

## Information for you

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## **Intrahepatic Cholestasis of Pregnancy**

#### **About this information**

This information is for you if you have been diagnosed with intrahepatic cholestasis of pregnancy (ICP), also known as obstetric cholestasis.

It may also be helpful if you are a partner, relative or friend of someone in this situation.

The information here aims to help you better understand your health and your options for treatment and care. Your healthcare team is there to support you in making decisions that are right for you. They can help by discussing your situation with you and answering your questions.

Within this leaflet, we may use the terms 'woman' and 'women'. However, it is not only people who identify as women who may want to access this leaflet. Your care should be personalized, inclusive and sensitive to your needs, whatever your gender identity.

A glossary of medical terms is available on the RCOG website at: https://www.rcog.org.uk/forthe-public/a-z-of-medical-terms/.

## **Key points**

- ICP is a condition that affects how your liver works when you are pregnant. It is sometimes called obstetric cholestasis.
- It usually happens towards the end of your pregnancy and will get better after you have given birth.
- ICP can make your skin very itchy but you will not have a rash.
- Your ICP will be monitored with regular blood tests to check your liver function and the levels of bile acids in your blood.
- If you develop ICP there is an increased chance that your baby may be born early.
- For a few women with severe ICP, there may be an increased chance of stillbirth.

## What is intrahepatic cholestasis of pregnancy?

ICP is a condition that affects your liver during pregnancy. ICP causes a build-up of bile acids in your body. Bile acids are made in your liver and they help you to digest fat and fat soluble vitamins. The main symptom of ICP is itching of your skin without any rash. ICP usually starts towards the end of the pregnancy (the third trimester) but can happen earlier. It should get better when your baby has been born.

ICP is uncommon. In the UK, it affects about 7 in 1000 women (less than 1%). It is more common among women of Indian-Asian or Pakistani-Asian origin, with up to 15 in 1000 women (1.5%) affected. It is often not clear why it develops in one pregnancy and not another.

#### What does ICP mean for me?

ICP can be a very uncomfortable condition. It does not have any serious consequences for your health during pregnancy but can be very distressing. If you experience anxiety or low mood because of ICP discuss this with your healthcare professional who can arrange additional support.

#### **Itching**

Itching can start at any time during pregnancy, but usually begins after 28 weeks. It can vary from mild to intense and persistent and can sometimes be very distressing. It may include the palms of your hands or soles of your feet. The itching tends to be worse at night and can disturb your sleep.

There is no rash with ICP. The itching will get better soon after birth and causes you no long-term health problems.

#### **Jaundice**

Rarely, women with ICP can develop jaundice. This is where your skin and eyes become yellow because of liver changes. Jaundice will get better after you have had your baby.

## Pre-eclampsia

You may be more likely to develop pre-eclampsia (high blood pressure and protein in your urine during pregnancy) or to have gestational diabetes and your healthcare professional will advise you what checks you may need for these conditions. Further information can found in the RCOG patient information Pre-eclampsia (https://www.rcog.org.uk/for-the-public/browse-all-patient-information-leaflets/pre-eclampsia-patient-information-page/) and Gestational diabetes (https://www.rcog.org.uk/for-the-public/browse-all-patient-information-leaflets/gestational-diabetes/).

## How is ICP diagnosed?

### **Symptoms**

Itching is very common in pregnancy, affecting 25 in 100 women (25%). Most women who have itching in pregnancy will not have ICP. However, itching can be the first sign of ICP and if you experience this, you should tell your health care professional.

#### **Examination of your skin**

Your skin will be examined to check whether your itching is related to a skin condition, such as eczema. It is possible that you may have more than one condition.

#### **Blood tests**

You will be offered blood tests to help diagnose ICP. These include:

- Liver function tests (LFTs). These are blood tests that look at how well your liver is working. Some of these can be raised in ICP.
- Bile acid test. This is a blood test that measures the level of bile acids in your blood. Bile acids are raised in ICP. Your bile acid levels can be abnormal even if your liver function tests are normal. Bile acid levels can also be raised in other conditions apart from ICP.

Some women may have itching for days or weeks before their blood tests become abnormal. If your itching persists and no other cause is found, your liver function tests and bile acids should be repeated.

If your symptoms are unusual, start very early in your pregnancy or don't get better after your baby is born, you may be offered further investigations including more blood tests and a scan of your liver. You may also be referred to a liver specialist. This is to make sure that you don't have another cause for your itching and raised bile acids.

## What does ICP mean for my baby?

• There is an increased chance that your baby may pass meconium (open their bowels) before they are born

This makes the water around your baby a green or brown colour. Your baby can become unwell if meconium gets into their lungs during labour.

There is an increased chance of you having an early birth.

The chance of having your baby preterm (less than 37 weeks) is higher if you have ICP. This may be because you go into labour naturally or because your healthcare team advises you to give birth early.

There are no known long term health risks to your baby.

However there is a small increased chance that your baby will need to go to the neonatal unit when they are born, especially if they have been born early.

## What about the chance of stillbirth?

Your chance of having a stillbirth depends on the level of bile acids found in your blood as well as any other pregnancy complications you may be experiencing.

If your bile acid levels are between 19 and 39 micromol/L (Mild ICP) and you do not have any other risk factors, the chance of you having a stillbirth is no different to someone who doesn't have ICP.

If your bile acid levels are between 40 and 99 micromol/L (Moderate ICP), and you do not have any other risk factors, then the chance of you having a stillbirth is similar to someone who doesn't have ICP until you are 38–39 weeks' pregnant.

If your bile acid levels are 100 micromol/L or more (Severe ICP), your chance of having a stillbirth is higher than someone who doesn't have ICP and is around 3%. Most of these stillbirths happen after 36 weeks of pregnancy.

If you have other factors (such as gestational diabetes and/ or pre-eclampsia) or are having a multilpe pregnancy (twins or triplets) you may have a higher chance of stillbirth and this may affect when your healthcare team recommend that you give birth.

#### What extra care will I need?

Once you have been diagnosed with ICP, you should be under the care of an **obstetrician**. Your blood tests will usually be repeated after one week and an individualised plan of care will be made for you depending on your circumstances. In some women, the level of bile acids may return to normal with no treatment, and your healthcare professionals may check again whether you definitely have ICP.

You should keep a close eye on your baby's movements and if you are worried, you should go to your local maternity unit for a checkup straight away.

You do not need any additional scans of the baby because you have ICP.

Whether you are advised to have your baby in a consultant-led maternity unit with a neonatal unit will depend on your bile acid levels.

#### Can ICP be treated?

When your baby is born your ICP will get better.

Treatments to improve your itching are of limited benefit but might include:

- Skin creams such as aqueous cream, with or without the addition of menthol
- Antihistamines, which may help you sleep at night
- Some women have found that having cool baths and wearing loose-fitting cotton clothing helps to reduce the itching.
- There is a medication called ursodeoxycholic acid, which may slightly reduce itching in a small number of women.

There is no treatment available that helps your baby or that will make your bile acid levels better. Ursodeoxycholic acid may reduce your chance of giving birth prematurely but it does not prevent stillbirth.

A daily dose of vitamin K may be recommended for a small number of women as rarely ICP may affect blood clotting. Most women will not need this.

## When is the best time for my baby to be born?

The recommended timing of your baby's birth will depend on the level of bile acids in your blood and also whether you have any additional risk factors such as multiple pregnancy, gestational diabetes or pre-eclampsia. To reduce your chance of having a stillbirth, you might be asked to consider a planned birth rather than waiting to go into labour naturally.

If you are having one baby and your pregnancy has had no other complications, the following recommendations apply to you:

- Planned birth by the time of your due date (40 weeks) may be considered if your bile acids are raised between 19 and 39 micromol/L. If you have no other risk factors you may also consider waiting to go into labour as your risk of stillbirth is no different to someone without ICP.
- Planned birth at 38–39 weeks' gestation may be recommended if your bile acid levels are 40–99 micromol/L and if you have no other risk factors.
- Planned birth at 35–36 weeks' gestation may be recommended if your bile acid levels are 100 micromol/L or more.

Your health care professional will discuss your options with you depending on your individual situation, so that you can make an informed choice about how you give birth. Your options will be to choose an **induction of labour**, to choose a planned caesarean birth or to wait until you go into labour naturally. You do not need to have a planned caesarean birth just because you have ICP.

A plan will be made for monitoring your baby's heartbeat in labour depending on your circumstances and preferences. If your bile acids are more than 100 micromol/L or if you have other risk factors, you will be advised to have continuous monitoring of your baby's heart using a machine called a CTG.

Having ICP does not affect your pain relief options in labour. For more information about pain relief during labour see the Labour Pains website (labourpains.org) from the Obstetric Anaesthetists' Association.

## What follow-up should I have after birth?

ICP symptoms get better after birth. It can take several weeks for your blood tests to return to normal. At your 6-week postnatal check your healthcare professional should make sure that your itching has gone away and arrange blood tests to make sure that your liver blood tests and bile acids have returned to normal. If you still have symptoms or if your blood tests have not returned to normal by this time, you may be referred to a specialist for further investigations.

## Is there anything else I should know?

There is an increased chance that you will have ICP again in future pregnancies.

Your liver function tests and bile acids should be checked at the start of any future pregnancies and you should tell your healthcare professional if you develop any symptoms.

ICP does not affect your choice of **contraception** once your liver blood tests and bile acids have returned to normal. If you take an estrogen containing contraceptive such as the combined pill and develop itching you should see your health care professional immediately for review.

If you have had ICP, it is still possible for you take HRT in the future.

#### **Further information**

ICP Support: https://www.icpsupport.org

British Liver Trust: https://britishlivertrust.org.uk

## Making a choice

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## **Ask 3 Questions**

If you are asked to make a choice, you may have lots of questions that you want to ask. You may also want to talk over your options with your family or friends. It can help to write a list of the questions you want answered and take it to your appointment.



- 1. What are my options?
- 2. How do I get support to help me make a decision that is right for me?
- 3. What are the pros and cons of each option for me?

\*Ask 3 Questions is based on Shepherd HL, et al. Three questions that patients can ask to improve the quality of information physicians give about treatment options: A cross-over trial. Patient Education and Counselling, 2011;84: 379-85

http://aqua.nhs.uk/resources/shared-decision-making-case-studies/

#### Sources and acknowledgements

This information has been developed by the RCOG Patient Information Committee. It is based on the RCOG Green-top Guideline No. 43 *Intrahepatic Cholestasis of Pregnancy* published in July 2022. The guideline will contain a full list of the sources of evidence we have used. You can find it online at: www.rcog.org.uk/gtg43.