# Schizophrenia

A guide for adults with schizophrenia receiving care in the community 2023 update





Ontario Health is committed to improving the quality of health care in the province in partnership with patients, health care professionals, and other organizations.

To do that, Ontario Health develops quality standards. These are documents that outline what high-quality care looks like for conditions or processes where there are large differences in how care is delivered, or where there are gaps between the care provided in Ontario and the care patients should receive. These quality standards set out important steps to improve care. They are based on current evidence and input from an expert committee that includes patients, caregivers, health care professionals, and researchers.

This patient guide accompanies the quality standard on <u>schizophrenia</u> <u>care in the community for adults</u>. It outlines the top 15 areas where providers can take steps to improve care for people aged 18 years and older with a diagnosis of schizophrenia. The patient guide also includes suggestions on what to discuss with your health care providers, as well as links to helpful resources.

This guide was originally developed in 2018, and was revised in 2023 to reflect updates to the *Schizophrenia: Care in the Community for Adults* quality standard.

To learn more about high-quality hospital care for people with schizophrenia, please see Ontario Health's *Schizophrenia: Care for Adults in Hospitals* <u>quality standard and patient guide.</u>

If you are a family member or caregiver, this guide was created with you in mind, too, to give you the information you need to ask informed questions of your family member's health care professionals.

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.

Below is a summary of the top 15 areas to improve care in the community for people with schizophrenia.



# **Quality Statement 1: Care Plan and Comprehensive Assessment**

#### What the standard says

Adults with schizophrenia have a care plan that is regularly reviewed and updated, and that is informed by a comprehensive assessment.

#### What this means for you

- 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.
- 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.

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.





### Quality Statement 2: Physical Health Assessment

#### What the standard says

Adults with schizophrenia receive a physical health assessment on a regular basis.

#### What this means for you

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.



### **Quality Statement 3: Self-Management**

#### What the standard says

Adults with schizophrenia have access to information and education that supports the development of self-management skills.

#### What this means for you

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



# **Quality Statement 4: Family Education, Support, and Intervention**

#### What the standard says

Families of adults with schizophrenia are given ongoing education, support, and family intervention that is tailored to their needs and preferences.

#### What this means for you

- 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 professional 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.



# Quality Statement 5: Access to Community-Based Intensive Treatment Services

#### What the standard says

Adults with schizophrenia have timely access to community-based intensive treatment services based on their needs and preferences.

#### What this means for you

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



#### **Quality Statement 6: Housing**

#### What the standard says

Adults with schizophrenia have a safe, affordable, stable living environment that reflects their needs and preferences.

#### What this means for you

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.



### **Quality Statement 7: Antipsychotic Monotherapy**

#### What the standard says

Adults with schizophrenia are prescribed a single antipsychotic medication, whenever possible.

#### What this means for you

- 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.



# **Quality Statement 8: Treatment With Long-Acting Injectable Antipsychotic Medication**

#### What the standard says

Adults with schizophrenia are offered the option of a long-acting injectable antipsychotic medication.

#### What this means for you

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.



### **Quality Statement 9: Treatment With Clozapine**

#### What the standard says

Adults with schizophrenia whose symptoms have not responded to previous adequate trials of treatment with two different antipsychotic medications are offered clozapine.

#### What this means for you

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. Clozapene is taken by mouth.



## **Quality Statement 10: Continuation of Antipsychotic Medication**

#### What the standard says

Adults with schizophrenia whose symptoms have improved with antipsychotic medication are advised to continue their antipsychotic medication for the long term.

#### What this means for you

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.



# **Quality Statement 11: Cognitive Behavioural Therapy for Psychosis and Other Psychosocial Interventions**

#### What the standard says

Adults with schizophrenia are offered cognitive behavioural therapy for psychosis and other evidence-based psychosocial interventions, based on their needs.

#### What this means for you

- 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 health care professional 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 problemsolving skills.

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



# Quality Statement 12: Promoting Physical Activity and Healthy Eating

#### What the standard says

Adults with schizophrenia are offered readily accessible interventions that promote physical activity and healthy eating.

#### What this means for you

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.



## **Quality Statement 13: Promoting Smoking Cessation**

#### What the standard says

Adults with schizophrenia who smoke tobacco are offered pharmacological and nonpharmacological interventions to help them reduce or stop smoking tobacco.

#### What this means for you

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.



# **Quality Statement 14: Assessing and Treating Substance Use Disorder**

#### What the standard says

Adults with schizophrenia are asked about their substance use and, if appropriate, they are assessed for substance use disorder and offered treatment.

#### What this means for you

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.

To learn more about treatment for opioid use disorder and alcohol use disorder, please see Ontario Health's <u>Opioid Use Disorder</u> and <u>Problematic Alcohol Use and Alcohol Use Disorder</u> quality standards.





# **Quality Statement 15: Employment and Occupational Support**

#### What the standard says

Adults with schizophrenia who wish to find work or return to work are offered supported employment programs. Adults with schizophrenia who are not seeking paid work are supported in other occupational or educational activities, in accordance with their needs and preferences.

#### What this means for you

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

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.

Suggestions on what to discuss with your health care providers to help you receive high-quality care	
	Who will be involved in my care and what are their roles?
	What could my treatment include? (Consider discussing things like
	antipsychotic medication and nondrug interventions) What benefits and side effects should I expect from my medication? How will we manage side effects if they happen?
	How can I live well with schizophrenia? (Consider discussing things like healthy eating and exercise, addressing smoking and substance use, family involvement, and housing and employment)
	When and who should I call if don't feel better or my symptoms get worse?
	Where can I get more information and support?
	uggestions on what to share with your health care providers to help ou receive high-quality care
	Any concerns or questions you have about your condition and care plan
	Who you want to include in decisions about your care (like a family member, friend, or caregiver, if you agree)
	Questions about why you are taking a medication or how to take it
	, , ,
	people cannot afford medication and other people may experience side
	effects that cause them to stop taking medication)
	Whether you are in need of basic items—such as food or heat—for your health
_	and well-being
	Any other questions or concerns you might have



Early Psychosis Intervention Ontario Network (EPION) <u>help4psychosis.ca</u> This website provides a list of Ontario-based early psychosis intervention programs for people living with psychosis. It also provides education and support for families.

## Institute for Advances in Mental Health (IAM) One-to-One Support Line bit.ly/3gwIHYh or call 1-855-449-9949

At IAM, a support line is available via telephone or email for people living chronic mental illness, including schizophrenia and psychosis, and their families. The support line can assist with a wide array of items, including housing, employment, crisis planning, addiction and substance use, and navigating and connecting with resources in the community. Education and workshops for families are also available on the website.

#### Schizophrenia Society of Canada schizophrenia.ca/education/

The "Education" section of this website provides reliable Canadian-based information, tools, and support for individuals living with mental illness and their families.

## Schizophrenia: An Information Guide by the Centre for Addiction and Mental Health <a href="bit.ly/3Fa4ak4">bit.ly/3Fa4ak4</a>

This guide is for people with schizophrenia, their families, and anyone else interested in better understanding this condition and what it is like to experience it. This guide aims to answer questions people may have about schizophrenia and can also help people know what questions to ask their heath care provider.

ConnexOntario connexontario.ca or call 1-866-531-2600 ConnexOntario provides 24/7 service information via telephone, text messaging, online chat, or email. It aims to link services and supports in the community to people with mental health and addictions conditions, including schizophrenia, and their families.

#### **Need more information?**

If you have any questions or feedback about this guide, please contact us at QualityStandards@OntarioHealth.ca or 1-877-280-8538 (TTY: 1-800-855-0511).