

# Strengthening Families Together

3rd Edition



A REASON TO HOPE. THE MEANS TO COPE.  
SCHIZOPHRENIA SOCIETY OF CANADA  
SOCIÉTÉ CANADIENNE DE LA SCHIZOPHRÉNIE  
UNE SOURCE D'ESPOIR, DE SOUTIEN ET D'ENTRAIDE.

# Strengthening Families Together

3rd Edition

## Helping Canadians Live with Mental Illness

The **Schizophrenia Society of Canada** is interested in hearing from you.

If you find this resource helpful, or if you have any suggestions or questions, please let us know.

E-mail messages can be sent to [info@schizophrenia.ca](mailto:info@schizophrenia.ca), or phone 905.415.2007.

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This edition, designed to meet the needs of a range of families, including those who are newer to psychotic illness, was made possible by a grant from the Crabtree Foundation and Eli Lilly Canada. We thank all of our funders for recognizing the importance of educating families and other member of the natural support community about mental illness and allowing us the freedom to create a responsive, impartial, and flexible program for Canadians. We remain truly amazed by and grateful for their generosity and commitment to excellence.

In addition, the **Schizophrenia Society of Canada (SSC)** wishes to acknowledge the work of the Schizophrenia Society of Ontario (SSO), who in collaboration with the Mood Disorders Association of Ontario (MDAO) began the work of adapting the SFT material to meet the needs of early intervention families.

We would like to acknowledge the following individuals whose feedback contributed to the third edition of Strengthening Families Together: Ms. Deborah Deacon (SSO), Ms. Jay-Me Woods (SSO), Ms. Amanda Varnish-Sharma (SSO), Ms. Catherine Bancroft (MDAO), and Bonnie Pape.

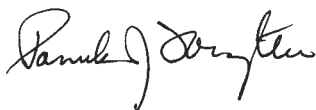
To all of you, we express our sincere appreciation and gratitude. We look forward to the continuing evolution of Strengthening Families Together as the needs of families and their loved ones change, and we remain dedicated to creating a responsive and timely education program.



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# Introduction

# Introduction

Welcome to the Schizophrenia Society of Canada's Third Edition of the Strengthening Families Together Program.

Helping families and friends find ways to cope with psychosis is important to both the ill person and the family as a whole. Siblings may feel disenfranchised, wondering what is going on at home and why their brother or sister is acting so strangely. Family members and friends often feel overwhelmed, hearing for the first time about anti-psychotic medications, early intervention approaches, and what "being psychotic" really means. They may need to adjust their expectations and lifestyle, learn new information about mental illness, psychosis and recovery, and discover the challenges of navigating the health system.

Participating in an education program, such as Strengthening Families Together, gives families and friends an opportunity to discover the information they are searching for in an environment of mutual support. It teaches them how to reduce their own stress levels, and it better equips them to take on their new responsibilities. And it can show them a future where recovery is possible.

## History of the project

In 2003, the Schizophrenia Society of Canada created the first Canadian-based psycho-education program for families and friends of individuals living with schizophrenia. Sponsored by AstraZeneca Canada Inc., **Strengthening Families Together** (SFT) is a 10-session national education program that provides information about living daily with a mental illness for families and friends of individuals with schizophrenia and other related disorders. 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; they can learn how to connect with others through membership in the group or through their local provincial society and chapter/branch.

**Awareness:** Families gain access to reliable and consistent information about mental illness and mental health services; they also develop an understanding of recovery and of the impact of stigma.

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

The primary target group for SFT has traditionally been parents of adult children with schizophrenia. However, with the increase of early psychosis intervention programs throughout Canada, many of our provincial societies are working with more and more families and friends of young people who have recently developed a psychotic illness. The needs of this group are substantially different than the needs of those for whom the original program was developed. Because of the effectiveness of early intervention and our growing understanding of psychotic illnesses, the focus of SFT has shifted from managing illness to recovery.

With appropriate early intervention, the consequences associated with untreated psychosis can be avoided or greatly minimized, and the great majority of people recover well or fully from their initial episode of psychosis.

To reflect this new reality, the SSC, in collaboration with the Schizophrenia Society of Ontario, has created a third edition of the SFT program to meet the needs of all families and friends who are coping with psychotic illness.

## What does “recovery” mean?

The recovery process is dynamic, affected by a number of interacting factors. These include the treatment environment, medication and psychological therapies, factors within the person and factors within the person’s family and social environment. The recovery process will vary from person to person and take different lengths of time for each person. Research shows that active family support can have an important impact on the recovery process.

Specific issues to be dealt with in the recovery phase include helping the person and family make sense of the illness experience and helping the person to re-establish a confident sense of themselves, which will allow them to return to the level of functioning they had before their illness.

Following recovery from a first episode, a significant number of people will never experience a recurrence of psychosis. Others will develop recurring episodes of psychosis, but be relatively well in between and continue to live a productive life.

## Program outline:

Most young people experiencing psychosis for the first time are living in the family home. The family can play a significant role in promoting the recovery of their family member. But, in order to do so, the family too requires education, support, and inclusion in the therapeutic process.

This program has been designed to provide education, skill-building, and support for families with a loved one who is experiencing psychotic illness. It is meant to complement – not replace – early psychosis intervention treatment.

The specific information addressed by the program includes:

- Facts about psychosis – treatment and recovery
- Coping as a family
- Dealing with crisis
- Daily living tips
- Supporting yourself and your loved one
- Effective communication
- Living with mental illness
- Promoting recovery
- Advocacy and understanding the mental health system



# Session 1: Introduction to the Program



# Session 1: Introduction to the Program

handout

## Facts about Strengthening Families Together

Strengthening Families Together is a program of the Schizophrenia Society of Canada. Our mission is to improve the quality of life for those affected by schizophrenia and psychosis through education, support programs, public policy, and research. The program grew out of the strong belief that Canadian families have a right to consistent educational information on psychotic illnesses, regardless of where they reside.

This ten-session national education program for family members and friends of individuals who have experienced psychosis aims at increasing accessibility to Canadian-based information on the topics associated with psychosis and recovery.

Strengthening Families Together is about more than education; it is about strengthening family members and friends of individuals who have experienced psychosis 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 psychosis, treatment options, causes, research, and available mental health services, in the hopes of diminishing the stigma attached to the experience of psychosis.

### Tools

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

## National program with a local connection

While Strengthening Families Together is a nationally coordinated program, it can be adjusted to meet the needs of families at the local level.

- Facilitators are encouraged to: incorporate local resources (such as inviting area professionals as guest speakers and providing information on local services); adjust the order in which the ten sessions are delivered.
- Inspired by the peer support movement, Strengthening Families Together encourages chapter/branch family and consumer volunteers and consumers to become facilitators.
- Each program site is equipped with the core materials to facilitate the program. They include the information on each of the topics, from understanding psychosis to learning about the causes and treatment options to uncovering the maze that is the mental health system.

## Participation guidelines

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

- Include everyone!
- Encourage everyone, 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 discussed in the sessions should be considered confidential and private.



## Glossary of important terms

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** The shortest and most intense period of schizophrenia, when the most serious symptoms are found.

**affective disorder (also known 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** 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).

**akathisia** 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 akathisia.

**akinesia** A state of reduced movement; lack of muscle movement.

**alogia** 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.

**amenorrhea** Absence of menstrual periods. This can be a side effect of antipsychotic medications.

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

**anosognosia** 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** Blocking the action of acetylcholine, one of the chemicals the body makes to help nerve cells communicate with each other. This describes a group of the most common side effects of psychotropic medications, including dry mouth, blurry vision, palpitations, and constipation.

**antidepressant** Medication used to treat depression. See medications.

**antipsychotic** A group of medications used to treat psychosis. There are two 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), akathisia (restless limbs), and tardive dyskinesia (permanent, irreversible movement disorders). See medications, neuroleptics.

**anxiolytics** Medications used to reduce serious anxiety, tension, and agitation. They used to be known as minor tranquilizers.

**apathy** A lack of interest.

**atypical antipsychotics** See antipsychotic, medications.

**avolition** The individual lacks energy, spontaneity, and 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, and then suddenly feel very sad and 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** 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** 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.

**central nervous system (CNS)** The brain and spinal chord. The CNS is responsible for coordinating the activities of all parts of the brain and spinal chord.

**chronic schizophrenia** The long period of time, following a period of acute schizophrenia, during which the symptoms are much less serious.

**cognitive impairment** Cognitive abilities include knowing, thinking, learning, and judging. Cognitive impairment means the individual is experiencing difficulty with memory, concentration, and decision-making. (These are also called executive skills.)

**concurrent diagnosis** A concurrent diagnosis is made when an individual shows symptoms of both a mental illness and 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.)

**CT scanning, computerized tomography** A technique using X-rays or ultrasound waves to produce an image of interior parts of the body. For example, it can be used to view parts of the brain as an aid to diagnosis.

**delusion** 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.

**depersonalization** A feeling that a person is becoming unreal, or that a person's mind is being separated from his/her body. Also known as derealization.

**depression** Feelings of sadness, hopelessness, helplessness, and worthlessness. In many cases the affected individual has a lack of energy and motivation. Sometimes physical symptoms such as slow movement and speech are also present.

**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 known 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** 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** Involuntary movements, usually of the head, face, neck, or limbs.

**dyspnea** Shortness of breath or difficulty breathing.

**dystonia** 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** The buildup of watery fluid in parts of the body.

**electroconvulsive therapy (ECT)** A treatment that is occasionally used for serious depression, catatonic schizophrenia, and mania. A convulsion is produced by passing an electric current through the patient's brain while under general anesthesia. ECT is used primarily for patients suffering from extreme depression for long periods, who are suicidal, and who do not respond to medication or to changes in circumstances.

**electroencephalogram (EEG)** A recording of the electrical activity from various parts of the brain. It is used to study the brain's electrical activity; the results may be used to help make a diagnosis.

**extrapyramidal symptoms (EPS)** 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** Refers to a period where the individual's thoughts become very accelerated.

**florid symptoms** The symptoms are obviously worsening.

**galactorrhea** 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 and childlike to angry and aggressive. A positive symptom of schizophrenia.

**hallucination** A false perception of something that is not really there. Hallucinations may be seen, heard, touched, tasted, or smelled by the ill individual.

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

**hypertonicity** Excessive tension of muscles.

**ideas of reference** The unfounded belief that objects, events, or people are of personal significance. For example, a person may think that a television program he/she is watching is all about him/her.

**inappropriate affect** Reacting in an inappropriate manner, such as laughing when hearing bad news.

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

**limbic system** Group of brain structures composed of the hippocampus and amygdala. Associated with memory storage, the coordination of autonomic functions, and the control of mood and emotion.

**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** 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.

**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 to separate generic names from brand names to reduce confusion.

- **antidepressants:** these are normally slow-acting drugs, but if no improvement is experienced after six weeks, they may not be effective at all. Some side effects may occur such as dry mouth, drowsiness, or headaches.
- **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 the blood, skin, liver, and eyes. Periodic monitoring of blood and liver functions is advisable. See antipsychotic.
- **mood stabilizers:** one example is lithium carbonate, which is 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 called mood normalizers.

- **tranquilizers:** generally referred to as benzodiazapines. These medications can help calm agitation and anxiety. Examples include Valium, Librium, Ativan, Xanax, Rivotril.

**mental disorder/mental illness** A term which describes a variety of psychiatric (emotional, thinking, and behavioral) problems that vary in intensity and duration, and may recur from time to time. Major mental illnesses include anxiety, mood, eating, and psychotic disorders. Mental illnesses are diagnosable conditions that require medical treatment as well as other supports.

**mental health** Describes a balance between the individual, his/her social group, and the larger environment. These three 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 and 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.

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

**multifactorial** A term used by doctors in describing the causes of an illness; the term means “multiple factors.”

**multiple personality disorder** A personality disorder categorized by the appearance of two 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.

**neuroleptics** A group of medications used in the treatment of schizophrenia and other serious mental illnesses with psychosis. *See* antipsychotics, medications.

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

**non-compliant** This means that the ill individual is not taking his/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.

**outpatient** An individual who comes to the hospital for medical or surgical care but does not need to remain in the hospital afterwards as a patient.

**paranoia** A mental state that includes unreasonable suspicions of people and situations. A person who is paranoid may be suspicious,

hostile, feel very important, or may become extremely sensitive to rejection by others. 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.

**Parkinsonism** 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 antipsychotic medications. *See* neuroleptics.

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

**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.

**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.

**positron emission tomography (PET)** A technique used to evaluate the activity of brain tissues. PET scanning is used as a research tool in schizophrenia, cerebral palsy, and similar types of brain damage.



**postural hypotension** 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.

**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.

**prodromal phase** The first or early stage of an illness, before the onset of the full-blown illness.

**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** 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** 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** Drugs used in the treatment of mental illnesses. See antipsychotic, medications.

**rapid or sudden onset schizophrenia** The symptoms develop quickly, and the individual experiences dramatic behaviour changes in a matter of a few days or weeks.

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

**recovery** Recovery is both a process and a goal. It is learning to successfully manage a disorder, having control over symptoms, and having quality of life. Recovery is defined differently for each individual, but is generally thought to include measures such as: hopefulness, renewed meaning and purpose, managing the symptoms of schizophrenia, remission from substance abuse, living independently, having a job, having friends and social support, and quality of life.

**residual schizophrenia** Signs of schizophrenia which may remain in some people after the most serious schizophrenic episode has passed.

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

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

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

**serotonin** 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.

**serotonin-dopamine antagonists (SDAs)** Also known as “atypical” or “newer” antipsychotics. Unlike their predecessors, this newer class of medications treats both the positive and negative symptoms of schizophrenia and other serious mental illnesses, with fewer side effects. Examples include Seroquel (quetiapine fumarate), Clozaril (clozapine), Zyprexa (olanzapine), and Risperdal (risperidone). See antipsychotics, medications.

**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 tremours, 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 caused by medication. See antipsychotics, extrapyramidal symptoms, medications, neuroleptics.

**split personality** There is no such thing as a “split personality.” This is a common mistaken belief about schizophrenia. See multiple personality disorder.

**stereotypical behaviour** A description of repeated movements that have no obvious cause and are more complex than a tic. The movements may be repeated in a regular sequence; for example, rocking backwards and forwards or rotating the body.

**stupor** 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** 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** This term refers to a person’s belief that thoughts have been stolen from his/her mind. Also known as thought withdrawal.

**thought broadcasting** This term refers to a person’s belief that his/her thoughts are being made known to others, usually through the radio or television.

**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 delusion – 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 a person's belief that thoughts are being put into his/her mind.

**topectomy** 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 medications and other treatment methods have not been effective.

**torticollis** A contraction of one or more of the neck muscles on one side, resulting in an abnormal position of the head. Also called wry neck. See dystonia.

**tranquilizer** A medicine which produces a calming effect. The so-called "major tranquilizers" are used to treat serious mental disorders; the minor tranquilizers are often used to treat anxiety.

**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.

**typical antipsychotics/standard antipsychotics** Older, first-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.

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

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## Recommended book list

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 they offer very personal points of view that may help you feel less alone.

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

- For books, it helps to have both the title of the book and the author's name.
- For articles, you'll need the title of the journal, title of the article, author's name, volume number, and year of publication. Some mental health organizations have small libraries where you can borrow books. You may be asked for a deposit, which is refunded when the books are returned.

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

## Reference books

*Beyond Crazy: Journeys Through Mental Illness* by Scott Simmie and 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*  
ed. Peter J. Weiden (NY: W.W. Norton & Co, 1999) ISBN: 0393703037

*The Broken Brain: The Biological Revolution in Psychiatry* by Nancy Andreasen  
(New York: Harper & Row, 1984) ISBN: 0060912723

*The Burden of Sympathy: How Families Cope with Mental Illness* by David A. Karp  
(NY: Oxford University Press, 2001) ISBN: 0195123158

*Family Caregiving in Mental Illness* by Dr. Harriet P. Lefley  
(Thousand Oaks, Ca: Sage Publications, 1996) ISBN: 0803957203

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*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: Times Books, 1998) ISBN: 0812928997

*Hidden Victims: An Eight-stage Healing Process for Families and Friends of the Mentally Ill*  
by Julie Taillard Johnson (NY: Doubleday, 1988) ISBN: 0385242123

*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) ISBN: 0874779235

*How to Live With a Mentally Ill Person: A Handbook of Day-to-Day Strategies* by Christine Adamec  
(NY: John Wiley & Sons, 1996) ISBN: 0471114200

*I Am Not Sick, I Don't Need Help* by X. Amador with A. Johanson  
(NY: Vida Press, 2000) ISBN: 0967718902

*It's Nobody's Fault: New Hope and Help for Difficult Children and Their Parents* by Harold Koplewicz  
(NY: Times Books, 1996) 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 Ill* 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 Sherry Dinner  
(NY: Lothrop, Lee & Shepard Books, 1989) ISBN: 0688084931

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

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

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

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

*Understanding and Treating Mental Illness: The Strength & Limits of Modern Psychiatry*  
by John Cleghorn with Betty Lou Lee (Toronto: Hogrefe and Huber, 1991) ISBN: 0920887201

*When Madness Comes Home: Help and Hope for the Families of the Mentally Ill* 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: 0874776953

## 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

*Antidepressant Survival Program: How to Beat the Side Effects and Enhance the Benefits of Your 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, L.C. Thériault, & P. Richard  
(Beresford, NB: Publik-Art Ltd., 1992) ISBN: 0969659504

*Riding the Roller Coaster: Living with Mood Disorder* by Marja Bergen  
(Kelowna: Northstone, 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 and 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>

*Understanding Depression: A Complete Guide to its Diagnosis and Treatment*  
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, B.C.: 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. Amador (NY: The Free Press, 1996) ISBN: 0684824078

*You Mean I Don't Have to Feel This Way?* by Collette Dowling (NY: Scribner, 1991) ISBN: 0684192578

## Recovery

*A Journey to Recovery: A Consumer and Family Guide to Assessment and Treatment* (2007), is a new resource from the Schizophrenia Society of Canada that provides consumers and family members with plain-language information on the clinical treatment of schizophrenia. It was produced through a partnership between the SSC and the Canadian Psychiatric Association (CPA). The project adapted the CPA's *Clinical Guidelines for the Treatment of Schizophrenia* into a user-friendly format to assist consumers and families as they navigate their way through assessment and treatment of the illness. Available for download at: <http://www.schizophrenia.ca/mysql/CPAGuidelinesFinalE.pdf>

*Mental Illness: a Guide to Recovery* (2004), by Bob Bennett. Using his own experience of recovery and the accompanying learning, Bennett provides information on both mental disorders and practical skills for recovery.

*On Our Own* (1978), by Judi Chamberlin has been referred to by some as the “psychiatric survivor’s bible.” L.R. Frank, a co-founder of the Network Against Psychiatric Assault and Madness Network News, states that, “no other book in the field has done more to educate the public about abuses inherent in the psychiatric system and about the possibilities of positive individual and social change outside the psychiatric system. By pointing out some of the ways in which people can understand themselves better and work for and with each other, *On Our Own* has enabled many who have borne psychiatric labels to turn their lives around, to live their lives happily, creatively, and meaningfully.”

*On Our Own Together* (2005), edited by Sally Clay, provides an in-depth look at eight successful peer-run programs for adults with serious mental illnesses. It provides an understanding of the philosophy, work, and healing power of peer-run programs.

*Out of the Shadows at Last: Transforming Mental Health, Mental Illness and Addiction Services in Canada* (2006), is the final report of the Standing Senate Committee on Social Affairs, Science, and Technology. This in-depth report includes excerpts from many of the thousands of personal testimonies presented to the committee by consumers and family members.

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*PACE Recovery READER* (2003), provides research-based documentation for the *PACE Recovery Workbook* produced by the National Empowerment Center in Lawrence, Massachusetts. The reader includes articles from clinicians, first-person accounts, and recovery research reports.

*Psychological and Social Aspects of Psychiatric Disability* (1997), edited by Spaniol, Gagne, and Koehler, provides a variety of articles examining the experience of mental illness and recovery from consumer, family, and clinical perspectives. An excellent introduction to the concept of recovery.

*Recovered, not Cured: a Journey Through Schizophrenia* (2002), by Richard McLean is a unique first-person narrative account. Using a creative combination of his own words and illustrations, McLean invites the reader into his world of living with schizophrenia.

*Recovery and Wellness: Models of Hope and Empowerment for People with Mental Illness* (2001), edited by Catana Brown, describes the “recovery model” and shows how to use it more effectively. It examines the major constructs of the model, describes the process, and provides guidelines for incorporating wellness and recovery principles into mental health services.

Recovery and the Conspiracy of Hope (1996), a paper presented at the Sixth Annual Mental Health Services Conference of Australia and New Zealand, Brisbane, Australia, is available for download at [http://www.patdeegan.com/pdfs/articles\\_hope.pdf](http://www.patdeegan.com/pdfs/articles_hope.pdf)

*Recovery from Severe Mental Illnesses: Research Evidence and Implications for Practice* (2006), vol. 1. Edited by Larry Davidson, Courtenay Harding, and LeRoy Spaniol. A broad collection of articles and research reports examining the possibility of recovery and what helps people improve.

*Recovery in Mental Illness: Broadening Our Understanding of Wellness* (2004), edited by Ruth O. Ralph and Patrick W. Corrigan. An excellent collection of articles exploring the phenomenon of recovery from mental illness.

*Return to Community: Building Support Systems for People with Psychiatric Disabilities* (1995), by Paul J. Carling continues to be a very relevant call to action that provides a detailed, practical approach to integrating people with serious mental illnesses into the community.

*Shifting the Paradigm in Community Mental Health towards Empowerment and Community* (2001), a report by Nelson, Lord, and Ochoka, examines the changes in community mental health values, policies, and practices in Kitchener-Waterloo between 1984 and 1988. Published by University of Toronto Press in 2001.

*Upstairs in the Crazy House: The Life of a Psychiatric Survivor* (2002), is the work of Pat Capponi, a leading mental health advocate and well-known psychiatric survivor in Canada. In this book, Capponi describes her experiences of being sent to live in a boarding house and in poverty, and how she rebuilt her life.



## Recovery workbooks

*Pathways to Recovery*, a product of the University of Kansas, School of Social Welfare, is a self-help workbook which may be used individually or in groups. It differs from many other recovery self-help materials in that it does not focus on psychiatric disorders; instead it helps people discover how they can use their strengths and resources to set goals and achieve recovery.

*Wellness Recovery Action Plan (WRAP)*, by Mary Ellen Copeland, is a popular and effective self-help tool for people with a variety of physical and emotional symptoms. WRAP has helped people use their self-help skills more easily to monitor their symptoms, decrease the severity and frequency of symptoms, and improve the quality of their lives.

## 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 & Helping Professionals*  
by R. Miller & S.E. Mason (NY: Columbia University Press, 2002) ISBN: 0231126255

*Family Care of Schizophrenia: A Problem-solving Approach in the Treatment of Mental Illness* by  
Ian Falloon, Jeffrey Boyd, and Christine McGill. (NY: Guildford Press, 984) ISBN: 0898629233

*Getting Your Life Back Together When You Have Schizophrenia* by Roberta Temes  
(Oakland: New Harbinger., 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

*Living with Schizophrenia: A Positive Guide for Sufferers and Carers* 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 Manual for Families, Consumers & Providers* by Dr. E. Fuller Torrey  
(NY: Perennial Library, 1988) ISBN: 0060962496

*Understanding Schizophrenia: A Guide to New Research on Causes and Treatment* 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 and 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

*Obsessive-Compulsive Disorder: New Help for the Family* by H.L. Gravitz  
(CA: Healing Visions Press, 1999) ISBN: 0966110447

*Over and Over Again: Understanding Obsessive-Compulsive Disorder* by Fugen Neziroglu and  
Jose A. Yarura-Tobias (San Francisco: Jossey-Bass Publications, 1997) ISBN: 0600355349

*When Going Through Hell... Don't Stop: A Survivor's Guide to Overcoming Anxiety & Clinical Depression*  
by Douglas Block (Portland: Pallas Communications, 2000) ISBN: 0929671023

*When Once is Not Enough: Help for Obsessive-Compulsives* by Gail Steketee & Kerrin White  
(Oakland, CA: New Harbinger Publications, 1990) ISBN: 0934986878

## Personal stories

*A Brilliant Madness: Living with Manic-Depressive Illness* by Patty Duke and Gloria Hochman  
(NY: Bantam Books, 1992) ISBN: 05503072560

*Angelhead: My Brother's Descent into Madness* by Greg Bottoms (NY: Crown, 2000) ISBN: 0609807145

*An Unquiet Mind: A Memoir of Moods and Madness* by Dr. Kay Jamison  
(NY: A.A. Knopf, 1995) ISBN: 0679763309

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*The Beast: A Reckoning with Depression* by Tracy Thompson  
(NY: G.P. Putnam & Sons, 1995) ISBN: 0399140778

*Call Me Crazy: Stories From the Mad Movement* ed. Irit Shimrat  
(Vancouver: Press Gang Publishers, 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: 0374135029

*Daughter of the Queen of Sheba* by Jacki Lyden  
(Boston: Houghton Mifflin, 1997) ISBN: 0395765315

*The Four of Us* by Elizabeth Swados (NY: Plume, 1993) ISBN: 0452269601

*The Ghosts Behind Him* by Doris Ray (Prince George: Caitlin Press, 1999) ISBN: 0920576779

*Imagining Robert: My Brother, Madness, and Survival: A Memoir* by Jay Neugeboren  
(NY: Morrow, 1997) ISBN: 0688149685

*In the Jaws of the Black Dogs* by John Bentley Mays (Toronto: Viking, 1995) ISBN: 0670861138

*Just Checking: Scenes from the Life of an Obsessive-Compulsive* by Emily Colas  
(NY: Pocket Books, 1998) ISBN: 067102437X

*Mad House: Growing Up in the Shadow of a Mentally Ill Sibling* by Clea Simon  
(NY: Doubleday, 1997) ISBN: 0385478526

*My Mother's Keeper: A Daughter's Memoir of Growing up in the Shadow of Schizophrenia* by  
Tara Elgin Holley & Joe Holley (NY: W. Morrow, 1997) ISBN: 0688133681

*On the Edge of Darkness* by Kathy Cronkite (NY: Doubleday, 1994) ISBN: 038542194X

*Passing for Normal: A Memoir of Compulsion* by Amy S. Wilensky  
(NY: Broadway Books, 1999) ISBN: 0767901851

*Tell Me I'm Here* by Anne Deveson (Camberwell, 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: 0767901908

*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, Canada, K0G 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 (Vancouver: The Family Service of the North Shore, 2000) Order direct from: 101-255 West 1st 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 (Ottawa: Ottawa Hospital, General Campus, August 2000)

*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; e-mail: [bcss.prov@telus.net](mailto:bcss.prov@telus.net)

*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; e-mail [bcss.prov@telus.net](mailto: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; e-mail: [bcss.prov@telus.net](mailto: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

e-mail: [publisher@schizophreniadigest.com](mailto:publisher@schizophreniadigest.com)

website: <http://www.schizophreniadigest.com>

## On-line booklets

The Truth about Schizophrenia: Why You Should Change Your Thinking about Youth's Greatest Disabler.

Edited by Jane Burpee and Chris Summerville. <http://www.mss.mb.ca/booklet.pdf>

Manitoba Schizophrenia Society: <http://www.mss.mb.ca>

British Columbia Schizophrenia Society: <http://www.bcscs.org>

Schizophrenia Society of Nova Scotia: <http://www3.ns.sympatico.ca/ssns>

AMI Quebec – Alliance for Mentally Ill: <http://www.amiquebec.org>

## Video resource list

### **Beyond the Blues: Child and Youth Depression (2004)**

Statistics reveal that depression in youth has increased by one-third in the past thirty years. Untreated, it costs in lost educational opportunities, lost social opportunities, and lost time. Through the personal stories of three young people, this film traces the journey of depression, from early signs to diagnosis and treatment.

### **The Bonnie Tapes (1997)**

Conversations about one woman's struggle with schizophrenia – as seen by her, by her parents, and by her sister.

*What happens when mental illness enters the life of a family? How does the person struck by the illness feel? What are some of the steps on the road to recovery?*

**Order through:** The Mental Illness Education Project [http://www.miepvideos.org/shop/more\\_bonnie.html](http://www.miepvideos.org/shop/more_bonnie.html)

### **Child and Youth Mental Health Series (2005)**

This powerful four-part series offers practical tools for understanding the problems and finding solutions to mental health problems among children and youth; problems include depression, anxiety, and psychosis. Each documentary explores causes, symptoms, impact on family, and treatment. Available through the National Film Board of Canada <http://www.nfb.ca>

### **Families Coping with Mental Illness (1996)**

The ten people in this video discuss the impact and issues related to having a family member with a severe mental illness. Two social workers lead the discussions. The focus is on helping families deal with common problems, avoid mistakes, and deal with the long-term nature of mental illness, and on offering practical solutions. The experience of bipolar disorder and schizophrenia in a child or sibling is discussed, as well as the imperative need for family members to set limits and make time for them to avoid burn out.

Available through the Centre for Addiction and Mental Health (CAMH) lending library at [www.camh.net/about\\_addiction\\_mental\\_health/libraryaudiovisuals.html](http://www.camh.net/about_addiction_mental_health/libraryaudiovisuals.html)

### **First Break (1997)**

Three percent of Canadians will experience a psychotic episode at some point during their lives. This video explores the different outcomes of a first episode of mental illness on three young adults and their families. Shot over a year, the video dispels the myths and questions the stigma associated with mental illness while providing a powerful portrait of coping.

For the making of *First Break*, three young adults and their families courageously come forward and illuminate, with compelling candour, their personal experiences. Over a one-year period, Simon, Ariadne, and Shely allow us to share in their ongoing challenge of living with a diagnosis of mental illness, and its impact on their self-identities and family relationships. As a result, we are provided with a valuable perspective on the hopes, frustrations, and achievements of three young adults whose lives have been dramatically changed by a first break.

Available for purchase through the National Film Board of Canada at [www.nfb.ca](http://www.nfb.ca)

### **I Love You Like Crazy: Being a Parent with Mental Illness (1999)**

Eight mothers and fathers who have mental illness discuss the challenges they face as parents. No one knows how many parents must cope with mental illness while raising children, but it is a far larger number than is generally realized. This video is an introduction to some of the problems these parents are dealing with as they strive to be effective, supportive, and loving mothers and fathers.

Available for purchase through the Mental Illness Education Project, Inc. at [www.miepvideos.org/shop/index.html](http://www.miepvideos.org/shop/index.html)

### **Inside Outside (2004)**

A film by Pat Deegan and Terry Strecker which depicts the experiences of eight persons with substantial histories of institutionalization, as they transition from psychiatric hospitals and nursing homes into the community.

### **Mental Illness in the Family (1997)**

This first film focuses mainly on the subjective effects experienced by a family whose daughter suffers from a severe mental illness. Bonnie has schizophrenia. The emphasis is on ways the family is able to preserve itself, to deal with feelings of helplessness and guilt, and their attempt to preserve secrecy.

### **My Name is Walter James Cross (2001)**

A film written and produced by psychiatrist David Dawson of Hamilton, Ontario. The character Walter James Cross is a composite of some of Dr. Dawson's patients. Walter tells the story of his life with schizophrenia – an excellent depiction of what this experience can be like, especially when scarcely available services and supports fail to focus on recovery.

### **OCD: The War Inside (2001)**

They seem like ordinary people. They have no physical disabilities, and appear as functional as the next person. But their lives have been shadowed by the crippling effects of obsessive-compulsive disorder, a misunderstood anxiety disorder characterized by intrusive thoughts, nagging fears, and ritualistic behaviour. This film documents the personal stories of several individuals who fight to survive a war inside their minds. Their stories reveal a deeper aspect to the disorder, which goes beyond the constant hand washing, door locking, and other repetitive acts typically associated with OCD.

Available for purchase through the National Film Board of Canada at [www.nfb.ca](http://www.nfb.ca)

### **One Day at a Time – A Video (2001)**

In this 28-minute video, several members of a first-episode-psychosis parent-support group in London, Ontario, describe their experiences as parents of young people with psychosis. This video was originally conceived as a means of providing parents new to the experience of psychosis in the family with information and support from other parents. While the video should prove useful in this context, it may also have broader educational and advocacy applications. Order from CMHA National at <http://www.cmha.ca/english/intrvent>

### **Out of the Shadow (2004)**

Susan Smiley, Jonathan Oppenheim, Joel Plotch, et al.

*Out of the Shadow* is the story of Susan Smiley's secret struggle to deal with her mother's schizophrenia within the confines of the public health system. This film is a story of madness and dignity, shame, and love, illuminating a national plight through one family's journey. Available at [www.outoftheshadow.com](http://www.outoftheshadow.com)



### **The Politics of Memory**

A presentation by Patricia Deegan, examines how the history of psychiatric treatment has been recorded by mental health professionals and others. This powerful and emotionally provoking film supports the argument behind the consumer/survivor empowerment movement. This film is available for purchase at: [www.patdeegan.com](http://www.patdeegan.com)

### **Recovery: the experience and the evidence**

A film by Patricia Deegan. In this presentation Pat recounts her experiences with schizophrenia and her subsequent recovery. She also presents the viewer with the evidence supporting the concept of recovery in a variety of research studies. This film is available for purchase at: [www.patdeegan.com](http://www.patdeegan.com)

### **Voices of Resiliency (2006)**

*Voices of Resiliency*, produced by the Manitoba Schizophrenia Society, was filmed in large part during the Schizophrenia Society of Canada's "Voices of Resiliency" conference, held in Winnipeg in July 2006. A candid look at a cross-section of people living with schizophrenia and depression – each with their own story of recovery. Hear the heart-warming and thought-provoking stories of people who are living proof that mental illness is not what it used to be... Recovery is possible! To order please visit [http://www.mss.mb.ca/dvd\\_form.php](http://www.mss.mb.ca/dvd_form.php)

### **West 47th Street (2003)**

A documentary which follows four individuals through their experiences at Fountain House, the original Clubhouse in New York City. This is another powerful documentary, depicting the value of empowerment, as well as the hope of recovery fostered in an environment promoting self-determination and personal responsibility. To order, contact Lichtenstein Creative Media <http://www.LCMedia.com>

## 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:

- 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 provide links to other sources of information.

### Anxiety disorders

<http://www.anxietybc.com> Anxiety Disorders Association of British Columbia

<http://www.adam.mb.ca> Anxiety Disorders Association of Manitoba

<http://www.anxietyontario.com> Anxiety Disorders Association of Ontario

<http://www.anxietynetwork.com> The Anxiety Network

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

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

<http://www.amiquebec.org> Alliance for the Mentally Ill in Quebec

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

<http://www.bpsso.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

## Session 1: Introduction to the Program | handout

<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 & Anxiety Treatments

<http://www.depression.org> National Foundation for Depressive Illness (USA)

<http://www.eufami.org> European Federation of Family Associations 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

### Early intervention in psychosis

<http://bcss.org> British Columbia Schizophrenia Society

<http://www.cmha.ca/english/intrvent/> Canadian Mental Health Association Early Psychosis Intervention Project

<http://www.gethelpearly.ca> Ontario Working Group on Early Intervention in Psychosis

<http://www.psychosissucks.ca/epi> Fraser Health Authority Early Psychosis Intervention Project

<http://www.thesoonerthebetter.ca> Early Psychosis Treatment Service Calgary Health Region

<http://www.pepp.ca/index.html> The Prevention and Early Intervention Program for Psychoses, London, ON

[http://www.camh.net/About\\_CAMH/Guide\\_to\\_CAMH/Mental\\_Health\\_Programs/Mood\\_and\\_Anxiety\\_Program/guide\\_early\\_intervention.html](http://www.camh.net/About_CAMH/Guide_to_CAMH/Mental_Health_Programs/Mood_and_Anxiety_Program/guide_early_intervention.html) Centre for Addiction and Mental health Mood and Psychosis Early Intervention Clinic

<http://www.gethelpearly.ca> Ontario Working Group on Early Intervention in Psychosis

<http://www.lynxtracks.ca/early.html> Early Psychosis Intervention program, Peterborough ON

## Outside Canada

[www.prime.unc.edu/](http://www.prime.unc.edu/) PRIME (USA and Canada)

<http://auseinet.flinders.edu.au/> Early Intervention Network for Mental Health in Young People, Australia

[www.eppic.org.au](http://www.eppic.org.au) Early Psychosis Prevention and Intervention Centre (EPPIC), [www.iepa.org.au](http://www.iepa.org.au)  
International Early Psychosis Association (IEPA), Melbourne, Australia

[www.earlypsychosis.org/](http://www.earlypsychosis.org/) Early Psychosis Australia

[www.cdhb.govt.nz/totara/default.htm](http://www.cdhb.govt.nz/totara/default.htm) Totara House, New Zealand

[www.youthline.co.nz/index.htm](http://www.youthline.co.nz/index.htm) Youthline New Zealand [www.trippin.co.nz/contents.html](http://www.trippin.co.nz/contents.html) Trippin, New Zealand

[www.iris-initiative.org.uk/](http://www.iris-initiative.org.uk/) Initiative to Reduce the Impact of Schizophrenia, UK

[www.tips-info.com](http://www.tips-info.com) TIPS – an information program to reduce the duration of untreated psychosis, Norway

[www.swepp.ch/](http://www.swepp.ch/) SWEPP, Switzerland

[www.lightship.org/home.htm](http://www.lightship.org/home.htm) Beacon of Hope (USA)

## General mental health websites

<http://www.nami.org> National Alliance for the Mentally Ill (USA)

<http://www.narsad.org> National Alliance for Research on Schizophrenia & Depression (USA)

<http://www.nisad.org.au> Neuroscience Institute of Schizophrenia and Allied Disorders (Australia)

<http://www.nmha.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

<http://www.lightship.org> The Beacon of Hope. Help for the partners of those touched by mental illness

<http://www.mentalhealth.com> An award-winning site with an encyclopaedic 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> An online resource for schizophrenia and mental health information

## Mood disorders

Some provinces do not yet have mood disorders associations. The national website has useful links for various regions in Canada.

National <http://www.mooddisorderscanada.ca>

Alberta <http://www.obad.ca>

British Columbia <http://www.mdabc.ca>

Manitoba <http://www.depression.mb.ca>

Ontario <http://www.mooddisorders.on.ca>

Quebec <http://amiquebec.org>

## Recovery

CMHA – Empowerment and Recovery in Mental Health  
[http://www.cmha.ca/bins/content\\_page.asp?cid=284-683-1480-1497-1511-1471&lang=1](http://www.cmha.ca/bins/content_page.asp?cid=284-683-1480-1497-1511-1471&lang=1)

National Empowerment Center <http://www.power2u.org>

Pat Deegan and associates [www.patdeegan.com](http://www.patdeegan.com)

## Schizophrenia

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

<http://www.schizophrenia.ab.ca> Alberta

<http://www.bcss.org> British Columbia

<http://www.mss.mb.ca> Manitoba

<http://www.schizophrenia.ca/ssnb> New Brunswick

<http://www.ssnl.org> Newfoundland and Labrador

<http://www.ssns.ca> Nova Scotia

<http://www.schizophrenia.on.ca> Ontario

E-mail: [schizophreniapei@pei.aibn.com](mailto:schizophreniapei@pei.aibn.com) Prince Edward Island

<http://www.schizophrenie.qc.ca> Quebec

<http://www.schizophrenia.sk.ca> Saskatchewan

<http://www.schizophrenia.com> 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

## Facts about mental illness

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 the 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 Canadians 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.** A person’s thinking, feeling, and relating are disrupted. All family members are affected.
- **Treatable!** Appropriate medical care and rehabilitation enable many people to recover and live productive lives.

**Severe mental illnesses are NOT:**

- **Anybody’s fault.** They are not caused by poor parenting or weak character.
- **A life sentence.** Great advances have been made in understanding brain functioning, and with appropriate treatments and supports, people can recover.
- **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.

## Did you know?

Of the ten leading causes of disability worldwide, five 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 \$7.33 billion in 1993. Less than 4% of medical research funding goes to mental illness research.

## Psychosis

- The word “psychosis” is used to describe conditions which affect the mind, where there is some loss of contact with reality. Psychosis varies greatly, and the term covers a number of related illnesses.
- Psychosis is most likely to occur in young adults and is quite common. Around 3 out of every 100 people will experience a psychotic episode, making psychosis more common than diabetes.
- Psychosis is found all over the world, in all races, in all cultures, and in all social classes.
- With time and the right treatment, most people make a full recovery from the experience. Many may never have another episode. A minority experience psychotic symptoms on a daily basis.
- Psychosis can happen to anyone. Like any other illness, it can be treated.

## Mood disorders

- They can occur at any age. Approximately one in four of all women and one in eight 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 to 2% of the population.
- 80 to 90% of people with major depression can be treated successfully.
- During their lifetime, about 5 to 12% of men and 10 to 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.

## 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 one-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
<b>Mood disorders</b>	
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%

\*Estimated percentage of the population who have the disorder during any one 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 style="list-style-type: none"> <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 style="list-style-type: none"> <li>• Insulin</li> <li>• Diet changes</li> <li>• Healthy lifestyle</li> </ul>
Cancer	Lungs	<ul style="list-style-type: none"> <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 style="list-style-type: none"> <li>• Surgery</li> <li>• Chemotherapy</li> <li>• Radiotherapy</li> <li>• Healthy lifestyle</li> </ul>
Mental Illness	Brain	<ul style="list-style-type: none"> <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 style="list-style-type: none"> <li>• Medication</li> <li>• Psychotherapy</li> <li>• Support systems</li> <li>• Healthy lifestyle</li> </ul>

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

## Recovery

- Recovery is both a process and a goal. It is learning to successfully manage a disorder, having control over symptoms, and having quality of life.
- Recovery is defined differently for each individual, but is generally thought to include measures such as: hopefulness, renewed meaning and purpose, managing the symptoms of psychosis, living independently, being engaged in meaningful activity, having friends and social support, and quality of life.
- Family members and friends need to know that recovery can be a long road, full of ups and downs.
- Families are on their own journey of recovery as they deal with the personal “chaos” and losses that they experience.
- Families can help by engaging in their own recovery process, while being as supportive, understanding, and patient as possible as their loved one finds his/her way.
- People who are recovering tell how important it is to have someone who believes in them and maintains hope.

## What helps people recover?

- People move toward recovery on different paths, so the supports that are needed are different for each individual.
- Love and support from family and friends are key elements in recovery.
- Most people with mental illness report that recovery involves reaching their personal goals in life.
- A range of options, such as self-help groups, access to integrated treatment of mental health and substance use problems, and vocational and housing support help promote recovery. The first step to recovery can occur in any number of situations, circumstances, and/or events, which may lead a person to seek treatment or a self-help alternative.
- Getting enough exercise and rest and eating well are all essential to maintaining recovery. Light exercise, such as a daily walk, helps people feel better physically and helps counteract the side effects of some medications.
- It is important to note that recovery occurs as a result of a person’s internal desire to change his/her life. Service providers may facilitate but not force this process.

## Sources:

Mental Illness Awareness Week Guidebook 2001, Canadian Psychiatric Association.

<http://www.cpa-apc.org/MIAW/guidebook/facts.asp>

Basic Facts About Schizophrenia, British Columbia Schizophrenia Society. <http://www.bcscs.org>

Youth's Greatest Disabler, Schizophrenia Society of Canada. <http://www.schizophrenia.ca/info.html>

Ten Facts You Should Know about Schizophrenia, Schizophrenia Society of PEI.

<http://www.schizophreniapei.pe.ca/QuickFacts.html>

Mood Disorders Association of Manitoba. <http://www.depression.mb.ca/facts.htm>

Centre for Addiction and Mental Health. [http://www.camh.net/depression/understanding\\_depstats.html](http://www.camh.net/depression/understanding_depstats.html)

Centre for Addiction and Mental Health. [http://www.camh.net/depression/understanding\\_depstats.html](http://www.camh.net/depression/understanding_depstats.html)

Mood Disorders Association of Manitoba. <http://www.depression.mb.ca/facts.htm>

*Mental Illness Awareness Week Guidebook 2001*, Canadian Psychiatric Association.

*The Last Taboo*. Scott Simmie and Julia Nunes (Toronto: McClelland & Stewart, 2001), p.122.

Centre for Addiction and Mental Health. [http://www.camh.net/depression/understanding\\_depstats.html](http://www.camh.net/depression/understanding_depstats.html)

*A Report on Mental Illnesses in Canada*. Chart Health Canada. Ottawa, October 2002.

<http://www.hc-sc.gc.ca/pphb-dgsps/publicat/miic-mmac>

## 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” or that “something is not right.” The person who is ill usually becomes distant. The change in behaviour 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 which specific illness is affecting the individual.

Diagnosis is based on 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. A person’s diagnosis may even change over time.

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 fourth 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.

### 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, friends, social workers, school, police, or other authorities.

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

- 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 individual, 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/her brain disorder.

## The biopsychosocial model

Serious mental illnesses are complex illnesses that are defined by their symptoms. In considering the causes of these symptoms, doctors are concerned with biological, psychological, and social factors that affect the person. Each of these areas may contribute to the cause of mental illness, and each is also considered important in the treatment process. The word for this is *Biopsychosocial*.

**bio = biology:** This deals 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.

**psycho = psychology:** 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 social environment, including cultural background and stressful events. Intervention involves setting up support systems for the individual.

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

## 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. One of them is a multiple-choice question, and you may have multiple answers.

- How many movies have you seen with characters who had a mental illness?
- How many of those characters were:
  - quiet, unassuming neighbours
  - hardworking, struggling artists
  - dangerous, violent individuals with no friends
  - 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.

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 inaccurately (for example, *The Snake Pit*; *The Cell*; *Me, Myself & Irene*). The media often show 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, the ongoing stigma surrounding mental illness is an unacceptable reality.

Society’s understanding about serious mental illnesses lags far behind the facts. People with mental illness are discriminated against because of general ignorance. People with mental illnesses carry, 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, because of their illness, they are 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.



## Myths about mental illness

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

### The fear of danger

In today's media reports about mental illness, there is a tendency to emphasize a supposed link between violence and mental illness. News stories regularly suggest that there is a strong connection between mental illness and crime. But the majority of people who are violent do not suffer from mental illnesses. In fact, people with a mental illness are more likely to be the victims, rather than the perpetrators, of violence.

Because the media often quote dramatic statistics to underscore their case, a look at the broader picture is essential. For example, studies have found that the rate of violence (defined as threatening, hitting, fighting, or otherwise hurting another person) for people with mental illness is 3 to 5 times the rate of the general public. On its own, this is a worrying figure. But it is similar to how much more violent men are than women.

Recent studies have showed that alcohol and substance abuse far outweigh mental illness in contributing to violence. A 1996 Health Canada review of scientific articles found that the strongest predictor of violence and criminal behaviour is not major mental illness, but past history of violence and criminality.

Reshaping beliefs is not an easy task. But it is important to correct the misleading information about this issue, because it leads to intolerance and negatively impacts the lives of people with mental illness and our society as a whole. Learning the facts about violence and mental illness is an important first step in building realistic attitudes about this complex issue.

*(Source: CMHA National [www.cmha.ca](http://www.cmha.ca))*

### 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. In some cultures people believed mental illness was the work of evil spirits; in other cultures, people believed bad blood, poisons, or lack of moral integrity caused it. As people learn more about the real nature of mental illness, we can hope that many of these harmful beliefs will fade.

## Fear of violence

Mental illness plays no part in the majority of violent crimes committed in our society. The assumption that any and every mental illness carries with it an almost certain potential for violence has been proven wrong in many studies.

There is a relationship between violent behaviour and symptoms which cause the person to feel threatened and/or involve the overriding of personal control. Examples of these criteria include specific symptoms such as command hallucinations and feeling that one's mind is being dominated by outside forces.

(Source: CMHA National [www.cmha.ca](http://www.cmha.ca))

The three primary predictors of violence are:

- history of 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 severe, people who are acutely ill may inappropriately end up in jail. Most of these individuals are jailed for committing minor or “nuisance” crimes (e.g., shoplifting, disturbing the peace, public drunkenness). Prisons have become the new asylums of the twentieth 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.

As you may have noticed, many of the myths surrounding mental illness involve blaming the individual for the illness. Dr. Nancy Andreasen, author of *The Broken Brain* and *Brave New Brain*, has stated that asking someone who suffers from a mental illness to “shape up” or exert more self-control is about as fair (and medically sound) as asking a person who has recently suffered a heart attack to try to run up a few flights of stairs.

An individual who may have been absent from work because of 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 deserve compassion, patience, and understanding. As one individual stated, “Have a look around the average psychiatric ward of a hospital and note the almost total absence of ‘Get Well Soon’ floral and balloon bouquets.”

## Reducing stigma

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 U.S. psychiatrist who has schizophrenia, believes that the best thing anyone can do in fighting stigma is stop using pejorative language. Words like “crazy,” “nuts,” and “psycho” offend 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.”

Expressions 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.

# Schizophrenia Society of Canada

## Who are we?

The Schizophrenia Society of Canada (SSC) is a national registered charity that has been in operation since 1979. Our mission is to improve the quality of life for those affected by schizophrenia and psychosis through education, support programs, public policy, and research.

Using a federation model, we work with 10 provincial societies and their more than 100 chapters and branches to help individuals with schizophrenia, and their families and friends, 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 improve the quality of life for those affected by schizophrenia and psychosis through education, support programs, public policy, and research.

## 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 integrated 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 visit our website at <http://www.schizophrenia.ca>

## How can you help?

You can become a member, a volunteer, and/or a donor. All three are needed at the national, provincial, and community levels to improve the quality of life for those affected by schizophrenia and psychosis through education, support programs, public policy, and research.

### Member?

As a member, you will be connected with people who understand and share similar concerns for loved ones affected by 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, fundraising, family support, and advocacy at the national, provincial, and community levels.

### 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

### Alberta

Schizophrenia Society of Alberta  
328 Capital Place  
9707-110 Street  
Edmonton, AB, T5K 2L9  
Phone: (780) 428-0400  
Toll Free in Alberta: 1-800-661-4644  
Fax: 1-866-273-1780  
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Website: [www.schizophrenia.ab.ca](http://www.schizophrenia.ab.ca)

### British Columbia

British Columbia Schizophrenia Society  
#201, 6011 Westminster Highway  
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E-mail: [bcss.prov@telus.net](mailto:bcss.prov@telus.net)  
Website: [www.bcscs.org](http://www.bcscs.org)

### Manitoba

Manitoba Schizophrenia Society  
100-4 Fort Street  
Winnipeg, MB, R3C 1C4  
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Toll free in Manitoba: 1-800-263-5545  
Fax: (204) 783-4898  
E-mail: [info@mss.mb.ca](mailto:info@mss.mb.ca)  
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Website: [www.schizophreniasociety.nb.ca](http://www.schizophreniasociety.nb.ca)

### Newfoundland & Labrador

Schizophrenia Society of Newfoundland  
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### Northwest Territories

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## Nunavut

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## Saskatchewan

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## Yukon

British Columbia Schizophrenia Society  
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Richmond, BC, V7C 4V4  
Phone: (604) 270-7841  
Toll Free in BC: 1-888-888-0029  
Fax: (604) 270-9861  
E-mail: [bcss.prov@telus.net](mailto:bcss.prov@telus.net)  
Website: [www.bcss.org](http://www.bcss.org)

## Confronting the dark

*Jennie Emmott*

As a seven-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 storytellers 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 fluorescent 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 life 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 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.

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“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.



## Session 2: Facts about Psychosis

# Session 2: Facts about Psychosis

handout

## 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 tumours 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, when unusually excited or happy (manic), the person may believe he/she is special and can perform amazing feats. When depressed, the person may hear voices telling him/her to commit suicide.

## What causes psychosis?

Over the years there have been several theories about what causes psychosis. While the brain is not yet fully understood, most researchers believe there is no single cause of psychosis. Like other illnesses such as heart disease or diabetes, psychosis may be caused by a combination of biological and environmental factors.

Biological factors include genetic predisposition to the illness (family history of psychosis), brain injury or infection, prenatal infection, or birth complications. The presence of these factors may mean a person is more vulnerable or susceptible to developing psychosis.

Environmental factors are often referred to as “stressors” that might trigger an episode of psychosis. Stressors could include drug use or situational anxieties (e.g. starting college, moving to a new city, loss of a parent or grandparent). As with any medical condition, it’s not someone’s fault if he/she becomes ill with psychosis. The degree of vulnerability varies from person to person. Likewise, the amount or type of

stress that might trigger psychosis would differ for each individual. For example, a person with low vulnerability could experience lots of stress but not develop psychosis. By contrast, someone with high vulnerability may not be able to withstand even minimal amounts of stress. Vulnerability to psychosis is not a weakness and it is not the result of poor parenting.

Psychotic symptoms may emerge in response to stress or drug abuse; they may 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 who is developing schizophrenia.

## The phases of psychosis

Like other physical illnesses, psychosis occurs in stages. These are referred to as the phases of illness. Psychosis has three phases: the prodromal phase, the relapse or active phase, and the residual or early recovery phase.

**It is important to remember:** psychosis is episodic and recurrent; it is not a “linear” illness 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 and sleeping habits. Features of this phase include: reduced concentration, reduced motivation, lack of energy, depressed mood, anxiety, social withdrawal, irritability, suspiciousness, and 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, hallucinations, disordered thinking, and agitated or bizarre behaviour.

## Residual/early recovery phase

This phase constitutes the first six months following acute treatment. The focus is on developing a psychosocial framework for further recovery as positive symptoms recede.

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

## Recovery

During recovery, the illness becomes more stable, and the individual’s ability to function increases. The individual may be able to consider increasing his/her level of functioning by returning to school, work, or a life skills training program.

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.

## Types of psychoses

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

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. 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 tumour. 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 or divorce, or an important change of circumstances, like being laid off. Symptoms can be severe, but the person usually makes a quick recovery.

### **Schizophrenia**

Schizophrenia refers to an illness in which the psychotic symptoms have been present for a period of at least six 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 moods. If people 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.



## Facts about schizophrenia

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

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

Schizophrenia is diagnosed after specific symptoms are present for a period of at least six 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 ten per cent 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 you're 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 schizoaffective disorder and schizophreniform disorder.

Schizoaffective disorder is an illness where the features of schizophrenia and mood disorder seem to exist at the same time. That is, the person exhibits symptoms of both schizophrenia and a mood disorder (either bipolar disorder or clinical depression).

Schizophreniform disorder is similar to schizophrenia in that two 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 admissions 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 (eight per cent) than those with any other illness except cardiovascular illness. In Canada, someone suffering from schizophrenia is using one out of every twelve hospital beds.

### **Facts you should know about schizophrenia**

- Schizophrenia is a biochemical brain illness that results in disordered thinking, delusions, hallucinations, and a lack of energy and motivation.
- Schizophrenia typically strikes people in their late teens or twenties.
- Schizophrenia strikes one in every one hundred people. That adds up to 280,000 individuals who have or will have schizophrenia in Canada in their lifetime.
- Schizophrenia patients occupy one in every twelve hospital beds in Canada—more beds than are needed for any other single illness, except cardiovascular illness.
- In 2004, the direct health care and non-health care costs of schizophrenia were estimated to be \$2.02 billion. This cost combined with the additional costs of lost productivity due to morbidity and mortality (estimated at \$4.83 billion) totals a cost estimate of \$6.85 billion.
- Schizophrenia has no cure, yet.
- Schizophrenia drastically affects people's quality of life. Many people in prison have the illness, as do about one-third of Canada's homeless persons. Forty per cent of people with schizophrenia try to commit suicide; ten per cent succeed.
- 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.
- 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.
- Schizophrenia suffers from very low public awareness. People with schizophrenia and their families suffer because of too little research, and too little understanding.
- Recovery is possible. A number of longitudinal studies recognized by the World Health Organization indicate that up to seventy per cent of people with schizophrenia experience personal, social, and/or illness recovery.



## Causes of schizophrenia

Sometimes schizophrenia-like symptoms may occur with other illnesses, such as Huntington's disease, phenylketonuria, Wilson's disease, epilepsy, tumour, encephalitis, meningitis, multiple sclerosis, and numerous others. The real schizophrenia is diagnosed when these other conditions are excluded as the source of 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 with emotion), the thalamus (which coordinates outgoing messages), and several other brain regions may also be affected.

### Schizophrenia is NOT:

- caused by childhood experiences
- caused by poverty
- caused by domineering mothers/passive fathers
- caused by parental negligence, and
- caused by guilt, failure, or misbehaviour

*Sources: Facts You Should Know About Schizophrenia, Schizophrenia Society of Prince Edward Island. <http://www.schizophreniapei.pe.ca/QuickFacts.html>; Learning about Schizophrenia: Rays of Hope (3rd Revised Edition), Schizophrenia Society of Canada (2005).*

# Facts about 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 a person'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, and also sadness and grief.

## Facts and statistics

Clinical depression is the most common form of mental illness and can occur at any age or stage of life. Approximately eight per cent 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 may be because men are less likely to seek help for the illness. Physical and hormonal factors, as well as pregnancy, postpartum depression, and menopause may also contribute to the difference in numbers.

Approximately ten to fifteen per cent 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:

- apathy
- changes in appetite or weight – usually a decrease; a few individuals gain weight, and this is referred to as atypical depression
- excessive crying
- changes in sleep, either not sleeping at all (insomnia) or excessive oversleeping (hypersomnia)
- unexplained aches or pains
- headaches
- social withdrawal
- change in productivity
- pessimism
- persistent sadness or despair
- feelings of hopelessness, guilt,
- lack of energy or motivation
- self-blame
- fatigue
- feeling worthless
- difficulty in thinking or concentrating

- feeling anxious or irritable
- difficulty making decisions
- pacing and fidgeting
- inability to feel pleasure in previously enjoyed activities (anhedonia)
- persistent thoughts of suicide

Some of these symptoms may happen because of 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 because it drastically reduces the quality of the individual's daily life.

## Types of depression

**Dysthymic disorder** is a common form of milder 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 two years.

**Postpartum depression** is experienced by new mothers after they give birth and may be caused by hormonal changes. Postpartum depression can last anywhere from a few weeks after delivery to a few months. A small percentage of these women (ten per cent) 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 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.

### Depression is NOT:

- a character flaw
- a sign of weak character
- contagious

### How is clinical depression treated?

- Treatment for clinical depression involves a combination of medication (antidepressants), psychotherapy (talk therapy), education, and support groups.
- Counselling and psychotherapy are considered extremely helpful for this illness. During psychotherapy, an 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 (SSRIs). SSRIs 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 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 forty-five 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 patients’ 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, usually about of what happened immediately before or during the treatment. Some 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 know 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 women have.
- **Co-morbidity.** 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, unresolved trauma and anger, or the death of a loved one can contribute to clinical depression.

*(Source: information sheet on depression by the National Mental Health Association, 2005)*

# Facts about 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
- Feeling grandiose (inappropriately high self-esteem)
- Persistent elevated and euphoric mood
- Aggressive behaviour
- Excessive talking (pushy behaviour)
- Talking too fast or too loud
- Racing thoughts
- Excessive spending
- Poor judgment
- Lack of sleep
- Loss of ability to control impulses
- Easily irritated
- Unusual sexual behaviour
- Easily distracted

## **Depression**

- The symptoms are the same as in 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 of 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.

- Mixed states
- Severe mania
- Mild to moderate mania (hypomania, cyclothymia)
- Regular/balanced
- Mild to moderate depression (postpartum depression, seasonal affective disorder, reactive depression, dysthymia)
- Severe depression

*(Source: NIH Publication No. 01-3679 – Bipolar Disorder)*

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 severe mania in some people.

In the past, people with bipolar disorder may have been misdiagnosed with schizophrenia because of the similarities 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 I:** Bipolar I 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 hallucinations during either a manic or depressive episode.

**Bipolar II:** The individual experiences depression and hypomania, which is milder than mania. Individuals with bipolar II do not experience psychotic symptoms.

**Cyclothymic disorder:** This illness is considered a chronic, milder version of bipolar disorder and lasts for at least two 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.

**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.

**Rapid cycler:** People experience four 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 antidepressants may contribute to the cause of this condition. As in every case of illness, a correct diagnosis will ensure proper treatment.

## 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 three to four doctors and spend more than eight 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 effects 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.

*(Source: What is Bipolar Disorder, from Mood Disorders Canada)*



# Facts about anxiety disorders

## Quick facts:

- Anxiety disorders/conditions are the most common mental health concern in Canada.
- At any time, one in every ten adults is experiencing an anxiety disorder. Over the course of a lifetime, one in four 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
- rapid heartbeat
- depersonalization (feeling detached from your body or mental process.  
An example would be feeling you are in a dream)
- muscle tension/aches

## Types of anxiety disorders

**Generalized anxiety disorder (GAD):** GAD is characterized by excessive, unrealistic worry that lasts six 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, a 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 such places.

**Post-traumatic stress disorder (PTSD):** PTSD can follow an exposure to a traumatic event, for example experiencing a sexual or physical assault, witnessing a death, experiencing the unexpected death of a loved one, or living through 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, which can include difficulty sleeping, irritability, and poor concentration.

**Social anxiety disorder/social phobia (SAD):** SAD is characterized by extreme anxiety about being judged by others, or about 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 palpitations, 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 disorders?

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.
- Psychosocial treatments 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 (SSRIs), tricyclic antidepressants, benzodiazepines, beta blockers, and monoamine oxidase inhibitors (MAOIs).
- Combination therapies are often used.



# Facts about 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). This anxiety disorder can include both obsessions and compulsions. The obsessive thoughts and compulsive behaviours can occupy many hours of the day, making many tasks very difficult for the individual to accomplish and making it hard to enjoy 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 will 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 be counting over and over again.

## Types of OCD

OCD symptoms can vary from person to person. Here is a list of the most typical personality profiles of those suffering with OCD; it is common for people to experience a combination of these traits.

Checkers feel compelled to check objects such as door locks and the “off” settings of 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. Checkers often develop elaborate checking rituals that make it difficult for them to complete daily tasks.

Washers and cleaners have an irrational fear of contamination. They compulsively avoid potential contaminants. They have obsessions about diseases spread by dirt, germs, viruses, and foreign substances. They live with the constant dread of becoming contaminated or contaminating others. Washers and cleaners often wash and clean their hands, clothes, and houses countless times a day, though they never feel clean or “safe” from contaminants.

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 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 words, to counteract their disturbing thoughts.

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. But since 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 the 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 is used to treat the compulsions. The technique used in this therapy is called exposure and response prevention (ERP). 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 practise coping exercises and to confront the belief that the compulsive behaviour can prevent a disaster.

# 5 Steps to help a family member

## 1: Learn to recognize symptoms

When odd behaviour is experienced or observed, it makes good sense to seek advice from a doctor. The odd behaviour could be an acute episode (something that happen suddenly), or symptoms may develop over a period of time.

Symptoms that are especially important to note:

- marked change in personality
- a constant feeling of being watched
- difficulty controlling 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. The 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.

## 2: Get proper help

**You need to take the initiative:** If you notice symptoms of mental illness, ask your doctor or other health care professional for an assessment or referral. Family members are usually the first to notice symptoms, and first to 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 the health care professional toward a more accurate assessment and treatment.

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 centres throughout the country. Check your phone book, or contact your provincial Schizophrenia Society to find the centre nearest you.

## 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.

**While maintaining confidentiality, you should be able to discuss these topics 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 about the role you can play in supporting the patient's treatment plan. By your attitude and behaviour, try to show the patient 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 patient maintain a record of information on:

- symptoms that have appeared
- all medications, including dosages
- all treatment plans and coping strategies
- effects of various types of treatment and strategies
- appointments and contact information

Keep daily records. Keeping track of information is an effective way for everyone to be involved in the process of the person getting well.

#### 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 the patient's treatment. Professionals may include psychiatrist, social worker, case manager, occupational therapist, and others.

**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's helpful 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. Be sure to let the person know you believe in him/her. Your own sense of hope can help speed his/her recovery.



**Help the individual who is ill 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 increase independence. It is important to set limits on how much the family will tolerate certain behaviours, for example, 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 that might be stressful can also help.

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

## 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 and 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 individual who is ill and to also attend to the needs of the whole family. As Julie T. Johnson notes: “Mental illness often disables the entire family.” Siblings, children, spouses, and parents of people with schizophrenia need special attention and support.

**Practice good mental health:** Examine your family’s system of coping; look at how it influences your response to the mental illness and the person.

**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 may 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.

## Voices from the shadows

*Paul Wilson. "Streetbeat." The Hamilton Spectator, 14 May, 2002*

**V**oices from the shadows; 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 piggy, 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. I 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 Center 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 a taste 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 24 hours in a wheelchair gives them an understanding that no classroom lecture can. So Deegan and colleagues, other “experienced voice hearers,” produced a tape to let people walk a mile in a schizophrenic person’s shoes. 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 two 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 than 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 ease 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.’”

## The voices activity - handout

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1 Rhodes's leash was attached to Maddy, but not to Rhodes's hand—it was left to dangle behind the dog. The pound patrol recognized the man and dog from previous encounters, and moved to find out what was going on.

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.

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's 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 two SPCA vans, two SPCA people, two police cars and two officers." Rhodes believes he and Maddy were following the letter of the law. "It says all dogs must be on leash no longer than two metres—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.

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2 In 1995 my family moved to Whitehorse in the Yukon. We stayed two years.

Brrr! Our first January, the temperature dropped to minus 48 degrees for three 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 two 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-county 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!

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

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.

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

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 6th Street into Burnaby.

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

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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 eight years old. I liked her a lot and I didn't care if I wasn't famous. I was happy!

## Session 3: Psychosis Causes and Treatment

# Session 3: Psychosis Causes and Treatment

handout

## Facts about the causes of mental illness

Over the last couple of decades, it has become increasingly clear that most 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 cause the gene's instructions to be incorrect, or it might cause the instructions to 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 such as schizophrenia or bipolar disorder. However, each of these genes is thought to increase a person's vulnerability by just 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

These 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 such as schizophrenia than in individuals who do not develop schizophrenia. Examples of the obstetric complications that have been studied include prematurity, forceps delivery, Caesarean section, pre-eclampsia, 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 two 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 two 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, for example a car crash or bereavement; a change in living circumstance such as divorce or loss of job; or a more long-term stress, for example 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, such as amphetamines and cocaine, can cause a condition known as “drug-induced psychosis.”

This psychosis can last up to a few days, and is often characterized by hallucinations, delusions, memory loss, and confusion. The condition usually results from prolonged or heavy street-drug use, and it responds well to treatment.

Other drugs, including marijuana, may 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). Cannabis use has been shown to make people who are already vulnerable to psychosis four times more likely to become ill with psychosis. Those people are also likely to experience their first symptoms at a younger age.

## Stress-vulnerability model

Serious mental illnesses may be made worse by stressful factors in the individual’s environment. The stress-vulnerability model says that people have different sensitivities to their environment and therefore some people are more likely than others to develop mental illness when exposed to environmental stress. Some people think this difference in sensitivity is caused by different amounts of genetic vulnerability factors.

Although we cannot change the amount of genetic vulnerability we have, we can do something to alter our environmental vulnerability. By reducing stress, we can reduce the chances of a relapse—reducing environmental vulnerability.

There are also a number of factors that can protect individuals from developing psychosis. These include: good coping skills, good social supports, and medication. These factors are particularly interesting in relation to recovery and relapse prevention. People can actively work to increase protective factors and reduce risk factors even when a family history of psychosis is present.

*(Source: Mental Illness Fellowship of Australia: The stress-vulnerability-coping model of mental illness <http://esvc000144.wic027u.server-web.com/pdfs/Stress%20vulnerability%20coping%20model.pdf>)*

## Protective factors

Just as there are vulnerability factors for mental illness, there are also protective factors. Identifying and using those protective factors 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/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.

**Important:** A variety of biological factors, personal history factors, and environmental stress can influence a person's vulnerability to psychosis. Psychotic disorders appear to result from an intersection of high stress and high vulnerability.

*(Source: The Causes of Mental Illness, developed by Jehannine Austin, Genetic Counsellor, Department of Psychiatry, UBC, Vancouver; Early Psychosis Intervention (EPI) Program, Peace Arch Hospital, White Rock, B.C.)*



# Facts about treating psychosis

## What treatments are available for psychosis?

There is no instant cure for psychosis, but people can and do recover. The experience of psychosis 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 psychosis to learn about all the different treatment and support options available so they can play an active role in their recovery.

### Medication

The medications used to treat psychosis, commonly referred to as antipsychotics, are generally effective for decreasing the psychotic (or active) symptoms of psychosis, 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). Many people with psychosis will also need medication during stable phases (also called *maintenance* or *recovery* phases).

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 psychosis. Rather, it should be used in addition to other therapies described in this section.

### Additional pathways to recovery

Although medication is almost always necessary in the treatment of psychosis, 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 supportive 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. In this section you'll find information on some of the other approaches and supports that can aid recovery. For further information on the recovery process, please see the readings for Session 8.

## Facts about medication

In Canada, there are three types of medications commonly used to treat symptoms related to schizophrenia, mood disorders, and anxiety disorders.

**Medications have two names:** a generic or chemical name and a brand or trade name. The brand name is most commonly used. Different generic manufactures now make many of these medications, so the name on the label may be slightly different than what you see in the list. The list shows the generic name first, then, in parentheses, the brand name.

### Antipsychotic medication

antipsychotics (1st generation)	antipsychotics (2nd generation)
chlorpromazine (Largactil)	quetiapine (Seroquel)
fluphenazine decanoate (Modecate)	risperidone (Risperdal)
fluphenazine (Moditen)	olanzapine (Zyprexa)
flupenthixol (Fluanxol)	clozapine (Clozaril)
haloperidol (Haldol)	
loxapine (Loxapac)	
methotrimeprazine (Nozinan)	
pericyazine (Neuleptil)	
perphenazine (Trilafon)	
pimozide (Orap)	
pipotiazine (Piportil)	
thioridazine (Mellaril)	
trifluoperazine (Stelazine)	
zuclopenthixol (Clopixol)	

## Uses

The first-generation antipsychotics, also known as typical antipsychotics, were introduced back in the 1950s. At the time, they made a significant impact on the treatment of people with psychotic illnesses. Many people did well on these medications, but others experienced side effects. As a result, the second-generation antipsychotics (also called atypical antipsychotics) were developed. The second-generation antipsychotics work differently than the first-generation do, and they are used much more commonly today. Their main advantage is that they cause fewer extrapyramidal side effects than the older agents do.

The second-generation antipsychotics have benefited people with mood symptoms, so they are increasingly being used to treat mood disorders such as bipolar affective disorder.

Antipsychotic therapy takes several weeks (or months, in some cases) to show its full benefits. Antipsychotics don't "cure" mental illness but rather treat the symptoms, and they are often taken over the long term to prevent relapse. It may take a few tries to get the "best fit" in terms of response and side effects. The fit is very important because the individual may need to take these medications long term. Individuals who are ill often need much encouragement and support at this time.

## How it works

The action of the antipsychotic drugs is very complex and not fully understood. One thing we do know is that these medicines decrease the amount of dopamine (a chemical found in the brain) in certain parts of the brain. Unfortunately, the older agents decreased the amount of dopamine in areas where it should not be decreased, thus causing extrapyramidal side effects. The second-generation agents work more selectively on the dopamine system, and troublesome side effects occur much less often. The antipsychotics also affect levels of serotonin (a chemical in the brain involved in mood), which can be helpful with other symptoms.

## Side effects

There can be side effects with antipsychotic medication. Keep in mind that each person's reaction to a medication is unique.

**Dry mouth:** a common side effect of many psychiatric medications. If it is bothersome, chewing sugarless gum or sucking on sugarless candy may help.

**Excessive salivation:** flupenthixol (Clozapine) can cause excessive salivation, usually when a person starts taking the drug, or when the doctor is adjusting the dosage.

**Dizziness:** occurs most often when the medicine is started or when the dose has been recently increased. People notice it when they get 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 dizziness. 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. Most often noticed when people try to focus on objects that are close up (e.g. reading).

**Constipation:** a common side effect of many psychiatric medications. Regular exercise, drinking plenty of fluids, and eating a diet rich in fibre will all help. Eating bran and fresh fruits and vegetables provides fibre. If constipation persists, medication may be needed; discuss the problem with the treatment team.

**Sedation:** 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 the medication is given. Caution is advised when driving or when doing activities that require the person to be alert or wide awake.

**Weight gain:** occurs more frequently with the atypical antipsychotics. Not all people will gain weight, and the amount gained can vary greatly from person to person. There are 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. Patient and treatment team should monitor this side effect closely.

**Elevated cholesterol:** appears to occur more frequently with the atypical antipsychotics. Tell the family doctor your loved one is taking antipsychotic medication, and check cholesterol levels.

**Elevated blood sugar:** Atypical antipsychotic medications may cause an increase in blood sugar levels. If your family member has diabetes, the effects of the diabetes could get worse; other people report new-onset diabetes after taking atypical antipsychotics. Check blood sugar levels frequently, especially if there is a family history of diabetes, and look for signs of the disease: increased thirst, increased need to urinate, and weight change, especially weight loss.

## Extrapyramidal side effects (EPS)

These occur much less frequently with the atypical antipsychotics than with the typical ones.

**Dystonia:** a muscle spasm that affects different muscles within the body. Type of dystonia depends on which muscle is involved. The most common dystonias involve the eyes (roll backwards), head/neck (tilts backwards), jaw (locks into place), and tongue (feels fat or thick). Dystonia is most likely to happen very early in treatment – often in the first week – or when medications are increased. There is medication to make the dystonia go away very quickly.

**Akathisia or restlessness:** Causes a person to feel tense or restless on the inside, or to feel figidity and unable to stay still. This side effect usually happens in the first few months of treatment, or after an increase in dose. There are treatments to make the individual more comfortable.

**Pseudoparkinsonism:** Antipsychotic medication may cause the patient to experience the symptoms of Parkinson's disease. These include: tremors, usually in the hands/fingers, stiffness in the joints, and slowed body movements. There are treatments for pseudoparkinsonism.

**Tardive dyskinesia (TD):** a movement disorder that can occur in any part of the body. Common signs of TD include smacking of the lips, twitching, sticking out of the tongue, movements of the jaw, fingers and toes. Prevention of TD is important. Monitor for these signs; if they appear, discuss with the treating doctor.

**Neuroleptic malignant syndrome:** an extremely rare side effect of antipsychotic treatment. Symptoms include heart palpitations (beating too fast or irregularly) confusion, a lot of sweating, unusual muscle stiffness, fever, and loss of bladder or bowel control. If you notice any of these signs, seek medical attention immediately.

## Mood stabilizers

Many of these medications are classified as anticonvulsants – they were designed to treat seizure disorders – but are 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

Except for lithium, all medications listed are anticonvulsants; they were developed to treat 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 anticonvulsants 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 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.

**Nausea (stomach upset) and mild 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 problems:** 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/sleepiness:** 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.



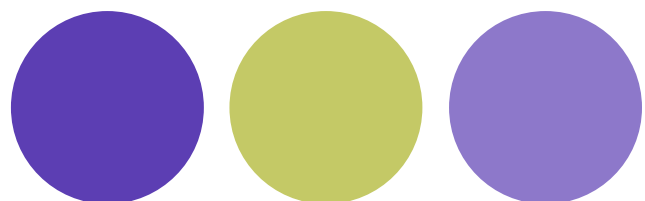
## Cautions with Lithium

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 it 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 the medication. Taking the medication with food or milk should help.

**Sedation/dazed feeling/sleepiness:** 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.

**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:** mild 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 *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. 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).

## Antidepressants

- 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)
- tranlycypromine (Parnate)
- trazadone (Desyrel)
- trimipramine (Surmontil)
- venlafaxine (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 they work

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.

**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.

**Please note:** 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.

## Education

Education about psychosis is essential for the individual and the family. Education and information allow the family and the person with psychosis to take an active role in the recovery and rehabilitation process, and to do so from an empowered position. The family is considered an essential part of the assessment, treatment, and recovery process for people with psychosis. To be effective in this role without becoming overburdened or exhausted, families need information, support, sufficient time for professional consultation, and respite mental health services.

Benefits of education include:

- Learning about the illness
- Improving coping skills
- Improving interpersonal skills
- Decreasing rate of relapse
- Lowering stress levels
- Helping build a support network

## Case management

Treatment plans often involve different services. In some communities, case managers or community mental health workers are involved in the ongoing management of care for the individual. Case managers coordinate support services, such as housing, day treatment, or financial services, and also connect individuals to community volunteer services 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 the services he/she needs.

## Social and living skills training

Social and living skills training is an effective way to help individuals with psychosis relearn a variety of skills necessary for living independently. The training can be for an individual or for a group. It provides opportunities for people to acquire skills they have not been able to develop because of particular life circumstances; relearn skills that were lost or reduced because of the disabling effects of psychosis or particular life circumstances; and enhance existing skills so they can function more effectively.

## Vocational training and rehabilitation

Work has the potential to be a “normalizing” experience and to provide benefits such as enhanced personal satisfaction, increased self-esteem, additional income, financial independence, social interaction, and recreational and companionship opportunities. Most important, it is frequently identified as a goal of people with psychosis. Any person with psychosis who expresses an interest in gaining employment, or who may benefit from employment, should receive help to find, get, and keep a job. Even if just part-time, employment is an important step on the road to recovery.

## Participating in the broader community

The important element in any of these options is people’s own choices about where and how they wish to participate.

Examples include:

- Enrolling in college or university courses – academic accommodations are available to facilitate participation
- Taking part in interest groups, sports, recreation, and hobbies
- Volunteering
- Attending a Clubhouse or other social support groups

## 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 to seeking to help people understand their own thoughts, feelings, and patterns of behaviour.

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.

## Counselling

Counsellors listen without judgment and help individuals explore issues that are important in the recovery process. A counsellor does not give advice; a counsellor acts as a guide so individuals can work things out for themselves. Attending regular counselling can be extremely beneficial to both the individual with psychosis and his/her 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 three broad groups: behavioural (or behaviour modification, which aims to modify behaviour), humanistic (which aims to increase self-understanding), and psychodynamic (which is based on the teachings of Freud). Behaviour modification can be very helpful for some people. Similarly, humanistic therapy can have benefits for some individuals. Research into the use of psychodynamic therapy for people with psychosis has consistently failed to support its effectiveness; evidence suggests that it is harmful and therefore it is not recommended.

## Cognitive therapy

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

## Peer support, self-help groups

Many people find it helpful to talk about their experiences with others who have been in similar situations. Peer support, much like it sounds, involves people with a mental illness offering support and strength to other people with a mental illness. There are also peer support groups for family members.

Self-help groups can be a wonderful way to give and receive support, and to build stronger support systems. People can get practical help by working through their problems with others; they can also develop strong support networks among their peers. And they can draw on their own strengths to help others. Involvement in peer support groups often leads to individuals and family members feeling less isolated, Peer support can help the individual learn techniques that help him/her live with a mental illness.

Self-help groups are often run by local organizations. Your local Schizophrenia Society, Mood Disorders Association, Anxiety Disorders Association, or Canadian Mental Health Association will have information about specific self-help groups available in your community.

## Alternative therapies

Alternative therapies have been used by people for thousands of years, and some people find them very helpful in the recovery process. 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, tai chi (meditation in movement), yoga (exercise that concentrates on breathing and stretching), and orthomolecular medication (use of vitamins and minerals). A person should consult a doctor concerning the use of alternative therapies.

## 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 to school or work) may need to be relearned. Community mental health programs can help people learn how to reintegrate into their community.

Skills such as communication and stress management (sometimes referred to as social skills) are also very important. Community support programs can help individuals with vocational (job) rehabilitation and educational goals. Skills training has an enormous impact on improving the individual's self-esteem and allows the individual to actively participate in his/her community.



## Clubhouse

The very first Clubhouse was started in the 1940s in New York by a group of ex-psychiatric patients. The Clubhouse is 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 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

The Clubhouse idea is founded on the realization that recovery from serious mental illness must involve the whole person in a vital and culturally sensitive community. A Clubhouse community offers respect, hope, mutuality, and unlimited opportunity to access the same worlds of friendship, housing, education, and employment as the rest of society.

Clubhouse 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 is unconditional, unless a person presents a significant threat to the Clubhouse or its community.

The International Center for Clubhouse Development (ICCD) is a global network that creates opportunities for people living with mental illness to be respected members of society. Not all mental health peer support organizations use the word “clubhouse” or follow the Clubhouse model. For more information on the Clubhouse and a list of international members, please see the ICCD website at [www.iccd.org](http://www.iccd.org).

## Interest groups

Interest groups can provide individuals with a source of social support. People can pursue their hobbies or interests and meet others at the same time. This offers individuals an opportunity to shed their patient role and connect with their community. (Examples of interest groups include volleyball teams, writing groups, and craft groups.)

## Facts about psychosocial interventions

Psychosocial interventions address the psychological and social aspects of a person. These interventions provide education and practical skills to help the person cope with his/her mental illness. Psychosocial interventions can also reduce psychological vulnerability by lowering the effect of stress. These treatments complement medication treatment and encourage individuals to maintain a strong support system.

### Benefits of psychosocial intervention

- Provides a supportive and encouraging environment through interacting with others who have had similar experiences. An individual can work and learn from others, giving and receiving emotional support on a regular basis.
- Improves personal and family relationships that have been affected by the illness.
- Educates people who have 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 centres and other resources by promoting involvement in different activities.

### Examples of psychosocial interventions and supports

- Education for patients and family members
- Case management
- Skills training
- Social support
- Vocational training and supports for employment
- Supports for secondary and post-secondary education
- Peer support, self-help groups
- Inclusion in the broader community
  - Volunteering
  - Interest groups (sports, hobbies)
- Talk therapies
  - Psychotherapy
  - Cognitive behavioural therapy (CBT)
  - Exposure and response prevention therapy (ERPT)
  - Family therapy
  - Group therapy

## Psychotherapy

How it works:	Benefits:	Who can benefit:
<p>The individual talks to a professional (therapist or psychiatrist) on a regular basis, focusing on current or past experiences, problems, feelings, &amp; relationships.</p>	<ul style="list-style-type: none"> <li>• helps an individual cope with emotional distress</li> <li>• learn more about themselves, their thoughts, actions, and behaviours</li> <li>• learn new coping skills</li> <li>• relief from stress &amp; anxiety</li> </ul>	<p>People with:</p> <ul style="list-style-type: none"> <li>• schizophrenia</li> <li>• bipolar disorder</li> <li>• clinical depression</li> <li>• obsessive compulsive disorder</li> <li>• family members</li> </ul>

## Cognitive behavioural therapy (CBT)

How it works:	Benefits:	Who can benefit:
<p>Individuals focus on changing negative thought patterns they may have developed over the years. Individuals are usually taught relaxation techniques &amp; given homework assignments to help practise their newly acquired skills.</p>	<ul style="list-style-type: none"> <li>• feel more involved throughout this active approach</li> <li>• leads to improved self-esteem</li> <li>• learn new coping skills that provide relief from depression, stress, and anxiety</li> </ul>	<p>People with:</p> <ul style="list-style-type: none"> <li>• schizophrenia</li> <li>• bipolar disorder</li> <li>• clinical depression</li> <li>• obsessive compulsive disorder</li> <li>• family members</li> </ul>

## Exposure & response therapy (ERPT)

How it works:	Benefits:	Who can benefit:
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 practise skills between appointments.	<ul style="list-style-type: none"><li>• feel more involved throughout this active approach</li><li>• leads to improved self-esteem</li><li>• learn new coping skills that provide relief from stress, depression, and compulsive behaviour</li></ul>	People with: <ul style="list-style-type: none"><li>• obsessive compulsive disorder</li></ul>

## Family therapy

How it works:	Benefits:	Who can benefit:
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.	<ul style="list-style-type: none"><li>• greater understanding of the family dynamics</li><li>• greater understanding of individual needs within the family</li><li>• helps all family members develop healthy communication skills</li></ul>	People with: <ul style="list-style-type: none"><li>• schizophrenia</li><li>• bipolar disorder</li><li>• clinical depression</li><li>• obsessive compulsive disorder</li><li>• family members</li></ul>

## Group Therapy

How it works:	Benefits:	Who can benefit:
<p>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.</p>	<ul style="list-style-type: none"><li>• feel less isolated and alone with their problems</li><li>• builds a strong support system within the community</li><li>• helps build self-esteem when the group focuses on problem solving rather than problems</li></ul>	<p>People with:</p> <ul style="list-style-type: none"><li>• schizophrenia</li><li>• bipolar disorder</li><li>• clinical depression</li><li>• obsessive compulsive disorder</li><li>• anxiety disorders</li><li>• eating disorders</li><li>• family members</li></ul>

For more information on how to find a professional counsellor or therapist, contact your health care professional or go through professional associations (e.g., Canadian Professional Counsellors Association). Also check if your medical insurance will cover therapy costs.

## Session 4: Coping as a Family

# Session 4: Coping as a Family

handout

## The challenges and needs facing family members

When someone in your family has a mental illness, all the family members face unique challenges and have different needs.

### All family members and friends need

- information & education
- support
- certain skills that will increase coping ability
- 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 available services and resources in the community. A support system is vital and can include family members, friends, co-workers, professionals, and advocacy groups (for example, the Schizophrenia Society of Canada, the Mood Disorders Association of Canada, the Canadian Mental Health Association). And family members need coping skills, communication skills, stress management skills, and problem-solving skills.

The lists and descriptions of challenges and needs will help you identify and understand what each family member may experience.

### The person who is ill

#### Challenges

- complying with medication schedule
- establishing trusting relationships with others
- seeking professional assistance
- finding a support group or maintaining existing relationships
- coping with symptoms, lost skills, and a changed future

## Feelings of loss

- loss of relationships
- loss of educational opportunities
- loss of jobs
- loss of earning potential
- loss of money
- loss of hope and dreams for the future

## Needs

- a job
- a home
- a friend
- to be treated with patience and understanding
- support
- care
- medical attention

## Children and adult children

Children and adult children need to find validation from a healthy adult source. Receiving guidance from a respected role model will help foster resiliency and give children opportunities to learn much-needed coping skills. Some children will need to be reminded that it is not their job to shoulder the responsibility for the situation. A guiding influence would alleviate some of the emotions offspring may feel toward their ill parent.

Experiences will vary depending on the age of the child at the onset of the illness. If the child was very young when the illness first occurred, 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 contribute to the feelings of loss.

## Challenges

- having to grow up very quickly
- loss of a role model
- loss of love, comfort, guidance
- alienation from peer group
- neglected needs
- growing up in an atmosphere of secrecy and shame
- stigma of growing up in the "weird" house
- loss of "well" parent, who may be overwhelmed by illness of spouse



## Feelings

- guilt
- fear of also becoming ill
- fear of the ill relative
- fear of having children
- fear of telling others about mental illness in their family
- grief that “never ends”
- depression
- anxiety
- hopelessness
- isolation
- a skewed sense of “normal”

## Needs

- validation
- guidance from a respected role model
- new coping skills
- reminders that they need not shoulder the responsibility for the situation



## Siblings

Siblings also require assistance and validation from a healthy adult source. Siblings may attempt to shoulder too much responsibility, or they may try to fill the void they think has been created by the illness. Siblings may feel left out or experience resentment if the situation is not treated openly.

Siblings and offspring may need to be reminded of their roles. The various responsibilities of each family member should always reflect his/her particular role, age, and concerns. Siblings' experiences will depend on birth order and age relative to the ill sibling. Young family members need information and assistance that is age-appropriate.

### Challenges

- having to grow up very quickly
- loss of sibling support and companionship
- alienation from peer group
- compensate with parents for loss of sibling
- growing up in an atmosphere of secrecy and shame
- neglected needs
- parental loss, when parents are overwhelmed

### Feelings

- survivor's guilt
- fear of also becoming ill
- fear of the ill relative
- fear of having children who may become ill
- fear of telling others about mental illness in their family
- grief that "never ends"
- anger
- sadness
- anxiety
- isolation
- a skewed sense of "normal"
- anger with parents for lack of attention

### Needs

- assistance and validation from an adult
- reminders not to take on responsibility for the sibling's illness

## Spouses

When a spouse becomes ill from a mental or physical illness, the impact on the relationship can be devastating. Spouses are often the caregivers; their needs are set aside as they support the ill partner.

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 support other family members.

### Challenges

- loss of intimacy
- loss of income
- coping with ill spouse's withdrawal
- coping with disturbed sleep patterns
- coping with financial difficulties
- coping with being the primary caregiver and "single parent"
- shouldering the plans for the future alone
- finding a balance between personal needs and the needs of the spouse
- lack of peer support and social life

### Feelings

- loss
- grief
- sadness
- shame
- fear
- anger
- caught between the needs of the spouse and the needs of the children

### Needs

- peer support group
- activities that alleviate personal stress
- counselling to resolve emerging issues

## Parents

Parents often play a central role in the care and treatment of their offspring's illness. Parents need to know that all family members will be affected differently by the situation and will develop their own coping strategies. No one can control other people's reactions, but parents can provide an environment where it is safe to discuss the impact of the illness. They can also reach out to others in similar circumstances through support groups, for example, church groups, friends, extended family.

Many parents seek out services regardless of their child's age. The role of caregiver varies in intensity and duration, depending on the offspring's network of support and progress.

### Challenges

- becoming primary caregivers
- coping with marital discord as a result of the stress
- balancing their own needs as well as those of other family members
- coping with feelings of stress, anxiety, and fear
- coping with feelings of guilt
- coping with an "unimagined future"
- lack of peer support

### Feelings

- guilt
- blame
- sadness
- loss
- bitterness
- fear of the ill relative
- fear of the future
- fear of telling others about mental illness in the family
- isolation
- withdrawing from a social life

### Needs

- coping strategies
- support groups

## Multigenerational family member

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. Dual loss can be emotionally draining and overwhelming for the family. The multigenerational family member also shares all the challenges and experiences felt by other family members.

## Loss and grief

In the book *Grieving Mental Illness: A Guide for Patients and Their Caregivers* by Virginia Lafond (1994), grieving begins “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 with a loved one who 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. All members of the family struggle to accept the realities of an illness that is treatable, but not curable.

Lafond’s book explores the stages of the grieving process from the perspective of those with the illness and those who provide care (family members). Lafond stresses that before the grieving process can begin, families need to acknowledge the loss.

Acknowledging the loss requires everyone touched by mental illness to look at what the illness has done and is doing to bring unwanted and unanticipated changes in family 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 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 to those living with the illness and to their caregivers. Sadness often gives 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. Given the unhealthy and unhelpful messages we receive about anger, it can be a challenge to find healthy ways of expressing it. 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 and is often masked by other emotions. It can be difficult to pinpoint the exact source of our fears. Some fears reflect the stigma associated with mental illness. We may be afraid of rejection or misunderstanding. The key is to clearly focus on what we fear, and develop ways to cope.

**Acceptance:** Acceptance means facing the consequences of mental illness, then building and practicing coping skills working toward recovery. Signs of acceptance include giving ourselves permission to acknowledge our feelings of grief; regaining a sense of control in our lives; and changing our expectations, hopes, dreams, and goals to fit life with a mental illness. Acceptance is not passive. It includes activities such as ongoing pursuit of information about mental illness and developing coping skills.



# Leave my stuff alone!

*A story for young teen siblings*

*Text by Diane Froggatt*

**“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.

What had she done that made him so mad? Had she gone into his room for anything? She couldn’t exactly remember. And she certainly wasn’t “spying” on him. That was a very odd thing to say.

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 talking 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 two 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 people

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.

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Other pamphlets by World Fellowship for Schizophrenia and Allied Disorders:

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](http://www.world-schizophrenia.org) or write to:

124 Merton Street, Suite 507, Toronto, Ontario, Canada M4S 2Z2

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## Session 5: Self Care

# Session 5: Self Care

handout

## Facts about caregiving

Caregivers are individuals who provide or wish 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 neighbour. You may be a young person, but you find yourself in the position of needing to support a person who is ill or in recovery.

Not all people with mental illness need a caregiver. Some people with mental illness are able to manage their illness very well on their own.

The role of a caregiver can be both challenging and rewarding. According to the Victoria Order of Nurses (VON) Caregiver Best Practice Guidelines, caregivers generally identify with one or more 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 that encourage 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 national 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

People can help caregivers feel a part of their loved one's treatment process without disclosing confidential information about the loved one. Caregiver organizations suggest that some information can and should be shared, and that the sharing does not breach confidentiality. Mental health professionals generally agree that informal caregivers are "coping, grieving, and positive treatment resources." Family caregivers need information and tools to support them, and help them navigate the complex mental health system.

# 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.

### The result of ignoring your own needs:

- 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, or the family dog
- Directly expressed to your ill relative
- Passive-aggressively expressed to the family member you are struggling with (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

## Caregivers bill of responsibilities

I have the responsibility:

- 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 (without harm to others).
- 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 responsibility 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.

*(Source: The Alberta Caregivers Association)*

## Tools: caregiver burnout

### Check any that apply:

- I feel fatigued, as if I have less energy than usual.
- Lately, everything feels like it takes tremendous effort.
- I am having difficulty getting a good night's sleep.
- I wake up feeling tired or exhausted.
- I am more susceptible to colds, flus, or headaches than before.
- I feel frustrated, sad, and impatient most of the time.
- I am feeling anger and resentment.
- I am experiencing more mood swings or crying spells.
- I feel overwhelmed, and I worry about the future a lot.
- I feel more disjointed and disorganized than usual.
- I notice I have withdrawn from social events and have no desire for social contact.
- I feel as though I've lost my sense of humour or my ability to enjoy life.
- I feel more unsatisfied than usual.
- I am ignoring my own needs and avoiding setting aside time for myself.
- I feel very self-critical; I blame myself for everything.

## Stress in the caregiving family

When we add the responsibilities of caregiving to the routine pressures of family and professional life, we naturally feel stress. In turn, stress affects the health and well-being of the caregiver family members, 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 the same in the caregiver and the person dealing with the illness.

Symptoms include:

- Anger, sometimes leading to physical violence
- Anxiety
- Denial
- Depression
- Dissatisfaction with life
- Exhaustion
- Guilt
- Irritability
- Stress-related physical conditions

Caregivers offer a wide range of physical and emotional help; their stressors vary depending on the intensity of their involvement and their relationship to the person in need. These caregiver 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.”

*(Source: National Profile of Family Caregivers in Canada – 2002: Final Report*

*[http://www.hc-sc.gc.ca/hcs-sss/pubs/home-domicile/2002-caregiv-interven/det-anal\\_e.html](http://www.hc-sc.gc.ca/hcs-sss/pubs/home-domicile/2002-caregiv-interven/det-anal_e.html))*

According to a Health Canada report titled National Profile of Family Caregivers in Canada – 2002, the groups most likely to say caregiving has affected their emotional health included women (32%), younger caregivers (36%), those caring for family members younger than 45 (39%), and those caring for someone with a mental disability (47%).

### Don't forget

In this program we talk a lot about recovery from mental illness, and how we can support recovery from psychosis. As a family member or friend of a loved one with psychosis, you too are on your own journey of recovery. Some of the things you may be recovering from include: loss and devastation, frustration with inadequate mental health services, disruption to your family system, and emotional problems.

While you can't do the recovery work for your loved one, you can support them in their recovery as you journey forward on your own path toward recovery.





## Learning to handle stress

- Stress may increase depression and make everything seem worse. Learning to handle stress will help with your own and your loved one's 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 for 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!

*(Source: Caregiver Stress: The Impact of Chronic Disease on the Family by Elisa Sonnenberg, Swedish Medical Centre)*



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.

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Continue to do	Start doing	Stop doing
Emotional		
Spiritual		
Physical		
Social		
Intellectual		

Here are some suggestions that other caregivers have included in their self care plans:

### **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 counsellors

### **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.

*(Source: MS Society of Canada Taking Care: A Travel Guide for Your MS Caregiver Journey SAFE Program, Oklahoma City Veterans Affairs Medical Center)*

## 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.

### Now we can begin.

First take a deep breath. *Hold it for three 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 centring 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 mild 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 toward 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 at 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 favouring 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.

# Support systems and respite

## Support systems

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. 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)
- Recreation time with others at least once a week
- 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

Broadly defined, “respite” 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 caregivers periodic breaks from their duties by stepping in to take the ill person on planned outings or visiting them at home.



**Some reasons for using respite services:**

- Respite can alleviate tension that builds up in the home
- Without the use of respite, many caregivers have no one to help them with the burden of responsibility
- Some families are never able to take a vacation because they are too worried about their family member who is ill
- 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 collect the energy required to care for someone who suffers from a mental illness
- Respite provides caregivers with an opportunity to attend to their personal needs
- Respite is beneficial to caregivers and care receivers
- Using respite services can 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 family member who is ill (depending on the extent of the disability) while the primary caregiver goes away for a vacation
- an escort for doctors' appointments or to groups offering social or community services

**Group activities can include:**

- community meals, outings to restaurants
- cultural or leisure activities (museums, theatre, nature centres, movies)
- day or weekend camps
- special events

Respite can help families cope by providing relief from the 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. Some provincial schizophrenia societies, such as the one in British Columbia, offer respite services. Please contact your provincial society for respite services in your community.

**You can also contact:**

- VON Canada (national) <http://www.von.ca>
- Canada Red Cross (national) <http://www.redcross.ca>

## Session 6: Communication

# Session 6: Communication

handout

## Effective communication skills

Families coping with the ups and downs of a mental illness need to communicate effectively. Sometimes it's not what you say but how you say it that is important. Developing effective communication skills means finding ways to express yourself and your needs in a clear and respectful manner.

### Communication do's & don'ts

When communicating your needs, you want to be assertive. Communicating assertively means that you state your wishes directly and honestly, while simultaneously taking others' needs into account.

**LISTEN**ing is to:

Listen attentively to the words (verbal) and expressions (non-verbal)

Involve yourself – be interested in what is said

Show respect – treat adults as adults

Take time to reflect on what is said

Empathize – respect how others feel

Never accuse, blame, or belittle

**SPEAK**ing is to:

Share your feelings honestly by using “I” messages

Present issues and concerns, not past ones

Express your thoughts and concerns, both negative and positive

Acknowledge the other person's feelings

Keep it simple and clear

## 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 can be challenging

## Don't

- criticize
- focus on the illness
- argue about past events
- take anything personally
- interrupt
- resort to name-calling
- be judgmental
- tease your family member about symptoms
- raise your voice; yelling or shouting will never help you communicate your thoughts
- generalize. Be specific; words such as “always” or “never” are loaded and unhelpful (for example: “You never lift a finger around here”)
- use patronizing or authoritative statements such as “You’re acting like a child” or “You’ll do as I say, young lady”

## “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 to express negative feelings.

### The “I message” works like this:

- I feel \_\_\_\_\_, when you \_\_\_\_\_.

### Some examples:

- 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:

I feel	when you miss your appointment at the doctor’s office.
I feel	when you forget to mow the lawn as 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 do not 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.

Here are three good communication skills, adapted from *When Someone You Love Has a Mental Illness* by Rebecca Woolis (1992).

## Expressing negative feelings

Expressing negative feelings can be the most challenging of communication skills. It can create additional anxiety and nervousness and cloud our best intentions to deliver our message in a clear and respectful manner.

Tips to help you express 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 his/her 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 toward 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

Tips to help you 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 you would like the other person to do or say.
- Let him/her 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:

- consider various treatment options, including medications
- 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 may require you to adjust the way you communicate, so you can increase your chances of being understood.

Tips about symptoms of mental illness and corresponding adaptations:

Symptom 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

# Talking to others about mental illness

Adapted from *When Someone You Love Has a Mental Illness*, by Rebecca Woolis (1992)

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 others what you feel comfortable telling them.

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. 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 listener is not important to you (e.g., waitress, gas station attendant) or if the timing is bad, you can ignore the bizarre behaviour and say nothing at all. You can also say 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 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?

There are many things you can say so that others better understand mental illness.

### Some information that can be helpful:

- Although the exact causes of psychotic illness are not yet known, many illnesses have a strong biological/genetic component.
- Psychosis is very common. At least three per cent of Canadians will experience psychosis at some point in their lives.
- Psychotic illness affects thinking, behaviour, feeling, and judgment.
- The course of psychotic illness is often unpredictable, and symptoms can come and go for no apparent reason.
- Effective medications can make a big difference in alleviating symptoms and supporting recovery.



- Some mental illnesses can be quite severe and chronic. Severe illness often has a strong impact, both emotionally and financially, on the ill person and those close to him/her. The ill person needs need a great deal of support and understanding. Some mental illnesses can be quite mild, requiring only minimal supports.
- Mental illness is not contagious.
- Individuals with mental illness are rarely dangerous; rather, they generally tend to fear people and be quite introverted.
- With new approaches and earlier intervention, people can recover from even serious mental illnesses. Although they may still need services or supports, they can get on with their lives.

### What should we tell the children of a parent with mental illness?

- You are not to blame – you didn't do anything wrong!
- 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 suggestions).
- Both parents love you and will be here for you to the best of their abilities.
- It's okay to ask questions.
- Please tell us how you feel.
- 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 some day?
- Foster supportive relationships between the child and people outside the immediate family. It's important for the child to have a good support system of friends, and to have activities outside the family.
- Children should not be promised that the parent will get well and stay well forever.
- People with mental illness can recover and lead lives of meaningfulness and purpose.



# IDEAL method of problem solving

In our everyday life, we encounter many challenges and problems we need to solve. According to the research, people who cope effectively:

- work on one problem at a time.
- try new approaches to the problem.
- stay open to suggestions from others.
- use flexible and creative thinking.

When you are confronted with a problem, try the **IDEAL** problem-solving technique:

**Identify:** Define the problem before you try to tackle it. Start with the most urgent or the simplest problem, and focus on that problem.

**Describe:** List everything you might do to solve the problem.

**Evaluate:** Look at your list of possible solutions, and 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.

If you encounter a problem that seems too difficult to manage, use your support system and get help.

## “Fixing people – when they’re ready”

by Michael Evans

If you’re a problem solver you probably enjoy fixing things and giving advice, seeking out information and arguing for change. These skills will serve you well if you’re trying to help your loved ones fix a leak, but not if you’re trying to fix them, research shows. When you want someone to become more healthy or give up bad habits, simply doling out good advice and urging them on won’t create change. To truly increase your chances of influencing family and friends toward healthy behaviours, you need a crash course in motivational interviewing and the stages of change.

Developed by clinical psychologists William Miller and Stephen Rollnick, mostly in studies of heavy drinkers, motivational interviewing has now been applied in situations from water disinfection practices in Zambia to people’s eating styles. Its value in helping doctors was shown in research published in last week’s *Archives of Pediatrics and Adolescent Medicine*. The journal profiled research capturing the daily interaction of pediatricians with parents. It’s a tricky thing to talk to parents about their obese children, and the doctors used the non-confrontational style inherent in motivational interviewing to make their case. “What you want to do is get the patient to take responsibility for their behaviours,” lead author Robert Schwartz of Wake Forest University School of Medicine in Winston-Salem, N.C., told Reuters News Agency. The technique uses open-ended questions such as:

- What worries you about your current behaviour?
- What would be a small change that you could start with?
- What would it take to make you feel more confident about changing?
- Or even, sounds like you’re not really interested in help right now.

In the lexicon of motivational interviewing, this is “change talk.” It starts with where the person is rather than where you want them to be. When I first became a doctor, I wanted to convert all my smoking patients to non-smokers right away. Most felt that stopping smoking was a health priority. But most didn’t quit. Later on in my practice, I met a woman who was having unprotected sex with her HIV-positive husband once a month. I was shocked because it seemed to be a meditated decision. I outlined the risk and she understood. She was smart, if sad. But, like the smokers, she didn’t change.

To understand why people make health decisions that don’t seem wise – and how motivational interviewing can influence them - it helps to understand more about why people change. The rational thought would be that someone would change their health behaviours based on, well, rational thought. A cancer diagnosis should be a powerful predictor of whether a person is able to quit smoking, but the medical literature shows that it is not. What does predict success is having the benefit of a counselling style described by Carl Rogers, founder of client-centred therapy, as “accurate empathy” (skillful, reflective listening with a non-judgmental attitude), along with warmth and genuineness. If you have these skills and attributes, you understand not only the importance of change but also of people’s level of confidence and readiness to make that change.

Instead of a major event making up their minds, patients often describe a subtle personal moment – like hearing a comment from a grandchild – as their turning point. As the psychiatrist James Gordon famously noted: “It is not that some people have willpower and others don’t, it is simply that some people are ready to change and others are not.”

The stages of change were developed by psychologists Carlo Diclemente and James Prochaska, again in the setting of addiction. Taking one of my smokers, they would decide what mode the patient was in: “pre-contemplation” (not really thinking of quitting); “contemplation” (thinking about it), ready for “action” (setting a date to quit) or in “maintenance” mode (quit and trying to keep it that way).

Motivational interviewing is focused not on getting them to quit today, but on shifting from one stage to the next. Counsellors use specific techniques that allow them to roll with the patient’s needs. A good example is the “decisional balance,” where a patient is asked to reflect not only on the pros but also on the cons of changing or not changing. Traditional counselling tends to focus on the negatives of continuing a behaviour. But my own clinical success seems to come from the opposite. Counter-intuitively, my experience is that when I ask patients to discuss what they like most about smoking, this appears to open the door to quitting. We all know the downsides, but when we mull the upsides (taking a break, camaraderie, weight control) it gives us an understanding of how to take control and reduces the resistance to change.

For the woman who was having risky sex with her HIV-positive husband, her decision seemed more understandable after we discussed what she saw as the merits. She said she felt less depressed after sex, that the act connected her to a world she felt largely disconnected to. She also said her husband had a history of violence, and that she felt the risk of HIV transmission was the lesser hazard. It wasn’t until we had a shared understanding of these factors that we could start working together.

With motivational interviewing, small successes are reinforced and built upon. The result is gradually picking up new patterns of behaviour, coupled with a better sense of the Holy Grail of sustaining a healthy lifestyle – self-efficacy. The feeling that you’re capable of making changes in your life. It’s said that the conversation of motivational interviewing is a dance, not a wrestle. Are you ready to tango?

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Michael Evans is an associate professor at the University of Toronto and staff physician at the Toronto Western Hospital. His article “Fixing people – when they’re ready” appeared in the *Globe and Mail* on 29 May, 2007.

## Session 7: Living with Psychosis

# Session 7: Living with Psychosis

handout

## Facts about housing

Housing is fundamental to mental health. A decent, affordable, safe, and private space – a home – to call your own can be so easy to take for granted. Having it doesn't make life perfect, but it's hard to work on other parts of your life, including managing a mental illness, without it.

It has been shown that there is a strong link between having access to safe, secure, and affordable housing and better health. Therefore, having supportive housing should help improve overall health and, in particular, mental health.

People with mental illness need safe and affordable places to live. They also need the right kind of support to live successfully in these settings. Consumer choice is associated with housing satisfaction, residential stability and emotional well-being, and recovery.

Having a mental illness or a substance use problem often restricts a person's options to access, afford, and maintain the very kind of home that would help promote recovery. Because of a lack of supported housing options, once discharged from hospital or treatment centre, many people with mental disorders or addictions have only substandard boarding houses or dangerous hotels to go home to.

### The experience of people with mental disorders

One reason for this is the episodic nature of mental illness. People with mental health problems often lose their income during long periods of illness and repeat visits to the hospital. They may have trouble paying the rent and may eventually lose their furniture and all of their household contents, along with their address.

Some people in this situation may decide they are better off on the street, but without a fixed address, they may be cut off from a range of social services – including health care. Without access to medications and support, the person's symptoms may worsen and force them back into hospital, often for a longer period than the previous visit.

A small number of people may go without treatment for the disorder until they are arrested, and depending on the circumstances, end up in B.C.'s criminal justice system. Emergency rooms also repeatedly see and discharge frequent users, many of whom are mental health clients, with most recovery gains lost when the person is back on the street.

Known as the “revolving door syndrome,” this cycle is perpetuated by the lack of affordable housing and emergency supports available for people with mental illness.

Significant numbers of people manage some type of mental health problem, but the majority will not want or need specialized housing. They use their own resources to live in the community like any other citizen. In some cases, however, especially where the illness is more serious, the need for a specialized resource comes into play. Current research suggests that many individuals, even with serious mental illness, can live in independent living arrangements with appropriate supports.

## Types of housing for people with mental illness

### Supported housing

Supported housing is a place that is affordable, even for individuals on income assistance.

Supported housing is not treatment, but it does help people maintain their links to treatment and get maximum benefit from it. Staff are there to help you keep your appointments with a mental health counsellor and a physician, and to help you take your medication. These supports are in addition to the help you would get from a mental health professional at a community team or a doctor’s office.

Supported living staff also help clients learn basic skills to manage a household, look for a job, or go back to school. People living in supported housing speak passionately about how it has changed their lives for the better. They speak about how having an affordable place to live and support staff to help manage day-to-day challenges gives them the energy to focus on getting well. They say this is the key to putting the pieces of their lives back together.

- group homes provide subsidized rent; tenants share a home and the services of a community living support worker
- supported apartment buildings are built especially for people with mental illness; subsidized rent and daytime support are provided
- satellite apartments are leased in private market buildings; tenants have access to subsidized rent and outreach services
- supportive hotels: single rooms are leased and managed by non-profit societies; on-site staff support provides services to adults with mental illness

## Residential

- licenced community residences provide 24-hour supervision with professional staffing available on a daily basis; staff supervise use of medications unless a resident applies for permission to take his or her own medications
- supported living homes offer support staff during daytime hours; residents take their own medications
- family care homes are privately owned and provide care and supervision to one or two individuals who wish to live in a family setting

## Emergency accommodation

- emergency facilities offer short-term accommodation for people with no other immediate housing options available to them. Length of stay is usually less than 90 days

## What does adequate housing for people with mental illness look like?

- choice of housing arrangements according to an individual's wants and needs
- units that are clean, quiet, safe, and close to amenities and support services
- access to housing located in a variety of neighbourhoods
- affordable housing units and furnishings to accommodate the needs of people on fixed or low incomes
- access to flexible, 24-hour supports as needed
- options for maintaining the same housing arrangement regardless of changes in a person's mental health needs

*(Sources: Housing for People with Mental Disorder and Addictions.*

*<http://www.heretohelp.bc.ca/publications/factsheets/housing>*

*Centre for Addiction and Mental Health. Housing Discussion paper.*

*[http://www.camh.net/Public\\_policy/Public\\_policy\\_papers/housingpaper.html](http://www.camh.net/Public_policy/Public_policy_papers/housingpaper.html))*



## Living at home – setting limits

*(Source: Family Toolkit. [www.heretohelp.bc.ca](http://www.heretohelp.bc.ca))*

If, as a family, you decide that your family member will be living with you, it may be necessary to set reasonable limits on what behaviours will be tolerated. Some of these rules may be for your loved one's benefit, other may be for the benefit of others living in the household.

The following are some guidelines that may be helpful in setting limits when your family member lives with you:

- As a family, decide on the rules or conditions under which the person can live at home. For example, staying up late at night may be tolerated, but use of alcohol is not.
- Communicate these limits clearly. It may be helpful to write them into the relapse prevention plan.
- Anticipate that these limits will be tested.
- Be prepared to take action to enforce limits if necessary.
- Keep a record of how the situation works and how all family members are affected. This will help you evaluate how well things are, or are not, working. The record may also be useful, if needed, to demonstrate to the person who is ill that a different housing environment would work better.
- As a family, meet with the therapist to clarify treatment issues.

Families often feel very guilty if they must make the decision not to have their relative 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 person who is ill 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.

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.

## Facts about concurrent disorders

*(Source: Schizophrenia and Substance use: Information for Families [www.schizophreniaandsubstanceuse.ca](http://www.schizophreniaandsubstanceuse.ca))*

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 co-occurring disorder.

There is no single type of concurrent disorder. This is one of the reasons 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.

About 50% of people diagnosed with schizophrenia will also have problems with substance use and/or dependence. About half of youth who are experiencing a first episode of psychosis have or will develop a substance use disorder. This makes substance use a common concern of the family and friends of people with psychotic disorders.

Alcohol is the most commonly abused substance among individuals with psychotic disorders, followed by marijuana. Most people with schizophrenia are also dependent on nicotine (70 to 90%).

Because substance use problems are so common among people with psychotic disorders, families need to be alert to the earliest signs of problem substance use. If such signs are missed or ignored, the consequences can be serious, including relapse and hospitalization, difficult family relationships, loss of employment or entitlement to benefits, financial hardship, and/or incarceration.

## Why do people with psychosis use substances?

Research has shown that people with psychosis and other mental disorders often use drugs and alcohol for the same reasons as everyone else – to feel better or different, to relax and have fun, and to be part of a group. Other reasons for drug use include curiosity or experimentation, to relieve stress, overcome boredom, isolation and inhibitions, and to “fit in” socially.

These motivations may be intensified for a person with psychosis as a result of decreased vocational, recreational, and interpersonal opportunities, as well as the distress and disempowerment associated with having a mental illness. Some say that people with psychosis use substances to cope with their symptoms.

## Explanations particular to people with psychosis

There are several possible explanations for why people with schizophrenia use substances at a higher rate than the general population

One theory, called “primary addiction theory,” is based on literature that suggests there may be a common cause of both psychosis and substance-use disorders. For example, a person could be born with a genetic predisposition to both psychosis and substance use, or these could appear together in response to stressors in the environment. Another possible explanation suggests that the two disorders could develop independently but then, directly or indirectly, they affect one another.

People with psychotic illness may use substances to “self-medicate,” that is, to cope with the symptoms of their illness, such as anxiety and depression, or the side effects of medication.

## Risk factors

There are common factors that place people at risk for either substance use or mental health problems, or both: poverty or unstable income, difficulties at school, unemployment or problems at work, isolation, lack of decent housing, family problems, family histories, past trauma or abuse, discrimination, and biological or genetic factors.

People with concurrent disorders have described their own experiences with alcohol and other drugs and their pathways to recovery. Generally, they don’t talk about using drugs to “treat” their mental illness, but describe confused attempts to survive the stress of mental illness, the powerlessness of being a “patient,” victimization, lack of opportunities, and hopelessness.

## Early intervention in psychosis and substance use

Early intervention programs have been shown to be effective in reducing both problem substance use and psychotic symptoms. For people experiencing their first episode of psychosis, early intervention services may help detect and reduce substance use before it becomes a more serious disorder.

## What is the impact of using substances on someone who has a psychotic illness?

The use of street drugs or the excessive use of alcohol is harmful to the physical and mental health of all people, but the risks associated with drug use are even greater for people who have experienced psychosis.

This is best understood by the fact that psychosis and substance use interact with one another to make each diagnosis worse. As a result, the combination of these disorders can have serious and negative effects on many areas of people's lives, including work, relationships, health, and safety.

There is increasing evidence that having psychotic disorders may make individuals "supersensitive" to the effects of alcohol and other drugs. This means that they will experience more of the negative consequences from even fairly small amounts of alcohol and other drugs.

But substance use in turn affects the course of illness and treatment of people with psychosis, even when small amounts of substances are used. People with a serious brain disorder like psychosis who take illegal drugs and/or abuse alcohol are more likely to have relapses, are more likely to require hospitalization, and are less likely to respond well to treatment.

Substance abuse can reduce the effectiveness of treatment for psychosis in a number of ways. It can interfere with the effectiveness of medications used to treat psychosis, and can also contribute to people discontinuing their medication. Substance abuse also reduces the likelihood that people will follow through with their service providers' suggestions for managing their illness.

## Impacts of substance use

For the individual	For family members
Increased risk of making the symptoms of a mental illness worse with substance abuse, possibly bringing on an episode of mania or psychosis	Increased family conflict and tension, miscommunication, and mistrust; family's attempts to be supportive may fall apart
Increased risk of suicide	Increased levels of stress
Increased risk of poverty and homelessness	Feelings of shame, guilt, and blame
Increased risk of illegal activity and incarceration (jail sentence)	Feelings of anger or frustration
Increased risk of violent behaviour and domestic violence	Feeling depressed and/or hopeless
Increased risk of victimization	Increased risk of being abused
Increased risk of unemployment and instability	Increased levels of confusion
Loss of support systems	
Increased levels of stress	
Feelings of shame and guilt	
Increased physical health problems (risk of contracting hepatitis or HIV/AIDS through sharing needles or unprotected sex)	

## What are some common misconceptions about concurrent schizophrenia and substance use?

When a person has mental illness and is also using substances, their situation risks being misunderstood, and they may not get the timely help they need. A person with a substance use problem, their friend, or a family member may think the beginning symptoms of mental illness are “just the drugs,” that is, a reaction that will go away when the drug use stops.

On the other hand, some families may neglect to mention their relative’s problem drug or alcohol use to health care professionals because they believe it is a symptom that will clear up once the person receives treatment for the mental illness. Others view drinking or drug use as the best “leisure” activities a person with serious mental illness can expect.

## What is the true picture?

In fact, substance abuse is just as devastating for people with mental illness as it is for other people, if not more so. People with concurrent disorders can get caught up in a vicious cycle that involves multiple living problems resulting from poverty, lack of support systems, isolation, physical illness, housing difficulties, disrupted family functioning and interpersonal relationships, and negative experiences with previous treatment.

In addition to some of the changes in behaviour that psychotic illness can bring about, a person who is also using substances will most likely experience a worsening of their psychiatric symptoms. Substance use can also make their behaviour more challenging.

## Signs that your family member may have problem substance use

You may notice your relative:

- Is spending more time acquiring and using substances, and less time in their usual activities
- Has greater financial difficulties because
  - the cost of using substances can become significant
  - in some cases substance use can lead to job loss, which creates further financial problems
- Becomes more agitated, hostile, or aggressive
- Experiences more frequent and intense psychotic episodes
- Stops taking prescribed medications
- Misses appointments
- Gets kicked out of school
- Loses their job
- Has difficulty getting or maintaining appropriate housing because
  - some supportive housing facilities ban substance use and will evict tenants over problem substance use

It can be difficult to tell if what your relative is going through is an ongoing psychosis or a temporary reaction to drug use. Often families prefer to interpret the changes in their family member's behaviour as a passing problem of substance use rather than as a sign that there may be serious mental health problems developing.

Because it is difficult to distinguish between a toxic psychotic state (brought on by drug use) and a first episode of psychosis, it is always a good idea to seek help from a professional.

## Which came first, the psychosis or the substance use?

People often wonder, “Which came first: the mental health problem or the substance use problem?” Often it’s hard to tell. It is more useful to think of them as independent problems that interact with each other.

Some stimulating drugs, like amphetamines and cocaine, can actually cause psychosis. When induced by drugs in this way, the result is 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.

Psychosis can also be “drug assisted.” For a person who is already at risk for psychosis, some drugs, such as marijuana, can give the process a boost. These drugs “unmask” the person’s vulnerability and can trigger the onset of a drug-assisted psychosis.

On the other hand, problem substance use may follow the onset of a psychotic illness and can be an attempt to deal with certain psychotic symptoms.

The important thing to understand is that for a person who may have a biological predisposition to develop psychosis, the impact of substance use can be more serious than for someone who does not have this vulnerability.

## Information on specific substances

People living with psychotic disorders tend to use substances that are affordable, easily accessible, and readily available. The most common substances used by people with schizophrenia and psychotic disorders are alcohol, marijuana, and cocaine. Prescription drugs like tranquilizers and sleep medication can also be misused.

Sometimes people may use a number of substances. The types of substances people with schizophrenia use may change depending upon what stage they’re at in their life. People who are older may not use street drugs as much as alcohol, or they may misuse over-the-counter drugs.

It’s often believed that “hard drugs” are more of a problem than marijuana and alcohol. It’s true that narcotics like heroin and stimulants such as cocaine or crack and ecstasy are serious problems, and can be dangerous for anyone, especially someone with a psychotic illness. Hallucinogens like mushrooms and LSD are dangerous as well, especially since they can mimic psychosis in those without any underlying vulnerability to psychosis.

But marijuana and alcohol, more commonly available than the “hard drugs,” should not be dismissed as harmless. On the contrary, new research is showing that using marijuana can create serious problems for people who are vulnerable to psychosis, and can lead to earlier psychotic relapses in young people recovering from a first episode of psychosis.



Marijuana use has been shown to trigger and worsen psychosis in young people who are vulnerable to psychosis, and may even cause psychotic illnesses in people who would not otherwise suffer from them.

There is increasing research evidence to show that, particularly when someone starts using marijuana in their teens and uses heavily, marijuana can trigger early onset of psychotic illnesses. For those who do become ill, approximately 15% will continue to have psychotic symptoms even after they stop using.

For people who are already vulnerable to psychosis, cannabis use has been shown to make people four times more likely to become ill with psychosis. They are also likely to experience their first symptoms at a younger age.

Alcohol too creates problems. It can compound the sedating effects of antipsychotic medication, it increases depression, and it can make it harder for people to stick with their treatment and supports to manage their psychosis.

Most people experience a worsening of their psychotic symptoms when they are using substances.

## Helping your family member get help

The decision to seek help for a relative or friend can be a difficult one for many reasons.

- The person may not wish to get help, or may not see that there is a problem
- It can be unclear how to proceed and where to go for help
- You may not know exactly what the problem is

It is immensely challenging and frustrating to deal with someone who is in distress but refusing to get help. If you suspect your family member or friend has a mental health and/or substance use problem, it's important to be open and honest when speaking with them about it. Here are some guidelines that can help.

- If the person appears to be a danger to self or others, seek help immediately.
- Let the person know that you have noticed changes in their feelings and behaviour, and ask if they are having difficulties.
- Listen to what they have to say and try to solve the problem together.
- Encourage the person to speak with their doctor or mental health professional. Offer to accompany them to the appointment.
- If the person does not believe they have a problem, encourage them to speak with someone else they trust.
- Allow the person to stay in control by offering choices of ways you can help them.
- Offer to help the person find out about where they can get assistance.
- Reassure them that it's okay to seek help, even if they think they can cope without it.
- Stay positive about the future and reassure them that things will improve

## How are concurrent disorders 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 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 disorders 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

*(For more information on dealing with Concurrent Disorders, please refer to [www.schizophreniaandsubstanceuse.ca](http://www.schizophreniaandsubstanceuse.ca))*

## Concurrent disorders: Do's and Don'ts

Things to keep in mind when dealing with a friend or family member with a concurrent disorder

### Do

- show support and understanding.
- learn about addiction and mental illness. Invest some time reading or researching the available literature.
- encourage the individual to seek help.
- treat both addiction and mental illness as a disease.
- acknowledge accomplishments.
- seek out support for yourself. It is important to take care of yourself. Seek the advice and support of other families coping with dually diagnosed relatives.

### Don't

- blame, shame, argue, nag, preach, or lecture the individual. Let go of past mistakes. Bringing up broken promises will create a tense and stressful environment.
- make threats. Under certain circumstances, it may be necessary to set boundaries to ensure you and other family members are safe.
- be confrontational and coercive. For example, saying, "After all we've done for you..." or "If you cared about us..." will not change the situation.
- try to overprotect the individual. Rescuing someone from the consequences of their actions won't help them learn to manage their addiction. Learn the difference between helping and enabling.
- participate in the individual's substance abuse. Sharing a drink will only make it appear as though you condone drinking.
- expect perfection. There may be relapses. Remain supportive and encouraging. Acknowledge that it is difficult to recover from an addiction.

## When dealing with someone with concurrent disorders

### 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.

# Dual diagnosis

by *Stephanie Roberts*

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 disorders 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 10 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 than 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 per cent 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, who 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 health care 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 you’re in your late 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 had 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, 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 programs 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, 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 Alcoholics 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.”



## Session 7: Living with Psychosis | handout

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 diagnoses. 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."

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Stephanie Roberts is a Toronto-based writer.

*(Source: Schizophrenia Digest magazine, Winter 2003)*

# Estate planning

by Marvin Ross

## Preparing for the future is essential

No 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 in considerable 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 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 a 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 either 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.

*(Source: The Advocate, Winter 2001-2002, with permission of the Schizophrenia Society of Ontario)*

- 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 cars 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 or 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.

*(Source: Ottawa, Ontario-based lawyer Ken Pope and Wealthcare, an Ontario-based medical-financial integrated planning service)*

## Parents 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 lifelong care even after the parents are no longer there.

Based on the Burnaby, B.C. Planned Lifetime Advocacy Network (PLAN), seven 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 interests 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 service 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."

*(Source: Schizophrenia Society of Canada 2001)*

# Daily living tips

## For family and friends living with someone who has a mental illness

### Recognize your limits

- 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.
- 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.

### 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.

### Encourage a sense of structure

- **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 and 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.

### Maintain a calm 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 practise calming activities (e.g., playing quiet music, reading, or gardening).
- Ignore the “annoying but unimportant” things. The concept of “picking your battles” can be very helpful, as some issues just aren’t worth arguing about!

**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 you 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.

**Report aggressive behaviour:**

- If someone is persistently aggressive, report actual or threatened violence to the treating health professionals (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.



## Setting goals and expectations

It is important to review and compare your goals and expectations with your loved ones. This process 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.

### 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 regular 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

### Establish realistic short-term and long-term goals

Discuss goals with your relative. His/her interests, 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.

- Basic skills for independent living: The ability to shop, cook, clean, manage money, use public transportation. How independently has your relative lived?
- Interpersonal skills: The ability to establish and maintain relationships, carry on conversations, and make eye contact.
- 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 able 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, he/she may want to start by learning the basics on how to operate a computer. This does not mean enrolling in a complex college program, but maybe starting with an introductory course at a local community centre or learning centre. Encourage your relative 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 recognize his/her success.

**Step 6:** Establish long-term goals. Now that your relative has accomplished some short-term goals, help him/her 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.

## 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

- 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 death 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:** 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
- not 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 increased 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.



## 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 manage 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.

### 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.

#### Don't's

- 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.
- Don't use continuous eye contact.
- Don't block the doorway.
- Don't argue with other people about what to do.

# A family crisis plan

## 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

## 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.

## 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. Other 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 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 police 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.

# Family crisis plan form

(complete this form with your loved one)

Name:

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Address:

---

Phone number:

---

**My informal support team includes**

1.

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2.

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3.

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**My formal support team includes**

Family doctor:

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Psychiatrist:

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Mental health caseworker:

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Outlined below is what my family and I would like to happen if I am in crisis as a result of mental illness:

**Crisis A)**

The situation:

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My plan to resolve this situation:

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**Crisis B)**

The situation:

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Plan for resolution:

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**Crisis C)**

The situation:

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My plan for resolution:

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Release Form: If my crisis as a result of my mental illness appears to be life-threatening, or if my actions may result in bodily harm to myself or others, I hereby agree that my support team are not obligated to follow my plans as outlined in the Family Crisis Plan Form, but will help me in any way they can.

Date:

---

Signature:

---

## Family crisis contact list

Family doctor name:

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Phone:

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Psychiatrist name:

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Phone:

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Community mental health team phone:

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Mental health emergency services phone:

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Crisis plan notes:

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## Police crisis information

Please take this person to hospital. Important: This person is *not* a criminal. This person has a mental illness. Please treat him/her with compassion and dignity. Thank you.

Name: \_\_\_\_\_

Age: \_\_\_\_\_

Hair colour: \_\_\_\_\_

Eye colour: \_\_\_\_\_

Height: \_\_\_\_\_

Weight: \_\_\_\_\_

Allergies, high blood pressure: \_\_\_\_\_

Current medications and dose: \_\_\_\_\_

Diagnosis: \_\_\_\_\_

Suicidal: \_\_\_\_\_

Violent: \_\_\_\_\_

Date of last doctor visit: \_\_\_\_\_

Date and duration of last hospital visit: \_\_\_\_\_

Doctor name & phone number: \_\_\_\_\_

Emergency contact person: \_\_\_\_\_

Relation to patient: \_\_\_\_\_

Address: \_\_\_\_\_

\_\_\_\_\_

Day phone: \_\_\_\_\_

Night phone: \_\_\_\_\_

## Facts about suicide

- 90% of suicide victims have a diagnosable psychiatric illness
- 80% of suicides are carried out by persons who have a depressive illness
- Women make 3-4 times more suicide attempts than men, but men complete suicide more often, probably because they choose more lethal methods
- 40% of people with schizophrenia attempt suicide and 10% complete the act
- 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. Whether deliberate or accidental, 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

**An individual may be at risk of suicide when he/she:**

- exhibits feelings of worthlessness
- expresses hopelessness about the future
- hears voices instructing him/her to hurt or kill himself/herself
- expresses a sense of powerlessness to change his/her situation
- abuses drugs or 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: writing a will, giving away favourite possessions
- has made previous attempts, or makes suicidal gestures (cutting his/her wrists, taking too 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 three ways; they are listed in order of increasing risk and seriousness.

- **Ideation:** thoughts or feelings about harming or killing himself/herself without any immediate plan or intention of acting on the feelings
- **Gestures:** self-destructive acts that a person connects with feelings or thoughts of suicide (taking ten aspirins); these are often a way for the person to communicate his/her feelings to others and should be responded to
- **Attempts:** an action with a potentially lethal outcome

## What to do if someone is suicidal

- **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.
- **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 a suicide hotline.
- **Be supportive.** Listen in a non-judgmental, compassionate manner. This gives the individual an opportunity to vent his/her feelings and offers him/her relief from being alone with the pain. Reassure the person that there is help for his/her problems and that he/she 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 may have made without first talking to you, to a mental health professional, or to 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.
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 need 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 best 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 checkup, 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 your loved one 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

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 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

*(Source: I Am Not Sick, I Don't Need Help. X. Amador with A. Johanson [NY: Vida Press, 2000] ISBN: 0967718902)*

## Session 8: Recovery



# Session 8: Recovery

handout

## What does recovery from mental illness mean?

Emerging in the mid 1980s, recovery from mental illness continues to evolve as a concept and reality. Recovery has been described from the perspective and understanding of consumers, clinicians, and family members. Recovery has been described as a process; a vision; and as an outcome. The publication of first-person recovery narratives in professional journals, consumer and family organization newsletters, newsmagazines, newspapers, and on the Internet provide us with a rich resource to gain more knowledge about this concept. Clinical research studies also provide a wealth of information.

Despite the growing body of literature, and many excellent descriptions of recovery, a clear, concise, all-encompassing definition has yet to be offered. The best definition at this point may be from William Anthony of Boston University (1993). He tells us: “Recovery is a deeply personal process of changing one’s attitudes, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful life even with the limitations imposed by disability. It involves developing new meaning and purpose in life as one grows beyond the catastrophic effects of illness/injury.”

Patricia Deegan, a pioneer in the mental health recovery field, completed a doctoral degree after years of coping with major mental illness. Deegan emphasizes that people with mental illness are not passive recipients of rehabilitation services. They do not “get rehabilitated” in the sense that cars “get tuned up” or televisions “get repaired.” Rather, they are courageous participants in a way of life that includes employment, social interaction, sports, community service, and other activities.

Recovery does not mean cure; it is a hopeful attitude, a way of approaching the day. Practitioners and caregivers working with people with mental illness need to see the person as more than the illness, and understand that:

- recovery goes beyond rehabilitation; it may involve a kind of transformation
- recovery is a unique (individual) journey
- recovery may not mean symptom free

According to Deegan, recovery from the illness is only one part of the process. Many individuals with mental illness must also rebuild a sense of self-worth and recover from the side effects of unemployment, long periods in treatment settings, and the stigma and discrimination attached to mental disorders.

Reclaiming these aspects of life can be more difficult than recovering from the illness itself. Crushed dreams may take a long time to mend, especially if the person has had few opportunities to direct his or her own life.

*(Sources: P. Deegan, “Recovery as a Journey of the Heart.” In L. Davidson, C. Harding, and B.L. Spaniol (Eds.), Recovery from Severe Mental Illness: Research Evidence and Implications for Practice, Vol. I [Boston: Boston University Centre for Psychiatric Rehabilitation, 2005], pp 57-68. CMHA National Office, [www.cmha.ca](http://www.cmha.ca) <<http://www.cmha.ca>> )*

# Recovery

This article was obtained from the Family Toolkit section of the heretohelp.bc.ca website, which is sponsored by the B.C. Partners for Mental Health and Addictions Information. The article focuses on the recovery of a family member experiencing a mental illness.

Recovery is a process and a goal – it is learning to successfully manage a disorder, having control over symptoms and having a quality of life. It involves overcoming the negative impact of a psychiatric disability despite its continued presence. It has also been described as a way of living in order to make the most out of life. It is less about returning to a former state than about realizing the potential person you can become. It is about getting on with life in spite of having a mental illness.

With the development of new treatments and a better understanding of mental and substance use disorders, research now indicates that the majority of people with mental illness will experience significant recovery.

Recovery from a mental illness is not unlike recovery from chronic physical illnesses such as diabetes. In both cases the person may need to make lifestyle adjustments to accommodate the limitations that result from the illness.

After a person has been diagnosed, their mental health professional will work with them to develop a treatment plan. Depending on the diagnosis, the treatment plan may include the use of medications, therapy or counselling or another type of treatment. Other supportive services such as housing or educational programs may also be suggested.

Recovery involves sticking to a treatment plan and working with the mental professional to evaluate the effects of the treatment. Plans should be reviewed and revised if something isn't working. Remember, though, it can take time before the full beneficial effects are seen. Encourage your family member to become an active partner with their treatment team. The more they learn about their illness and treatment options, the better able they will be to make decisions about their health and well-being.

**Supporting a person to cope with setbacks and stay well means:**

- Learning to be aware of the ups and downs in managing a mental illness.
- Being positive about managing problems/illness.
- Taking a realistic approach to relapse and developing a plan.
- Acknowledging the tough times or setbacks and reminding the person of past successes.

Although we may think of recovery as being able to engage in day-to-day activities like work, having relationships and choices such as where a person resides, there is also a very personal nature to recovery. A sense of hope, self-esteem and well-being are also important components of recovery. Without a belief that life will get better, there is unlikely to be any motivation to help oneself. Self-esteem is often shaken by a diagnosis of mental illness.

Having a sense of control over one's life (including management of an illness) helps a person to feel better about themselves and who they are. Love and acceptance from family members and friends help a person to feel good about themselves. In addition, the skills and abilities a person develops help them value the contributions they can make.

A common denominator of recovery is the presence of people who believe in and stand by the person with mental illness. It is in this context that families can significantly aid in recovery.

**Positive factors in promoting recovery:**

- Strong social support networks
- Stable living condition
- Safe and structured environment
- Sense of purpose or direction, feeling of contributing to society
- Someone to discuss experiences and feelings with and provide practical help
- A good understanding of what has happened
- Physical well-being
- Effective medication without distressing side effects
- Sense of realistic expectation and hope about the future

*(Source: Family Toolkit. [www.heretohelp.bc.ca](http://www.heretohelp.bc.ca))*



# Approaches to recovery

## The medical model

The medical model is the traditional approach to recovery from severe mental illness. It considers recovery to be a reduction in symptoms, a reduced need for medication, and a reduced need for medical and social care services. This approach to recovery tends to consider people with mental illness as passive recipients of treatment and services.

## The recovery model

In recent years there has been increased recognition that recovery can refer to a person's improved capacity to lead a fulfilled life that is not dominated by illness and treatment. This is known as the "recovery approach" or "psychosocial rehabilitation."

In contrast to the medical approach, the recovery approach does not require people to experience reduced symptoms and reduced need for medical and social care; it is about experiencing improved quality of life and higher levels of functioning despite the illness.

Recovery in this sense does not mean the illness has gone into complete remission. It means that over time, through what for many is a long and difficult process, individuals come to terms with their illness, learn first to accept it and then move beyond it. They learn to believe in themselves as individuals, learn their strengths as well as their limitations, and come to realize that they have the capacity to find purpose and enjoyment in their lives despite their illness. The recovery approach focuses upon the potential for growth within the individual. That potential can then be developed by integrating medical, psychological, and social interventions. The recovery model sees individuals with mental illness as active participants in the recovery process.

## Can people with severe mental illness recover?

Over time, most people with schizophrenia will make at least a partial medical recovery. Within ten years of the onset of illness

- Approximately 25% will be in complete remission;
- 25% will experience substantially fewer symptoms;
- 25% will have slightly reduced symptoms;
- 15% will still experience the same level of symptoms; and
- 10% will be dead, often as a result of suicide or accident.

Medical outcomes are better over longer periods of time. Many people will need to take medication for a long time in order to control symptoms and prevent relapse. As people get older their symptoms may change and/or become less severe. Changes in symptoms may lead to different medications being prescribed, and this may assist medical recovery.

A number of factors can be used to predict medical recovery but these are only indicators. Factors which suggest that a good recovery is likely include:

- Good adjustment prior to the start of the illness;
- A family with no history of schizophrenia;
- Developing the illness at an older age;
- Sudden onset of the illness; and
- Onset of the illness following a major life event.

Progress and recovery can be helped significantly by positive attitudes and constructive support from family, friends, and professionals. Providing training and support to enable people with mental illness to regain social skills and life skills, to engage in work or education will all assist in recovery. Some people with a diagnosis of mental illness will continue to experience symptoms, much of the time or periodically. If, through support and training, they can learn to live fulfilled lives, despite their illness, then they can be thought of as recovered.

Recovery, in the sense of leading a fulfilled life despite an illness, requires a belief by both the person with the illness and those around them that the ill person will recover. It requires a commitment to recovery and a recovery strategy, as well as resources to enable recovery and opportunities to share personal growth with others also seeking to recover. Finding a sense of meaning and purpose even in suffering is often thought of as a useful step. For some individuals the illness itself and the adversity associated with it may stimulate personal growth. For others the journey to recovery will feel hard. How far and how quickly each individual recovers will vary widely and it is important to recognize and value every step no matter how small.

## Self-management

Self-management is an important part of the recovery approach. It is about taking control of your own life. It is something we all do in coping with life's difficulties and choosing how we want to live our lives. Self-management can be broken down into four parts: support; stimulation; medication; and planning.

## Support

It is important that you get the right support. Family and friends may try to overprotect you, leading to feelings of being stifled and frustrated. Alternatively friends and family may become distant and angry, increasing your feelings of isolation. Talking to people about what support you want will help everyone to meet your needs in the best way for you.

## Stimulation

It is important that you find the right balance between doing too little, so that your life becomes a vacuum, and doing too much, so that you are under stress and more vulnerable to your symptoms. There may be some activities that are too stressful for you but there may be new activities that you can try and enjoy. Try to learn to recognize situations that are difficult for you and try to find ways of coping with these situations, perhaps with the help of other people.

## Medication

Talk to your psychiatrist or doctor about your medication to ensure that you are receiving the right treatment for you, that side effects have been eliminated as far as possible and to explore whether you are on the optimum dose. What medication works for one may not work for another and it's likely to take time to find the best one for you.

## Planning

Plan in advance what you want to happen if you experience future acute episodes of your symptoms. Make sure that people know what you want to happen and what they need to do. Consider making an "advance statement" explaining how you want matters to be dealt with, so that it can be held in your medical records and also by a relative or friend you trust.

**About the Author:** Rethink is the largest severe mental illness charity in the UK. We are dedicated to improving the lives of everyone affected by severe mental illness, whether they have a condition themselves, care for others who do, or are professionals or volunteers working in the mental health field.

*(Source: Recovery from severe mental illness. [www.rethink.org](http://www.rethink.org))*

Session 9: Understanding the Mental Health System and Advocacy

# Session 9: Understanding the Mental Health System and Advocacy

handout

## Demystifying mental health legislation

It is difficult for us to provide specific information on mental health legislation here because there is so much variation according to which province you're in. There are, however, some underlying commonalities, which we will outline here.

There are three main acts that outline your rights with respect to mental health services. The Mental Health Act is a set of rules decided by the provincial legislature that gives doctors and psychiatric facilities certain powers and gives patients particular rights. These laws apply in general hospital psychiatric units and psychiatric hospitals but not in mental health clinics. The Health Care Consent Act deals with rules for consenting, or agreeing, to treatment. The Substitute Decisions Act deals with how decisions can be made for a person and the appointment of powers of attorney for personal care and property.

**The Mental Health Act deals with many in-patient issues, including:**

- when someone can be taken and admitted to a psychiatric facility involuntarily
- how a person can be kept in the hospital
- who can see a patient's records in the facility, and how to arrange to see them
- a patient's right to information and right to appeal being involuntarily admitted, held in a facility, denied access to records, and so on

### Being admitted to hospital

#### Voluntary admission

Most people are admitted voluntarily to a psychiatric facility. They choose to enter the hospital for help with a problem. To be admitted voluntarily for care, you can get a doctor's recommendation or go to the emergency department of a psychiatric or general hospital or a local distress centre. You will be admitted if you need observation, care, and treatment provided by an in-patient psychiatric facility.



## Involuntary admission

Admitting someone against his or her wishes is a much more difficult situation for everyone concerned. The law identifies various ways to admit a person to a hospital as an involuntary, or certified, patient. The person must be seen to be a danger to himself or herself or to others, or at risk of serious physical impairment due to a mental health problem.

A person can also be admitted involuntarily if the following are all true:

- The person received treatment for a mental health problem before
- The person showed clinical improvement as the result of the treatment
- Based on the person's history and condition, it is likely that the person will cause harm to himself or herself or others, or will suffer substantial mental or physical deterioration or serious physical impairment
- The person has been found to be incapable of consent and a substitute decision-maker (SDM) consents to treatment on his or her behalf and the substitute decision-maker is the person who has legal authority to make treatment or other personal care decisions for a person who is incapable
- The person is not suitable for informal or voluntary admission

A person can become an involuntary patient (required to stay in the hospital) if they meet the criteria or conditions described above. How long they have to stay in the hospital depends on how long they continue to meet the involuntary criteria or conditions. The Mental Health Act requires that certain forms must be used to admit patients and keep them in the hospital involuntarily, and to let them know about their rights.

If your family member or friend is an involuntary client, he/she cannot leave the hospital unless permitted under conditions set by a doctor. If the person disagrees with being committed to (or kept in) the hospital, he/she can apply to the Consent and Capacity Board to have the doctor's decision reviewed. Members of this board are not part of the health care team responsible for the person's care.

## Consenting to or refusing treatment

The Health Care Consent Act sets out the rules for making decisions about treatment.

Individuals have the right to make a decision about their treatment if they are capable of doing so. Individuals are considered capable of making a decision about treatment if they are able:

- to understand the information that is relevant to the decision about the treatment and
- to appreciate the likely consequences of consenting to or refusing the treatment (or of not making the decision at all).

While in the hospital, a person can refuse psychiatric treatment if he/she is considered mentally capable to decide on treatment.

All people have the right to get information from their doctor before consenting to treatment.

**That information should include:**

- the nature of the treatment
- expected benefits of the treatment
- important risks of the treatment
- important side-effects of the treatment
- other approaches that could be taken
- what will probably happen if they don't have the treatment

**When your family member or friend is not capable of making decisions about his/her treatment:**

If your loved one is found incapable of making treatment decisions, a substitute decision-maker (SDM) is asked to make decisions for them. The SDM has to make choices based on what the individual said they would want when they were capable. If they didn't express any wishes, the SDM must act in the person's "best interests."

An SDM may be a person's guardian, a power of attorney for personal care, someone appointed by the Consent and Capacity Board or a family member. If no one is available to act as an SDM, the Office of the Public Guardian and Trustee assumes this role.

## When a person is not able to manage their finances

If your family member becomes a patient in a psychiatric facility or unit, their doctor may find that they are incapable of managing their money and property. To be judged "incapable of managing your property" means you are not able to understand important information about your finances and cannot appreciate the consequences of making or not making financial decisions.

Unless the person already has a guardian of property or has made a power of attorney for property that states who will make money and property decisions for him/her, the Public Guardian and Trustee (PGT) becomes the guardian of property under the Mental Health Act and makes those decisions. The PGT is a government worker who will manage the person's property by making sure that money owed to him/her is paid and bills and other expenses are paid. The PGT may let another person (e.g., a family member) take over responsibility if the person shows that he/she has a plan for managing the property in a way that is fair and appropriate.

If you think there is a risk that your family member might be found incapable of managing his/her finances, you can work together to set up a power of attorney for property to allow someone – you or someone your family member trusts – to take care of these responsibilities (such as paying the mortgage or credit card bills). If the person is found to be incapable of managing his/her property or finances, and has not already made a continuing power of attorney when capable, the court may select a guardian of property for him/her.

*(Source: "Understanding Your Rights" in Challenges & Choices: Finding Mental Health Services in Ontario. Centre for Addiction and Mental Health. <http://www.camh.net>)*

## Practical things you can do

There are a number of things you can do to navigate the mental health system:

- Familiarize yourself with parts of the Mental Health Act; for instance, the forms that have to be filled out for a mandatory psychiatric assessment and possible hospitalization. Family support programs are also a good place to find this kind of information.
- Suggest to your family member that he/she consider making a power of attorney for personal care or property in the event that he/she may become incapable of making decisions about personal care (including treatment) or money and other property.
- Write a journal with details of your family member's problem. This could include the history of the problem (e.g., when the problem started, how it began and progressed, how many times he/she had symptoms and what they were) as well as a record of treatment (e.g. hospitalizations, medications, and a list of the health care professionals who treated your family member). It may help to prepare the history with another family member; different people may have had different experiences or may remember things differently.
- Prepare a list of questions before you meet with the people who are helping your family member. Here are some questions you might ask, depending on whether your family member is already in a hospital or is still being assessed:
  - Are there any resources to help me cope?
  - Who will assess (or who has assessed) my family member?
  - When will we know how long my family member will be kept in hospital?
  - What are visiting hours? Can children come?
  - Can I bring food or gifts?
  - Can I meet the social worker and primary care nurse to discuss plans for leaving the hospital?
  - Can I be involved in my family member's care team?
  - Will you contact me before my family member is discharged?

## How families can advocate for systems change

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 are needed, and how they can take an active role in implementing 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 they "Board Certified"?
- **Ask lots 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 centred" 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.** These are 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:

- **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.** 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 e-mail "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.

*(Source: Adapted from *Advocating for Your Child: 25 Tips for Parents* by David Fassler. Center for the Advancement of Children's Mental Health [CACMH], Columbia University.)*

# Schizophrenia Society of Canada Advocacy Toolkit



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This Advocacy Toolkit was developed as a cooperative effort between the Schizophrenia Society of Canada ([www.schizophrenia.ca](http://www.schizophrenia.ca)) and Advocacy Solutions ([www.advocacysolutions.ca](http://www.advocacysolutions.ca)).

## Purpose:

The purpose of the Schizophrenia Society of Canada (SSC) Advocacy Toolkit is to provide people living with mental illness, caregivers, and supporters with some basic information to assist in their advocacy and media efforts.

For many using this tool kit, you may have limited knowledge or experience around advocacy and dealing with the press. Indeed, you may never have had occasion to speak to an elected official about an issue before, nor contacted the media. This guide is meant to introduce the core concepts of advocacy and working with the media, as well as provide you with the practical steps you need to start advocating on your own behalf.

We encourage you to share what you learn from this document with others engaged in mental health advocacy. We also strongly encourage you to share your efforts with other mental health consumer and family members. And you can find out more about SSC's advocacy efforts, including additional tips and resources, by visiting our website at [www.schizophrenia.ca](http://www.schizophrenia.ca).

The Schizophrenia Society of Canada, founded in 1979, is dedicated to improving the quality of life for those affected by schizophrenia and psychosis through education, support programs, public policy and research. Its membership includes people living with schizophrenia and related mental disorders, their family and friends, and mental health professionals who work directly with consumers and their families. The SSC works with 10 provincial societies and their over 100 chapters and branches in a federation model to: raise awareness and educate the public in order to reduce stigma and discrimination; support families and individuals; advocate for legislative change; and support research through the SSC Foundation and other independent efforts.

Please take the time to tell us about the advocacy and media work you've done. It will ultimately help us more effectively coordinate our joint efforts and be successful.

## Schizophrenia Society of Canada

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## Advocacy – core concepts

### What is advocacy?

- Advocacy is defined by the Canadian Oxford Dictionary as “verbal support or argument for a cause, policy”.
- More simply, it is telling your story to someone in government (an elected politician or a bureaucrat), through various means, with the express purpose of compelling them to do (or not do) something.
- It is a process, that normally takes time to realize tangible results.
- It is not, for example, what protesters do when they chain themselves to a tree to prevent it from being cut down – that’s activism.
- Advocacy is not radical; it’s reasonable, grounded in sound, rational thought.
- There is no one way to do it – advocacy is personal to your own style or comfort level.
- It is empowerment – exerting some form of control and initiating some form of action around issues that matters to you or others.
- It is action, bringing about tangible change – it is more than just raising awareness or educating people about your issues.

### Why is advocacy important?

- Because decision-makers react to those credible groups or people who most effectively bring their issues to the forefront of the public agenda.
- Because all governments have competing interests and concerns that must be addressed, as well as their own policy priorities and fiscal challenges – those who can best engage in this process will have their voices heard.
- Because those who choose not to engage will have no say in decisions that could fundamentally impact their lives.
- Because you as voters, taxpayers and citizens have the power to affect change around your issues.

The following subheadings will take you through the core concepts of advocacy.

### Knowing your issues

- You need to demonstrate that you know your issues and the core facts surrounding them, in order to establish credibility.
- Be able to discuss your issues in the context of a story, using examples of real people like you who are being impacted – **your personal experience or story is the key to effective advocacy.**
- Ideally, if you are advocating to a politician, your examples will incorporate constituent concerns or reflect their personal interests.



### Positioning your issues

- Find out what matters to the people that you represent, if you are advocating on behalf of an organization – this will help to frame your issues.
- Build alliances with other people around common issues and move forward as a united force.
- Look for third party advocates who may be willing to take your issues to decision-makers on your behalf ie. physician, former Member of Parliament (MP).

### Understanding the government's agenda

- Know what matters to the government of the day in terms of their over-arching public policy goals.
- Try to incorporate your issues within their agenda.
- Offer solutions – policy positions that represent a “win” for both your cause and the decision-maker you are advocating to, are the best.
- Politicians want to be re-elected – frame your issues with this in mind.

### Building relationships

- At the heart of effective advocacy is impeccable relationships with key politicians and government officials.
- Look for people within your immediate circle of family, friends and associates who have established relationships with the people you need to see.
- Go beyond your immediate circle to find connections through acquaintances and others, and use these links to secure introductions with decision-makers.

### When you have no relationships

- Make an appointment to visit your local elected representatives.
- Invite local politicians to your events.
- Communicate with them consistently about what you are doing.
- Offer to support them in their work, by building opportunities for them to get their messages out to constituents.
- Offer to provide them with information or other resources that may be of assistance.
- Ask them to provide you with key introductions to others in government.
- Go to local events where you know policy influencers will be in attendance.

## Process for developing an effective advocacy strategy

Outlined below is the three step process that you (as an individual or as part of a larger concerted effort) can start to do right away to create an actual advocacy strategy that you can then implement in support of your issues. These steps are very practical and do not require substantial resources. However, successful advocacy does require some measure of time, commitment and a willingness to stick with it.

### Step 1: developing key messages

- **Identification**
  - Define the issues that are important to you.
  - Decide which of these issues you want to advocated for.
  - Craft key messages to support your position around these issues.
  - Distill all information down to its simplest form.
  - Develop consensus on the issues.
  - Be able to separate fact from fiction ie. ensure you can prove the content of your key messages.
- **Framing**
  - Develop 3 key messages that explain the salient points of your issues in simple language.
  - Each key message should be 25 words or less.
  - Each key message must be clear, compelling and consistent.
  - Practice presenting your key messages to someone with no knowledge of your issues and see if they understand them.
- **Knowing to whom to advocate**
  - Determine if your issues fall within federal, provincial or local jurisdiction, or some combination.
  - If you do not already have existing relationships with all of your local elected representatives, contact them and introduce yourself and your issues.
  - Do the same with any locally-based bureaucrats (including municipal/regional government staff people) and political staffers that may have an impact on your issues.
- **Knowing when to advocate**
  - Timing is everything – if your issues are in the media and top of mind for decision-makers, that is the moment you should make your views known.
  - Newly elected politicians often look for issues to champion – try to position your issues as ones they should consider taking on as their own.
  - Make sure that at election time, you approach all of your local candidates with your issue concerns, not just the person seeking re-election.

## Step 2: advocacy tools

- These are the means of delivering your key messages.
- Anything you have or produce that is used by you to communicate with members, supporters or people outside of your advocacy effort, is a potential tool.
- Sample advocacy tools include
  - website
  - newsletter
  - personal meeting
  - telephone call
  - voice mail information
  - letter/fax/e-mail
  - direct mail campaign
  - advocacy day
  - brochure
  - fact sheet
  - news release
  - newspaper/periodical article/op editorial/PSA/advertorial
  - published book
  - information session
  - e-advocacy

## Step 3: presenting your “ask”

- Using your selected advocacy tools, deliver your key messages and ask the decision-maker for the one thing you need to support your policy issues, not a list of what you want.
- Your one ask must be tangible – more than just asking someone for support or help.
- As with your key messages, consensus on the ask will be important, because people engaged in your cause may have varying perspectives on what the effort needs.
- Sometimes opportunities will present themselves that will make the ask very timely.

## Meeting with your elected representatives

Of all of the tools you may choose to employ in support of your advocacy efforts, one of the most effective is a personal meeting with your locally elected federal or provincial representatives. It allows you to deliver the key messages and ask directly to the people that need to hear it the most. This section will walk you through the process of preparing, attending and following up from a personal meeting.

### Finding your MP

Finding your Member of Parliament (MP) and his/her contact information is easy. Log on to the Elections Canada website at [www.electionsCanada.ca](http://www.electionsCanada.ca) and type your postal code in the box. There you will find all of the contact information you need. Elections Canada can also be reached at 1-800-463-6868.

Or, look in your local telephone directory in the Blue Pages under Members of Parliament.

### Finding your Provincial Member of Parliament

Every province has a comparable agency to Elections Canada that oversees provincial general elections.

- Alberta: [www.electionsalberta.ab.ca](http://www.electionsalberta.ab.ca)
- British Columbia: [www.elections.bc.ca](http://www.elections.bc.ca)
- Manitoba: [www.elections.mb.ca](http://www.elections.mb.ca)
- New Brunswick: [www.gnb.ca/elections](http://www.gnb.ca/elections)
- Newfoundland and Labrador: [www.elections.gov.nl.ca](http://www.elections.gov.nl.ca)
- Northwest Territories: [www.electionsnwt.ca](http://www.electionsnwt.ca)
- Nova Scotia: [www.electionsnovascotia.ns.ca](http://www.electionsnovascotia.ns.ca)
- Nunavut: [www.elections.nu.ca](http://www.elections.nu.ca)
- Ontario: [www.electionsontario.on.ca](http://www.electionsontario.on.ca)
- Prince Edward Island: [www.electionspei.ca](http://www.electionspei.ca)
- Quebec: [www.electionsqbec.qc.ca](http://www.electionsqbec.qc.ca)
- Saskatchewan: [www.elections.sk.ca](http://www.elections.sk.ca)
- Yukon: [www.electionsyukon.gov.yk.ca](http://www.electionsyukon.gov.yk.ca)

### Contacting your elected representative

- Telephone the local constituency office and advise the person who answers who you are and that you live in the riding.
- Take notes during the conversation.
- Ask to make an appointment to meet with your federal or provincial elected representative as soon as possible to discuss the issues of concern to you.
- Note the name of the person you speak with.
- If you are told that your elected representative is too busy to meet with you right away, insist that you'd still like to meet with him/her, but that you'd be pleased to meet with an assistant if that could be arranged quickly.
- Be flexible in deciding the date and time of the meeting.
- Immediately upon booking an appointment, confirm the date and time in a letter, fax, or e-mail to the person you spoke with, including:
  - the issues you'd like to discuss and what you want to achieve;
  - a list of people who will be attending the meeting (patient, spouse, caregiver, health professional). Include no more than three people at the meeting.

### Before the meeting

- Know your elected representative – research his/her background on the political party's website.
- Provide any material that you want your representative to read ahead of time (keep it brief).
- Just prior to the meeting, telephone the representative's office and confirm who you will be bringing, and ask for information on who will be attending along with the representative.
- In that same call, confirm the date and time once again.

### At the meeting

- Arrive 10 minutes prior to the meeting.
- After exchanging pleasantries, you have one minute within which to ensure that you have engaged your elected representative.
- In that first minute, you must indicate:
  - who you are;
  - why you are there (your 3 key messages);
  - what you need your elected representative to do for you (your ask).
- Tell your story with sincerity and passion, indicating why it is an important issue.
- Take notes.
- Know the core facts and present the ones you feel most relevant to supporting your story.
- If you are asked a question that you do not know the answer to, commit to getting the information requested.
- Repeat your key messages throughout.
- Conclude with the ask – what tangible thing you want to see happen, for example, for your elected representative to write a letter on your behalf to another official in government.
- Know how long the meeting is and leave enough time for discussion and interaction.
- Let your elected representative speak – effective advocacy is about presenting, listening, and responding.
- If you are unclear about something, ask for clarification. Do not be afraid to ask questions, but keep them focused on the issue at hand.
- Be patient. Your key messages are likely a few of many your elected representative will hear that day.
- Establish clear follow-ups, with timelines and assigned responsibilities.

### After the meeting

- Take a moment to discuss and evaluate the meeting with the people who attended with you.
- Provide any requested information right away.
- Call, write, fax, or e-mail to thank your elected representative for meeting with you.
- Follow up shortly thereafter to track progress and advise what you are doing to move the issue forward. Be persistent!

### What not to do:

- Don't threaten anyone.
- Don't talk down to or belittle anyone.
- Don't waste anyone's time.
- Don't present repetitive versions of the same argument.
- Don't engage in an emotional display of anger or frustration.

## Writing letters

One of the most popular advocacy tools is letter writing – or more specifically, writing a letter to your elected representative. Such letters can be delivered by post, fax, courier, or e-mail.

### Letter writing tips:

- Always ensure that the first paragraph of your letter clearly states that you are a constituent of the elected representative that you writing to and tells that person why you are writing to them ie. what is your issue.
- The second paragraph should ideally focus on your story or experience as a person impacted by mental illness and link back to the main issue you're writing about.
- The next few paragraphs should note your core facts and deliver your 3 key messages, providing further information about why you are writing this letter.
- Then set out your ask – the tangible thing you need your elected representative to do for you.
- Conclude by thanking him/her and asking for a written response – and if you've asked him/her to do something like write a letter on your behalf, indicate that you'd like a copy of that letter.
- Always include your full name, address, and other contact information, for example telephone number, e-mail address.



[www.schizophrenia.ca](http://www.schizophrenia.ca)

## Sample letter

Name

Street Address

City, Town Postal Code

Date

Dear (Mr. Ms. Mrs.) (Surname),

I am writing as one of your constituents to express my concerns as someone affected by mental illness, and to ask for your help.

On May 9, 2006 the Senate Standing Committee on Social Affairs, Science and Technology released its final report on mental illness and mental health, entitled *Out of the Shadows at Last*. The document provides a blueprint to build an innovative and leading-edge mental health system that will enhance services and outcomes for all Canadians living with psychiatric illness.

The report, prepared by Senator Michael Kirby and his colleagues, contains some 118 recommendations to improve the lives of people living with mental illness. Many organizations in Canada strongly support the recommendations contained in the report and have been encouraging the federal government to move forward on implementation.

I am writing to you as my elected representative because I want Ottawa to move quickly on a key recommendation previously tabled by the Committee: the establishment of a Canadian Mental Health Commission. Such a body would mobilize federal, provincial, and territorial governments, as well as non-governmental organizations, to gather information on the state of mental illness and address service needs in a coordinated and comprehensive fashion. This would provide an accurate picture of the mental health system in Canada and ensure that services are equitable and accessible across the country.

Unfortunately, no action has been taken to date, despite the call in the report for the Commission to be up and running by **September 1, 2006**.

During the last federal election campaign, the Conservative Party of Canada expressed its support for a national commission on mental health in a letter to the Canadian Alliance on Mental Illness and Mental Health, stating, the Conservative Party of Canada and Member of Parliament (and then Health Critic) Steven Fletcher “have long called for a Mental Health Commission of Canada and a Conservative government will ensure that such a commission is established.”



Now is the time to put these words into action. That is why I am asking you to write to the Minister of Health to request that he immediately establish and fund the Canadian Mental Health Commission.

Your willingness to take action now will demonstrate your support for a Canadian Mental Health Commission and the vital first step towards a national strategy on mental illness. The sooner it is operational, the sooner we will begin to see improvements for individuals and families affected by mental illness.

Thank you for your commitment.

I look forward to receiving a response from you.

Sincerely,

Your Name

Address

Town, Province

Postal Code

cc. The Right Honourable Stephen Harper, Prime Minister  
The Honourable Tony Clement, Minister of Health

## Organizing a Petition

Petitions can be a very effective way to raise awareness of your issues (including your 3 key messages and ‘ask’) with elected representatives. While the sample petition below is from the Ontario Legislature and there may be variations from jurisdiction to jurisdiction, the following is a general guide to having your federal or provincial elected representative present a petition on your behalf. Your local MP or provincial member will be able to provide you with more detail about developing petitions to Ottawa or your provincial legislature.

### Step 1:

The first thing you need to do is decide on the wording of your petition. Your petition should tell a story, setting out the issue at hand and asking the government to take a particular action to address the matter.

“Whereas the government of Ontario’s health insurance plan does not cover the cost of the PSA (prostate specific antigen) test as an early method of detection for prostate cancer in men;

“Whereas mammogram tests for women are fully covered by the Ontario insurance plan for early detection of breast cancer, and the PSA test for men is only covered once the physician suspects prostate cancer,

“We, the undersigned, petition the Legislative Assembly of Ontario as follows:

“We support Bill 201. We believe PSA testing should be covered as an insured service by the Ontario health insurance program. Prostate cancer is the most commonly diagnosed cancer in Canadian men. At least one in every eight Canadian men is expected to develop the disease in their lifetime. Some five million Canadian men are currently at risk in their prostate-cancer-risk years, which are between the ages of 45 and 70. For many seniors and low-income earners, the cost of the test would buy up to a week’s worth of groceries for some individuals.”

### Step 2:

**Start to disseminate the petition**

- Print multiple copies and distribute to people within your community. You can also e-mail the petition and ask people to print copies.
- Make sure you keep track of who you sent the petitions to and when you sent it.
- Make sure you indicate that the completed petitions are to be returned to you (and perhaps one other person). Provide a mailing address, e-mail address, and contact telephone number.
- Ask individuals to send back the petitions they have completed within a certain period of time. You can always send out another round to people within your community in subsequent months.

### Step 3:

While the petitions are circulating, contact your local elected representative.

- Telephone his/her office and tell him/her you are collecting signatures on a petition. Read/send a copy of the petition to him/her. Ask if your elected representative will agree to present the petitions in the legislature. You must get confirmation of their commitment to present the petitions, preferably in writing. If he/she agrees to present the petitions, make an appointment to see him/her to deliver them.
- If he/she does not or will not agree to present the petitions, say you'll find another elected representative in the province who will do so.
- At the meeting with your elected representative, tell him/her when you would like the petitions presented in the federal or provincial legislature.
- Get confirmation of a date for presentation, and hand the completed petitions to your representative.
- Ask your representative to sign the petition, and have some pictures taken of the group of you meeting. You may also want to invite the local media to attend the meeting, write a story, and take some pictures, but confirm with your representative ahead of time.
- Stay in contact with your representative's office until the presentation date, just to make sure everything is on track.

## How to work with the media

The media may be broadly defined as the business of conveying information, although the term generally refers to the mass communication of publications and broadcast (including newspapers, magazines, radio, television, and the internet). An **editor** is a person responsible for the editorial aspects of a newspaper, magazine, or television broadcast. **Reporters or journalists** discover information about news events and either describe or write about them for a newspaper or magazine or for radio or television. A **press officer** is a person working within an organization whose specific role is to deal with the media.

### Developing a relationship with the media

The first rule in establishing a relationship with the media is that your communication must always qualify as news.

It is important that your news meets some or all of the following criteria.

- **Information:** does it contain something that listeners, viewers or readers don't already know?
- **Timeliness:** is the information being provided well enough in advance to allow it to be taken advantage of within the season, schedule or calendar?
- **Accuracy:** will factual information help people understand something better or in an unbiased way?
- **Significance:** will it affect the lives of listeners, viewers or readers?
- **Scope:** does it have an impact on the majority of the community?
- **Interest:** is it intrinsically able to attract and hold public attention?
- **Uniqueness:** is it unlike any other information, or if similar, has it an element that makes it stand out?
- **Human Interest:** is it relevant on a personal level to many people because of a home town or family aspect?
- **Relevance:** is it a topic that enhances public understanding of a constant, or pressing local issue?

Although the media are generally driven by unanticipated events, they still provide a powerful and far-reaching opportunity to communicate your key messages.

## Communicating issues and messages to the media

There are several ways in which you can create and enhance your relationship with those working in the media and convey a positive impression about your issues. These suggestions will help you gain the most from the media.

- Develop a list of media contacts that includes editors, reporters and journalists who cover health issues and keep them informed of important activities and issues you or your group are working on.
- Identify publications that cover the types of news relevant to your issues.
- Familiarize yourself with these publications.
- When you first call, ask whether it is a good time, or if they would like to be contacted later.
- Ask how they would like to receive information (fax, e-mail, phone, etc).
- Ask what kind of stories interest them.
- Make sure you get their direct phone line, fax and/or e-mail.
- Keep a note of reporter responses – it may be worth opening a file in which you keep notes of what has been discussed each time contact is made.
- When you subsequently call, remind the reporter of what was discussed before, for example, you might remember we spoke about the issues affecting cancer patients a few weeks ago. This helps build a relationship.
- Invite them to any event your organization may have. They are more likely to remember you after a face-to-face meeting.
- Answer all media enquiries promptly, fully, accurately and courteously. If you do not know the answer, find it and get back to the reporter immediately or refer the reporter to another appropriate source for the information such as the BMC. In this way, you can establish your group as a valuable and helpful information resource and develop an effective relationship to secure balanced, consistent and frequent coverage in the future.
- All reporters work by deadlines. Your first question must always be, “What is your deadline?” You must provide the information quickly so that the reporter meets that deadline. If you do not provide the information in time, your side of the story will not be told. Furthermore, that reporter will not come back to you on other stories.
- Stress facts and keep to the main story. Many reporters react against attempts at self-promotion. At the same time, use your contact with the reporter to explain what your issues are. There might be future story possibilities if that reporter understands the issues in context, beyond the particular aspect in which he/she is currently interested.

Give all reporters equal access to information. Favouring one reporter can be extremely damaging to your relationships with others. If reporters contact you for a story, their initiative should be respected; there is no obligation to call other reporters. When dealing with reporters who appear hostile, skeptical, or disinterested, do not react emotionally. Discuss issues calmly and back up statements with facts. Do not lose your temper or act defensively, as this can easily result in an uncomplimentary story. It is not worth approaching the media with a story unless it is newsworthy. Appearing desperate and wasting reporters' time will result in your issue being ignored.

## The interview

### Suggestions to ensure a successful interview:

- Be warm and caring, yet professional.
- Use clear language that is easy to understand. Try not to use specific terminology or sound like you are quoting complex medical documents. Neither reporters nor the audience can relate to something they do not understand.
- Have a positive attitude. Welcome the interviewer and his/her questions.
- Try to find out who else is being interviewed for the story.
- Be prepared. Make sure you have all the facts ready to support your story and that they come to mind easily. Do not exaggerate or make claims that you can't back up.
- Anticipate questions that might be asked and think how you will respond. You may even ask for a list of questions in advance so you can prepare answers.
- Take the point of view of the public interest. Put yourself and your supporters squarely on the side of the people.
- If asked a direct question, give a direct answer.
- Answer one question at a time. If more than one question is asked at a time, answer your favourite first. Ensure you have finished answering the first before moving on and answering subsequent questions.
- Support answers with human interest stories that are relevant to the issue being discussed. This not only backs up your statement, but also ensures you are seen as being on the side of those in need.
- Never speculate. Only give factual information that you can verify.
- If a question contains incorrect information or inappropriate language, do not repeat it, even to deny it. You may answer the question, but repeating any defamatory question may result in a misquote.
- Always tell the truth, even if it is unpleasant. The public trust and credibility of your issues relies on its integrity. It is important not to be seen to be hiding anything.
- Avoid 'off the record' discussion. Do not make a statement unless you want it quoted.
- Consider a possible follow up to the interview. Keep a note of the points the interviewer was particularly interested in or misinformed about, and provide detailed information on them immediately.

## Media spokespersons

Some suggestions to help you prepare for an interview:

- Ensure the chosen spokesperson feels comfortable talking with the media and has some human interest stories to tell – it is best to have the person directly affected by the issue act as spokesperson.
- Identify a spokesperson ahead of time. If possible select one spokesperson for each topic who can speak on that subject with credibility.
- Work with the spokesperson in advance, making sure they understand all the key points and how they may emphasize them effectively.
- Keep spokespeople informed with all the latest news in the field of the expertise.
- Conduct practice interviews.

## The news conference/briefing

The difference between a news conference and a news briefing relates to the value of the news. The news conference makes an announcement, or delivers information that is of a critical nature. The news briefing is less formal, and is used to provide an overview or background information on something that is of interest to the public or the press. Both are on the record. A news conference or briefing provides an opportunity to present detailed facts, to clarify confusing issues, and to answer questions from reporters. News conferences are not recommended. **They should only be used when the story really warrants it or as a damage limitation exercise.** Reporters do not want to waste their valuable time.

News briefings are generally less formal and cameras are not present. They may therefore be held in an ordinary meeting room. A news conference will however require special arrangements, and the following suggestions should be considered:

- Fix a time that is appropriate for the media, bearing in mind reporters' deadlines.
- Identify a location that is convenient for the media. Avoid rooms with windows or mirrors as these can cause problems for cameras.
- Prepare an agenda that provides details of each presentation and those taking part.
- Invite reporters several days in advance, and follow up with telephone calls.
- Provide a lectern (a stand for the spokesperson) with a microphone for speakers, as well as a space for reporter microphones.
- Ensure that all materials and the lectern are appropriately branded with a logo or the name of your organization.
- Arrive in advance to check the room is in order and that everything is in place and to test the equipment.
- Start promptly; do not waste reporters' valuable time.
- Have a well prepared opening presentation that does not last more than 5 minutes. If you can't say it in five minutes look at your presentation again and edit it. The presentation should be followed by a question and answer session.
- Provide media kits for reporters that should include: news release; copy of opening presentation; charts and fact sheets; and any other relevant information. This could also be available on a CD or DVD.
- Ensure someone is assigned to answer any follow up phone calls.

## The written media

### Writing a news release

The news release is the most common method of drawing media attention to a particular item of news. The focal point or subject matter may differ from culture to culture, but the basic structure of a news release is the same. The most important aspect of a news release is the lead (first paragraph) which must contain the essential elements.

#### The lead serves two purposes:

- to provide the most important facts; and
- to gain the attention of readers, so they will want to know more

#### The 5 Ws of the story:

- Who?
- What?
- Why?
- When?
- Where?

A news release should then proceed to give a more detailed account, but with each subsequent paragraph containing facts of lesser importance than the previous one. If editors have to cut text due to limited space for a story, they tend to cut from the bottom. All news editors will want the facts in a readable and orally comprehensible format. Avoid unnecessary adjectives, adverbs or editorial opinions. If an opinion is an essential part of the story, write it as a direct quote from the relevant person. Ensure the news release is concise. Remember to keep it short and simple. Once you have sent a news release to your media contacts, follow it up with a telephone call. As a news release is considered an invite to a reporter to investigate or to a journalist to write an article, ensure that the appropriate people (press officer, spokesperson etc.) are available to answer their questions. If they are busy with another journalist, try to have a further person who can manage an 'interview' schedule and arrange an exact time at which an interview can be conducted or call can be returned.



## Types of stories

- **News stories.** These are generally reported in many media outlets (newspapers, magazines, television, radio, and internet). The resulting story generally presents information provided in a press release.
- **Feature stories** are offered with the expectation of a major story, often accompanied by photos. Such features are written by a journalist assigned to the story by the newspapers, magazine, or radio or television station. This journalist will conduct one or more interviews, often in the subject's home or place of business. To place such a feature story you will need to send out a pitch letter to sell the story; send to just one journalist at a time. A feature story is a very effective way of developing the identity of an organization and furthering public understanding of an issue. Unlike a straight news item, a feature story allows some in depth examination of a particular aspect of your issue. The writer will have much greater scope for descriptions, explanations, human interest anecdotes (or case studies) and examples that appeal to the audiences' emotions. When thinking of a feature story, first identify the target audience. Where does public understanding need to be enhanced? Are there any negative rumours that persist about your issues or your organisation? A single positive feature can do more to enhance the image of your group than a dozen factual reports. A feature is an excellent way in which to deal with an issue. Discuss with the editor ideas that may make an interesting feature which would appeal to their audience.

## Electronic media

The great majority of people will have access to both television and radio, which are two of the most effective tools for communicating your key messages. In addition, they may have access to the internet.

### Radio

Despite the growth of television, radio remains popular. People listen to the radio in their cars, while working around the house, when walking and exercising. The programming range and number of stations make radio a highly accessible and effective way to communicate. The overall radio audience is large and varied, but by targeting a particular programme or channel you may reach a particular group in terms of age, gender and area of interest.

**For radio interviews:**

- Maintain a distance of 14-20 cm (6-8 in) from the microphone.
- Talk normally. Microphones are very sensitive and volume will be adjusted accordingly during transmission.
- Avoid shuffling papers.
- Assume the microphone is live and you are on air, unless told otherwise. Save any personal remarks for when you are certain the microphone is off.
- Ask for a brief rehearsal, though rarely will this be possible.

**Television**

The visual advantage of television is obvious. In many countries it offers the best opportunity to get the message through to the greatest numbers in the shortest time. It may target particular sectors of the population including opinion leaders, major donors and government officials. There are various types of programmes that can convey your key messages: news, talk shows, documentaries, etc. However, the primary requirement that newspapers and radio do not have – the information must be visual.

**For television coverage:**

- Ensure your story is newsworthy. Extensive resources are used in covering a news story for television. If a station is disappointed they may be reluctant to cover future stories.
- Telephone news directors of stations well in advance; do not rely on a news release alone.
- Ensure you have good visuals. Television needs an interesting scene, voice, face or some other way of visualizing your story.
- Check out the location and ensure adequate electrical outlets are available for equipment. You may wish to enquire about requirements in advance.
- If there are speeches or prepared statements ensure you have printed copies to give reporters, possibly as part of a media kit.
- Schedule the event in the morning to give plenty of time to prepare the final item for the evening news.
- Have a person affected by your issue – a patient, a caregiver, a health care provider – tell their story. The most interesting aspect of television is about people.

## Tips for top interviews on camera

Television requires particular preparation and skills.

- Approach an interview as an important opportunity to get across the key messages important to your story/issue, not just to respond to questions.
- Prepare carefully. Determine the three most important points you want to make and repeat them often. Use anecdotal examples to add colour and credibility to every assertion.
- Find the focus of the interview well enough in advance to anticipate the questions.
- Know the format and style of the interviewer or reporter.
- Provide the reporter with background material in advance.
- Arrive early so you can become accustomed to the setting and have a chat with the interviewer.
- Dress appropriately and remember your body language.
- Look, listen, and speak to the person talking to you, not at the camera or yourself on the monitor.
- Say the most important information first, and don't get lost in the details.
- Do not discuss, as it will make you sound equivocal.
- Do not defend in such a way to make you sound defensive.
- Do not debate!
- Challenge any effort to put words in your mouth.
- Once filming begins assume you are on air until told otherwise.

## Questions to ask before a broadcast interview

- Live or taped interview?
- Panel or one-on-one?
- Length of interview?
- Name of show?
- Name of interviewer?
- Location of interview?

## The 3 Cs of an interview

- **Confidence:** Be confident in your knowledge. You know your subject better than the journalist.
- **Clarity:** Use clear, conversational style, and avoid jargon.
- **Control:** Take charge of the interview. Preparation is the key. There is no such thing as a wrong question, only a wrong answer.

## Questions to ask when the media call

Before conducting an interview, ask:

- Who do you work for?
- What's your beat?
- What's the story about?
- Who else are you interviewing?
- What's your deadline?

## Photography

“A picture is worth a thousand words.” Napoleon Bonaparte, French general, politician, and emperor, 1769-1821. Despite Napoleon’s famous observation, only a *good* picture is worth a thousand words. Indeed, pictures can make all the difference and are one of the most dramatic ways of enforcing a story. Furthermore, a story is more likely to get printed with a good picture. However, health care and patient issues can be difficult to photograph. Many people do not like pictures that deal with the reality of illness. You will need to think hard about how to convey your message within a picture that will really grab the readers’ attention, drive their curiosity, and make them want to read more.

## Tips for good photography

- Think what the picture says.
- Take people-centred pictures. People are what the story is about.
- Ensure the logo is clearly visible, but not anywhere it would not naturally be placed. You do not wish the picture to look faked.
- Gear the photo to the theme. For example, show people in action.
- Faces speak for themselves, so highlight them, particularly interaction between people.
- Make the scene interesting. Do not just show a face, but include some action or the environment in the background.
- If your photo depicts celebrities, try to seek out opportunities when they are doing something or interacting with others.
- Ban pictures of photo donations (usually cheques), and force photography to be more creative.
- Do not have more than four people in one photograph.
- Avoid dark backgrounds.

## When media call – quick tips

Remember to review your key messages before doing the interview.

Before conducting an interview, ask:

- Who do you work for?
- What's your beat?
- What's the story about?
- Who else are you interviewing?
- What's your deadline?

If your interview is for the broadcast media, also ask the following questions:

- Is the interview live or taped?
- A panel or one-on-one interview?
- What is the length of the interview?
- Name of the show?
- Name of interviewer?
- Location of interview?

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