



ITP 'n stuff

Answers to questions about teenage ITP

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INTRODUCING ITP...

This booklet was written to answer some of the questions you may have about ITP. Learning about the condition will help put you in control so that you can make the decisions about your care or treatment. Many teenagers with a chronic illness find that taking an active part in their care helps them feel stronger and better equipped to cope.

If you have just been diagnosed with ITP it can seem very scary at first, especially if you have never heard of it before – even its name can sound serious – immune thrombocytopenia – it's hard enough just to say!

But once you do begin to know a little about ITP you'll probably find that it's not nearly as terrifying as it seemed at first. Of course, there may have to be some changes to the way you do things, like being more careful and not doing dangerous sports. Most people with ITP live a normal life; you don't die early (unless you fall off a cliff or something, but that's nothing to do with ITP) and you don't have to go on a boring diet, or stop having fun.

What you do have to do is accept that you have ITP, be a bit more careful about knocks and injuries, then learn to live with it and get on with your life. And sometimes the ITP just goes away on its own – isn't that nice, especially as you didn't ask for it in the first place!

There will be doctors to see, platelet counts to have, treatments and stuff like that – but you don't have to be different and most people won't need to know that you have ITP unless you decide to tell them. Because in almost every way you'll be as normal as everyone else, unless you're one of those rare people who have complications.

ALL ABOUT ITP

What is ITP?

ITP is a disorder in which your immune system, for some reason best known to itself, suddenly decides to start zapping the platelets circulating in your blood and although your bone marrow is busy making new ones, it can't keep up.

Normally, the platelets clump together at the wound to act as the initial plug to stop bleeding while the complete clotting process takes place. But if you don't have enough platelets you may experience longer than normal bleeding before it stops.

Is ITP the same as haemophilia?

Not quite. In fact there are 13 factors working in the blood which help it to clot properly (which is very complicated, as you can imagine) and if one or more of them are missing there can be difficulties with the clotting process. With ITP a lack of platelets is the problem, but in haemophilia one of the 13 factors (usually factor 8) is low or missing. In both disorders there can be troublesome bleeding, but the bleeding symptoms are different. Another difference is that haemophilia is inherited (and permanent), but you don't get ITP from your parents, so don't give them grief about it!

What does it actually mean?

Immune means a disorder of the body's immune system, and thrombocytopenia means there is a shortage of platelets. It used to be called idiopathic thrombocytopenic purpura (idiopathic means of unknown origin and purpura means that the skin has purple bruises) but that was even more difficult to say so fortunately doctors decided to shorten the name!

What are the symptoms of ITP?

Usually the first thing you'll notice is unexpected bruising, often without causing any pain, or you may have nosebleeds or black mouth blisters. Girls might find that their periods are extra heavy or last longer than usual.

How does the doctor know it's ITP?

ITP is normally diagnosed by a platelet count. A sample of blood is taken and the platelets counted on an electronic machine. A normal platelet count is between 150 and 400 and if you have ITP it might be as low as 1 or 2!

If the count is really low (20 or less) this may lead to bleeding problems. There are other tests which can be done to check for ITP, like a bone marrow examination or measuring the antibody levels (all high-tech stuff), but these may not be necessary in straightforward cases.

Exactly what is a platelet count?

As you might expect, it's a way of counting the number of platelets in a fixed quantity of blood. Normal blood contains 150,000 – 400,000 platelets in a cubic millimetre of blood, and if you had 25,000 platelets in your cubic millimetre of blood you would have a platelet count of 25.

On extremely rare occasions people with ITP are told they have a count of zero. This means they have too few platelets circulating in their blood to register on the counting machine when the blood sample is taken, but not all platelets circulate in the blood.

How do I know it's not something more serious?

ITP is caused by your body's immune system getting confused and is not the start of another illness, like cancer or leukaemia. In the unlikely event that you have any other problems in addition to ITP symptoms your doctor will run additional tests, but teenagers with a low platelet count usually have 'simple' ITP.

Why does ITP happen?

The reason it happens is not known, but it's to do with the body's defence mechanism which zaps healthy platelets. The immune system guards your body against infections by killing off 'foreign' organisms which it discovers wandering about inside you. Unfortunately, in ITP the immune system wrongly attacks your platelets.

Did I catch it?

No, you didn't catch it. ITP cannot be caught by someone and you can't give it to someone else (not even your worst enemy). You may have got it after a viral infection, like a sore throat or a cold, but it often comes on without any apparent reason. Sometimes people get a low platelet count after taking certain medicines, in which case the medication will usually be stopped unless you have more important reasons for it to be continued.

I'm still scared I might not live so long.

There's no evidence to show that people with ITP live shorter lives than anyone else and the only real risk is from a severe haemorrhage which is very, very rare. If you want the honest truth, there's much more risk to your life span from regular smoking, binge drinking or taking street drugs than there is from having ITP. So now you know!

I'm TERRIFIED of needles!

You are not alone, but most teenagers with ITP (or haemophilia) do get used to blood tests and take them in their stride. A few unlucky people have a needlephobia which makes them feel faint, light-headed, sweaty and sick. Relaxation can help to reduce these symptoms: try slow deep breathing, counting, or lying on your back, and don't watch the needle. Ask for your blood test to be done in the phlebotomy department (the place in hospital where they take blood tests all day long) as phlebotomists are much better at it than doctors or nurses!

TREATMENT – OR NOT?

Should my ITP be treated?

You may think it's important that ITP should be treated, but that's not always necessary – especially as it often gets better of its own accord. Whether it is treated or not depends not so much on your platelet counts, but whether you have bleeding

problems. You might just have to be regularly monitored (which is called 'watch and wait') but your consultant will advise which is the best course of action for your particular case.

What sort of treatment is there?

If your platelet levels are low with troublesome bleeding (like nosebleeds or mouth blisters) you may be given steroid pills called prednisolone. This is given in high doses for a short period of time as it slows down the destruction of the platelets. It can also stabilise the blood vessels and reduce the risk of bleeding.

Another treatment given is intravenous immunoglobulin (another difficult name!), which is drip fed directly into one of your veins over several days in hospital. It may be referred to under another name as it is made by several drug companies under different trade names, but it is often called IVIG for short.

Who will be treating me?

This can depend on your age, your treatment and sometimes where you live. If the ITP is very mild you may only need to see your GP at your local surgery, but usually you will be seen in hospital. Most people under 16 years will be seen by a paediatrician (a specialist in childhood illnesses), but if you are over 16 you will be seen by a haematologist (a blood specialist). Quite often the paediatrician and

the haematologist will put their heads together and work out your treatment between them. So if you are approaching 16 years the haematologist will probably know all about you when the transfer takes place. Although you may be adult size before reaching 16 it is important that you do not have the strong drugs that are sometimes prescribed for adults, and this is the reason that you see a paediatrician who knows what is best for someone of your age.

Are the drugs dangerous?

Prescribed drugs go through rigorous testing and all the side effects are listed, so reading the leaflet that comes with them can be scary, but remember that not everyone gets all or even any of the side effects listed. So that you know what you're up against, you'd better know that steroids can cause mood changes, weight gain, sleeplessness, acne and indigestion, but these will all disappear again when you stop taking them. Longer term steroids have more possible side effects but your doctor knows this and will work out the dose carefully so that you only take as much as you really need.

If you have immunoglobulin, you could experience temporary headaches, nausea, light headedness, shakes & shivers, or even a slight fever while it is being given. If these symptoms become severe the infusion will be stopped but you could be given anti-histamine or cortisone treatment to help you before any future immunoglobulin treatment.

Can diets or alternative medicine help?

We've run lots of surveys of our members with ITP over the years, and although they have tried lots of different things we don't know of any diet, herbs or alternative therapy that can work a magic cure (whatever the advertisements say!). Always be suspicious of adverts for wonder cures on the internet – if it sounds too good to be true it probably is! Many of these quack remedies are not tested for safety, and just because something is made from a plant extract doesn't mean it can't make you ill.

Suppose treatment doesn't work?



Every person is an individual and what works well for one person may not work so effectively in another. It may take a while to get your treatments properly sorted out, so try to be a patient patient while this is done. If treatment with drugs doesn't seem to be successful a splenectomy may be considered depending on the severity of your symptoms.

A what??

A splenectomy is the surgical removal of your spleen (under anæsthetic of course). The spleen is responsible for filtering out 'foreign' or waste products from the blood but – this is the complicated bit – somehow, your healthy platelets get coated with 'antibodies' (which are normally meant to attach themselves only to foreign organisms in your body) and because they've been coated with antibodies the spleen (which is only doing the job it is meant to do) quickly zaps the platelets. It's a kind of bodily 'own goal'.

BUT, the spleen is a very important organ in so many other ways and a splenectomy is hardly ever done in teenagers (unless it is damaged in an accident) because they often recover from ITP on their own accord and removing the spleen would have been unnecessary. Also, people who have had their spleen removed (who are known as 'asplenic') are more likely to get infections and fevers and will probably have to be on antibiotics for the rest of their lives. They'd also need to be vaccinated against pneumococcus and haemophilus before the operation as well.

If I need an ITP specialist, how do I find one?

If you are having real difficulty with ITP you (or your parents) can ask that you be referred to a paediatric haematologist or professor of haematology (depending on your age) at your nearest big teaching hospital, or ask to see one of the ITP Support Association's specialist medical advisors. To get this second opinion you will need to be referred to the new doctor by your consultant or GP so your new doctor sees your medical notes and knows what has happened to you so far.

Will a splenectomy be successful?

Can be: About 60-70% of those who have one find that it's fully successful and at least the others usually have better platelet counts. But, you can't put the spleen back once it's taken out so doctors usually try to sort out the problem with other treatments first.

FRIENDS & SCHOOL**Coping with friends**

You might find it hard to cope with feeling different to friends and classmates, and may be tempted to keep your ITP a secret. But remember that lots of teenagers have health conditions such as asthma and eczema, some have learning difficulties like dyslexia, others may have problems at home – very few escape without something they wish they didn't have to put up with. Learning about ITP in this book will help you if you decide to explain it to your friends.

What should I tell my friends?

ITP is not infectious, so tell your friends that there is nothing to fear from being near you and there's no need for them to treat you any differently now, since you're just the same person as you were before the ITP was diagnosed. They do have to be careful not to bash you or knock you around because you can bruise easily, but you have to be more careful about that as well now.

Coping with school

You may have time off school seeing doctors and having blood tests, so it is important to make sure your teachers know if you have missed work or get behind with homework or course work. If it gets to be a real problem ask your parents to talk to the head teacher; don't let things build up so you get stressed about the work. If ITP or its treatments make you feel tired try to pace yourself and take a rest or break at regular intervals.

Should I tell my school about the ITP?

A very good idea. The ITP Support Association has a Guidelines pamphlet which gives teachers some useful information about ITP. The Association can also supply an ITP HealthCare Card which gives urgent medical information about you and who to contact in case of an emergency. These are only £5 each, are the size of a bus pass.

Will there be any jobs that I can't do?

When you leave school or university, there will be just a few jobs you can't do – if you have ITP you won't pass the medical to join the army, navy, RAF or police, nor would it be a good idea to be a professional rugby player, or a stunt artist and jump out of moving trains. But that still leaves you lots of choice and when you leave school there is no reason why you can't go to university or college, or to start work full time. It might be an idea if your tutors/employer know about your condition and, if necessary, we can give him or her any information that is needed.

Anyone else I need to tell?

Well, your dentist ought to be told. We have a leaflet written specially for dentists which you can ask for (free, with a stamped addressed envelope) which gives information about treating patients with ITP. If you see any other medical practitioner (like an osteopath or physiotherapist – people who deal with bones and muscles, etc.) they should be informed also. Otherwise use your normal, common sense about telling people.

COPING WITH YOUR FAMILY

Why don't my family understand how I feel?

People with ITP usually don't look ill. If you have younger brothers or sisters they may wonder what all the fuss is about, especially if they can't see anything particularly wrong. It may be hard for them to understand what you are going through, so talk to them and get them on your side. Things will probably be easier for everyone once the emotions are out in the open.

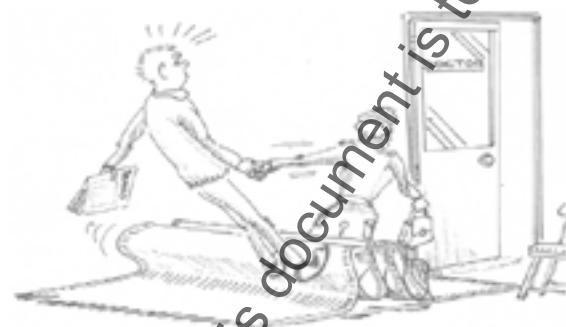
Your parents, if you still live at home, may be having their own problems. For example, they may be worried about you and not want to show it in case they make it worse for you, so talk to them also and share your feelings so that you understand each other.

If you are newly diagnosed with ITP your parents will no doubt be anxious to support you and learn about the condition with you. If you have grown up with ITP since childhood you may know lots about it, but you and your parent(s) may find it difficult to adjust as you learn to take charge of your own health care and your parent(s) learn to step back from taking the decisions. Your parents don't suddenly switch off worrying about you when you become a teenager, so it helps to keep everyone happy if you keep them in the loop.

Should my parents see the consultant with me?

It all depends on your age and the kind of relationship you have with your parents. If you are 13 years old one or both parents would be highly advised to come with you, but if you are 18 things may be very different, especially if you now live on your own, with friends or with a partner. It is often a good idea to go with someone anyway, as two heads are better than one at remembering either what was said by the consultant or what you need to tell him/her. So although you are growing up fast don't be afraid to go with a parent, partner, friend or boy/girlfriend.

Also, it can sometimes be helpful to write down beforehand what you need to say to or ask the consultant; medical people are often very busy indeed and things can be forgotten in the heat of the moment. Don't be frightened of medical jargon – if you don't understand something ask what it means.



WHAT ELSE?

What's the best way to stop a nose bleed?

Pinch the sides of the nose just below the bone, but above the nostrils (or you could use a swimming clip which gives gentle, even pressure). Sit quietly for 5 minutes, then unpinch the nose (or remove the swimming clip). Keep still for another 5 minutes, then gently wash the dried blood away to reduce nasal irritation. Ice packs on the nose are also useful to stem the blood flow.

Shaving and hair removal

If you cut yourself shaving it may take a little longer than normal for it to stop, so use electric or safety razors to avoid nicks. Waxing can cause bruises and pulling eyebrow hairs out may cause bruising or bleeding, but hair removal creams can be used.

What about emergencies?

The vast majority of people with ITP will never experience an emergency relating to their ITP, but it is best to know when you should get yourself to Accident and Emergency (A & E) and then you won't be needlessly worrying. As a general guide, if you have a fall and hit your head, get your head knocked hard in some way or have an extremely severe headache with sickness and loss of vision, then it is best to get straight down to A & E to check you haven't got any bleeding in your head. In the very unlikely event that you do, don't panic, they will give you platelets and other treatment to deal with it quickly. If you have any bleeding that can't be stopped that would be a good reason to call an ambulance or get someone to take you to A & E for prompt treatment (and make sure the receptionist is told you have a bleeding disorder and need to be seen quickly.) If you are involved in any accident requiring first aid, always tell the paramedics or doctors that you have ITP. You and your parents should never feel afraid to call NHS direct or your GP if you have unusual symptoms or health worries, but always go to A & E if you have bad bleeding or a blow to the head. If your spleen has been removed you should seek medical help if you get a fever (temperature with shakes and shivers) as this may mean you have an infection which (because you don't have a spleen) needs extra antibiotics to zap it.

Will ITP make my acne worse?

ITP should not make acne any worse, but steroids often do. If spots bleed they might take a bit longer to stop bleeding. Your doctor should be able to help with any particular acne problems, but if the problem does not get better, your doctor could refer you to a skin specialist (dermatologist).

Can I have body piercing or a tattoo?

Very sorry and all that, but if your platelet count is below 50 it would not be sensible to have your ears (or any other part of you) pierced because you may have difficulty stopping the bleeding. This also applies to tattooing, where bleeding could cause the tattoo to turn into a tattoo of a bruise! If you had your ears pierced (say) before the ITP came on you don't have to worry about that, it's just future piercings that you need to avoid. Hopefully, the ITP will improve and you can make your own judgement about that when it does.

What if the ITP doesn't go away?

If the ITP lasts longer than twelve months it is called a 'chronic' condition and there are many people who live happy, fulfilled lives with chronic ITP. Remember that the word 'chronic' in this context doesn't mean that the ITP is very bad, but simply that you've had it for over a year. You could have chronic mild ITP and lead a perfectly normal life in every respect, or you might have more troublesome symptoms which is known as chronic severe ITP. If your ITP doesn't go away you may feel like you're on an emotional roller-coaster, going through the ups & downs of platelet counts and symptoms, but in spite of this you should still be able to live a fairly normal life.

DIETS, DRUGS, AND VACCINATIONS

What about drugs?

Remember that aspirin or products related to it, like Ibuprofen (often sold as Nurofen) can make your symptoms worse because they make the few platelets you have less effective. But you can use paracetamol instead – and always follow the dosage instruction on the label. There are many drugs which have aspirin in them, especially ones for colds and flu, so do ask your chemist to check for you before you or your parents buy any over-the-counter drugs for you to take.

If you need a prescription drug for a condition other than ITP it is a good idea to remind the doctor you have few platelets as some drugs can make ITP worse.

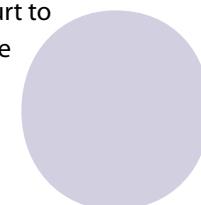
As far as drugs that you don't get from your doctor are concerned everyone knows how dangerous it can be to get involved with these drugs, the sort you buy from dealers and in some night clubs and discos. Ecstasy can help to prevent blood from clotting so it is especially bad for people with ITP.

Also, you never know what other additives and impurities dealers put into their drugs and whether something they add will worsen your ITP as a result. Best to keep away from drugs altogether so you can make the most of life.

What about vaccinations and injections?

People with ITP can still have injections. If your platelet count is below 20 they have to be given under the skin (subcutaneously) instead of into the muscle (intramuscularly). So bad luck if you were hoping that ITP would stop you having a BCG or meningitis vaccination.

Now, if you're given immunoglobulin infusions or steroids for the ITP you should have a three month gap before having those injections otherwise they may not work. The same applies to holiday vaccines and those given if you have a splenectomy. Your doctor should know this, but it wouldn't hurt to remind him/her in case he's overstretched, overworked and underpaid!!



This document is to be viewed on www.itpsupport.org.uk

LIFESTYLE

Should I restrict my life-style?

If you were heavily involved in very energetic or aggressive sports and activities before the ITP came on you may have to restrict those while your platelet count is low. There is no reason why you can't do swimming and non-contact sports but don't forget to wear the appropriate head gear, knee, elbow or shin pads – ALWAYS! it's very important and wearing one could help to save you from serious injury. At home you can work out on the Wii fit and, of course, you have a good excuse to sit quietly at the computer or flop in front of the TV! Try to live as normally as you can – eat healthily, work hard, sleep well and be positive about life – because you will always find that new interests and friendships will come along and you can still enjoy life!



Sometimes I feel very down about getting ITP

Living with ITP may present you with new challenges and you may feel you are on an emotional roller coaster. Feeling sad, disappointed, upset or angry is not unusual, but most people with ITP soon learn to take it in their stride. You may find it helpful to share your feelings or concerns with a close relative, friend, your doctor or someone at the ITP Support Association. Also, your parents may need to talk to someone and we can help there as well.

It may help you to overcome your frustrations if you focus on your capabilities and strengths rather than your limitations.

Is it OK to go on holiday or school trips abroad?

Sure it is! It'll do you good. Just take a few precautions and all should be well – so here's a check-list or three.

Before you go:-

- If you get many nosebleeds and you intend to fly check with your doctor that you'll be OK. You don't want to have problems on the flight due to the aircraft cabin pressure.
- Check on your vaccinations with your doctor. If you have been on steroids or immunoglobulin, vaccinations can't be given until 3 months have passed.
- Contact the holiday insurance company and tell them you have ITP or you may find you are not covered by the insurance if you need to make a claim.
- Try to find out what ITP is called in the country you are going to, just in case you have any problems. The ITP Support Association has holiday information leaflets available in some European languages – contact info@itpsupport.org.uk for further details.
- Check with your tour operator or school where the nearest doctor and hospital are situated, in the event of an emergency.
- If you are not with your parents make sure someone understands about your ITP.

When you set off:-

- Pack any medication you are taking.
- Take a noseclip with your hand luggage for nosebleeds.
- If you have an ITP Healthcare card or medic alert jewellery don't forget to take it.

And when you get there:-

- Enjoy yourself and try to forget about ITP!

GIRLIE PROBLEMS (OK GUYS, YOU CAN SKIP THIS PAGE!)

What about periods?

Teenage girls with ITP may find that their periods are longer and heavier than usual. Don't put up with it and be miserable if it becomes a problem, but tell your consultant . If he thinks it necessary you may be given tranexamic acid to take during your period (which helps your blood to clot) or a 'hormonal preparation' (something like the contraceptive pill) to take over several months at a time so you only have occasional periods. He may refer you to a gynaecologist to discuss the options. You needn't feel embarrassed talking to a male doctor about this as they are well used to hearing such things, but if you do feel uncomfortable get your mum to talk to him or ask if you can talk to a female doctor or nurse.

If you carry a special little bag or make-up bag with sanitary towels/tampons, wipes and a small plastic bag for used pants and a spare pair, you will feel more confident that you won't get caught out.

Will I be able to have babies with ITP?

Your ITP may disappear long before you think about having a baby, but if it doesn't, don't worry, women do have babies with ITP. When the time comes it would be sensible to talk to your haematologist before planning a family, and once pregnant a care plan should be worked out between your obstetrician and haematologist to ensure that all goes well for you and the baby.

Can I pass on ITP to my baby?

It is not a genetic condition, so your baby can not inherit it from you. On very rare occasions your ITP may give the baby low platelets during the pregnancy and for a couple of weeks after being born, but as soon as the baby starts to develop its own immune system its platelet count will return to normal.

AND FINALLY...

We hope you found this booklet useful. If you have any questions e-mail us at info@itpsupport.org.uk and we will do our best to answer them.

The ITP Support Association is always looking for ways to promote ITP awareness and raise funds for ITP research. If you can help us by persuading your school to hold a non-uniform day or by taking part in a fundraising or sponsored event in aid of our charity we would be delighted to hear from you. Anyone who raises money for our cause receives a certificate and if they send a photo it will appear in our quarterly journal The Platelet.

So here at the ITP Support Association we all wish you the very best of luck for the future and hope you get better soon.