Imatinib

Imatinib is a targeted treatment used for some people with chronic myeloid leukaemia (CML).

Summary

- Imatinib is a type of medicine called a tyrosine kinase inhibitor (TKI).
- It comes as tablets or capsules that you take every day. The number of tablets you need to take should be printed on the named label on the medicine packaging.
- You will have regular blood tests to check how well your CML is responding to imatinib.
- Your haematology team will also carry out tests to check how your body is coping with imatinib treatment.
- Side effects of imatinib are usually mild to moderate. Some people have very few side effects, whereas other people experience more serious side effects.
- Some side effects can be serious if they are not treated promptly. Contact your haematology team straight away if you get:
    - Rapid weight gain
    - Signs of infection
    - Unexpected bruising or bleeding
    - Tell your haematology team if you get any other side effects. They may be able to suggest things to help.

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

Download our leaflet about imatinib

About imatinib

Imatinib is a type of medicine called a tyrosine kinase inhibitor (TKI). It blocks an abnormal protein called BCR-ABL, which is a type of tyrosine kinase. This abnormal protein is present in people with CML. It encourages the blood-forming cells in your bone marrow to make too many white blood cells. Blocking the protein helps stop the leukaemia cells from multiplying.

There are several different brands of imatinib, but they all contain the same active medicine. Brand names include:

- Glivec
- Imatinib Milpharm
- Imatinib Zentiva
- Nibix

Imatinib is a common first treatment for CML that has been used successfully for over 20 years. It is suitable for adults and children over 2 years old. Your haematology team might recommend it for you if:

- You have just been diagnosed with CML.
- You have progressed from the chronic phase to the blast phase of CML and you have not had imatinib before. If this is the case, you are likely to be offered other treatments alongside imatinib.
- Your CML has been treated with peginteferon-alfa but it did not work well, stopped working or caused side effects that were hard to cope with.

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Before taking imatinib

Before starting your course of imatinib, your haematology team will carry out checks to make sure it's suitable for you. These include:

- Checks of your heart health, like taking pulse and blood pressure measurements, and an electrocardiogram (ECG)
- Blood tests to measure the level of fats and sugars in your blood
- Blood tests to check for viruses like HIV or hepatitis B

They will also check to see if you have any medical conditions such as diabetes, lung conditions or liver problems.

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How to take imatinib

Imatinib comes as tablets or capsules containing 100mg, 400mg or 600mg of imatinib. The number of tablets or capsules you need to take depends on the dose and the strength of the tablets or capsules. This should be printed on the named label on the medicine packaging. If you are not sure, ask your doctor or nurse.

- You should take imatinib every day as prescribed so it can work as well as possible. Try and take it at the same time every day if you can.
- Swallow the imatinib tablets or capsules whole with a large glass of water. Take them during or straight after a meal to help avoid a stomach upset.
- Do not take imatinib with grapefruit or grapefruit juice because this affects how much of it your body absorbs.
- If you have difficulty swallowing the tablets or capsules, you can dissolve them in water or clear apple juice. The leaflet that comes with your medicine should have instructions on how to do this.
- If you forget to take your imatinib tablet or capsule, take it as soon as you remember. But if it is nearly time for your next normal dose, skip the missed tablet or capsule. It is important not to take a double dose.

Dose

Most adults with CML take 400mg or 600mg imatinib every day. Your haematology team may suggest a higher or lower dose, depending on your circumstances. They will tell you what dose they recommend for you.

- People over 65 can usually take the same dose as younger people.
- People with liver or kidney problems usually start on a dose of 400mg. This might be reduced if needed.
- Children’s doses are based on their body weight.

You usually take imatinib once a day, although if you are on a higher dose your haematology team may suggest taking it twice a day.

> "My treatment was one pill a day, I didn’t have to go through IV chemo, I wasn’t likely to lose my hair and the side effects from my medication were minimal. Most days I felt normal."
>
> — *Jo, diagnosed with CML at 34*

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Precautions

Imatinib can make your skin more sensitive to the sun. It is important to use sunscreen with a high sun protection factor (factor 50) on exposed areas.

Some medicines or drugs may interact with imatinib. It is important to tell your haematology team about any medicines or supplements you are taking. This includes prescribed medicines and medicines you have bought yourself without a prescription. Examples include:

- Paracetamol
- Herbal medicines such as St John's Wort
- Medicines to prevent blood clots, like aspirin or warfarin
- Grapefruit or grapefruit juice

Imatinib may make you feel dizzy or drowsy or cause blurred vision. Take care if you are driving or using tools or machinery.

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Pregnancy and breastfeeding

Imatinib 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 imatinib and for at least 15 days after you stop.
- If you're taking imatinib and you think you might be pregnant, tell your haematology team as soon as possible. They will talk to you about your treatment options. They may recommend stopping treatment for a while or switching to a different treatment.
- If you are planning to get pregnant in the future, tell your haematology team. They will talk to you about your treatment options.

Breastfeeding

Imatinib passes into breastmilk. We do not know what effect this has on breastfed babies or children. You should not breastfeed while you are taking imatinib.

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Monitoring

During your treatment with imatinib, you will have regular tests to check how well your CML is responding to treatment. These will usually be blood tests and sometimes bone marrow tests.

You are likely to have blood tests every 3 months at first. If imatinib is working well for you, this might reduce to every 6 months.

Monitoring your response to treatment

Tests to monitor how well your CML is responding to imatinib look at:

- Your blood cell counts.
- The level of the *BCR-ABL1* fusion gene in your white blood cells. This is called ‘molecular response’.

Your haematology team will use the results of these tests to check how well imatinib is working for you.

What your molecular response means

Molecular response is the most sensitive and accurate measure of response. It is measured using a blood test called PCR.

There are different levels of molecular response (MR):

- MR1: Less than 1 in 10 white blood cells (10%) has the *BCR-ABL1* fusion gene. If imatinib is working well, you should reach MR1 within 3 months of starting treatment.
- MR2: Less than 1 in 100 white blood cells (1%) has the *BCR-ABL1* fusion gene. If imatinib is working well, you should reach MR2 within 6 months of starting treatment.
- MR3: Less than 1 in 1,000 white blood cells (0.1%) has the *BCR-ABL1* fusion gene. This is sometimes called a **major molecular response** (MMR). If imatinib is working well, you should reach MR3 within 12 months of starting treatment.

- MR4: Less than 1 in 10,000 white blood cells (0.01%) has the *BCR-ABL1* fusion gene. This is sometimes called a **deep molecular response** (DMR). If you reach and maintain a DMR, you might eventually be able to stop treatment.
- MR5: Less than 1 in 100,000 white blood cells (0.001%) has the *BCR-ABL1* fusion gene. This is also called a **deep molecular response** (DMR). If you reach and maintain a DMR, you might eventually be able to stop treatment.
- Levels below MR5 cannot usually be detected. This is called a **complete molecular response**.

If your *BCR-ABL1* levels have dropped, but you haven't quite met the required targets, you may be in a 'warning' category. You should discuss your options with your haematologist.

Your molecular response can be used to detect any difficulties in treatment early on. It is an essential part of safe monitoring if you can stop treatment.

Monitoring your body's response to imatinib

Your haematology team will also check how well your body is coping with imatinib treatment. This might include:

- Blood tests to check how well your liver, kidneys, pancreas and thyroid are working.
- Blood pressure checks. Imatinib can increase your blood pressure. If this happens, your doctor might prescribe blood pressure medications. If your blood pressure is very high, you may need to stop taking imatinib for a while.
- ECG checks and blood tests to check your heart health.
- Blood tests to check your blood sugar and fat.

Long term follow-up

Once you have reached a response to treatment, your haematology team will make a follow-up care plan for you. You will have regular follow-up appointments to check for any signs of relapse or complications.

> "I accept I'll be having blood tests and taking medication for the rest of my life but while this disease is part of my life and always will be, I won't let it define me."
>
> — *Marisa, diagnosed with CML at 18*

It is important to go to your follow-up appointments. This is so your team can check how well your treatment is working and how your body is coping. You are likely to have blood tests every few months, and possibly a bone marrow test if you lose response.

Your follow-up appointments will continue in the long term. How often you have appointments will depend on your individual needs - for example, any support you need to manage ongoing side effects.

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How long to take imatinib

Most people carry on taking imatinib for as long as it is working. Your haematology team may suggest stopping imatinib 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

Your haematology team might also discuss reducing your dose, or stopping treatment completely.

Reducing your imatinib dose

Your haematology team might suggest reducing your dose of imatinib if you are getting difficult side effects or you are in a major molecular response.

They will monitor your treatment response closely after reducing your dose. If you lose your response, they might slowly increase the dose until you reach a response again. The aim is to find the lowest dose that works for you. This keeps your risk of side effects as low as possible.

Stopping imatinib

Your haematology team might discuss stopping imatinib completely if:

- You have been taking it for at least 3 years (ideally 5 years) **AND**
- Your CML has been in DMR (MR4 or MR5) for at least 2 years

This is called treatment-free remission. Your haematology team will talk to you about the benefits and risks of treatment-free remission, so you can decide if it's something you would like to try.

We have separate information about treatment-free remission.

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Side effects

You may get some side effects while you are taking imatinib. For most people, these side effects are usually mild to moderate. They may differ from day to day. Some people have very few side effects, whereas other people experience more serious side effects.

The possible side effects of imatinib are very similar to those with other TKIs. Some are more common, and some less common. Most people with CML need to take one of the TKIs. Your haematology team should tell you about the likelihood of key side effects with different medications.

If you are getting side effects that are difficult to cope with, your haematology team might suggest reducing your dose of imatinib. They may then try slowly increasing it to find a dose that works for you.

> **Tell your haematology team if you get any side effects. They may be able to adjust your dose of imatinib, prescribe medicines to help, or suggest things to help you cope.**

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Serious side effects

> **The following side effects may be serious and require treatment. Contact your doctor straight away if you have any of these side effects.**

- Rapid weight gain or swelling in most of your body. This is because imatinib can cause your body to retain water. Medicines called diuretics can help treat water retention.
- Infection. This may be due to a low white blood cell count, which means you can't fight infections as well as usual. If you get an infection, you need prompt treatment. Signs of infection include:
    - High temperature over 37.5°C or severe chills
    - Sore throat
    - Cough
    - Pain when you wee or weeing more often than usual
    - Diarrhoea
- Unexpected bruising or bleeding like nosebleeds, bleeding gums, blood spots or rashes – your levels of platelets may be low.
- Feeling very tired or short of breath – your level of red blood cells may be low.
- Any other unusual or worrying symptom.

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Very common side effects

Very common side effects affect more than 10 in every 100 people who are taking imatinib.

Very common side effects include:

- Headache
- Feeling tired
- Feeling sick or being sick

- Diarrhoea – if this affects you badly, your doctor might prescribe anti-diarrhoeal medicine
- Tummy pain
- Rash – if this affects you badly, your doctor might prescribe steroid cream
- Puffy eyes
- Muscle cramps, or joint, muscle or bone pain
- Weight gain
- Low blood counts

This is not a full list of all the side effects that can happen. The patient information leaflet has more information.

> **If you are worried about any side effects or symptoms you have, contact your haematology team.**

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Common side effects

Common side effects affect more than 1 but less than 10 out of every 100 people who are taking imatinib.

Common side effects include:

- Loss of appetite
- Difficulty sleeping
- Feeling dizzy
- Tingling, numbness or other changes in your sense of touch
- Changes in taste
- Dry, sore, red or watery eyes
- Blurred vision
- Flushed skin or a pinprick rash

- Breathlessness or cough – if this is caused by fluid in the lining of your lungs, your doctor might prescribe oral steroids
- Nose bleeds
- Bloating or wind
- Heartburn or acid reflux
- Constipation
- Dry mouth
- Flushing and bleeding
- Changes in liver function – your doctor might prescribe steroids if needed
- Itching
- Swollen face
- Dry or red skin that may be sensitive to sunlight
- Hair loss
- Night sweats
- Joint swelling
- Weakness, high temperature, chills and shaking
- Weight loss

This is not a full list of all the side effects that can happen. The patient information leaflet has more information.

> **If you are worried about any side effects or symptoms you have, contact your haematology team.**

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If imatinib does not work

If imatinib hasn't worked, or has stopped working for you, there are lots of other options. These include:

- Increasing your dose of imatinib.

- A different TKI. All TKIs work in slightly different ways. If your CML does not respond to imatinib, it might still respond to a different one. Some people try several different TKIs.
- A stem cell transplant using donor cells. This is called an allogeneic stem cell transplant.

Your haematology team will tell you which option they recommend for you.

> "I was placed on 400mg of imatinib, but it caused me bone pain, so after a couple of months with no improvement I was switched to 100mg of dasatinib which I stayed on for about 12 years. Ultimately, dasatinib caused me a lot of fatigue so I have recently started on asciminib. As CML patients we are very fortunate to have many treatment options available to us."
>
> — *David, diagnosed with CML*

We have separate information about:

- Second- and later-line treatments for CML
- Stem cell transplants

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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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