

# Living life *with* ITP

Information about ITP. How ITP can affect you. What treatments are available, as well as suggestions and advice to enable you to live your life in the best way possible.





## What is ITP?

A low platelet (thrombocyte) count is a common indicator of ITP, which is caused by the immune system attacking the body's healthy platelets. This in turn leads to an increased risk of different forms of bleeding.

Platelets help your body stop bleeding after an injury by clotting the blood in the damaged blood vessel. When you have an abnormally low platelet count, it is called thrombocytopenia. Your platelet count is measured by taking a blood sample.

## Frequently asked questions about ITP

ITP can occur in both children and adults. It is somewhat more common among women than men, and the risk of developing ITP is higher the older you get.

3.3

PER  
100,000

Every year 3.3 people per 100,000 adults are diagnosed with ITP

9.5

PER  
100,000

9.5 adults per 100,000 have been diagnosed with ITP



ITP is more common among women than men, and mainly occurs between the ages of 30 and 60



Most children affected by ITP are between the ages of 2 and 6 at the time of diagnosis

## Causes of ITP

Your body's own immune system attacks the platelets. The damaged platelets are then transported away, usually via the spleen.

Sometimes when you have ITP, fewer platelets than normal are produced. The reason for this is still not known.

In some patients, ITP may be linked to viral or bacterial infections, such as glandular fever or other common viral infections. These infections can activate or initiate an immune response resulting in ITP. A minority of children with acute ITP will develop chronic ITP.

## Two types of ITP

There are two types of ITP: primary ITP and secondary ITP.

**Primary ITP** occurs when you have low levels of platelets in your blood that cannot be explained by other causes or conditions.

**Secondary ITP** is caused by the immune system being triggered by something, for example:



**Following a viral or bacterial infection**



**Following vaccination**



**Following exposure to a toxic substance**



**In association with another illness  
(Such as systemic lupus erythematosus, HIV and lymphoma)**

Some patients will have only one acute episode of ITP, and then their platelet count returns to normal levels after a short time without any need for treatment. Other patients will have a reduced platelet count for a longer period of time. Most of them do not need any treatment. However, there is a group of patients with ITP who may develop refractory or chronic ITP. A disease is called refractory if specific treatments do not have any effect. These patients often have very low platelet counts over a long period of time, despite the fact that more than one form of treatment has been tried.

## Symptoms of ITP

You can have one or more symptoms of ITP



**Bruises that do not have an obvious cause, or if you bleed easily following minor injuries or cuts**



**Nosebleeds, bleeding gums or dark-coloured blood blisters in the mouth**

## Diagnosing ITP

An investigation into ITP must rule out other causes. Therefore, it can include a thorough check-up with physical examinations, blood tests, imaging tests, and sometimes bone marrow biopsies.

A healthy individual has billions of platelets circulating around their body. In simple terms, doctors usually estimate a normal platelet count to be between 150 and 400 billion per litre of blood. The threshold for the diagnosis of ITP is 100 billion platelets or less per litre of blood.

## Treatment for ITP

- **Wait and see.** No treatment will be given for the time being, but your doctor will carry out regular check-ups to monitor your condition.
- **Treatment options.** There are a number of different treatments available to help increase your platelet count. Your doctor will discuss appropriate options with you.
- **Surgical intervention.** Surgery may be necessary if you need to increase your platelet count, and medication is not suitable or does not have the desired effect. Then your doctor may discuss removing your spleen, also known as a splenectomy.

Treatment is only needed if you have pronounced symptoms of ITP and/or a very low platelet count. Treatment is rarely given to patients with a platelet count of over 30 billion per litre of blood. Unless it is necessary due to another illness or treatment, for example if you need anticoagulants due to heart disease.



**Small spots on the skin that are called petechiae**



**Feeling tired or exhausted**



**Blood in the faeces or urine**



**Heavier periods than normal**

## **ITP and pregnancy**

Sometimes a low platelet count can be detected when a woman is pregnant. It is relatively common as pregnancy itself can reduce the platelet count, and it accounts for 70–80 percent of all new cases.

It is normal for the platelet count to drop during the third trimester. During this period, the platelet count is also measured more frequently to ensure that the expectant mother has an adequate platelet count for a healthy birth.

In a small number of cases of pregnant women with ITP, the foetus's platelets can also be affected. However, they usually increase about a week after birth when the baby has started to develop its own immune system.

**If you are uncertain about anything related to your ITP, always ask your doctor!**

## ITP in children

ITP in children, as well as in adults, is a diagnosis of exclusion. That is, a diagnosis can only be made after other possible diseases have been ruled out.

### **Symptoms in children are the same as in adults and may include:**

- Bruises without an obvious cause.
- Small spots on the skin that are called petechiae.
- Excessive bleeding from the gums or nose as a result of minor injuries.
- Dark blood blisters in the mouth
- Blood in the faeces or urine.
- Periods that are heavier than normal.

Most children with ITP do not have severe problems with bleeding despite a low platelet count.

It can be difficult when girls with ITP get their period. Then it is important to discuss any worries and concerns you may have with your doctor or nurse.

Other awkward situations can arise when you have visible bruises. In the case of adolescents and young children, there may be speculation about abuse and mistreatment. Therefore, it is important to inform the staff at your child's preschool or school about their diagnosis.

Treatment for ITP in children is often not necessary. If treatment is required, it is the same as for adults with ITP. Decisions about treatment are based on the child's medical history and lifestyle.





# ITP and lifestyle

## Your diet

It is always beneficial to have a healthy lifestyle, including following general dietary recommendations and eating fruit and vegetables.

You should inform your doctor if you are taking any medication, dietary supplements or other substances. They can affect your immune system as well as your platelet count, but they can also interact with other prescription drugs. Talk to your doctor before taking NSAIDs such as acetylsalicylic acid, diclofenac and ibuprofen, etc.

## Your lifestyle

Try to avoid activities with a high risk of impact and injuries that can cause internal bleeding. If your child has ITP, it may be necessary to avoid contact sports and activities such as climbing, cycling or skateboarding. Wear helmets and other protective gear if your child still wants to participate in such activities.

It can sometimes be helpful to keep a diary to see the connection between the platelet count and any complications.

**Most  
importantly  
of all**

**The vast majority  
of people with ITP should  
be able to live a full  
life and have a good  
quality of life.**



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