Ibrutinib

Ibrutinib is a targeted medicine used to treat some people with chronic lymphocytic leukaemia (CLL).

Summary

- Ibrutinib is a targeted medicine used to treat chronic lymphocytic leukaemia (CLL).
- It comes as tablets that you take every day. The number of tablets you need to take should be printed on the named label on your medicine packaging.
- You will have regular blood tests to check how well your CLL is responding to ibrutinib.
- Your haematology team will also carry out tests to check how your body is coping with ibrutinib treatment.
- Side effects of ibrutinib are usually mild to moderate. Some people have very few side effects, whereas other people experience more severe side effects.
- Some side effects can be serious if they are not treated promptly. Contact your haematology team straight away or go to A&E if:
  - You think you might have an infection.
  - You have bleeding, such as blood in your poo or pee, nosebleeds, bleeding gums, heavy periods or bruising.
  - You are feeling confused, slurring your words or not making sense.
  - You have blue, grey, pale or blotchy skin, lips or tongue. This may look different on brown or black skin.
  - You have a rash that doesn’t fade when you roll a glass over it.
  - You have difficulty breathing, shortness of breath or breathing very fast.
  - Your heart rate is fast or uneven, or you have chest pain.
- Tell your haematology team if you get any other side effects. They may be able to prescribe medicine or suggest things to help.

Do not stop taking ibrutinib without discussing it with your haematology team.

Download our leaflet about ibrutinib

What is ibrutinib?

Ibrutinib is a targeted medicine that blocks a protein called BTK. This protein helps CLL cells to grow and multiply. Blocking it stops CLL cells from growing and dividing.

Ibrutinib is a common treatment for CLL that has been used successfully in the UK since 2017. The brand name for ibrutinib is Imbruvica.

> "Ibrutinib was the first of the ‘BTK inhibitor’ tablets approved to treat CLL. Many of our patients have benefited from treatment with this drug."
>
> — *Professor George Follows, Consultant Haematologist*

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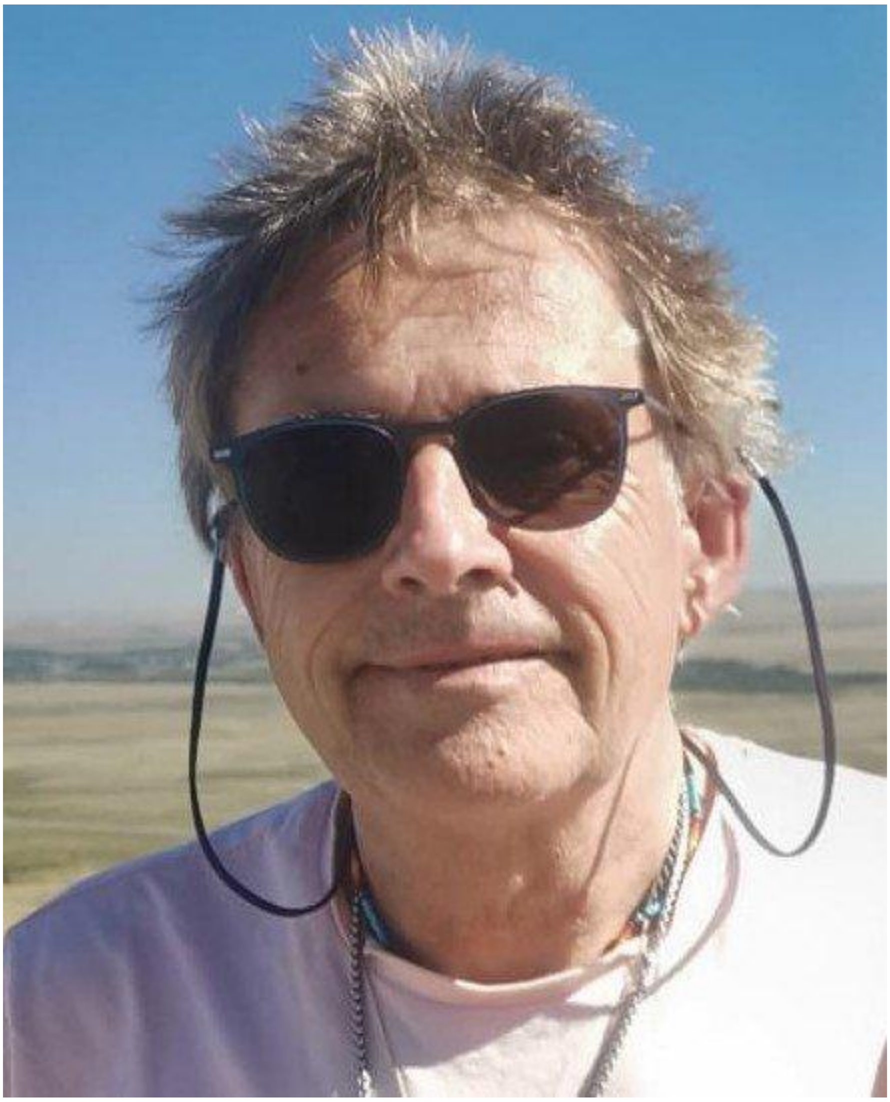
Who might take ibrutinib?

Ibrutinib is suitable for adults. Your haematology team might recommend it for you if:

- You have genetic changes in your CLL cells called *del17p* or *TP53* mutation or
- You have already had at least one previous treatment for CLL



"With CLL, you can have a good quality of life. I had traditional chemo and was then on ibrutinib for 6 years. I've travelled the world – from the Amazon to Asia. I did my bucket list and just kept going."

— *Steve, living with CLL since 2011*

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Before taking ibrutinib

Before starting your course of ibrutinib, your haematology team will carry out checks to ensure it is suitable for you. These include:

- Checks of your heart health

- Blood tests to check your white blood cell count, kidney function and liver function
- Blood tests to check whether you have any infections that could flare up during treatment, such as viral hepatitis
- Your team may recommend other tests, depending on your circumstances

Your haematology team may ask if there is any possibility you might be pregnant. Ibrutinib should not be taken during pregnancy.

Things to tell your haematology team

Some medicines, supplements and food may interact with ibrutinib. It is important to tell your haematology team about any medicines you are taking.

This includes prescribed medicines and medicines you have bought yourself without a prescription. Examples include:

- Herbal medicines such as St John's Wort
- Some medicines used to prevent blood clots, like warfarin
- Some antibiotic, antifungal and antiviral medicines
- Some medicines used to treat epilepsy
- Some medicines used to treat high blood pressure or heart problems
- Some medicines used to treat depression or obsessive-compulsive disorder
- Some cancer medicines
- Some anti-sickness medicines used alongside chemotherapy

Ibrutinib tablets contain lactose. Tell your haematology team if you are lactose intolerant.

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How to take ibrutinib

Ibrutinib comes as tablets you take by mouth.

- Swallow your ibrutinib tablets whole with a glass of water.
- Do not break or chew your tablets.
- Try to take ibrutinib at about the same time every day, if you can.
- Avoid grapefruit or bitter oranges (Seville oranges), including the fruit, fruit juice or supplements containing them. This is because they affect how much ibrutinib your body absorbs.

- Do not take supplements containing St John's Wort while taking ibrutinib. This is because it affects how much ibrutinib your body absorbs.
- If you also take medicines called digoxin or methotrexate, you should take these at least 6 hours before or after taking your ibrutinib.

If you miss a dose

If you forget to take ibrutinib:

- Take it as soon as you remember on the **same day**
- If it's the **next day** by the time you realise you forgot to take it:
    - Skip the missed dose
    - Take your next dose at the usual time

> **It is important not to take a double dose. If you've taken more ibrutinib than you should, talk to your doctor, nurse or pharmacist. Or go to the hospital immediately. Take your medicine and the leaflet from its box with you.**

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Dose

Ibrutinib comes as tablets containing 140mg, 280mg, 420mg or 560mg of ibrutinib. The number of tablets you need to take depends on the dose and strength of the tablets. This should be printed on the medicine packaging. If you are not sure, ask your doctor or nurse.

Most adults with CLL take 420mg of ibrutinib once a day. Your haematology team may suggest a higher or lower dose if needed. They will tell you what dose they recommend for you.

- If you have liver or kidney problems, you usually have a lower dose.
- If you are taking some other medicines, you might also have a lower dose.

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Where to take ibrutinib

You take ibrutinib at home (or anywhere you are staying). You do not have to go to hospital to take it.

> **You do not have to keep ibrutinib in the fridge. Keep it safe where children cannot see or reach it.**

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How long to take it for

> **Do not stop taking ibrutinib without discussing it with your haematology team.**

Most people carry on taking ibrutinib for as long as it is working. Your haematology team may suggest stopping ibrutinib and trying a different treatment if:

- It is not working well
- It stops working
- You are having side effects that are difficult to cope with
- Check-ups show it is affecting other parts of your body, like your heart, liver or kidneys
- You become pregnant

Rarely, stopping ibrutinib may lead to a ruptured spleen. Your haematology team will monitor this by feeling your tummy and doing ultrasound scans.

> **After stopping ibrutinib, tell your haematology team straight away if you get:**
>
> - **Pain in the left upper part of your tummy**
> - **Pain below your ribs on the left**

> - **Pain in the tip of your left shoulder**

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Monitoring

Your haematology team will monitor you to check how well ibrutinib is working and how well your body is coping with it.

- You'll have regular blood tests to check your blood cell counts
- You'll also have blood tests to check how well your liver and kidneys are working
- You'll have regular blood pressure checks
- Your doctor or nurse will examine you to check for heart or lung problems, signs of infection, and changes in your skin
- You may have other examinations and scans to check the size of your lymph nodes and organs, like your spleen

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Precautions

There are some precautions to be aware of when you are taking ibrutinib.

- Ibrutinib can make you vulnerable to infections. You might need to take medicines to prevent infections while taking ibrutinib.
- You should avoid eating grapefruit. This includes the fruit, fruit juice, or foods or supplements containing them.
- You should avoid eating bitter oranges (Seville oranges). This includes the fruit, bitter orange juice or food made with bitter oranges, like marmalade.
- If you need surgery or to have a tooth out, you'll need to stop ibrutinib for a few days before and after. This is to reduce your risk of bleeding. Your doctor will tell you exactly when to stop taking ibrutinib and when to start it again.
- Ibrutinib might make you feel tired, dizzy or weak. This might affect your ability to drive or operate machinery.

"If you’re taking ibrutinib and your GP prescribes you a new medicine, ask them to check that it’s safe to take with ibrutinib."

— Helen, living with CLL since 2015

Protecting yourself from skin cancer

Ibrutinib can increase your risk of getting some types of skin cancer.

It is important to protect your skin from the sun by keeping your skin covered, wearing a wide-brimmed hat, and using a high factor suncream (SPF 30 or higher).

Check for symptoms like a growth, an unusual patch (this can vary in size, colour and texture), a new mole or a change in an existing mole. If you notice any, contact your GP.

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Fertility, pregnancy and breastfeeding

We do not know what effect ibrutinib has on fertility or pregnancy. Based on animal studies, it may harm unborn babies, especially during the early stages of pregnancy.

- If you could get pregnant, it's important to use effective contraception while you are taking ibrutinib and for up to 3 months after you stop.
- If you're taking ibrutinib and you think you might be pregnant, tell your haematology team as soon as possible.
- If you are planning to get pregnant in the future, tell your haematology team. They will talk to you about your treatment options.

Breastfeeding

We do not know if ibrutinib passes into breastmilk or what effect it might have on breastfed babies or children.

> **You should not breastfeed while you are taking ibrutinib.**

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Possible side effects

You may get some side effects while you are taking ibrutinib. Some people have very few side effects, whereas others get more serious side effects. They may differ from day to day.

Your haematology team should tell you what side effects to look out for and who to contact if you need to.

If you are worried about any symptoms or side effects, contact your haematology team. You do not have to wait until your next appointment.

Your haematology team might:

- Prescribe medicines to help manage some side effects
- Suggest things you can do to help you cope with side effects
- Lower your dose of ibrutinib if your side effects are serious or difficult to cope with
- Recommend pausing or stopping ibrutinib, if needed

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Side effects you might notice

This is not a full list of all the side effects that can happen. The patient information leaflet in your medicine package has more information. Or you can find the leaflet in the Electronic Medicines Compendium.

Here, we list some of the more common side effects of ibrutinib. These affect more than 1 in every 100 people who take ibrutinib.

- **Infections.** Contact your team straight away if you think you have an infection. Look out for:
    - A high temperature (38°C or higher)
    - Shivering, chills or sweating
    - Sore throat, sneezing, blocked or runny nose or earache
    - Cough, chest pain or shortness of breath
    - Burning or stinging when you pee, or peeing more often than usual
    - Sickness or diarrhoea

- **Unexpected or unusual bruising or bleeding** like nosebleeds, bleeding gums or heavy periods. Look out for blood in your poo or pee, or red or purple spots under your skin. This may look different in black or brown skin. Tell your team if you notice any of these.
- **Tummy problems.** You might get diarrhoea, constipation, indigestion or heartburn. You might feel sick or be sick. If you have these side effects, your team can give you medicines to help.
- **Muscle, bone or joint pain or muscle spasms.**
- **Swollen hands, feet or ankles.**
- **Changes to your skin and nails.** You might get a rash, redness, hives, skin infection or brittle nails. This might look different in black or brown skin.
- **Sore mouth or mouth ulcers.**
- **Headaches or dizziness.**
- **Weakness, pain or tingling in your hands or feet.**
- **Blurred vision.**
- **Lung problems.** Ibrutinib can sometimes cause inflammation or scarring of the lungs. You may have symptoms like shortness of breath or a dry cough. If this happens, your doctor might stop ibrutinib for a while or adjust your dose.
- **Heart problems.** Contact your doctor if you get a fast or irregular heartbeat, chest pain, feel very breathless or lightheaded, or have swollen legs or ankles. They will check your heart function. If there are problems, they might suggest stopping ibrutinib.

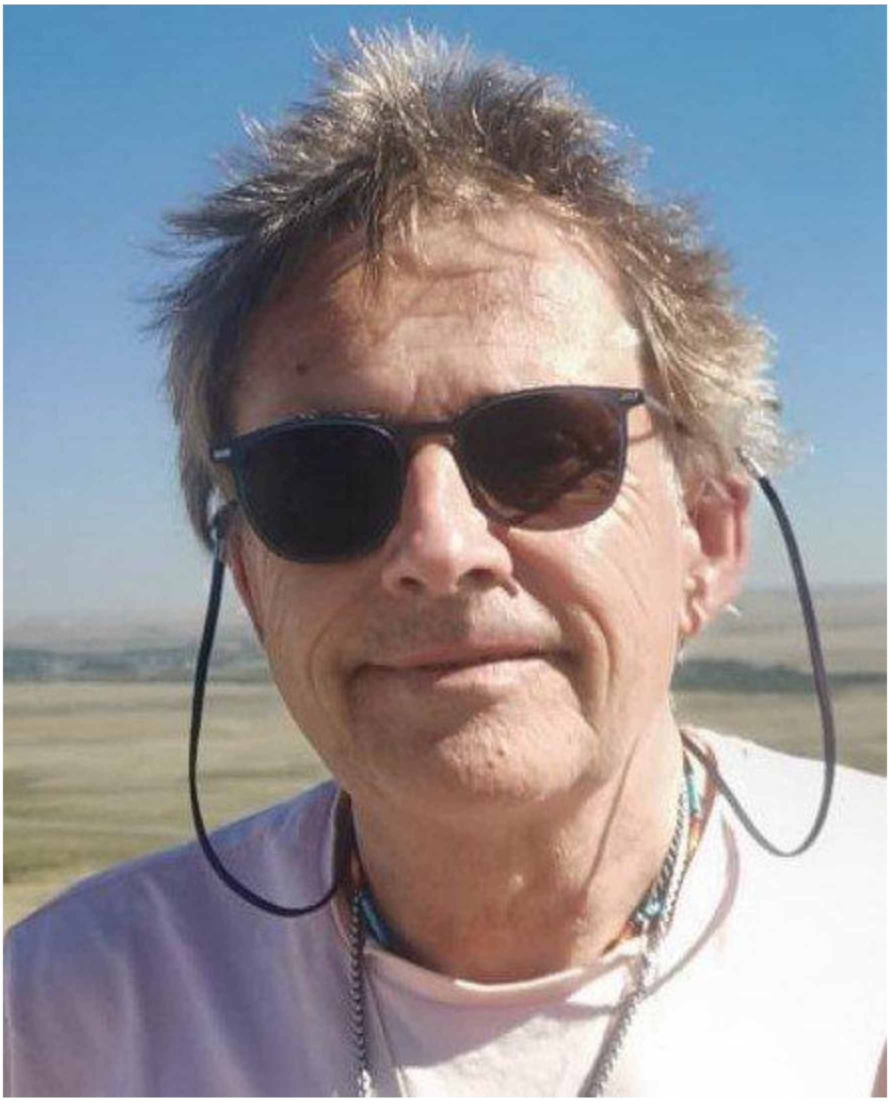
Sepsis

Ibrutinib can cause a severe response to an infection called sepsis. In clinical trials, this happened to around 3 in every 100 people taking ibrutinib. So it did **not** happen to around 97 in every 100 people taking ibrutinib.

Sepsis is serious and needs prompt treatment.

> **Contact your doctor straight away if you get symptoms like:**
>
> - **Confusion, slurred speech or not making sense**
> - **Blue, grey or pale, blotchy skin, lips or tongue (on black or brown skin look on the palms of the hands or soles of the feet)**
> - **A meningitis-like rash, which does not fade when you roll a glass over it**

- **Breathing difficulties, such as breathlessness or rapid breathing**



"If you have to go to A&E, tell the staff you have blood cancer and the treatment you're on. Your team might give you a Patient Alert Card to keep with you. In a medical emergency, these cards let people know what medicine you're taking and help keep you safe."

— *Steve, living with CLL since 2011*

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Side effects your team might notice

There might be some side effects your haematology team find during regular checks and blood tests. These include:

- High blood pressure. If this happens, you might need blood pressure medicines.
- Low levels of white blood cells called neutrophils (neutropenia). This makes you more vulnerable to infections.
- Low levels of platelets (thrombocytopenia). This can cause unusual bruising and bleeding because platelets help your blood to clot. You might need a transfusion if your platelets fall below a safe level.
- Changes in the level of salts in your blood. This can be a sign of kidney problems.
- High levels of uric acid in your blood. This can cause gout.
- High levels of white blood cells. This might happen when you first start ibrutinib. Your white blood cells may go up before they come down again. It doesn't mean your CLL is getting worse.

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Rare side effects

Rarely, ibrutinib might cause serious side effects, including:

- Allergic reaction
- Stroke
- Immune system problems
- Heart problems

These affect less than 1 in every 100 people taking ibrutinib. So, they do **not** happen to more than 99 in every 100 people. However, if they happen, they can be serious, so it's sensible to know what to look out for.

> **Contact your doctor immediately if you develop any of the following symptoms while taking ibrutinib:**
>
> - **Swelling of your face, lips, tongue or throat, difficulty breathing or an itchy, bumpy rash**
> - **Memory loss, sudden confusion or trouble thinking**

- **Difficulty walking, loss of balance or coordination**
- **Sight loss**
- **Sudden numbness or weakness in your limbs, particularly on one side**
- **Problems speaking or understanding speech**
- **Sudden severe headache**
- **Breathlessness or difficulty breathing**
- **Swelling of your feet, ankles or legs**
- **Weakness or tiredness**
- **Fever, chills, body aches and other cold or flu symptoms**
- **Yellowing of the whites of your eyes or your skin (this can be harder to see on black or brown skin)**

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If ibrutinib doesn’t work

If ibrutinib is not working well, your doctor will discuss your options with you. They might suggest changing your dose, pausing or stopping treatment. They will talk to you about other treatment options that might be suitable for you.

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Need support?

You are not alone. We're here for you whether you have a diagnosis yourself or know someone who has. If you'd like advice, support, or a listening ear, call our freephone helpline on 08088 010 444 or send a WhatsApp message to 07500 068 065.

Talk to us →

Help us improve our information

We aim to provide information that’s reliable, up-to-date, and covers what matters to you. Please complete our short survey to help us improve our information and make sure it meets your needs.

Complete our short survey →

About our information

This information is aimed at people in the UK. We do our best to make sure it is accurate and up to date but it should not replace advice from your health professional. Find out more about our information.

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