Canada, it's estimated that 40 % of those with schizophrenia live with their parents—many for their entire lives.

"If something were to happen to me, would it all come crashing to a halt?" --Gordon Thompson, parent

Parents say they're the last line of defense for their children because governments failed to come through on promises to redirect money saved by closing psychiatric hospitals to outpatients psychiatric care, group homes and other services to the mentally ill people in the community.

Among those people with schizophrenia who aren't faring as well, parental involvement in many aspects of their daily lives is paramount.

"You have to help with all the day-to-day things," says Sharon Sutherland, also of Edmonton. That means making sure that bills and rent get paid, that groceries are in the refrigerator, that her son Greg's medical appointments are kept and his medication given. "You can't buy that kind of help, so it falls on the parents."

And then there are the equally important interventions when the illness takes control and Greg begins to slide into a psychotic state. When his thoughts turn to suicide and grandiose visions cloud his judgment, Sharon is there—talking in a calm, steady voice, gently suggesting that things aren't what they seem.

With her unwavering support, Greg, a 39-year-old who was diagnosed with atypical schizophrenia at age 17, hasn't had to be hospitalized now for the last eight years.

But Sharon is getting older. While other parents her age ease their way into retirement, travelling and golfing and doting over spoiled grandchildren, Sharon watches over Greg and wonders: who will take care of him when she's gone?

"It's a grave concern for me," says Sharon, now in her early 60s. "I'd like to think he's do well, but if I drop dead tomorrow... he would have a very tough row."

The Toronto chapter of the Schizophrenia Society of Ontario encourages parents to set up discretionary trust funds in which trustees—siblings, friends or other family members—oversee finances of the person with schizophrenia. Parents with adult children still living at home are also encouraged to find alternative housing for their offspring before it is too late. Too many parents, though, don't plan ahead for their eventual deaths.

"There's one mindset that says, 'I don't want to talk about it so I won't" says Bridget Hough, president of the Toronto chapter. A recent survey by the chapter of the population it serves, shows time is running out: 38% of caregiver parents are between 65 and 74 years old, and 27% are over the age of 75. "There's a problem waiting to happen," says Hough.

At the Schizophrenia Society of Saskatchewan, Executive Director Art Godzilla spends a good portion of his time encouraging elderly parents—like 90-year-old mom who still cares for her live-at-home son who himself draws an old-age pension—to arrange independent living for their children while they still can.

"They're (parents) burned out and stressed out," said Gondziola. "They're deeply affected by the ramifications of this disease."

A new study designed to provide insight into the needs of parents of children with schizophrenia is already appearing to confirm anecdotal evidence in both Canada and the U.S.: that aging caregivers aren't planning early enough for alternate care.

Dr. Jan Greenberg is one of two professors at the university of Wisconsin-Madison in the midst of the 5 year study launched in 1999. The recently completed first wave of interviews of the families of 300 people in which a family member has schizophrenia show that few parents have done formal planning.

"They're (parents) really unclear about what kinds of decisions need to be made" Greenberg tells *Schizophrenia Digest*. "It's a constant source of st4rain in the parents' lives."

Toronto's Hough says many parents expect other sons and daughters to pick up the torch and care for their siblings with schizophrenia when the parents die. But the University of Wisconsin study is revealing that approximately half the siblings have no intention of assuming the responsibility.

"Most of them (siblings) have their own kids and their own career responsibilities" Greenberg says.

Greenberg's study, which includes interviews with people with schizophrenia, also reveals how horrific the thought of losing their parents is for those afflicted by serious mental illness.

### **WORDS OF WISDOM**

We want to create a new team-a team that places your relative, their fr4iends, neighbours and family at the heart of the solution. Instead of "What variety of services and programs will my relative need?" the question becomes, "What is a good life?"

(Excerpt from A Good Life, by Al Etmanski)

We had one person say they hoped they had the courage to kill themselves," Greenberg says. "That's how overwhelming it is to them."

"They're afraid of being homeless. They're afraid of being alone."

The study will conduct interviews twice more over the five-year period to track how people with schizophrenia fare when their parents die.

Sharon Sutherland admits that she, like many parents, has procrastinated when it comes to developing a care plan for Greg for when she is no long to be there. She intends to rewrite her will and write an informative history of his illness for future healthcare workers.

And Gordon Thompson plans to continue to make sure his daughter grows in her independence and is ready for the time when he won't be there to help. "I know in a way I should be backing off," he says, "but it's difficult."

#### PARENT'S CREATE LEGACIES OF LOVE

A growing number of parents of children with schizophrenia and other mental and physical disabilities are assembling grassroots support teams to ensure their children will have life-long care even after the parents are no longer there.

Based on the Burnaby, B.C. Planned Lifetime Advocacy Network (PLAN), 7 new Canadian organizations have sprouted up in the last couple of years or are in the process of being established in Quebec, Ontario, Nova Scotia, and elsewhere in British Columbia, with the goal of providing lifelong care plans.

PLAN, a non-profit agency, provides families with peace of mind through assistance with legal, financial, and estate planning, and offers financial resources for adult children with disabilities without impacting government financial support they receive. But PLAN's uniqueness stems from its commitment to all aspects of quality of life, not just legal and financial security.

Al Etmanski, who has a daughter with Down's Syndrome, was one of a handful of parents who came together in 1989 to form the original Canadian PLAN in British Columbia. At first, the parents thought they might be able to provide care plans for perhaps 75 people. Today, that PLAN serves 4,500 families and its family-oriented format is being duplicated in cities across North America—indicative of the huge demand for such a service. Inquiries on how to duplicate the program are also coming from as far away as Australia, Scotland, and Ireland.

As important as the pragmatic aspects of PLAN are in ensuring adequate housing, financial support, and other practical services, just as vital in guaranteeing the continued independence and quality of life is the program's philosophy of creating personal networks'—close-knit circles of friends, relatives, and others who form long-lasting relationships with the consumers.

Suffering from schizophrenia too often also means living with loneliness. The loss of parents can only make that isolation worse. Under PLAN, though, personal network members will always be there to encourage adults with disabilities to pursue their interests and dreams. A consumer who is an avid model airplane builder or train buff, or who adores horses, for instance, will be paired with people with similar interests. Etmanski said being allowed to realize dreams and pursue interest's means that the disabled adults will have a high quality of life, not just a financially secure life.

"If there aren't people who care about them then (consumers) can be lost in a fairly impersonal society," says Etmanski. "if you ask the average citizen to participate in someone's life, who has a common cause or interest, they will respond," he says. "That network is like sunshine, fertilizer, tender love and care—the people blossom."

Etmanski delves into the PLAN philosophy in his acclaimed book, A Good Life, in which he explores issues such as creating a special needs trust, ending the isolation and loneliness of people with disabilities, alternatives to formal legal guardianship and other issues.

A key component of the Canadian PLAN format is that it receives no government funding: it is funded through fees paid by parents, through charitable foundations, and from legal and financial services providers who recognize that PLAN's families represent a significant market.

That independence from government money means that PLAN can be a forceful advocate for families when their needs are at odds with government, and allows PLAN to tap into the personal commitment of volunteers rather than relying on government-funded staff.

The value of that independence was demonstrated in 1996 when PLAN organized family protests and successfully defeated an attempt by B.C. provincial bureaucrats to force disabled children to draw down assets in trust funds before they could qualify for government benefits.

Tom Cain, coordinator of an affiliated PLAN program established in Lethbridge, Alberta in the late 1990s, says that knowing their children will have a caring, dedicated circle of supporters to watch over them is a deep comfort for aging parents.

One elderly Alberta woman with a disabled daughter was at first hesitant to accept PLAN's offer to put together a support network for her, says Cain. But, convinced to reach out to others in part by her own deteriorating health, the woman accepted.

Nearing the end of a meeting to organize her daughter's support network, the woman turned to Cain.

"She said a thousand pound weight had been lifted off her chest," he says.

In the United States, the National PLAN Alliance—PLAN standing for Planned Living Assistance Network—is another non-profit model that provides legal, financial and estate planning. The U.S. PLAN, which is unrelated to its Canadian counterpart, now has 23 member programs in 18 states and continues to grow.

Carol Obloy, Executive Director of the Saratoga Springs, N.Y.,-based PLAN Alliance in the U.S., says going through the PLAN process forces parents to face several realities: their own mortality, the need for proper estate, legal and financial documents, "and most critically, letting go of the involvement in the care and safety of their relative—and that's very difficult," she says.

"We do not promise to take the place of a family," says Obloy. That's not possible.

"But we can arrange it so most everything a family does can be done."

<sup>\*</sup>From Schizophrenia Society of Canada, Summer 2001

# **Article 2** > Estate Planning

By Marvin Ross

# Preparing for the future is essential

**N**o one wants to think about it, but having a valid will and doing estate planning is essential. It is particularly important if you have assets and/or children, and even more important if you have a child with a disability.

Not having a will can result inconsiderable delays in disbursing your assets, as your estate will be distributed by a court administrator. This distribution is based upon a provincial formula and money may go to people you do not wish to leave anything to.

You may also be leaving your estate in legal limbo, which will delay the distribution of funds and result in extra costs and taxes for your heirs. The distribution of assets could be delayed for up to one year from the date of death and assets may have to be sold at unfavourable rates. Your heirs might also wind up paying hefty estate taxes.

Although you can buy legal will kits, it is important to consult a lawyer and/or an independent estate planner, especially if you have an heir with a disability and you have reasonable assets. Even something as simple as owning your own house would constitute reasonable assets.

After planning for the needs of your family, you can help others through a planned giving provision in your will. This can benefit you, your heirs and a charity of your choice. Not only can you help others but you can provide tax relief for you now and your estate later on.

There are many ways to make a planned gift, and it's best to consult with an expert to find out what is best for you. Here are some of your options:

**Gifts of annuities:** Charitable gift annuities are a safe and secure investment that provides you with a guaranteed income for life based on a blend of capital and interest. When you die, any capital that is left can be given to charity of your choice. A charitable tax receipt can be issued either when the annuity is purchased or at the time of death.

**Gifts of real estate:** The deed for a property is given to the charity and a charitable tax receipt is issued for fair market value that can be used to reduce taxes against current income.

**Residual interest gifts:** If you still wish to use the property that you plan to donate, you can do so even though it has been deeded to the charity. The tax receipt that you get is for the present value of the residual interest.

Charitable remainder trust: An option for people who want to continue to receive the income from their assets but who would eventually like those assets to go to a charity. A charitable remainder trust can be set up with bonds, securities or any other investments. You keep the income generated by the trust but the management of the investments is administered by the trust on your behalf. This gift is not later subject to probate and other estate costs. In addition, you receive a tax receipt for the present value of the remainder of the trust based on a formula set by Revenue Canada. This provides you with tax relief now rather than later.

Gifts of stocks or mutual funds:Donating stocks or mutual funds rather than cashing them in can also generate considerable tax savings, as you will be taxed at your tax rate on only 25% of the capital gain rather than on the normal 50%.

**Gifts of life insurance:** This can be an inexpensive method of making a large donation to the charity of your choice. You simply name the charity as the beneficiary of the policy while you continue to make the premium payments. This will also provide you with a tax receipt now but the value of the insurance policy will not add to your estate.

This is not intended as a definitive list or full explanation of the options that you have for estate planning. That would be based on your particular case and needs, which should be evaluated with your own accountant, an independent specialist in estate planning and/or your family and local advisor. Personal and family considerations should always be taken into account.

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#### **Estate Planning Tips**

- **»** Don't wait to prepare a will. If you die before you complete one, government bureaucrats will decide what to do with your assets, possibly tying up your assets for a considerable period of time.
- » Prepare an inventory of all your assets and liabilities, such as RRSPS, personal property such as cares and jewellery, real estate, and investments such as mutual funds and stocks.
- » Identify your estate planning objectives.
- Seek specialized legal counsel to make arrangements for a trust in your will that will meet the ongoing needs of your child. Don't assume that every lawyer or financial advisor has expertise in creating trusts for people with disabilities that do not jeopardize government benefits.
- » Consider asking your lawyer or financial advisor for references.
- Ensure that your trust is carefully worded so that your child is deemed not to legally own the asset, so government benefits will not be jeopardized. Instead, assets should be in the care and control of a trustee, to be administered for the benefit of the beneficiary
- » Have your will professionally reviewed regularly, to ensure that it has not been impacted by changes in government legislation of your personal family situation.
- **»** Make sure there are family discussions of financial plans to ensure there is understanding and cooperation of everyone involved.
- **»** Know your rights: there are legitimate ways to leave a financial legacy for your child without affecting their government assistance.

Sources: Ottawa, Ontario-based lawyer Ken Pope and Wealthcare, an Ontario-based medical-financial integrated planning service.

# Facts about > The Basic Brain

Many people have compared the human brain to a computer. The truth is your brain is a complex information processing system—more unique and complicated than the newest computer models available. It is the control centre for everything that you do.

Your body temperature, blood pressure, heart rate, and breathing are all controlled by your brain. The brain also provides you with the ability to think, plan, speak, dream, reason, imagine, and experience emotions. Your 5 senses of sight, sound, smell, touch, and taste are all processed through your brain.

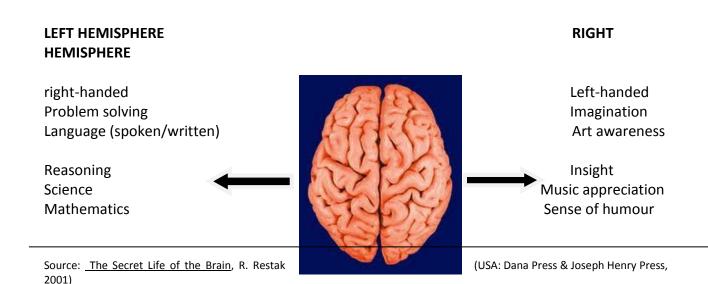
#### The brain is made up of three main areas:

1. THE CEREBRUM -

This part of the brain is made up of two distinct hemispheres and is responsible for higher brain functions such as thinking, memory, language, sensation, emotional expression, and decision-making. The cerebrum makes up about nine-tenths of your entire brain. (the cerebrum is sometimes called the CEREBRAL CORTEX; the cerebral cortex is the grey surface area that covers the cerebrum like a tight-fitting shower cap.)

- **2. THE CEREBELLUM** (little brain) -
- This part of the brain is responsible for muscle coordination and movement.
- 3. THE BRAIN STEM -

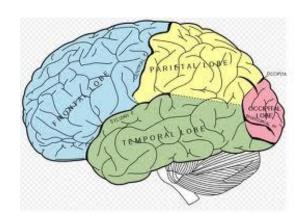
This is the part of the brain responsible for the regulation of many of the automatic functions of your body, like heartbeat, blood pressure, and breathing.



The **CEREBRUM** is divided into 2 halves, called the left and right hemispheres. The 2 separate hemispheres are connected by the corpus callosum, a thick bundle of nerves. The left hemisphere controls the right side of your body, while the right hemisphere is connected with the left side. So if you are right-handed, chances are your left hemisphere is in charge.

For most people, the left hemisphere is generally the analytical, logical side (the side of the brain that balances the chequebook), and the right hemisphere is the creative part of the brain (the part that appreciates going to the art gallery, or laughing at jokes). These hemispheres communicate with one another to help logically process all the information gathered by your senses.

The **CEREBRUM** is further divided into 4 major lobes. Each lobe has a distinct role and purpose.



**Frontal Lobes:** Deal with "executive functions" such as decision-making, foresight, reasoning, planning, emotions, and problem solving (also some parts of speech and movement)

**Parietal Lobes:** Deal with perceptions of stimuli related to touch, temperature, pressure, and pain

**Temporal Lobes:** Deal with functions like hearing, understanding speech, and some memories.

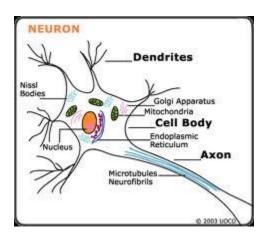
**Occipital Lobes:** Deal with vision (also called the visual cortex)

The various lobes of the brain (as well as many other parts) work together to enable you to perform many tasks and functions that you might naturally take for granted.

#### **NEURONS & NEUROTRANSMITTERS**

Your brain is made up of roughly 100-billion nerve cells called **neurons**. Neurons are known as messenger cells. The main job of the neuron is to receive and transmit messages from your brain to other parts of your body.

Early in the 1900's, scientists discovered that the nerve cells—the neurons—did not actually touch. Neurons produce "messenger" chemicals called **neurotransmitters**. This means that Neurotransmitters allow neurons to TRANMIT MESSAGES to each other. Messages jump from one neuron to the next across tiny gaps (roughly one millionth of an inch wide!) called synapses.



A neuron basically consists of 3 parts: the **cell body, dendrites,** and the **axon**. Dendrites look like thin, branching threads, and the axon is much thicker, like a cable. Axons send messages, while dendrites receive them.

The following is a simple breakdown of how neurons communicate:

- 1. Axons release neurotransmitters (the "message") away from the cell body.
- 2. The neurotransmitter crosses the synapse (the tiny gap) and attaches to a receptor (dendrite) on the surface of another neuron.
- 3. The dendrite receives the neurotransmitter and brings the message to the cell body.
- 4. After delivering the message, the neurotransmitter is reabsorbed by the original "sender" cell.

Some researchers believe that an imbalance in the neurotransmitters can result in brain disorders. In fact, medications for mental illness regulate the various neurotransmitters.

NEUROTRANSMITTER	WHAT IT APPEARS TO DO	PROBLEM AREAS (IMBALANCES)
Dopamine	Regulates emotions and perceptions; controls muscle tension.	Lack of = muscles tighten up (Parkinson's Disease) Too much = over-activates areas of perception; things are seen and heard which are not real.
Serotonin	Controls blood pressure; regulates mood, emotions, sleep/wake, and appetite.	Lack of = you may feel depressed and drowsy  Too much = you may experience headaches, loss of appetite; you may feel sick.
Noradrenaline (also called norepinephrine)	Controls heart and blood pressure, sleep, mood, emotion, and alertness. Regulates energy and drive.	Lack of = you may feel depressed, sedated, or dizzy  Too much = you become anxious
Glutamate	Activates nerve cells.	Lack of = you may feel drowsy or sedated  Too much = you may become anxious; parts of your brain will be overactive
GABA	Has a sedative effect.	Lack of = you may feel anxious or excited  Too much = you may feel drowsy or sedated

# Facts about > The Causes of Mental Illness

Over the last couple of decades, it has become increasingly clear that most diseases and illnesses are caused by a combination of inherited genetic or biological factors (or genetic vulnerability), together with environmental vulnerability factors. Mental illnesses are no different.

# Genetic Vulnerability Factors: How do genes cause diseases?

Genes can have mistakes in them. This is quite common, and everyone has at least some genes with mistakes in them. However, in some people, these mistakes can sometimes cause health problems. We call these genetic mistakes *mutations*.

Mutations can cause health problems because they can change the instructions for making a protein contained within the gene. A mutation may make the genes instructions incorrect, or it might make the instructions make no sense.

Because having a mutation in one gene is not enough for a person to develop a mental illness, the genes that are involved in mental illness *do not cause* mental illness; they only *confer susceptibility or increase vulnerability* to mental illness.

#### Genes that can increase vulnerability to mental illness

In the last couple of years, researchers around the world have been trying to find the genes that might increase a person's vulnerability to mental illness.

Genes that make proteins involved with sending messages in the brain have been found on many different chromosomes. Recently, mutations in some of these genes (on chromosomes 1, 6, 8, 12, 13, and 22) have been found to increase the chances of a person developing mental illnesses like schizophrenia or bipolar disorder. However, each of these genes is thought to increase a person's vulnerability by a small proportion.

Although we can be quite confident that some of the genes found are involved with increasing susceptibility, we don't yet have a clear understanding of how they do so. This is because we don't yet fully understand how they work.

**IMPORTANT** – It is unlikely that an individual with mental illness will have a mutation in each of the many different genes that may increase susceptibility to mental illness. Different individuals may have different combinations of several genetic vulnerability factors.

# **Environmental Vulnerability Factors**

The following vulnerability factors can affect the development of a mental illness.

#### **Obstetric complications**

Research has found that difficulties during delivery are more common in individuals who are later diagnosed with a mental illness like schizophrenia than in individuals who do not develop schizophrenia. Examples of the obstetric complications that have been studied include prematurity, forceps delivery, caesarean section, preeclampsia, and bleeding during the pregnancy. However, the effect of obstetric complications on risk for schizophrenia (which has been most extensively studied) is very small. A person who has experienced these problems is about 2 times more likely to develop schizophrenia than someone who has not experienced them.

#### Head injury

Recent research has shown that individuals with schizophrenia are more likely than people without schizophrenia to have a history of childhood head injury. Again, the effect of childhood head injury on risk of mental illness is small. A person with a history of a childhood head injury is about 2 times as likely to develop schizophrenia as a person who has no history of childhood head injury.

#### Stressful life events

Mental illnesses are influenced by stressful life events. People often report feeling that a stressful event was the trigger for an episode of illness. Stressors can include sudden misfortunes like a car crash or bereavement; a change in living circumstance like a divorce or loss of job; or a more long-term stress like employment insecurity, relationship insecurity, or the demands of college or school. There is evidence that if someone who has a mental illness can live a calm and relaxed life at home, then their problems are less likely to return.

#### Drug use

Certain drugs can trigger episodes of mental illness. For example, some stimulating drugs, like amphetamines and cocaine, can cause a condition known as a "drug-induced psychosis." This psychosis can last up to a few days, and is often characterized by hallucinations, delusions, memory loss, and confusion. This usually results from prolonged or heavy street-drug use, and it responds well to treatment.

It is thought that other drugs, including marijuana, can trigger the onset of an episode of mental illness in someone who is already at increased risk of mental illness (for example, someone with a strong family history of mental illness).

**IMPORTANT**— It is unlikely that a person with mental illness will have all of the environmental vulnerability factors listed above! An individual may have one, two, several, or none of the factors and still have a mental illness.

# **Stress-Vulnerability Model**

Serious mental illnesses are believed to be made worse by stressful factors found in the individual's environment. The model of *Stress-Vulnerability* says that people have different sensitivities to their environments and are therefore more likely to develop mental illness when exposed to them. This difference in sensitivity is thought to be due to different amounts of genetic vulnerability factors.

While we can't rule out the possibility that mental illness might be caused by just genetic vulnerability or by just environmental vulnerability, there is growing proof that, in the majority of cases, the interaction of the two has the greater impact.

Given that we cannot change the amount of genetic vulnerability we have, we can do something to alter our environmental vulnerability. By reducing stress, you can reduce the chances of a relapse—reducing environmental vulnerability.

#### **Protective Factors**

Just as there are *vulnerability factors* for mental illness, there are also protective factors. Identifying and using those *protective factors* on an ongoing basis can greatly diminish the risk of relapse or of developing the illness in the first place.

A protective factor for someone who has already had an episode of mental illness might include, for example, taking his or her medications, participating in a rehabilitation program, or having access to ongoing support.

Research is also being done to identify protective measures to prevent the development of mental illness for those at risk.

The Causes of Mental Illness, developed by Jehannine Austin, Ph.D. M.Sc., Genetic Counsellor, Department of Psychiatry, University of British Columbia, Vancouver and the Early Psychosis Intervention (EPI) Program, Peace Arch Hospital, White Rock, BC

# Facts about > The Treatment of Mental Illness

Brain disorders are not yet *curable* illnesses, but they are treatable. The best treatment usually includes the following:

- Medication to help cope with symptoms and prevent relapse.
- **Psychosocial treatment and rehabilitation** to help individuals regain and retain social, educational, and occupational functioning.
- **Education** for individuals and families (sometimes called psychoeducation) to learn about coping with the illness and its complications, dealing with stress, and problem solving.

BRAIN DISORDER	RECOMMENDED TREATMENTS
SCHIZOPHRENIA	Medical: Typical or Atypical Antipsychotics  Psychosocial: Education, Case Management, Skills  Training, Peer Support, Clubhouse, Interest Groups, Self-help Groups, Psychotherapy (various)
BIPOLAR DISORDER	Medical: Mood Stabilizers, Antidepressants, Mood stabilizers or Antipsychotics Psychosocial: Education, Case Management, Skills training, Peer Support, Interest groups, Self-help groups, Psychotherapy (various)
DEPRESSION	Medical: Antidepressants (various types), *Electroconvulsive therapy (ECT) Psychosocial: Education, Peer Support, Interest groups, Self-help groups, Psychotherapy (various)
OBSESSIVE-COMPULSIVE DISORDER	Medical: Antidepressants, (particularly the SSRI's); other treatment strategies that either boost the effects of SSRI's or treat comorbid symptoms (like anxiety), such benzodiazepines, moods stabilizers, and antipsychotics  Psychosocial: Education, Peer Support, Self-help, Psychotherapy (especially Exposure and Response Prevention Therapy or Cognitive Behavioural Therapy).

<sup>\*</sup>Electroconvulsive therapy is only recommended in cases of severe, suicidal depression, or when the patient may have psychotic or catatonic symptoms. For more information about ECT, consult a health care professional.

### Facts about > Medication

The following information provides an overview of the three types of medications most commonly used to treat symptoms related to schizophrenia, mood disorders and anxiety disorders in Canada.

Medications have two names: a generic or chemical name and the brand or trade name (in italics and parentheses). The brand name is the one that is most commonly used. Different generic manufactures now make many of these medications, so the name on the label may be slightly different.

#### ANTIPSYCHOTIC MEDICATION

#### Antipsychotics (1<sup>st</sup> Generation)

Chlorpromazine (Largactil)
Fluphenazine decanoate (Modecate)
Fluphenazine (Moditen)
Flupenthixol (Fluanxol)
Haloperidol (Haldol)
Loxapine (Loxapac)
Methotrimeprazine (Nozinan)
Pericycazine (Neuleptil)
Perphenazine (Trilafon)
Pimozide (Orap)
Pipotiazine (Piportil)
Thioridazine (Mellaril)
Trifluoperazine (Stelazine)

Zuclopenthixol (Clopixol)

#### Antipsychotics (2<sup>nd</sup> Generation)

Quetiapine (Seroquel)
Risperidone (Risperdal)
Olanzapine (Zyprexa)
Clozapine (Clozaril)

#### **Uses**

The first generation antipsychotics, also known as typical antipsychotics, were first introduced back in the 1950's. At the time, they made a significant impact on the treatment of people with psychotic illnesses. While many people continue to do well on these medications, others didn't tolerate them well from a side effect standpoint. As a result, the second generation antipsychotics were developed. Second generation antipsychotics are also called atypical antipsychotics because they work differently than the 1<sup>st</sup> generation do. The second generation antipsychotics are used much more commonly today. Their main advantage is that they cause fewer extrapyramidal side effects than the older agents do.

Because, the second generation antipsychotics have been shown to benefit mood symptoms, they are increasingly being used to treat mood disorders such as Bipolar Affective Disorder.

Antipsychotic therapy takes several weeks to months, in some cases, to see the full benefit of their use. Antipsychotics don't "cure" mental illness but rather treat the symptoms, and are often taken long term to prevent relapse. It may take trying more than one type to get the "best fit" in terms of best response and fewest side effects. Given that the individual may need to take these medications long term, this is very important. As a result, ill individuals often need much encouragement and support at this time.

#### How it works

The way that antipsychotic medication works is very complex and not fully understood. Part of the antipsychotic action is believed to happen when these medicines decrease the amount of dopamine (a chemical found normally in the brain) in certain parts of the brain. Unfortunately, the older agents not only decreased the amount of dopamine in areas where it was of benefit but also decreased it in other areas where it wasn't. This led to extrapyramidal side effects. The second generation agents work more selectively on the dopamine system, so that these troublesome side effects occur much less often. They also affect serotonin levels (a chemical in the brain involved in mood) and are therefore thought to better help other symptoms.

#### Side effects

The following are some possible side effects of antipsychotic medication. Keep in mind that each person's reaction to a medication is as unique.

*Dry mouth*—is a common side effect of many psychiatric medications. If it is bothersome, chewing sugarless gum or sucking on sugarless candy may help.

*Dizziness* – If it occurs it is most often when the medicine is first started or when the dose has been recently increased. It is noticed when getting up too fast from sitting or lying down. Getting up more slowly, for example dangling your feet over the edge of the bed for a minute or so, should help prevent this fr4om happening. This side effect rarely lasts beyond a couple of weeks.

Blurred vision – also a common early side effect that generally lasts no more than a couple of weeks. It is most often noticed when trying to focus on objects that are close up (e.g. reading).

Constipation – is a common side effect to many psychiatric medications. Regular exercise, drinking plenty of fluids and eating a diet rich in fiber will all help. Eating bran, fresh fruits and vegetables are all good ways to get fiber. If constipation persists, discussion with the treatment team may be necessary as medication may be needed.

Sedation — is often the greatest during the first few weeks of therapy and often lessens with continued treatment. If it continues or is bothersome, the doctor may wish to change the dose or the time(s) of day that the medication is given. Caution is advised when driving or when doing activities that require the person to be alert or wide awake for.

Weight gain—occurs more frequently with the atypical antipsychotics. Please keep in mind that not all people will gain weight and the amount gained can vary greatly from person to person. There are also differences in weight gain potential amongst the various antipsychotic agents. Some people notice an increased appetite when taking these medications. Weight gain tends to start very early in treatment if it is going to occur. Ill individuals and their treatment team should monitor this side effect closely.

Cholesterol—appears to occur more frequently with the atypical antipsychotics. It is important that the family doctor be aware that the individual is taking an antipsychotic medication. The cholesterol level should be checked on a periodic basis as determined by the treatment team.

Blood sugar—Worsening diabetes and new onset diabetes has been associated with the atypical antipsychotics. As a result, periodic checks of the individual's blood sugar are advised especially if there is a family history of diabetes. It is also important that family members be aware of the signs of diabetes including increased thirst, increased need to urinate, and weight change (especially weight loss).

#### Extrapyramidal Side effects (EPSE)

These occur much less frequently with the atypical antipsychotics than with the typical ones. There are different types of EPSE:

Dystonia – a muscle spasm that affects different muscles within the body. There are different types of dystonia, which depend upon which muscle is involved. The most common dystonias involve either the eyes (roll backwards), head/neck (tilts backwards), jaw (locks into place) or tongue (feels fat or thick). They are most likely to happen very early in treatment (often in the first week) or with increase in dose. If dystonia occurs, a side effect medication can be given to make it go away very quickly.

Akathisia or "restlessness" – Sometimes the person may just feel tense or restless on the inside, and other times the person may feel frigidity or unable to stay still for any length of time. This side effect, if it occurs, will happen in the first few months of starting treatment or after an increase in dose. There are options to treat this side effect so that the individual feels more comfortable.

"Pseudoparkinsonism" – Medication doesn't actually cause the person to have Parkinson's disease but rather, to have symptoms similar to what a person with Parkinson's disease may have. These include: tremors, usually in the hands/fingers, stiffness in the joints, or slowed body movements. There are a variety of treatment options if this occurs.

Tardive Dyskinesia (TD) — is a movement disorder which may happen in some people taking an antipsychotic over a period of time (the disorder happens over a period of time, or taking the meds over time causes the disorder?). These movements can occur in any part of the body but often involve the face causing smacking of the lips, twitching, sticking out of the tongue or movements of the jaw. Finger and toe movements are also some of the more common TD signs. Prevention is most important as sometimes these movements may not go away. The treatment team monitors for these signs on an on-going basis. If you note any unusual movements, discuss it with the treating doctor.

Neuroleptic Malignant Syndrome — is a side effect that occurs VERY RARELY with antipsychotic treatment. However, it is important that the family members be aware of the symptoms so that medical attention can be sought immediately in the unlikely event that it occurs. Symptoms include palpitations of the heart (beating too fast or irregularly) confusion, a lot of sweating, unusual muscle stiffness, fever, and loss of bladder or bowel control.

#### **MOOD STABILIZERS**

Many of the medications listed are classified as anti-convulsants (used to treat seizure disorders) but have been found to be beneficial in treating mood symptoms.

Lithium Carbonate (Lithane, Carbolith)
Lithium Carbonate Slow Release (Duralith)
Valproic acid (Depakene)
Divalproex Sodium (Epival)
Carbamazepine (Tegretol, Tegretol CR)
Lamotrigine (Lamictal)
Oxcarbazepine (Trileptil)
Topiramate (Topamax)
Gabapentin (Neurontin)

#### **Uses**

Aside from Lithium, all of the agents used as mood stabilizers are anti-convulsants. Their first use was in the treatment of seizure disorders. Early studies with these drugs have shown an improvement in mood in patients who were using them to control seizure. As a result, there has been much research into the use of various anti-convulsants in the treatment of mood disorders. Some of them have shown to be of more promise than others.

The ones that are most commonly used are Divalproex, Carbamazepine and Lamotrigine. Lithium also remains a mainstay in the treatment of bipolar disorder. The treatment of bipolar disorder is often complex as some individuals have more depressive phases and others have more "highs" or mania. Certain mood stabilizers are better at treating a particular phase. For example, Lamotrigine appears to be better at treating depression than mania.

These medications are also used to treat other psychiatric illnesses. They are sometimes added to an antipsychotic medication in individuals with schizophrenia and schizoaffective disorder to improve symptom control, especially mood symptoms. Lithium is also used to boost the effect of an antidepressant especially mood symptoms. Lithium is also used to boost the effect of an antidepressant especially in those that have failed to respond fully to antidepressants.

#### **Side Effects**

The following are some possible side effects of mood stabilizers. Keep in mind that each person's reaction to a medication is unique.

#### Lithium – side effects

Nausea (stomach upset) and mid diarrhea – is often an early side effect that usually goes away as the body gets used to taking it. Taking lithium with food or milk should prevent this from happening. If this continues or is bothersome, the doctor should be consulted.

*Increased thirst, increased urination*—many people taking lithium notice an increase in thirst and find that they have to go to the bathroom more often. It is important to maintain normal salt and water intake.

Weight gain – some individuals may gain weight. The amount may vary from person to person. Before a person begins any diet or exercise plan, it is important that it be discussed with the doctor first. (see cautions)

Thyroid gland — Lithium may cause a problem with the thyroid gland. The thyroid gland makes hormones that affect many body functions. From time to time, a test to check on the levels of thyroid hormone is done. If a problem does develop, a thyroid hormone pill should correct it. Lithium does not need to be stopped even if this happens.

Sedation/dazed feeling – can occur with Lithium. Changing the time of day that an individual takes lithium (dose closer to bedtime) may help this. If it persists or is bothersome, the doctor may also look to other ways to improve concentration and energy level.

*Tremor* – a slight shaking of the hand may occur.

#### **Cautions with Lithium**

Lithium is unique in that the amount that the body needs is very exact and can be measured in the blood. People taking lithium should have their levels checked on a regular basis. The frequency of checks often depends on the length of time that the person has been taking the medication. When lithium is first started, the levels are checked more often.

Any illness that results in a loss of a large amount of salt or water from the body (fever, heavy sweating, vomiting, and diarrhea) can cause the body to have too much lithium. Diet and exercise programs can also affect the amount of lithium in the body. A person who takes lithium may still diet and exercise but is should be done with the supervision of the treatment team.

Certain medications (some used for pain, heart conditions and blood pressure) can also affect the level of lithium. You can buy some of these medications without a prescription. It is very important that any doctor providing care to the individual be aware that the person is taking lithium. Always check with the pharmacist before taking any other medicine.

It is helpful that family members and friends be aware of the signs of too much lithium so that they may recognize them should they happen. Seek medical attention if there is: unusual drowsiness, muscle weakness, sudden loss of appetite, confusion, slurred speech, tremor (more noticeable than what the person may normally have), difficulty with balance, nausea (stomach upset), vomiting or diarrhea. Pay special attention to signs of these symptoms if they occur after the first few weeks of therapy.

#### Anticonvulsant mood stabilizers – side effects

*Nausea* (stomach upset) – is often an early side effect that goes away as the body gets used to it. Taking the medication with food or milk should help.

Sedation (sleepiness) {include sleepiness in sedation explanation above} —is often more noticeable when the medication is first started or when the dose has been increased. Sedation often lessens as the body adjusts to the medication. If it persists or is bothersome, discussion with the doctor is necessary as the dose may need to be decreased or the time(s) of day that the medication is given may need to be changed. Caution is advised when driving or when doing activities that require the person to be alert or wide awake for.

Weight changes – some of these medications cause weight gain, while others possibly cause weight loss.

Difficulty with balance/gait, dizziness – are fairly common early side effect that occur as the body gets used to taking the medication and usually lessen or go away with continued treatment.

Double or blurred vision -- also are early effects that can occur, and that lessen and go away as the body gets used to the medication.

Tremor (mid shakiness)

Rash – skin rashes can occur with several of these medications. Any rash should be brought to the immediate attention of the doctor. Rashes caused by Lamotrigine and carbamazepine especially, MAY be serious.

Hair loss – in the vast majority of cases the hair will grow back even with continued treatment and will always grow back if the medication is stopped. If this happens the person is encouraged to discuss it with his/her doctor to decide on the best course of action.

#### **Cautions**

Serious side effects are very rare with anticonvulsant mood stabilizers. From time to time, these are {what are} monitored in the blood. However, if any of the following are noted, the person should seek immediate medical attention: extreme nausea and vomiting, yellowing of the skin or eyes, easy bruising or bleeding, unexplained fever or sign of infection (sore throat, mouth ulcers).

#### **Antidepressant Medication**

Amitriptyline (Elavil)

Bupropion (Wellbutrin SR,XL)

Citalopram (Celexa)

Clomipramine (Anafranil)

Desipramine (Norpramin)

Doxepin (Sinequan)

Estalopram (Ciprolex)

Fluoxetine (*Prozac*)

Fluvoxamine (Luvox)

Imipramine (*Tofranil*)

Mirtazepine (Remeron)

Moclobemide (Manerix)

Nortriptyline (Aventyl)

Paroxetine (Paxil)

Phenelzine (Nardil)

Sertraline (Zoloft)

Tranylcypromine (Parnate)

Trazadone (Desyrel)

Trimipramine (Surmontil)

Venlafazine (Effexor XR)

#### Uses

Antidepressants are most commonly used to treat depression. However, they are also used to treat a number of other conditions including: obsessive compulsive disorder (OCD), panic disorder, generalized anxiety disorder (GAD), phobias including social phobia, post-traumatic stress disorder (PTSD) as well as in the management of certain types of pain.

#### How it works

All antidepressants work by boosting the amount of certain neurotransmitters in the brain. These neurotransmitters (serotonin, norepinephrine and dopamine) are naturally present but are believed to be reduced in individuals with depression. The difference in the many antidepressants lies in which neurotransmitter(s) they increase and how they increase it. One antidepressant hasn't really been shown to be more effective than another when equivalent doses are used. We know that everyone responds differently to these medications. It may take trying more than one type to get the "best fit" in terms of best response and fewest side effects. It takes several weeks to see the full benefit of an antidepressant. As a result, individuals need much encouragement and support at this time.

#### Side effects

The following are some possible side effects of antidepressant medication. Keep in mind that each person's reaction to a medication is unique.

Headache – is often an early side effect as the body is getting used to the medication and very often goes away. The doctor or pharmacist can suggest a pain reliever for short term use.

Stomach upset (nausea) – This is often an early effect that usually goes away. Taking the medication with food or a glass of milk should help.

Sedation (sleepiness) or insomnia (difficulty sleeping) – certain antidepressants cause sleepiness and are better taken at night. Other medications, when taken close to bedtime, can cause problems with getting a good night's rest. The doctor may wish to change the times of day that the person is taking the medication if either is a problem. Caution is advised when driving or when doing activities that require the person to be alert or wide awake for.

*Increased sweating* – if bothersome, change in therapy may be needed.

Weight changes -- both weight loss and weight gain can occur with antidepressants. Certain antidepressants are more likely to cause one than the other.

Sexual side effects – antidepressants can cause a decrease in the desire for sex. They can also interfere with the ability to have sex. Sexual difficulties may occur due to a number of factors. If this occurs with an antidepressant, please consult your doctor to determine the cause of the problem and discuss the best course of action. Certain antidepressants are less likely to cause sexual side effects, so changing medication may be one option.

#### **Cautions**

While not addictive, antidepressants should never be stopped "cold turkey". Sometimes, people may want to stop them because they don't think that they are working or they no longer feel that they may need them. These medications should always be tapered and discontinued under the advice of a doctor.

There is much talk about whether antidepressants increase suicidal thoughts and actions. While these risks are now being closely studied, this remains very controversial. It is recommended that you seek immediate medical attention if you notice an increase in agitation and/or suicidal or homicidal thoughts, at any point during treatment.

<u>Please note:</u> The information on side effects in this handout is not complete and lists those most commonly experienced. For more detailed information about a particular medication and its side effects, please consult with a doctor or pharmacist. Also, if you note any serious reaction to a medication, we recommend you seek immediate medical assistance.

# Facts about > Treatment Issues

#### **Adherence**

An important issue in the treatment of mental illness is *adherence* (also referred to as *compliance*. Adherence is when the individual takes his/her medication regularly as determined by his/her doctor, as well as sticks to the other aspects of the treatment plan (e.g., attending rehabilitation appointments, proper self-care, meeting with case manager). Non-adherence is when the individual does not follow through with his/her treatment plan and does not take his/her medication correctly.

There are a number of reasons why someone with a serious mental illness may become non-adherent:

- Stigma associated with illness; medication is associated with the illness instead of seen as a link to being healthy
- Does not believe he/she has a mental illness and so doesn't understand the need to take medication or follow through with the treatment plan.
- May feel embarrassed about having to take medication, attend counseling, go to rehab, etc.
- Some medication side effects may be very unpleasant (weight gain, drowsiness, sexual problems)
- No relief from symptoms (it may take some time for the medications and other therapies to have an effect)
- Starts to feel better and may stop taking his/her medication or attending other appointments, believing it is no longer necessary
- May forget to take medication or attend appointments
- Doesn't understand medication schedule or may have trouble with the scheduling
- Due to his/her illness, may be paranoid about taking medication (e.g., believes he/she is being poisoned)
   or about sharing personal information with his/her health care professional
- Concern about taking medication and becoming "addicted"
- Has a concurrent disorder and is also using alcohol or drugs
- Financial barriers (cost of medication and other therapies)

### Ways to help someone who is non-adherent:

- Become informed about mental illnesses and the role of medication and other therapies
- Find out why your relative isn't taking his/her medication or following through with appointments; ask in a sincere way and listen non-judgmentally
- Avoid lecturing, scolding, or punishing someone for not following his/her treatment plan
- Suggest the person talk to his/her doctor, case worker, or other treatment team member
- Encourage the individual to avoid stress, alcohol, and street drugs
- Find health care professionals who are effective members of the treatment team
- Support the individual's development of a trusting relationship with his/her doctor or other treatment team member
- Help the person to focus on the benefits of medication, not just the side effects
- If side-effects are a challenge, help him/her to focus on any possible day-to-day benefit of the drug, such as sleep or anti-anxiety effects
- Be alert to the early signs of relapse; often a person's realization about the need for medications will "go out the window" when acute symptoms return
- Simplify the medication routine; psychotic symptoms and/or problems in thinking often interfere with an individual's ability to follow the prescribed routine (the pharmacist can be a major ally when dealing with this kind of situation)
- Encourage the individual to talk with his/her doctor before making any changes in his/her medication routine.
- Try to avoid direct power struggles; in general, it is better to have the doctor or other treatment team member do the "arm twisting"

# What are> Psychosocial Treatments

Psychosocial treatments are treatments that address the psychological and social aspects of the individual. These types of treatments support the individual in his/her goal of recovery by providing education and practical skills to help the individual cope with his/her mental illness. Psychosocial treatments can also reduce psychological vulnerability by lowering the impact caused by stress on the individual. These treatments complement medication treatment and encourage individuals to maintain a strong support system.

#### **BENEFITS OF PSYCHOSOCIAL TREATMENTS:**

- Provides a supportive and encouraging environment through interacting wit6h others who have had similar experiences. An individual can work and learn from others with shared experience, giving and receiving emotional support on a regular basis.
- Improves personal and family relationships that have been affected by the illness.
- Educates people with a brain disorder and their family members, and encourages them to work together on a treatment plan
- Increases the likelihood that the person will continue to take the prescribed medication.
- Ensures strong support systems are in place to help identify early warning signs of stress or relapse.
- Enhances coping skills to help minimize the stresses that could contribute to relapse.
- Provides structure and a connection to community centers and other available resources by promoting involvement in different activities.

#### **EXAMPLES OF PSYCHOSOCIAL TREATMENTS:**

- Education for5 patients and family members
- Case management
- Skills training
- Peer support/self-help groups
- Clubhouse
- Interest groups (sports, hobbies, etc.)
- Psychotherapy
- Cognitive Behavioural Therapy (CBT)
- Exposure & Response Prevention Therapy (ERPT)
- Family Therapy
- Group Therapy

#### **EDUCATION**

Education is vital for people with mental illnesses and their family members. Learning about their illness and strategies for living day to day is an important process. Individuals who are educated about their illness are better able to take an active part in their well-being, and research suggests they are less likely to relapse.

- Benefits of education include:
- Learning about the illness
- Improving coping skills
- Decreasing rate of relapse
- Lowering stress levels
- Helping build a support network

#### CASE MANAGEMENT

Treatment plans often involve different types of services. In some communities, Case managers or Community Mental health workers are involved in the ongoing management of care of the individual. Case managers coordinate available support services, like housing, day treatment, or financial services, and also connect the individuals to community volunteer or vocational services. They can also assist in daily activities and provide emotional support for the individual. Case management is important, and where it doesn't exist, the individual or a family member may become an informal case manager. Learning about what is available in the community is critical to ensuring the person has access to services needed.

#### **SKILLS TRAINING**

After an individual develops a brain disorder, there may be a loss of social and personal skills, especially if the period of illness included a psychotic episode. Certain skills (personal grooming habits, shopping, going back to school or work) may need to be relearned. Community mental health programs can assist people with a mental illness to learn ways that will help them reintegrate into their community.

Teaching skills such as communication and stress management (sometimes referred to as social skills training) are also very important. Community support programs can help individuals with vocational (job) rehabilitation or educational goals. Skills training has an enormous impact on improving the individual's self-esteem and allows the individual to actively participate in his or her community.

# PEER SUPPORT/SELF-HELP GROUPS

Peer support, much like it sounds, involves people with a mental illness offering support and strength to others with a mental illness. Much like a self-help group, the idea entails helping each other stay healthy. Often this can lead to an individual feeling less isolated, and help him/her to learn techniques to deal with living with a mental illness.

Self-help groups can be wonderful places to give and receive support, and to build stronger support systems. Your local Schizophrenia Society, mood Disorders Association, Anxiety Disorders Association, or Canadian Mental Health Association will be able to assist with specific self-help groups available in your community. What to look for in a self-help group: a group of people who are successfully dealing with similar issues.

#### **CLUBHOUSE**

The very first Clubhouse was started in the 1940s in New York by a group of ex-psychiatric patients. Clubhouses are based on treating people as individuals and giving them respect and dignity.

All operate according to a common set of standards.

The Clubhouse philosophy is built on these four beliefs:

- A guaranteed right to a place to come.
- A guaranteed right to meaningful work.
- A guaranteed right to meaningful relationships.
- A guaranteed right to a place to belong.

Clubhouses users are called members and have access to all the activities of the Clubhouse, regardless of diagnosis or level of functioning. Membership is for life and unconditional, unless a person presents a significant threat to the Clubhouse or its community.

#### INTEREST GROUPS

Interest groups can provide individuals with another source of social support. People can pursue their hobbies or interests and meet others at the same time. This again offers individuals an opportunity to feel less isolated. (Examples of interest groups include volleyball teams, writing groups, or craft groups.)

# **PSYCHOTHERAPY (TALK THERAPY)**

The goals of talk therapy are:

- Building (or rebuilding) self-esteem
- Teaching new coping skills
- Teaching new ways of coping with difficult emotions
- Teaching new ways of dealing with difficult symptoms
- Teaching ways to come to terms with past difficulties

It's best to find a therapist through a recommendation. A good balance would be a therapist who may challenge a person to see things differently and to make positive changes in his/her life, while also being sensitive and understanding of the individual's particular needs.

When researching the various types of therapy, it is important to look for one most suited to the person's goals. It is important to have a goal with therapy, whether to maintain health, learn better coping skills, or build a stronger support system.

#### **Psychotherapy**

#### How it works:

The individual talks to a professional (therapist or psychiatrist) on a regular basis, focusing on current or past experiences, problems, feelings, & relationships.

#### Benefits:

- Helps an individual cope with emotional distress
- Learn more about themselves, their thoughts, action, behaviours
- Learn new coping skills
- Relief from stress & anxiety

#### Who Can Benefit:

People with:

- Schizophrenia
- Bipolar disorder
- Clinical depression
- Obsessive compulsive disorder

Family members

#### Cognitive Behavioural Therapy (CBT)

#### How it works:

Individuals focus on changing negative thought patterns they may have developed over the years. Individuals are usually taught relaxation techniques& given homework assignments to help practice their newly acquired skills.

#### **Benefits:**

- Feel more involved throughout this active approach
- Leads to improved selfesteem
- Learn new coping skills that provide relief from depression, stress, and anxiety

#### Who Can Benefit:

People with:

- Schizophrenia
  - Bipolar disorder
  - Clinical depression
  - Obsessive compulsive disorder

Family members

#### **Exposure & Response Therapy** (ERPT)

#### How it works:

Individuals are exposed to their fears or anxieties during the therapy session, and are then taught techniques to avoid the compulsive rituals. Homework assignments help individuals practice skills between appointments.

#### **Benefits:**

- Feel more involved throughout this active approach
- Leads to improved selfesteem
- Learn new coping skills that provide relief from stress, depression, and compulsive behaviour.

#### Who Can Benefit:

#### People with:

 Obsessive compulsive disorder

#### Family Therapy

#### How it works:

Similar to all the other forms of talk therapy, only the whole family is involved. The therapist ensures that everyone gets the chance to voice his or her feelings and concerns.

#### **Benefits:**

- Greater understanding of the family dynamics
- Greater understanding of individual needs within the family
- Helps all family members develop healthy communication skills

#### **Who Can Benefit:**

#### People with:

- Schizophrenia
- Bipolar disorder
- Clinical depression
- Obsessive compulsive disorder
- Family members

#### **Group Therapy**

#### How it works:

A group of people meet together on a regular basis to discuss their current issues or problems with each other (usually a mental health professional is also present to offer support and guidance). Suggestions for solutions may be made by group members. This type of therapy is very helpful for people going through similar types of problems.

#### **Benefits:**

- Feel less isolated and alone with their problems
- Builds a strong support system within the community
- Helps build self-esteem when the group focuses on problem solving rather than problems

#### Who Can Benefit:

#### People with:

- Schizophrenia
- Bipolar disorder
- Clinical depression
- Obsessive compulsive disorder
- Anxiety disorders
- Eating disorders
- Family members

For more information on how to find a professional counsellor or therapist, contact your health care profession or go through professional associations (e.g., Canadian Professional Counsellors Association). Also check if your medical insurance will cover therapy costs.

# What is > Recovery

For someone with a severe mental illness, it may seem almost dishonest to talk about recovery. After all, the conditions are likely to persist, in at least some form, indefinitely. How can someone recover from an incurable illness? The way out of this dilemma is by realizing that whereas the illness is the object of curative treatment efforts, it is the person who is the object of recovery efforts.

Recovery can be viewed positively in terms of things to be actually recovered. These things may be grouped into three broad categories:

- 1. **Functions** may be recovered as in the ability to read, to sleep restfully, to work, to have coherent conversations, to raise children, and to drive a car.
- 2. **External things** may be recovered as in an apartment, a job, a social life, playing in a band, family relationships, and going back to school
- 3. *Internal states* can be recovered as in feeling good about oneself, satisfaction, self-confidence, spiritual peace, self-identity other than mentally ill, and self-responsibility

Consider the following phases of recovery:\*

# Phase 1

#### "Overcoming Stuckness"

- Acknowledging and accepting the illness
- Having desire and motivation to change
- Finding/having a source of hope and inspiration



#### Regaining what was lost and moving forward

- Recovery as a process of learning and self-empowerment
- Recovery as a process of learning and redefinition
- Recovery as a process of reaching a satisfactory level of functioning that is acceptable to the individual



#### **Improving Quality of Life**

- Striving to attain an overall sense of well being
- Striving to reach new potentials of higher functioning

Recovery from a mental illness involves much more than recovery from the illness itself. People with mental illness may also have to recover from the stigma, the negative consequences of unemployment, and the disappointment of unrealized/unfulfilled dreams and/or lost opportunities.

Recovery is often a complex, time-consuming process. It is also a very individualized experience that is unique to each person living with a serious mental illness. Persons with mental illnesses are not a homogeneous group, and thus there is not one single pathway to recovery. Recovery is what people with disabilities work toward. The various treatments available for mental illnesses, combined with clinical services, family and community support, and rehabilitation help, facilitate the process of recovery.

Recovery for people with a mental illness means adjusting to a life with a chronic illness by rebuilding self-esteem and developing strong support systems.

The recovery process is an ongoing, lifelong journey for each individual.

<sup>\*</sup>Three Phases of Recovery from Exploring Recovery from the Perspective of People with the Psychiatric Disabilities. Psychiatric Rehabilitation Journal (1999, 22(3), 219-231 by S.L. Young & D.S. Ensing

# **Article 1** > Navigating the Complex Issue of Compliance\*

By Dr. Irvin Epstein

There have been many great advances in the management of psychosis and schizophrenia over the past 20 years. The introduction of more selective antipsychotic medications, recognition of the use of lower doses, and focused psychosocial options, have led us toward the obtainable goal of an enhanced quality of life for people with this illness.

There continue to be many obstacles and challenges. The number one problem is the high potential for relapse. The key reason for relapse is that patients are not able to maintain compliance or agree with the treatment plan. Compliance, also known as concordance and adherence, is best defined as: "the extent with which an individual's behaviour is in agreement with the advice given." Compliance requires a dedicated effort to continue not only on their medications, but to also reduce stressors in their life and maintain an appropriate lifestyle.

Non-compliance is a multi-factorial phenomenon and is a crucial factor in wellness and outcome. It can occur at any stage in the illness, however there is increased evidence that insight and compliance are better if the illness is caught and treated early.

There is a strong correlation between compliance and one's insight into their illness, evidence of negative features and level of cognitive impairment at the time of their psychotic break. It has a profound effect on prognosis directly related to the 'biological toxicity,' that is, the functional decline as a consequence of illness progression. Denial or failure to appreciate that one is ill and needs medical intervention creates an obstacle for everyone in the partnership. Similarly, if someone is suspicious, mistrustful, and has substantial paranoia about others, they are often difficult to engage and may not accept advice for taking an antipsychotic medication and attending to follow-up appointments.

Non-adherence is the primary reason for 'the revolving-door patient' and carries a tremendous cost to the individual in the form of demoralization and self-depreciation. This behaviour also strains relationships with their caregivers and families. A number of researchers have shown that individuals with repeated episodes of psychosis lose insight with each subsequent episode.

A recent study showed that about 50 per cent of first-episode patients were non-compliant with their medication regime. One case that illustrates the challenges in dealing with a first episode patient involved our work with a pleasant and personable 22-year old female university student who had developed a first episode of psychosis in her third year of university. She was hospitalized after her family was concerned that she was becoming increasingly suspicious of other students and faculty, and she developed grandiose beliefs that her university was monitoring her thoughts and broadcasting them on the internet.

She developed paranoid ideas about her family and was suspicious of the motivations of the treatment team. She had a pattern of lengthy, repetitive hospitalizations. She could never acknowledge her illness or accept treatment.

In the first two years there was a sense of anguish and frustration for everyone because she would stop her medications within weeks of discharge and soon be re-admitted to hospital. There were increasing worries that she was jeopardizing her education and becoming more bizarre in her behaviour.

The final chapter was precipitated by a crisis in which she believed that neighbours had joined the plot to record her thoughts. She was brought by police to the emergency room and admitted for a longer period of time. We found a good medication regime and were gradually able to develop a level of trust and cooperation. This was the longest documented period that she had been on medication and it led to almost complete remission of her positive symptoms.

#### NON-ADHERENCE IS THE PRIMARY REASON FOR "THE REVOLVING-DOOR PATIENT."

Fortunately, at that time, Community Treatment Orders were being introduced to our province and our patient accepted the idea that it may prove beneficial. The result is that she regained insight when it seemed all hope was lost, and she has had a good recovery and remission of her paranoid symptoms. She returned to good personal functioning, family harmony, and interest in furthering her education, and a new-found appreciation of life and in her future.

There are a number of factors associated with poor compliance with the therapeutic plan that need to be addressed. First, all medications have the potential to cause side effects and it is important to discuss this with the treating doctor or nurse at every appointment. It is also imperative to maintain a healthy lifestyle, including getting an adequate amount of sleep every night, eating regular nutritious meals, and reducing one's level of stress.

Avoid the use of alcohol, illicit drugs (marijuana and hallucinogens), and over-the-counter medications (antihistamines or analgesics). A combination of discontinuing one's medication and using illicit substances will undermine the therapy and lead to increased risk of morbidity and hospitalization by about seven times. Also, stay clear of holistic or herbal formulations. The majority of these products will interfere with the efficiency and metabolism of antipsychotic medications and may lead to adverse reactions. They may even be toxic to the body.

In summary, it is important to anticipate that over half of patients will be non-compliant and that this may be preventable by creating a dialogue for problem solving and by developing a trusting partnership at the earliest stages of treatment. We must always work with the recognition of a person's belief system and provide reassurance in the situation. An individual's poor trust and suspiciousness, lack of desire to relinquish control, emotional regression, and lack of insight need to be overcome if the treatment is going to succeed. This requires commitment together with an understanding and empathetic approach.

Patients need to be encouraged to voice their concerns regarding any problems or side effects that they may attribute to the medication, such as: sedation, extrapyramidal side effects, and drooling. Individuals who are withdrawn may need to be offered diagrams or photos and instructions for multiple medications, and doses need to be simplified and monitored regularly. The purpose of all medications needs to be clarified at every appointment.

Psychoeducation for patients begins early in the treatment process, and family or caregivers need to be aware of all the elements of the treatment plan. Recent advances in the area have focused on brief group therapy to assist with the above-mentioned obstacles in the treatment. This often needs to be supplemented with literature or videos about the benefits of compliance and the risks of not following the plan completely. Failure to anticipate resistance and denial will lead to ignorance, fears, and increased distress for the patient.

The goal of better adherence carries with it the hope of improved symptom control, better interpersonal functioning, and optimism for both the patient and their families. While much has been done in the area, we need to refine our skills and continue to work harder in changing the course of schizophrenia and create optimism for the future.

#### TEN RULES FOR INCREASING COMPLIANCE:

- 1. Acceptance and understanding the facts of the illness is important
- 2. Restructuring your life to lower stress
- 3. Understand the need for medications and the need to continue under doctor's orders
- 4. Work with the doctor and team to reduce side effects
- 5. Your medications are not addictive or habit-forming
- 6. Never stop your medications on your own
- 7. Always talk to your doctor if you want to change medication
- 8. Stop use of all substances; they can only make you worse
- 9. Stop or cut down on smoking; it interferes with your health
- 10. Do not use over-the-counter or herbal products; they are not proven and some are dangerous

#### **About the Author:**

Dr. Epstein is director of the PRIME (Prevention Through Risk Identification Management and Education) Clinic at the Centre for Addiction and Mental Health in Toronto.

<sup>\*</sup>Schizophrenia Digest magazine, Fall 2002 edition

# **Article 2** > The Compliance Conundrum

# **Complex Factor Influence Acceptance of Treatment\***

When the first antipsychotic medications were introduced in the 1950s and 1960s, there was widespread hope that the tide had turned in the battle against schizophrenia. But while medication have revolutionized treatment of the brain disorder and allowed hundreds of thousands of North Americans to live outside of institutional settings, a disturbingly high rate of non-compliance—the refusal or inability of patients to stay on their medications—remains one of psychiatry's most puzzling and troubling conundrums.

By some estimates, a staggering 74% of people with schizophrenia stop taking their antipsychotic medication within 2 years of discharge from treatment. That, say experts, takes a heavy toll on both individuals and society as a whole in terms of increased suicide rates, higher risks of violence, homelessness and costly rehospitalization.

Newer antipsychotics developed in the 1990s are proving to be more effective than older drugs in controlling symptoms of schizophrenia, with the benefit of fewer side effects. And third generations drugs on the horizon are expected to be an improvement over the best medications available today.

But because non-compliance is believed to be the result of a number of factors—self-denial of mental illness, social isolation, embarrassment, the doctor-patient relationship, and restrictive formularies among them—experts say just how much compliance rates will be affected by newer medications isn't yet clear. What is crystal clear is the destructive impact of failing to comply with prescribed medication.

Mainstream media in Canada, the U.S., and England have carried prominent headlines in recent years of highprofile acts of violence involving people with schizophrenia who were not taking their medication. Then there are the issues of high suicide rates, growing homelessness, and a burgeoning number of mentally ill people running afoul of the law and ending up in jail.

Certainly, they are not all societal ills that can be blamed on non-compliance alone. A lack of affordable housing in many cities, punitive disability programs that force many mentally ill people to live in poverty, and a justice system poorly designed to cope with mental illness all factor in. But non-compliance, experts say, is a prime contributor to all these problems.

"Antipsychotic non-compliance in schizophrenia is a major public health problem," says Dr. Christian Shriqui, a Quebec psychiatric who participated in an international roundtable meeting held recently in London, England. The roundtable, which included psychiatric experts from Canada, the U.S., the United Kingdom, France, Germany, Italy, Austria, and Denmark, focused on the distressing side effects often associated with some medications used to treat schizophrenia.

It was the introduction in the early 1990s of clozapine, the first of the second-generation antipsychotics, that focused attention on the adverse effects antipsychotics have on patients' cognition, social skills, and quality of life, says Dr. Shriqui. Patients whose physicians switched them to clozapine from older drugs often experienced 'awakenings,' and reported feeling more alert and less apathetic—in general, 'more alive.'

The adverse effect of some antipsychotics is often described by patients as 'feeling zombie-like,' or 'living in a chemical straight-jacket.' Older medications can cause a number of unwanted symptoms known as extrapyramidal side effects (EPS), including muscle spasms, muscle rigidity, listlessness, fidgeting, and restlessness. Long-term exposure to conventional antipsychotics also increases the risk of developing Parkinson's disease-like symptoms, known as tardive

dyskinesia (TD), including uncontrolled movements and twitching. For patients already burdened with the stigma of mental illness, the side effects can often be intolerable and a source of anxiety and shame—so much so that they may be reluctant to go out in public, furthering their isolation.

Professor Richard Borison, head of the department of psychiatry and a professor with the department of pharmacology at the Medical College of Georgia, was one of the participants in the roundtable meeting in London. Borison says antipsychotic drug-induced Parkinsonism increases with age, eventually affecting 40 to 75 per cent of people with schizophrenia. Sadly, he says, psychiatrists often mistake the signs of Parkinson's-like symptoms—a 'mask-like' face, poor posture, and an inability to respond in social settings, for instance—as being the result of schizophrenia's so-called negative symptoms.

"Drug-induced Parkinsonism impairs enormously the social responsiveness of patients, and this clearly hinders integration back into the community," says Borison. "Psychiatry is effectively robbing patients of important components needed for leading a normal life."

If you don't try medication you'll never know what might have been. What we're meant to do on this Earth may never get done.

Jo-Ann Paley

These symptoms can be reduced in many patients by the use of anticholinergic medications, but these medications, too, produce side effects such as dry mouth, blurred vision, constipation, and short-term memory loss. The newer generation of antipsychotics, known as atypicals, produces fewer of the movement disorders, but some carry their own risks such as weight gain, sleepiness, and sexual difficulties.

Jo-Anne Paley is willing to risk side effects in order to live her life to the fullest.

The Winnipeg, Manitoba resident was working as a research assistant, spending months at a time poring over microfilm. The strain of the work started to make it more and more difficult to concentrate. "My brain was like a spider web that was clogged," she recalls. Around that time, in 1980, she began to experience hallucinations and delusions, including the belief that she was talking to God.

She was hospitalized and eventually ended up being prescribed an older antipsychotic that produced side effects such as excessive sleepiness that made concentration difficult and caused a blunted effect. Since 1997 she has been taking clozapine. Because the medication carries a risk with a small percentage of patients of a potentially life-threatening drop in white blood cell counts, Paley must have her blood tested every two weeks. But Paley, who has a daughter, is on the board of directors of the Manitoba Schizophrenia Society and who 2 years ago started a bimonthly newsletter for the society's women's program, says it's a risk she's willing to take in order to live life to the fullest.

"If you don't try medication you'll never know what might have been," she says. "What we're meant to do on this Earth may never get done."

Some studies have found that as many as half of the people with serious mental illness are not receiving any treatment at any given time, a statistic due in no small part to self-denial: fully 55 % of seriously ill people not seeking treatment say they do not believe they have a problem, according to a recent study based on data from the U.S. National Comorbidity Survey.

"Even among patients who accept that they have schizophrenia, human nature is such that people with a variety of illnesses—including diabetes and heart disease—may decide to stop taking their medication once they feel better," says Dr. Mark Vanelli, a psychiatrist on the faculty of Harvard Medical School. For many people with schizophrenia, medication is also perceived as something they are forced to take. "It's human nature that you don't want to do something you feel pressured to do," he says.



Ian Chovil was in the hospital, homeless and in jail.

Complicating physicians' and family members' efforts to determine if a patient is non-compliant is the difficulty in determining if patient relapse is due to non-compliance or non-response to antipsychotic medication. Effectiveness of antipsychotic medication isn't universal: a drug that helps one patient immensely may be only partially successful or not successful at all for another patient. "Non-compliance may be a result of relapse, as opposed to the reverse," says Dr. Peter Weiden, director of the Schizophrenia Research Program at the State University of new York in Brooklyn, New York.

Dr. Weiden says some patients may also be tempted to stop taking their medication because, in many cases, distressing side effects disappear quickly once the patient stops complying, while the protective effects of the medicine remain for some time—in effect, luring people with schizophrenia into the belief that they can be 'well' without their medication.

Restrictive formularies—complex master lists that Canadian Provinces and U.S. health maintenance organizations use to determine what drugs are available for coverage—are also partially to blame for high noncompliance rates.

Because older medications can cost a fraction of a cent a day while newer medications can be very expensive, people with schizophrenia are often forced to take older and less effective antipsychotic medications due to limited formularies designed to reduce costs.

A national survey commissioned by the Schizophrenia Society of Canada last year found that more than half of psychiatrists said there have been instances in which they did not prescribe their first choice of medication because of barriers such as bureaucratic red tape or formulary restrictions. Of those who did not prescribe their first choice, 81 per cent said it had a negative impact on patient well-being.

The results of such restrictions are intolerable side effects, according to the U.S. National Mental Health Association. "Consumers choose to live without medication rather than endure (side effects)," the association says.

Numerous studies have shown a direct link between noncompliance and relapse. That has worrisome implications for patients' long-term health, with research suggesting that each successive relapse worsens a patient's condition—that it may actually be causing damage within the brain.

Advocates of antipsychotic medication in the treatment of schizophrenia are hopeful that new research into techniques for delivering long-term dosages of medication could help with compliance rates and in avoiding relapses. University of Pennsylvania researchers are developing an implantable pellet that may be able to deliver a steady dose of antipsychotics for up to a year.

"Patients who need antipsychotic drugs often fail to comprehend the profound severity of their illness, and may stop taking their medication during temporary periods of impaired judgement" says Dr. Steven Siegal, the head of the study and a member of the division of neuropsychiatry at the University of Pennsylvania's School of Medicine. Long-term dosages may be a powerful tool in reducing non-compliance rates, he says.

For Guelph, Ontario resident Ian Chovil, having schizophrenia and not receiving treatment will result in an inevitable outcome.

"You end up in hospital, on the street, or in jail," he says. "It's just a matter of time."

Chovil, 48, knows because he's been in all three places. Once one of the top students in mathematics in all of Ontario at one point during high school, his life began to unravel by the time he was 17 and symptoms of schizophrenia surfaced.

As his illness progressed untreated, delusions were taking over his life. He believed Tibetan Buddhists were reading his mind and that he had caused the 1980 eruption of Mount St. Helens in WashingtonState. He believed aliens would rescue him from Earth. Over a period of years he ended up in hospital, homeless, battling alcoholism, and eventually in jail for several nights after breaking windows at a rooming house.

A turning point in his 10-year struggle with the illness came with a court order that he received treatment for the next 3 years as part of his probation. He was eventually diagnosed with schizophrenia, began antipsychotic treatment in 1990, sobered up, and gradually let his delusions go.

With today's better medications and interventions, no one should ever have to go through what he went through, says Chovil.

"I think it is realistic to set a standard that no one will ever experience more than one psychosis in their life time, in the same manner that no one expects to ever have two heart attacks."

<sup>\*</sup>From Schizophrenia Digest magazine, Fall 2002 edition

# Facts about > The Evolution of the Mental Health System in Canada

### Where It All Began

During the early part of Canada's history, there were few ways of effectively treating serious mental illness. Residential centres (referred to as asylums or psychiatric hospital) were built to provide safe settings for the care of people with mental illness and to protect individuals from harm. In the early 1960s, the introduction of psychotropic drugs (antipsychotic medications) resulted in the de-institutionalization of many people with serious mental illness. While the discovery and use of these medications was not a cure for mental disorders, they were capable of reducing or controlling the positive symptoms of psychosis (e.g., delusions, hallucinations). The use of medication enabled many people to be discharged back into the community.

The use of antipsychotic medications, which enabled many people to leave the hospital, was not matched by the development of necessary community services to enable people to live lives of quality in the community. As discharges from psychiatric hospitals increased, so did the number of readmission. This is sometimes referred to as the "revolving door syndrome." The need to design a strong mental health system capable of providing a continuum of care, which follows a patient, wherever they may be, continues to be a focus of mental health service reform.

# **Mental Health Legislation**

Various legal acts (legislation) provide the legal framework for the care, treatment, and hospitalization of people suffering from mental illness who are incapable of making their own life decisions. These include Mental Health Acts, Guardianship and Substitute Decision-Maker Acts, the Canadian Charter of Rights and Freedoms, and the Criminal Code of Canada.

#### **Provincial Mental Health Acts**

Mental health acts are designed to protect the individual's right to autonomy and self-determination—which includes the right to refuse treatment—as well as the right of very ill persons to receive the treatment necessary to restore and maintain their functioning. The act also protects the safety of the community. Each province has its own mental health act, which is important to keep in mind when trying to get services for a person. Regulations set out in one mental health act may not apply to another province.

Provincial mental health acts deal with a variety of issues pertaining to services for the mentally ill. These usually include:

- Which hospitals are considered "psychiatric facilities"
- How and when a person may be brought to a psychiatric facility
- How a person may be admitted to a psychiatric facility voluntarily
- How a person may be admitted to a psychiatric facility involuntarily
- Treatment authorization and refusal (informed consent)
- Access to patient information
- The rights of patients to information and legal review
- Assisted community treatment (leave and community treatment orders)

The emphasis is to assess and treat psychiatric cases so that the individual can remain in a setting that is as non-restrictive as possible.

If you believe your relative needs to be assessed or may require admission to a psychiatric facility, there are generally three options available:

- 1. Accompany the family member to his/her physician or to a walk-in clinic. If the situation is urgent, you can go to the emergency room of a general hospital, preferably one where the person is known or where his/her psychiatrist attends.
- 2. Go before a judge or magistrate to apply for an order that the family member be medically examined. This usually requires an appearance in person before the judge. There is likely an application form that must be filled. This can be obtained from the health authority or provincial government in charge of health services. If you are unsure where to locate a judge, contact your local health authority or police detachment.
- 3. If the situation is urgent or poses a threat to anyone, the police have the authority to take a person for medical examination if they believe the circumstances warrant it. The exact criterion used by police varies from province to province.

#### **Guardianship and Substitute Decision-Makers Acts**

Matters such as powers of attorney and guardianship relate to long-term arrangements for substitute decision-making regarding finances, property, and personal care. Advance directives are written plans that enable people to specify their wishes regarding their treatment and care should they become too ill and require treatment. It is important to check with your provincial government regarding provincial guardianship and substitute decision-making regulations or consult with a lawyer regarding legal agreements.

#### **Canadian Charter Rights and Freedoms**

Rights "on arrest and detention" apply to people who have a mental disorder when they are involuntarily committed. These include the right:

- To be properly informed of the reasons [for detention]
- To retain and instruct counsel without delay and to be informed of that right
- To have the validity of the detention determined by way of *habeas corpus* (procedure used to bring a person before a court) and to be released if the detention is not lawful

In addition, mental health acts spell out other rights that patients/clients must be informed about. These include, for example, the right to apply to a tribunal (called a Review Board or Review Panel) for release from a hospital, the right to regular reviews, and the right to apply to the courts.

#### The Criminal Code of Canada

People with mental illness unfortunately may come into conflict with the law. The Criminal Code sets out regulations for persons with a mental illness who are being processed through the legal system.

#### These include:

• Police or crown prosecutors can use their discretionary authority to divert a person from the criminal justice system to the mental health system and not charge or proceed with charges.

- The court can remand a person for psychiatric assessment to determine if the person is fit to stand trial (able to understand court proceedings and instruct his/her lawyer).
- The court can order a person found unfit to stand trial to comply with treatment in order to restore his/her fitness.
- If the court finds the person "Not Criminally Responsible on Account of Mental Disorder" (NCRMD) they can order the person to be detained at a forensic psychiatric facility. [NOTE: Neither the court nor the review board at the facility can order a person to take treatment.] However, provincial Mental Health Acts usually provide a means for authorizing treatment for a person.
- The judge can build in conditions in probation orders that may facilitate access to treatment, although the court cannot force a person to take treatment

#### Canada Pension Plan/Quebec Pension Plan

The Canada Pension Plan pays a monthly benefit to qualified individuals who have contributed to the Plan and who are disabled according to Canada Pension Plan legislation. The province of Quebec has their own pension plan.

#### More information can be obtained at the following websites:

Canada Pension Plan: <a href="http://www.hrdc-drhc.gc.ca/isp/cpp/disabi">http://www.hrdc-drhc.gc.ca/isp/cpp/disabi</a> e.shtml

Quebec Pension Plan: <a href="http://www.rrq.gov.qc.ca/an/invalidite/06.htm">http://www.rrq.gov.qc.ca/an/invalidite/06.htm</a>

#### **Governance of Mental Health**

The 3 levels of government—federal, provincial, and local health authorities—are involved in the provision of mental health services.

Departments administering health and/or social services are known by different names in different provinces. They could be referred to as the Department of Health, the Ministry of Health Services, the Ministry of Health and Wellness, or the Department of Health and Social Services. Provincial governments regularly reorganize their administrative structure. Departments and ministries may undergo name changes or programs may be shifted between departments or ministries.

Most provinces have regionalized the delivery of health services through the creation of regional health authorities. Again, the authorities are referred to by different names in different provinces; for example, Regional Health Authorities, Local Health Authorities, or District Health Councils.

University departments of psychiatry or other organizations that receive part or all of their funding from any of the 3 levels of government may also provide some mental health services.

#### **Federal Government**

Aside from veterans and First Nations peoples, the federal government does not directly provide health services to Canadians.

Instead, the federal government is the ultimate authority regarding the structure of the Canadian health system. It is responsible for both providing provinces with the majority of their funding for health services, and assuring the 5 principles of the Canada He3alth Act are upheld by the provinces.

The federal government's tax structure is also important to mental health clients and/or their families. Mental health clients and/or their caregivers are entitled to tax credits may also be directed to Revenue Canada.

#### **Provincial and Territorial Governments**

The responsibility for the administration, development, and delivery of health services, including mental health services, falls to the province and, to a lesser degree, the territories.

The provincial government and its health department is the ultimate authority regarding the delivery of health services and is the source of most health and service information. The websites of provincial health departments are good places to access basic information as well as contact information for all health services, including those pertaining to mental health.

The authority for the administration of the region is shared with the federal government in the Territories. Consequently, accessing information regarding mental health services may necessitate contacting either or both levels of government.

#### **Local Health Authorities**

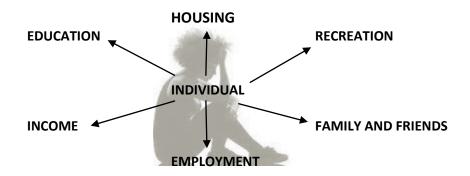
In recent years, most provincial health departments have decentralized the delivery of health services onto local health authorities. Typically, these authorities are responsible for the day-to-day operation of health services and insuring a continuum of services (for example, from community nursing programs to long-term care facilities). This decentralization was implemented to promote an improved responsiveness to the health needs of the community.

Information or concerns regarding specific services and/or programs should be directed to the local health authority. Typically, contact information can be found in the blue pages of your telephone directory or through the health authority's websites.

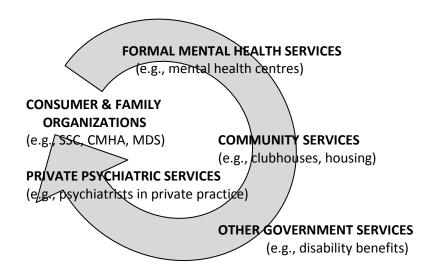
#### **Other Players**

In addition to these levels of government, there are a number of other players in the mental health system: psychiatric units and hospitals, nurses, law enforcement officials, and forensic psychiatric services, among others.

# [ THE BASIC NEEDS OF A PERSON WITH MENTAL ILLNESS ]



# [ SERVICE SYSTEM ]



# **Map Of The Mental Health System**

# Feeling confused? Disoriented?

.....You are not alone; the mental health system is a complicated animal. This map illustrates the main stops and services available in the mental health system.

ILL PERSON >>>	Emergency (HOSPITAL)		
	Family Doctor or Private psychiatrist		
	Mental Health Centre		
IN-PATIENT SERVICES >>>	Hospital Psychiatric Units		
	Provincial or Regional Mental Health		
Centres			
	And Psychiatric Hospitals		
OUT-PATIENT AND COMMUNITY SERVICES >>>	Crisis Services		
	<b>Community Outpatient Team</b>		
	Psychiatrist/Family Doctor		
REHABILITATION >>>	Vocational or Employment Preparation		
	Psychoeducation		
SUPPORT SERVICES >>>	Housing		
SS. I S. I. SERVICES FFF	Financial Assistance		

# Facts about > The Mental Health System

The best entry point into mental health or other related services is your physician. You physician can provide you with information regarding available services or to make referrals to specialists, community programs, or treatment facilities.

#### **In-Patient Services**

#### **Hospital In-Patient Units**

Diagnostic and treatment services are provided on an inpatient basis in designated psychiatric units within general hospitals. These services are for people with serious mental illness whose psychiatric symptoms require 24-hour monitoring. Individuals are admitted into hospital when they experience an acute phase of their mental illness and need stabilization.

Hospital stays generally last from a few days to one or two weeks, but sometimes a longer stay is required. The length of stay depends on how sick a person is and how well he/she responds to medication and therapy treatment. The earlier a person seeks help when problems first arise, the less likely he/she will need a lengthy hospital stay.

Discharge planning is an integral part of psychiatric care. Basically, it involves making decisions about what the person will need for support. This planning should begin almost immediately after someone has been admitted to hospital, and should include the patient and family.

A discharge plan involves planning for every major part of the patient's life as he/she moves back into the community. This may include vocational planning, finding employment, or re-integrating an individual into the life of her/his family. Traditionally, the most common features of discharge planning have been housing, financial support, psychiatric care in the community, medications, and establishing or re-establishing a social support network. Although the mental health team working with the patient is involved in discharge planning, the social worker may be the best person to speak with.

In some hospitals, *day treatment programs* may also be available. Day programs consist of educational, therapeutic, social, and recreational aspects, and may include both individual and group therapies. The goal is to help individuals increase their coping skills and improve overall functioning. The goal of inpatient care is to restore the individuals' capacity to live as independently as possible.

Psychiatric inpatient services generally include:

- Crisis intervention
- Supportive therapy
- Group therapy
- Assertiveness training
- Communication skills
- Stress management
- Medication reviews
- Psychological testing
- Other physical therapies, including ECT
- Support and education for family members
- Alternative therapies, such as music or art therapies

#### **Provincial or Regional Mental Health Centres and Psychiatric Hospitals**

These specialized centres and hospitals provide acute psychiatric services to individuals who are experiencing serious symptoms of a mental illness, as well as extended treatment and rehabilitation services to persons with severe and persistent mental illnesses. These services are for patients with psychiatric problems that are difficult to manage and are of medium to long-term duration (unstable conditions and the need for highly specialized intervention are key).

Services usually include:	Services	usually	/ inc	lude:
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$   \sqrt{} $	24-hour psychiatrist and nursing services
	Diagnostic and treatment services
$\checkmark$	Consultation for involuntary admissions
$\checkmark$	Acute care treatment via a psychiatric unit or psychiatric hospita
$\checkmark$	Intensive case management
$\checkmark$	Family support, including counseling

Psychiatric hospitals also sometimes serve as specialized forensic centres for long-term care and long-term forensic services, and for the observation and treatment of cases that present high security risks.

#### **Out-Patient and Community Services**

☑ Behaviour management programs

Out-patient services are community-based programs provide services to individuals with a serious mental illness who live within a hospital service area, including aftercare to individuals who have been inpatients.

Community mental health services are comprised of health, social, vocational, recreational, volunteer, occupational therapy, and educational services, as well as housing and income support. Included in these services are: mental health promotion; the prevention of mental health problems; the treatment of acute psychiatric disorders; and support and rehabilitation services for people with severe and persistent psychiatric disorders.

In most instances, community mental health centres can be directly contacted by anyone for support. Mental hea

alth '	therapists or caseworkers, psychologists, and counsellors in centres offer direct clinical programs for:
$\checkmark$	Adult community support services
V	Adult short-term assessment and treatment

☑ Geriatric services

Thes

se s	services include the following:
$\checkmark$	Intake, orientation, and assessment
$\checkmark$	Case management
$\checkmark$	Psychosocial rehabilitation to assist independent community living, including the development of
	personal skills, social supports, and prevocational/vocational programs
$\checkmark$	Supportive housing or assistance with locating appropriate housing
$\checkmark$	Crisis stabilization
$\checkmark$	24-hour emergency response via psychiatric unit day visits
$\checkmark$	Forensic community services

#### **Crisis Services**

Crisis teams or services may also exist in some communities. These are usually 24-hour, 7-days/week service available to people who are experiencing a mental health crisis. A 24-hour, 7-days/week crisis line service may also be available.

In rural areas, the hospital emergency rooms, ambulance, and police may be the only resources available to people outside of regular working hours.

Crisis intervention refers to active treatment and support offered as soon as possible after a person has been identified as being in acute distress.

Crisis	services	mav	incl	lud	e:
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- ☑ Telephone crisis services
- ☑ Mobile crisis units
- ☑ Crisis residential services
- ☑ Psychiatric emergency/medical services in hospitals

#### Crisis services generally provide:

- ☑ Assessment and planning
- ☑ Crisis support/counseling
- ☑ Medical intervention
- ☑ Crisis stabilization
- ☑ Review/follow-up/referral
- ✓ Information

#### Rehabilitation

Psychosocial rehabilitation refers to non-medical treatments or services that are provided to help a person recover from their mental illness. The term generally refers to a range of social, educational, occupational, behavioural, and cognitive interventions that can assist a person to reach their maximum potential. This can be distinguished from acute care where the focus is on symptom stabilization.

Psychosocial programs and day treatment programs provide opportunities for:

- ☑ Teaching skills related to community living and work activities
- ☑ Building networks of peer support
- ☑ Teaching self-help community activities
- ☑ Providing a place where individuals can learn how to relate to persons and communicate their needs and desires successfully

Most rehabilitation programs are designed to help people with mental illness in the areas of social activity education, employment, and education. Rehabilitation specialists include occupational therapists, recreational therapists, and case managers, and, in some settings, social workers, nurses, and peer support workers.

When a person experiences a chronic mental illness, the person has experienced a major medical injury. Depending on the severity of illness, length of time between onset and treatment of illness, and age of onset, a broad spectrum of losses may occur. Because each person is an individual, services need to be tailored to the needs of each client.

Psychosocial rehabilitation programs are designed with the goal of helping individuals to acquire or regain the practical skills needed to live and socialize in the community.

#### **Vocational or Employment Preparation Programs**

Through vocational rehabilitation, persons learn the skills needed to both find and maintain work in a variety of settings (e.g., volunteer work and supported employment).

#### **Supported Employment**

Supported employment operates on the belief that people, regardless of the severity of their illness, can do meaningful work in typically work settings—if they so choose and if they are provided with access to a range of needed supports.

Employment supports include a range of activities to help people prepare for the workforce and/or to support them in the workplace. They offer a range of services including:

- Vocational assessment
- Job preparation counseling
- Resume writing
- Training and job placements
- Educational and skills training opportunities
- On-the-job supports
- Job coaching
- Transitional employment programs (whereby agencies partner with the business community to employ people who have a mental illness)

#### **Support Education Programs**

Supported education programs have expanded in the last few years, partly in response to the increased number of people with mental illness who have recovered well enough to enter the educational system. Some colleges and universities also provide assistance, preparation, and advocacy to individuals with psychiatric disabilities who desire to pursue post-secondary education or training.

#### **Psychoeducational Programs**

Educational programs can assist people with mental illness to manage their symptoms, identify warning signs of relapse, and modify problematic behaviours. Topic areas may include goal setting, social or communication skills, medication management, illness awareness, education and coping, assertiveness training, understanding depression, and anxiety management. These programs may be available through hospitals or community mental health centres.

## **Peer/Consumer Support Services**

Through peer support services, consumers have opportunities for social interaction with their peers in non-clinical settings. Peer support occurs in the context of self-help groups, clubhouses, drop-in centres, and support networks.

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Peer supports are self-help initiatives that use non-service models to engage in:

- Mutual support
- Advocacy
- Cultural activities
- Knowledge development
- Skills training
- Public education
- Economic development

#### **Clubhouses**

In 1948, a group of people who had in a psychiatric out-patient program in New York City decided to form their own group and establish a meeting place. They wanted a place where they would belong unconditionally; where they would be members of a club, not patients in a hospital; where they would have mutual support; and where membership would be life-long. This was the first clubhouse to be established and was called *Fountain House* is still in operation.

Clubhouses are community-based rehabilitation programs and typically offer:

- Vocational opportunities
- Planning for housing
- Problem-solving groups
- Case management
- Recreational activities
- Academic preparation

Individuals can learn or regain skills necessary to live a productive and empowering life.

Clubhouse programs are typically designed to instill a sense of belonging in the community and to enhance individual supports. Members at clubhouses are involved in the planning, implementing, and evaluating of programs. Participation in different activities provides an opportunity for members to learn, maintain, or improve personal, social, and pre-vocational skills.

## **Other Support Services**

#### Housing

People with mental illness need safe, clean, appropriate, and sustainable housing that can provide a level of support consistent with their needs.

Ideally the housing arrangements should be based on:

- People's strengths and abilities for independent living
- Their ability to live safely
- Their ability to make decisions in their own best interest
- Their requirement for supervision

In most provinces there are a number of housing options for people with mental illness.

They typically include:

- Groups homes
- Boarding homes
- Shared accommodations
- Independent apartments
- Supported housing

The level of functionality of the ill person is a key determinant when examining housing options. It is, therefore, important to understand the level of support or supervision that each option offers.

**Group homes** vary considerably in the degree of support they offer. Supervision may range from 24 hours a day to one person dropping in periodically. There may or may not be some in-house counseling or life skills training. Rules and policy differ from one to another.

**Boarding houses** and **shared accommodation** typically offer little supervision, and housing in the form of an apartment requires an ability on the part of your relative to function well in an independent situation. Initially, a considerable degree of family support would be advisable. There are usually waiting lists for supportive housing such as group homes.

**Supported housing approach** is a model based on the use of general housing (e.g., apartments) dispersed in the community with the provision of flexible individualized supports

**Staffed community residential housing** is also needed for people with special needs including those with substance use problems.

Unfortunately, most communities have not been able to provide a continuum of residential options. Since deinstitutionalization, there has been an increasing awareness of the need for safe, affordable housing. While many people with mental illness live with their families, for others this is not possible or practical. The growing number of homeless people with mental illness speaks to the need for federal and provincial programs to assist people with mental illness.

#### Income

Disability benefits fall outside of mental health programs but nonetheless are an important component of the recovery process. Your relative may qualify for Canada Pension Plan disability benefits or provincial disability benefits.

Generally speaking, a contributor (someone who has contributed to Canada Pension Plan) is considered disabled under Canada Pension Plan if they have a physical or mental disability that is both **severe and prolonged**. "Severe" means that the person's condition prevents him/her from working substantially in any gainful occupation or job. "Prolonged" means that the condition is long term or may result in death. The person must also have normally contributed to the Canada Pension Plan for at least 4 of the past 6 years. Benefits begin after 4 months of total permanent disability and continue while the person remains totally disabled to a maximum age of 65.

Therefore, if your relative's mental illness will seriously affect his/her ability to earn an income, and will do so for more than a temporary period, you should encourage him/her to consider applying. Ple4ase remember, you should seek further information about CPP than is provided here in this program.

Definitions of disability vary significantly between provincial disability assistance programs across Canada. Contact your provincial government for details about benefits available in your province for people with mental illness who are unable to work.

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Definitions of disability vary significantly between provincial disability assistance programs across Canada. Contact your provincial government for details about benefits available in your province for people with mental illness who are unable to work. Case workers or managers can assist individuals in applying for disability benefits. In some communities, advocates may be available to help with filing claims or appeals.

#### **Disability Tax Credit**

I you are a person with a disability or you support someone with a disability; you may be able to claim the deductions and tax credits on your tax return. For more information, please contact the Canada Revenue Agency or go to their website at: <a href="http://www.cra-arc.gc.ca/tax/individuals/segments/disabilities/menu-e.html">http://www.cra-arc.gc.ca/tax/individuals/segments/disabilities/menu-e.html</a>

## **Tools** > The Ulysses Agreement

A Ulysses Agreement is an informal *care, treatment, and personal management agreement* plan made by the individual with a mental illness with other family members, friends, and/or mental health professionals who are involved as members of a support team.

While the agreement is not a legally binding document, it represents a positive way for the individual to take an active part in his/her treatment, and offers an opportunity for the individual to plan for and build a strong support base in the event of a relapse. The agreement will also help and individual to feel he/she is **not** alone in coping with his/her illness.

## The Story of David B.:

David B. was diagnosed with bipolar disorder at the age of 28. Before his diagnosis, David had completed his Bachelor's degree in Political Science and was working as a bartender to save up money to travel with two of his best friends from school. Occasionally, David would stay late after the bar closed and have a drink with his coworkers before they all went home. One night, David was very intoxicated and got in trouble with the police.

David has been taking a mood stabilizer and seeing a psychiatrist as well as a probation officer. His symptoms of mania include: decreased sleeping with increased activity, excessive energy, grandiosity, inflated self-esteem, increased interest in activities, overspending, incurred heavy debts, extreme irritability, and denying that he has bipolar disorder and refusing treatment. Recently David has started to become very depressed and has feelings of uselessness, hopelessness, and excessive guilt. His parents, sister, and brother-in-law are very worried. David is willing to try creating a Ulysses agreement.

#### Points to consider when creating a Ulysses Agreement

- Who is part of the support team?
- What are the symptoms/indicators of being unstable (in need of medical intervention)?
- What is the plan of action?
- What other personal business needs to be taken care of?

Remember, you cannot create a Ulysses Agreement without the ill individual, nor should you try to push an individual to create one when he/she is not well.

The following is an example of a Ulysses Agreement\*:

#### **CARE, TREATMENT, & PERSONAL MANAGEMENT AGREEMENT**

Date: June 20, 2003

#### THIS IS AN INFORMAL AGREEMENT

Between <u>David (Dave) Edward Beamish</u> , of <u>555 Main Street</u> , in the City of <u>Moncton</u> ,				
Municipality of	, in the Province of <u>New Brunswick</u> , and the following persons			
Judith Langley, my menta	health nurse, 555-8626			
Nancy Osprey 555-5287, I	r. Steve Hall, 555-1843			
Sam Tom my probation of	icer, (see CARE), 555-8834			

These people are trusted friends and family who have had experience with me and my illness. They have agreed to be members of my support team and to follow the guidelines set out below.

#### **PURPOSE:**

The purpose of this Ulysses Agreement is to provide a clear set of guidelines for actions to be taken by members of my support team in the event that I exhibit indications that I am becoming unstable and unable to care for myself. These symptoms are outlined below.

#### **MY SYMPTOMS ARE:**

The following are my symptoms of mania:

- 1. Decreased sleeping with increased activity
- 2. Excessive energy
- 3. Grandiosity, inflated self-esteem, thinking I am better or more powerful than others
- 4. Increased interest in activities, overspending, incurring heavy debts
- 5. Extreme irritability, very demanding and angry when others do not jump to my commands
- 6. Unpredictable emotional changes
- 7. Talking more and faster than usual, shouting people down
- 8. Thinking processes speeded up, jumping from one topic to another, racing thoughts, flight of ideas
- 9. Denying that I have manic depression, refusing treatment, denying that I need lithium

<sup>\*</sup>The information concerning this Ulysses Agreement was created for the purpose of illustrating how to complete the form.

Any four of the symptoms require action, as outlined below, to be taken.

#### PLAN OF ACTION FOR MANIA AND DIRECTIONS FOR POLICE INVOLVEMENT:

For symptoms of mania, the following action should be taken by members of my support team:

- As many members of the team as possible shall consult each other and contact Nancy, as she has
  experience with my mania. If Nancy is not available, Steve should be contacted.
- Nancy will alert Dr. Tang re what action is going to be taken as set out in this Ulysses Agreement.
- Nancy will contact the director of the mental health centre.
- The director of the mental health centre will contact the police and request that they pick me up for 72-hour observation in hospital, preferably the Royal Columbian Hospital.
- If possible, any one of my support team or a worker from the mental health centre should go with the police to pick me up as I have experienced difficulty with the police in the past.

#### MY SYMPTOMS OF DEPRESSION:

The following are my symptoms of depression:

- 1. Feeling of uselessness, hopelessness, excessive guilt
- 2. Slowed thinking, forgetfulness, difficulty in concentrating and in making decisions
- 3. Not responding to the phone or to messages
- 4. Too tired and weak to do anything
- 5. Increase in appetite and weight
- 6. Decreased sex drive
- 7. Suicidal thoughts

Several of the symptoms require action, as outlined below, to be taken.

#### PLAN OF ACTION FOR DEPRESSION:

For symptoms of depression the following action should be taken by members of my support team:

- As many members of the team as possible will consult each other and contact Nancy.
- If Nancy is not available, Steve should be contacted.
- Nancy will alert Dr. Tang that action should be taken as set out in this Ulysses Agreement.
- Dr. Tang will instruct a mental health nurse to go to my apartment at 555 Main Street to assess the situation. If there is a need for treatment, I trust my psychiatrist to decide whether to treat me at home or in hospital. I usually do not need to be hospitalized when I am depressed.
- I do not need the police involved if I am depressed.

Tools > The Ulysses Agreement					
EMPLOYER:					
(outline steps to be taken with regard to employer)					

#### TREATMENT WHILE IN HOSPITAL:

I hereby authorize Dr. Tang to provide the treatment that he believes to be in my best interests, even though I may at that time withhold my consent to such treatment or state that I do not want to be treated.

I will see my psychiatrist two times per week during any medication changes and have my lithium level checked weekly. Once the medication is stabilized, I will see my psychiatrist one time per week and get my lithium level checked once a month.

The results of the blood test should be given to Dr. Tang, my probation officer, Sam Tom and I. The purpose of Sam Tom receiving the results of the lithium level is to ensure that the lithium levels are maintained, not to monitor the results of the lithium levels.

#### **MEDICATION:**

I am allergic to chlorpromazine, sow while in hospital I SHOULD NOT BE GIVEN CHLORPROMAZINE under any circumstances. My normal course of treatment for mania is to take Haldol and to be re-established on lithium. I am sensitive to Haldol.

Otherwise, I hereby authorize Dr. Tang to provide the treatment that he believes to be in my best interests even though I may at that time withhold my consent to such treatment or state that I do not want to be treated.

**ADDITIONAL INSTRUCTIONS:** (e.g., care of children while person is in hospital or any other personal business that needs to be taken care of.)

## FAMILY, HOME, AND DISSEMINATION OF INFORMATION:

My mother and Patrick, 555-432	•	should be inform	ned if I become hospita	ilized or leave town:	Audrey and Frank
DATED this	20	day of	June	20 <u>03</u>	_
SIGNED, SEALI	ED AND DE	LIVERED			
Signature of all	members of	my support tean	n		
Dr. <u>Ta</u>	ang		_		
Ju	dith Langley		_ (member of suppo	rt team)	
Na	ancy Osprey		_ (member of suppo	rt team)	
Dr. St	eve Hall		_ (member of suppo	rt team)	
Sa	m Tom		(member of suppo	ort team)	

CARE, TREATMENT, & PERSO	
Date:	<u> </u>
THIS IS AN INFORMAL AGREEMEN	т
Between	, (nar
of	(address) in the City of,
Municipality of	, in the Province of, and
The following persons:	
Dr	(phone number)
These people are trusted friends and t	amily who have had experience with me and my illness. They have agr
These people are trusted friends and for to be members of my support team and the purpose:  The purpose of this Ulysses Agreemer	amily who have had experience with me and my illness. They have agr nd to follow the guidelines set out below. It is to provide a clear set of guidelines for actions to be taken by mem
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#### **PLAN OF ACTION:**

	nily should consult one anoth be taken:	er. If they agree that I am showing signs of deterioration, the following steps
1.	Family will alert Dr Agreement.	regarding what action is to be taken as set out in this Ulysses
2.		believes that I should be hospitalized, the above named will then contact they pick me up for observation/assessment in hospital.
3.		
4.		
5.		
-		
(Outlin	e steps to be taken with regar	rd to employer)
	MENT WHILE IN HOSPITAL y authorize Dr.	: to provide the treatment that he believes to be in my
	terests, even though I may at	that time withhold my consent to such treatment or state that I do not want
MEDIC	CATION:	

<b>ADDITIONALY INSTRUCTIONS:</b> (e.g., care of children while person is in hospital or any other personal business that needs to be taken care of)				
FAMILY, HOME AND DISSEMINATIO OF I	NFORMATION:			
My or leave town. They can be contacted at				
DATED this day	of	20		
SIGNED, SELAED AND DELIVERED				
Signature of all members of my support team	1			
Dr	_			
	(member of support team)			
	(member of support team)			
	(member of support team)			
	(member of support team)			

## Who's Who

Like mental health services, there are a variety of people who work in the field of mental health. The job titles of mental health professionals also vary from province to province. Below are some of the types of professionals you may encounter. Wherever possible, we have included other titles that may refer to a similar type of position. It is important to learn in more detail the types of professionals who offer services in your province.

#### **GENERAL PRACTITIONER (GP)**

Most mental health problems are dealt with by GPs. They are often the first point of contact for people seeking help. GPs can talk through (less serious) mental health issues, prescribe medication, or make a referral to a psychiatrist or other mental health service.

#### **PSYCHIATRIST**

Psychiatrists are medically qualified doctors who have taken further training and specialize in mental disorders. Psychiatrists work in private practice or can be attached to a hospital or mental health centre. Psychiatrists can diagnose mental disorders, prescribe treatment (including medications), and provide psychotherapy.

#### **PSYCHIATRIC NURSE**

Psychiatric nursing is a specialized area of nursing. Psychiatric nurses typically focus on prevention, treatment, and rehabilitation for people with mental illness. They work in hospitals or mental health centres, and may offer individual, family, or group therapy. Psychiatric nurses also work in administrative roles and in public education.

#### **PSYCHOLOGIST**

Clinical psychologists have a PhD in clinical psychology and are licensed to practice in the province. They provide services such as psychological assessments and psychotherapy (e.g., behavioural approaches to treatment).

#### **SOCIAL WORKER**

Social workers are involved in mental health services in a variety of ways. They often offer help on practical matters, such as housing or social assistance benefits. Some may offer counseling. Social workers sometimes work in hospitals with individuals and their families to support them through crises or help with discharge back into the community.

#### PRIMARY THERAPIST OR CASE WORKER

This is often the person in charge of the client's case and is responsible for coordinating the rehabilitation process with the rest of the mental health team.

#### **OCCUPATIONAL THERAPIST**

This is a rehabilitation specialist who can provide functional assessments and interventions in the area of personal life, leisure, education, and work.

#### CASE MANAGERS AND OUTREACH WORKERS

These individuals assist chronically or severely mentally ill individuals who may be homeless to obtain the services they need in order to live in the community. Services they can assist with include medical care, social services, and assistance with housing, income, vocational rehabilitation, and mental health. Because mental health services are not coordinated, case managers can help to monitor a person's needs and ensure that the appropriate services are put in place, or help the person access the agencies that provide the services.

## **QUESTIONS TO ASK HEALTH CARE PROFESSIONALS**

The best protection for you and your relative in dealing with these baffling disorders is to arm yourself with knowledge. Asking questions is a good approach to participating in your family member's treatment. It is also helpful for you to have this information in order to be able to help the individual with mental illness.\*

#### **ABOUT THE SERVICE**

You have a right to know the professional expertise of the professionals involved in the treatment and care of your loved one. When considering seeing any health care professional such as a social worker, psychologist, family therapist, and/or mental health worker, make sure you feel comfortable with them.

Here are some questions to ask during or prior to your first appointment:

- How long have you been working in the field of mental health?
- What training and experience do you have?
- What is your basic approach to treatment?
- How much will your service cost and do you offer sliding scale fees?

#### **ABOUT THE ILLNESS**

- What is your diagnosis?
- What are some signs and symptoms I should be aware of?
- Do you have any literature available in your office about the illness? Do you know where I might find some more information?

#### **ABOUT THE TREATMENT PLAN**

Questions for any healthcare professional:

- What will happen? Will my family member get better or worse?
- How long will my relative need to receive treatment for this illness?
- What do you recommend as a treatment plan?
- How often do you need to see my family member?
- How can you help my family members and significant others cope with this illness?
- What if my relative refuses to attend appointments or refuses treatment—how can I help him/her with this?
- Are there any self-help groups available to aid my family member or myself?
- What goals should I help my family member attain?
- Who else should be involved in this plan? Are there other programs or professionals he/she should be referred to?

<sup>\*</sup>With excerpts from Learning about Schizophrenia: Rays of Hope, Schizophrenia Society of Canada

Questions specific to a psychiatrist/doctor and pharmacist:

- How often does my family member need to take his/her medication? Should he/she take the medication with or without food?
- What happens if he/she misses a dose?
- Is it okay for my family member to drink, smoke, or drive while taking his/her medication?
- What side effects might my family member experience form the medication?
- Are there certain foods or over-the-counter drugs my family member should avoid while taking the medication?
- Are there other drugs that may help if this medication is not successful?

#### **ABOUT GETTING HELP**

- If my family member's symptoms return, what should I do? Should I take him/her to the hospital?
- In case of an emergency, whom should I contact? What is their number?
- What could cause a relapse? Could a relapse occur even if my family member is taking his/her medication and following his/her treatment plan?
- Is there anything else you think I should know about, and can I contact you with my questions or concerns in the future?

#### **ABOUT LIFESTYLE CHANGES**

- Are there any lifestyle changes that can help my relative better manage his/her illness?
- What resources are available that could help him/her with:
  - Eating better
  - Exercising regularly
  - Social support
  - Managing stress

#### **ABOUT OUTLOOK**

What are my family member's chances of successfully managing this illness?

#### TALKING WITH YOUR HEALTH CARE PROFESSIONAL

As a patient, you have many rights to ensure your safety, health, and well-being. Knowing and understanding patient rights can make your visits to a psychiatrist or other health care professional more informative and beneficial for both you and your doctor. You can have a more effective consultation with your psychiatrist if you are well informed. It's important that you and your family are part of the decision-making process with the psychiatrist.

After all, it's your treatment. And the processes and effects will be easier to understand if you are as informed as possible.

#### As a patient, you have the right to:

- 1) Complete information on your diagnosis and against which criteria, as specified in the Diagnostic and Statistical Manual of Mental Disorder\*, the diagnosis has been made
- 2) Have your diagnosis explained in language that you clearly understand
- 3) Have an interpreter
- 4) Decide whether a friend or family member shall be with you when discussing diagnosis, treatment, medication, etc.
- 5) Decide whether a friend or family member shall be present with you when undertaking individual treatment.
- 6) Know if your psychiatrist considers an initial diagnosis to be provisional (i.e., not yet confirmed). If so, you have the right to have the implications of a provisional diagnosis explained
- 7) Discuss the diagnosis with your psychiatrist and to raise any concerns you may have; for example, if you believe the diagnosis may be incorrect
- 8) Know the reason why your treating psychiatrist may make a referral and whether the referral is for a second opinion or because of his/her limited clinical experience
- 9) Information about the foreseeable risks and benefits of proposed treatments and alternative treatments, and the opportunity to choose the treatment with which you would like to proceed
- 10) Give informed consent to medication and/or treatment. Informed consent is consent obtained freely after understandable information is given to you, in language you fully understand

#### TALKING WITH YOUR HEALTH CARE PROFESSIONAL

- 11) Comprehensive information about any proposed medication, what problem the medication is treating, and why a particular medication is chosen as opposed to an alternative. Comprehensive information should also include an explanation about the side effects of medication and discussion about alternative methods of treatment.
- 12) Know the nature of correspondence between your psychiatrist and the referring general practitioner
- 13) Be fully informed about the principal treatment method or technique your psychiatrist intends to use to treat you (i.e., psychotherapy, cognitive therapy, pharmacology, exposure and response prevention, etc.). You have the right to know why your psychiatrist has concluded that the chosen treatment method or technique is the most appropriate for you and to have this information communicated to your referring general practitioner
- 14) Raise your own issues and discuss your questions, concerns, or comments, in addition to what the psychiatrist wishes to discuss
- 15) Seek a second opinion
- 16) Obtain additional information about your condition through your psychiatrist, including appropriate written information such as brochures and contact details of support groups
- 17) Voluntarily stop treatment or medication at any time, provided your treatment is not mandated through a court order. If you consider stopping treatment, your psychiatrist can explain the implications and/or side effects of stopping treatment without medical supervision. Please note, the laws around involuntary treatment are different in each province. Consult the Mental health Act in your province for more information
- 18) Request access to your health records under Canada's Privacy Act. 1980-81 82-83, c. 111, ISch. II"1". Please note, disclosure of any personal information requested under subsection 12(1) that relates to the physical or mental health of the individual who requested it, may be refused where the examination of the information by the individual would be contrary to his or her best interests.

#### **REMEMBER:**

You and your family are an essential part of your treatment team. The more informed you are, the better your treatment outcome will be.

## CASE MANAGERS LESSEN THE LOAD FOR CONSUMERS, FAMILIES<sup>1</sup>

When Gayle Leverton speaks about Dalvinder Obhi, her voice has a hint of reverence that underlies just how large an impact Obhi has had on the lives of Leverton and her son.

Leverton's teenaged son began to experience a battery of symptoms, including hallucinations, in September of 2000. Doctors, puzzled by his symptoms, at first thought he might be suffering from attention deficit disorder or some other illness. The frightening hallucinations worsened: by December, he had a psychotic breakdown and he was rushed to a hospital emergency ward in his home city of Winnipeg, Manitoba.

The young man was diagnosed with schizophrenia and prescribed antipsychotic medication. Upon his release, Leverton found herself struggling alone to cope as his main caregiver. Unlike other illnesses, she says, people with schizophrenia and their loved ones are often left to fend for themselves upon release from hospital.

"You're on your own," she says. "Nobody knows what to do."

"(People) feel so isolated and feel like they're the only people in the world going through this."

Like many people diagnosed with the illness, her son was at first having a difficult time accepting that he had a serious mental illness. Leverton had to constantly monitor him to make sure that he took his medication—even resorting to rummaging through his dresser drawers looking for unused medication.

"I was always skulking around counting his pills," Leverton says. "I felt so guilty."

This past spring, the solitary burden of helping her son cope with his illness was lightened: a friend referred her to Obhi, an intensive case manager with the Winnipeg Regional Health Authority. Finding a case manager has changed the mother-son relationship for the better, says Leverton.

"I don't have to be the bad guy now," she says. "it gets me off the hook.

I get to be the mom again."

Case management programs have been set up in a number of Canadian provinces and U.S. states in reaction to the de-institutionalization process that sent hundreds of thousands of people, once housed in psychiatric institutions, into the community. Whereas in institutions consumers had many services at their fingertips—food, housing, medication, therapy—many find it difficult to access fragmented services in their community and end up becoming isolated.

Obhi ensures Leverton's son, now 21, takes his medication and coordinates doctor appointments. More than that, she acts as a sounding board for Leverton's son to express any problems he may be reluctant to talk to his mother about.

"She'll address things with him that I can't," Leverton says.

This summer, Obhi used her connections to help Leverton's son find a full-time security job—something that has had a tremendous impact on his self-esteem.

"He thinks he's great now; I think he's great now," says Leverton. "He's not stuck in the basement anymore—he's out and he's meeting people and he's doing things."

Dr. Ralph Aquila, director of residential community services at St. Luke's-Roosevelt Hospital Center in New York City, says clinicians and case managers can play a huge role in recovery through services such as finding suitable housing and opening doors with employers.

"Our experience is that no matter how ill one is deemed, when asked what they would like out of life, our patients generally answer: 'A nice place to live, some friends, and a job,'" he says.

The Canadian Psychiatric Association says the keys to integrating people with schizophrenia, who often find it difficult to deal with multiple services, are continuous and comprehensive services. Case managers, the association asserts, have been proven to improve clients' quality of life and reduce re-hospitalization rates.

Case managers, the association asserts, have been proven to improve clients' quality of life and reduce-re-hospitalization rates.

Leslie Vieni, a registered nurse and case manager with the Centre for Addiction and mental Health's (CAMH) First Episode Program in Toronto, says case managers have to wear numerous hats in their jobs. As part of their assessment to determine if they qualify for CAMH services, clients are referred to a case manager such as Vieni. Together, case manager and client sit down and draw up a mutually agreed upon plan on how to achieve the client's goals—often involving finishing their education or finding a job. The CAMH model also includes families as part of the treatment plan.

"You're forging an alliance," says Vieni. "There's a real partnership with patients and their families."

Vieni, working with a multidisciplinary team including occupational therapists and social workers, helps clients to come to terms with their diagnosis and discuss the pros and cons of treatment. She will also help clients with their housing needs, will act as a liaison with high schools or universities by working with guidance counsellors, and help them navigate through the bureaucratic red tape involved in government disability programs. When necessary, Vieni will also act as a mediator between her client and his or her psychiatrist.

Although the meetings are primarily office based, Vieni spends much of her time on the road whether it's home visits to clients who have moved, going with them to housing appointments, or accompanying them to a job site where they hope to find work.

In the CAMH program, it's usually expected that clients will see their case managers on a regular basis for a year to two years. Typically, the schedule of meetings with clients is most intensive early on in the treatment plan.

As clients' condition improves and they gain independence, case managers may refer them to other agencies or services. Eventually, they may only need to see their case manager every six months or so.

Heather Hobbs is a case coordinator with the Psychosis Disorder Team at the Hamilton Health Sciences McMaster Campus, in Hamilton, Ontario. Unlike case management models that may take services to clients in their 'own turf,' the Hamilton program operates out of an outpatient clinic setting and deals one-on-one with consumers. The program operates a separate program for family members.

Like Vieni, Hobbs and her clients draw up a treatment agreement at the outset, designed to help clients reach their goals. Eventually, clients are referred to a voluntary alumni program in which they keep in touch with Hobbs and her coworkers over a period of 10 to 14 years. It's rewarding to see former clients who have moved on to complete their education, find jobs, and develop relationships, Hobbs says.

"Over time you can see people recover and mature," she says. "They move on to try new things and new experiences. It's very encouraging."

Unfortunately, many people with schizophrenia are unable to find case managers or must wait for long periods to be referred to one. The Canadian Mental Health Association's Peel Region branch says the waiting list for case management services in the region—which includes Mississauga and Brampton, two cities with populations of several hundred thousand people apiece—is more than a year long. In more isolated communities, it's even more difficult finding a case manager, if not impossible.

Terry-Lee Marttinen lives in Sault Ste. Marie, a small city in northern Ontario. Five years ago, her daughter Tara began to hear voices and became uncommunicative when she was 16 years old. Marttinen called local mental health agencies but was stymied in her search for help. Through a stroke of luck, she thought to call the Prevention and Early Intervention Program for psychoses (PEPP) program at the London Health Sciences Centre in London, Ontario and the program agreed to see Tara—even though she lived outside of the program's catchment area. Because of her distance from the PEPP program, Tara did not qualify for a case manager.



Terry-Lee Marttinen acted as her daughter Tara's case manager.

Marttinen, a single mom, scoured the internet for information on the illness. With bulldog-like tenacity, her research uncovered the important things necessary in Tara's recovery, such as stress management techniques, ensuring ample rest, and paying particular attention to proper nutrition.

"It was a complete lifestyle change," says Marttinen. "A lot of it was just intuition."

Marttinen held parties at home to ensure Tara didn't lose contact with friends, and had to explain to her high school principal why her daughter needed Fridays off, because of physical exhaustion. Twice a year, mom and daughter made the long trek to London to see a psychiatrist.

The hard work paid off. Tara maintained an A average throughout high school and she never needed to be hospitalized. She is now in her second year of part-time studies at the University of Western Ontario in London and has her own modest apartment. Six months ago, Tara started a support group for other young adults who have had early intervention treatment.

Tara, now 21, realized acting as a case manager took a toll on her mother. "It shouldn't have been all on my mom's shoulders," she says. And she wonders how other young people who develop schizophrenia and who don't have a parent capable of doing all the research that her mother did fare without a case manager.

"Some parents don't have the ability to do what my mother did," she says.

Marttinen, meanwhile, hasn't let distance interfere in the close relationship she has with her daughter.

"I (still) talk to

Tara every day," she says. "I'm there for her."

#### **CASE MANAGEMENT VERSUS ACT**

Case management is often confused with a similar service, known as assertive community treatment (ACT) or assertive outreach. Many health care professionals often routinely intermix the two terms. Although the two types of services have similar goals—fewer relapses, shorter hospital stays, higher client satisfaction and lessening the burden of care among family members—there are some differences.

Unlike case management, which usually involves one person acting as advocate for a particular client, ACTs employ a multi-disciplinary team approach in which each team member—typically consisting of backgrounds such as nursing, psychiatry, occupational therapy and social work—share caseloads. Each member of the team works with clients, visiting them in turn.

In ACT, all contacts with clients usually take place on clients' own turf, whether it is in their home or somewhere they feel comfortable in, such as a coffee shop.

The ACT model typically is designed so workers carry low caseloads, often with no more than 10 clients per team member. Most ACT models also make services available 24 hours a day, seven days a week.

ACT services can vary widely, from helping to take care of bills, to finding suitable housing, to arranging for care of pets and helping with crises. ACTs are often reserved for clients who may be unwilling to come to a centre for services. Other characteristics of potential ACT clients can include:

- Frequent re-admissions to hospital
- A history of violence (to themselves or others)
- Known to misuse substances
- A history of poor medication compliance
- Can become isolated and withdrawn because of an inability to take care of themselves.

# What are?> The Essential Elements Of A Mental health System<sup>1</sup>

## The Essential Elements of a Mental Health System

- **Client and family centered:** System involves the person and the family in treatment/care planning and management.
- Goal-oriented: Treatment and supports help consumers manage their symptoms and build on their strengths
- Accessible and flexible: Responsible service listens to and understands the problems and acts promptly and appropriately
- **Comprehensive:** System takes into account all aspects of the person's physical, psychological, social, financial, and spiritual needs; makes use of a variety of professionals, resources, and support personnel to provide a range of series in all settings, including the community, facilities, and acute care
- Specialized: Services take into account the specific needs of the individual
- Accountable: System assures the quality of the service delivered and monitors this in partnership with the client and family

#### Key Elements and Approaches in a Mental Health System

These key elements and approaches are part of "best practices" and should be made available regardless of community size or location.

**Education:** Knowledge is the cornerstone of the mental health system. Persons with mental illness, their families, and other informal caregivers need a basic understanding about what is happening when a person is experiencing a mental disorder. Mental health professionals need specialized expertise in the complexities of mental illness care.

**Family support and involvement:** Because the majority of care for people with serious mental illness is provided by family care-givers, it is vital that support be provided to maintain the physical and mental health needs of the family. Family members have a wealth of knowledge, and their involvement or care plan can make a huge difference in how well a person copes with his/her mental disorder.

**Psychosocial rehabilitation and recovery:** Helping people who have a mental illness find enjoyment and meaning in their lives is essential to recover. Providing these supports that help them retain as much control over their lives as possible is just as important as medical interventions. The aim of psychosocial rehabilitation is to promote optimal performance in cognition, interpersonal skills, self-care, leisure, and accessing of community resources.

**Housing:** Housing is recognized generally as a critical determinant of health. As important as the physical structure is the social environment. An optimal environment creates a milieu in which individuals do more than just exist; they experience quality of life, finding pleasure in their retained strengths and assistance with tasks they can no longer perform independently.

**Integration and continuity of services:** Case management and integration of information systems are the basis of client-centered care. Many different options for integrating services and providing continuity are possible.

**Evaluation of services:** Evaluation of services and delivery is important for developing ongoing efforts to improve the quality of the mental health system. Clients and families should have the opportunity to both participate in and comment on findings.

**Volunteers, mentors, and peer counsellors:** Considerable support is provided by the many individual and organizational volunteers who assist in the "informal system of care" for people with mental illness. These individuals who volunteer their energy and time also need to have adequate knowledge about the problems and needs of the people they are helping.

**Advocacy and protection:** Vulnerable individuals must be protected and assisted in accessing services that they need and to which they are entitled. Legislation that enables and supports advocacy and protection is one important component of the mental health system. In addition, various community agencies and organizations provide advocacy and monitor services to ensure that the legislation and the available services are used properly.

**Health promotion and prevention:** Promotion of wellness and prevention of illness or injury must be given high priority to ensure that individuals do not suffer needlessly.

Adapted from <u>Best Practices for the Mental Health Care of Older Adults</u>
Penny MacCourt, Betsy Lockhart, Martha Donnelly, Health Canada, October 2002
<a href="http://www.hc-sc.gc.ca/seniors-aines/seniors/pubcat\_e.htm#cargiving">http://www.hc-sc.gc.ca/seniors-aines/seniors/pubcat\_e.htm#cargiving</a>

## Facts about> Living Arrangements<sup>i</sup>

There are a number of options for the ill person's living arrangements. They include living: at home with parents, in a group home, in a boarding house, in an apartment, in a room, or in shared accommodations. The level of functionality of the ill person will be a key determinant when examining housing options. It is, therefore, important to understand the level of support or supervision that each option offers. Group homes may vary considerably in the degree of support they offer. Supervision may range from 24 hours a day, to one person dropping in periodically. There may or may not be in-house counseling of life skills training. Rules and policy may vary considerably. It is obviously necessary to know precisely what is offered before you and your relative can make a decision whether a particular group home is appropriate. Boarding houses and shared accommodation may offer little supervision, and housing in the form of an apartment requires an ability to function well in an independent situation. Initially, a considerable degree of family support is advisable.

Because there are usually waiting lists for supportive housing such as group homes, you should place your relative's name on a list as soon as possible, once a mutually satisfactory decision has been reached. A decision about housing can often be emotional. Contributing families suggest the following guidelines to help you with your decision.

#### In general, at-home arrangements seem to work best under the following circumstances:

- The ill person functions at a fairly high level, has friendships, and is involved in activities outside the house
- If there are young children, their lives are not negatively affected
- Interaction among family members is relaxed, and
- The ill person intends to take advantage of available support services

#### In general, at-home arrangements are NOT appropriate in the following circumstances:

- The main support person is single, ill, or elderly
- The person with schizophrenia is so seriously ill that there is little or no chance to lead a normal family life
- Children become frightened and resentful, and feel like they are living in a hospital
- Marital relationships deteriorate
- Most family concerns revolve around the person with schizophrenia
- No support services are used, or services are not available, and
- The individual is habitually aggressive, and the threat of violence disturbs the household

If the ill individual prefers to live at home, the family as a group should have interviews with the therapist to clarify treatment issues. You should keep a record of how the situation works and how all family members are affected. This will help you to evaluate how well things are, or are not, working. The record may also be useful, if needed, to demonstrate to the ill person that a different housing environment is required.

Families often feel very guilty if they must make the decision not to have the ill person live at home; this appears to be especially true for women. If your experience is similar, consider the following comments of a mother who had to make this decision: "A break should be made at some point, and often it is easier for the ill person to adjust to the transition to a group home, boarding home, or whatever, while you are still available to give support and encouragement, as well as your assistance to participate in activities offered in the community.

Otherwise, they will eventually have to make this adjustment without your help."

Consult with a social worker, community resource person, or other appropriate experts regarding the move toward independent living.

#### INDEPENDENT LIVING

If ill individuals achieve a good level of functional recovery, one of their goals might be to eventually have an independent living arrangement (once they have attained an appropriate age). You should gradually begin to plant this concept in an ill person's mind. Subtle hints can be dropped such as: "If you decide to live on your own..."; "When you decide to live on your own..."; "When you start to live on your own, you'll need to know how to do your own laundry."; "When you live on your own, you'll be glad you learned how to use the Laundromat." Time should be allotted between progressive statements to allow for digestion and acceptance of the idea. Leaving the family home is difficult, but a necessary part of life for all of us.

Families suggest that at some point you and the ill individual make a commitment about when the move will occur. Work together (with the social worker, if there is one) to set a date that allows plenty of time to seek and approve accommodation. For example, you may come to an agreement that in six months, on May 1, John will be ready to live on his own, in whatever form of housing he and you have decided will be best.

Once the move has been completed, ill persons may feel some resentment about it. It is very important to help them so that they do not feel abandoned by you. You may have to make an extra effort during the first few weeks to reinforce the idea of the move as a positive step.

- Be a friend. Call and visit the ill person often, and make dates to go places and do things
- Encourage self-esteem by offering praise and support
- Respect the ill person's wishes and concerns as much as possible

As well as emotional support, you may have to get involved in such things as housework, shopping, cooking, and management of finances. The amount of daily assistance the ill person needs will, of course, depend on the condition of his/her illness.

Allowing for your family's background and traditions, the relationship should become less intense over time. At first the person may wish to come home every weekend. This is fine for the first few weeks or months. Then, however, you should begin to pick the occasional weekend when he/she will not return home. You should have a valid reason, such as "We'll be away that weekend."

Gradually decrease visits to one or two weekends a month. You may also find that at first, the ill person will phone home constantly, often three of four times a day. If this persists, the use of an answering machine may be advisable. You can then return phone calls as you deem appropriate. As time passes, the person should become more confident and comfortable with his/her living arrangement, and the number of phone calls and visits should settle into a normal pattern.

## Facts about > Concurrent Disorder

Concurrent disorder is a term used to refer to a condition in which a person has both a mental illness and a substance use problem/disorder. Other terms you may hear are comorbidity, dual diagnosis, dual disorder, or mentally ill chemical abuser.<sup>1</sup>

DSM-VI defines a substance use problem as a maladaptive pattern of substance use leading to clinically significant impairment or distress, as manifested by *one* (or more) of the following:

- 1. Recurrent substance use resulting in failure to fulfill role obligations
- 2. Use in situations in which it is hazardous
- 3. Substance-related legal problems
- 4. Continued use despite recurrent social or occupational problems caused by the drug

There is no *single type* of concurrent disorder. This is one of the reasons why diagnosing someone with a concurrent disorder may be difficult. For example, an individual with schizophrenia who abuses marijuana and an individual with bipolar disorder who drinks would both be considered to have a concurrent disorder.

Often the behaviour caused by drug or alcohol abuse can mimic the symptoms of a mental illness. This is another reason that dual disorders are difficult to detect. To make an accurate diagnosis, doctors usually have to wait for the individual to go through detoxification, a period of time where the body is cleansed of the alcohol or drugs. Only then can doctors determine if the behaviour is the result of a substance abuse, or if it is a result of a mental illness. This time period varies depending on the substance being used by the individual.

#### What causes a concurrent disorder?

The exact causes of mental illnesses and addiction problems are not known at this time. People are often curious about which came first, the mental illness or the addiction problem. There is no easy answer to that question. For some individuals, a mental illness may be present before they begin to misuse substances. And while we know that drug and alcohol abuse does not cause mental illness, in some cases, long-term use of alcohol can result in clinical depression.

It is often difficult to determine if an individual turned to alcohol or drugs as a means of coping with symptoms of mental illness, or if there was an underlying vulnerability that precipitated both the mental illness and the substance use problem. According to National Comorbidity Survey (NCS) data, mental illness precedes substance abuse 90% of the time.

## Why would an individual with a mental illness misuse drugs or alcohol?

A list of reasons might include the following:

- An individual may feel more socially accepted while on drugs as opposed to being considered mentally ill
- An individual may develop a social group of friends through drug/alcohol abuse.

- An individual may be using drugs in an attempt to 'self-medicate; possibly trying to calm down, relax, feel happy or escape from stress.
- An individual may be attempting to alleviate side effects of their own medication.

#### **How is Concurrent Disorder Treated?**

In the past, people with concurrent disorders were seen as unsuitable for treatment of the addiction problem. Many drug and alcohol programs do not accept clients who are actively using any kind of psychoactive medications, even those for therapeutic reasons. Other obstacles include the different philosophical orientations and the lack of a common language needed for communication between the addiction's services and the mental health system. Mental health services have also traditionally refused to accept people with mental illnesses who actively use substances.

Researchers believe that the best approach for individuals with concurrent disorder is to combine treatment of both conditions together. This is called **integrated treatment.** 

Examples of integrated treatment may include:

- Case management, outreach, and other needed services, such as help with housing, money management, or relationships
- Special counselling and groups specially designed for people with concurrent disorders
- Education regarding medications and other steps to recovery from both illnesses
- Help in understanding the effects of substance abuse on their lives
- Supported employment services
- Information and supports for family members and friends

Unfortunately, these types of services are still not widely available.

#### How common is concurrent disorder?

Concurrent disorder is more common than you might think. Many researchers now talk about concurrent disorder as a widespread problem that occurs with regular frequency. Another American study done by the National Institute of Mental Health listed 7 major mental disorders and showed how much each disorder would increase an individual's risk for substance abuse.<sup>2</sup>

<sup>&</sup>lt;sup>2</sup>NMHA Factsheet: <u>Substance Abuse Dual Diagnosis</u> (<u>http://www.nmha.org/infoctr/factsheets/03.cfm</u>)

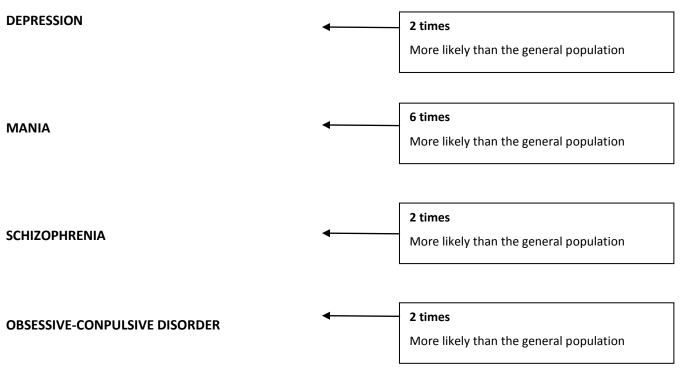
#### **PSYCHIATRIC DISORDERS AND SUBSTANCE ABUSE**

Psychiatric disorder:	Increased risk for substance abuse
Manic episode	14.5%
Schizophrenia	10.1%
Major depressive episode	4.1%
Obsessive-compulsive disorder	3.4%

As the above research shows, an individual with schizophrenia has a 10.1% higher than average risk of substance abuse.

#### Risk of developing alcohol dependence

According to the *Best Practices Guide on Concurrent mental health and Substance Use Disorders* prepared by the Canadian Centre for Addiction and Mental health in Canada, the risk of developing alcohol dependence is much higher for people with a mental illness.



## Facts about > Addiction

Addiction is the physical need for a substance (physiological substance dependence) (Bernstein and Nash, 1999). Anyone can become addicted; there is no such thing as an *addictive personality*. Addiction is often a lifelong illness that requires treatment. Recovery is possible. Addiction involves compulsive need **AND** the continued use of harmful, habit-forming substances.

An individual with a chemical dependency will be wrapped up in the need to get the drug or alcohol, and will also continue to use the substance even *though* he/she may experience negative after-effects. The individual will also find it difficult to limit his/her use of the drug or alcohol.

#### The **ELEMENTS OF ADDICTION** are:

[	- ·	· · · · · ·	
-	Drug Craving	Compulsive Behaviour	Negative after-effect for health

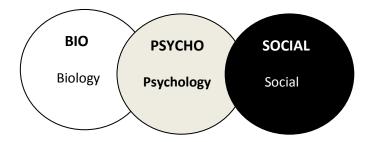
Alcohol and drug addiction will affect many of the organs in the body, and will most definitely affect how the body works. Substance abuse can also cause chemical changes to occur within the individual's body.

#### What causes addiction?

The exact cause of addiction remains unknown. Why do some people become addicted while others do not? Can a person have a genetic predisposition (a biological connection through family history) to addiction? For years scientists have researched the physical and psychological aspects of addiction. From these studies, a few theories have emerged as researchers continue to question whether addiction is biochemical, behavioural, or genetic.

Remember the word we discussed back in our first session about serious mental illness? The word *Biopsychosocial* also applies to the research being done in the field of addiction.

Researchers have found that there are two types of dependence experienced by people who are addicted: **physical** and **psychological**. In the case of a physical dependency, the body may have developed an over-reliance on the chemical and the individual will suffer physical symptoms of withdrawal when he/she does not use the substance on a regular basis. With a psychological dependence, the individual feels unable to cope without the drug of choice. A psychological dependence is exacerbated by low self-esteem and a lack of self-confidence.



## **BIOPSYCHOSOCIAL FACTORS IN ADDICTION**

	<ul> <li>Genetic factors; belief that addiction is an inherited disease</li> <li>Neurochemical imbalance (the imbalance in brain chemistry is present before drug use)</li> <li>Addictive quality of drugs</li> <li>Brain chemistry imbalance caused by drugs</li> </ul>
PSYCHOLOGICAL (MENTAL)	<ul> <li>"Self-medicating" to avoid feeling anxious or depressed, or to avoid other problems</li> <li>Using the drugs because he/she enjoys the effects</li> <li>Using drugs in reaction to traumatic experiences (self-medicating)</li> <li>Motivated by self-destructive beliefs ("I don't matter" or "No one cares about me")</li> </ul>
SOCIAL (ENVIRONMENTAL)	<ul> <li>Associating with "bad company"; environment</li> <li>Wanting to be accepted by a group: bonding with the group; peer pressure</li> <li>Trying to escape from a harsh reality (e.g., economic conditions)</li> <li>Availability of alcohol or drugs</li> </ul>

# Facts about> How Drugs and Alcohol Affect the Body

## MAIN TYPES OF SUBSTANCE ABUSE

DRUG TYPE	DRUGS IN THIS GROUP	DESIRED EFFECTS	SIDE EFFECTS OF DRUG USE
OPIATES Also called OPIOIDS NARCOTIC ANALGESICS PAINKILLERS	CODEINE, MORPHINE METHADONE, HEROIN, OPIUM	Opiates, also known as painkillers, do exactly as their name suggests—they reduce pain. People who take this type of drug do so to relieve emotional and/or physical pain. Opiates affect the central nervous system and mimic the action of neurotransmitters in various parts of the brain.	Side effects of this type of drug may include nausea, seizures, vomiting, and a loss of motor control. There may also be some depression and disturbed sleep. Fatal overdoses cause respiratory failure.
HALLUCINOGEN	Ecstasy (E), LSD (acid), MARIJUANA, MUSHROOMS, HALLUCINOGENIC, AMPHETAMINES, PEYOTE, MESCALINE	Hallucinogens alter people's perception of what is happening. This type of drug also causes feelings of insight or dissociation— (this means the individual feels he/she has a greater understanding of issues in his/her life—or he/she feels removed from them). These drugs can also cause a relaxed state, talkativeness, hunger, laughing fits, and heightened sensory experiences.	Withdrawal symptoms can include fatigue, depression, anxiety, and irritability. In severe cases, individuals may experience panic about abstinence or withdrawal. Heavy users of marijuana also appear to lack energy and motivation. Hallucinogens, like most drugs, will aggravate mental health problems.
DEPRESSANT Also called SEDATIVE	ALCOHOL, BARBITURATES (downers), MARIJUANA, HASHISH, TRANQUILIZERS (sleeping pills), INHALANTS (also called SOLVENTS; e.g., glue, nail polish remover, lighter fuel)	Depressants relieve tension and anxiety, which allows the individual to relax. These drugs work by suppressing neural activity in the brain. Individuals feel calm and "mellow." Some individuals feel a dizzy euphoria and experience a loss of fear.	These drugs can cause light-headedness, dizziness, drowsiness, slurred speech, and loss of muscle coordination. They also cause sleepiness or unconsciousness, and slow down the heart rate. Memory loss can occur, especially for the period of time one is on the drug. Other side effects include anxiety, anger, and nightmares.
STIMULANT	CAFFEINE, TOBACCO, AMPHETAMINES (uppers), COCAINE, CRACK	Stimulants boost energy levels, and people end up feeling more alert, confident, and able to concentrate. The drug works by stimulating (exciting) the central nervous system, and as a result individuals feel much more energetic.	Except for caffeine and tobacco, stimulants may cause a temporary psychosis for some people. High doses can result in anxiety, nervousness, panic, delirium, and hallucinations.  Some experience fatigue, hunger, or depression during withdrawal.

# What is?> The Impact of Concurrent Disorder On The Individual & The Family

#### FOR THE INDIVIDUAL

- Increased risk of exacerbating the symptoms of a mental illness with substance abuse, possibly bringing on an episode of mania or psychosis
- Increased risk of suicide
- Increased risk of poverty and homelessness
- Increased risk of illegal activity and incarceration (jail sentence)
- Increased risk of violent behaviour & domestic violence
- Increased risk of victimization
- Increased risk of unemployment and instability
- Loss of support systems
- Increased <del>levels</del> of stress
- Feelings of shame and guilt
- Increased levels of physical health problems (increased risk of contracting diseases like hepatitis or HIV/AIDS through sharing needles or unprotected sex)

## FOR THE FAMILY MEMBERS

- Increased family conflict and tension caused by substance abuse; increased levels of confusion, miscommunication, and mistrust; family's attempts to be supportive may then fall apart
- Increased levels of stress
- Feeling shame, guilt, and blame
- Feelings of anger or frustration
- Feeling depressed and/or hopeless
- Increased risk of being abused

# What are?> The Warning Signs of Concurrent Disorder

## How can you tell if someone has a concurrent disorder?

Dr. Agnes B. Hatfield suggests that if you suspect your family member may be struggling with a concurrent disorder, you should be on the lookout for the following warning signs:

- Your family member suddenly has money problems
- Valuables disappear from your house
- Your family member has a new set of friends
- There are physical signs like needle marks, or dilated or pinpointed eyes
- You find drug items or equipment in the house

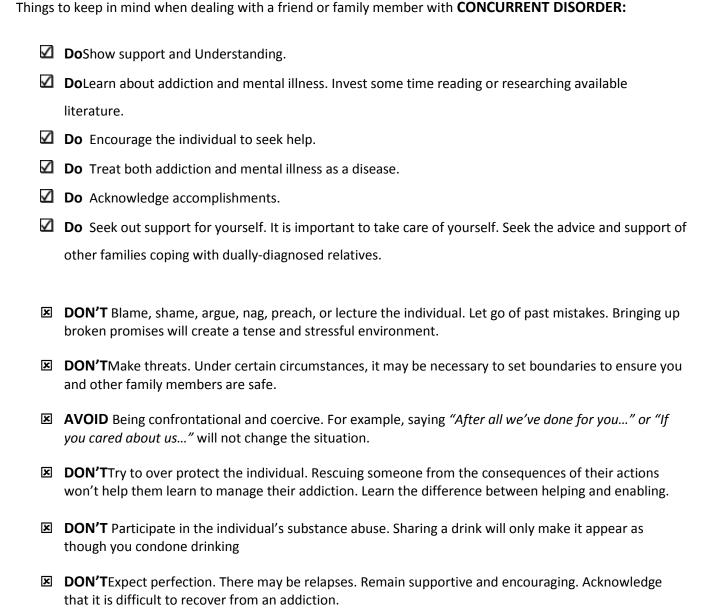
#### Examples of miscellaneous drug items include:

- Cigarette rolling paper
- Syringes
- Burnt knives
- Any unidentifiable pills or powders
- Metal clips (these are called roach clips)
- Pipes used for marijuana or hash (these are smaller than regular pipes)

#### The following items may be used to cover up drug or alcohol use:

- Mouthwash or breath mints
- Eye drops
- Incense, scented candles, air fresheners

## Tools> Concurrent Disorder: Do's and Don'ts



When dealing with someone with **CONCURRENT DISORDER**:

#### **☑** BE SUPPORTIVE

Be calm and understanding. Avoid being critical or moralistic. Give credit for any accomplishments the individual makes on the path to recovery. Acknowledge that it is hard to cope with an addiction and a mental health problem.

#### **☑** BE SENSITIVE

Encourage the individual to avoid problem substances and remove such substances from your home environment. For example: it would be awkward and uncomfortable for someone with an alcohol problem to watch you relax and drink two glasses of wine with dinner.

## **☑** BE SENSIBLE

Learn about behaviour that may be enabling the individual to carry on a chemical dependency. Examine whether any of your own personal behaviours may contribute to enabling the individual, and make the appropriate changes. For example: giving someone money that may be used to buy drugs, cancelling their appointments or work due to "a cold or flu." A delicate balance is obviously required, since an individual with a concurrent disorder needs help, support, and understanding.

## Facts about> Mental Illness & The Criminal Justice System

It is a sad reality that people with serious psychiatric illnesses come into conflict with the law, sometimes as a direct result of symptoms, or as a result of treatment failure or a concurrent diagnosis of alcohol or substance abuse.

#### How often does this occur?

A study of the prevalence of mental illness among admissions to the Vancouver Pre-trial Services Centre revealed that 15.5% of accused held at the centre had a major mental disorder (e.g., schizophrenia, major affective disorder). Various research studies indicate that arrests are often preceded by the use of alcohol or drugs, unavailability of treatment, stopping of medication for their illness, and the resulting psychiatric crises. Although arrests are common, the charges typically relate to minor offences (sometimes called "nuisance" offences). A small percentage of people with mental illness do commit acts of violence.

## Vulnerability of the mentally ill

Mental illnesses are characterized by symptoms that make individuals prone to behaviours that can lead to criminal charges.

Such symptoms can include:

- ☑ Impaired judgment
- ☑ Lack of impulse control
- ☑ Suspiciousness
- ☑ Lack of inhibitions
- Paranoia
- ✓ Inability to trust others
- ☑ Delusions
- ☑ Hallucinations
- ☑ Hyperactivity
- ✓ Irritability
- ☑ Inability to concentrate
- ☑ Impairment in communicating with others

For example, auditory hallucinations such as voices, may command them to engage in acts of violence toward others, or paranoid delusions may cause them to attack out of fear. Many people with serious mental illness use alcohol or illegal drugs, which can also lead to trouble with the law. Some support themselves by stealing or prostitution. Many commit other more minor crimes while trying to survive, such as trespassing to sleep in buildings.

#### **Predictive Factors**

*Predictive factors* of someone with a mental illness committing a crime include: **not taking medication and a history of violence and the use of alcohol or substances.** 

Homelessness and mental illness together are also strong predictors of involvement with the correctional system, according to both U.S. and Canadian research studies. Mentally ill persons who are homeless are particularly vulnerable to involvement with the criminal justice system. Several surveys (including two Canadian studies) have shown that among homeless people, those who report psychiatric illness or hospitalization are most likely to have a history of arrest or incarceration.

#### What are the causes for the increase of incarcerations?

De-institutionalization and inadequacy of community mental health services, along with issues such as the right to refuse treatment, have been suggested as reasons why many people with mental illness end up in the court system, and often in jail.

The criminal justice system has made attempts to do what it can within the limits set out by criminal law. However, our justice system was not designed or equipped to deal with health and social problems.

For people with mental and addictive disorders who do not receive the health and social service supports they require, the administration of criminal justice becomes an elaborate bridge that leads nowhere.

A ten-year study at the Surrey, B.C. Pre-trial Services Centre\*\* estimates that of the people assessed as having a mental illness or substance use disorder:

- 25% were charged with theft and possession of stolen property
- 4% were charged with break and enter
- 15% were charged with common assault
- 7% were charged with harassment or threatening
- 8% were charged with possession of drugs or possession with the purpose of trafficking
- 9% were charged with fraud, mischief or other related offences
- 15% were charged with Criminal Code driving offences
- 5% were charged with drug production, trafficking and importing/exporting
- 12% were charged with serious assaults, sexual assaults, weapons offences, robbery, and murder

<sup>\*\*</sup>Statistics Canada is exploring a national study that will provide a more national view.

## **Services Provided through Corrections Branch Services**

Although medical treatment is available to people in jails and prisons, prisoners with mental illness have the right to refuse treatment. If symptoms of the illness are not readily apparent or the person does not believe he/she is ill or in need of help, the prisoner can stay untreated for the duration of the sentence.

Services for people with mental illness or substance useproblems who are remanded or sentenced to custody typically include:

- Medical assessments, including mental health
- Requests by an inmate for medical services
- Transfer to hospital when an inmate cannot be treated in a corrections centre
- Core programs such as life skills program, substance abuse management programs, and family violence and anger management programs

Persons on probation, parole, or who have a conditional sentence can request a referral for assessment and treatment or counselling. Probation or conditional sentences may include conditions that require the person to attend certain programs for treatment.

## In Search of Treatment:

Justice services for people with mental illness are often the entry point for treatment for a number of reasons:

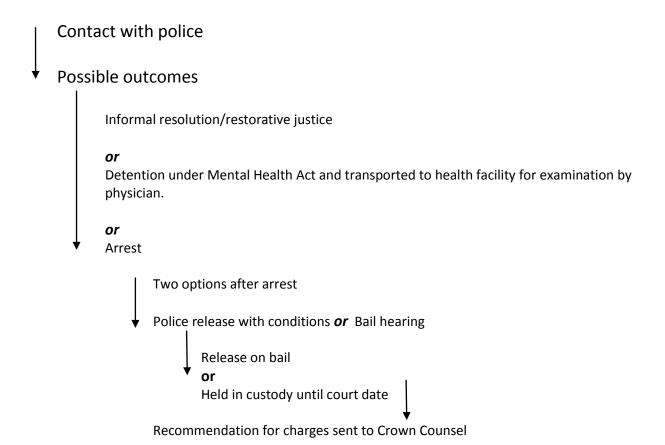
- Through the commission of an offence, the mental illness becomes apparent to government services.
- People with mental illness often don't recognize they have a problem or are unwilling to use available
  health series. They refuse offered help. If they are diagnosed and given prescribed medications, they
  may refuse to continue taking the medication or combine them with illegal drugs. Others prefer to "selfmedicate" rather than take the prescribed drugs.
- Some people are incapable of accessing services due to their medical condition or their personal and social situation. For example, basic shelter in a safe environment is primary to getting treatment of any kind. People with mental illness may require help to identity what services are available, to make an appointment, and to follow admission procedures. Some do not have identification necessary for obtaining medical help. Some have exhausted (emotionally and financially) the support they might have received through family and friends that would assist them to get help.
- Some people are unable to access services because those services are unavailable to them. These services may not exist or may not be available at the time they are needed (i.e., cannot be accessed upon demand).

## **Mapping the Criminal Justice System**

The criminal justice system is a complex process. The following map outlines some of the steps within the Criminal Justice System.

If you are dealing with a person who is involved with the criminal justice system, we strongly encourage you to ask legal representatives about the aspects relevant to the person's situation. Local police, crown counsel, and defense lawyers or legal aid can provide assistance.

## Stage 1: Encounter with police



## Stage 2: Psychiatric assessment (legal process)

Possible outcomes

Fit to stand trial

Person is tried in court for the charge

Unfit to stand trial

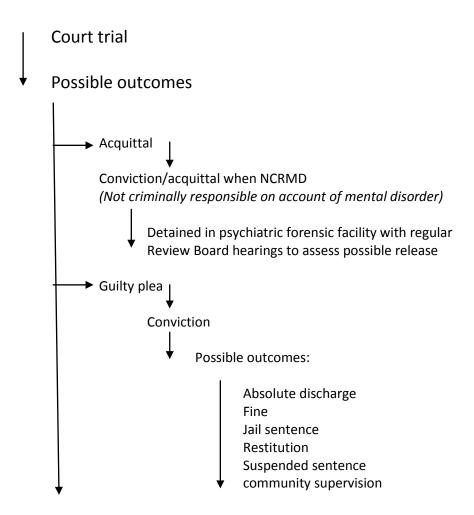
Involuntary detention and treatment at forensic psychiatric facility until fit to stand trial

NCRMD (Not criminally responsible on account of mental disorder)

Commitment to psychiatric forensic facility

Review Board hearing to asses if person can be released back into the community.

# Stage 3: Trial and sentencing



# Facts about > The Players and Procedures of the Criminal Justice System

The criminal justice system is a complex process and the information in this handout is only a general guideline. If you are dealing with a person who is involved with the criminal justice system, you are encouraged to ask a legal representative about the aspects relevant to the person's situation. Local police, crown counsel, and defense lawyers or legal aid can provide assistance.

#### The Police

Under provincial mental health acts, police have the power to take a person with a suspected mental disorder without delay to a designated mental health facility for examination by a physician. (Please remember that the criteria for detaining and transporting a person to a psychiatric facility for assessment vary from province to province.) The police may be called because the person is causing a disturbance in a public place, but in some cases, families call the police because they believe their relative is in need of immediate assistance and the relative refuses to go voluntarily.

When families are involved, the police will likely seek the assistance of support people to better evaluate the best level of intervention for the person. Information about symptoms or previous history of diagnosis, treatment, or hospitalization—and whether the person is taking medication—is very helpful to the police when they are called.

The decision to charge a person is based on:

- The seriousness of the offence
- The person's ability to understand the need to attend court
- The person's and the community's needs for safety
- Whether release is in the public's interest

When the police suspect a person has a mental illness, their report to crown counsel includes a description of behaviours and any relevant information they have received from others, such as family members. The report is used to determine whether to lay charges against a person).

Crown counsel may stay proceedings if the person:

- (a) is certifiable under the Mental Health Act
- (b) can be managed in a general psychiatric unit
- (c) has no, or minor, criminal history

#### Fitness to Stand Trial and Not Criminally Responsible by Reason of Mental Disorder

At any point in the legal process, a judge can order a 30-day psychiatric assessment.

The two most common reasons are:

- There is a question of a person's mental status to understand the trial process (Unfit to Stand Trial)
   Or
- (2) There is a question of the person's mental status at the time the crime was committed (Not Criminally Responsible by Reason of Mental Disorder)

If either is determined, the person will be sent to a forensic psychiatric facility for assessment.

A person is *unfit to stand trial* if he/she suffers from a mental illness that prevents him/her from conducting a defense or instructing his/her lawyer to do so. This includes an inability to understand the nature of the proceedings, or their possible consequences, or to communicate with his/her lawyer.

If he/she is found *unfit to stand trial*, then any plea entered is set aside. The judge can, under the Criminal Code, authorize treatment (for up to 60 days) to restore a person's fitness to stand trial. The person will be remanded into custody at psychiatric institution or ordered to submit to treatment. If the person becomes fit to stand trial at a later date, he/she can be tried at that time.

A person is considered *not criminally responsible by reason of mental disorder* if the court decides that, at the time of the offence, an offender was mentally ill to a degree that he/she cannot be held criminally responsible for this/her actions (i.e. the person did not know that what he/she was doing was wrong). This is a legally-determined decision arrived at through the legal process.

It is important to be aware that any prior *Unfit to Stand Trial or Not Criminally Responsible by Reason of Mental Disorder* (NCRMD) findings **do not** preclude a person being charged with a new offence.

#### **Guilty Plea**

A person who has been charged with an offence has the option of pleading guilty to the crime at any time in the process. Pleading guilty should not be done until after the person has had an opportunity to meet with a lawyer.

#### Trial

Trial procedures vary depending on whether the offence is classified as a "summary" or "indictable" offence. Summary offences tend to be less serious ones; indictable offences more serious. In the trial, crown counsel presents their case first, and then the case for the defense is presented. After both sides have presented their witnesses and facts, the judge will ask the defense counsel and then the crown counsel to summarize the evidence and make arguments for the judge to acquit or convict.

The judge usually gives a verdict fairly soon after crown counsel has completed the arguments. If there is an acquittal, the person is free to leave. If there is a conviction, the judge will either deal with sentencing immediately or set another date for a sentencing hearing.

#### **Conviction/Sentencing**

The decision to convict rests with the judge and/or jury. The crown, defense, and the judge ensure the consideration of NCRMD status where it is appropriate. Findings of *Not Criminally Responsible by Reason of Mental Disorder* can result in the person being held in a forensic psychiatric facility or supervised in the community by a forensic clinic, until a review board determines he/she is appropriate for full release.

#### Custody

Offenders with a mental illness who are sentenced to jail are usually placed with the general prison population, unless they require protective custody or other special placement (for example, suicidal behaviour requires placement in a special observation unit).

If an individual shows signs of serious mental illness while in prison, he/she is referred to the medical staff. Physicians will assess the person, and if the mental disorder needs psychiatric treatment and meets other criteria, they may recommend the offender be moved to a provincial mental health facility under the *Mental Health Act*. The person is involuntarily committed and will receive treatment while in the mental health facility. The person will remain in a mental health facility until he/she can be safely placed back into the community or released if his/her sentence is over.

While in the correctional facility the staff works with the offenders to develop a case management plan that prepares the offenders for their eventual release. A correctional case management plan provides risk management appropriate to the individual's risk level, and accessing resources that address ongoing treatment and support needs of the individual.

#### **Community Sentences**

Community sentences such as *probation or a conditional sentence* may include conditions that direct the mentally disordered person to certain services, or may require him/her to reside in certain places or to abstain from alcohol and illegal drugs.

Community management focuses on managing the person's risk to the community, and on linking him/her to available services that will help reduce the risk of further criminal behaviour.

#### **Legal Assistance**

Generally, it is a good idea to always obtain legal help when a person has been charged with an offence. Duty counsel are usually available to assist people at a bail hearing (at no cost), however, they typically have many cases and may not be able to give your relative's case all the attention it needs.

Legal aid may be available for the person accused. Contact information should be available in your local telephone directory or by contacting a community service organization.

It is important to be aware that information about your relative's case is **confidential** unless he/she gives permission to the lawyer to discuss the case with you.

#### **Forensic Psychiatric Services**

Every province offers forensic psychiatric services. These services typically include both a secure facility for assessment and treatment, as well as regional community clinics or centres.

Referrals to forensic services typically include:

- 1. **Assessment:** a person is remanded by the courts for psychiatric assessment to determine fitness to stand trial or to assist in determining whether a person should be found not criminally responsible on account of mental disorder;
- 2. **Treatment:** Persons who have been found unfit to stand trial or not criminally responsible may be committed to a forensic psychiatric hospital for treatment;

- 3. **Temporary Absences:** offenders serving time in a provincial prison who have been certified under the Mental Health Act can also be referred to a forensic psychiatric hospital for treatment of their mental illness;
- 4. Bail or Probation Orders: the person is sent to a clinic on a court order for bail or probation.

#### **Review Board**

Once an accused person has been found *unfit to stand trial or not criminally responsible by reason of mental disorder* (NCRMD), the person usually comes under the jurisdiction of the Review Board. Every province has a review board. The Review Board is responsible for decisions as to the custody, community release, and ultimately the absolute discharge of accused persons found by the courts to be either unfit to stand trial or not criminally responsible on account of mental disorder under the Criminal Code of Canada.

The Review Board is an independent tribunal established under the Criminal Code of Canada and is comprised of three members: a lawyer, a psychiatrist, and a mental health professional (often a social worker/psychologist). Its mandate is to protect public safety while also safeguarding the rights and freedoms of mentally disordered persons accused of committing an offence.

In making a disposition, the Review Board takes into consideration:

- $\sqrt{\phantom{a}}$  The protection of the public (whether the accused presents a risk)
- $\sqrt{\phantom{a}}$  The accused's mental condition
- $\sqrt{\phantom{a}}$  The reintegration of the accused into society
- $\sqrt{\phantom{a}}$  The accused's other needs

Three types of dispositions are possible:

- 1. Custody in forensic psychiatric facility
- 2. A conditional discharge (conditions could include supervision, counselling, prohibition against alcohol, drugs, or weapons)
- 3. Absolute discharge (similar to a pardon)

If the Review Board determines the accused is fit to stand trial, the accused is returned to court. The court will once more try the case and render a verdict. Persons who are found NCRMD are entitled to a review hearing at least every 12 months to reassess the extent to which the person presents a risk to the public and whether any restrictions or conditions that have been imposed should be changed.

## Special programs for mentally ill accused

#### **Community Treatment Orders**

Community Treatment Orders (CTO) allows some provincial mental health systems to provide the benefits of deinstitutionalized treatment to a seriously mentally ill person. Orders allow the patient to enjoy the freedom of living within the community and to consent in advance to any treatment or detention that might be necessary should his/her condition deteriorate. While re-entry generally involves doctors, family members, and general social contacts, in some cases the patient may come into contact with the police and be returned to his/her treatment program immediately.

#### **Court Diversion**

In some provinces, mentally ill persons charged with minor offences may be sent directly to a treatment program rather than go through full court procedures. Diversion also serves to provide the correctional system with relief from treatment, safety, and control issues mentally disordered persons may present while incarcerated (Nuffield, 1997). Diversion may occur upon contact with police, initial incarceration, or upon arrival in court. In Ontario, for example, the accused may be referred to a caseworker at an initial hearing in provincial court. Diversion is generally only available to those accused who are willing to participate in a treatment program, or who are covered by a community treatment order in those provinces where they are available.

# **Article 1**> Dual Diagnosis<sup>1</sup>

By STEPHANIE ROBERTS
Stephanie Roberts is a Toronto-based writer.

Jim Wallace sank into a 32-day drunk when his mother died. She was the one person who was always there for him, and now she was gone. Wallace began swallowing 19 ounces of hard liquor a day, choosing oblivion over painful consciousness. It was a familiar pattern for the South Carolina resident, who had missed his eldest daughter's graduation because he was drinking.

"Any time I had a loss or disappointment, it would just incapacitate me for a while," Wallace says. Sadness chased by heavy drinking had been a dominant theme since his teens, but it wasn't until he was 36 years old that he was finally diagnosed with a bipolar disorder. He revolved through psychiatric units for years, more times than he can recall. His psychotic episodes and bizarre behaviour worsened, but he refused to look beyond the booze.

"It kept getting worse" Wallace says. "I knew I had a problem but I rationalized it. I didn't mind being a drunk, but I sure as hell didn't want to be mentally ill.

Wallace's struggles with the double whammy of mental illness and substance abuse—also referred to as dual disorders, concurrent disorders or co-occurring disorders—is an all-too-common story among the millions of Canadians and Americans suffering from illnesses such as schizophrenia and bipolar disorder.

"Co-occurring disorders are an expectation, not an exception" says Dr. Kenneth Minkoff, an internationally recognized expert on dual diagnosis from Massachusetts and assistant professor of psychiatry at Harvard Medical School. Roughly half of all people with schizophrenia abuse substances, and between 40 and 60 per cent of people with substance disorder, also have at least one mental illness, research suggests. In December, the U.S. Substance Abuse and Mental Health Services Administration unveiled a report that said between seven and ten million Americans have at least one psychiatric disorder as well as an alcohol or drug abuse disorder.

#### Substance Abuse Makes Treatment Of Mental Illness More Difficult

Dr. Wilson Lit, a psychiatrist who directs a treatment program for dual diagnoses at the Homewood Health Centre in Guelph, Ontario, says patients with schizophrenia who also abuse substances aren't picky about the type of drug they choose: cocaine, hashish, marijuana, speed, heroin, PCPs (phencyclidine)—if they can get their hands on it, they'll use it.

The consequences of dual diagnosis are dire: experts say those who abuse drugs or alcohol are far more likely to end up relapsing, living on the streets, in jail, committing suicide or becoming infected with HIV or tuberculosis. Social networks of friends and family members are often left in tatters, and hallucinations and delusions can worsen.

While some recent American and British studies refute the long-held belief that people with mental illness are more prone to violence aimed at others that the general public is, it's generally accepted that adding substance abuse to the equation increases the risk of violence. A recent review of homicides in the United Kingdom implicated substance abuse as a significant factor in more than half of murders committed by people with a mental illness. Another British study found 79% of male prisoners who had a drug dependency also had at least two mental disorders.

Dr. Lit says a minority of people with schizophrenia who abuse substances are more likely to act violently, as a sort of pre-emptive self-defense due to extreme delusions and paranoia of attack from others. But much more common, he says, are cases in which those with the illness become victims themselves. "It's often the case that they're very vulnerable, so they're frequently abused and attacked and the likelihood of that is greater with concurrent disorders," Dr. Lit says.

If substance abuse carries such serious consequences, why do so many mentally ill people still risk it? That, like many aspects of dual diagnosis, is complicated. Dr. Lit says many people abuse alcohol or drugs because they are in denial of their mental illness, or to self-medicate to mask symptoms such as hallucinations.

Rick White knows that. The 42 year-old New Brunswick resident, suffers from schizophrenia and who had his first psychotic episode in 1985, says he turned to alcohol and hashish to block out auditory hallucinations.

"I'd get home to my apartment and the voices were there" he says.
"I knew if I went to the pub and had a few beers, the voices wouldn't be there."
Eventually, White was using drugs and alcohol on a daily basis. "It's a vicious circle once you get started" he says.

It was only after a life-threatening situation in which he jumped from a moving car because of a terrifying hallucination, and his employer at the time asked him to resign, that White stopped drinking. He has since returned to work and last June received a national award from the Schizophrenia Society of Canada for his many volunteer contributions.



Agnes Hatfield, a professor emeritus with the University of Maryland's, Department of Human Development, says substance abuse can often help the mentally ill to reduce levels of anxiety or depression, at least temporarily. This segment of the population can also suffer from "downward drift," says Hatfield—the isolation created by poverty and loss of a support network leads them to live in marginal neighbourhoods where drug use prevails, but where they are more accepted.

For both healthcare professionals and family members, distinguishing between the mental illness and addiction is difficult because the symptoms of either illness can mimic each other. And often it is difficult to say if one caused the other, or if the two emerged independently.

Wallace, now 68, thinks his drinking predated his mania and depression, but he's not certain. He remembers hitting the bottle with friends as a teenager in his hometown of Gaffney, South Carolina. |I enjoyed it for a while," he says in a slow southern drawl. "I saw it as a tool for socialization. I could dance better and I could talk to the girls better." As his life went on and his vulnerability to stress and uncomfortable situations worsened, his drinking progressed. "All it did was cause oblivion," Wallace says. "The next day I was a whole lot worse off."

Dr. Lit is familiar with the profile. "Imagine that in you're in your teens and you wake up one morning and you're hearing voices. This can be extremely frightening." Dr. Lit says people are drawn to using more drugs as a way of fooling themselves. "They can tell themselves I don't have a mental illness—I'm just stoned on drugs."

Researchers are still puzzling why some people are more susceptible than others are to dual disorders. Causes seem complex and interwoven. Some evidence suggests a shared biological vulnerability—that people more prone to develop a psychotic illness may also be more at risk to develop an addiction, or vice-versa.

Dr. Graeme Cunningham, a psychiatrist who is director of the addiction division at Guelph's Homewood Health Centre, said at the Canadian Psychiatric Association's annual meeting in Alberta in November that the genetic link to addiction is already well documented. "There will always be those (people) genetically loaded to be addicted and alcoholic" he said.

One line of study suggests that physical changes inside the brain may take place after developing either a mental illness or a substance abuse problem, increasing vulnerability to the other.

South Carolina's Wallace paid—and continues to pay—a heavy price for his drinking. he attempted suicide and at one point was reduced to living in the woods. His family and friends witnessed his deterioration helplessly.

"In the beginning they tried to stick with me, but it got to the point where it was going to put them in the hospital, too," he says. "One by one I lost the people I loved." None of his three children will speak with him today, years after his recovery from drinking. "I knew I had a substance problem, but I denied it and I continued to deny it up until the end," he says.

Finally, it became too much to bear—the losses, the isolation and the pain. The turning point came when he was living in the woods. His second wife found him and asked him to attend an Alcoholics Anonymous meeting. He agreed, just for her. It would be the best decision he had made in decades.

During the first meeting, Wallace had an epiphany. "I saw these people has something I didn't have. They weren't hopeless and they weren't helpless." He quit drinking, but still struggled with his symptoms. He moved to a larger city with more resources and entered a treatment centre. It wasn't easy, but he took responsibility for his recovery.

Implementing a recovery plan for people with dual diagnoses is challenging, experts say, because these patients are more likely to resist treatment, relapse, and lack motivation to change and be cognitively impaired—in other words, it is more difficult for them to learn. Complicating treatment is a dearth of integrated problems that can address both the mental illness and the substance abuse problem.

Kathleen Sciacca, a psychologist in New York City, developed the first integrated treatment program for dual diagnoses in 1984. Unfortunately, such programs are a rarity, she says. More often than not, psychiatrists treating schizophrenia will demand clients detoxify first, while addiction programs may bar entrance if consumers are psychotic. "If you go to Italy, Sweden, Spain, Canada, the U.S., the problem is the same," says Sciacca.

The University of Maryland's Hatfield refers to it as "ping-pong" therapy, in which clients are referred back and forth between substance abuse programs and psychiatrists. "What is needed are hybrid programs that address both illnesses together."

Fuelling the problems in treatment programs are fundamental philosophical differences between psychiatry and addiction programs. While addiction programs often preach total abstinence, psychiatrists say a more effective and realistic goal is harm reduction—a gradual, phased in reduction in substance abuse. "Having 10 drinks a day is better than having 20 drinks a day," says Dr. Lit.

The intervention of friends and family members—collectively confronting a loved one over their addiction—may well work for people with just substance abuse problems alone. But dual diagnosis experts caution against a confrontational approach for the mentally ill.

The University of Maryland's Hatfield says blunt confrontation may produce levels of stress in mental health consumers that actually exacerbate symptoms or even cause relapses.

Helping those with psychiatric disorders to change, rather than demanding they do so, is important, and emphasizes New York's Sciacca. "(We) try to draw out from the client's perspective the reasons they think they should change. We want that person to change their whole way of thinking about this, so change is sustained—not just because someone else wants them to do it."

For Wallace, the desire to finally address his drinking problem began at that first AA meeting. "They looked better than me" he says. "They talked better than me. They dressed better than me." While hybrid programs with experts in treating both mental illness and substance abuse remain rare, Dr. Minkoff says the importance of such integrated services—and the scale and cost of not addressing dual diagnoses—is gaining recognition.

So, too, is a slightly evolved form of self-help groups modeled on the Alcoholic Anonymous model, such as Dual Recovery Anonymous (DRA), with chapters world-wide. The familiar 12 steps to recovery from AA remain, but with changes—such as replacing the word "God" with "Higher Power."

Gordon Hill, a 58-year-old Guelph, Ontario man who also has a bipolar illness, attended his hometown DRA meetings for several years. Hill says the meetings helped him because: unlike other groups such as Alcoholics Anonymous and Narcotics Anonymous (NA), DRA doesn't discourage participants from taking their prescribed psychiatric medication. At DRA meetings, he says, he also felt free to discuss mental illness. "In AA and NA you really can't talk about mental illness" he says. "They don't want to hear it. you can feel very put down".

Wallace, who triumphed in his battle with his companion demons, now steps into the ring for others with dual diagnose. He has worked as a client advocate for various organizations in South Carolina for 20 years. he recently returned to his hometown and lives a few doors down from the house he shared with his mother as a boy.

His advice to other consumers? Take advantage of community resources, comply with medication and listen to professionals you trust. Above all, he delivers a message to hang on to.

"Life is not helpless. Life is not hopeless" he says. "Life is good and you need to get a good life. It's not painless, but it's good."

## Tips: dual diagnosis

Things to do and realize if a loved one with mental illness is abusing drugs or alcohol:<sup>2</sup>

- Do not regard it as a family disgrace. Recovery from addiction can come about just as with any illness.
- Do not nag, preach, or lecture. You may only increase your relative's need to lie or may force him/her to make promises he/she cannot keep.
- Do not use an "if you loved me" appeal. This will only increase your loved one's guilt.
- Be careful about using threats. Idle threats will reinforce your loved one's feeling that you don't mean what you say.
- Do not hide or dispose of the drugs or alcohol. This may push your loved one into a state of desperation.
- Do not let your loved one persuade you to use drugs or alcohol with him/her on the grounds that he/she will use less. It rarely does.
- Avoid feeling jealous if your loved one turns to other people for help.
- Do not expect an immediate recovery. There may be relapses and times of tension and resentment.
- Do not try to protect your loved one from using drinking situations—it's one of the quickest ways to push one into relapse. They must learn on their own to say "no."

<sup>&</sup>lt;sup>1</sup>Schizophrenia Digest magazine, Winter 2003

<sup>&</sup>lt;sup>2</sup>Source: <u>Dual Diagnosis: Substance Abuse and Mental Illness;</u> a National Alliance for the Mentally Ill paper by Agnes B. Hatfield.

## Article 2> Forensics Demystified

Forensics Demystified: Brockville hospital tries to build understanding about patients who come into contact with the law<sup>1</sup>

BROCKVILLE—Forensics: It's the place where mental health and justice intersect, and for many it's a source of confusion and misunderstanding. For people within the system, however, the forensic program can be a gateway to treatment and recovery. Organizers of a public forum held in January at the Brockville Psychiatric Hospital hope to dispel some to the myths about the system that's responsible for people with mental illness who come into conflict with the law.

People who have committed a crime enter the forensic system if they are ordered for psychiatric assessment and treatment by the court system. They become part of the mental health system after they have been charged with a crime, but have been found either unfit to stand trial or not criminally responsible (NCR) because of ta mental illness.

The forensic system is a complex network that involves police, courts, hospitals, and the Ontario Review Board, a five-member panel that determines whether people found unfit to stand trial or NCR should be kept in custody and if so, where.

Throughout Ontario, about 800 people have NCR status, many of whom have been given a conditional discharge and live in the community with treatment. Alistair

Deighton is one of them. He credits the Royal Ottawa Hospital's forensic program as the reason he now lives at home with his family.

Seven years ago, Deighton was in a Cornwall jail, sleeping on a mattress on the floor, suffering from untreated schizophrenia. Deighton had been arrested in the shooting death of his 18-year-old son, the tragic consequence of years of struggle with untreated mental illness.

He spent nearly three months in jail before a bed in the Royal Ottawa Hospital's forensics unit finally became available. He started in a double-locked unit, was eventually granted outdoor privileges, and later moved into supervised living. After two years of treatment and rehabilitation, he was able to return home.

Deighton and his wife Sheila, who live in a small eastern Ontario town with their two university-aged sons, told the Brockville forum that the forensic team provided the support to get the family through a horrific, unimaginable tragedy.

"The forensic program provided us with responsible treatment and management, and a full range of services, not only for Alistair, but for our family," said Sheila Deighton, now executive director of the Ottawa chapter of the SSO.

Deighton, who has become an advocate for people with schizophrenia and their families, says the forensic system remains a mystery to many Ontarians in part because people who have had experience with the system are reluctant to come forward with their stories.

"In itself a diagnosis of mental illness is a major obstacle," she says. "To have the added burden of a forensic assessment makes it even more difficult."

Brockville's 59-bed forensic unit will eventually be reduced to 44 medium security beds. The remaining 15 minimum-security beds will be moved to Ottawa when the BPH closes in 2004. The hospital will also service a secure treatment unit, for people with mental illness in the corrections system.

This close link between the mental health and corrections systems adds to the public's confusion about forensics, says Jim Allin, administrative director of the forensic program at the Royal Ottawa and Brockville Psychiatric hospitals. But the aims of the two systems are very different, he says.

"In the health care system we reduce risk by ensuring people are treated. It's a very different way of managing risk than in the correctional system," said Allin.

And treatment is key. "There's been a long-term misconception that people with mental illness are no more likely to be violent than the rest of the population," said Allin.

But that's only true of people who are being successfully treated. Evidence suggests that people with serious mental illness who are untreated are six to seven times more likely than the general population to be physically violent, according to psychiatrist John Bradford, clinical director of the Royal Ottawa's forensics program. Combined with drugs or alcohol, the risk is even higher.

"The aim of the (forensic) system is to balance the individual's need for treatment with the need to protect the public," said Bradford.

<sup>&</sup>lt;sup>1</sup>The Advocate, Schizophrenia Society of Ontario, Spring 2002. Reprinted with permission of Schizophrenia Society of Ontario

#### **Resources**> Concurrent Disorder

#### **BOOKS**



<u>Celebrating Small Victories: A Primer of Approaches & Attitudes for Helping Clients with Dual Disorders</u> *By Ken Montrose, Dennis C. Daley* (Minnesota: Hazelden Foundation, 1995) ISBN: 1568380925

<u>Dual Diagnosis: Challenges of Serving Seriously Mentally III Substance Abusers</u> (Study Centre Press, 1998) ISBN: 0936434996

<u>Dual Diagnosis: Counselling the Mentally III Substance Abuser Second Edition</u> *By Katie Evans & Michael Sullivan* (Guilford Press, 2000) ISBN: 1572304464

<u>Dual Disorders: Counselling Clients with Chemical Dependency & Mental Illness</u>

By Dennis C. Daley (Minnesota: Hazelden Information and Educational Services, 1993) ISBN: 0984864491

<u>The Dual Disorders Recovery Book: A Twelve-Step Program for Those of Us with Addiction and an Emotional or Psychiatric Illness</u>

By Hazelden Information and Educational Services (Minnesota, 1993) ISBN: 0894868497

Improving Treatment Compliance: Counselling and Systems Strategies for Substance Abuse & Dual Disorders By Dennis C. Daley & Allan Zuckoff (Minnesota: Hazelden Information and Educational Services, 1999) ISBN: 1568382812

Treating Coexisting Psychiatric & Addictive Disorders: A Practical Guide

By Norman S. Miller (Minnesota: Hazelden Information and Educational Services, 1994) ISBN: 0894869728

The Twelve Steps and Dual Disorders

By Tim Hamilton and Pat Samples (Minnesota: Hazelden Information and Educational Services)

ISBN: 1568380186

The Twelve Steps and Dual Disorders Workbook

By Tim Hamilton and Pat Samples (Minnesota: Hazelden Information And Educational Services)

<u>Today I Will Do One Thing: Daily Readings for Awareness & Hope for Those of Us with Addiction & Emotional or Psychiatric Illness</u>

By Hazelden Meditations ISBN: 1568380836

The Hazelden Foundation in the U.S. publishes many of the books listed. For more information contact:

#### **Hazelden Foundation**

P.P. Box 11 - C03

Center City, Minnesota 55012-0011

Phone: 1-800-257-7810 Fax: 1-651-257-1331 <u>www.hazelden.org</u>

#### **WEBSITES**



Alberta Alcohol & Drug Abuse Commission <a href="http://corp.aadac.com/home.asp">http://corp.aadac.com/home.asp</a>

Canadian Society of Addiction Medicine – *Good site for medical professionals, scientists, & medical students* <a href="http://www.csam.org">http://www.csam.org</a>

Concurrent Disorders – Centre for Addiction and Mental Health (CANADIAN) http://www.camh.net

Dual Diagnosis Website (AMERICAN)

Mental Illness, Drug Addiction and Alcoholism, MIDAA(R), MICA

This website has information on treatment and program development for dual disorders. Great links to other websites, plus a new section on dual diagnosis resources for professionals, families, and people with dual disorders. http://users.erols.com/ksciacca

Dual Diagnosis Recovery Network (AMERICAN) <a href="http://www.dualdiagnosis.org">http://www.dualdiagnosis.org</a>

Dual Recovery Corner (AMERICAN) http://websitebudget.com/dualrecovery

Dual Recovery Anonymous World Services (AMERICAN)

Central office: PO Box 8107, Prairie Village, Kansas, 66208 Toll-free: 1-877-883-2332

http://draonline.org/index.html

The Dual Diagnosis E-Mail Group

This group is dedicated to offering experience, strength, hope, and support for those suffering from alcoholism addiction and mental illness. <a href="http://www.angelfire.com/journal/bipolaralcoholic">http://www.angelfire.com/journal/bipolaralcoholic</a>

Dual Diagnosis (AMERICAN) http://www.bipolarworld.net/Diagnosis/Dual Diagnosis/dudiag.htm

Dual Diagnosis: Index Page (AMERICAN)

Excellent information about the physical effects of various types of drugs.

http://www.toad.net/~arcturus/dd/ddhome.htm

Dual Diagnosis Booklet (BRITISH)

Clear and concise information available for download.

http://www.mind.org.uk/mindpdfs/Understanding dual diagnosis.pdf

Drug & Alcohol Treatment & Prevention Global Network (AMERICAN)

http://www.drugnet.net/metaview.htm

Drugstory

An informational resource for entertainment writers and feature journalists. http://www.drugstory.org

National Institute on Drug Abuse (AMERICAN)

http://www.nida.nih.gov/NIDAHome.html

National Mental Health Association – Dual diagnosis fact sheet (AMERICAN)

http://www/nmha.org/infoctr/factsheets/03.cfm

#### For family and friends living with someone who has a mental illness

#### 1. Recognize your limits:

You should decide what level of support and care you are **realistically** able to provide. Explain this to the friend or relative with the mental illness as well as the health professionals involved in his/her care. This will ensure that the type of support you are unable to provide can be arranged in another way. You should also discuss options for future care with health professionals and other family members and friends. This will ensure continuity of care when you are unable to fulfill your role as a caregiver.

#### 2. Define clear expectations for every family member:

- Families function smoothly when expectations for each person are clear and consistent. For example, delegation of household chores should be made explicit and reviewed periodically.
- Consequences for failure to meet expectations should be clear and appropriate.

#### 3. Develop plans to cope on a day-to-day basis:

It is important to encourage a sense of structure in the life of a person with a mental illness. You can:

- **Develop predictable routines** for example, regular times to get up and eat; introduce gradual changes to prevent boredom.
- **Break tasks into small steps** for example, encourage someone to shower more by helping them put out towels an\d choose clean clothes.
- **Try to overcome a lack of motivation** for example, encourage and include the person in activities.
- Allow the person to make decisions even though it can sometimes be difficult for him/her to do
  this and he/she may keep changing their mind; try to resist the temptation to make the decision for
  the person.

#### 4. Maintain a clam atmosphere in the home:

- Avoid excessive stimulation, such as having frequent company, loud music, violent television programming, etc.
- You and your loved one may discover and practice calming activities (e.g., playing quiet music reading, or gardening).
- **Ignore the "annoying but unimportant" things.** The concept of "picking your battle" can be very helpful, as some issues just aren't worth arguing about!

#### 5. Develop plans to deal with disturbed behaviour:

Try and discuss strategies with the person and health professionals to deal with:

- **Suicidal thoughts** talk about the thoughts with the person and discuss why he/she is having them. Suggest things to distract the person from the suicidal thoughts. If the thoughts persist, especially if the person experiences hallucinatory voices that suggest suicide, inform his/her doctor.
- Manipulative behaviour for example, where the person with the illness tells one person untrue stories about mistreatment by the others who care for him/her. Establish whether the behaviour is being used to get extra help and support. Try and involve the person in activities which will make him/her feel less resentful toward others. Check out the stories before your react.
- **Aggressive or violent behaviour** this may be associated with psychotic symptoms or alcohol or drug abuse. Involve health professionals promptly. For aggressive behaviour associated with extreme stress, try to develop an atmosphere that is open and relaxed.

#### 6. Report Aggressive Behaviour:

If someone is persistently aggressive, you should report actual or threatened violence to the treating health professional (and the police, if necessary) immediately. If you live with someone who is persistently aggressive, seriously consider ways you can live apart. It is very likely that living apart will work out better for both of you.

## **Tools**> Setting Goals & Expectations

It is important to review and compare with your relative your goals and expectations and his/hers. Clarifying these will help keep your relationship positive and healthy, and provide you with some direction on how to best support your loved one in the pursuit of his/her goals.

#### 1. Clarify your expectations

List what each of you expects from the other:

- Your ill loved one needs to be clear about his/her expectations for friends/family members. For
  example, ask him/her to identify what type of support he/she expects to receive from family/friends
  (e.g., to live with his/her parents or a sibling; to be able to depend on someone for transportation or
  financial support).
- Caregivers should state what they expect from their ill loved one. For example, tell the loved one how you want him/her to contribute to the home (if living with him/her), how you expect him/her to behave, and your expectations regarding self-care (e.g., taking medication as prescribed and attending regular4 appointments with health care providers).

Be prepared to review the expectations periodically as a person's illness can progress or worsen, affecting his/her ability to meet expectations.

Keep in mind that expectations should be positive and achievable. Positive and reasonable expectations serve to provide guidance, create faith, establish hope, and promote self-confidence and self-esteem.

Avoid common unrealistic expectations, for example:

- That the recovery will be speedy
- That the person will return to a past level of functioning
- That the person will never again be hospitalized or have a relapse

#### 2. Establish realistic shot-term and long-term goals

Discuss goals with your relative. His or her interest, wishes, and level of functioning need to be considered in any plans that are developed.

#### **Step 1**: Assess the most recent level of functioning in each major area listed below.

Assess the current overall level of functioning by evaluating the following major areas:

- 1. *Basic skills for independent living:* The ability to shop, cook, clean, manage money, use public transportation. How independently has your relative lived?
- 2. *Interpersonal skills:* The ability to establish and maintain relationships, carry on conversations, and make eye contact.
- 3. *Educational and vocational skills:* Has your relative completed high school or post-secondary education? Has he/she held a job? What type of job and for how long?

A higher functioning person will:

- Be competent in at least two of the above areas
- Have no symptoms that consistently interfere with functioning
- Show motivation and initiative to progress to a high level of functioning

Remember that the level of functioning of people with mental illness can change rapidly. You must be prepared to adjust your goals and expectations based on your relative's current level of functioning.

#### **Step 2**: Determine in which areas the person wants to and is to improve.

#### Step 3: Develop small steps toward improvement in one or two of these areas.

For example: If the person wants to improve his/her vocational skills, the person may want to start by learning the basics on how to operate a computer. This does not mean enrolling him/her in a complex college program, but maybe starting with an introductory course at a local community centre or learning centre. Encourage the person to set small steps; this increases his/her likelihood of success and helps him/her work toward the longer term goal.

**Step 4:**Choose one area to focus on, and do not move to another until the first has been mastered or your relative becomes too frustrated to continue.

#### **Step 5**: Celebrate success

As each step is accomplished, take the time to congratulate your relative and help him/her to recognize his/her success.

#### **Step 6:** Establish long-term goals

Now that your relative has accomplished some short-term goals, help him/her to identify the long-term goals he/she would like to accomplish for a specific area. For example, if the short-term goal was to learn how to cook and manage money, a long-term goal may be to live on his/her own.

## Facts about> Relapse Prevention Planning

With a serious mental illness, relapse refers to a return of acute symptoms. Brain disorders like schizophrenia, bipolar disorder, clinical depression, and obsessive-compulsive disorder are episodic illnesses, meaning that symptoms or periods of illness come and go. So it makes sense to expect, and be prepared for, an eventual return of acute symptoms, even when the individual is doing fine.

Relapse can occur for a number of reasons, as well as for no apparent reason. An individual may feel discouraged after a relapse, and so it is important to remember that experiencing a relapse is not a "failure." An individual who relapses can recover.

#### Possible RISK FACTORS FOR RELAPSE include:

- It may be that he/she has stopped taking medication, or that the dosage is not high enough to prevent that return of acute symptoms, or even that the medication has stopped working.
- The individual may have a poor doctor-patient relationship, or may not be receiving enough support from community services.
- The individual may have recently experienced severe mental stress the d3eath of a loved one, the loss of a job, a move to a new home.
- The individual is physically exhausted, or is using alcohol or street drugs to feel better.
- The individual may be experiencing anosognosia (lack of awareness of being ill).

#### Keep in mind...

Dr. E. Fuller Torrey writes that the signs and symptoms of relapse tend to be constant for the individual, so **the changes that announced the relapse last time are likely to be THE SAME ones that will signal relapse next time.** 

#### **WARNING SIGNS OF RELAPSE:**

- ☑ Anxiety and tension
- ☑ Trouble concentrating
- ☑ Trouble sleeping
- ☑ Restlessness
- ☑ Depression
- ✓ Not being able to remember things
- ☑ No being able to enjoy things (or loss of interest in things)
- ☑ Being preoccupied with one thing
- ☑ Denial of illness
- ☑ Talking in a nonsensical way
- ✓ Negative thoughts about oneself
- ✓ Negative beliefs about others
- ☐ Changes in expression of feelings (more hostile or increase episodes of euphoria; extreme moods)
- ☑ Changes in personal care (stops bathing or changing clothes)
- ☑ Changes in appetite (usually eating less)
- ☑ Changes in level of activity (increases or decreases)
- ☑ Changes in sexual activity
- ☐ Changes in social activity (refuses to see friends or withdraws)

#### **RELAPSE PREVENTION PLANNING may include:**

- ✓ Getting more rest
- ☑ Reducing stress (work or other obligations)
- ☑ Exercising
- ☑ Structured routine
- ☑ Changing medication dosages
- ☑ Increased visits with the doctor or psychiatrist
- ☑ Education and awareness about relapse
- ☑ Developing an individual prevention plan, and following this plan when symptoms of relapse begin to emerge

As the last point emphasizes, knowing the course of the illness in the individual is most important in taking steps to avoid a relapse.

#### PERSONAL RELAPSE PREVENTION PLAN

SIGNS OF RELAPSE (List behaviours that indicate signs of relapse)		STRATEGIES (List possible coping methods)	

## **Tools**> Dealing With A Crisis Situation

In a crisis, it is very important to stay in control of your emotions and reactions. Maintaining this control will enable you to cope and help your ill relative through this difficult time.

Families who have been through psychotic episodes warn that no amount of preparation can fully protect you from the shock and panic you will feel when the ill person enters this stage.

Learning about Schizophrenia: Rays of Hope (Schizophrenia Society of Canada)

#### **GUIDELINES THAT MAY HELP IN A CRISIS:**

#### ☑ Do's

**Try to remain as calm as possible**— Speak slowly and clearly in a normal voice. Make statements about the behaviour you are observing: "You are afraid/angry/confused. Please tell me what is making you afraid, etc." Repeat questions or statements when necessary, using the same words each time.

**Decrease other distractions** – Turn off the television, radio, etc. If other people are present, ask them to leave the room. Talk one at a time. Try saying, "let's sit down and talk," or "let's sit down and be quiet."

**Allow the person to have personal "space" in the room**— Understand that too much emotion on your part can upset the individual further.

#### **図** DON'TS

**Don't shout.** If the person appears not to be listening to you, it may be because other "voices" are louder.

**Don't criticize.** The individual cannot be reasoned with at this point.

**Don't challenge** the person into acting out.

Avoid continuous eye contact.

Don't block the doorway.

**Don't argue** with other people about what to do.

## A Family Crisis Plan<sup>1</sup>

#### What is a Family Crisis Plan\*?

- These are plans designed by the person who experiences mental illness and his/her family to assist in the management of a crisis if and when it occurs.
- Crises are often experienced by the mentally ill and their family members.
- It is helpful to have a crisis plan to follow and support teams in place to help you according to your wishes, in the event of a crisis.

#### Who are these plans for?

These plans are for people with a mental illness and their family members who have no case manager support and no formal community supports from the mental health system.

#### **Your Family Crisis Plan Form**

- Prepare your plan when your family member is well and thinking clearly.
- Discuss your plan with your family and members of your support teams.
- You may wish to have them assist you in the design of your plan.
- Be sure to sign and date your Individual Crisis Plan Form.

#### Your Information Release and Confidentiality Form

- This form must be signed by the family and each support team member.
- Keep the originals in a safe place.
- It is advisable to revise this form every 6 months to a year.

#### Working with your support team

Give each member of your team a copy of your Family Crisis Plan Form and the Information Release and Confidentiality Form when completed so they can give you the support you wish as you resolve your crisis.

#### How this works

When you phone any members of your support teams because your family is in a crisis due to the mental illness of a family member or loved one, these forms ensure that everyone:

- Knows your plan as you have laid it out
- Can help according to your wishes
- Knows who else is on your support team and can work with them to help you
- Knows they are legally protected as they work to help you resolve the crisis

<sup>&</sup>lt;sup>1</sup>Family Mental Health Initiative of Simcoe County, 5 Bell Farm Road, Barrie ON L4M 5G1 Ph: 705-725-0363

#### When your Crisis Plan may not work

If your crisis situation is life threatening or could possibly cause you or others bodily harm, the family's wishes as outlined in the Individual Crisis Plan may not be respected.

#### Emergency phone numbers to keep on hand to call in a crisis:

- ◆Support team members ◆ Family members ◆ Parents ◆ Mental health crisis line ◆ Family doctor ◆ Psychiatrist
- ◆ Baby sitter ◆ Friend ◆ Others

#### When the police get involved

People who have been through a crisis agree that they were hesitant to call the police. They felt that they were treating the ill individual as a criminal, and that they were giving up and abandoning the person. However, in some situations they had no other choice. Many people discovered that the statement, "I am calling the police," calmed the individual.

#### When you phone the police:

- Explain that the individual is in urgent need of medical help, and he/she has been diagnosed as having a mental illness (if this is the case)
- Briefly describe what the individual is doing (making threats, damaging property); state that you need police assistance to get the person to a hospital
- Make sure that the police know whether the individual is armed, or if there are accessible weapons nearby

Some police forces have specially trained officers who know how to handle psychiatric emergencies. Some police officers have little knowledge of, or experience in dealing with this sort of crisis. Your own attitude or emotional state may be a factor in conditioning police reaction (for example, a hostile reaction to an officer misunderstanding an important detail will only cause more tension).

Once they have arrived, the police will try to assess the situation and decide what should be done. While the police are present, you may have the chance to phone the individual's doctor or psychiatrist to ask for advice. Inform the policed if you have been advised by the doctor to take the person to a particular hospital.

After the police have the information they need, they may take your relative to a hospital emergency department. If you are not able to go to the hospital, ask the police to phone you back and let you know what has happened. You will want to find out if your relative has been admitted to the hospital, and whether or not treatment is being given. Keep a record of all of the information.

# **Crisis Plan**

[ INDIVIDUAL CRISIS PLAN ]		
Name:		
Address:		
Phone Number:		
My informal support team in	ncludes	
1		
2		
My formal support team inc	ludes	
Family doctor:		
•		
Outlined below is what my illness:	family and I would like to happen if I am in crisis as a result of	of menta
Crisis A)		
The situation:		
My plan:		
iviy pian.	Suggestion: Use separate sheets for various	
Crisis B)	types of crisis situations and your plans to	
Crisis B)	resolve them. Focus on specific situations and	
The situation:	the resolution for each, including the support	
My plan:	members who can best help you in each	
Crisis C)	particular situation.	
The situation:		
My plan:		
iviy pian.		
	It of my mental illness appears to be life threatening, or if my actions may result in bodiny support team are not obligated to follow my plans as outlined in the Family Crisis Pla	
DATE:	SIGNATURE:	

[ FAMILY CRISIS CONTACT	IST]	
COMMUNITY CRISIS LINE:_		
FAMILY DOCTOR:	(Name)	
	(Phone)	
PSYCHIATRIST:	(Name)	
	(Phone)	
COMMUNITY MENTAL HEA	TH TEAM:	
MENTAL HEALTH EMERGEN	CY SERVICES:	
CRISIS PLAN NOTES:		

If possible, this plan should be discussed with the individual when he/she is well.

[ POLICE CRISIS INFORM	MATION ]		
Please take this person to	_		Hospital.
<b>IMPORTANT:</b> This person compassion and dignity. T		on has a mental illness. Please	treat him/her with
Name			Age
Hair colour	Eye colour	Height	Weight
Current medications & do	se		
Suicidal		Violent	
Date of last doctor visit			
Date of last hospital visit_		How long	
Name of doctor			
Doctor's phone			
Emergency contact persor	1		
Relation to patient			
Contact person address			
Day phone			
Night phone			

<sup>&</sup>lt;sup>2</sup>Adapted from How to Live with a Mentally III Person: A Handbook of Day to Day Strategies by Christine Adamec (NY: J. Wiley & Sons, 1996)

## Facts about > Suicide

**FACT:** 90% of suicide victims have a diagnosable psychiatric illness.

**FACT:** 80% of suicides are carried out by persons who have a depressive illness.

**FACT:** Women make 3—4 times more suicide attempts than men. But men complete suicide more often, probably because they choose more lethal methods.

**FACT:** 40% of people with schizophrenia attempt suicide and 10% complete the act.

**FACT:** Thoughts of taking one's own life are so common in mood disorders that they are considered a symptom of the disorder.

Sometimes a suicide is methodically planned and deliberately committed. At other times, a suicide may be accidental—that is, the victim is acting out a hallucination or delusion when in a psychotic state. Someone experiencing psychosis will be unaware that he/she is endangering himself/herself. Some individuals have walked out onto busy highways late at night or jumped off balconies believing that no harm would befall them. In either of the above situations, there are some preventive measures you can take, although you can never guard completely against the possibility of suicide. The first step in prevention is to know the warning signs.

#### Warning signs of suicide

The following are some signs that an individual may be at risk of suicide:

- ☑ Exhibits feelings of worthlessness
- ☑ Expresses hopelessness about the future
- ☑ Hears voices instructing him/her to hurt or kill himself or herself
- ☑ Expresses a sense of powerlessness to change his/her situation
- ☑ Abuses drugs and alcohol
- ☑ Has recently experienced a loss such as a death of a relative or friend, a separation, loss of job, home, money, status, self-esteem, or health
- ☐ Talks about killing himself/herself ("Everyone would be better off without me")
- ☑ Has access to lethal means (such as weapons or pills)
- ☑ Has a specific plan for how he/she would kill himself/herself
- ✓ Neglects his/her physical appearance and personal welfare
- ☑ Makes "goodbye" gestures, making out a will, giving away favourite possessions
- ☐ Has made previous attempts, or makes suicidal gestures (cutting his/her wrists, taking to many pills).
- ☑ Exhibits sudden changes in mood from severe depression to inexplicable happiness.
- ☑ Feels indestructible in a manic or delusional state.

#### Assessing the level of risk

Someone's likelihood of suicide is usually expressed in one of the following ways (listed in order of increasing risk and seriousness):

- **1. Ideation:** thoughts or feelings about harming or killing oneself without any immediate plan or intention of acting on the feelings.
- 2. **Gestures:** Self-destructive acts that a person connects with feelings or thoughts of suicide (taking 10 aspirins); these are often a way for the person to communicate his/her feelings to others and should be responded to.
- **3. Attempts:** an action with a potentially lethal outcome.

#### What to do if someone is suicidal

- 1. TALK ABOUT IT. Many people do not want to broach the subject for fear that talking about suicide may give someone an idea and that this would make a tense situation worse. It's more likely that the individual may feel relieved to be able to talk about it. Talking about it will also help inform you about the steps you can take to aid the individual, and will allow you the opportunity to urge him/her to seek professional help.
- 2. GET HELP IMMEDIATELY. It's important to take the threat seriously. People sometimes mistakenly think that those who talk about suicide don't do it. Do not assume that the individual is being melodramatic, or making a big deal out of something you think is less significant. It is extremely important to get help as soon as possible. An individual who feels suicidal may be afraid to admit it for fear of being told he/she is stupid, foolish, or manipulative. When someone does come forth with his/her honest feelings, it is vital that he/she is met with help. Contact the individual's doctor, family and friends to build a stronger support network. If you don't know what to do, call a professional for help, such as a community mental health service or suicide hotline.
- 3. BE SUPPORTIVE. Listen in a non-judgmental, compassionate manner. This gives the individual an opportunity to vent his/her feelings and offers the person relief from being alone with his/her pain. Reassure the person that there is help for his/her problems and that the person is not "bad" or "stupid" because he/she is thinking about suicide. Ask the individual to make an agreement to not act on any plans he/she is thinking about suicide. Ask the individual to make an agreement to not act on any plans he/she may have made without first talking to you, a mental health professional, or a hotline. Remove any objects that the individual could use to harm himself/herself. Remind the person of recent accomplishments. Patience and empathy are necessary. Express your concern and care, and your willingness to help.

**An important note:** Occasionally, a suicide occurs without warning and nothing can prevent it from happening. Also consider seeking help for yourself, as you may have experienced intense anxiety and worry from this incredibly stressful situation.

#### Hospitalization through involuntary admission

#### How does someone become an involuntary patient?

There are two reasons for a person being held as an involuntary patient: (1) the person is a danger to himself/herself, another person, or may unintentionally injure himself/herself; Or (2) the person's condition is deteriorating and he/she requires hospitalization. In most provinces and territories, physicians have the legal authority to commit a person to an in-patient ward.

#### What happens during an involuntary admission?

The first priority is to ensure a patient's safety. To do so, hospital staff needs to know his/her medical and psychiatric history, including a complete history of medication and allergic reactions. If the immediate safety of the ill person is at risk, he/she will likely be medicated promptly. It is vest if the ill individual agrees to take oral medication, giving him/her a sense of participation in resolving the crisis. If the person cannot be convinced, however, the physician can insist on an injectable medicine.

Once safety is established, a full assessment begins. The first step is often a thorough psychiatric examination, physical check-up, and a psychosocial assessment regarding the patient's entire life circumstances. Family members or close friends can provide crucial information, both about the circumstances leading up to the current episode and about relevant personal history. When admitted to a hospital, a patient's valuables and money will normally be locked up for safekeeping until discharge. It is worth making a list of these and any items of clothing and other personal effects that the ill person takes to the hospital.

The results of the full assessment should provide a diagnosis and a preliminary treatment plan. For in-patients, that plan almost always includes daily medication. It should also include good nursing care and emotional support provided by hospital staff. In the first few days of the acute phase of illness, it is the medication together with a therapeutic environment that makes up the bulk of treatment efforts. A number of treatment activities can be added in the later stages of hospitalization (or at home if not hospitalized) once the worst of the episode is over.

To the degree that the ill individual becomes able, he/she can:

- Learn more about the illness
- If it was a relapse, try to figure out what may have triggered it
- Negotiate a more long-term treatment plan with the mental health staff
- Communicate with friends and family
- Plan for a gradual return to work or school, after the leave of absence
- Begin to resume recreational activities

Not every patient will be able to begin the long-term treatment activities after a few weeks in hospital; many will need a long stabilization phase. Remember: It is physically exhausting to experience a psychotic episode.

## **Dealing with betrayal**

As Dr. Xavier Amador writes: even if you believe seeking a commitment is the best thing for your family member, it doesn't mean you won't have emotional fallout. The ill individual is likely to feel betrayed and may not be very receptive to talking with you.

These are some of the recommendations from Dr. Amador's book to help mend the relationship:

#### **☑** DO

- Acknowledge the feelings of betrayal
- Explain why you felt you had to do what you did
- Be honest that you would do it again

#### **☒** DON'T

- Deny the feeling of betrayal
- Expect to be forgiven right away
- Blame your loved one for what you felt you had to do
- Be misleading about what you would do in the future

<sup>&</sup>lt;sup>1</sup>I Am Not Sick, I Don't Need Help by X. Amador with A. Johanson (NY: Vida Press, 2000) ISBN-0967718902

# Facts about> How Families Can Advocate For Systems Change<sup>1</sup>

Families can be effective agents of change in mental health systems. They bring knowledge, energy, determination, and a commitment to helping their relatives.

To be an effective advocate, family members need to learn what system changes for their loved one and others living with mental illness.

#### Individual advocacy for your relative:

- Get a comprehensive evaluation. Mental illnesses are complex and at times confusing. A full assessment often involves several visits. Effective treatment depends on a careful and accurate diagnosis.
- Insist on the best. Talk to physicians, therapists, guidance counsellors, and other families. Find out who in your community has the most experience and expertise in evaluating and treating your relative's particular illness. Check the clinician's credentials carefully. Are they appropriately licensed or certified in your province? If he or she is a physician, are "Board Certified"?
- Ask a lot of questions about any diagnosis or proposed treatment. Encourage your relative to ask any
  questions he or she may have, as well. Remember that no one has all the answers, and that there are
  few simple solutions for complex psychiatric disorders. In addition, all treatments have both risks and
  benefits. Make sure you and your relative understand the full range of treatment options available so
  you can make a truly informed decision.
- Insist on care that is "client centered" and which builds on your relative's strengths. Ask about specific
  goals and objectives. How will you know if treatment is helping? If the problems persist or worsen, what
  options and alternatives are available?
- Ask about comprehensive "wrap around" or individualized services, geared specifically to the needs of your relative and family. Are such services available in your province or community? If not, why not?
- Be prepared. One of the most important things you can do to help your loved one is to keep all
  information, including past consultation and treatment reports, in an organized place. Records can easily
  be misplaced, delayed, or even destroyed. Maintaining a file with all relevant information can help avoid
  unnecessary duplication of previous treatment efforts.
- Feel free to seek a second opinion. Any responsible mental health professional will be glad to help with referrals or by sharing information. If you or your loved one has questions about the diagnosis or the proposed course of treatment, by all means arrange for an independent consultation with another clinician.
- Help and support your loved one in his/her efforts to learn about his/her illness. Use books, pamphlets, and the Internet to help your relative understand his/her symptoms and treatment options.

If your loved one is of school age, work with the schools, Insist on access to appropriate mental health
consultation services. You can also suggest in-service training programs to enhance awareness about
mental illnesses. Ask to be included in any and all school meetings held to discuss your loved one's
situation.

#### National or provincial advocacy for all individuals living with mental illness, including your own:

- Become politically active. Meet with your local, provincial, and national government representatives.
   Question candidates about their positions on access to necessary and appropriate mental health services. Decision makers are more likely to be influenced and persuaded by personal stories than by data, statistics, or the opinions of professionals.
- Build coalitions and work with local advocacy and family and mental health organizations such as the Schizophrenia Society of Canada (SSC), the Canadian Mental Health Association (CMHA), Mood Disorders Association, and Anxiety Disorders Association at the local, provincial/regional, and/or national level.
- Support your relative's involvement in self-advocacy. Encourage him/her to connect with consumer/patient groups engaged in advocacy endeavours.
- Fight stigma. Develop an ongoing local education campaign that reiterates the key messages:
  - Mental illnesses are very real illnesses
  - They affect people from a variety of socio-economic and cultural backgrounds
  - Fortunately, They are also quite treatable, especially if treatment begins early and is individualized to the needs of each person
- Use the media. Write letters to the editor and/or pieces on mental health issues. Meet with local reporters covering health care topics. Suggest story ideas to local TV stations.
- Work with local professional organizations. Psychiatrists, psychologists, social workers, psychiatric
  nurses, and mental health counsellors are natural allies with a common advocacy agenda. Professional
  organizations may also have access to resources, including funds for lobbying and/or public education
  initiatives, from their national associations.
- Talk to other families. Seek out and join local family support groups. If none exist, consider starting one. Develop an email "listserv" to facilitate communication. Circulate articles, information, and suggestions about local resources.
- Attend regional and national conferences on issues related to mental illness. Such meetings provide
  information, ideas, camaraderie, and support. Sharing experiences with other families is both helpful
  and empowering.
- Don't give up. Aim for and celebrate incremental victories and accomplishments. Remember, advocacy is an ongoing process!

There's no right or wrong way to be an advocate for your loved one. Advocacy efforts and initiatives should be individualized to your province, community, and the particular issues, circumstances, and needs within your family. Advocacy is also hard work. Even when people want to help and are willing to listen, it takes lots of time and energy to change the system. But when it works, and it often does, the outcome is clearly worthwhile. You really can make a difference, both for your relative, and ultimately for all who need and deserve access to appropriate and effective mental health treatment services.

<sup>&</sup>lt;sup>1</sup><u>Adapted from Advocating for Your Child: 25 Tips for Parents</u> by David Fassler, M.D., Center for the Advancement of Children's Mental health (CACMH), Columbia University