Understanding immune thrombocytopenia (ITP)

Cancer Services and Clinical Haematology

Information and treatment plan

Last reviewed: November 2024
Next review: November 2027
Leaflet number: 613 Version: 4

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

Visit www.leicestershospitals.nhs.uk for maps and information about visiting Leicester's Hospitals
To give feedback about this information sheet, contact InformationForPatients@uhl-tr.nhs.uk

What is ITP?

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

Platelets help blood to clot when we injure ourselves. They act as a first 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 7 days. They are then removed by the spleen. The spleen 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. The white cells destroy things they should not. 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 lower the antibody levels in the blood. They stop the immune system from destroying the platelets. You will usually be given a short course of a high dose of steroids. This will then be gradually reduced.

Steroids must not be stopped suddenly as your body will start to rely on them.

A common side effect of taking steroids is irritation of the stomach lining. You will usually get a medication to reduce this risk. Other side effects include high sugar levels (diabetes), higher 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 has antibodies from human donors. It is given through a drip into your vein (intravenously) over a few hours. If you have 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). This 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

TPO RA: Thrombopoietin receptor agonists : romiplostin (also known as NPlate®) and eltrombopag (also known as Revolade®) Avatrombopag (also known as Doptelet) . They trigger the bone marrow to make more platelets

Immunosuppressants or immune modulators also called steroid sparing agents. Mycophenolate mofetil (MMF), azathioprine, cyclophosphamide, cyclosporine, Rituximab and fostamatinib. These adjust the immune system to stop or reduce making the antibody against own platelets

Long-term follow-up

Most 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 2 years.

You should always mention ITP if any treatment (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 Immunoglobulis…………………….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…/…./…

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Haematinics: date …/…./……..

B12……..Folate…….Ferritin………..Vit D……

DEXA scan

Date:…/…./…….. Report:……….

Date:…/…./…….. Report:………...

LDH…………………………

Haptoglobin………………….

Reticulocyte………………….

Clotting screen……………….

D-dimers…………………………

Medication plan

Date	WBC	Hb	Platelets	Neut	Bleeding symptoms	Prednisolone dose	IVIg	MMF/ Aza/ rituximab	TPORA	Other

Other medication

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Medication plan

Date	WBC	Hb	Platelets	Neut	Bleeding symptoms	Prednisolone dose	IVIg	MMF/ Aza/ rituximab	TPO-RA	Other

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Medication plan

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Other medication

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Contact details

Emergency (24 hour help line)	**Phone: 0808 178 2212**
Osborne Assessment Unit (24 hours)	Phone: 0116 258 6681

Osborne Day Ward (Monday to Friday 8:00 am to 5:00 pm) (for infusions)

Phone: 0116 258 5263

Clinic coordinator (to change appointments or ordering medicines)

Phone: 0116 258 6138

Haematology Clinic Reception Desk (Monday mornings only)

Phone: 0116 258 5708

Haematology Clinic Nurses’ desk (on clinic day)

Osborne Building Leicester Royal infirmary

Phone: 0116 258 5759

Sources of further information

UHL Medicines Information Centre (Monday to Friday 8:30 am to 5:30 pm)

Phone: 0116 258 6491

ITP Support Association

www.itpsupport.org.uk

اگر آپ کو یہ معلومات کسی اور زبان میں درکار ہیں، تو براہِ کرم مندرجہ ذیل نمبر پر ٹیلی فون کریں۔
على هذه المعلومات بلغةٍ أخرى، الرجاء الاتصال على رقم الهاتف الذي يظهر في الأسفل
જો તમને અન્ય ભાષામાં આ માહિતી જોઈતી હોય, તો નીચે આપેલ નંબર પર કૃપા કરી ટેલિફોન કરો

ਜੇ ਤੁਸੀਂ ਇਹ ਜਾਣਕਾਰੀ ਕਿਸੇ ਹੋਰ ਭਾਸ਼ਾ ਵਿਚ ਚਾਹੁੰਦੇ ਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਹੇਠਾਂ ਦਿੱਤੇ ਗਏ ਨੰਬਰ ‘ਤੇ ਟੈਲੀਫੋਨ ਕਰੋ।
Aby uzyskać informacje w innym języku, proszę zadzwonić pod podany niżej numer telefonu

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