

Immune Thrombocytopenic Purpura (ITP) in Pregnancy

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 women 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. Immune thrombocytopenic purpura (ITP) is a condition which causes the number of platelets in your blood to be reduced. Platelets are what makes blood clot and they are needed to help you stop bleeding and bruising after an injury. If you do not have enough platelets in your blood, you are likely to bruise very easily or may be unable to stop bleeding if you cut yourself.

ITP is a type of autoimmune condition (auto means against yourself). ITP causes your body's immune system to destroy your platelets. White cells in your blood and your spleen (an organ in your tummy) are part of your immune system. One of their actions is to produce antibodies, which help your body to fight infections. If you develop an autoimmune condition, your immune system can become overactive and the white blood cells will start to destroy things they shouldn't, such as your own platelets. This happens mainly in the spleen.



A normal platelet count is between 150 and 400 thousand million platelets per litre of blood. This is usually referred to by doctors just using the first three numbers, such as 150 or 400. You are unlikely to get bleeding symptoms unless your platelet count is below 20 or even 10. It is safe to perform most operations (and to have a vaginal birth) as long as your platelet count is more than 50. In order to have an epidural, your platelet count will usually need to be above 80. There are other methods of pain relief available and your obstetrician (hospital doctor) and anaesthetist (anaesthetic doctor) will discuss these with you. If you were diagnosed with ITP before you became pregnant, you may find that your pregnancy will either make the ITP better or worse. Most women and birthing people who are known to have ITP before they become pregnant do not require any treatment in pregnancy.

Diagnosis of ITP during pregnancy can be difficult, as there is no test to prove that someone has ITP, and low platelet counts for reasons other than ITP are very common in pregnancy. Your doctor will organise a number of different blood tests to make sure there is no other reason why your platelet count has fallen.

Will having ITP be harmful to my baby?

In ITP, antibodies stick to platelets – these antibodies then tell the spleen to destroy them. The antibodies can sometimes cross the placenta into your baby's circulation and stick to your baby's platelets. This can lead to your baby's platelets being destroyed.

About 1 in 4 babies born to mothers who have ITP will have a low platelet count at birth, but only 1 in 10 will have a platelet count low enough to cause a chance of bleeding. There is no relationship between how high your own platelet count is and whether your baby's platelet count will be normal or lower than normal at birth. The only factor which may predict the platelet count of your baby at birth is if you have previously had a baby who was born with a low platelet count.

In a study of babies born to mothers with ITP, mild bleeding symptoms in babies after birth were common, but only 1 baby had significant bleeding. This baby had additional medical problems, which made it more likely to bleed easily.

ITP doesn't cause babies to bleed while they are in the womb. This can be caused by another condition you may come across called NAIT (neonatal alloimmune thrombocytopenia), where babies can have bleeding complications before they are born.

Possible treatments that may be considered for your baby after birth are shown on page 6.

How is ITP treated in pregnancy?

Most women and birthing people with ITP in pregnancy will not require treatment. All treatments for ITP can have side effects and your doctor won't recommend treatment unless you have bleeding symptoms or your platelet count is very low (usually below 20 during pregnancy, or below 50 as you approach your expected due date). If you have concerns about side effects of the treatments you are offered, your doctor will be happy to discuss them further with you.

Prednisolone

The drug most commonly used to treat ITP is prednisolone, which is a type of steroid. This comes as a tablet. Steroids work by stopping your immune system from destroying your platelets.

Steroids are a good treatment for ITP and short courses are usually taken without any problems. However, steroids can have side effects, especially if you need repeated courses or you need to take them for a long time. Some of the side effects can stop your white cells from working properly – this increases your chance of getting infections.

Steroids also have other side effects, such as thinning of the bones (osteoporosis), stomach ulcers and high blood sugars (diabetes). They can change your facial appearance and cause thinning and bruising of the skin. You may feel that you want to eat more while you are on steroids and therefore you are more likely to put on weight. However, steroids have been used for decades in pregnancy and are considered safe and they do not cause the baby any harm.

Once you start taking steroids, it is very important that you do not stop them suddenly, as this may cause side effects. If you are worried about possible side effects, please discuss your treatment with your doctor before making any changes to your medication.

Intravenous immunoglobulin

The other treatment often used in pregnancy is intravenous immunoglobulin (IVIG). This is a medicine containing antibodies which is given into a vein, usually in your arm, through a drip (intravenously). Antibodies are produced by white blood cells, to fight infections. It is a human blood product, which means that the antibodies have been collected from many blood donors. This means that **if you receive IVIG you will never be able to donate blood in the UK**, even when you recover from ITP.

Nobody understands exactly how IVIG works to treat ITP, but it is thought that the extra antibodies stop your own white blood cells from destroying your platelets.

IVIG is given as an infusion (liquid mixture) through a drip into a vein over a few hours.

What are the advantages of IVIG?

IVIG works quite quickly, usually within a few days. Unfortunately, the effect only lasts a few weeks at most and so it will not cure your ITP. In pregnancy it is generally given as you approach your due date, so that your platelet count is high enough for you to have a vaginal birth or caesarean section, if needed.

What are the disadvantages of IVIG?

There is a small chance of a reaction (such as a fast heart rate or breathlessness) while the IVIG is being given, so you will be monitored closely during this time. There is also a small chance of developing a rare complication called aseptic meningitis. This causes a headache, neck stiffness and a dislike of bright lights. This usually gets better on its own, but if you develop any of these symptoms after treatment with IVIG you must get medical help immediately.

IVIG can very rarely cause kidney damage and there is also an extremely small chance (less than one in many millions) of getting infections such as hepatitis and HIV (this is because IVIG is made from donated blood).

Will ITP affect what happens when I go into labour?

Your platelet count will be monitored very regularly during your pregnancy, so that treatment can be given to raise your platelet count before giving birth, if needed. For most women and birthing people, ITP does not change their birth plan. As long as your platelet count is above 50, you can have either a vaginal birth or a caesarean section.

As we will not know whether your baby has a low platelet count until after they are born, we will try to avoid any interventions which may cause bleeding during the birth, such as the ventouse (suction cup). If you have previously had a baby born with a very low platelet count, the option for a planned caesarean section will be discussed with you.

What will happen after my baby is born?

A sample of your baby's blood will be taken from the umbilical cord to check their platelet count. If it is low, they will need to be monitored carefully with blood tests until the low platelet count increases. The paediatrician (baby doctor) may also recommend an ultrasound scan of your baby's head if their platelet count is very low.

Even if your baby has a low platelet count they are likely to otherwise be very well and you and your baby should be able to be discharged home. **However, if your baby develops any bleeding after you have left hospital, contact the Accident and Emergency Department (A&E) at the John Radcliffe Hospital on 0300 304 7777 urgently**.

You can also ring 999 for immediate help and advice.

Your baby will need to be reviewed and their platelet count checked.

Symptoms of bleeding can include:

- bleeding from the mouth or nose
- blood in your baby's urine or stools (poo), or in the nappy
- a rash of dark purple spots (that often look like pinpricks on your baby's skin), that do not fade when pressed
- a change in your baby's behaviour, such as becoming very sleepy or irritable.

It is very unlikely that your baby will need treatment, even if their platelet count is low. Treatment may be required if their platelet count is below 30, or if your baby has any bleeding symptoms. Babies are usually treated with a platelet transfusion. This involves donor platelets being given to your baby through a drip into a vein.

Transfusions in the UK are very safe. There is a small chance your baby will have a high temperature or reaction (such as a rash) during the infusion, but this can be treated with paracetamol or other medications, if needed. The chance of your baby getting a viral infection such as HIV and hepatitis is extremely rare. Less than one in a million babies will get a viral infection after a platelet transfusion. If your baby is given a platelet transfusion, it is important that you tell them this when they are older, as they will also not be allowed to donate blood.

As your baby's low platelet count is due to antibodies crossing from your circulation into their circulation before birth, the problem will get better once these antibodies have gone. This usually happens in the early weeks after giving birth. Very rarely, treatment with IVIG or steroids may be recommended for your baby. Your paediatrician (baby doctor) will discuss this with you in more detail, if necessary.

How will ITP affect future pregnancies?

If you have ITP, it may become worse during pregnancy. If you have had a baby before and your ITP became worse during that pregnancy, it is likely this will happen the next time you are pregnant. If your baby is born with a low platelet count, it is likely that if you become pregnant again and develop ITP, this baby will also be born with a low platelet count. It is important you tell your GP and haematologist (a doctor that specialises in blood disorders) if you are thinking about becoming pregnant again, so they can discuss this with you.

Will there be any long-term effects as my baby grows up?

Once the antibodies have broken down after a few weeks, your baby will have a normal platelet count and there will be no effect on their normal growth and development. Autoimmune conditions can sometimes run in families, but it is unlikely that your child will suffer with ITP later in life. Page 11

Where can I find further information?

The ITP support association has a very good website, which has some useful information about steroid treatment and IVIG. Their website address is: **www.itpsupport.org.uk**

If you have any specific questions, your haematologist, midwife, obstetrician and/or paediatrician will be able to help you.

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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