

Isotretinoin for children and young people

An information guide for parents, carers and young adult patients

The purpose of this guide is to give information about the use of isotretinoin to parents, carers and young people undergoing treatment for 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 isotretinoin?

Isotretinoin is a form of Vitamin A. It is often used to treat severe acne. It also affects the growth of certain types of cells and is known to prevent the growth of some human neuroblastoma cells. There is evidence that this drug improves survival in patients with high-risk neuroblastoma. Isotretinoin may also be known as 13-cis-retinoic acid or 13-CRA.

What preparations of isotretinoin are available?

Isotretinoin is available as 10mg and 20mg capsules for patients who are able to swallow whole capsules. It is available as a 20mg/ml liquid for those who cannot swallow whole capsules.

Where can I get isotretinoin from?

Isotretinoin must only be obtained from your treating hospital. Please remember to bring all medication with you at each hospital visit.

How is isotretinoin given?

Isotretinoin is given by mouth as whole capsules or as liquid, and should be taken with food.

The capsules must be swallowed whole with plenty of water or juice. Do not chew the capsules. The liquid is suitable for giving via an NG or PEG feeding tube.

Isotretinoin (capsules or liquid) is given twice a day for 14 continuous days, and this will be repeated according to the treatment plan. Your doctor or pharmacist will tell you how much medicine to give and this will also be on the medication label.

Important to know:

Isotretinoin capsules contain soya bean oil so should not be taken by anyone who has a soya allergy. The capsules are also not recommended to be taken by anyone who has a peanut allergy. Discuss any soya or peanut allergies with your doctor. The liquid does not contain soya so is fine for anyone to take. The liquid has a 'tutti frutti' flavour.

Isotretinoin liquid is ordered by the pharmacy for individual patients and must be stored carefully in the original box and kept away from all sources of light.

How to give isotretinoin liquid by mouth:

1. Remove the bottle from the box
2. Shake the bottle well for 30 seconds immediately before use
3. Measure the dose using the oral syringes provided by your hospital
4. Give the dose within two minutes of shaking the bottle
5. Return the bottle to the original box

How to give isotretinoin liquid via a nasogastric (NG) tube or PEG:

1. Remove the bottle from the box
2. Shake well for 30 seconds immediately before use
3. Measure the dose using the oral syringes provided by your hospital
4. Give the dose within two minutes of shaking the bottle

After giving via a nasogastric (NG) tube follow all of the flushing steps below:

1. Flush with 5 ml of olive oil
2. Flush with 5 ml of milk (or milk feed)
3. Flush the tube with 5 - 10 ml of water

If you are unsure about any of this, ask a nurse or pharmacist to go through these steps with you and ask them to answer any questions that you may have.

Do not take any other medicines containing vitamin A whilst taking Isotretinoin. If you are not sure about other medicines, ask your doctor or pharmacist.

Are there any side effects?

It is important to remember that everyone reacts differently to medicines. Some will have very few side effects whilst others will have more. The side effects listed below will not affect everyone who is given isotretinoin.

What are the common side effects?

Dry skin, lips and eyes

Moisturiser and lipsalve containing vitamin E should be applied regularly throughout treatment. Use them at least four to six times a day. Start using the moisturiser and lip salve before there are any signs of dry skin or lips. If very dry or cracked skin or lips continues, please contact your medical team.

Isotretinoin can also cause a skin rash. Contact your medical team if this happens.

Sensitivity to sunlight

Isotretinoin causes the skin to be more sensitive to sunlight. This means skin may burn more easily than usual. It is important to avoid strong sunlight and other forms of UV light. When out in the sun, always use a sunscreen with a sun protection factor (SPF) of 50 or higher and wear long sleeved clothing and a hat.

Reduced bone marrow function

Blood counts will be checked regularly to see how the bone marrow is working. A low neutrophil count means there is a greater risk of infection. A low haemoglobin count indicates anaemia, which can cause more tiredness than usual. A low platelet count may cause bruising or bleeding.

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

Effects on the liver

Isotretinoin can cause some changes to how the liver works. This should return to normal when the treatment finishes. Regular blood tests will be taken to check liver function (called LFTs - liver function tests). Sometimes the dose of isotretinoin may be altered depending on the LFT result. Your doctor will explain if this is needed. 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 medical team for advice.

Increase in blood fats

Isotretinoin can cause raised levels of some fats in the blood (triglycerides). This will not have any noticeable effect.

What are the less common side effects?

Back pain

Isotretinoin can cause back pain, and joint and muscle aches. Pain relief can be given if this happens.

Mood alterations

Isotretinoin can cause mood alterations, anxiety and aggressive tendencies. Contact your medical team if these symptoms are experienced.

Which tests/investigations may be needed?

Blood tests for liver and kidney function and the level of triglycerides in the blood are taken routinely before each treatment with isotretinoin. It is important that these tests are within the normal range before another cycle of isotretinoin is given. A urine sample will need to be given to check for traces of blood or protein. A general check will be done for skin condition.

Isotretinoin is harmful to unborn children. There are strict rules about ensuring patients are not pregnant while taking isotretinoin. Isotretinoin must not be given to girls who may be pregnant or are likely to become pregnant in the near future. The doctor will discuss this with you and, if appropriate, a pregnancy test may be carried out on a fresh urine sample. This will be repeated for each cycle of isotretinoin.

Does isotretinoin interact with any other medicines?

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

Is there anything else I should know about or do?

Contact your treating hospital if:

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

How should isotretinoin be handled and stored?

- always handle medicines with care
- keep out of reach and sight of children
- store the capsules and liquid at room temperature
- keep out of direct sunlight
- ensure the liquid is always stored in the box and protected from light
- isotretinoin liquid has a short expiry once opened, so make sure you write the date opened on the box and know how long it can be used for
- handle as little as possible and always wear gloves

Important note for parents or carers who are administering isotretinoin - if you are pregnant or think you could be pregnant, please discuss handling instructions with your doctor, nurse or pharmacist. It is very important that you do not directly handle the capsules or liquid.

Any isotretinoin capsules or liquid 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'
www.cclg.org.uk/publications

Pregnancy

If you are sexually active while taking anti-cancer medicines or drugs, it is important that you 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 contraception for.

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 isotretinoin, 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 information

CCLG: The Children & Young People's Cancer Association publishes a variety of free resources to order or download at www.cclg.org.uk/publications



Scan to order or download this factsheet or any other CCLG publications FREE of charge.

Young Lives vs Cancer provides practical support and advice for children and young people affected by cancer and 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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We are CCLG: The Children & Young People's Cancer Association, a charity dedicated to creating a brighter future for children and young people with cancer. Powered by expertise, we unite the children and young people's cancer community, driving collective action and progress.

We fund and lead pioneering research, provide trusted information and guidance for children and young people with cancer and their families, and bring together professionals to improve treatment, care and outcomes.

Our expert information helps children and young people, and everyone supporting them, to navigate the challenges of cancer and its impact, offering reassurance and clarity when it's needed most.

We make every effort to ensure that this information is accurate and up to date at the time of printing. Information in this publication should be used to supplement appropriate professional or other advice specific to your circumstances.

Our work is funded by donations. If you would like to help, visit www.cclg.org.uk/donate or text 'CCLG' to **70085** to donate **£3**. You may be charged for one text message at your network's standard or charity rate. CCLG will receive 100% of your donation.



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