Patient Reference Guide

Schizophrenia

Care in the Community for Adults
Quality standards outline what high-quality care looks like. They focus on conditions or topics where there are large variations in how care is delivered, or where there are gaps between the care provided in Ontario and the care patients should receive.

This guide addresses variations and gaps in care in Ontario that need attention when it comes to care in the community for people with schizophrenia. It is based on the best available evidence and was created in partnership with people with schizophrenia, their families, and health care professionals.

The quality standard, available on our website, contains more information. You can find it at hqontario.ca.

In this guide, we use the following terms:

**Care in the community:** Includes primary care, hospital outpatient care, rehabilitation, correctional facilities, and community supports and services.

**Caregiver:** Someone who provides unpaid care and support for you, such as family members, friends, or anyone else you identify.

**Family:** The people closest to you, including parents, a significant other, children, siblings, friends, or personal supports. You define who your family is and how they will be involved in your care.

**Health care professional:** The many types of people who may be part of your health care team, which may include:

- Psychiatrists
- Primary care providers, such as a family doctor or a nurse practitioner
- A nurse, occupational therapist, pharmacist, physiotherapist, psychologist, or social worker

**Recovery:** Living a satisfying and hopeful life, even when there may be ongoing symptoms of schizophrenia.
This guide is for people with schizophrenia, their families, and their caregivers. It can help you know what to ask for when receiving care in the community and to make sure you receive the highest-quality care.

Schizophrenia is a chronic mental health condition that usually begins in late adolescence or early adulthood. There is no cure for schizophrenia, but many people can “recover.” “Recovery” is a term commonly used by the mental health community. It means you are able to live a satisfying and hopeful life, even when you may be experiencing ongoing symptoms of your illness.

You and your family don’t have to do this alone. Your health care professional will want to help you live the best life you can, and to build a relationship of trust with you and your family. The more they know about you and your goals, the better they can help create a plan for treatment and recovery that meets your needs.

If you or someone you care about has schizophrenia and is receiving care in the community...

You can use this guide to work with your health care professional to develop a care plan that works for you, including access to culturally appropriate care. We encourage you to use this guide to ask informed questions about schizophrenia care, and to learn more about how you and your family can get the supports you need.

Care plans can be very different for each person, so it is important to work closely with your health care professional to create a care plan that works for you.

Here are some things to consider.
Who Will Provide My Care?

- Depending on where you live and your needs, you might have a health care team or one health care professional providing your care.

- A health care team is a group of health care providers who work together to care for you. Your care team may include doctors, nurses, social workers, occupational therapists, volunteers, peer support workers, or spiritual care providers.

If you do have a health care team, they should provide you with the name and contact information for the person who is coordinating, communicating, and providing your care on an ongoing basis. This includes when information about your care is being shared with other members of the health care team and between health care settings (such as between a hospital and your family doctor’s office).

What Is a Care Plan?

- A care plan is a written document between you and your health care professional that you agree to. It describes your goals, the care and services you will receive, and who will provide them. Your health care professional should work with you to update your care plan regularly, and your family or caregivers can be involved in making and updating the plan, if you agree.

- Your care plan should be informed by a thorough assessment of your physical and mental health. This will include questions about your medical history and what medications you are taking. It also should look at your social situation, your goals, how you are feeling, and how you are coping with the impact of symptoms on your daily life.

- As part of your regular appointments, your health care professional should assess you for health problems that are common in people with schizophrenia, such as diabetes, weight gain, heart disease, and lung disease. These assessments might result in changes to your care plan.
What Is a Community Treatment Order?

- A community treatment order is a legal order, issued by a physician, to provide a comprehensive plan for community-based treatment or care for a person with a serious mental illness who has had difficulties maintaining their mental health in the community.

- If you are on a community treatment order, your care plan and goals will be used to inform your community-based treatment plan, whenever possible.

What Could My Treatment Include?

- Your physician or nurse practitioner should offer both antipsychotic medication and nondrug interventions, as needed, to treat your symptoms.

- Depending on your needs, your health care professional may connect you with specialized services in the community. There are various options such as:
  - An early psychosis intervention program if you are experiencing schizophrenia for the first time. Psychosis is a treatable condition that affects your mind and can result in difficulty deciding what’s real and what’s not.
  - Something called “assertive community treatment.” This is a team of health care professionals working together to provide you with various services to meet your needs—such as medications, counselling, life skills, and housing and employment supports.
  - Something called “intensive case management.” This is similar to assertive community treatment, but in this instance a case manager is at the core of your supports, connecting you to services to meet your needs, such as medication support, mental health programs, and housing, employment, life skills, and justice services.

These services are designed to help you to live in the community, manage your symptoms, and reach your goals.
Antipsychotic Medication

- Antipsychotic medication reduces the intensity of psychotic symptoms, including hallucinations and delusions. Your health care professional should discuss with you the potential benefits, harms, and side effects of antipsychotic medication so that you can make informed decisions about your care together. If you have family or others involved in your care, they should also receive this information.

- Usually, a health care professional will offer one antipsychotic medication at a time. However, there might be times when they recommend more than one antipsychotic medication.

- If your symptoms don’t get better or you experience significant side effects when taking an antipsychotic medication, talk to your health care professional about switching to a different medication.

- You may want to take your antipsychotic medication as a long-acting injection so you don’t have to remember to take it every day. Your health care professional should talk with you early in your treatment about whether this would be a good option for you. Depending on the medication, you would get an injection every 2 weeks to every 3 months. Not all antipsychotic medications can be given as a long-acting injection.

- If you have tried at least two different antipsychotic medications and your symptoms continue to be distressing, talk with your health care professional about taking a medication called clozapine.

- If an antipsychotic medication works to make your symptoms better, you will likely need to keep taking it to prevent symptoms from recurring. Your health care professional should review your medication with you once a year to make sure it continues to work for you and to address any side effects.

Nondrug Interventions

- You should be offered nondrug interventions as part of your treatment, based on your needs. Two types are cognitive behavioural therapy and cognitive remediation.

- In cognitive behavioural therapy, you would talk with a therapist about your thoughts and beliefs and learn how they can affect the way you behave and deal with problems.

- In cognitive remediation, you would perform learning activities that help you improve your memory, concentration, and problem-solving skills.
How Can I Live Well With Schizophrenia?

- A healthy lifestyle can help improve your physical and mental health. Your health care professional should give you information about programs that help you exercise and eat healthy foods.

- Alcohol and drugs may make your schizophrenia symptoms worse and make your treatment less effective. Your health care professional should ask if you use alcohol and drugs and offer you treatment (if you need it) to help you stop using them.

- Quitting or cutting down on smoking can help improve your physical and mental health. Your health care professional should talk with you about ways to stop smoking or smoke less.

- It’s easier to focus on your recovery when you don’t have to worry about having somewhere to live. Your health care professional should connect you with services that can help you find a safe, affordable, stable place to live, as well as support services (such as medication management, income supports, meal preparation, assertive community treatment or case management, and recreational and support activities), if you need them.

- Your health care professional should talk with you about programs that could help you to achieve your goals for work and education.

How Can I Learn More About Schizophrenia?

- Your health care professional should give you information to help you learn about schizophrenia and your treatment options to manage your condition so you can be actively involved in developing your care plan. You should also be given information about support services and groups that are available in your community and online.
I’m a Family Member—What Can I Do to Help?

• This guide was created with families in mind, too, to give you the information you need to ask informed questions of your family member’s health care professionals. Families can play a vital role in supporting a person’s recovery, promoting their well-being, and providing care.

• If you are a family member of someone who has schizophrenia, the health care professionals should give you opportunities to learn about schizophrenia and to get support if you need it. This is important so you can help your family member while also looking after your own needs.

Everybody is different, and some options may not apply in your situation. If you have questions about your care, it is important to speak with your health care professional.
Looking for More Information?

Please contact us at qualitystandards@hqontario.ca or 1-866-623-6868 if you have any questions or feedback about this patient reference guide.

The quality standard, available on our website, contains more information. You can find it at hqontario.ca.

About Health Quality Ontario

Health Quality Ontario is the provincial advisor on the quality of health care. We are motivated by a single-minded purpose: Better health for all Ontarians.

Our quality standards are concise sets of statements outlining what quality care looks like for conditions or topics where there are large variations in how care is delivered, or where there are gaps between the care provided in Ontario and the care patients should receive. They are based on the best available evidence and are developed in collaboration with clinical experts from across the province, and patients and caregivers with lived experience with the topic being discussed.

For more information about Health Quality Ontario and our quality standards, visit hqontario.ca.