

Oral isotretinoin guide for young people

This information will help you to decide if oral isotretinoin is right for you

- Oral isotretinoin is a very effective treatment for severe acne, but it has some potentially serious side-effects.
- Read this information carefully and keep it somewhere safe so that you can read it again.
- You are also recommended to watch the information video: www.bad.org.uk/pils/isotretinoin-patient-video

Name of medicine

Oral isotretinoin

Brand names: Roaccutane, Reticutan, Accutane

How does this medicine work?

- Oral isotretinoin reduces the production of sebum – an oily substance made by the skin. It also reduces the stickiness of the outer layer of the skin which helps unblock pores.
- It reduces the number of spots and, for many, can clear their skin; it is used if other treatments have not worked.

What are the possible side-effects?

 **Oral isotretinoin may cause serious side-effects. Whilst these are rare, it is important to be aware of the potential risks in order to make an informed decision about whether to take isotretinoin.**

 **If you're worried about any side effects, stop taking isotretinoin and contact your dermatology team.**

Side-effects you must do something about

 **If you develop a severe rash, swelling of the lips or difficulty breathing or swallowing within minutes of taking isotretinoin, call '999' as you could be having an allergic reaction.**

 **If you have suicidal thoughts or thoughts of harming yourself, stop taking isotretinoin and seek urgent medical help.**

 **It is very important not to become pregnant whilst taking isotretinoin (read on for further information).**

Common side-effects of oral isotretinoin

- Your skin may become more sensitive to the sun and have an increased risk of sunburn. Use a high factor sun block (at least SPF 30) and reapply it often, or wear long sleeves and trousers and a hat. You should not use sun (tanning) beds.
- You may experience dry skin, lips, and eyes. Very dry skin is at risk of infection, wounds take longer to heal, and it is more likely to peel. Use an oil-free light moisturiser and lip balm regularly. If your skin becomes very dry, contact your dermatology team.
- Your skin may be more delicate than normal whilst taking isotretinoin and for 6 months afterwards. It is best to avoid waxing, epilation, dermabrasion or laser treatment. You should be able to shave, but use a moisturiser after.
- If your eyes are dry, you may find contact lenses uncomfortable. Artificial tear eye drops may help.
- Your muscles and joints may ache after exercise.

Less common side-effects of oral isotretinoin

 **If you develop severe headache, nausea (feeling sick), vomiting (being sick), blurred vision, diarrhoea with blood or you notice your skin/eyes looking yellow, contact your doctor.**

- Some people find their hair may become thinner but it will usually recover after the end of the treatment.
- Isotretinoin sometimes affects vision, especially the ability to see at night. If this happens, speak to your doctor.
- You may get nose bleeds and a sore throat.
- You may experience a lack of interest in sex, vaginal dryness, difficulty getting/keeping an erection or general sexual dysfunction.

Side-effects relating to your mental health

- We know that people with acne are more likely to have anxiety and depression than people without acne. This is the case whether or not they are taking isotretinoin.
- Acne and acne scars may affect self-confidence which can lead to low mood, especially in young people. Several studies have shown that isotretinoin can improve negative mood changes caused by acne.
- However, there are some reported experiences of worsening mood or changes in behaviour, including violence, aggression, feeling more hostile towards others, or a loss of contact with reality (psychosis).
- Extremely rarely, isotretinoin may be associated with young people hurting themselves (self-harm) or suicide.
- If you have ever had low mood, suicidal thoughts or any other mental health issues, please talk with your dermatology team about this before starting treatment.
- If you or your friends and family notice any changes in your feelings or behaviour whilst taking isotretinoin, stop taking it and contact your dermatology team to discuss whether isotretinoin is suitable for you.

Side-effects to unborn babies during pregnancy

- Isotretinoin may cause serious harm to the development of a baby. It also increases the risk of miscarriage.
- If you are sexually active (having sex), tell your doctor. You should use two methods of contraception. You will also need to have a pregnancy test each month before receiving your next 30 days' of isotretinoin capsules.
- If you do have unprotected sex whilst taking isotretinoin (or in the month after completing treatment), you will need to consider emergency contraception – contact your doctor, pharmacy or a sexual health clinic as soon as possible. Stop taking oral isotretinoin.
- Isotretinoin does not affect fertility long term. You should avoid pregnancy for 1 month after finishing isotretinoin but there is no risk to an unborn baby after this time.

Anything else to know before taking oral isotretinoin?

- You will need to have a blood test before starting isotretinoin and during treatment to monitor your blood.
- It is important not to drink alcohol to excess whilst taking isotretinoin as it increases the risk of liver damage. Do not exceed the government guidelines on alcohol consumption; maximum of 14 units per week

Practical advice for taking oral isotretinoin

How much should I take?

 Oral isotretinoin comes in 5mg, 10mg or 20mg capsules. Your dermatology team will work out what dose (how many capsules) you should take.

- The dose may be increased depending on if your acne is improving and if you have any side-effects.

 **It is important that you follow your doctor's instructions about how much to take.**

Do not increase the dose without discussing it with your doctor first.

- The capsules contain a small amount of highly processed soya oil. While this is not normally a risk to people with peanut or soya allergy, you should tell your doctor if you have these allergies or if you have ever had an allergic or other reaction to any medicine. Further information on soya allergy is available here: www.skinhealthinfo.org.uk/condition/isotretinoin-and-soya-allergy

How and when should I take it?

- Oral isotretinoin is usually taken once each day. This can be in the morning or the evening.
- It is absorbed better into the body with food or a drink which contains some fat, such as whole milk.
- It should be taken with or after a main meal - it should not be taken on an empty stomach.
- The capsules should be swallowed whole with a drink.
- You should not chew or open up the capsules.
- Take it at the same time each day so it becomes part of your routine. This will help you to remember to take it.

What if I am sick (vomit) after taking it?

- If you are sick less than 30 minutes after taking it, you can take the same dose again.
- If you are sick more than 30 minutes after taking it, you do not need to take another dose. Wait until the next normal dose.

What if I forget to take it?

- If you remember on the same day, take the missed dose.
- If you do not remember until the next day, do not take the missed dose. Just take the same dose as normal.

What if I think I have taken too much?

- You are unlikely to do harm if you take an extra dose of oral isotretinoin by mistake.
- If you are concerned that you may have taken too much, contact your doctor or NHS services (details at the end of this leaflet). Have the medicine packaging with you if you telephone for advice.

When should the medicine start working?

- It usually takes about 4 weeks for oral isotretinoin to start working, although it may take longer.
- It is important that you continue to take it regularly, even if you're not sure whether it is helping.
- Your acne may get worse during the first few weeks of treatment (flare up) before it improves. If this happens, contact your dermatology team.
- Oral isotretinoin is usually taken for at least 6 months.

Can other medicines be taken at the same time as oral isotretinoin?

- Most medicines can be taken safely with oral isotretinoin, including paracetamol and ibuprofen.
- However, it should **not** be taken with some medicines that you get on prescription. Tell your doctor or pharmacist that you are taking isotretinoin.
- Check with your doctor or pharmacist before taking any other medicines. This includes herbal or complementary medicines.

Where should I keep this medicine?

- Keep it in a cool dark place such as a cupboard.
- It should not be kept in the fridge.
- Make sure that children cannot see or reach it.
- Keep the medicine in the packaging it came in.

Useful resources for more information

Your dermatology team will be able to give you more information about oral isotretinoin and about other medicines used to treat acne. You can also get information from:

• British Association of Dermatologists (BAD)

Information leaflet on acne: www.bad.org.uk/pils/acne

Patient information video - understanding the benefits and risks of isotretinoin:

www.bad.org.uk/pils/isotretinoin-patient-video

Scan the QR code to watch the patient information video:



• Royal College of Psychiatrists

Advice on oral isotretinoin and mental health www.rcpsych.ac.uk/mental-health/mental-illnesses-and-mental-health-problems/isotretinoin-and-mental-health

• **England: NHS 111**
Tel 111 www.nhs.uk

• **Scotland: NHS 24**
Tel 111 www.nhs24.scot

• **Northern Ireland: NI Direct** www.nidirect.gov.uk

• **Wales: NHS 111 Wales**
Tel 111 111.wales.nhs.uk

• **Acne support website**
www.acnesupport.org.uk

www.medicinesforchildren.org.uk



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The primary source of information is the UK Government's Commission on Human Medicines' Isotretinoin Expert Working Group (2023), the British Association of Dermatologists, the Royal College of Psychiatrists and the British National Formulary for Children. For details on other sources used, please contact us via www.medicinesforchildren.org.uk. We take great care to make sure that the information in this leaflet is correct and up-to-date. However, medicines can be used in different ways for different patients. It is important that you ask the advice of your doctor or pharmacist if you are not sure about something. This leaflet is about the use of these medicines in the UK and may not apply to other countries. The Royal College of Paediatrics and Child Health (RCPCH), the Neonatal and Paediatric Pharmacists Group (NPPG), WellChild and the contributors and editors cannot be held responsible for the accuracy of information, omissions of information, or any actions that may be taken as a consequence of reading this leaflet.