



Schizophrenia: The Journey to Recovery

A Consumer and Family Guide to Assessment and Treatment



Canadian Psychiatric Association
Dedicated to quality care
Association des psychiatres du Canada
Dévouée aux soins de qualité



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.



Note to Readers:

Anecdotal stories have been included in this booklet to help you in understanding schizophrenia. While the situations are true, no real names have been used in order to protect individual privacy.

The Canadian Psychiatric Association and the Schizophrenia Society of Canada gratefully acknowledge funding for this publication from the Public Health Agency of Canada.

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If You are Reading this Booklet

A diagnosis of schizophrenia is a life-changing event for individuals and their families. Questions rush in: What do we do? How did this happen? How will we cope? Who can help us? Is there a cure?

This booklet is designed to help you, your family or a friend with schizophrenia to understand how schizophrenia can best be treated and managed. Everything will feel pretty chaotic and unpredictable at first. However, with consistent treatment and care, many people can learn to live and work successfully with schizophrenia.

This booklet is an important reference as you navigate the mental health system. You will learn the meaning of new and important medical and technical terms.

People in health care have their own words. You need to know them, understand them and be able to use them. It will give you a way to get some control over what is happening to you or around you. You will find a Glossary of Terms at the end of the booklet plus online listings on where to get more information.

You will learn about what experience has shown are the best ways to assess and treat people living with schizophrenia.

You will probably want to read some sections of this booklet several times. It is important that you understand what is happening or should be happening. This is a booklet you will want to carry with you when you visit health care professionals. There will be many things to remember.

This booklet will guide you on the types of health services and support that should be available. Unfortunately, health services and support are not equally accessible throughout Canada, even in many major urban centres. This booklet will help you figure out what services should be available so that you can advocate for those services. And, as you feel stronger, you may decide to help bring some needed services into your community.

Our title, *The Journey to Recovery*, reflects the hope that many people can and do recover from the illness to attain a quality of life that is meaningful to them. Recovery means different things to different people. It can include: controlling the symptoms of schizophrenia, living independently, having a job, having friends and social support, and quality of life. Recovery is not the same thing as being cured -- individuals may continue to experience symptoms and require ongoing treatment and supports. Recovery is an continuing journey for individuals, and their families, as they strive to live the most satisfying and productive lives possible within and beyond the illness.

The information here will help you gain some feeling of control. This will give you some very important peace of mind on the journey to recovery.

Introduction

Schizophrenia is a very complex disorder of the brain. It is believed to be caused by a chemical imbalance. There is no blood test for it. There is no cure for it yet. But, with thorough assessment, careful treatment and strong support for each individual, the chances of successfully living with schizophrenia can be greatly improved. Newer approaches to treatment and medications are making it possible for many people with schizophrenia to live full and productive lives

In the past, schizophrenia has had a very poor public image. Many people think they know what schizophrenia is based on movies, fictional books and quotes from the famous and not so famous. But you won't find the real meaning of schizophrenia in any of those places.

This booklet is for people living with schizophrenia, their families, friends and other caregivers. It is based on the Clinical Practice Guidelines for the Treatment of Schizophrenia that were issued by the Canadian Psychiatric Association (CPA) in November 2005. The CPA guidelines were developed following extensive research and analysis of thousands of scientific studies and articles. The CPA guidelines describe the current science-based evidence and recommend best practices for the treatment of schizophrenia. It is important to remember that these guidelines are not rules. They are the best guide available for health professionals at this time and may change as more knowledge is gained.

The *Canadian Psychiatric Association Clinical Practice Guidelines: Treatment of Schizophrenia* are available on the CPA web site at: www.cpa-apc.org/Publications/Clinical_Guidelines/schizophrenia/november2005/index.asp

Schizophrenia is a serious treatable brain disorder which affects a person's ability to think, feel and perceive. It is a biological illness.

Schizophrenia is *NOT* caused by:

- poor parenting
- domineering mothers/passive fathers
- guilt, failure or misbehaviour
- childhood experiences
- poverty

Schizophrenia is *NOT*:

- the result of any action or personal failure by the individual or family
- a split or multiple personality
- rare – it strikes all races, cultures and social classes

What is Schizophrenia?

Schizophrenia is a serious but treatable brain disorder. It affects a person's ability to know what is real and what is not. The symptoms include delusions, hallucinations, disturbances in thinking and communication, and withdrawal from social activity. The symptoms are thought to be caused by disturbances in the flow of information in the brain. Unfortunately, it is a disorder that often develops among people 15-25 years of age – a critical developmental period in a young adult's life.

Causes of Schizophrenia

The exact causes of schizophrenia are not yet known. Researchers are looking at a number of factors that may affect brain development such as injury, viruses, lack of oxygen, diseases, toxicity, etc. There is very strong evidence that there is a genetic link but that research is still ongoing.

Symptoms of Schizophrenia

As with other illnesses, symptoms may vary from person to person. For many families, there is a period of time when it is difficult to decide whether the person is having a really rough time that will eventually clear up or whether there is something more serious happening. For people developing schizophrenia there is a period of time before they have a psychotic episode. Health professionals call it the "prodromal" period. As the disease develops, you may notice symptoms such as:

- Deteriorating grades or quality of work
- Withdrawal from family and friends
- Moodiness, suspicion, anxiety, fear, aggressiveness
- Changes in personal care and hygiene which cause concern
- Lack of interest and motivation
- Loss of feeling or emotions

During this time, the person's ability to think clearly and logically will get worse. Their thinking may appear unusually slow or too fast or they may not respond at all. Each person is different. One person may think people on the bus are talking about her (delusion). Another person may hear a voice in his head (hallucination). One person may laugh at a sad story while another may be unable to show any emotion at all.

As the symptoms get worse, the ill person may deny anything is happening and try to keep their feelings inside. They may avoid people, places and situations where their symptoms might be noticed. They may feel panic, anxiety and fear as they try to hide the illness.

Remember!

- People with schizophrenia can experience extreme sensitivity as a result of their illness. Their brains are sending mixed messages from the eyes, ears, nose, skin and even taste buds. Until treatment begins and coping strategies are learned, they have limited control over their actions or reactions.
- The sooner the symptoms are recognized and treatment is started, the sooner a person living with schizophrenia can work at getting their life back on track.
- Patience and reassurance is essential to help people with schizophrenia feel they will have support throughout their recovery.

Stages of Schizophrenia

The medical and research communities have agreed that there are three distinct phases people go through when they have schizophrenia:

Phase 1: Acute This is when major symptoms make it clear that the individual needs medical help. It may come on very gradually or quite suddenly.

Phase 2: Stabilization This is the time when the illness is out of the acute stage and symptoms are reduced.

Phase 3: Stable or chronic The acute symptoms are being managed but there may still be difficulty with ability to function and periodic relapses into Phase 1 and 2.

Remember!

- Don't try to go it alone! People living with schizophrenia need strong networks of support from family members, friends, peers and their health care team. Whether you have schizophrenia or are close to someone who does, you will need ongoing support as you deal with the challenges you will face.
- The best recovery is made possible by combining effective treatment and strong support networks.
- Family involvement and understanding are essential to recovery.

Part 1: The Assessment Process

During the assessment period, you will hear many technical terms you are probably not familiar with. Some may even be confusing. For example, in psychiatry, “positive” symptoms are not at all positive the way we usually understand that term. This section of the booklet will help as you or your loved one goes through the assessment process.

Canadian Psychiatric Association (CPA) General Principles for the Assessment of Schizophrenia

1. Assessing *both* mental and physical symptoms is key at all phases of the illness, including signs, activities of daily living, level of functioning and side effects.
2. Additional information and history from family members, caregivers, health care professionals and others are usually essential for a more complete understanding of symptoms, signs and functioning.
3. Ongoing follow-up by the same clinician(s) to monitor improvements or worsening of symptoms is recommended.
4. Since patients will often not volunteer complaints and information to clinicians, it is important to have active, specific questioning and informed examination and investigation from family members, caregivers and health care professionals
5. The patient’s competency to accept or refuse treatment must be periodically assessed and recorded.

What is psychosis?

Psychosis is the term for a state of mind in which thinking becomes irrational and/or disturbed. A person with psychosis has a loss of contact with reality because of delusions, hallucinations or other severe thought disturbances.

Assessing for Schizophrenia

Schizophrenia is a very complex disorder with a range of symptoms that can also be found in other illnesses. An essential step during the assessment period is to identify other conditions which may exist and come to an accurate diagnosis. Some conditions may need to be ruled out before deciding on a formal diagnosis of schizophrenia.

This kind of complex assessment will involve a range of specialists including psychiatrists, psychiatric nurses, social workers and others. It may take a number of weeks, months or even years to fully understand the disorder. Each person is unique. The assessment needs to provide as complete a picture as possible so that treatment can be tailored to the individual. The clearer this picture is, the better recovery can be.

Assessments must also be ongoing throughout a person’s life. Some tests need to be repeated regularly as a way of keeping track of overall health and wellness. This is true for anyone managing a chronic medical condition.

Not all of the assessments which follow are necessary for every person. Also, some tests may not be available in every community or clinical setting. Some of the assessments which may be done include:

Type of Assessment*	Purpose
Blood work <ul style="list-style-type: none"> • Blood chemistries • Blood sugar • Hematology • Toxicology screen • Lipids 	<ul style="list-style-type: none"> • Check kidney, liver and thyroid function • Screen for diabetes and when there is weight gain • Complete blood count (CBC) • Screen for substance use or abuse • Cholesterol tests; total cholesterol, low density and high density lipoproteins, triglycerides
Body Mass Index (BMI)	<ul style="list-style-type: none"> • Monitoring for healthy waist circumference when changing medications and every three months when stable. General measure recommended for all adults
Cognitive function <ul style="list-style-type: none"> • Neuropsychological testing 	<ul style="list-style-type: none"> • Testing could include working memory, attention, visual learning and memory, reasoning and problem solving, etc. These tests are not about “right” or “wrong” answers; the objective is to find out how the brain is working
Cardiovascular	<ul style="list-style-type: none"> • Pulse and blood pressure • Monitor when changing medications
Endocrine and sexual function	<ul style="list-style-type: none"> • Lack of sexual interest or drive or lack of sexual functioning such as inability to get an erection or have an orgasm can be caused by a number of social or physical reasons including medications. If a person has concerns in this area they should speak with their physician • Identify any behavioural risk factors for sexually transmitted diseases or HIV
Extrapyramidal symptoms and signs	<ul style="list-style-type: none"> • Side effects caused by too much dopamine blockade due to antipsychotic medication. They can be stopped by adjusting the dose or type of medication. Symptoms include Parkinsonism (rigidity, tremor), uncontrollable movement in the face, arms and legs, etc.

Genetic	<ul style="list-style-type: none"> • Only needed if there are physical signs suggestive of a genetic abnormality • Screen for chromosome deletion syndrome
Infectious diseases	<ul style="list-style-type: none"> • Screen for syphilis, hepatitis or HIV if a behavioural risk factor has been identified
Level of function	<ul style="list-style-type: none"> • Ongoing assessment of social, occupational or vocational and living situation
Psychopathology	<ul style="list-style-type: none"> • Monitor positive and negative symptoms; disorganization; mood; suicide, aggression or impulsivity
Substance Use/Abuse	<ul style="list-style-type: none"> • Alcohol • Tobacco • Street drugs • Prescription/Over the counter
Structural brain	<ul style="list-style-type: none"> • CT or MRI if it is considered necessary • Helps to rule out brain damage and supports the diagnosis of schizophrenia as an illness

* The range of assessment may depend on available resources in the community or nearby.

“First episode” of psychosis

The first time someone shows clear signs of psychotic behaviour is called the first episode. The assessment process is similar to an acute phase assessment.

The physician will need a detailed history about the time leading up to the first episode including:

- When changes in behaviour were first noticed and how behaviour has changed
- Duration of psychotic signs and symptoms
- Recent decline in level of functioning
- Presence of depression
- Impaired attention and concentration
- Substance use or abuse
- Any family history of psychosis
- How long the psychosis has gone untreated
- Social and academic functioning in childhood and adolescence

Positive and negative symptoms

- **Positive symptoms** – new behaviours – of schizophrenia include hallucinations, delusions and thought disorders.
- **Negative symptoms** – behaviours taken away – include lack of motivation, energy and interest, blunted or flattening of the emotions, reduced communication and social withdrawal.

This assessment will be done at a very stressful time in the progression of the illness. Family support is extremely important. Having just one person who will take on the role of health advocate can make a significant difference to successful recovery. But, the more support you have the better.

Remember!

- Do not go alone. Bring someone with you, preferably the same person, each time you visit a health care professional.
- Ask questions. The better you can understand what is happening, the better you can work towards recovery. Keep asking questions until you are sure you understand.
- Take notes. Either you or your support person should take notes. Stressed people can't remember everything.
- Build a support network. Talk to your medical team and ask them to tell you about all the supports that may be available to you in health, social assistance, employment, housing, education, vocational training, etc. [Please see *Section 4: Service Delivery* in this booklet.] If they can't answer your questions, contact the Schizophrenia Society in your province (listed at the end of this booklet).

Chances of a relapse

It is an unfortunate fact that people with schizophrenia often relapse. However, like all people with a chronic condition, it is important to:

- watch for a return of symptoms
- take medications exactly as prescribed
- learn ways to cope with stress
- lead a healthy lifestyle

Did you know?
There is a 90% chance of relapse within 1 year among people who do not take their medication as prescribed.

Stressors such as major family events, exams, hassles at work or home or other illnesses may trigger relapse. There is usually fair warning – a week or more – that a person is relapsing into psychosis:

- Trouble sleeping
- Social withdrawal
- Anxiety, depression, decreased insight

Preventing a relapse is most successful when you take medication exactly as prescribed and report any distressing side effects so that the medication can be changed or adjusted. In the words of health professionals, successful “adherence to treatment” also involves maintaining a good relationship with the clinician or health care team and having family who know about the illness and can watch for signs and symptoms.

Risk of suicide

Depression is a common symptom in people who are developing schizophrenia and those who are living with it. The loss of hopes and dreams combined with inadequate recovery leads to between 4 and 6 in 10 people with schizophrenia attempting suicide. Some people may also have a hallucination that tells them to attempt suicide. Between 5 and 10% of people with schizophrenia die by suicide.

The people most at risk for suicide are those who:

- are male
- have depression
- are within 6 years of their first hospitalization
- are young
- have a high IQ
- were high achievers with aspirations before the onset of schizophrenia
- are aware of their loss of functioning

Suicidal behaviours

- Person talks about what it would be like to die or how to go about committing suicide
- Makes comments such as “when I’m gone”
- Gives away special belongings
- Talks about how to split up possessions; is concerned about having a will
- Feels that they are worthless: “I’m no good to anybody”
- Shows signs of hopelessness about the future: “What’s the use”
- Shows signs of hearing voices or seeing visions that may lead to suicide

Get help as soon as possible!

- If someone you know with schizophrenia talks about suicide, take it very seriously
- Contact the psychiatrist, therapist, hospital or community medical emergency response team immediately
- Get help – go to the hospital or nearest emergency department
- Police are often called in crisis situations and can assist in getting an individual to a hospital for an assessment
- If suicide is attempted, call 911, an ambulance or the emergency number of the nearest hospital
- Call someone to be with you at the hospital or at home
- Don’t try to handle the crisis alone

Substance use and abuse

Substance abuse is very common among people with schizophrenia. And, for many people, multiple substances are abused including alcohol, tobacco, marijuana, amphetamines (speed) and other drugs. Over-the-counter drugs such as antihistamines and pain killers can also be abused. Up to 80% of people with schizophrenia are smokers. Unfortunately, many people who abuse substances aren’t considering changing their substance use lifestyle. Again, the support of family and peer support can be very helpful. [See additional information in Part 3 of this booklet.]

Remember!

- People with schizophrenia are more sensitive to the effects of drugs and alcohol than those without the disease
- Substance misuse as a way to cope is not a healthy answer. Talk to your physician!
- Developing a healthy lifestyle is essential to a good recovery from schizophrenia.

Physical health monitoring and recovery

All people need to take care of their health, both physical and mental. People with chronic conditions such as schizophrenia, diabetes and arthritis have to take extra care in managing those conditions. Part of that care includes regular monitoring of their health. This includes regular check-ups, blood tests, monitoring blood pressure, cholesterol measurement, body mass tracking and avoiding weight gain. The physician may add other diagnostic tests depending on the individual's health.

People with schizophrenia who also have conditions such as diabetes need to be especially careful about managing their health and balancing their medications. Having a healthy lifestyle that includes proper nutrition and regular exercise is very important to successful recovery and management of chronic conditions.

Privacy Rights

"Without the patient's permission, which those with mental illness/addiction may not be competent to give, a physician cannot share personal information with his or her caregivers, parents, siblings or children." Page 65

"Health care professionals should take an active role in promoting communication between persons living with mental illness and their families." Page 69

Out of the Shadows At Last
Senate Report May 2006

Remember!

- Make sure your physician knows about ALL medications you are taking including prescriptions, over-the-counter drugs and herbal remedies. Serious drug interactions are possible when some of these products are mixed.
- Bring all medications to each doctor's appointment. It is then much easier to monitor what is being taken.
- Always check with your doctor and/or pharmacist about using alcohol when taking medications. Most prescription medications should not be mixed with alcohol.

Support of family and friends

- Offer to go with the person to medical appointments and assessments as their health advocate.
- Keep a point-form diary to note signs and symptoms of developing illness or relapse. Be sure to note the date and time you noticed the behaviour, other people who were present, anything that may have triggered the situation and any observations that could help a physician or crisis team if it becomes necessary.

- Stay calm and avoid any judgmental comments. Schizophrenia is a frightening and stressful illness for those who experience it and their families and friends. Remaining as calm as possible can be very helpful to someone whose senses are all on over-drive.
- Learn as much as you can about schizophrenia, its diagnosis and treatment.
- Learn the many ways people living with schizophrenia learn to cope and move forward with their lives. (Please see the section on *Where to Get More Information*)

CPA Recommendations for the Assessment of Schizophrenia

- Symptoms and signs of illness and functional impairment should be carefully evaluated. Psychosis is seen in a number of illnesses. It is important to consider other potential diagnoses (this is called “differential diagnosis”).
- Suicidal and aggressive thinking and behaviour should be regularly assessed. It is a fact that people with schizophrenia are at increased risk for suicide and aggression.
- Substance abuse is common in patients with schizophrenia. Regular assessment of substance use and abuse is necessary.
- Neuropsychological testing is suggested for patients with first-episode psychosis and those with poor response to treatment.
- People living with schizophrenia may not follow their treatment properly and have a relapse. Symptoms, level of function and other signs that someone is not following their treatment should be assessed regularly.
- Some people with schizophrenia have measurable brain abnormalities. Computed tomography (CT) or magnetic resonance imaging (MRI) should be done when the illness is first assessed and in patients with refractory illness (treatment-resistant schizophrenia).
- People with schizophrenia are at risk for a number of other conditions. Regular clinical and laboratory monitoring for movement disorders, obesity, diabetes, hyperlipidemia and sexual dysfunction should be done.

Part 2: Treatment and Medications

Even as the assessment process continues, relief of symptoms can begin with the use of carefully prescribed medications. The medical profession calls this “pharmacotherapy”. Since each person’s experience of schizophrenia is unique, their medication plan will also be unique. The type and dosage of medications will vary for each individual.

In the acute and stabilization phases, medications may need to be frequently monitored and adjusted until a balance is reached between symptom relief and side effects. As with the treatment of most chronic conditions, there is a fair amount of trial and error before the right balance is achieved. This is normal and necessary.

The information and guidelines in this resource apply only to medications available in Canada.

Canadian Psychiatric Association (CPA) General Principles for Pharmacotherapy

The CPA has nine general principles to guide medical professionals in deciding on medications and pharmacotherapy. These principles apply only to medications available in Canada.

1. Treatment with antipsychotic medications is an essential component of a treatment plan for most people with schizophrenia.
2. Psychosocial approaches work together with medication to support people in following their treatment and living successfully in the community.
3. Medications must be tailored to the individual since each person responds differently. The person’s current condition and previous history of medication and side effects needs to be considered. Patients with a first episode of psychosis usually require a lower dosage, as do the elderly.
4. Patients must be involved in decisions about and choices about medication. This includes being provided with information on the risks and benefits of both taking and not taking medications. Since there is a major benefit in taking medications, physicians should recommend them strongly and seek the patient’s agreement in taking them.
5. Side effects will vary depending on the patient’s general health, the progress of their disorder and the length of time they have been taking the medication.
6. Keeping the treatment program as simple as possible, such as a once-a-day dose, can help people to manage their medications and treatment.

7. The medication dosage should be kept within the normal range. Physicians should document and justify their reasons for prescribing a dosage outside the normal range.
8. There is no clinical evidence to support the use of more than one antipsychotic at a time.
9. Regular and ongoing monitoring is equally important to determine when patients respond well to medication, when they don't respond well and when they develop side effects.

Main medication treatment strategies

The medication treatment strategies for schizophrenia depend on which phase of the disorder is being treated: acute, stabilization or stable. The table below shows the main treatment strategies for each phase:

Phase	Status	Treatment Strategy
Developing (called Prodromal)	<ul style="list-style-type: none"> • Growing concern about noticeable changes in behaviour • Mild/intermittent psychotic symptoms, drop in functioning, family history of psychosis 	<ul style="list-style-type: none"> • Suggest person see doctor for symptoms such as depression, difficulty sleeping, excessive fatigue • Try to maintain a calm environment to reduce stress and anxiety • Discourage alcohol and substance misuse • Offer low-dose antipsychotic medications
Acute	<ul style="list-style-type: none"> • Signs and symptoms indicate that urgent medical treatment is needed • Major disruption for patient and family 	<ul style="list-style-type: none"> • Seek emergency treatment • Comprehensive assessment, particularly for danger to self or others • Begin to establish the physician-patient relationship to build trust and effective communications • Begin taking medication as soon as possible for best result • Ensure patient is aware of and understands the medications and treatment process being prescribed

Stabilizing	<ul style="list-style-type: none"> • Signs and symptoms being treated with medication • Person requires less care 	<ul style="list-style-type: none"> • Ongoing monitoring of medications, dosage and potential side effects • Dosage adjustments as necessary • Continuing communication between physician and patient to strengthen the relationship to support the person in following their treatment successfully • Ongoing and strong family support to encourage person to follow their treatment plan
Stable	<ul style="list-style-type: none"> • Symptoms have been reduced as much as possible • Level of function has stabilized or improved 	<ul style="list-style-type: none"> • Longer-term psychosocial approaches will combine with medication treatment to bring about successful recovery • Other rehabilitation strategies including education, learning and vocational training can be pursued • Self-help and peer support will help person to manage their condition and move forward in their life.

Antipsychotic Medications

Specialists in schizophrenia describe antipsychotic medications as being either first-generation or second-generation. Second-generation medications provide effective symptom relief and have fewer side effects than first-generation medications.

The medication treatment for people with schizophrenia is unique to each person. It will depend on a number of factors including severity of symptoms, overall health, presence of other conditions, etc. Finding the right balance of medications – whether they are first- or second-generation – that provides ongoing symptom relief will take some time.

Second-generation antipsychotics are recommended as first-line treatment because they are more effective than first-generation antipsychotics for treating negative, cognitive and depressive symptoms. The second-generation antipsychotic medications are:

- Olanzapine/Zyprexa (also available in quick dissolving tabs “Zydis”)
- Risperidone/Risperdal (also available in quick dissolving “M tabs” and long acting injectable-“Consta”)
- Quetiapine/Seroquel
- Clozapine/Clozaril

First-generation antipsychotics such as Clopixol/Acuphase, Chlorpromazine (CPZ), Haloperidol (Haldol) may be used for emergency treatment of symptoms and calming/sedating. However, they have more side effects than the second-generation medications. A long acting first-generation injectable is available called Flupenthixol (Fluanxol).

Side effects and their management

Side effects happen when there is a drug reaction that causes other symptoms. Some side effects, such as a dry mouth or constipation, are mild and can be tolerated. Others, such as fevers or body tremors, are more severe and the medication must be changed or the dosage adjusted.

Side effects vary from person to person and some are more common than others. Common side effects associated with antipsychotic

George’s story:

When George went for a check-up a few months ago, his family doctor ordered cholesterol tests. The tests showed that George had high cholesterol levels so his doctor prescribed cholesterol-lowering medication. It’s been 3 months and George’s cholesterol level has stayed stubbornly high. His doctor suggested stopping his antipsychotic medication. Fortunately, George got in touch with his psychiatrist who reminded him that he must keep taking his clozapine as a way to manage his condition and enjoy good quality of life. The psychiatrist recommended daily exercise and a healthier diet as one way for George to manage his cholesterol levels.

medications can include, but are not limited to, constipation, dizziness, weight gain, glucose abnormalities, sexual side effects and feelings of a fast or irregular heartbeat. In some instances, particularly with first generation antipsychotics, there may be neurological side effects that can be very serious. Lists of side effects and recommendations for their management are available from your doctor or pharmacist.

Brand name drug vs. a generic drug

When getting a prescription filled, some provinces and private medical plans require that a generic equivalent be used instead of a brand name drug.

Brand name drug: has patent protection for its original manufacturer (an example is Tylenol, which contains acetaminophen).

Generic drug: identical to the brand name drug but can be produced only after the original brand patent protection has expired (an example is acetaminophen bought under the pharmacy's label). A generic drug is usually less expensive.

Special medication considerations for women

Research has shown that women are affected differently than men when it comes to living with schizophrenia. Women may:

- be older than males when the illness develops
- be likely to have more comorbid conditions such as diabetes or obesity
- experience more side effects from medications

For women with schizophrenia who are pregnant, experts generally agree that the safest option is to avoid the use of antipsychotics during the first trimester (first three months of pregnancy). If this cannot be avoided, the lowest possible dosage for the least amount of time may be needed.

Remember!

- When you start a new medication, your body needs time to adjust. Taking a long-term treatment drug is not like taking an aspirin for a headache. It takes time for the drug to take effect – sometimes days or weeks. Try to be patient.
- Side effects vary from person to person. Many are temporary and will go away as your body adjusts. Contact your doctor if the symptoms continue or are bothersome.
- Do not stop taking your medication until you speak to your doctor, unless you are having a life-threatening reaction such as difficulty breathing or erratic heartbeat.
- Many medications will make you drowsy or make your muscles feel stiff. Speak to your doctor if the symptoms are really bothering you.
- Some medications will make you gain weight. If the medication is helping to reduce your symptoms and improve your quality of life try increasing your exercise and making healthier food choices.

CPA Principles for Phase-specific Medication Treatment

The CPA principles for medication treatment for schizophrenia are:

Acute Phase

1. The assessment in the acute phase should be as comprehensive as possible under the circumstances.
2. Particular attention needs to be paid to the potential for danger to self or others.
3. During the acute phase, the person's experiences need to be acknowledged. Communications should be clear, simple and include family and support persons where possible. Explaining the patient's rights and any legal process is essential.
4. Medication treatment should be started as soon as possible. The risks and

benefits of medications should always be explained.

5. All the above principles apply in emergency situations. Emergency medication strategies are available to contain the patient and maintain the safety of others.

Stabilization Phase

1. The goal in this phase is to reduce the intensity and duration of psychotic symptoms as much as possible, minimize side effects and encourage the person to follow their treatment plan.
2. Medications used for short-term control of agitated behaviour during the acute psychotic phase may not be the best choice during the stabilization phase.
3. Adjust the dosage to the individual within the normal range for each medication. Try to get the patient's cooperation in following their medication plan completely and consistently.
4. Significant and sustained reduction in acute psychotic symptoms often takes 4 to 8 weeks. Improvements in other symptoms and functioning may take much longer. Improvement may continue over one year or more of uninterrupted treatment.
5. Stopping or reducing antipsychotic medication during this phase places the patient at high risk for relapse.

***Stick with your medication treatment program!
It's the best way to start moving towards recovery
and getting your life back on track***

Stable Phase

1. Relapse prevention is one of the most important goals of medication treatment in this phase.
2. Over the longer term, other goals include minimizing negative symptoms and other conditions and promoting improved functional ability.
3. There is a lot of variation in the dosage of antipsychotic medications needed for functional recovery with minimal side effects.
4. It is crucial to have the patient participate in their treatment plan and to address personal barriers and resistance to ongoing therapy.
5. Assessments should take place at least every 3 months to review dosages, choice of antipsychotic medications and to monitor for drug-induced side effects.
6. There are no predictive factors indicating which patients can safely and permanently discontinue antipsychotic medication.

CPA Recommendations for Medication Treatment

- Antipsychotic medications are needed for nearly all patients experiencing an acute relapse. The choice of medication should be tailored according to what is happening with the patient.
- In first-episode psychosis, dosages should be started in the lower half of the treatment range.
- Maintenance of medication is needed to avoid relapse in the stabilization and stable phases.
- Antipsychotic medication for the treatment of a first-episode psychosis should be continued for a minimum of one year following first recovery of symptoms and indefinitely for multi-episode schizophrenia.
- Long-acting injectable antipsychotic medication should be considered for people who do not follow their treatment program consistently or who have trouble taking oral medication regularly.
- Clozapine may be indicated for people who have tried two or more other antipsychotics without sufficient improvement in positive symptoms, have intolerable side effects or unremitting aggressive or suicidal behavior.
- A major depressive episode during the stable phase of schizophrenia may indicate the need for a trial of an antidepressant.

Part 3: Moving Towards Recovery

As we now know, schizophrenia is a complex disorder of the brain thought to be caused by a chemical imbalance. A successful recovery needs to involve a number of approaches that go well beyond medication and hospitalization. Research and experience show that the best basis for recovery involves active participation of the individual and family in ongoing treatment. This includes education, training and skills development not only for coping with schizophrenia but with life in general.

Knowledge is a powerful tool for the person and family living with schizophrenia. The more that is known about schizophrenia and how it can affect people's perceptions about the world around them and their internal world, the better those perceptions can be understood.

This section of the booklet describes some of the most effective ways to work towards a successful recovery using psychosocial approaches. These approaches involve a number of specialists and trained support people including psychologists, nurses, social workers, occupational therapists, supported employment specialists, peer support workers, etc. Not every community will have all these specialists. However, it is important to be aware of what may be helpful and available when setting goals for the treatment and management of schizophrenia.

What is recovery?

"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".

William Anthony (1993)
Boston University

"The concept of recovery is rooted in the simple and yet profound realization that people who have been diagnosed with mental illness are human beings... The goal is to become the unique, awesome, never to be repeated human being that we are called to be... one of the most essential challenges that face us is to ask *who can I become* and *why should I say yes to life.*"

Patricia Deegan, PhD (1996)
"Recovery is a journey of the heart"

Psychosocial approaches are those that help people in their relationships with others, with groups and with society as a whole.

Canadian Psychiatric Association (CPA) General Principles for Psychosocial Interventions

1. The best way to manage schizophrenia is through a combination of medication therapy and a range of other approaches which are collectively called psychosocial interventions. These approaches can complement medication therapy to improve clinical symptoms, functional capability and quality of life.

2. Effective psychosocial approaches can support people in following their medication plan, reduce the risk of relapse and readmission to hospital, reduce distress caused by symptoms, improve functioning and quality of life. These approaches provide support for patients, their families and caregivers.
3. Conditions commonly seen in people living with schizophrenia include anxiety disorders, depression and substance abuse. These conditions need to be recognized and addressed through psychosocial approaches.
4. Psychosocial approaches are best started when the acute symptoms have been relieved and the patient can be successfully involved in treatment.
5. Psychosocial interventions should be adjusted to the stage of the illness and the needs of the patients and their families.
6. Listening and attending to the patient's concerns develops empathy, rapport and a good therapeutic relationship. It can also help patients commit to following their treatment plan.
7. Patients, their families, and caregivers should be educated about the course and treatment of the disorder, as well as about ways to reduce risk of relapse. It is also important to provide a realistically hopeful attitude for the future. The physician is a very important partner in this process.
8. The clinical team, the patient and family members should develop shared, realistic goals for treatment and recovery. Progress toward these goals should be carefully monitored and evaluated.
9. Treatment providers should share plans for early recognition of relapse and crisis response with the patient, family and caregivers.
10. All patients should have access to proven programs that develop skills for activities of daily living, meeting vocational and educational goals, managing finances, developing and maintaining social relationships and coping with the impact of symptoms.
11. Staff providing psychosocial interventions should be appropriately trained.

Keys for successful recovery

There is no magic pill that will guarantee successful recovery from schizophrenia. And, there is no complete cure. But there are many steps you can take to help you on the journey to recovery including:

For the person living with schizophrenia:

- Effectively managing your medication treatment each and every day
- Actively working with your health care team to set goals for rehabilitation
- Taking an active part in your rehabilitation, including a healthy lifestyle and learning ways to cope with everyday stress

For the family of a person living with schizophrenia:

- Providing love, support and encouragement
- Becoming as knowledgeable as possible about the disease and the best ways to manage it
- Encouraging your loved one to develop skills, abilities and coping mechanisms that work for them

Sometimes “no” is the right answer

People with schizophrenia are often very sensitive to stress and over-stimulation of the senses. It is important to understand that there may be times when a person living with schizophrenia will need to avoid some situations, like crowded gatherings, noisy events, etc. Even family gatherings may be too much at times. Respecting someone’s right to say “no” at times is important to their recovery.

Peer support and self-help

Research is showing that self-help and peer support are very important to recovery. Persons living with schizophrenia need to be closely involved in their rehabilitation, not just to stabilize their symptoms, but also to regain their ability to function in society and improve their quality of life.

The increasing number of self-help programs, including peer-run services and peer-support workers, provide supports that go well beyond standard health care. Some research shows that peer support can help people improve their self-esteem, their self-worth and help them develop social networks. These approaches support the inclusion of people with schizophrenia in our society. They help by developing practical skills and “street smarts”.

Financial Considerations

Each individual and family will have their own financial situation to assess. Having a family discussion about plans for rehabilitation will likely include talking about how to pay for some very important services. Talk to the local Schizophrenia Society to learn more about the services available in your community or region. Some peer-support programs are led by volunteers and cost very little or nothing. Supported employment programs may be funded so you or the family will not have to pay to access their services. The local Schizophrenia Society will have the information you need to make informed decisions.

Disclosure: To tell or not to tell

As symptoms stabilize and you move into recovery, you’ll need to think about whether to tell people you have schizophrenia.

Adults living with schizophrenia have a legal right to have their privacy and human rights respected. You are not required to tell an employer or landlord that you have schizophrenia unless you feel comfortable doing so.

Diet, nutrition and exercise

Living with schizophrenia is a major challenge for our bodies and our minds. The healthier your body is, the better able it is to:

- get the full benefit of medications
- avoid or ease side effects
- prevent or better manage other conditions such as depression, diabetes and obesity

Many antipsychotic medications cause drowsiness or promote weight gain. That makes it especially important to:

- make the best food choices possible
- avoid caffeine and sugars
- avoid processed foods – most are high in salt and sugar
- get out regularly for walks and fun activities with family and friends
- avoid smoking (which is not good for anyone's health), and
- avoid alcohol and other drugs

Christian's story:

Diagnosed with schizophrenia at age 20, Christian slid into depression and alcoholism. After a number of relapses, he talked about ending it all. His older brother took him home and stayed with him. He found emergency medical support. Later, with the help of his brother, Christian joined a support group. After months of counseling and therapy, Christian felt strong enough to face life with schizophrenia. He is now employed part-time as a peer support counsellor with a local community agency.

Education and employment

With balanced medication and active involvement in their recovery, more and more people living with schizophrenia are finding it possible to go back and finish their schooling, start their careers or get back into the competitive workforce.

Increasingly, there is a movement towards getting people employed as soon as possible, with lots of job-support services. This approach is called supported employment.

Supported employment:

- develops job opportunities appropriate for each individual
- works to get a rapid placement
- emphasizes competitive employment – regular jobs that people without a disability are also doing
- provides ongoing support after job placement begins
- integrates vocational and mental health services

The good news is that research is showing that supported employment:

- leads to better employment rates among people with severe mental illness
- does not lead to increased stress or triggering of symptoms

- may have positive effects on self-esteem
- may have a positive effect on lowering the likelihood of relapse

Skills training

One of the most difficult things about living with schizophrenia is what it does to a person's social life. For young people, it may mean losing friends, social activities and time from school. The changes in behaviour brought on by the disease can affect social skills and life skills. As the person recovers, these skills may need to be relearned. The degree of skills training needed depends on each individual, their age when the disease developed and how it affected their ability to learn.

Social skills training: Works to improve interpersonal skills – making conversation, making friends and social interaction through:

- learning about verbal and nonverbal communications
- modeling, role playing, rehearsing social behaviours, getting helpful feedback
- practice and homework to transfer the learning and behaviours to day-to-day social situations

Life skills training: Focuses on activities of daily living including:

- managing money
- domestic skills
- personal self-care such as grooming and hygiene

While more research is needed to scientifically measure the effectiveness of these approaches, people with schizophrenia have said that this type of training is helpful. Gradually pushing your comfort zone is part of a successful recovery. The key is to find a balance between taking charge of your life and maintaining the supports you need to prevent a relapse.

Cognitive-Behavioural Therapy

Cognitive-behavioural therapy is a form of psychotherapy that is widely used for treatment of depression. In the last decade it has been shown to be useful in schizophrenia. It involves establishing a relationship, examining and challenging basic assumptions about one's life and setting small but feasible tasks that lead to long-term change. Cognitive behaviour therapy has been shown to be useful for managing symptoms that persist even after medication treatment including the management of anxiety and depression.

Schizophrenia alters a person's perception of reality. It makes it difficult to understand what is real and what is not real. It is important for people living with schizophrenia and those close to them to:

- understand the nature of the illness and always encourage the patient's active involvement in their treatment
- try to identify things that may make the symptoms worse, such as crowds, loud noises, lack of routine, substance use and lack of exercise and then work to address them
- learn and practice skills for coping with stress and reducing symptoms
- develop problem-solving strategies to reduce the possibility of relapse

Family planning

Up to one-half of people with diagnosed schizophrenia are married or living with an intimate partner. Where one or both of the partners are living with schizophrenia, family planning raises a number of issues:

- the benefits and risks of stopping medication before pregnancy, including the potential for a relapse
- the genetic risk that the child will develop schizophrenia (thought to be about 1 in 10 where one partner has schizophrenia and 4 in 10 where both partners have schizophrenia)
- risk for postpartum depression
- the responsibilities of parenting and caregiving for a child
- the availability of outside supports such as grandparents
- the desire to be a parent
- the worries and wishes about becoming a parent with a dependent child

People living with schizophrenia need to talk with people they trust about family planning. It is a huge step both for couples and for women considering raising a child alone. Being able to talk to people you feel comfortable with can help you make a decision that is right for you.

Family care

Having a family member with a chronic condition affects the entire family. For families living with schizophrenia it is important to keep things in perspective and learn to cope effectively with stress. Steps need to be taken to support caregivers so they don't burn out.

Remember!

- You can only help another person if you take care of yourself first. On airplanes, they tell you to put on the oxygen mask yourself before you try to help someone else, including your child. It's the same with all caregiving. **Take care of your health and well-being first:**

- Build a support network of family, friends and community agencies, including your local Schizophrenia Society.
- Understand that you need to have regular breaks and free time – plan weekend getaways and vacations and take them. You need and deserve them.
- You need to take breaks even if the person with schizophrenia is not living in your home. There is still significant stress to your life.
- Taking a break doesn't mean you can't handle things. It means you are being a responsible caregiver who knows the importance of taking care of yourself.
- If you feel depressed and stressed, get help! Find support or treatment. Your life has changed and possibly been turned upside down. Who wouldn't be stressed?
- Talk as a family:
 - Younger members of the family need to be reassured that it is unlikely they will develop the disease
 - Older members of the family need to understand the nature of schizophrenia and the possibilities for treatment and recovery
 - Everyone needs to understand that the person with schizophrenia will do best with loving support and understanding

CPA Recommendations for Psychosocial Approaches to the Treatment of Schizophrenia

Psychoeducation: Educating people with schizophrenia about their illness and giving them practical training in how to manage it can help them stay with their medication treatment and prevent relapse.

Vocational approaches: A wide range of possibilities should be considered for people who are able to work, including volunteer work and supported or transitional employment.

For many people it is important to have goals for paid employment. Supported employment programs – which pay people to do real, regular work – appear to offer the best approach for getting into the workforce.

Skills training: Social skills training should be available for patients who are having difficulty and/or experiencing stress and anxiety about social situations.

Proven life skills training approaches should be available for patients who are having difficulty with tasks of everyday living.

Cognitive-behavioural approaches: Cognitive therapy should be offered to treatment-resistant people with schizophrenia.

Family approaches: Education and support programs for family members should be part of the routine care for patients with schizophrenia. Research suggests that these programs should last more than nine months and include features of engagement, support and skills-building and not just information or knowledge sharing.

Peer support, self-help and recovery: Public education about mental illness should include stories from people who have schizophrenia.

Services provided by peers should be included in the continuum of care for people with schizophrenia including group-based skills training by and for consumers, peer support and public education programs.

Treatment of associated conditions: Consideration should be given to the use of cognitive-behavioural approaches for the treatment of stress, anxiety and depression in patients with schizophrenia. Techniques used in other areas may be helpful.

Substance use: For people with schizophrenia who also have substance abuse problems, integrated programs should be available. This means that the same program should deal with the schizophrenia and the addiction. In practice, this includes assessing for addictions and assessing the readiness to change. It should also include offering simple interventions for addictions such as motivational interviewing. Some people with schizophrenia may need to attend special groups for those with addictions and psychosis or even enter special residential programs. A few people with schizophrenia whose symptoms of psychosis are easier to manage may find that they can attend AA meetings or other addictions counseling programs.

Part 4: Service Delivery

As mentioned earlier in this booklet, there are many differences in the ability of communities of all sizes to provide the full range of services needed for mental health. It can also be difficult to navigate the health care system to bring together all the needed supports for people living with schizophrenia.

We are learning that access, availability and continuity of care are very important in supporting a person's recovery from schizophrenia. Schizophrenia is a chronic illness. There will always be a need for people living with schizophrenia and their families to have regular access to service and support.

The Canadian Psychiatric Association (CPA) has set out five general principles to guide health service providers on what should be available to support people with schizophrenia in their treatment and recovery.

CPA General Principles for Service Delivery and the Treatment System

1. All patients should have access to a full range of services that provides comprehensive care, including physical care.
2. All patients in longer-term programs should have a written care plan that should be available to family members, with the patients' permission, when possible.
3. The range of care should include 24-hour crisis services, acute inpatient care in a medical setting, non-medical crisis stabilization, acute day hospital treatment, community-based rehabilitation, integrated addiction services, comprehensive services for early psychosis, assertive community treatment programs, consumer-driven services such as club houses and supported employment programs.
4. All patients should have access to a range of housing support, including long-term hospital care, supportive housing in the community, independent housing with supports or affordable general housing.
5. Services should be accessible in the patient's own language and in their geographical area.

Access

Access to adequate treatment is especially important at the time of the first episode of schizophrenia. Unfortunately, treatment is often delayed for an average of one to two years. At first, there may be delays in trying to get help. Then there may be more delays within the health care system, both in medical care and in mental health care.

Remember!

- You may have to advocate very strongly and persistently to make sure you get the services and support you or a family member may need.
- Keep up the pressure. Times are changing for mental health care in Canada. There is growing awareness that people with mental health issues have the same rights to treatment and support as all Canadians.

Availability

Waiting times are a serious issue throughout the health care system. This is especially true for assessment and treatment of serious psychiatric illnesses. In many areas of the country, the range of services that are needed to help people living with schizophrenia don't yet exist. The May 2006 Senate Report: *Out of the Shadows At Last* found that "social supports such as employment assistance and adequate housing, education and research, and self-help and peer support" are the most important to people living with psychiatric illnesses.

Remember!

- Consumers and family members are the best advocates for change
- Join your local Schizophrenia Society, find support and help make a difference!

Coordination and continuity of care

It's important to remember that the majority of people living with schizophrenia receive most of their care in the community. However, sometimes people with schizophrenia do need to be hospitalized. This makes it very important to coordinate between hospital care, community care and primary health care.

Ideally:

- Every person should have a family physician they visit regularly for overall health monitoring. If there is any change in treatment of the main psychiatric disorder, this should be communicated to all professionals involved in that person's care such as a case manager, social worker, addictions counsellor or occupational therapist.
- Mental health issues and addiction issues should be treated together and at the same time.
- People being treated on an outpatient basis should be reminded of their appointments in writing or by phone.
- People participating in a case management program should keep contact with the same treatment team even if the individual case manager moves.

Did you know?

The value of lost productivity in Canada that is attributable to mental illness alone has been estimated at some \$8.1 billion. More recently, if substance abuse is taken into account as well, that estimate grows to a loss to the economy of some \$33 billion annually.

Out of the Shadows At Last
May 2006, page 178

The main goal in coordinating care is to make sure people don't fall through the cracks each time there is a change in their condition or their support networks.

Potential Community Services and Support For People with Schizophrenia

Not all of the services described in the table below may be available in your community. It may take some time and pressure on your part to be successful in getting the services you or a family member may need. For some people, starting up a self-help or peer support group with others in the community may be part of the recovery process!

Service	Condition/Issue	Your Local Contact Info	Notes
Family Physician or General Practitioner	<ul style="list-style-type: none"> • Overall health monitoring; regular check-ups • Referrals to specialists 		
Psychiatrist	<ul style="list-style-type: none"> • Assessment • Medication treatment • Counselling • Referrals for rehabilitation 		
Nurse	<ul style="list-style-type: none"> • Primary care giver • Medication administration • Counselling 		
Family Worker	<ul style="list-style-type: none"> • Provides education and support for significant others 		
Pharmacist	<ul style="list-style-type: none"> • Monitors medications • Provides advice on over-the-counter medications and how they may interact with prescription medications 		
Psychologist	<ul style="list-style-type: none"> • Can provide behaviour and thinking (cognitive) therapies to assist with recovery • Referral may be required for some private health care plans 		

Service	Condition/Issue	Your Local Contact Info	Notes
Social Worker	<ul style="list-style-type: none"> • Can assist with a variety of approaches for the individual and family depending on where they work: social agency, hospital, school board • Can be assigned in hospital for in-patient and for out-patient support and follow-up • Can be requested through other sources such as school, social welfare office, etc. 		
Occupational Therapist	<ul style="list-style-type: none"> • Assists people of all ages with developing physical abilities (strength, coordination and balance) and mental abilities (memory, organizational skills, ways of coping) • Some services are covered by provincial medical plans • Referral by physician is usually required 		
Addictions Counsellor/ Program	<ul style="list-style-type: none"> • Assists with alcohol and drug treatment and rehabilitation • May be private or group • If necessary, should be part of health care team • Referrals available through agencies, hospitals, etc. or in yellow pages 		
Dietician/ Nutritionist	<ul style="list-style-type: none"> • Assists with advice and planning for diet and nutrition • Support management of obesity, diabetes, and metabolic syndrome 		

Service	Condition/Issue	Your Local Contact Info	Notes
	<ul style="list-style-type: none"> • May be referred by hospital, physician, occupational therapist and others • Formal referral not required for private practice 		
Schizophrenia Society (Local/provincial)	<ul style="list-style-type: none"> • Assists with research information, self-help groups and other community supports 		
Early Psychosis Program	<ul style="list-style-type: none"> • First episode assessment, treatment and research 		
Case Management	<ul style="list-style-type: none"> • Individual and tailored treatment with goal of more independent living. Includes patient teaching, medication management, and connection to other resources. 		
Assertive Community Treatment (ACT)	<ul style="list-style-type: none"> • For hard-to-engage or treatment-resistant patients who may need additional or more intense community support. • Team-based and outreach approach to case management • Multi-disciplinary • Helps reduce hospital readmissions; improves housing and occupational functioning • Requires a referral 		
Mobile Crisis Services	<ul style="list-style-type: none"> • Specialized, multi-disciplinary team that provides assessment, crisis intervention and referral to ongoing care • May help avoid hospitalization 		

Service	Condition/Issue	Your Local Contact Info	Notes
Outpatient and Community	<ul style="list-style-type: none"> • Follow-up to help people follow their treatment plan • Help with accessing a range of community supports and resources • In many areas, the community mental health clinic provide comprehensive biological, psychosocial, and social supports from the multi-disciplinary team 		
Home-based Acute Care	<ul style="list-style-type: none"> • Where there is manageable risk, consumers and families generally prefer home-based care than other forms of care 		
Day Hospital	<ul style="list-style-type: none"> • Alternative to acute inpatient care, outpatient care and as a place for vocational rehabilitation • Useful service where there is limited access to acute inpatient services 		
Supported Employment Program	<ul style="list-style-type: none"> • Assistance with placement in competitive employment • Follow-up support 		
Respite Care	<ul style="list-style-type: none"> • Area facilities and programs that will care for an ill person so the family can have a break. Can include day programs, short stays (2-3 days) and sometimes longer stays (up to 2 weeks) 		

Looking to the Future

Our understanding of schizophrenia and mental illness overall is improving every year. Active scientific and clinical research and analysis are improving our understanding of how schizophrenia develops, and what works to help improve the lives of those who live with the illness.

We now know that a variety of approaches – both medical and psychosocial – need to be brought together to treat people effectively and work towards recovery.

We also know that ongoing treatment and support will be needed throughout a person's life if they are to manage their condition effectively.

In recent years, there have been significant improvements in treatment and rehabilitation. However, much remains to be done. One of the key areas for advancement lies in public education to reduce the stigma of mental illness in general and schizophrenia in particular.

People living with mental illnesses are, first and foremost, human beings with abilities and capacities that need to be explored, nurtured and strengthened. We need to be seen, heard and respected. For those of us living with schizophrenia, what we need most is hope – hope for our recovery and our future. That hope lies in working together as individuals and as a society in a shared journey towards recovery.

Where to Get More Information

Schizophrenia Society of Canada

50 Acadia Ave., Suite 205
Markham, ON L3R 0B3
Tel: 905-415-2007
Email: info@schizophrenia.ca
Web: www.schizophrenia.ca

Canadian Psychiatric Association

141 Laurier Ave. W., Suite 701
Ottawa, ON K1P 5J3
Tel: 613-234-2815
Email: cpa-apc.org
Web: www.cpa-apc.org

British Columbia Schizophrenia Society

#201, 6011 Westminster Highway
Richmond, BC V7C 4V4
Toll-free in BC: 1-888-888-0029
E-mail: bcss.prov@telus.net
Web: www.bcss.org

Schizophrenia Society of Ontario

130 Spadina Avenue, Suite 302
Toronto, ON M5V 2L4
Tel: (416) 449-6830
Toll Free in ON: 1-800-449-6367
E-mail: sso@schizophrenia.on.ca
Web: www.schizophrenia.on.ca

Schizophrenia Society of Alberta

5th Floor, 9942 - 108 Street
Edmonton, AB T5K 2J5
Toll Free in AB: 1-800-661-4644
E-mail: info@schizophrenia.ab.ca
Web: www.schizophrenia.ab.ca

Société québécoise de la schizophrénie

7401, rue Hochelaga
Montréal, QC H1N 3M5
Toll-free in QC: 1-866-888-2323
E-mail: info@schizophrenie.qc.ca
Web: www.schizophrenie.qc.ca

Schizophrenia Society of Saskatchewan

P.O. Box 305
Regina, SK S4P 3A1
Tel: (306) 584-2620
E-mail: sssprov@sasktel.net
Web: www.schizophrenia.sk.ca

Schizophrenia Society of New Brunswick

Victoria Health Centre
P.O. Box 562
Miramichi, NB E1V 3T7
Tel: 506-622-1595
E-mail: ssnbmiramichi@nb.aibn.com
Web: www.schizophrenia.ca/ssnb

Manitoba Schizophrenia Society

100 - 4 Fort Street
Winnipeg, MB R3C 1C4
Toll Free in MB: 1-800-263-5545
E-mail: info@mss.mb.ca
Web: www.mss.mb.ca

Schizophrenia Society of Nova Scotia

P.O. Box 1004 Nova Scotia Hospital
Room 409, Simpson Hall
Dartmouth, NS B2Y 3Z9
Toll-free in NS: 1-800-465-2601
E-mail: ssns@ns.sympatico.ca
Web: www.ssns.ca

Schizophrenia Society of Newfoundland and Labrador

205 - 206 West Block, Waterford Hospital
Waterford Bridge Road
St. John's, NL A1E 4J8
Tel: (709) 777-3335
E-mail: ssnl1@yahoo.ca
Web: www.ssnl.org

Schizophrenia Society of Prince Edward Island

P.O. Box 25020
Charlottetown, PE C1A 9N4
Tel: (902) 368-5850

Other organizations

Canadian Association of Occupational Therapists
CTTC Building, Suite 3400
1125 Colonel By Dr
Ottawa ON K1S 5R1
Toll-free: 1-800-434-2268
Web: www.caot.ca

Canadian Association for Supported Employment
P.O. Box 307
919 Centre Street North
Calgary, AB T2E 2P6
Tel: 403-283-0611
Web: www.supportedemployment.ca

Canadian Association of Social Workers
383 Parkdale Avenue, Suite 402
Ottawa, ON K1Y 4R4
Tel: 613-729-6668
Web: www.casw-acts.ca

Canadian Coalition of Alternative Mental Health Resources
Contact the National Network for Mental Health
Toll-Free: 1-888-406-4663
Web: www.ccamhr.ca

Canadian Mental Health Association
180 Dundas Street W., Suite 2301
Toronto, ON M5G 1Z8
Tel: 416-484-7750
Web: www.cmha.ca

Canadian Nurses Association
50 Driveway
Ottawa, ON K2P 1E2
Toll Free: 1-800-361-8404
Web: www.cna-nurses.ca

Dietitians of Canada
Tel: 416-596-0857
Web: www.dietitians.ca

National Network for Mental Health
Suite 604 - 55 King Street
St. Catharines, ON L2R 3H5
Tel: 905-682-2423
Toll-Free: 1-888-406-4663
Web: www.nnhm.ca

Canadian Psychological Association
141 Laurier Avenue West, Suite 702
Ottawa, ON K1P 5J3
Toll free: 1-888-472-0657
Web: www.cpa.ca

Registered Psychiatric Nurses of Canada
201,9711-45 Ave
Edmonton, AB T6E 5V8
Toll free: 1-877-234-7666
Web: www.rpnaa.ab.ca

The National Youth in Care Network
332 Bank St. Suite 207
Ottawa, ON K2P 2N2
Toll free: 1-800-790-7074
Web: www.youthincare.ca

National online referral to local alcohol and drug treatment in the provinces and territories
Toll free: 1-877-801-5475
Web: www.drugaddictiontreatment.ca

Glossary of Terms

There are many technical terms that are used by professionals when talking about schizophrenia. The following list of terms and definitions may help you in your communications with members of the health care team. Remember, if you don't understand something, keep asking for an explanation until you are sure you understand.

Access: The extent to which an individual who needs care and services is able to receive them. Access is more than having insurance coverage or the ability to pay for services. It is also determined by the availability of services, acceptability of services, cultural appropriateness, location, hours of operation, transportation needs, and cost.

Acute phase: The time in the development of schizophrenia when symptoms become severe enough that medical help is needed. These symptoms may emerge very gradually or quite suddenly.

Activities of Daily Living (ADL): These are usual activities like walking, doing errands, completing chores and taking care of personal hygiene. An ADL assessment helps to understand how well a person is able to function on their own.

ACT programs: ACT stands for Assertive Community Treatment. ACT is designed as an alternative to hospitalization. It provides 24-hour continuous care and service within the community. Team members directly treat, rehabilitate and support clients within a planned, coordinated and efficient case management process.

Advocate: Someone who is informed and experienced, able to maintain privacy, a good listener who understands another person's mindset, is empathic but able to keep their own emotions in check, never dictates and is willing and able to speak for others.

Antipsychotics: These are the specific medications used in the treatment of mental illness such as schizophrenia. They are used to control psychotic symptoms such as delusions and hallucinations. The second-generation antipsychotics also improve negative symptoms, cognitive functioning and depression to some extent.

Blunted affect/Flat affect: Flattening of the emotions. Some people with schizophrenia seem unable to feel or show emotion. Facial expressions and hand gestures may be limited or non-existent.

Caregiver: In the health care field, a caregiver is someone such as a doctor, nurse or social worker who helps to identify, prevent or treat an illness or disability. In the community, a caregiver is the primary person in charge of caring for a child or a dependent adult; usually a family member or foster parent.

Chronic: A chronic condition is one that lasts a minimum of one year, limits your activities in some ways and will require ongoing care and management. Examples of chronic conditions include diabetes, arthritis, heart disease and schizophrenia.

Cognitive approaches: The mental processes we use that help us gain knowledge including thinking, reasoning, judgment, intuition, perception, remembering, imagining and learning words.

Comorbid: Like all people, those with schizophrenia can have other illnesses and conditions. Comorbid disorders can be either physical (heart disease, obesity, diabetes) or psychiatric (depression). Addiction to alcohol or other drugs is another comorbid condition, as is smoking. These are all conditions that can affect the effective treatment of schizophrenia and even reduce life expectancy.

Concurrent Disorders: A concurrent disorder combines both a mental health problem and a substance use problem. Someone with major depression who also abuses alcohol has a concurrent disorder, for example, as does a person with schizophrenia who abuses cannabis. It is uncertain how many people have concurrent disorders but it is known that people with mental illnesses have higher rates of addiction than people in the general population

Delusion: A fixed belief that has no basis in reality. People with delusions are often convinced they are famous people, are being persecuted or are capable of extraordinary accomplishments.

Depression: A complex assortment of symptoms that affect our ability to function. The symptoms can be wide-ranging and vary from person to person. Some symptoms include feeling sad, difficulty in concentration, decreased ability to do ordinary work, low self-esteem. Many people have periods of depression which go away on their own. For those who are depressed for more than two weeks in a row, they may have clinical depression that may require professional treatment and possibly medication.

Diagnosis: The study of the signs and symptoms of a disease or mental condition using a variety of tests and observations. Schizophrenia is one of

many diagnostic categories used in psychiatry. It is important to remember that a diagnosis should not label a person “a schizophrenic” but label their condition as “a person living with schizophrenia”.

Dissociative disorder (Split or Multiple Personality): Rare condition indicated by the absence of a clear and comprehensive identity. In most cases two or more independent and distinct personality systems develop in the same individual. Each personality may alternately inhabit the person’s conscious awareness to the exclusion of the others, but one is usually dominant. The various personalities typically differ from one another in outlook, temperament, and body language and might assume different first names.

Dual diagnosis: The presence of two medical conditions or diseases at the same time. An example would be schizophrenia and depression. Another would be schizophrenia and obesity. Another would be schizophrenia and substance abuse.

Genetics: A branch of biology that scientifically studies how we may inherit some things from our parents and ancestors. It may include the way we behave and can include medical conditions such as heart disease and a range of chronic conditions.

Hallucination: An abnormal experience in perception. A person having a hallucination may see, hear, smell, taste or feel things that are not there. To them it is very real.

Intervention: An action that is intended to alter the course of a disease or condition. With schizophrenia, there are a number of medical, psychiatric and psychosocial (see definition below) interventions that are known to support the recovery process.

Involuntary admission: The process of having someone admitted to hospital who does not want to go, does not wish to be treated or is unable to provide consent. Involuntary admission normally requires that the person's health or safety be at risk or for the protection of the public. In some provinces, two physicians – one of whom is a psychiatrist – must certify that the person has a mental disorder that requires care, protection and medical treatment in hospital; is unable to fully understand and make an informed decision about treatment; and/or is likely to cause harm to self or others or to suffer substantial mental or physical deterioration if not hospitalized.

Mental illness/mental disorder: Abnormality or irregularity in the brain that causes substantial disorder of thought, mood, perception, orientation or memory. This may grossly impair judgement, behaviour, capacity to reason or ability to meet the ordinary demands of life.

Negative symptoms: Negative symptoms of schizophrenia include:

- lack of motivation or apathy
- lack of energy or interest
- blunted affect (see definition above)

Neuroimaging: Photographic or digital studies of the nervous system. One example is Magnetic Resonance Imaging (MRI), a painless way to get a full picture of the brain to see how the brain is structured and/or functioning.

Neuropsychological: A branch of psychology that tries to understand the relationship between behaviour and the neurological condition of the brain and nervous system.

Paranoia: Delusional thinking and suspicion of people and situations. People with paranoia may think others are ridiculing them or plotting against them.

Their suspicion is not based on fact or evidence.

Positive symptoms: Positive symptoms of schizophrenia include:

- delusions (strange and strongly-held beliefs that defy logic, e.g. being watched, spied upon or plotted against)
- hallucinations (hearing voices, seeing visions that are not there or experiencing unusual body sensations)
- thought disorders (fragmented and disorganized thinking; incoherent and illogical speech)

Primary health care: This is the first level of contact with the health system to promote health, prevent illness, care for common illnesses and manage ongoing health problems. The focus is on keeping people healthy and managing illness early to increase the chance for recovery.

Prodromal phase: This is the time before clearly-identifiable psychotic symptoms have been noticed. Friends, teachers and family may notice a number of behavioural symptoms and changes but it has not reached the acute phase, where there is a clear need for medical help.

Psychiatrist: A licensed medical physician who specializes in treating mental and emotional disorders.

Psychoeducation: A process of providing information and education about an illness, its diagnosis, common or recommended interventions, as well as opportunities for questions and feedback that are provided to a patient and his/her spouse or family.

Psychologist: Practicing psychologists are regulated and licensed experts in mental processes and behaviours. A practicing psychologist is trained to assess and diagnose problems in thinking, feeling and behaviour as well to help people overcome or manage these problems.

Psychosocial: Looks at the effects of mental health on the social areas of a person's life. For example, people with schizophrenia may have difficulty making and keeping friends or keeping employment. With successful treatment of both the psychological side of schizophrenia and its social effects, a person may have a much better recovery.

Psychosis: A range of serious thought disturbances that prevents people from understanding the difference between the real world and the imaginary world. Symptoms include hallucinations, delusions, irrational thoughts or fears.

Rehabilitation: A training approach that helps restore physical and/or mental health to the best of a person's ability and capacity.

Schizophrenia: Schizophrenia is a serious but treatable brain disorder. It affects a person's ability to know what is real and what is not. The symptoms include delusions, hallucinations, disturbances in thinking and communication, and withdrawal from social activity. The symptoms are believed to be caused by disturbances in the flow of information in the brain.

Supported employment: Supported employment is real work in an integrated workplace. Ongoing support is provided by an agency with expertise in finding employment for people with disabilities. Supported workers do work that would be done by anyone in the work force if it were not done by the person with a disability. Supported workers are paid at least minimum wage or the standard wage for the position.

Acknowledgements

The Canadian Psychiatric Association and the Schizophrenia Society of Canada would like to sincerely thank all those involved in guiding the development of this resource booklet:

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Special thanks to **Dr. John E. Gray**, Ph.D., Past President of the Schizophrenia Society of Canada for his leadership in developing the concept for *Schizophrenia: The Journey to Recovery – A Consumer and Family Guide to Assessment and Treatment*.



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