

Intrahepatic Cholestasis of Pregnancy (itching liver disorder)

Information leaflet



Gender inclusive language in OUH Maternity and Perinatal Services:

- This leaflet uses the terms woman and birthing person, women and birthing people and mother throughout. These terms should be taken to include all pregnant people. Similarly, where the term parent(s) is used, this should be taken to include anyone who has main responsibility for caring for a baby.
- The term partner refers to the woman or birthing person's chosen supporter. This could be the baby's father, the woman or birthing person's partner, a family member or friend, or anyone who the woman or birthing person feels supported by and wishes to involve in their care.

You have been given this leaflet because you have been diagnosed with (or are suspected of having) a condition called intrahepatic cholestasis of pregnancy (ICP). In this leaflet we will give you information about this condition. If you still have any questions after reading this leaflet, please speak to your midwife, GP or obstetrician.

What is intrahepatic cholestasis of pregnancy or itching liver disorder?

(Previously known as obstetric cholestasis)

Intrahepatic cholestasis of pregnancy (ICP) is a condition that affects your liver during pregnancy. The main symptom is itching of the skin, but it doesn't cause a skin rash or spots. It most often affects the palms of the hands and soles of the feet. In England, around 1 in every 160 women and birthing people will develop ICP.

During your pregnancy you may require treatment to help relieve the itching. The itching will then get better by itself after your baby is born.

What causes Intrahepatic cholestasis of pregnancy (ICP)?

The causes of ICP are not yet fully understood. It is thought that it could be caused by the different hormones produced during pregnancy, or that genetic (inherited) factors may be involved.

Hormones

Pregnancy-related hormones may affect the way the liver works and cause ICP. The hormone oestrogen may have an effect on the way the liver deals with a number of substances, including bile salts. Bile is a yellowish fluid that contains waste products and chemicals (known as bile salts). Bile salts usually flow from the liver into the gut, to help the digestion of food.

In ICP, the flow of bile is reduced. This causes a build-up of bile salts in the body. It is thought that it is the effect of this build-up that causes the itching during pregnancy.

Genetic factors

ICP is more common in women and birthing people from certain ethnic groups, particularly those from South American and Scandinavian regions. ICP has also been found to run in some families. If you have ICP during one pregnancy, there is a high chance that it may happen again in a future pregnancy.

How is Intrahepatic cholestasis of pregnancy (ICP) diagnosed?

If you have symptoms that suggest you may have ICP, you will be offered tests to check the function of your liver. You may also be offered tests to check for other causes of abnormal liver function.

Consultation

Tests do not always involve getting results from a laboratory. Valuable information can be obtained from talking to you about your family and medical history and from looking at your skin.

Blood tests

You may have been offered one or more blood tests for ICP. These include:

Liver function test (LFT)

The liver function test involves a number of laboratory tests which look at how your liver is working. This test is performed on a sample of your blood. Specific liver enzymes (proteins that bring about chemical reactions in the body) are checked.

Bile acid (or bile salt) test

This test measures the level of bile acids in your blood. The bile acid level can be abnormal even if your liver function test (LFT) is normal. The bile acid level is measured in units called micromol/L.

In very severe cases of ICP, or if your healthcare team think there may be a different cause for your symptoms, you may be offered further blood tests or a scan of your liver.

How soon can I expect to be given a diagnosis?

For some women and birthing people with ICP, it can take several weeks after the itching begins before a blood test can detect any problem. In the meantime, you can use creams such as aqueous cream with menthol or calamine lotion to help with the itching.

If you have a normal bile acid and liver function test (LFT) and you are still itching, then you should be offered a repeat blood test every two weeks.

What does Intrahepatic cholestasis of pregnancy (ICP) mean for me and my baby?

ICP can be a very uncomfortable condition, but it does not have any serious consequences for your health. The main symptoms are:

Itching

Itching can vary from mild to intense and is usually persistent. The itching may start any time during pregnancy, but it usually starts after 28 weeks. The itching may occur on the palms of your hands and the soles of your feet. It may also spread over your arms and legs and less commonly, on your face, back and breasts. There is no rash or spots with the itching. Many women and birthing people have described the itching as constant and at times very difficult to cope with. You may need to be careful about scratching too hard as you may damage your skin.

The itching may be worse at night and might disturb your sleep. This can make you feel tired and exhausted during the day.

ICP and the itching will get completely better after the birth of your baby and cause no long-term health problems.

Other effects

Rarely, women and birthing people with ICP develop jaundice, which is yellowing of the skin due to liver changes. Some women and birthing people feel unwell and lose their appetite. Other signs of ICP are dark urine and pale bowel movements. If you experience any of these symptoms, you should seek advice from your caregiver.

People with ICP have an increased chance of developing gestational diabetes and pre-eclampsia. If you have ICP you will be monitored for these conditions.

Your baby

There is uncertainty about how this disorder may affect your baby. There is a small increased chance of stillbirth in women and birthing people with raised bile acids of more than 40 micromol/L. The chance of stillbirth is slightly higher when bile acid levels are very high (more than 100 micromol/L). There is not an increased chance of stillbirth with bile acids less than 40 micromol/L. Your doctor or midwife will discuss your individual chance with you.

Women and birthing people with ICP are more likely to have their baby early. This is partly due to the recommendation to induce labour early and due to an increased chance of going into labour early (this happens to 1 in 10 women and birthing people).

If the level of bile acids in your blood are high, you will have an opportunity to discuss the option of having your baby early. The risks and benefits of a planned earlier birth and induction of labour will be discussed with you. You will be fully supported in making a decision that you feel is right for you and your baby. The chance of needing a caesarean section is increased following induction of labour.

Will I need extra antenatal care?

Depending upon your circumstances, you may be advised to have additional antenatal checks to monitor your pregnancy. You will probably require blood tests every 1 to 2 weeks to monitor your bile acids.

Your healthcare professional will have a full discussion with you so that you can decide together what is best for you and your baby.

What treatment can I get?

Unfortunately, there is no cure for ICP except the birth of your baby. However, we can offer you a choice of treatments to help ease the symptoms. These might include:

- Skin creams, ointments and drugs to relieve the itching.
- A drug which may help to reduce itching called ursodeoxycholic acid. Recent research has shown that, ursodeoxycholic acid was not shown to significantly reduce bile acids or reduce itching. It is not licensed for treatment in pregnancy, however it has been used for a number of years and some women and birthing people may find it helpful if their itching is very severe. There is little evidence of any harmful effects.

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

There is considerable debate about the best time for a baby to be born if you have ICP. You may be offered early planned birth of your baby, and the risks and benefits of an early birth will be discussed with you.

There is also an increased chance of your baby being admitted to the Neonatal (newborn baby) Unit because they are a few weeks early. However, each pregnancy is different. Your individual options will be explained and discussed with you so that you can make an informed choice about what to do.

Why do I need to come to follow-up appointment(s)?

After the birth of your baby, it is important to have a follow-up visit with your GP. This is to make sure your itching has gone away, and your liver is working normally. The follow-up appointment should be at about six weeks after your baby is born. If you have continuing symptoms and abnormal liver function tests this might suggest a different problem and you should be referred to a specialist.

At your follow-up appointment your GP should:

- check that the itching has stopped
- take a blood test to check your liver function to confirm that your liver is working normally
- discuss the chance that ICP may happen again in a future pregnancy
- discuss contraceptive (birth control) options with you.

Is there anything else I should know?

- Little is known about how ICP affects a baby's development in the womb. There is no scientific evidence that ICP affects your baby's growth or causes disability.
- Some women and birthing people have found that having cool baths and wearing loose-fitting cotton clothing helps to reduce the itching.
- Drinking alcohol does not cause ICP. However, it is sensible to avoid alcohol intake when pregnant, especially when there is evidence of any liver disease.
- Some women and birthing people have found that high stress situations increase the itching. There are a number of ways you can help avoid stress, including relaxation classes, mindfulness practice, counselling, support groups and complementary medicine. You can discuss these options with your healthcare professional, who should be able to help.

Sources and acknowledgements

This information is based on the Royal College of Obstetricians and Gynaecologists' (RCOG) guideline on Intrahepatic cholestasis of pregnancy and their patient information leaflet. Both of these documents are available at www.rcog.org.

Chappell LC, Bell JL, Smith A (2019). Ursodeoxycholic acid versus placebo in women with intrahepatic cholestasis of pregnancy (PITCHES): a randomised controlled trial. *The Lancet*, 394: 849-60.

Ovadia C, Seed PT, Skalvounos A et al. (2019). Association of adverse perinatal outcomes of intrahepatic cholestasis of pregnancy with biochemical markers: results of aggregate and individual patient data meta-analyses. *The Lancet*, 393: 899-909.

Wikstrom Shemer et al. (2013) Intrahepatic cholestasis of pregnancy and associated adverse pregnancy and fetal outcomes: a 12-year population-based study. *BJOG* 120 (6) p717-723

Other organisations

Intrahepatic Cholestasis of Pregnancy Support

Website: www.icpsupport.org

Telephone: 07939 871 929

Email: helpline@icpsupport.org

The British Liver Trust

Website: www.britishlivertrust.org.uk/information-and-support/liver-conditions/intrahepatic-cholestasis-pregnancy/

We would like to thank the Oxfordshire Maternity and Neonatal Voices Partnership for their contribution in the development of this leaflet.

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

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