



MAKING CLOZARIL® a part of your treatment journey

Resources for you and your family



This brochure does not replace discussions with your doctor. You are strongly encouraged to ask your doctor any questions you may have.

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Organizations – national

Canadian Mental Health Association, National
250 Dundas Street West, Suite 401
Toronto, ON M5T 2Z5
Tel.: (416) 646-5557
Email: info@cmha.ca
www.cmha.ca

Schizophrenia Society of Canada
103 Harvest Drive
Steinbach, MB R5G 2C6
Tel.: (204) 223-9158
For assistance call: (204) 223-9158
Email: chris@schizophrenia.ca
www.schizophrenia.ca



HLS

HLS Therapeutics Inc.
10 Carlson Court, Suite 701
Etobicoke, Ontario M9W 6L2
www.hlstherapeutics.com



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Resources for you and your family

Organizations— provincial

Alberta

Schizophrenia Society of Alberta
Provincial Office
4809-48th Avenue
Red Deer, AB T4N 3T2
Tel.: (403) 986-9440
Fax: (403) 986-9442
Email: info@schizophrenia.ab.ca
www.schizophrenia.ab.ca

British Columbia

British Columbia Schizophrenia Society
Provincial Office
1100-1200 West 73rd Avenue
Vancouver, BC V6P 6G5
Tel.: (604) 270-7841 or 1-888-888-0029
Email: info@bcss.org
www.bcss.org

**BC Mental Health and Substance
Use Services**
www.bcmhsus.ca

Ontario

**Institute for Advancements in Mental
Health (IAM)**
95 King Street East, Suite 300
Toronto, ON M5C 1G4
Tel.: (416) 449-6830 or 1-800-449-6367
Fax: (416) 449-8434
https://iamentalhealth.ca

New Brunswick

Schizophrenia Society of New Brunswick
Mailing address: PO Box 562
Miramichi, NB E1V 3T7
Civic address: 1756 Water Street, Suite 103
Miramichi, NB E1N 1B5
Tel.: (506) 622-1595
Fax: (506) 352-0180
Email: ssnbmiramichi@gmail.com
www.schizophreniasociety.nb.ca

Newfoundland and Labrador

**Schizophrenia Society of Newfoundland
and Labrador**
Mental Health and Addiction Centre
Office: Room 1A 302, Lobby
St. John's, NL
Mail: 310 Prince Philip Drive
St. John's, NL A1B 3X5
Tel.: (709) 777-3335
Email: SSNL@nlhealthservices.ca
www.ssnl.ca

Nova Scotia

Hope For Mental Health*
*Formerly The Schizophrenia Society of Nova Scotia
PO Box 20006
R PO Spryfield
Halifax NS B3R 2K9
Tel.: (902) 333-2003
Email: Contact@hope4mentalhealth.ca
www.ssns.ca

Prince Edward Island

Schizophrenia Society of Prince Edward Island
Charlottetown, PE C1A 9N4
Tel.: (902) 368-5850
Email: schizophreiapei@pei.aibn.com

Quebec

Société québécoise de la schizophrénie (SQS)
7401, Hochelaga Street
Montreal, QC H1N 3M5
Tel.: (514) 251-4125 or 1-866-888-2323
Email: info@schizophrenie.qc.ca
www.schizophrenie.qc.ca

AMI-Quebec (anglophone association)
5800, Décarie Boulevard
Montreal, QC H3X 2J5
Tel.: (514) 486-1448 or 1-877-303-0264
Email: reception@amiquebec.org
www.amiquebec.org

CAP Santé Mentale
219-1990, Cyrille-Duquet Street
Quebec, QC G1N 4K8
Tel.: (418) 687-0474 or 1-800-323-0474
Support line: 1-855-272-7837
Email: info@capsantementale.ca

Saskatchewan

Schizophrenia Society of Saskatchewan
Provincial Office
1311 Saskatchewan Drive
Regina, SK S4P 0C9
Mailing address: Box 305 Station Main
Regina, SK S4P 3A1
Tel.: (306) 584-2620 or 1-877-584-2620
Fax: 1-306-584-0525
Email: info@schizophrenia.sk.ca
www.schizophrenia.sk.ca

Saskatoon Office
230 Ave R South, Room 219 and 220
Saskatoon, SK S7M 2Z1
Tel.: 1-306-374-2224
Email: info@schizophrenia.sk.ca

CLOZARIL®

and you

You were prescribed CLOZARIL® to treat your symptoms of schizophrenia.

CLOZARIL® is used in adults over 18 years of age who do not respond to, or who experience serious side effects with other drugs used for the same purpose.

CLOZARIL® belongs to a group of medicines called antipsychotic drugs. Antipsychotic medications affect dopamine and serotonin, chemicals found in the brain that enable communication between your nerve cells. Exactly how this medication works is not known. However, it seems that CLOZARIL® improves the balance of dopamine and serotonin in your body.

Blood monitoring

Regular blood testing must be done for as long as you are taking CLOZARIL®

Your doctor will do tests before you start treatment with CLOZARIL® and while you are taking it. These tests may include blood tests to monitor white blood cell count, blood sugar (glucose) and fat (lipid) levels in your body, and liver function. You may also have tests to monitor body weight as CLOZARIL® may cause you to gain weight.

Your body needs white blood cells to fight infection. In rare cases, CLOZARIL® can cause a life-threatening decrease of white blood cells. To ensure that your body has enough white blood cells, it is important to have regular blood testing done.

First 26 weeks:

Blood tests are required **every week** – the risk for developing a deficiency of white blood cells is highest during this time.

After 26 weeks:

You and your doctor will evaluate and determine if blood tests can be limited to **every 2 weeks** for the next 26 weeks.

After 1 year:

Following 52 weeks of continuous therapy, blood tests could be performed **every 4 weeks**, if your clinical condition permits it.



Regular blood testing is a condition for getting your medication



Pharmacists are part of your caregiver team and can only dispense your CLOZARIL® tablets if your blood testing is up to date. Make sure your blood tests are done regularly so your CLOZARIL® treatment is monitored.

Blood monitoring

CLOZARIL® is only available through a distribution system

CLOZARIL® is available only through a surveillance network called the CLOZARIL® Support and Assistance Network (CSAN®). Your doctor may choose to use **CSAN® Pronto®** — a device that can run blood tests using a blood sample collected from your fingertip during your regular doctor appointments.



If you have questions about CSAN® Pronto®, ask your doctor for more information.

Ways to help you remember to go for your blood tests

- Record all of your blood test dates on a calendar, in an agenda or in your phone.
- If your doctor requires that you go to the lab, try and go on the same day as your doctor's appointment – and make it the same day of the week each time.
- Have a friend or family member remind you about your blood test appointment.



Ask your doctor about the option of using CSAN® Pronto® for your blood collection.

Blood monitoring

Tell your doctor, nurse or pharmacist right away at the first signs of:



A cold



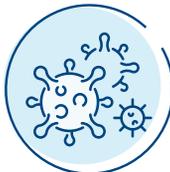
Flu-like symptoms



Fever



Sore throat



Any other signs of infection



Weakness

Your doctor may check your blood count and take further measures if necessary.

Do not stop taking CLOZARIL® suddenly as it may cause unwanted side effects. If you need to stop taking CLOZARIL®, discuss with your doctor how to slowly stop the medication.



Tips to help manage some side effects

Here are some tips to help you manage certain side effects you might have with CLOZARIL®:

Side effect	Helpful tips
 Constipation	<ul style="list-style-type: none">• Eat a high-fibre diet by including more fruits, vegetables and whole grain cereal• Drink plenty of water• Stay physically active• Be careful if you take other medications that can cause constipation• If you experience constipation, speak to your doctor, nurse or pharmacist
 Drowsiness/ feeling sleepy and light-headedness/ fainting	<ul style="list-style-type: none">• Avoid activities where a sudden loss of consciousness could cause risk to yourself or others (e.g., driving, using machines, swimming, climbing)
 Dizziness	<ul style="list-style-type: none">• CLOZARIL® may lower your blood pressure causing light-headedness or fainting• Rise slowly from sitting or lying position• Drink plenty of fluids

Do not stop taking your medication without talking to your doctor.

Management of side effects

Speak to your doctor or nurse if you experience these or any other side effects:

Side effect	Helpful tips
Bed wetting	<ul style="list-style-type: none"> • Avoid fluids before bedtime
Increased salivation	<ul style="list-style-type: none"> • At night, place a soft towel over your pillow • During the day, chew sugar-free gum
Weight gain	<ul style="list-style-type: none"> • Speak to your doctor • Talk to a dietitian about your eating habits* • Try to eat healthy food and avoid junk food • Add more exercise into your routine, like walking to your doctor's appointment or taking a bike ride in your neighbourhood*

Other possible side effects from using CLOZARIL® include:

- Headache
- Fever
- Confusion
- Blurred vision
- Falls and fractures
- Stuffy nose
- Dry mouth
- Trouble swallowing
- Sweating
- Heartburn
- Stomach pain
- Nausea
- Vomiting
- Diarrhea
- Urinating less
- Abnormal ejaculation (dry orgasm)
- Stuttering or slurred speech
- Obsessive thoughts and behaviours
- Having trouble reading
- Uncontrolled bending of the body to one side
- Feeling restless or not being able to stay still
- Muscle weakness, stiffness or pain
- Joint pain
- Swelling of the cheeks
- Rash on the body or face
- Itchiness
- Patches of skin discolouration

These are not all the possible side effects you may have when taking CLOZARIL®.

*It is recommended that you speak to a dietitian or doctor before changing your diet. Ask your doctor before starting an exercise program.

The role of your caregiver team



Your caregiver team is there to help make sure you receive the appropriate care throughout the course of your CLOZARIL® therapy. Don't forget that you also have a voice in your healthcare. It's important to ask questions and get to know your caregiver team and what each member can offer.

- **Your prescriber or psychiatrist** is responsible for the overall management of your condition and its progress. He or she will start your CLOZARIL® treatment.
- **Your nurse** is available to give guidance and support about any issues that affect your day-to-day living.
- **Your pharmacist** is responsible for dispensing CLOZARIL® and answering questions you might have about taking it. Please note that your pharmacist can only release CLOZARIL® if he or she has your blood test results or has confirmation that your test has been done.
- **Your social worker** may be a source of support to help you get the basic things you need or other services to help you function better. Your doctor or nurse may help you get in touch with a social worker.
- Services, such as **patient/family education and counselling**, may be offered within your community. Consult a member of your caregiver team or do an online search for the community health office nearest you. There are additional resources listed at the front of this booklet.
- **Your family and friends** can also offer valuable support.
- Your prescription of CLOZARIL® is available only through a distribution system that includes a team of healthcare professionals called the **CLOZARIL® Support and Assistance Network (CSAN®)** that will work together with your treatment team.

Remember: if there are any problems that make it difficult for you to follow your treatment, do not hesitate to discuss them with your doctor, nurse or pharmacist.



The role of your caregiver team

CLOZARIL® Support and Assistance Network (CSAN®)

CSAN® was established for healthcare professionals (like your doctor, pharmacist and nurse) to help manage the risks of adverse events with CLOZARIL®. CSAN® promotes communication between the clinic, laboratory and pharmacy to help ensure that when you take CLOZARIL® you get the appropriate care.

Keep this list of important telephone numbers handy in case you ever need to talk to someone

Physician name

Phone number

Pharmacist name

Phone number

Nursing unit

Phone number

Social worker

Phone number

Support group

Phone number

Other

Phone number

Other

Phone number

Answers to some frequently asked questions about CLOZARIL® therapy

How do I take CLOZARIL®?

Take CLOZARIL® exactly as your healthcare professional has told you to. If you think the dosage is too weak or too strong, you should discuss this matter with your doctor. To help you remember to take your medicine, try to take CLOZARIL® at the same time each day.

Treatment is usually started with one half of a 25 mg tablet once or twice on the first day; tablets can be taken whole or crushed. Your doctor will then gradually increase your dose depending on how severe your disease is and how well your body tolerates the medicine.

Why does my doctor need my consent?

The medication you are taking, clozapine, is produced by several different suppliers. Each supplier has a different monitoring system to ensure patient safety. Should your doctor and/or pharmacist (with the approval of your doctor) change the brand of clozapine you are taking, you will be transferred to a different monitoring system. Your doctor needs your consent so that your supplier can access your past white blood cell (WBC) count results from other suppliers and see if you have experienced a decrease in your WBC count in the past while taking clozapine.

Answers to some frequently asked questions about CLOZARIL® therapy

Why is personal information such as my initials, birth date, gender and health card number being collected and used for identification purposes?

This information will be collected and used for several reasons. Since this information is specific to you, it helps to ensure that your test results are not mixed up with those of another person on the same medication. Using this information also avoids the need to use your full name, which better protects your privacy.

Can my personal information be used for other purposes?

No. Your information will only be used to ensure that you are properly monitored while using any brand of clozapine.



What should I do if I plan to move or go on vacation?

If you are planning to move or go on vacation, tell your doctor as soon as possible. Your doctor will assist you in continuing your blood tests and medication.



How should I store my CLOZARIL®?

Your CLOZARIL® medication should be stored in its original container at room temperature (15 to 30°C), safely out of the reach and sight of children. Do not use after the expiry date shown on the bottle.

Answers to some frequently asked questions about CLOZARIL® therapy

What should I do if I miss taking a dose of CLOZARIL®?

If you miss a dose of CLOZARIL® and remember within 2 hours, take the dose right away. Otherwise, skip the missed dose and continue with your regular dosing schedule. Do not take double doses.

If you stop taking your dose for more than 2 days, do not start taking CLOZARIL® again. Contact your doctor for instructions on how to restart.

What should I do if I take too much CLOZARIL®?

If you think you, or a person you are caring for, have taken too much CLOZARIL®, contact a healthcare professional, hospital emergency department or regional poison control centre immediately, even if there are no symptoms.

Remember, do not stop taking CLOZARIL® without consulting your doctor.



What serious warnings and precautions should I know about CLOZARIL®?

CLOZARIL® can cause **severe neutropenia (agranulocytosis)**, a life-threatening decrease in your white blood cell count, which can lead to serious infection and death. Due to this risk, you must undergo regular blood testing if you are taking CLOZARIL®. Your doctor will enroll you in a monitoring system to make sure your blood tests are done regularly.

Heart problems, including myocarditis (inflammation of the heart muscle), pericarditis (inflammation of the lining of the heart), and cardiomyopathy (heart muscle disease) have occurred in people using CLOZARIL®. These reactions can be fatal. If you think you are experiencing a problem with your heart, get medical help right away.

There is a higher risk of death when medicines like CLOZARIL® are used in elderly patients with dementia. **CLOZARIL® is not for use in elderly patients with dementia.**

Answers to some frequently asked questions about CLOZARIL® therapy

What are some of the possible side effects of CLOZARIL®?

Tell your doctor or pharmacist as soon as possible if you get unexpected symptoms while you are using CLOZARIL®, even if you do not think that they are connected with the medicine.

Some side effects could be serious and should be reported to your doctor immediately. Others require that you ***stop taking CLOZARIL® and seek immediate emergency medical treatment.***

CLOZARIL® can cause serious side effects, including:

- Neuroleptic Malignant Syndrome (NMS) a condition that affects the nervous system
- Tardive Dyskinesia (TD) a condition that affects your movements that may be irreversible
- Severe skin reactions that can be life-threatening such as Stevens-Johnson syndrome (SJS), toxic epidermal necrolysis (TEN), drug reaction with eosinophilia and systemic symptoms (DRESS) and acute generalized exanthematous pustulosis (AGEP)

Serious side effects of CLOZARIL® and what to do about them

If you have any of the following rare or very rare serious side effects, talk to your healthcare professional if it is severe:

Rare:

- Liver disorder: yellowing of the skin or eyes, dark urine, abdominal pain, nausea, vomiting, loss of appetite

Very rare:

- Thrombocytosis (high blood platelets): headache, dizziness or light-headedness, chest pain, weakness, fainting, temporary vision change, numbness or tingling of the hands and feet

Serious side effects of CLOZARIL® and what to do about them

If you have any of the following very common, common, uncommon, rare or very rare serious side effects, talk to your healthcare professional:

Very common:

- New or worsening constipation

Common:

- Eosinophilia (increased numbers of certain white blood cells): abdominal pain, rash, weight loss, wheezing
- Hypotension (low blood pressure): dizziness, fainting, light-headedness, blurred vision, nausea, vomiting, fatigue (may occur when you go from lying or sitting to standing up)

Uncommon:

- Signs of infection: fever, severe chills, sore throat or mouth ulcers (sign of decreased white blood cells), nausea, vomiting, diarrhea, generally feeling unwell
- Tardive Dyskinesia (TD): muscle twitching or unusual/abnormal movement of the face or tongue or other parts of your body

Rare:

- Anemia (low level of red blood cells): fatigue, pale skin, headache, shortness of breath, dizziness, weakness, difficulty sleeping
- Diabetes (high sugar levels in the blood): excessive thirst or eating, dry mouth and passing large amounts of urine, unexplained weight loss, poor wound healing, infections
- Dysphagia: difficulty swallowing that can cause food or liquid to get into your lungs, problems with your esophagus
- Heart problems – myocarditis and/or pericarditis, cardiomyopathy (inflammation of the heart muscle and/or lining around the heart; heart muscle disease): abnormal heartbeat, chest pain that may resemble a heart attack, fatigue, fever and other signs of infection including headache, muscle aches, sore throat, diarrhea, or rashes, joint pain or swelling, leg swelling, shortness of breath

Serious side effects of CLOZARIL® and what to do about them

- Pancreatitis (inflammation of the pancreas): upper abdominal pain, fever, rapid heartbeat, nausea, vomiting, tenderness when touching the abdomen
- Signs of respiratory tract infection or pneumonia such as fever, coughing, difficulty breathing or wheezing
- Venous thromboembolism (blood clot in vein or artery): pain, tenderness or swelling in your arm or leg, skin that is red or warm, coldness, tingling or numbness, pale skin, muscle pain or spasms, weakness

Very rare:

- Fast and irregular heartbeat that persists when you are at rest, possibly with shortness of breath and swelling of the feet or legs
- Feeling sick, vomiting with severe/prolonged constipation
- Hyperglycemia (high blood sugar): confusion, nausea, vomiting, excessive thirst or eating, excessive urination, abdominal pain, headache, blurred vision, fatigue
- Increased liver enzymes in the blood: dark urine, fatigue, loss of appetite, yellowing of the skin or eyes
- Thrombocytopenia (low blood platelets): bruising or bleeding for longer than usual if you hurt yourself, fatigue and weakness

Serious side effects of CLOZARIL® and what to do about them

If you have any of the following common, uncommon or very rare serious side effects, stop taking CLOZARIL® and get immediate medical help:

Common:

- Neuroleptic Malignant Syndrome (NMS): pronounced muscle stiffness or inflexibility with high fever, rapid or irregular heartbeat, sweating, state of confusion or reduced consciousness
- Seizures: uncontrollable shaking with or without loss of consciousness
- Sudden weakness or numbness of the face, arms or legs and speech or vision problems

Uncommon:

- Myocardial infarction (heart attack): pressure or squeezing pain between the shoulder blades, in the chest, jaw, left arm or upper abdomen, shortness of breath, dizziness, fatigue, light-headedness, clammy skin, sweating, indigestion, anxiety, feeling faint and possible irregular heartbeat

Very rare:

- Allergic reaction: difficulty swallowing or breathing, wheezing, feeling sick to your stomach and throwing up, hives or rash, swelling of the face, lips, tongue or throat
- Nephritis (infection of the kidney): pelvic pain, pain or burning while urinating, frequent need to urinate, cloudy urine, blood or pus in the urine. Swelling especially face or legs
- Priapism: long-lasting (greater than 4 hours in duration) and usually painful erection of the penis
- Severe skin reactions: fever, severe rash, swollen lymph glands, flu-like feeling, blisters and peeling skin that may start in and around the mouth, nose, eyes and genitals and spread to other areas of the body, yellow skin or eyes, shortness of breath, dry cough, chest pain or discomfort, feeling thirsty, urinating less often, less urine

Other important information

What should I tell my doctor, nurse or pharmacist before using CLOZARIL®?

To help avoid side effects and ensure proper use, talk to your caregiver team about any health conditions or problems you may have, including if you:

- Have a fever or an infection
- Suffer from enlargement of the prostate
- Have a history of seizures (e.g., epilepsy)
- Have glaucoma (an eye condition)
- Have or have a family history of diabetes
- Have risk factors for developing blood clots, such as:
 - a family history of blood clots
 - being over the age of 65
 - smoking
 - being overweight
 - having a recent major surgery (such as hip or knee replacement)
 - not being able to move due to air travel or other reasons
 - taking oral birth control (“The Pill”)
- Have a history of colon disease or lower abdominal surgery
- You have stable pre-existing liver disorder
- Have heart disease or family history of abnormal conduction in the heart called “prolongation of the QT interval”
- Have low blood pressure
- Have a fast heart rate (tachycardia)
- Have had a stroke
- Have or have had lung disease
- Have Alzheimer's disease
- Have a condition called dementia
- Are pregnant or planning to become pregnant
- Are breast-feeding or planning to breast-feed; you should not breast-feed if you are taking CLOZARIL®
- Have a history of or are at risk of sleep apnea (a sleep disorder where your breathing is interrupted during sleep)
- Are at risk for aspiration pneumonia

Other important information

Tell your doctor or pharmacist the amount of coffee you drink and whether or not you smoke. A sudden change in these habits may alter the effect of CLOZARIL®.

You should also tell your doctor, nurse or pharmacist about all the medicines you take, including any drugs, vitamins, minerals, natural supplements or alternative medicines. The following may interact with CLOZARIL®: carbamazepine, phenytoin, omeprazole, rifampicin, erythromycin, cimetidine, valproic acid, medicines used to treat fungal infections (such as fluconazole, miconazole, clotrimazole), medicines use to treat depression (such as fluvoxamine, paroxetine, sertraline, fluoxetine, citalopram), ciprofloxacin, caffeine, tobacco smoking, narcotics, benzodiazepines, norepinephrine, epinephrine, MAO (monoamine oxidase) inhibitors, any drugs used to suppress bone marrow function, oral birth control medicines, medicines used to treat high blood pressure, medicines used to treat allergies, medicines used to treat psychotic disorders, medicines that cause constipation, medicines called “anticholinergic agents”, and alcohol.

Other important information

When should CLOZARIL® not be used?

Do not use CLOZARIL® if you:

- Are allergic to clozapine or any other ingredients in CLOZARIL®
- Are unable to undergo regular blood tests
- Have ever had a low number of white blood cells, except if this was following a treatment for cancer (chemotherapy)
- Have or have ever had bone marrow disease or are taking medication to suppress bone marrow function
- Have or have ever had a disease that affects your blood cell formation
- Have liver disease
- Have kidney disease or kidney failure
- Have heart problems such as myocarditis, pericarditis, cardiomyopathy, or heart failure
- Have severe nervous system depression
- Have uncontrolled seizures
- Have or have ever had a “paralytic ileus”, severe constipation, an obstruction of the bowel or any other condition which has affected your large bowel



Other important information



Are there any activities I should avoid?

Due to the risk of convulsions during CLOZARIL® treatment, you should avoid activities where a sudden loss of consciousness could cause risk to yourself or others (e.g., driving, using machines, swimming, climbing).



Can CLOZARIL® affect newborns?

In some cases, babies born to a mother taking CLOZARIL® during pregnancy may experience symptoms that sometimes resolve on their own, or in other cases may be severe and require the newborn to be hospitalized. Seek immediate emergency medical attention for your newborn if they have difficulty breathing, are overly sleepy, have muscle stiffness, floppy muscles (like a rag doll), are shaking or are having difficulty feeding.



Will CLOZARIL® make me sleepy?

CLOZARIL® can cause you to feel sleepy or dizzy and can affect your balance. This increases your risk of falling, which can cause fractures or other fall-related injuries, especially if you: take sedatives, drink alcohol, are elderly, or if you have a condition that causes weakness or frailty.



Who can I call if I have any questions or concerns?

If you have questions or concerns while you are taking CLOZARIL®, do not hesitate to contact your doctor or other members of your caregiver team. They will make sure that you get the support and care you need, when you need it.