

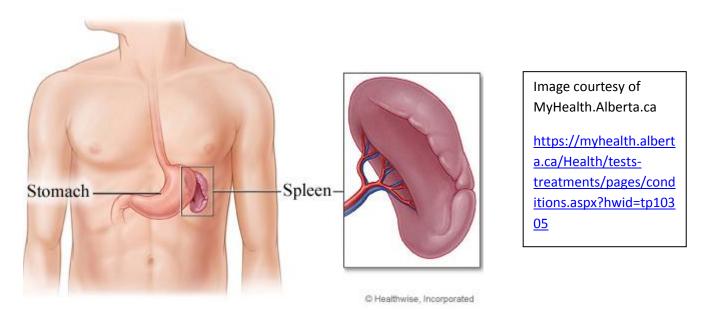
Immune Thrombocytopenia (ITP) Information for Patients

What is ITP?

ITP is a blood condition causing a low platelet count. A normal platelet count is 150 to 400 thousand million platelets per litre of blood. We normally use the first 3 numbers to refer to your platelet count.

Platelets help your blood to clot and stop you from bleeding if you suffer an injury or have surgery or dental work done. If you have a low platelet count, you may bruise easily or have difficulties stopping bleeding if you injure yourself.

When you have ITP, your immune system is overactive and makes antibodies that destroy your own platelets more quickly than you body can make new ones. Most likely, your platelets will be destroyed in an organ in your abdomen called your spleen.



If you are have ITP but are otherwise fit and healthy and not on any medications that may cause you to bleed, you are unlikely to have severe bleeding if your platelet count is above 20. It is safe to have most operations if your platelet count is above 50.

What are the symptoms of ITP?

Common symptoms of ITP include petechiae (pinprick rash of blood spots), easy bruising, nose bleeds, gum bleeds, blood blisters (black blisters on your tongue and the inside of your mouth), fatigue and unusually heavy periods.

How is ITP diagnosed?

There is no specific test to diagnose ITP but your doctor or a haematologist (blood specialist) will make this diagnosis if there is no other explanation for your low platelet count and there are no other unexplained abnormalities in your blood results.

A bone marrow biopsy may be done if you do not respond as expected to treatment, have other symptoms such as sweats and weight loss. Your doctor will explain this procedure in more detail, if it needs to be done

Who gets ITP?

ITP can affect people of any age or race.

In children, ITP often develops after a viral illness and gets better without any treatment.

In adults, ITP is more common in women. ITP in adults usually needs to be treated with medication. ITP can be associated with autoimmune disorders like SLE (Lupus); HIV or Hepatitis. If your ITP is associated with other disorders, you may require different treatment.

How is ITP treated?

If you need treatment, you will normally be given steroids. These help to reduce the rate of destruction of your platelets by your immune system. Steroids usually work well and are given for a short period of time. Steroids may take days to weeks to work. Dexamethasone and prednisolone are the common steroid preparations used.

Steroids are usually well tolerated if used for a short period of time. Potential side effects include increased risk of infection, increased appetite and blood sugars, thinning of bones (if used for long periods), erratic mood, sleep disturbance, weight gain and stomach ulcers. These side effects normally go away after stopping steroids. Your doctor may give you extra medications to help you to avoid some of these side effects.

You should not stop your steroids unless advised by your doctor. You may need to gradually cut down your dose to avoid problems such as weakness and fatigue.

What other treatment options are there?

Your doctor may consider other treatments in the following circumstances:

- a) you don't respond to steroids
- b) your ITP has come back quickly (relapsed) after your steroids have been stopped or the dose reduced
- c) your ITP has come back and you or your doctor do not want to use steroids again due to previous side effects.

If your platelet count is above 20 and your doctor does not consider you at high risk of bleeding, your doctor may not recommend any treatment and may simply monitor you and your platelet count, in order to avoid any potential side effects associated with treatment.

Other treatment options include:

Danazol (oral tablets)

This reduces platelet destruction and may take 3-6 months to work.

Potential side effects:

All patients – Abnormal liver function, increased cholesterol

Female patients - Male pattern hair growth

Dapsone (oral tablets)

We do not fully understand how this works in ITP. It may take 3 weeks to work.

Potential side effects:

Nausea, bloating, anaemia and skin rash

Helicobacter pylori treatment (oral tablets including tablets that reduce stomach acid and antibiotics)

Treating this infection may treat the potential cause for ITP.

Potential side effects:

Allergic reaction to tablets or antibiotics

Immunosuppressants (oral tablets, for example, azathioprine, cyclophosphamide, cyclosporine and mycopheonlate mofetil)

You may be given one of these tablets to reduce platelet destruction. They may take 4 weeks to 6 months to work.

Potential side effects:

Increased risk of infection, anaemia

(Your doctor will give you more detailed information on the specific tablet you are given.)

Intravenous Immunoglobulin (IVIg) – Intravenous infusion (Drip into vein)

This blocks platelet destruction temporarily and may take 24 – 96 hours to work.

Potential side effects:

Headache, fevers, chills, may cause meningitis - like reaction

Rituximab - Intravenous infusion (Drip into vein)

This reduces platelet destruction and may take 1 - 8 weeks to work depending on dose given.

Potential side effects:

Fever, chills, rash, increased risk of infection and rarely: allergic reaction

Splenectomy – operation (surgery) to remove spleen

This removes the major site of platelet destruction and may take 3 weeks to work.

Potential side effects:

Complications related to surgery (10%), death (0.2-1%), failure of treatment,

Long term: increased risk of infection or clots (stroke, heart attacks, clots in legs or lungs)

(You will be seen by your surgeon to discuss the procedure in more detail before making your final decision)

Thrombopoietin receptor agonists -

Eltrombopag (oral tablet)

Romiplostim (subcutaneous injection ("injection under the skin" once weekly)

These drugs increase the rate of platelet production and may take 1-2 weeks to work.

Potential side effects:

Headaches, abnormal liver function, increased risk of clots (heart attacks, strokes, clots in legs or lungs), risk of bone marrow scarring

When should I seek help?

You should seek help if you have been told that you need an operation or dental work or if you have any of the following problems:

- A nosebleed lasting 30 minutes or more
- Gum bleeding that occurs spontaneously or lasts for a long time after you have finished brushing your teeth
- Blood in your urine or stool
- Blood blisters in your mouth or on your lips
- Trauma including a fall from a height or head injury
- Persistent or severe headache with loss of vision, vomiting or drowsiness
- Very heavy periods

Who should I contact?

Please contact your GP urgently or your haematology team, if you have any of the problems described above.

Haematology Secretaries Royal Infirmary of Edinburgh (RIE) – For **routine** enquiries Monday-Friday 8:00 am – 4:00 pm Tel: **0131 242 6814**

Haematology Secretaries St John's Hospital (SJH) - For **routine** enquiries Monday-Friday 8:00 am – 4:00 pm Tel: **013506 523365**

Haematology Secretaries Western General Hospital (WGH) - For **routine** enquiries Monday-Friday 8:00 am – 4:00 pm Tel: **0131 537 3759** Haematology Registrar On –call (RIE or SJH or WGH) – For **urgent** enquiries or enquiries outside the times specified above Tel: **0131 536 1000** (ask for RIE or SJH or WGH Haematology registrar)

References and Further Reading

Thanks to the ITP Support Association UK team and Oxford University Hospital Team for allowing us to use their information leaflets to design this information leaflet. If you wish to do further reading, please see website links below.

ITP Support Association UK https://www.itpsupport.org.uk/index.php/en/

OUH Patient Information Leaflet <u>https://www.ouh.nhs.uk/patient-guide/leaflets/files/12388Pitp.pdf</u>

International Consensus report on ITP (Provan et al, 2010) <u>http://www.bloodjournal.org/content/bloodjournal/115/2/168.full.pdf?sso-checked=true</u>

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