

Understanding Immune Thrombocytopenia (ITP)

Cancer Services and Clinical Haematology

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Information and treatment plan

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This booklet belongs to the person whose details are below. If found please return.



Contact details for the healthcare staff looking after you

Consultants Dr M. Garg and Dr H. Qureshi

Allergies

Name/address of GP.....

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Telephone number.....

Other medical conditions

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Current medicines

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**Health information and support is available at www.nhs.uk
or call 111 for non-emergency medical advice**

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To give feedback about this information sheet, contact InformationForPatients@uhl-tr.nhs.uk

What is ITP?

Immune thrombocytopenia (ITP) was previously known as idiopathic thrombocytopenic purpura. ITP is a rare bleeding disorder in which the body's immune system (auto-antibody) destroys platelets in the blood.

Platelets help blood to clot when we injure ourselves: they act as an initial plug to stop blood leakage before the rest of the blood clotting process begins. They are made in the bone marrow and released into the bloodstream. They travel through the body for about seven days, before they are removed by the spleen. The spleen is an organ that lies at the top of the tummy (abdomen) under the ribs on the left-hand side.

ITP occurs when the immune system is over-active and the white cells destroy things they shouldn't. Usually this destruction occurs in the spleen.

ITP is an autoimmune condition ("auto" means against yourself). Some people with ITP have other autoimmune conditions (such as rheumatoid arthritis) or infections (such as HIV or hepatitis).

What are the treatment options for ITP?

No treatment

A normal platelet count is between 140 and 400. It is unusual to have any bleeding symptoms unless the platelet count is less than 10. Most operations and procedures are safe if your platelet count is more than 50. This means that not everyone with ITP will need treatment.

Steroids

If your ITP needs treating we will usually give you steroids. Steroids reduce the antibody levels in the blood and stop the immune system from destroying the platelets. You will usually be given a short course of a high dose of steroids which will then be gradually reduced.

It is important that steroids are not stopped suddenly as your body will start to rely on them.

A common side effect of taking steroids is irritation of the stomach lining and you will usually receive a medication to reduce this risk. Other side effects include high sugar levels (diabetes), increased risk of infection and, over time, thinning of the bones.

Intravenous Immunoglobulin (IVIG)

This may be used if steroids have not worked or if they are not suitable for you. IVIG contains antibodies from human donors and is given through a drip into your vein (intravenously) over several hours. If you receive IVIG you will not be able to be a blood donor in the future.

No one knows exactly how IVIG works but we think the extra antibodies stop your own cells from destroying your platelets.

The effects of IVIG only last for a few weeks but it does work quickly (within 24 hours). It can be useful if the platelet count needs to be raised quickly, for example if serious bleeding has occurred or for an operation or procedure.

It is possible to have a reaction to IVIG, so you will be monitored by the nurses.

A rare complication (which happens in less than 1 in 200 patients) of IVIG is swelling in the brain (aseptic meningitis) which causes a headache, stiff neck and dislike of bright lights. If this does happen it usually gets better within a few days.

There is a very small risk that you could become infected with a virus such as HIV or hepatitis (this happens in less than 1 case in many millions).

Other treatments for ITP

You may need other treatments if:

- Steroids did not work (this is known as refractory ITP)
- Your platelet count fell while the steroid dose was being reduced - (steroid-dependent ITP)
- Your ITP has relapsed and steroids are not the best treatment for you

There are other treatments which your doctors will discuss with you if they are needed:

- Removal of your spleen (splenectomy)
- Drug treatments such as rituximab, romiplostin (also known as NPlate®) and eltrombopag (also known as Revolade®)
- Immunosuppressants, for example mycophenolate mofetil (MMF), azathioprine, cyclophosphamide or cyclosporine.

Long-term follow-up

The majority of patients with ITP have a good result from treatment and will be able to come off their treatments. They are discharged from the clinic after attending clinic for two years.

They should always mention ITP if any intervention (especially surgical or dental) is planned. All patients have an open appointment to come back to ITP clinic by ringing the clinic coordinator.

When should I contact my GP or the hospital?

You should contact the hospital using the numbers at the back of this booklet if you have:

- a purple rash also called purpura (often on the lower legs) which does not fade when you press it. This may be a sign of a low platelet count. Please ask your GP to carry out a full blood count.
- minor bleeding symptoms such as nose bleeds or bleeding in the mouth. Please ask your GP to carry out an urgent full blood count or contact the haematology department.
- blood in your stools or sick (vomit) or black sticky stools or other signs of bleeding you may need urgent medical help. Please contact the haematology department or go to the emergency department of the nearest hospital.
- a severe headache when you have low platelets please contact haematology urgently. It may be a sign of bleeding into the brain. This is a very rare but serious complication of ITP.

On the next few pages there is space for you and your health care team to record any investigations you have had and any drug therapy that you have been prescribed.

Record of relevant investigations

Virology: date: .../.../.....

HIV.....

Hepatitis B Ag.....Hepatitis B core antibody.....

Hepatitis C.....

Helicobacter Pylori.....

Immunology: date .../.../.....

Serum Immunoglobulins.....paraprotein.....

Autoantibody screen.....

Coeliac screen.....

Anticardiolin antibody IgG.....IgM

B2 Glycoprotein IgG.....IgM.....

Lupus anticoagulant

PIFT:Date: .../.../.....

USS/CT abdomen .../.../.....

Thyroid Function test:

Bone Marrow Test : date.../.../...

.....

Haematinics: date .../.../.....

B12.....Folate.....Ferritin.....Vit D.....

DEXA scan

Date:.../.../..... Report:.....

Date:.../.../..... Report:.....

LDH.....

Haptoglobin.....

Reticulocyte.....

Clotting screen.....

D-dimers.....

Medication plan

[illegible]

Other medication.....

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[illegible]

Other medication.....

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[illegible]

Other medication.....

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Contact details**Emergency (24 hour help line)****Telephone: 0808 178 2212****Osborne Assessment Unit (24 hours)** Telephone: 0116 258 6681**Osborne Day Ward (Monday to Friday 8:00 am to 5:00 pm) (for infusions)**

Telephone: 0116 258 5263

Clinic coordinator (to change appointments or ordering medicines)

Telephone: 0116 258 6138

Haematology Clinic Reception Desk (Monday mornings only)

Tel: 0116 258 5708

Haematology Clinic Nurses' desk (on clinic day)

Osborne Building Leicester Royal infirmary

Tel: 0116 258 5759

Sources of further information**UHL Medicines Information Centre (Monday to Friday 8:30 am to 5:30 pm)**

Telephone: 0116 258 6491

ITP Support AssociationWebsite www.itpsupport.org.uk

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔
على هذه المعلومات بلغة أخرى، الرجاء الاتصال على رقم الهاتف الذي يظهر في الأسفل

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