HOPE & RECOVERY

Your Guide to Living with and Beyond Schizophrenia
ABOUT THE SCHIZOPHRENIA SOCIETY OF CANADA

The Schizophrenia Society of Canada is a national registered charity that has been in operation since 1979.

OUR MISSION
Build a Canada where people living with early psychosis and schizophrenia achieve their potential.

OUR VISION
We transform how people think with knowledge and youthful enthusiasm.

ABOUT THIS GUIDE
This guide has been developed to provide information and guidance to young people who have been diagnosed with schizophrenia, and those who support them. Our hope is that this guide will be a meaningful resource, with up-to-date and accessible information about living with and beyond schizophrenia, and setting the course toward recovery.
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This user-friendly guide is based upon the Canadian Schizophrenia Treatment Guidelines developed in 2017 by a multidisciplinary team of experts, patients, and family members from across Canada.

SSC board member Elizabeth Anderson and I were members of the multidisciplinary team. The guidelines were launched in September of 2017 by the Canadian Psychiatric Association and published in the Canadian Journal of Psychiatry. The target users of the guidelines are healthcare professionals. But the guidelines are also very useful to individuals living with schizophrenia and their families. The guidelines are based on up-to-date scientific evidence of what helps people to get better and experience recovery and well-being.

The last user-friendly guide was published in 2007 by the Schizophrenia Society of Canada. We have come a long way in the last decade in our understanding of how to address the complex issues associated with a diagnosis of schizophrenia. We know that early identification of and intervention in treating early psychosis leads to better outcomes for the individual and family. The following words were written by me in the 2007 guide. They are just as relevant today as ever before.

““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 mental 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 a 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 a 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.”

With great appreciation to the contributions of this user-friendly booklet, our goal is that those living with early psychosis and schizophrenia reach their potential as they move forward in their recovery journey!
HOPE AND RECOVERY: YOUR GUIDE TO LIVING WITH AND BEYOND SCHIZOPHRENIA

Schizophrenia is a complicated disorder which affects how a person perceives things, thinks, feels, and acts. Someone with schizophrenia may have difficulty distinguishing between what is real and what is imaginary; may be unresponsive or withdrawn; and may have difficulty expressing normal emotions in social situations.

Contrary to a commonly-held myth, schizophrenia is not split personality or multiple personality. The vast majority of people with schizophrenia are not violent and do not pose a danger to others.

Anyone can develop schizophrenia; it affects people of all races and cultures. The prevalence of schizophrenia is approximately 1 in every 100 people. Women tend to develop symptoms in their late 20s whereas the onset in men is typically in their early 20s.

If you’ve been diagnosed with this mental illness, you will likely have a range of symptoms. People with schizophrenia experience periods of time when they can’t think clearly and can’t tell the difference between what’s real and what’s not real. They may react inappropriately to other people or misinterpret the actions and emotions of others.

Researchers now believe the reason people diagnosed with schizophrenia experience different symptoms may be because schizophrenia is actually a group of different illnesses. Each illness is caused by different groups of genes, influenced by environmental and social factors. These genes malfunction, so to speak, and produce distinct symptoms.
THE GOOD NEWS IS: THERE IS HOPE.

Schizophrenia is treatable. Recovery is possible.

TO EXPERIENCE RECOVERY, YOU NEED ACCESS TO:

1. Caring, hopeful, and knowledgeable mental healthcare professionals, including a family doctor, who are recovery focused
2. Medication tailored to your cluster of symptoms
3. Monitoring of side effects of medication
4. Talk therapy
5. A peer support worker and peer support groups
6. Psychological and social programs that support recovery as well as other community supports and services
7. A network of supportive family and friends to assist in shared decision-making who will help you to advocate for what you believe will assist in your recovery
8. A personal relapse prevention action plan, such as the Wellness Recovery Action Plan® (WRAP®)
Depending on the severity of your schizophrenia, you may always need support and treatment. Recovery is on-going. Some speak of being “in recovery.” Others, “recovering forward.” And still others, “recovering from.”

Recovery from mental illness is a concept that has been largely developed by and described by people with lived experience with mental health problems. One widely used definition of recovery is the one developed by Dr. William Anthony:

“... a deeply personal, unique process of changing one’s attitudes, values, feeling, goals, skills and/or roles. It is a way of living a satisfying, hopeful and contributing life, even with the limitations caused by illness. Recovery involves the development of new meaning and purpose in one’s life as one grows beyond the catastrophic effect of mental illness.”

This guide is intended to help you, your family and friends, the people you work with, and anyone else who would like to learn about the best ways to help you get better and live a life of satisfaction. The first section of the guide is directed to you, particularly after you are first diagnosed with schizophrenia. The last section of this document has some suggestions for your family, friends, and colleagues. It will help you and your family and friends to read both sections of the guide.

This is an interactive PDF and all text that looks like this links to an external resource.
THE EMOTIONAL IMPACT

Getting a diagnosis of schizophrenia can be frightening. Part of that fear comes from the negative feelings some people have about this illness. You may be afraid to tell people you have schizophrenia or to seek help because of this stigma.

We believe the more we talk openly about schizophrenia and what helps people get better, the more we will reduce the stigma around this illness. We now know that the earlier that someone receives help, the greater their chance of recovery.

No matter what, you deserve understanding and the best treatment available. We are here to help. This guide is based on the latest evidence about how best to help you. We believe it is critical that the people helping you listen to you and understand your hopes, dreams, and goals. Remember, you are NOT your illness. A diagnosis is a label, not your identity!

CAUSES

We don’t know what causes schizophrenia. We do know there is a genetic component, but researchers haven’t yet identified all the genes involved. We know people are more likely to develop this illness if they have:

- Deletions or duplications of genetic materials, combined with exposure to severe stress or infections as children
- Experienced trauma-violence
- Used cannabis (particularly high strength THC) or other hallucinogenic drugs
- A parent, brother or sister with schizophrenia or other major mental illness (bipolar disorder, major depressive disorder).

This does not mean that if you have a family member with schizophrenia, that you will also develop it. Most people (up to 70%) with schizophrenia do not have another family member with schizophrenia.
**KEEP IN MIND:**

You are not alone. About one in every 100 persons living in Canada has schizophrenia.

- Both men and women develop schizophrenia.
- Young men often experience their first episode of schizophrenia in their late teens or early 20s.
- Young women usually experience their first later than males.

- Schizophrenia is treatable! In time, you can continue to pursue your goals: education, relationships, a career, and having a family.
- It is not your fault that you have this illness. We don’t know what causes schizophrenia. And we don’t yet have a cure for schizophrenia.
- A psychiatrist can diagnose and choose to prescribe medications to treat schizophrenia.

- Your input is vital in creating a treatment and recovery plan.
- Peer support workers and groups are most important for you and your family and friends.
- You can live with schizophrenia and still have hope, meaning, and life satisfaction.
SYMPTOMS OF PSYCHOSIS

The word psychosis is used to describe conditions that affect the mind, in which people lose touch with reality and have trouble distinguishing between what is real and what is not. A first episode of psychosis is often very frightening, confusing and distressing, particularly because it is an unfamiliar experience.

A number of mental illnesses can include psychosis as a symptom, including*:

**Schizophrenia**
A person has some psychotic symptoms for at least six months, with a significant decline in the ability to function.

**Schizophreniform disorder**
A person has some psychotic symptoms for more than one month and less than six months.

**Bipolar disorder**
With this type of illness, the symptoms of psychosis relate more to mood disturbance than to thought disturbance.

**Schizoaffective disorder**
A person will have symptoms of schizophrenia and, at some point in the course of illness, concurrent symptoms of a mood disturbance.

**Depression with psychotic features**
A person has severe depression and symptoms of psychosis without the mania associated with bipolar disorder.

**Drug-induced psychosis**
The use of drugs such as cannabis, cocaine, ecstasy, ketamine, LSD, amphetamines and alcohol can sometimes cause psychotic symptoms.

**Organic psychosis**
Sometimes, symptoms of psychosis may appear as a result of a physical illness or a head injury.

**Brief psychotic disorder**
This type of psychosis usually lasts less than a month. It is sometimes triggered by a major stress in the person’s life, such as a death in the family.

**Delusional disorder**
This type of psychosis consists of very strong, fixed beliefs in things that are not true, without the presence of hallucinations.

*Source: https://www.camh.ca/en/health-info/mental-illness-and-addiction-index/psychosis
Remember, psychosis is a symptom, not an illness. A mental or physical illness, substance abuse, a brain injury, extreme stress, or trauma can trigger psychosis as well.

The cluster of symptoms of psychosis is different for everyone. Symptoms may develop slowly over months or years or may appear very abruptly. Symptoms may come and go in cycles of relapse and remission.

**Behaviours that are early warning signs include:**

- Hearing or seeing something that isn’t there
- A constant feeling of being watched
- Peculiar or nonsensical way of speaking or writing
- Strange body positioning
- Feeling indifferent to very important situations
- Deterioration of academic or work performance
- A change in personal hygiene and appearance
- A change in personality
- Increasing withdrawal from social situations
- Irrational, angry or fearful response to loved ones
- Inability to sleep or concentrate
- Inappropriate or bizarre behaviour
- Thoughts of self-harm or suicide

Anyone who experiences several of these symptoms for more than two weeks should seek help immediately.

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**GETTING A DIAGNOSIS**

The process of receiving a diagnosis often begins when people experience major symptoms of psychosis. You may hear voices, lose contact with reality, or believe things that are not true in reality.

This can happen suddenly or over time.

You may know that something is wrong with you, but are afraid to seek help because you do not want to be known by the offensive, hurtful, and stigmatizing words and language people sometimes use to describe a person with a mental illness. You might also be afraid you will be treated differently if people know you have a mental illness.

Your family members or friends are very important in recognizing when something is wrong, because you might not be able to know that you need help. Your symptoms may be so severe that you may not realize how sick you are. This is referred to as “anosognosia.”

It is still vitally important to seek help.
WHAT IS A FIRST EPISODE?

Doctors call the first time people experience psychosis a “first episode” or “early psychosis.”

It’s important to get help as soon as possible at the start of the first episode because **the appropriate treatment may reduce or prevent full-blown schizophrenia**. Major cities across Canada have “first-episode” clinics or programs, which can help you access support networks and other services.

If you or someone you care about is experiencing psychosis, the first place to turn is to a family doctor. That doctor can talk with you about what you are thinking and feeling and may refer you to a psychiatrist.

It helps to take a family member or friend with you to appointments with doctors or other healthcare professionals. Your friend or relative can support you and give and receive information that you might not remember because of your illness, or because you may be nervous during your appointment.

If you don’t have a family doctor, you can go to a hospital emergency department or a crisis response centre closest to you.
It takes time to get a diagnosis of schizophrenia. It’s important for doctors to assess both physical and mental health. That means you may have to go to many appointments during this assessment period. You may also talk with nurses, social workers, psychologists, mental health workers and/or peer support workers.

It’s also important for your psychiatrist and other specialists to work together with your family doctor, if you have one. These professionals should form a team to support you. This support team is sometimes called a “circle of care” and may involve a family member.

When you are first being assessed, your care team should ask about:

- How your behaviour has changed
- When changes started and how long they have been going on
- What you are thinking, feeling, or experiencing
- Symptoms of depression and/or anxiety
- Your day-to-day activities and whether they have changed
- Your ability to concentrate or pay attention
- Whether you have used or are currently using drugs like cannabis or alcohol
- Past traumatic or violent experiences
- Your family history
- Your childhood
- Your marks and school performance
- Your friendships
- Whether you have thought about suicide or have made a plan to take your own life

A doctor or nurse practitioner should send you for blood tests to check how well your kidneys, liver, and thyroid are functioning to rule out other explanations for the things you are feeling and experiencing. A doctor or psychologist might also test your memory, reasoning, and problem-solving ability to see how your brain is functioning.

WHAT ARE ASSESSMENTS LIKE?

TIPS FOR GETTING THE MOST OUT OF YOUR APPOINTMENTS WITH SERVICE PROVIDERS:

1. Take someone with you.
2. Take notes or have someone take notes for you.
3. Ask questions. Ask as many times as you need to get an answer you understand.
4. Be honest, so your doctor understands everything you are experiencing, and you get the help you need.
Schizophrenia involves a range of problems with thinking (cognition), behaviour or emotions. Signs and symptoms may vary, but usually involve delusions, hallucinations or disorganized speech, and reflect an impaired ability to function. Symptoms may include:

**Delusions.** These are false beliefs that are not based in reality. For example, you think that you’re being harmed or harassed; certain gestures or comments are directed at you; you have exceptional ability or fame; another person is in love with you; or a major catastrophe is about to occur. Delusions occur in most people with schizophrenia.

**Hallucinations.** These usually involve seeing or hearing things that don’t exist. Yet for the person with schizophrenia, they have the full force and impact of a normal experience. Hallucinations can be in any of the senses, but hearing voices is the most common hallucination.

**Disorganized thinking (speech).** Disorganized thinking is inferred from disorganized speech. Effective communication can be impaired, and answers to questions may be partially or completely unrelated. Rarely, speech may include putting together meaningless words that can’t be understood, sometimes known as word salad.

**Extremely disorganized or abnormal motor behaviour.** This may show in a number of ways, from childlike silliness to unpredictable agitation. Behaviour isn’t focused on a goal, so it’s hard to do tasks. Behaviour can include resistance to instructions, inappropriate or bizarre posture, a complete lack of response, or useless and excessive movement.

**Negative symptoms.** This refers to reduced or lack of ability to function as you generally would. For example, the person may neglect personal hygiene or appear to lack emotion (doesn’t make eye contact, doesn’t change facial expressions or speaks in a monotone). Also, the person may have lost interest in everyday activities, socially withdraw or lack the ability to experience pleasure.

*Source: https://www.mayoclinic.org/diseases-conditions/schizophrenia/symptoms-causes/syc-20354443*
YOUR RIGHTS AND CONSENT TO TREATMENT

1. You have a right to privacy. Your care team cannot discuss your medical issues with anyone else without your permission, unless you are in danger of hurting yourself or someone else. This also includes extreme deterioration of health that puts your life at risk. You can specify in a release of information form what can be discussed and what cannot, if you choose to have one.

2. To help you, your care team may need information that family or friends can provide. It’s important to give your consent for the team to discuss your illness with someone you trust is important.

3. You have the right to know what is going on, and to make decisions about your care. It often helps to share that decision-making with trusted friends or family and your care team. You can use tools such as the Wellness Recovery Action Plan® to prepare for your wellness needs and to identify your trusted supports. Advance planning can also be explored through the Advanced Directives in your province.

4. Your doctor or care team should tell you about your rights and let you know if there are any legal issues involved.

5. Under your province or territory’s Mental Health Act, you can be assessed and/or treated without your consent if you might harm yourself or someone else, or you suffer substantial mental or physical deterioration. This is called involuntary assessment and treatment. If the risks are serious enough, you may be hospitalized. A member of your care team should explain your rights and give you a written document about them. A formal process is required for involuntary treatment which a family member or friend may initiate. If you don’t get information advising you of your rights, ask for it.

6. If you do receive involuntary treatment, you, your family, or your advocate have the right to ask the Mental Health Review Board to examine the decision and review your status. This involuntary treatment can only continue until you are no longer considered a risk to yourself or others. All of these procedures should be outlined in the information you receive. Mental Health Acts differ from province to province and territory to territory.

7. Involuntary admission is only used to ensure your safety or the safety of others.

8. Your right to privacy means you don’t have to tell your boss, your landlord, or anyone else that you have schizophrenia. You may find it helpful to speak with an advocate or a peer support worker to plan how, when, or if you will disclose your illness.
YOUR TREATMENT AND RECOVERY PLAN

Having a treatment and recovery plan designed just for you is important. There are different treatment options, and the best results come from a combination of medication, psychological treatment, and support services. A peer support worker can have “recovery conversations” with you to help you think about what would help you regain hope and satisfaction in life.

MEDICATION

Most people with schizophrenia need to take a type of medication called an “antipsychotic.” This is the general name for a group of prescription drugs that manage the symptoms of psychosis. These medications work particularly well for reducing hallucinations, delusions, and problems in thinking and planning. Antipsychotic medication is not addictive.

The medication prescribed for you will be based upon your unique cluster of symptoms. Your doctor should talk to you about side-effects, and the importance of taking your medication regularly.

Medications are available as once-a-day doses or injections taken once a week or once every three months. Many people find the long-acting injections (LAIs) more convenient. Also known as a “depot injection,” the injection is a slow-release, slow-acting form of your medication. It isn’t a different drug – it’s the same medication as the antipsychotic you would take in tablet or liquid form. It is administered by injection, and it is given in a carrier liquid that releases it slowly so it lasts a lot longer*. Anyone who has to take a daily pill knows that it can be tough to stay on schedule. But people with schizophrenia and other enduring forms of mental illness may have extra challenges in staying on their medication.

They sometimes don’t think they are sick, especially in the early stages of their illness. They may hear voices that persuade them not to take medication. They might stop as soon as their symptoms go away. Side effects of the medications can impact one’s quality of life. This is often the reason people refuse to take medication.

Your doctor will likely start you on a low dose of medication at first. The dose can be increased if necessary.

You may need regular blood tests to check the effects some medication may have on your weight and your cholesterol, and to make sure you don’t develop diabetes or cardiovascular problems. Your doctor or healthcare team should meet with you regularly, especially when you first start a new medication to make sure it’s working and that side-effects are at a minimum.

*Source: https://www.webmd.com/schizophrenia/schizophrenia-long-lasting-drugs#2
The following table lists antipsychotic medications currently approved by Health Canada and available in Canada as of September 6, 2018.*

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<th>Approved Dose Range</th>
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<td>Aripiprazole Oral</td>
<td>Abilify</td>
<td>10 mg – 30 mg / day</td>
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<tr>
<td>Aripiprazole IM LA</td>
<td>Abilify Maintaina</td>
<td>300 mg – 400 mg / 4 weeks</td>
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<tr>
<td>Asenapine</td>
<td>Saphris</td>
<td>10 mg – 20 mg / day</td>
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<tr>
<td>Brexipiprazole</td>
<td>Rexulti</td>
<td>2 mg – 4 mg / day</td>
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<td>Chlorpromazine</td>
<td>Generics</td>
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<td>Clozapine</td>
<td>Generic</td>
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<td>Flupentixol</td>
<td>Fluanxol</td>
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<td>Flavanxol Depot</td>
<td>20 mg – 40 mg / day</td>
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<td>Fluphenazine</td>
<td>Generics</td>
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<td>Modecate</td>
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<td>Zuclopenthixol decanoate IM LA</td>
<td>Clopixol Depot</td>
<td>100 mg – 400 mg / 2 – 4 weeks</td>
</tr>
</tbody>
</table>

*Source: https://hpr-rps.hres.ca/index.php?lang=en*
SIDE-EFFECTS

Medications have side-effects. Your care team will work with you to balance the benefits and the risks of any medication. If you notice side-effects, talk to your family doctor or your psychiatrist about them. They may switch you to a different medication or change the dosage.

Some common side-effects include:

- Weight gain which can be managed by becoming more active and by diet change
- Drowsiness which can be lessened by taking medications at night
- Constipation which may be managed by drinking more water and eating fibre-filled diets
- Dizziness and light-headedness which may occur after getting up from sitting or lying down
- High blood pressure and increased blood glucose levels which are important to monitor
- Sexual problems such as decreased libido, impaired arousal, and impaired orgasm
- Breast swelling and lactation (secretion) in women and men
- Tremors, stiffness, spasms, restlessness, or slow movements
- Dry mouth

If you are pregnant, or planning to have a child, talk to your family doctor about the medications you are taking as they may be unsafe for the unborn child. The doctor can discuss with you the possible risks to you if you don’t take your medication while pregnant.

ALCOHOL AND SUBSTANCE USE

Some people living with schizophrenia and/or other mental illnesses use or misuse street drugs or alcohol. Often people self-medicate to try to quiet the voices they hear, calm their disordered thoughts, deal with stress, or block out memories of traumatic experiences.

Check with your doctor about the use of alcohol while you are on your medication. Tell your doctor about other substance (street drugs) you are taking. Because the use of cannabis can trigger psychosis and interfere with your medication, it is wise to avoid using cannabis. It is very important that your doctor know about any addictions you may have to any substances. Use of substances can interfere with your mental health treatment. Mental illness and substance use or misuse must be treated at the same time, because both can negatively affect each other. With this knowledge your doctor may need to adjust your treatment plan.

Medication may or may not relieve all distressing symptoms, so support can be very helpful. Additional options that may be helpful to help with symptoms include cognitive behavioural treatment (CBT) or extra support through others who have found relief through strategies to self-manage hearing distressing voices.

TIPS FOR USING MEDICATION EFFECTIVELY:

1. Take your medication exactly as your doctor advises you to, at the same time and the same dose.
2. Don’t stop taking the medication without talking to your care team. If you think a medication is not working for you, ask if there are different ones you can try.
3. Stick with it. It may take time to find the right medication to help you, in combination with talk therapy, peer support groups, exercise, and other kinds of self-care.
MENTAL HEALTH AND SELF-CARE

Our mental health is not just how we feel and think. It is about building resiliency, bouncing back after problems and stress, and having a positive outlook on life. It includes good self-esteem and establishing a sense of identity and purpose. It is linked to our physical and spiritual health. Keeping physically active, eating well, and avoiding tobacco, alcohol, and drugs will have a positive impact on your mental health. Mental health also means having close relationships with people we care about and having a sense of purpose and meaning in our lives.

It helps to talk about who you are as a person, to identify your hopes and dreams, and to figure out how you can maintain relationships and friendships with other people. Discovering a purpose in life is both helpful and meaningful.

People in recovery often talk about a healthy spirituality or mindfulness that helps them maintain their mental health. Your mental health peer support group or peer support worker may be able to suggest activities and resources to help you take care of yourself.

We all have our ups and downs. To deal with daily challenges and to get the most out of life, we need to take care of our mental health.

HOW TO TAKE CARE OF YOUR MENTAL HEALTH:

- Accept who you are, your strengths and limitations
- Have a positive outlook on life, use humour, have fun, try something new
- Deal with problems effectively
- Build positive, meaningful relationships
- Stay connected to people you care about
- Take responsibility for yourself
- Set personal goals
- Ensure to schedule meaningful activities (volunteer, work, school...)
- Take good care of yourself, take breaks, enjoy hobbies
- Ask for help when you need it

TAKING GOOD CARE OF YOUR MENTAL HEALTH WILL HELP YOU TO

- Feel good about yourself
- Fulfill your wishes, dreams, hopes and goals
- Enjoy life more
- Enjoy better relationships
- Bounce back from difficult times
- Have more energy

No matter what's going on in your life or what you are dealing with, there are always things you can do to feel better. Small changes in the right direction can have a big impact. Remember, a person may have a mental illness and still maintain good mental health, resiliency, and a sense of well-being.
TALK THERAPY

Working with a psychologist or therapist, a process called “talk therapy”, is another important part of your recovery plan.

Finding a therapist that you trust and connect with is crucial. Your therapist should know about the latest mental health research, work from a recovery-focused perspective, be familiar with available resources, and work with you to help you stay hopeful about your recovery. You can also talk about any trauma or abuse that you may have experienced. Talk therapy helps to manage stress, thus reducing the risk of relapse.

THERE ARE SEVERAL DIFFERENT TYPES OF THERAPY THAT YOU MAY TRY, INCLUDING:

COGNITIVE BEHAVIOURAL THERAPY
Cognitive Behavioural Therapy (CBT) focuses on changing the way we think and act. Often we have developed negative thinking patterns which can influence our actions. CBT is usually short-term and can help you:
- Problem-solve
- Reduce anxiety and depression
- Decrease alcohol and/or drug use
- Overcome a sense of hopelessness or suicidal thoughts

DIALECTICAL BEHAVIOURAL THERAPY
Dialectical behaviour therapy (DBT) is a type of cognitive behavioural therapy. Its main goals are to teach people how to live in the moment, cope healthily with stress, regulate emotions, and improve relationships with others. The strategies of DBT can help a person with schizophrenia deal effectively with hallucinations and delusions. An individual learns to identify triggers in order to prevent or minimize psychotic episodes.

COGNITIVE REMEDIATION THERAPY
Cognitive Remediation Therapy (CRT) is a way of improving executive functioning skills like memory, concentration and organization. These programs can help if you are having trouble thinking and reasoning your way through decisions.

ACCEPTANCE & COMMITMENT THERAPY
Acceptance and Commitment Therapy (ACT) is a type of group therapy that helps you accept the difficulties that come with life. ACT is a form of mindfulness-based therapy, based on the principle that you can attain greater well-being by overcoming negative thoughts and feelings. ACT looks at your character traits and behaviour to help you reduce the ways you avoid unpleasant realities. ACT also addresses your commitment to making changes, and learning ways to stick to your goals.
LIVING WELL IN YOUR COMMUNITY

A big part of on-going recovery and relapse prevention is to create a meaningful life in your community. That’s why community mental health supports and services are important. Connecting to people and services that can help you meet your goals and live a mentally healthy life is part of your recovery journey.

Organizations such as the Schizophrenia Society of Canada, the Canadian Mental Health Association, the Mood Disorders Society of Canada, and other mental health organizations can assist you in finding local resources. You can find other community supports through your high school, university and college campuses, or within faith-based organizations.

These organizations often provide one-on-one peer support for people with lived experience of mental illness and mental health problems, and their family members. Many offer educational workshops on mental illness, recovery, mental health and well-being resiliency, mindfulness, spirituality, and talk therapies. These organizations also assist communities in advocating for improved mental health promotion and prevention as well as enhanced mental health services. They can help you live with and manage your mental health problem and advocate with you for what you need.

**There are many supports and services in the community:**
- Housing support
- Mental health workers
- Peer support workers
- Social workers
- Supported employment opportunities
- Educational supports
- Nutrition and exercise programs
- Disability organizations
- Peer support groups for you, and for your family, led by people with lived experience.
- Group therapy
- Financial management
- Mental health advocates
- Recovery and well-being colleges

Often, your care team will know about these services and can help you connect with them. Mental health and disability organizations and advocates have the most up-to-date information about programs available to help you experience a better, healthier life even though you may still experience symptoms of your illness.

There are many mental health apps available to smartphone users. One smart phone app is called “Booster Buddy”, which is a gamified app for individualized support. It was developed in Victoria, BC, Canada with a youth team.
HOSPITALIZATION
WHEN NEEDED

Most people with schizophrenia do not need to spend a long time in the hospital. After hospitalization, your continued treatment and recovery will happen in the community and will include doctor visits or outpatient clinics and peer support group meetings. Sometimes mental health workers might also visit you at home. Some communities have teams of mental health service providers, and a team member might visit or call each day to see if you need help. These are known as PACT (Program for Assertive Community Treatment) or ACT (Assertive Community Treatment) teams. If you are having a crisis, your healthcare team can support you. You might need a short stay in a hospital or crisis response centre if you:

- Are in danger of harming yourself or someone else
- Are concerned about your symptoms becoming more serious and leading to a possible relapse
- Are experiencing a problem with street drugs or alcohol
- Need a break from life stressors that are triggering your symptoms
- Require a treatment that you can only receive in hospital

You can develop a Wellness Recovery Action Plan® (WRAP®) to help you make decisions and share with your support team what your needs may be.

Hospital stays may feel scary. A peer support worker may be available for you to talk to. You have the right to have the healthcare workers explain what they are doing in ways you can understand. You also have the right to have any treatment plan outlined for you. You can apply to the Mental Health Review Board to review your case if you object to the way you are being treated. Many hospitals also have a patient advocate or patient representative you can talk to about any concerns. If you feel your rights have been violated, you can contact an Ombudsperson/Ombudsman about your complaint.

While controversial, Electroconvulsive Therapy (ECT) may be recommended as a treatment if your symptoms are severe and medications or other treatments have not worked. Generally speaking, ECT is safe and effective. ECT causes changes in brain chemistry that can relieve the symptoms of different mental illnesses, including schizophrenia.

If your doctor recommends ECT, he or she will explain how it works and will provide you with information about how you will feel afterward, and about your rights to accept or refuse the treatment.
YOUR PRIVACY

Your health information is private. The team of professionals working to support you will not share information about you without your consent, if you are legally an adult. They will keep that information confidential unless they need to share something with other professionals to keep you or someone else safe.

If someone in your health care needs to share information, they will ask you to sign a consent form and tell you why they want you to give them permission. You can detail how much information is shared within your consent form.

It is important for family, friends, and caregivers to learn enough about your health and your situation to be able to support you and your recovery. Health care providers do not have to tell your family, partner or caregiver everything you have told them. They will only share the information relevant to helping you stay safe and supporting your recovery.

You can choose the people who receive information you want to share. Some people even create a trusted circle of people who become part of their care teams. You can include friends in your trusted circle if you do not feel comfortable sharing with family members. It would help your doctor to know why you feel uncomfortable including a family member in your trusted circle. Again, a Wellness Recovery Action Plan® (WRAP®) may be helpful in creating your own personalized and updatable plan which you can share in whole or part with your key supporters.

KNOWING THE HEALTHCARE PROFESSIONALS ON YOUR TEAM

Your trusted circle should include a team of health care professionals you feel comfortable talking to and working with to take care of all aspects of your health. A psychiatrist may lead a team that includes some of these helpers, who should be culturally competent and safe, meaning they understand your cultural and spiritual needs and practices. Your team should prepare a written treatment or care plan and give you and all the team members a copy.

YOUR TEAM MEMBERS MAY INCLUDE YOUR:

- Family doctor
- Psychiatrist – a medical doctor who specializes in diagnosing and treating people with schizophrenia and other mental illnesses
- Psychologist – a trained specialist who can counsel you and provide treatment but cannot prescribe medication
- Mental health worker
- Social worker
- Peer support worker
- Occupational therapist
- Spiritual healthcare provider (minister, rabbi, imam, elder, pastor, etc.)
HEALTH AND MEDICATION TIPS

A few things that will help you get better:

- Get to know your healthcare team and what their roles are. Have their contact information available and ask who you should call first when you have a problem.
- Ask for help in making a recovery plan and a relapse plan. Keep a copy for yourself. Share it with someone you trust.
- Create a safety plan of what to do if you are feeling worse or thinking about hurting yourself or someone else. This is sometimes called an Advanced Directive.
- Give your medication time to work. You may need to try different medications to find out which one is best for you.
- Avoid drinking alcohol or using street drugs while you’re taking your medication because it interferes with the efficacy of the medication.
- Tell your doctor what other medications you are taking.
- Ask your pharmacist questions about your medication.
- See your family doctor regularly to monitor your physical health and address any side-effects of your medication.

As with any illness, it’s normal to consider stopping or reducing your medication because you feel better, or you feel the medication is not working for you, or because of the side-effects. Keep in mind that adjusting your medication on your own can bring on a relapse of symptoms. It is important to talk with your doctor about medication adjustments. If you change your smoking habits (more or less or quit), you should also advise your medical team.

TAKING CARE OF YOURSELF

Healthy eating, regular exercise, plenty of sleep, and stress management are all essential to your on-going health, well-being, and recovery.

Limit substance use. Using substances, including alcohol and tobacco, can all interfere with the ability of your medications to work and can make it even harder for you to work towards recovery. Some drugs, including cannabis, methamphetamine and cocaine, can spark a psychotic episode or worsen your symptoms. Research is demonstrating that the frequency of use, as well as the potency of the THC in cannabis you use, and the younger you are when you initiate use, the greater the risk for triggering psychosis or relapse. Check out www.cannabisandpsychosis.ca for more information about the link between cannabis use and psychosis.

Reduce or quit smoking. If you smoke, one of the best things that you can do to improve your health is to stop smoking cigarettes. People living with schizophrenia have high rates of respiratory problems due to long-term smoking. Ask your psychiatrist or family doctor about medications and supports to help you stop smoking. If you stop smoking be sure to advise your medical team as your medication doses may need to be reviewed.

Reduce your caffeine intake to help reduce anxiety, to improve sleep, and to balance brain chemistry.

Practice yoga, mindfulness, meditation, and other approaches to physical and spiritual wellness practices to help maintain your mental health.

Create a routine. Developing a daily routine can help you feel more in control of everything, cope with change, form healthy habits, and reduce your stress levels. Ensuring regular meaningful activity in your week has been shown to enhance recovery.

Stay connected and spend time with optimistic, supportive friends and family who can help you feel more hopeful and help ensure you are doing well.
**MANAGING A CRISIS**

If you are having suicidal thoughts, or find yourself making a plan about how to take your own life, or are thinking about hurting someone else, you need immediate help. These thoughts are usually temporary, but you need help to make sure you don’t act on them.

**Tell someone.** It could be your doctor, a mental health worker, a peer support worker, a spiritual advisor, a friend, or family member in your trusted circle.

**Develop a plan** on how to stay safe. If you have a safety plan, look it over to remind yourself of the steps you laid out in advance.

**Let people you trust know** that you need to spend time with them, so you are not alone.

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**FINANCIAL AND EDUCATIONAL SUPPORT**

If you have schizophrenia, it might be hard to stay in a full-time job or go to school. You may qualify for special disability supports if you are in school. Talk to your guidance counsellors or the disability support centre at your community college or university. These supports can help you get extra time for exams and assignments, as well as suggest technology that can help you.

You may also qualify for the Disability Tax Credit and/or an income support program in your province or territory that will help you get a monthly support cheque. If you do get the Disability Tax Credit, you can also write to the Canada Revenue Agency and ask them to re-assess the taxes you have already filed (they can go back 10 years) to get a refund.

You will need a doctor, a psychologist, or another healthcare practitioner to help you fill out forms to qualify for these programs. Your mental health worker or a social worker on your team can help you set up an appointment and complete the forms.

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**SUPPORTIVE HOUSING**

Having a safe and affordable place to live and being around people who understand your illness can help you in your recovery. Some communities have set aside apartments or created integrated housing specifically for people with schizophrenia or other mental illnesses. There are Housing First programs in several parts of Canada.

A mental health worker can help you find an affordable apartment.

Contact your local branch of the Canadian Mental Health Association or your provincial Schizophrenia Society. They can help.

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**REMEMBER:**

You can get better and it is possible to live in recovery. We know more today about what helps people live with and live beyond the effects of schizophrenia than we ever have before. Schizophrenia is treatable.

Recovery is possible with the help of a caring community that works against stigma, discrimination, and social isolation. There is help — and you are not alone.

Hope changes everything!
The love and support of family and friends plays an important role in schizophrenia treatment. If you have a loved one with schizophrenia, you may be struggling with any number of difficult emotions, including fear, guilt, anger, and frustration. You may feel helpless in the face of your loved one’s symptoms, worried about the stigma of schizophrenia, or confused and embarrassed by strange behaviours. You may even be tempted to hide your loved one’s illness from others.

But it’s important to remember that a diagnosis of schizophrenia is not a life-sentence for your loved one. Recovery is possible, especially with your support. To help someone with schizophrenia, it’s crucial you:

- Acknowledge the illness and its difficulties
- Don’t buy into the myth that someone with schizophrenia can’t get better or live a full and meaningful life
- Do your best to help your loved one feel better and enjoy life
- Pay attention to your own needs
- Maintain your sense of humour and remain hopeful
- Learn about the recovery philosophy and recovery-oriented care

Dealing with a loved one’s schizophrenia can be challenging. The following strategies can help you guide your loved one on the road to recovery without losing sight of your own hopes and dreams.
SUPPORTING
A LOVED ONE

A diagnosis of schizophrenia can have a large impact not only on the affected individuals, but also on the people closest to them. Here are some suggestions to help you help the person you care about.

- **Join a recovery group for families and friends** that can help you deal with grief, loss, stigma, discrimination, anger, and frustration about navigating the mental health system. Realize you are on your own recovery journey.

- **Focus on the strengths of the person** you care about, including activities they like and their talents. Celebrate their successes, no matter how small, to send a message of hope.

- **Take a course or join a program** to learn about schizophrenia, other mental illnesses, and recovery like those offered by the Schizophrenia Society of Canada, the Canadian Mental Health Association, and the various Recovery and Well-being colleges being developed across Canada.

- **Learn to recognize early warning signs** of a psychotic episode and help your friend or family member make a plan about what to do, who they want to have with them, and what their needs and wants are.

- **Provide reassurance.** If they are experiencing hallucinations, delusions or paranoid thinking, reassure the person that you believe that they believe what they are experiencing, and that their feelings are real.

- **Make an appointment with a social worker** or mental health worker to learn how you can help your family member or friend.

- **Learn motivational techniques**, like motivational interviewing, to help your friend or family member do things for themselves.

- **Advocate on behalf of your friend or family member**, by going with them to healthcare appointments or to ask for services. Talk with them about this valuable role you can play. If they are unwell, gently remind them that they agreed to let you help.

- **Do not argue with “the illness.”** Empathic listening and offering one’s listening ear can help de-escalate the situation.

- **Join their “circle of trust”** and consider making that a formal association of people who are committed to your friend or family member’s well-being throughout their life.

- **Visit regularly** when your family member or friend with a mental illness is in the hospital, and after they are discharged. That period can be a particularly lonely and difficult time and it’s an opportunity for you to demonstrate your support, understanding, love, and kindness.

- **Accompany your friend or family member** on a walk or another physical activity regularly.

- **Learn how to be a recovery focused family.** Family psychosocial education helps your family communicate and understand what it’s like to live with schizophrenia and how to support recovery. Sometimes it’s easier to talk about your feelings with someone who is not too close to the situation. Trained counsellors or group leaders can help you and your family, partner, or friends solve problems together. Meaningful, respectful family involvement reduces relapse.

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Supporting someone with any type of serious illness can be challenging. Here are some additional ways to help and support a friend or loved one who is living with psychosis:

- **Know the signs and symptoms of psychosis** and how it presents itself to your family member or friend specifically. No two people are the same.

- **Get your friend into treatment** and encourage them to stay in touch with their circle of care team. This can be tough. Sometimes people may resist or not want to continue with medication or other treatment strategies. The best you can do is encourage them and be supportive.

- **Give them space.** Yes, you want to help your friend, but hovering over them, constantly checking on them and not allowing them to live their life can cause stress, and stress can cause relapse. Part of recovery is learning how to live life and manage mental illness independently.

- **Have realistic goals.** While your friend is in treatment and deals with psychosis, they may need to step back a bit from school or work.

- **Remember that their beliefs or hallucinations seem very real to them.** Trying to apply logic to things they are saying, thinking or doing may not work when someone is having delusions or hallucinations.

- **Stay calm with your friend** if they are experiencing symptoms of psychosis. Tell them that you acknowledge that everyone has the right to see things their own way.

- **Be respectful, supportive and kind** when supporting your friend, but don’t be afraid to set personal boundaries for yourself. You do not have to tolerate dangerous or inappropriate behaviour.

- **Find support.** Check to see if there are any support groups in your area for your friend and/or yourself.

- **Visit when possible.** If your friend is in the hospital, go and visit them if you are able. The hospital may be scary and overwhelming for them, and a friendly face can help. Ask about visitor rules first.

- **Help your friend to avoid triggers** like substances or situations that can cause them to relapse or feel unwell.

- **Help with simple things.** Know that your friend may need help or support with things that might seem simple to you. The loss of concentration and clear thinking can be hard to adjust to for someone living with psychosis.

- **Remember that treatment is a process.** Medications can cause side effects and may need to be changed and adjusted. Be aware of this and try to be supportive.

- **Ask your friend how else you can help.** It may be as easy as just providing a distraction, asking them to do simple, relaxing things with you (like hanging out, watching a movie etc.) or just listening to them without judgement.

- **Set some boundaries for yourself,** and take care. You can’t help someone if you’re feeling overwhelmed yourself.
KEEP IN MIND:

CAREGIVER SUPPORT

If you are a caregiver for someone living with schizophrenia, it can be exhausting, both emotionally and physically. At times, you might feel trapped or depressed. Helping yourself to stay well is important for you and your friend or family member. It’s important to “put your own oxygen mask on first” so you are strong enough to help someone else.

1. Join a peer support or family/friend group for caregivers of people living with mental illness. You will be able to talk about your circumstances and your emotions with people who understand what you are experiencing.

2. Make your own doctor and your support system aware of what you are going through, so they can help you.

3. Seek reliable information and support, including from the Schizophrenia Society of Canada. You’ll find many resources, including helpful videos about peoples lived experience with schizophrenia, supporting a loved one and providing treatment.

4. Take Mental Health First Aid. MHFA is a basic 12-hour training course delivered in four modules of three hours each. Participants will learn how to provide initial help to people who are showing signs of a mental health problem or experiencing a mental health crisis. MHFA is offered by many branches of the Canadian Mental Health Association.

5. Enroll in Applied Suicide Intervention Skills Training (ASIST) which can help you respond to someone who is experiencing suicidal ideation.

6. Do NOT argue with “the illness” or try to talk people out of their delusions or hallucinations. Instead, acknowledge and talk about the feelings associated with delusions and hallucinations.

7. Learn de-escalation techniques by mirroring emotions and active listening to help calm the person. While not agreeing with the content of hallucinations or delusions, research has demonstrated that de-escalation techniques utilized by family and friends can have a positive effect on the person.

8. Don’t remind them to take their medication all the time. Instead, help your friend or family member set up a plan and a routine, including reminders on an app to take their medication. Check in periodically about how the routine is going. Some smart apps can be helpful to provide medication reminders and track adherence.
SUPPORTING SOMEONE DURING AN EMERGENCY

If your friend or family member with schizophrenia is experiencing a crisis, and you recognize the signs of a psychotic episode, you can help:

• Mirror the feelings they are experiencing – repeat the way you think they are feeling and reassure them that their feelings are real. This helps to de-escalate your friend or family member’s anxiety and, can help calm them down.

• Let them know you believe that they believe the hallucination or delusion they are describing or recounting to you. But do not say you believe the hallucination or delusion.

• Get help right away if your friend or family member is disoriented and does not know who they are, doesn't recognize you, or doesn’t know where they are, is confused, or is hearing or seeing things that are not real.

• Try to get your friend or family member to an emergency room if they are talking about taking their life or someone else’s and if they have made a plan to do that. Let the person know you will go with them and make sure they are safe.

• Call a mobile crisis team or the police if you are afraid for their safety or the safety of others. When you call, stress that this is a mental health issue. Some police services have trained officers who can de-escalate the situation.
OTHER RESOURCES:

Here are links to other online resources that you might find helpful:

EARLY PSYCHOSIS INTERVENTION

The Canadian Consortium for Early Intervention in Psychosis has resources for youth and family members.

The Centre for Addiction and Mental Health has developed a resource: First Episode Psychosis: An Information Guide

British Columbia Early Psychosis Intervention has developed a series of resources on recognizing symptoms of psychosis, getting help, and a toolkit that you and your mental health worker or therapist can use to help solve problems.

Psychosis 101 provides general information about psychosis.

The Early Psychosis Prevention and Intervention Centre (EPPIC) in Australia has some good information about psychosis and schizophrenia.

LIVING WITH SCHIZOPHRENIA

Schizophrenia.com is an internet community providing high-quality information, support and education to the family members, caregivers and individuals whose lives have been affected by schizophrenia.

The Manitoba Schizophrenia Society has produced Hope Changes Everything: A guide to recovery-oriented systems transformation.

The National Institute of Mental Health in the United States has also produced some excellent general information about schizophrenia.

The Centre for Addictions and Mental Health provides many resources on psychosis, schizophrenia, and recovery.

1. Schizophrenia: An Information Guide

2. Women and Psychosis: An Information Guide

Sane Australia has many great resources, including Three Optimistic Things About Schizophrenia

The Schizophrenia Society of Canada has produced a video Four Stories of Hope featuring people’s lived experiences of recovery.

INFORMATION FOR CAREGIVERS

Psycos has resources on the unique challenges of caring for someone with schizophrenia, as well as tips for ways that families and other caregivers can take care of themselves and their loved ones.

HelpGuide has produced a series of tips for Helping Someone with Schizophrenia.

The Mental Health Commission of Canada has created National Guidelines for a Comprehensive Services System to support family caregivers of adults with mental health problems and illnesses.

MEDICATION

Schizophrenia.com features up-to-date information about medication

The Schizophrenia Society of Canada has produced Your Recovery Journey, which includes resources and stories about how people with schizophrenia have used medication as a tool for recovery.

EMPLOYMENT

Mental Health Works has information on workplace accommodations to support employees who are living with mental health problems.

REMEMBER:

Neither online therapy courses nor apps replace the relationship with a psychiatrist and a mental health team. However, these sites may help supplement the treatment you are receiving:

For online therapy, try the following top cognitive behavioural therapy sites:

1. Cognitive Behavioural Therapy Online

2. Life Skills Online

3. CBT Training Online

4. MoodGYM Training Program

5. Online CBT for Anxiety

For a mobile app, try Sanvello, or Thought Diary, a cognitive behavioural therapy app.
FOR MORE INFORMATION, CONTACT:

The Schizophrenia Society of Canada and provincial schizophrenia societies.

The Canadian Mental Health Association which lists provincial divisions and local chapters.

The Mood Disorders Society of Canada which offers links to provincial resources.