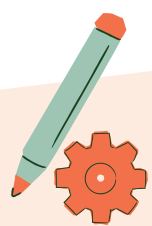


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# What to expect from clozapine

Clozapine is a medication used to treat psychotic spectrum disorders, including schizophrenia and schizoaffective disorder. It comes with specific requirements such as regular physical health tests, and understanding how this medication may affect you is important for your health and safety.

This resource guides you through what to expect when considering clozapine. While there can be side effects, many feel that the benefits outweigh the risks, as clozapine can help reduce symptoms of hallucinations and delusions, and for some, can improve quality of life and mental wellbeing.



**This resource was co-developed by young people who have experienced psychosis and taken antipsychotics including clozapine.**

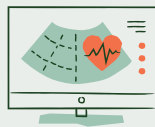


Clozapine can also be known under the brand names: Clozaril, Clopine  
There are different ways to take clozapine, including: tablets, orodispersible ('melt in your mouth') tablets, liquids.

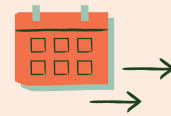
## Things to remember about clozapine



For many, clozapine has a positive impact on their lives.



You will need regular medical checks while taking clozapine.



It can take several weeks for the medication to have a positive effect, but you may experience side effects sooner.



Side effects include weight and appetite changes, sedation, sleepiness, constipation, saliva changes, feeling dizzy and fainting.



If you forget to take a dose, take it as soon as you remember – unless it's less than four hours until your next dose. If that's the case, skip the missed dose. Don't take two doses at once.



It's normal to have questions or mixed feelings about taking clozapine – you are not alone!

# Understanding clozapine side effects



One young person who used clozapine described it as having helped reduce their hallucinations and delusions, and said it was the first medication that truly worked for them. They referred to it as “life-changing”.

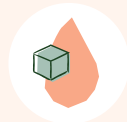
## Sedation (tiredness)



Clozapine can cause sleepiness, tiredness, or a heavy, jet-lagged feeling. This sedation often happens soon after taking it and usually improves over time, so it's important to time your doses to suit your routine.

If tiredness is impacting your day-to-day life, consider discussing supportive measures with your workplace or school.

## Higher blood sugar



Clozapine can affect how your body handles sugar, possibly raising blood sugar levels. This may increase appetite, cause weight gain, and raise the risk of diabetes over time.

If you already have diabetes, it's important to monitor your blood sugar with your glucose monitor and talk to your doctor about blood tests to check your levels. A healthy diet, regular exercise, and good lifestyle habits can help manage these issues.

## Constipation



It is common for those taking clozapine to experience constipation. You may be offered a laxative to help. Talk to your doctor if your bowel habits change, such as having fewer bowel movements in a week or increased difficulty going to the toilet.



## Feeling dizzy or faint



Some people may feel dizzy or faint when moving from lying down to sitting or standing. Counting to five before moving can help your body adjust. Avoid activities like driving or using stairs if you feel dizzy or faint.

## Saliva changes



Many people experience increased saliva production, leading to drooling or dribbling, particularly at night. Special pillows can help. This side effect often improves after the first few months, but can persist for some.

## Weight and appetite changes



Some people experience weight gain while taking clozapine more than other antipsychotics, usually within the first year. Weight changes vary by person, so it's hard to predict. If you're concerned about weight changes, it's best to talk to your doctor.

### Important reminder

While this information covers potential side effects of clozapine, everyone's experience is unique. If you're concerned or have questions, speak with your healthcare provider. They can offer personalised advice, help manage side effects, and ensure you have the support you need during treatment.





# Requirements for taking clozapine

There are rare but serious health risks with clozapine, so proactive health checks like blood tests and heart monitoring are necessary.

When starting clozapine, it's important to know:

1. Most people start clozapine in an in-patient unit (IPU) or through the hospital in the home program, which lasts for about a week.
2. You will need to undergo regular blood tests and will have your pulse, blood pressure, and temperature closely monitored.
3. You may also have tests to evaluate your heart health, such as an electrocardiogram (ECG) or echocardiogram (ultrasound).

## Regular blood tests are essential

While taking clozapine, you'll need weekly blood tests at first, then monthly once you've been taking it for 18 weeks.

These blood tests are vital because clozapine can sometimes cause a rare side effect called neutropenia or agranulocytosis, which affects white blood cells. Monitoring your count helps ensure your safety while taking clozapine.



## Your day-to-day on clozapine

### Most common impacts

#### Smoking

Let your doctor know if you change your smoking habits, because it can affect how much clozapine you need. If you smoke, you might need a higher dose. But if you switch to vaping or decide to quit, it could increase the risk of side effects.

#### Substance use

Clozapine blocks the effects of dopamine, which may result in a weaker "high" from some substances. However, increasing your dose of substances can be extremely dangerous and lead to serious health consequences.

#### Caffeine and caffeinated drinks

Drinking a lot of coffee, cola, or other caffeinated drinks can raise your clozapine levels, which isn't safe. If you suddenly cut back on caffeine, it might drop your clozapine levels too much. Talk to your doctor before making major changes to what you usually drink.

#### Alcohol

Combining alcohol with clozapine can increase feelings of drowsiness and unsteadiness, and it can be hard to predict how strongly alcohol will affect you.

#### Sleep

Clozapine can make you very sleepy, especially when you first start taking it or when your dose is increased. This often improves over time, so you may go to sleep earlier than usual and find it more difficult to wake up in the morning.



My friends and I would socialise in different ways to make sure it worked for everyone. Sometimes some of us stayed in while others went out, so we could all have fun and I wasn't left out when I felt tired from my medication. We talked openly about what we wanted to do, and my medication was just part of that conversation... - young person

### Other impacts to consider



#### Sex life

Clozapine may affect your sex drive, leading to changes in sexual desire or function. This is uncommon. If changes in sex drive are impacting your quality of life or relationships, speak with your doctor.

#### Sport

Most people play sports and exercise as normal while taking clozapine. It may affect your eyesight, coordination, and can cause dizziness or fatigue. Approach participating in sports with caution until you know how it affects you, and discuss concerns with your doctor and coach.

#### Socialising

Clozapine can make you feel drowsy, affecting social activities like going out with friends or partying at night. Consider taking clozapine at a different time, planning social events earlier in the day or switching to non-alcoholic drinks.

# Talking to friends and family about starting clozapine

Starting this conversation can feel tricky, so here are a few ways to begin:

Remember, you do not have to tell others the name of the medication or why you are taking it.

## Starting clozapine

**Person A:** I just wanted to mention that I've started a new medication. While I'm getting used to it, I might end up feeling really tired or have some different side effects.

**Person B:** What's the medication for?

**Person A:** It's for some health stuff I'm dealing with. I wanted to let you know because I might be tired when we hang out and might not be able to drive.

## Asking for help (medical)

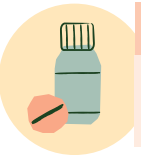
I'm feeling really unwell, and I think it might be because of the new medication. Can you help me get in touch with my doctor or call an ambulance?

## Asking for help (school and work)

I've started this new medication, and I'm feeling super tired and a bit out of it, so I'm having trouble concentrating. I need to take a break.

## What's the medication for?

I just wanted to mention that I've started a new medication. While I'm getting used to it, I might end up feeling really tired a lot or have some different side effects.



## Where can I get additional support?



Visit our **frequently asked questions online** to find out more about clozapine



### Peer support is available!

Peer support is when people give or receive support based on shared experiences of mental health concerns.



**Peer work resources on the Orygen website** provides additional information and resources about peer support



**Hearing Voices Support Group** is a mental health group that supports people to accept and live with their experiences.



**@psychosis\_understood** is a space made by young people who have experienced psychosis, with tips, stories, and resources about psychosis.



It is completely normal to have mixed feelings, questions and concerns about taking clozapine. Remember, you are not alone in this journey!

A big thank you to the young people who shared their lived experiences and helped design this resource!



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