



Oral imatinib for children and young people

An information guide for patients, parents and carers

The purpose of this guide is to give information on the use of imatinib in children and young people with cancer.

Please read this guide carefully alongside any patient information provided by the manufacturer. We have written this guide to give you more information about the use of this medicine in children and young people. Keep it somewhere safe so you can read it again.

What is imatinib?

Imatinib is a targeted therapy, a cancer growth inhibitor, used to treat certain types of cancer. It is often referred to as a tyrosine kinase inhibitor (TKI) because of the way that it works.

What preparations of imatinib are available?

Imatinib is available as 100mg and 400mg tablets or capsules and some hospitals may have an oral liquid containing 80mg per ml of imatinib.

Where can I get imatinib from?

You must only get imatinib from your treating hospital. Please remember to bring all medication with you at each hospital visit.

How is imatinib given?

Imatinib is given by mouth, usually once a day. It may sometimes be given twice a day. Imatinib should be taken with food, to help protect the stomach and should be taken whilst sitting in an upright position where

possible. Instructions will be on the label or on the dosing information chart. The tablets or capsules should be swallowed whole with plenty of water or apple juice. Do not break, crush or chew the tablets or capsules.

If your child is having nasogastric feeds (NG feeds), then the administration of imatinib can be timed around feeds. The nursing team or pharmacist at your hospital will be able to advise you on this.

The information below is for patients who are unable to swallow the imatinib capsules or tablets, and the liquid is not available.

How to give imatinib if you/your child is unable to swallow capsules or tablets whole

For each dose you will need:

- a pair of non-sterile disposable gloves
- apron and mask
- glass
- still water or apple juice
- oral syringe
- correct dose of imatinib

- kitchen towel
- sealable plastic bag

Follow the instructions below:

1. Put on the gloves, apron and mask.
2. Place some kitchen towel on the work surface.
3. Onto the towel, place a glass containing the still water or apple juice and a spoon.
4. Check all the information on the medicine is correct and that you understand the dose that is to be given.
5. Each 100mg of imatinib should be mixed in 50ml of water or apple juice, for example, 300mg of imatinib needs 150ml of water or apple juice.
6. Using a glass measuring cup or jug, measure the correct amount of still water or apple juice into a glass.
7. Slowly add the required number of tablets into the still water or apple juice.
8. Stir well with a spoon until the tablets are completely disintegrated. If using capsules, carefully open each capsule required one at a time, add the powder contents to the still water or apple juice and stir well.
9. Ensure the whole content of the glass is drunk immediately.
10. Wrap all the disposable utensils and gloves in the kitchen towel, seal in a plastic bag and place in the cytotoxic sharps bin.
11. Wash the glass and reusable utensils thoroughly in warm soapy water.
12. Wash hands thoroughly with soap and water.

If the amount is difficult to take, the tablets can be mixed in less liquid, although this may cause stomach irritation. Always discuss with a member of the pharmacy team before doing this.

Other drinks such as milk, orange juice or fizzy drinks must not be used as they react with the medicine.

Children with nasogastric (NG) tubes should be given imatinib by mouth if possible. If not possible, the tablets or capsules should be prepared with still water as described above and given immediately.

When each course is finished, or the cytotoxic sharps bin is two thirds full, the sharps bin should be sealed. At the next visit, please **RETURN** the sharps bin to your hospital or shared care centre.

Are there any possible side effects?

It is important to remember that everyone reacts differently to chemotherapy. Some will have very few side effects whilst others will have more. The side effects listed below will not affect everyone who is given imatinib and may be different if more than one chemotherapy drug is given.

What are the common side effects?

Reduced bone marrow function

Blood counts will be checked regularly to see how the bone marrow is working. A low neutrophil count can increase your/your child's risk of infection. A low haemoglobin count indicates anaemia which may cause unusual tiredness and a low platelet count may cause bruising or bleeding.

Please contact your hospital team if there are any signs of infection, especially a high temperature or unusual tiredness, bruising or bleeding.

Headache

Contact your hospital team if headaches develop.

Nausea (feeling sick) and vomiting (being sick)

Taking imatinib with food will help prevent nausea and vomiting. Anti-sickness drugs can be given to reduce or prevent these symptoms. Please contact your hospital team if sickness is not controlled.

Abdominal pain or diarrhoea

This is usually mild and will often improve over time. Please contact your hospital team for advice.

Skin rashes

Imatinib can cause a rash which may be itchy. The skin may be more sensitive to sunlight. Always use a sunscreen with a sun protection factor (SPF) of 50 or higher, and wear a hat when out in the sun. If skin blisters or peels contact your hospital team for advice.

Water retention

Imatinib can cause retention of water which might show as puffy eyes, swollen ankles, abdominal bloating, or rapid weight gain. Please contact your hospital team if any of these symptoms develop.

Effects on the eyes and breathlessness

If there is any eye pain or any difficulty with sight, or shortness of breath, contact your team immediately.

Muscle cramps

If muscle cramps develop, contact your hospital team for advice on treatment to help with these symptoms.

What are the less common side effects?**Temporary effect on liver function**

Imatinib can cause some changes to liver function. This should return to normal when the treatment is finished. If the liver function is seriously affected, then treatment will be changed. Blood tests will be taken to monitor liver function (called LFTs – liver function tests). If there is pain on the right side of the abdomen, yellowing of the skin and eyes, or signs of bruising or bleeding, contact your hospital team.

Growth

Some children taking imatinib may have slower than normal growth. Your medical team will monitor this carefully.

Is there anything else I should know about or do?

Contact your treating hospital if:

- a dose of imatinib is forgotten
- vomiting occurs after taking the dose
- too much imatinib is given

Which tests/investigations may take place before, during or after treatment with imatinib?**Full blood count**

A full blood count will be done regularly at your hospital or by your community team. The dose of imatinib may need to be adjusted according to the result. The new dose will be recorded on the label or on the patient dosing information chart.

Liver and kidney function tests

Blood tests to show how the liver and kidneys are working will be done before and during treatment.

Does imatinib interact with any other medicines?

Some medicines can affect how well imatinib works. Always tell the doctor about any other medication being taken. Check with your doctor or pharmacist before taking any other medicines. This includes supplements and herbal or complementary medicines.

It is important to avoid eating grapefruit or drinking grapefruit juice whilst taking imatinib as both may affect the way that imatinib works.

How should imatinib be handled and stored?

- always handle medicines with care
- keep out of reach and sight of children
- store the tablets, capsules and liquids at room temperature
- discard bottles of liquid 30 days after first opening
- keep out of direct sunlight
- handle as little as possible and always wear gloves
- if you are pregnant or think you could be pregnant, discuss handling instructions with your doctor, nurse or pharmacist

Any imatinib that has not been given, or is out of date, must be returned to your treating hospital. **Do not throw away at home.**

Please read the CCLG factsheet – ‘Safe handling of chemotherapy medicines’.

Pregnancy

If you are sexually active while taking anti-cancer medicines or drugs, it is important to use contraception such as condoms, the pill or coil to avoid pregnancy. You may need to take a pregnancy test to confirm you are not pregnant before taking this medicine. Contraception should continue for a while after treatment finishes. Your team will advise how long you should continue using contraception.

Fertility

Depending on the type, dose and combination of medicines given during your treatment, it is possible that fertility may be affected. For girls, this means that it may be harder for them to become pregnant in the future. For boys, this may mean that their sperm is less fertile which can affect their chance of having children in the future. If you would like more information about this, please discuss with your medical team.

If you have any questions about imatinib, please contact your treating hospital. This guide only gives general information.

Always discuss individual treatment with your medical team. Do not rely on this guide alone for information about treatment.



USEFUL ORGANISATIONS

Children's Cancer and Leukaemia Group (CCLG)

publishes a variety of free resources to order or download.
www.cclg.org.uk

Young Lives vs Cancer offers practical support to children and young people with cancer and to their families.
www.younglivesvscancer.org.uk

Macmillan Cancer Support offers support and advice to those affected by cancer.
www.macmillan.org.uk

EMC (Electronic Medicines Compendium) offers up-to-date, approved and regulated information for licensed medicines.
www.medicines.org.uk



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in CHILDHOOD
CANCER

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Children's Cancer and Leukaemia Group (CCLG) is a leading national charity and expert voice for all childhood cancers.

Each week in the UK and Ireland, more than 30 children are diagnosed with cancer. Our network of dedicated professional members work together in treatment, care and research to help shape a future where all children with cancer survive and live happy, healthy and independent lives.

We fund and support innovative world-class research and collaborate, both nationally and internationally, to drive forward improvements in childhood cancer. Our award-winning information resources help lessen the anxiety, stress and loneliness commonly felt by families, giving support throughout the cancer journey.

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If you have any comments on this factsheet, please contact us at publications@cclg.org.uk CCLG publications on a variety of topics related to children's cancer are available to order or download free of charge from our website.

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