

LIVING WITH ITP

Have you recently been diagnosed with **ITP**? If so, you are not alone. This helpful book will provide many of the answers to your questions:

- How will **ITP** affect me physically and mentally?
- What can I expect from the treatments?
- Will I still be able to travel, be active and enjoy my life and relationships?

Living with **ITP** has its challenges but it is still possible to lead a happy and fulfilling life.

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A patient's guide to immune thrombocytopenia

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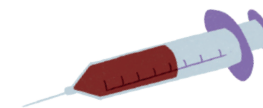


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SO I HAVE ITP – WHAT NOW?

Discovering that you have been diagnosed with ITP may be a **shock**. You may feel anxious about having a disease with a complicated name that you have never heard of before and you are sure to be wondering what the future will hold.

The information in this book will help you understand more about ITP. You will find out how it might affect your everyday life and how to deal with any **challenges** it may bring.

To try and understand how you are feeling right now, we have talked to adults of all ages who have been diagnosed with ITP at some point in their lives. As you read through the book you will hear their thoughts and experiences, which we hope will reassure you.

As you will find out, being diagnosed with ITP is NOT a life sentence and with the right **support** and information you should be able to look forward to the future with confidence.



Over the years the increasing knowledge and treatment of ITP has helped me lead a happy and fulfilling life. I have learnt so much about myself and my illness, and how individual experiences are so varied.

For me, one of the "good side effects" of living with ITP, has been to always have the value of life clear in your mind, and try to live it the best one can. So, I commit myself, every single day, on building a meaningful and happy life.

ALL ABOUT ITP

What is ITP?

ITP is a disease in which the body's immune system gets 'confused' and mistakes platelets (normal cells circulating in the blood) as an infection. It then makes antibodies that get rid of them. This results in platelet numbers falling below normal levels.

WHAT DOES IT STAND FOR?

ITP used to be known as **Idiopathic Thrombocytopenia Purpura** but thankfully is now called **Immune Thrombocytopenia** – or just **ITP**, for short.

I think we can all agree that before being diagnosed, most of us hadn't heard of ITP, Idiopathic Thrombocytopenia Purpura or Immune Thrombocytopenia, let alone know how to pronounce it!

ITP is what we call an **autoimmune disorder**.

- The word **immune** is used because your immune system does not correctly recognise platelets in your blood and begins to break them down. Your bone marrow has the job of making new platelets, but it can't keep up.
- The word **thrombocytopenia** means that the platelet level in your blood is low.

What is the immune system?

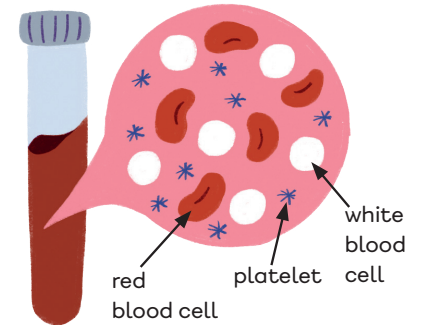
Your immune system is your body's **defence network**; the system of cells, tissues and organs that defends it from infection and disease. Usually, if your immune system detects something potentially harmful (like bacteria or viruses) it will spring into action and destroy the invaders to keep you healthy. But if you have ITP, your immune system gets confused – and we don't know exactly why.

What is a platelet?

Platelets are small sticky cells in your blood whose job is to stop you bleeding. If you cut or **injure** yourself, your platelets normally clump together to form a seal. This blood clot slows down the flow of blood and eventually stops it completely. But if your platelet count is low, your blood may not clot very well, which means you will bleed more heavily and for longer.

What is a platelet count?

A **platelet count** is exactly that – the number of platelets that can be counted in your blood. To find out your count, you'll need to have a blood test, after which an electronic machine is used to count the platelets.



- A normal platelet count varies according to age and sex, but it should be roughly between 150 to 400. This means 150,000 to 450,000 platelets per microlitre of blood.
- A low platelet count is anything under 150. In many cases of ITP, the platelet count is less than 20 and might even drop as low as 1 or 2.
- A person with a low platelet count will likely be experiencing symptoms such as **bruising, bleeding** and sometimes **tiredness**.

For the past year I religiously text my husband every Friday afternoon. There's nothing unusual in that, but the weekly message contains just a number, no words. Triple digits and we're happy; single digits and it's time to get family in to mind the children and pack a bag for hospital ... The number I text is my platelet count.

WHAT CAUSES ITP?

- ITP can come on after a virus, a vaccination or certain medications, but for most people the cause is **unknown**.
- There is a slightly higher incidence of ITP in pregnancy. It can also occur as secondary to other autoimmune conditions including lupus (SLE), diabetes, thyroid disorders, inflammatory bowel disease and after some immune treatments, such as cancer therapies, or after a transplant.
- You cannot 'catch' ITP or give it to anyone else. ITP may occur after experiencing a viral infection, like a sore throat or a cold, but it is not an infectious illness.
- While ITP is not usually a genetic or inherited condition, we are beginning to find some genes that might make you more likely to get ITP. It is very uncommon to have family members with ITP, but it does sometimes occur.

ITP can occur in anyone, at any age, and may last different amounts of time.

- **NEWLY DIAGNOSED ITP** (this used to be called acute ITP) describes ITP during the first three months of diagnosis. In some people, especially children, ITP only lasts this long and then goes away.
- **PERSISTENT ITP** describes ITP that lasts for up to a year.
- **CHRONIC ITP** describes ITP that lasts for more than a year. This is more common in adults. However, just because your ITP has lasted more than 12 months does not mean this is a lifelong condition.

The words **severe** or **mild** are sometimes used to describe the level of your ITP.



Your diagnosis

Everyone's **diagnosis** is different. You might have gone to a doctor with worries about bruises or bleeding, or perhaps a routine blood test showed that you have low platelets. You may have visited hospital for another reason, and they noticed something unusual. What's important is that you get the **RIGHT** diagnosis, however long it takes. For some people, it can be a big relief to finally know the cause of their symptoms.

I found out because my wife made me go for an MOT at the doc's because she thought my diet was bad (it was pork pie, dripping, bacon etc). After a blood test they found my count was in single figures and thought I had leukaemia!! So, they gave me a bed in the local hospital and after a few more tests and days in the cancer ward, they diagnosed me with ITP and started me on steroids. That was a bit of a relief, to be honest.

ITP is diagnosed by **blood tests** which show that the platelet count is low. Frustratingly there is no other diagnostic test for ITP, and low platelet counts can be caused by a lot of other disorders, including leukaemia. Your doctors may take a few days or weeks to decide that you have ITP, rather than something else. This can be very frightening, and frustrating. Some patients may need to have a **bone marrow biopsy**.

WHAT IS A BONE MARROW BIOPSY?

As all blood cells are made in the bone marrow your doctor may wish to examine some of the marrow blood. This usually involves a small sample being taken from the pelvic bone. The blood will be examined under the microscope to see if the bone marrow is making platelets. This is a routine procedure that is done all the time in haematology and it is usually done under a local anaesthetic. It can be a little bit painful, especially when the sample is taken, but it does not cause any long-term problems.

I went to my GP for a routine blood test for the blood pressure medication I was on. Having had the blood taken, we set off on the bus to do some shopping and had a pub lunch. When we got home there were numerous answer-phone messages asking me to contact the surgery at once. A very concerned GP said my blood results needed to be repeated, and that I should go immediately to the Haematology department at the local hospital who were expecting me. It turned out that my platelet count had been 1.

What happens in a diagnosis?

You will probably be in a **hospital** when you get your diagnosis, usually after being referred by a doctor for more investigations. Whoever talks to you will ask questions about your medical history and will want to know about any illnesses or conditions you've had before. You will be asked to describe your symptoms and examined to look at any signs of bleeding or bruising. Usually, a sample of your blood will be taken and sent off for a platelet count test.

You may also have further blood tests to look for other things that can cause a low platelet count, such as infections and other autoimmune diseases. Sometimes you might need an **ultrasound scan** of your stomach (to measure your liver and spleen) or a chest X-ray if the doctor thinks this is important.

My story starts back in 1995 when I noticed my body was covered in bruises and blood spots. A day later I had started to bleed from my gums and nose. My wife took me to our local hospital where they gave me blood tests and told me my platelet count was 1.

AFTER DIAGNOSIS

Being told you have a disease of any kind can be overwhelming. It's a lot to process and you may find that you didn't take in or understand all the information that was given. On returning home you may have more questions. This book will help with many of those questions, and there is much more information available on The ITP Support Association website. See page 68 for more details.

Prior to my initial appointment I was quite anxious with many thoughts and worries as to what caused my ITP. However, upon being diagnosed I felt much more at ease and comforted.

Having ITP means that you may be spending more time at hospitals because:

- You will need regular blood tests and check-ups
- If you have a worrying symptom, you'll need to visit A and E
- If you are very unwell, you might need to be admitted to hospital for treatment

Why me?

As we said earlier, for most people the causes of ITP are not known. It is not a common condition and there are usually only 3000 – 4000 ITP patients in the UK at any one time. Most general hospitals will look after a handful of adults and children with ITP every year.

I have never met someone with ITP face to face and it is quite an isolating disease as it is so rare.

So, you may well be thinking:

Why did this happen to me?

This is a question that many people ask themselves when they have been diagnosed with a potentially life-changing condition. It can be frustrating to not know exactly what caused your illness. It can leave you feeling angry, helpless and miserable. Look at pages 40–48 for some advice on dealing with these feelings. It might help you to know that there is a lot of research being done into the causes of ITP. Treatments are improving all the time.

It feels so incredibly unfair to be stuck with this illness and to have no explanation as to why. However, I've realised as I'm sure most people do, that unfortunately, sometimes life is just unfair, and we have to learn to run with what we've got.

The most important thing to remember is that it is **not your fault** that you have ITP. Nothing you or anyone else has done has caused it.

DOES ITP GET WORSE OVER TIME?

Unlike other autoimmune diseases, such as rheumatoid arthritis, ITP is not a progressive disease, which means it doesn't worsen over time. But the symptoms can fluctuate and change so it is not always easy to predict.

ITP is often a rollercoaster disease. Staying positive and hoping for better days and knowing they could just be just around the corner, any time soon, kept me ticking.

SYMPTOMS

It all started when I got an enormous bruise on my chest (the size of my whole hand) after catching it on the top corner of the car door in a tight car park. I didn't think anything of it at the time but noticed that I was getting bruises easily and after a week or two I started getting blood blisters in my mouth and black spots on my tongue.

Some people, especially those with a platelet count over 50, don't have any obvious symptoms. But, usually, the first signs of ITP are:

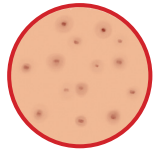
- **Unexpected bruises** and/or **a rash** that can look like tiny pinpricks.
- Getting heavy **nosebleeds**, gum bleeds or developing black blisters in your mouth and gums.
- If you cut yourself, you may bleed more than usual, and it may be hard to stop.
- Women might experience **long and heavy periods**. See page 61 for more about menstruation.
- Another sign of ITP is feeling much **more tired** than usual.



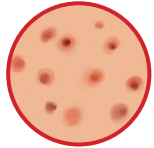
I had been to the doctors earlier in the year because I just felt so tired. I was crying at nothing and was exhausted all the time. My doctor started a series of tests which all came back normal, reassuring but frustrating. Then I had a blood test as part of a starved glucose test. A doctor phoned me later that day and told me that my platelets were at 7, and I must go to A&E.

Types of bruising

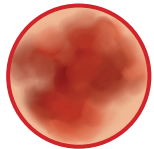
A bruise happens when the blood vessels under the skin break and leak blood into the surrounding area. This usually happens after a knock or impact, but ITP can cause bruises to appear by themselves, large or small. It also causes different types of bruising:



- **Petechiae** - small, reddish spots under the skin that look like pin pricks



- **Purpura** - red, purple, or brownish-yellow spots



- **Hematoma** - a clot of blood under the skin that looks like a lump

My dental hygienist noticed excessive bleeding, the same day of my Covid vaccination. Then over the weekend I noticed faint red spots on my arms and legs. Petechiae, I discovered after a few web searches, but I still can't pronounce it!

Less common symptoms of ITP include:

- Blood in the eyes
- Bleeding from the ears
- Blood in the urine or faeces
- Bleeding from the gut
- Bleeding into the brain

I was getting blood blisters in my mouth and my gums bled profusely when I brushed my teeth. It was frightening to wake up in the night with a mouth full of blood.

YOU AND YOUR MEDICAL TEAM

Once your diagnosis is complete, you will come under the care of a consultant doctor called a **haematologist**. This is a doctor who specialises in blood diseases and/or autoimmune disorders. You may also be attended to by a specialist nurse or nurses, and you are likely to be seen by other doctors from the team at your appointments. These people - your medical team - will be very important to you as you receive your treatment. They will give you expert advice and help you deal with the different daily changes that come with living with ITP.

Building a good relationship with **your medical team** is an important part of your care.

And the word **TEAM** is crucial.



The doctors and nurses that are helping you may be experts in ITP, but you are the only person who knows how you feel and what matters to **you**. It's important that you communicate and share your feelings with your team as you work together on your treatment plan. See page 22 to find out more about Shared Decision Making.

Appointments

It goes without saying that it is **very important** to attend your medical appointments. However, hospitals understand that life happens and can be unpredictable. If you need to cancel an appointment for any reason, try your best to let the hospital know as far in advance as you can and make sure that you get another appointment in place.

Missed appointments waste hospital time and money and can affect care for other patients. Keep a careful note of your appointment times and set yourself reminders if you need to.

Beginning treatment

At the moment, there is no known 'cure' for ITP but there are many treatments available to help with symptoms. Some are aimed at suppressing or confusing the immune system, while others raise your count by increasing platelet production.

WATCH AND WAIT?

ITP can sometimes be symptom-free and can get better or disappear on its own over time. Whether you are treated or not depends on whether you have bleeding problems, rather than just your platelet counts. You might find that you just need to be regularly monitored. This is called 'watch and wait' and your doctor will be the best person to advise you on this.

First line treatments

These are the first options that will be offered to patients.

- A drug called **Prednisolone** is commonly used to help with bleeding. Prednisolone is a steroid which comes in the form of tablets. It is usually taken in high doses for a short period of time, and then tapered down. Prednisolone slows down the destruction of your body's platelets and stabilises the blood vessels, to help reduce the risk of bleeding.

WHAT ARE STEROIDS?

Steroids are artificial versions of hormones that your body usually makes by itself. Taking steroids for a long period of time can cause side effects, but your doctor will work out your dose carefully so that you only get as much as you need. Some of these side effects can include mood swings, increased appetite, weight gain, sleeplessness, acne and indigestion. If you do get any of these symptoms, remember that they will disappear when you stop taking the steroids.

I started to learn some of the side effects of steroids. When some friends visited me, they kindly left an enormous bar of chocolate, one of those Cadbury Dairy milk things that are about a foot long. The following day when they called, it had all gone!

- Another first line treatment is called **intravenous immunoglobulin** - IVIG for short. This is drip fed through a cannula (a small plastic tube) into one of your veins over several days in hospital or a day unit. You may experience temporary headaches, nausea, lightheadedness, shivers or even a slight fever while it is being given. However, you should be given a premedication containing an antihistamine, paracetamol and a form of steroids (like prednisolone) to help with any symptoms before your IVIG is given. Some people need this medication for a few days after immunoglobulin treatments. If your symptoms become severe, the treatment will be stopped.

I became a regular at the oncology and haematology day ward for weekly, sometimes fortnightly rounds of IVIG along with tapering off steroids.

NAMES AND BRANDS

The drugs you are given may have a different name to the ones listed in this book. This is because they are branded with other names by the drug companies that make them. Always read the leaflets that come with the drugs as they contain essential information about possible side effects and other important facts.

Second line treatments

If first line treatment isn't having the required effect, you might be offered second line treatment. This usually involves medicines from two groups:

1. Immunosuppression medicines

These can help if your immune system is overactive and is decreasing your platelets. They sometimes take 2-3 months to start working. One example (but there are others) is **Rituximab**, which is usually given as an infusion into your vein using a cannula. This gets rid of the B cells in your blood (the cells that make the antibodies/proteins that cause platelets to be destroyed).

Rituximab was first developed as an anti-cancer treatment, but it is now frequently used for autoimmune conditions. It usually works for around two thirds of people with ITP.

Another immunosuppression medicine is called **Mycophenolate mofetil**. This is a daily tablet which reduces the activity of both the B and T cells in your blood, so it helps to stop platelets being destroyed. It can have a number of potential side-effects but only a handful of these are likely to happen. It can also take a month or two to start working.

2. Thrombopoietin (TPO) receptor agonists

These are newer medicines that work directly on the bone marrow, helping to increase the number of platelets that are made. You will need regular blood tests at the

beginning to check that your platelets don't get too high. There is a weekly injection called **Romiplostim**, and daily tablets called **Eltrombopag** and **Avatrombopag**. Your doctor or nurse will discuss which would suit you best.

Other drugs that might be offered to you include hydroxy-chloroquine, azathioprine, fostamatinib, sirolimus, ciclosporin, cyclophosphamide, vincristine, danazol and dapsone.

Further treatments

If you are in the approximately 10% of people who have ITP that is harder to treat (called **resistant** or **refractory**) you may be offered treatments that target different parts of the immune system. Sometimes combinations of immunosuppression and TPO receptor agonists are used together.

Clinical trials

You may also be asked if you want to be involved in a clinical trial as doctors are constantly researching new treatments for ITP. It is understandable to be concerned about taking part in clinical trials. However, all treatments and drugs are tested through trials and there are strict safeguards in place. You don't have to take part, but there is always a chance that your ITP may benefit from the trial, and it may allow you to access a drug that might work for you much sooner than through other channels. There are also trials that don't involve taking medications but might involve blood tests and questionnaires. These all help doctors and researchers to learn more about ITP.

My journey with ITP has been shaped by my involvement with a clinical trial. I have felt incredibly supported by the team from the beginning to now (over two years and follow up). If I had not taken part in this clinical trial, I am not sure my ITP journey would have been as easy.



WHAT IS TRANEXAMIC ACID?

Tranexamic acid is a medication that is often prescribed to those with ITP. It helps the blood to clot and can be very useful to stem nose bleeds, mouth/gum bleeds and heavy periods. If you are prescribed tranexamic acid, remember to take it out and about with you in case of emergencies. To get the best use from it, remember to take it three times a day as a tablet while you are bleeding. It may also be used before dental extractions.

What is a splenectomy?

In some cases, if treatments aren't working as they should, a **splenectomy** may be considered. This is removal of an organ on the left side of your stomach called the **spleen**.

With ITP the immune system treats platelets as foreign and gets rid of them. The spleen is responsible for taking out these damaged platelets and therefore its removal can help to keep more platelets circulating in the body.

Splenectomy used to be the standard treatment for ITP before drug therapies were developed, and it is still carried out in patients with chronic severe ITP (troublesome ITP for a year or more). It is often carried out as a **laparoscopy** (also called keyhole surgery) which has the advantage of a shorter hospital stay and quicker recovery time. However, some patients may need open surgery if the spleen is particularly large or there are other complications. People who have had a splenectomy need to ensure they follow guidance on having additional vaccinations and taking prophylactic antibiotics e.g. penicillin.

Splenectomy had been mentioned to me several times, but I had always rejected it, thinking it too drastic. However, in 2011 I finally made the decision. I had a transfusion before the operation, which was done by "keyhole surgery". I was in hospital for three days and was fully recovered in about two weeks... No ill effects, but I do keep a supply of penicillin in case I feel I am starting with a severe infection.

In 2010, I had my spleen removed because it was necessary for me to move on to the next stage of treatment, based on the medical advice available at the time. Looking back, there wasn't much information about how successful this procedure would be, and unfortunately it didn't work for me. Thinking about it now, I don't believe I would have gone through with the splenectomy, as I didn't benefit from it. I did have a few infections afterwards, but I managed to get through them, and the splenectomy itself hasn't caused me any ongoing problems.

ITP in pregnancy

Having a diagnosis of ITP should not prevent you from having a healthy baby. On rare occasions, ITP from the mother may give the baby low platelets during pregnancy and for a couple of weeks after the birth. However, as soon as the baby starts to **develop** its own immune system, its platelet count will return to normal.

Also, most mothers are able to safely **breastfeed** their baby.

For more information on pregnancy and childbirth, there is a book produced by the ITP Support Association, which they will send if you contact them. It is also available as a PDF on their website at www.itpsupport.org.uk. You can also speak to your medical team if you are considering becoming or become pregnant.



Shared Decision Making

If you have not heard this name before, **Shared Decision Making** is all about encouraging patients to take an active part in their own care. It's about working together to make the best decisions for you. It's important to know that:

- As a patient, you have the right to be involved in discussions and **decisions** about your treatment and care.
- Shared Decision Making can help you feel stronger and better equipped to cope.

If Shared Decision Making isn't mentioned to you, it is worth asking if it is something that can happen in the future. However, it is also fine for you to leave treatment decisions to your medical team. It is **your treatment** and you can decide how much of a role you play in decision making.

When I speak to the doctors and nurses, I am heard. Action is taken swiftly and I know that everything soon will be okay and I will get another chance.

The ITP Support Association has more information about Shared Decision Making on their website. Look for the pdf leaflet called *Immune Thrombocytopenia (ITP) management and care shared decision-making tool kit*.



AT HOSPITAL

Once diagnosed with ITP, it is likely that you will be spending more time in a hospital environment, whether it is for regular appointments, a longer ward stay or an emergency.

Get the most from appointments

The time that you have with your medical team is precious and often limited, so it is important to get the most from it.

- **Make a note**

It is a great idea to get yourself a special **ITP notebook**. Before your next appointment, think about exactly what you want to discuss and the questions you'd like to ask. Write them down so that you don't forget. You can refer to your notebook during your appointment and won't feel **frustrated** afterwards that you failed to get the information that you wanted. You can also use the book to make notes during your appointment about what is being discussed. You will be able to refer to this afterwards and remember the details and names of different drugs.



Immediately, I started keeping a running chart of my platelet counts and events during the past 11 years. This has proved to be an accurate reference for me.

• **Keep a diary**

As it can be a long time between appointments, it can be very useful to keep an ITP diary. Write down any symptoms you have day to day and make a note of dates when you start treatments with certain drugs or when you experience changes in lifestyle. This information can be incredibly helpful to you and your medical team as it will help you see if treatments and lifestyle changes are working or not. Making a diary can also help you set yourself goals for the future and encourage you to keep to them. These goals might be about keeping fit or eating a healthy diet - more about these from page 49.



Since day one, I've kept a journal chronicling my experiences, detailing the treatments along with the mental, emotional, and psychological highs and lows associated with the successes and failures.

• **Take a friend**

It can also be a good idea to take a friend or family member along with you to your appointment, especially if you feel unsure about anything or if you are worried about not making yourself clear. Remember though, if there is anything that you do not understand, doctors and nurses won't mind being asked to explain it more clearly - that's part of their job. You should never feel as though you are being a burden by asking for more information.



Waiting around

As we all know, medical staff have a heavy workload, and hospital appointments don't always run on time. Prepare yourself by taking along a few things to make your wait easier.

- Phone charger with a cable
- Refillable water bottle
- Healthy snacks - small bags of nuts/dried fruit, cereal bars, etc.
- Something to do, whether it's listening to a podcast, reading a book or catching up with work.

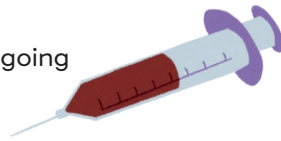
At first, I was stressed out by it all but after a while I thought it best to become a patient patient! As all patients know we spend a lot of time waiting to see doctors and others. I go prepared with something good to read. I get to know staff and other patients. I became patient about results too.

IT TAKES TIME

Remember, every person is an individual so what works for one person may not work for another. It may take a while to get your treatments established and working for you, so try to be patient while this is done. Treat your medical team with respect and remember that they are working very hard to help you.

Blood tests

Having ITP means that blood tests are going to be a regular event in your life. Most people get used to having bloods taken but there are things you can do to make it even easier.



1. Drink plenty of water before the test. This keeps your veins full of fluid which makes it easier for the tester to find a vein and to draw blood from it.
2. Always tell the person doing the test if you have any fears beforehand as they will do their best to reassure you and to help you feel comfortable. Many people, for example, are nervous about **needles**. The person doing your test will be able to help you manage this.
3. Look away! Don't feel you have to watch the needle going in (or the blood going out) if it makes you feel queasy. Close your eyes or look away and think of something else instead. It might help to imagine a place where you feel safe and relaxed: what can you see, feel, hear, and smell in this place?.
4. Breathe slowly in and out. See page 47 for a relaxing activity.

I'M SCARED OF NEEDLES

You are not alone. A small number of people have a phobia of needles, and the very sight of them makes them feel faint, shaky and sick. Relaxation exercises can help, but a serious phobia may need proper medical treatment and therapy. Do tell your doctor or consultant as early as possible if you think this applies to you.

I cope with having a blood test by not looking and talking about something else.

The injections were a nuisance but didn't really bother me – I felt that I was in good hands.

Hospital stays

On arrival at hospital, they showed me to a bed, I wondered why I needed a bed for a simple blood test, but all became clear. They took the blood and shortly after that a doctor arrived, He explained that in a normal person the platelet count is between 150 and 450, mine was three. I was to stay in bed and not go anywhere as a fall could cause a haemorrhage.

If you think you might be admitted to hospital overnight or for a longer stay, bring (or ask a visitor to bring along later):

- Light pyjamas (hospitals can get very hot)
- A robe to cover up for shower visits and slippers/slides for visits to the loo
- Toiletries like a toothbrush and toothpaste, deodorant, lip balm, plus a hairbrush
- An eye mask for sleeping and ear plugs (hospitals are brightly lit and surprisingly noisy)



If you are admitted to hospital, try not to worry. Remember that you are in the best place possible to get the treatment that you need. Getting enough rest will help you to recover, so use the ear plugs and eye mask and nap when you need to.



Hospitals have this unique feeling about them, as if time isn't real and nothing seems quite right.

TAXI

Always have the number of a reliable taxi service or set yourself up on a mobile app like Uber in case you need to get to hospital quickly.



Should I go to A and E?

It can be difficult to know if you should attend the **Accident and Emergency** (A and E) department. Ultimately, you know your body best and if something is really worrying you, you should make the trip. You should also go if any of the following occur:

- If you fall and hit your head, or if your head is knocked hard in some way, there is a possibility of internal bleeding. If the bump has resulted in a bad headache and feeling sick or dizzy, you must go to hospital
- If you have a **prolonged** (over 30 minutes) nosebleed which will not stop, despite pinching the nose
- Prolonged **gum bleeding**
- **Blood** in the faeces or urine
- A cut that **won't stop** bleeding

An unusually heavy period (e.g. lasting more than seven days, changing protection every two hours or less, or passing blood clots bigger than a 50p coin).

HOW TO STOP A NOSEBLEED

Pinch the sides of your nose just below the bone, but above the nostrils. A swimming nose clip is handy as you can use this instead of your fingers. Sit quietly for five minutes then un-pinch your nose. Keep still for another five minutes, then wash any dried blood away. An ice pack or a bag of frozen peas pressed on the nose can also help stem the blood flow.



If you have very bad nose bleeds, let your medical team know as you may need to see an Ear, Nose and Throat (ENT) doctor.

I had a severe nosebleed that lasted for twelve hours and ended up being anaemic.

Bring support

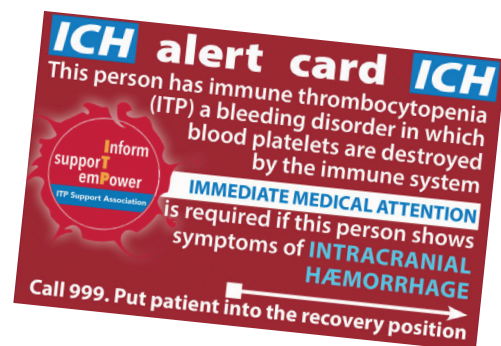
If you need to go to A and E, don't panic. Firstly, try to find someone to come along with you. It can be hard to speak up for yourself in big departments (especially if you're bleeding and anxious) so a family member or friend can be a big help for **communicating** with the staff.

When you arrive, keep calm and do your best to give clear information about your symptoms to the receptionist. If you are there for a medical reason that is not related to ITP, you must tell the receptionist and medical staff about your ITP as well – they need to know.

A and E departments can be quite **stressful** places and there are often very long waits, so be prepared (see the list on page 25). Always make sure you have your phone with you as you may need to contact others or book a taxi.

ALERT!

For emergencies, and especially if you are on your own, it is a good idea to carry an ITP Medical Alert Card or to wear a medical alert bracelet. The ITP Support Association can provide you with a free Medical Alert Card, if you email info@itpsupport.org.uk with your postal address. The card gives urgent medical information about you, your emergency contacts and is small enough to fit into your wallet or purse. Remember to always carry it with you.



YOUR SUPPORT NETWORK

Chronic illness can be a lonely place.

You don't have to tell anyone about your ITP if you don't want to. However, consider letting close family and friends know about your diagnosis as there may be times when you need support. It also helps to **share** your feelings with others close to you. Why not lend them this book to read?

I really appreciate family and friends. I'd be lost without my parents and their undivided attention and support. I believe ITP, in some ways, pulled us all closer.



Explaining ITP

It can be a **challenge** to explain what ITP is, especially when most people have not heard of it. The key is to keep it simple.



- Choose a moment when you have time to explain things properly and the person has time to **listen**. They may find it difficult to take it all in at first but remember, you don't have to tell them everything in one go.
- Explain that you've recently been diagnosed with ITP which is an immune condition. Because your immune system gets rid of the platelets in your blood, your platelet count is low, and this can lead to bleeding and bruising.
- Assure them that ITP is very **treatable** but that some of the symptoms, like heavy bleeding, might look a bit scary.
- Give them an action plan of what to do if any of your symptoms get out of control. They may need to speak up for you at hospital or on the phone.
- On an everyday basis you might want to let them know about things like feeling tired or anxious, **mood swings** or anything else that you sometimes get because of ITP or your treatment.
- Emphasise that there's no need to treat you differently - you are still the same person as you were before.

Telling children

- It is usually best to be **open and honest** with children, but this will depend on your child's age and personality. You are the expert when it comes to your child and you know best how much information they can cope with.
- Try to find a quiet time - perhaps during a walk - to explain why you are going to hospital more these days or why you sometimes feel very tired.
- Use **simple language**. You could try asking them what happens when they cut their knee. Explain that their blood makes a scab to stop the bleeding. Blood contains some tiny and very useful things that you can't see called platelets. Platelets stick together to help make the scab.
- The doctor did a test and told you that you have some thing called ITP. This means that your blood doesn't have enough little platelets so you might bleed a bit more than other people if you cut yourself. Sometimes you get nose bleeds or bruises, but it is nothing to worry about.
- Be very **reassuring**. Emphasise that the doctors are doing a good job looking after you and you will be fine. You might not be able to play football (or other activity) for a while, but it won't be forever.
- Explain that it is no-one's fault that you have ITP and nobody can catch it from you - so you can still hug and kiss them. Let your child know that they can ask you questions whenever they want and talk to you about how they feel.
- There is a children's book available to download on the ITP Support Association website called *I'm not a Bubble Wrap Boy*. It is about a child who is diagnosed with ITP and its simple **child-friendly** explanations may help your child to understand more.



Who else needs to know?

Make sure that your GP, dentist or any other medical practitioner that you see, e.g. physiotherapist, knows that you have a low platelet count because of ITP. Some members of the medical profession may not have heard of ITP, so don't assume anyone will know about it or how to recognise it.

As ITP is just so rare I have found myself spending so much of my time explaining my condition to so many people, including healthcare professionals, GPs, nurses, dentists and other practitioners. ITP is just not really known or understood by anyone who is not a specialist haematologist.

It is also a good idea to let your **boss** or a trusted work colleague know about your ITP in case you need time off for a hospital visit or if you suffer any symptoms during working hours. Your medical team may be able to help you with a letter to your work about ITP.

There followed a few years of regular relapses - three in 2006, in one causing some panic among members of a meeting when they saw me bruising and starting to wipe away the blood issuing from my mouth.

AT THE DENTIST

Your dentist must be told about your ITP because of potential issues with gums and bleeding. The ITP Support Association has a leaflet written especially for dentists, which you can request. Make sure you give this to your dentist before any appointment. Also tell your ITP doctor about any future dental procedure so that you can make a plan together.



EVERYDAY LIFE

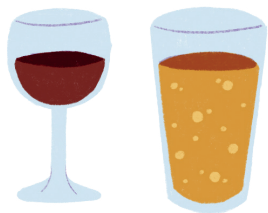
A diagnosis of a long-term health condition can feel like a bomb has **exploded** in your life. It is not uncommon to feel confused, angry, lost, or annoyed. Over time, you will gradually work out how to manage everything. Life may be a little different from what it was before, but it will still go on.

My ITP diagnosis forced me to come to the realisation, one I'm certain we all have at some point in our lives: that life does not stop to wait for you and the world continues to turn.

In the immediate aftermath of my diagnosis, my partner and family wouldn't let me perform certain physical tasks. However, as they learnt more about ITP from me, their concerns and anxieties lessened.

When you have ITP, it's important to avoid eating or drinking anything that could interfere with your blood's ability to clot.

- Try to limit how much alcohol you drink as it can make bleeding worse. (For more on alcohol, see page 50)
- Some common over-the-counter medicines can cause bleeding so should not be taken unless your doctor advises otherwise. These include **aspirin** and **ibuprofen** (which may be sold under different brand names). Be aware that aspirin is often included as an ingredient in other medications so always read medicine labels carefully. **It is fine to take paracetamol.**
- Some supplements and natural remedies are also not suitable for ITP patients. Let your doctor know about anything you would like to take.
- Blood-thinning medicines such as apixaban, warfarin, rivaroxaban and edoxaban can make you bleed even more. You can safely use these treatments, but you will need to have a high enough platelet count and might need extra treatment for your ITP. Your haematologist will need to manage this carefully.



Stay safe

It is best to avoid cuts and other injuries so be aware of the following if your platelet count is low.

- Take extra care using knives, scissors or other sharp tools.

- Wear gloves to protect yourself from **scratches** and **cuts** during activities such as gardening, crafts or DIY.
- Avoid high impact sports if your platelet count is low - see page 57.

In the bathroom



- To avoid gums bleeding, use a soft toothbrush to brush your teeth while your count is low. You may need to avoid **flossing** too. Don't forget to start flossing again as soon as your platelet count is safe (usually above 30) as it is important to keep good dental hygiene.
- Be **gentle** when blowing your nose to help prevent nosebleeds.
- You are less likely to get a cut if you use an electric razor instead of wet shaving.

Small changes for an easier life

- Arrange to get your food shopping delivered.
- Cook extra portions of food when you feel well and freeze them for days when your energy levels are low.
- Pace yourself. Try not to fit in too much in a day and **prioritise** the tasks that need doing first.

THINK AHEAD

With ITP it really helps if you can organise your life a little bit more. Things like making sure that you write down your appointment times, ordering repeat prescriptions before they run out, carrying your Medical Alert Card and taking tranexamic acid with you when you go out are just a few suggestions to make your life run more smoothly. It's a lot at first but rest assured it will all soon become part of your daily routine.

BODY ENHANCEMENTS

Tattoos, piercings, microblading – yes or no?

Whether you should undergo any of these treatments is a personal decision that only you can make. However, do be aware that your level of ITP could affect how you react to them. Every treatment comes with a risk, so it is about being aware of those risks and making an **informed decision** with your medical team.

- **Tattoos** are made using a tattoo machine containing needles to puncture the skin and implant coloured pigment. A tattoo is permanent.
- **Microblading** is semi-permanent makeup that gives the effect of newly shaped eyebrows. The process is similar to tattooing – as needles are used to implant pigment – but microblading will fade over a period of months.
- **Piercing** can be performed on various parts of the body with a needle or a piercing device. A small hole is made into which a stud or other piece of jewellery is inserted.



Why might it be risky?

All these procedures involve making tiny wounds or incisions in the skin and these can bleed if you have ITP. Apart from the risks of bleeding, ITP can also prevent the pigment from being properly implanted in tattoos and microblading. The healing process can also take longer than usual.

BEFORE OR AFTER?

If you had a piercing, tattoo or microblading done before you were diagnosed with ITP, then there's no need to worry – it's new ones that must be carefully considered.

Get advice

When making your decision, you should always speak with your doctor or nurse. Your current platelet count will make a big difference and whether or not your ITP is stable. If your count is low, your doctor is likely to advise you not to have any treatments as it may be very hard to stop the bleeding. This might be disappointing news but remember that it may not be forever.

It's disappointing when something you really want is not accessible to you. Especially something as personal and meaningful as a tattoo.

If your doctor thinks it is possible for you to go ahead, choose a reputable artist or piercer. Try to find someone who has experience of dealing with people who have blood disorders and contact them in advance to make sure that they know about your condition. It is very important that they – and you – strictly follow hygiene and safety measures to minimise the risk of getting an **infection**.

Hair Removal

If you want to remove body hair, you should avoid waxing or threading if your platelet count is low. Both procedures pull the hair out from the roots and can cause bleeding and bruising in ITP patients. Shaving with a razor carries the risk of cutting yourself so it is advisable to use an electric razor if this is your preferred way of removing hair.

Probably the safest way of removing hair is by using hair removal cream (although you must always do a patch test first in case you are sensitive to it). **Laser hair removal** is also an option but, as with all beauty treatments, you must tell your therapist about your ITP in advance. Non-invasive beauty treatments such as manicures and pedicures are usually safe.

YOUR MOOD AND MANAGING IT ALL

Having a health condition like ITP can really take its toll on your mood and well-being. Many of us feel **overwhelmed** at times but when you are also trying to cope with bleeding, tiredness or flare-ups, it's easy to let everything get on top of you.

Our thoughts and feelings are as much part of our body as other experiences. After all, the brain is also part of the body! In fact, research shows that people with long-term health conditions are more than twice as likely to feel anxious more generally and potentially their mood can dip down into **depression**.

We need to be aware that this disease not only affects our physical health but our mental health too. Compared to many sufferers I am very lucky, but it has messed with my head leaving me anxious about its inevitable return.



Stress and anxiety

It's normal to feel stressed out or worried when you're unwell. It's when these feelings overwhelm you that it can become a problem. If you find yourself feeling **anxious** for hours at a time over weeks on end, do let people around you know, including your GP and your ITP team. After all the ITP may not be the only thing that is stressful in your life, but it can just feel like the last straw. We can do so much to put practical and emotional things in place to make everything seem less overwhelming.



The causes of stress and depression are often within us. They consist of negative thoughts about situations, events and illnesses, etc. Such thoughts as 'I will never get better.' 'These new tablets will never work.' 'I can't live as I want to because of my ITP.' 'It will kill me in the end.' I try to challenge such thoughts and either reject them entirely or modify them in some way. Then maybe replace them with a positive thought such as 'I will get better – at least enough to live and enjoy life as best I can.'

What can I do?

- **Talk to someone**

Those close to you might not realise what you are going through and we know that it can be difficult to keep mentioning illness to friends and family since there doesn't seem to be much new to say. Yet it's the fact that it's going on and on that is the actual difficulty. There isn't a one-size-fits-all solution. But discussion with a professional to talk through your own situation and preferences can really help as can sharing experiences with other people dealing with ongoing physical difficulties.

- **See a professional**

Your GP will have talked to many patients who have experienced your feelings and they should be able to advise you about treatments. It's important you feel supported and **understood** by your GP so consider switching doctors if you don't feel this way. But remember that you don't need a referral from your GP to find a professional to talk to if you are generally anxious or are low in mood. You can look up **talking therapies** for your area on the internet and refer yourself. Or ask your hospital doctors if there is someone you can speak to who also understands your condition.

Ricocheting thoughts engulf me. Will I need treatment or will the platelet count rise without intervention? Do I carry on, battle, defy or surrender? If I need treatment, how will I manage work and childcare? Am I actually low or am I just really tired from juggling life...?



- **Be mindful**

Paying attention to what is happening right now, is being 'mindful'. It is actually quite hard for humans to stick to the present moment since we are always hopping back to the past and then rushing forward, but mindfulness practice can make a **huge difference**. If thoughts are going round and round in your head, try bringing your mind back to basics. Really notice what you are eating, the things around you, the street you're walking down. There is increasing evidence that if we can focus on the physical reality of everyday things, our brains can't busy themselves so much with memories or anticipation about what might happen next. Look at pages 69/70 for services that provide helpful resources, including mindful activities.

- **Get active**

This may be the last thing you feel like doing but it will be worth it. Any kind of physical activity helps **release stress** and tension. Exercise is scientifically shown to produce 'feel good' hormones in your body (called endorphins)

which improve your state of mind. You don't have to start training for a marathon – a simple walk will do, and a change of scene will also clear your head. If you don't want to venture out, yoga and stretching exercises are an excellent way to relax at home.



DRINK AND DRUGS

People sometimes turn to alcohol and drugs as a way of coping with stress. While these might make you feel better for a short while, they usually make you feel worse in the long term and can cause addiction issues.

If you find yourself drinking more than you used to or changing your mood with drugs and feeling unhappy with these shifts in your behaviour, don't feel embarrassed to mention it. These are human responses and if you are concerned, just reach out to a friend, a doctor or your ITP team.

- **Find a support group**

Joining a support group will help you connect with other people who have ITP or other health conditions. Many support groups are online, while others meet face to face. It can be enormously helpful to meet others in a similar situation and to share your experiences.

I felt like I was the only person in the world with this wacky blood disease – all alone with no one to talk to. I had no one to tell me that they'd been there, done that, and survived. And then, I discovered online support groups. Wow, I wasn't alone. I wasn't the only person suffering from ITP!



THE ITP SUPPORT ASSOCIATION

The ITP Support Association is a registered charity which aims to promote and improve the welfare of patients and their families. It offers a national helpline, local support groups (online and face to face), educational leaflets, and a quarterly newsletter, *The Platelet*. For details of how to join, see page 68.

I decided to do an internet search and found the ITP Support Association in the United Kingdom! So, so happy to have found them and to be able to join. I really found answers to many of my questions.

- **Tell your ITP team**

You may only be sharing your physical symptoms with your medical team at appointments. Don't be afraid to share your feelings and **mental state** too. They will have seen many patients who are experiencing similar feelings, and they may be able to point you in the right direction for help.

Remember that it's fine to feel whatever you're feeling, whether it's frustration, sadness or anger. These are difficult feelings that you may not have had to deal with before. However, there is much you can do to help yourself and to get support.

Life can be unfair and the sooner we realise that the better. Anger is an ugly emotion but one that is occasionally necessary to move on, good days and bad days are valid and must not be underestimated and finally, hope is an emotion that we could not, and should not, live without.

Do you have 'Scanxiety'?

'Scanxiety' describes a feeling of worry or dread that some people feel while waiting for a scan or blood test and for its results. It is something that many patients suffer from, so if you experience this, you are not alone. 'Scanxiety' can affect your sleep, work and other aspects of everyday life. Bear in mind the following:

- Focus on the **present**. You won't change the result by worrying about it. It is usually the fear of the unknown that causes the worry. Once you know the facts, you and your team will be able to do whatever is necessary to help.
- On the day of the scan or blood test, take something to read or do while you wait (maybe take a friend?) and have a **treat** to look forward to afterwards, however small.

- The waiting is difficult but try to remember that you've done the right thing by having the scan or test.
- Raise any of your worries with the doctor. It's part of their role.

Other ways of calming a busy mind

There's no time like the present for trying to reassure your worrying mind. See whether any of these activities work for you.

- **Visualisation**

Think about a place that makes you feel calm and peaceful, maybe a beach or green forest. Imagine what it looks like and how it feels to be standing there. What can you see, hear, touch and smell?

Try to stay inside this **peaceful place** for as long as you can.



- **Breathe it out**

1. Breathe in through your nose very slowly, while counting 1, 2, 3, 4 in your head.
2. Breathe out through your mouth slowly, again counting from 1 to 4. Think about your lungs expanding and contracting inside you.
3. Repeat for as long as you need to feel **calm**. Try not to think about anything else at all except for your breathing. It may help to close your eyes while you are doing this.

- **Body aware**

This one is best done alone and lying down if possible.

1. Close your eyes and visualise your body. Start with your feet, and then slowly imagine scanning your body from

bottom to top, ankles, legs, hips, stomach, chest, shoulders and head. Relax each part of your body as much as possible.

2. Now squeeze every muscle in your body tightly. Squeeze your toes together, make your hands into fists and tense your arms and legs. Hold this while you count to 10.
3. Now release your muscles and go back to relaxing. Repeat.

• Repeat a mantra

Quietly repeating a **positive statement** to yourself (sometimes called a mantra) can help reduce anxiety and help you feel at peace. Try these examples:

- I'm doing the best I can
- Let go of what I cannot control
- All will be well
- One step at a time
- Breathe in and breathe out

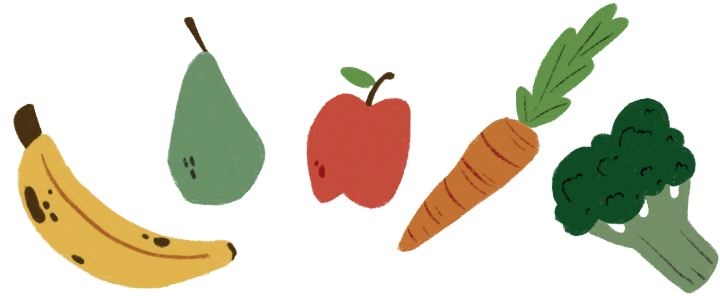
All will be well.



EATING WELL

Eating well can make a huge difference to your mind and body. A good diet helps you fight off infection, which is so important when dealing with an autoimmune condition such as ITP. Healthy food can also improve sleep, give you more energy and boost your mental health.

The current advice is to eat at least **five portions of fruit and vegetables** per day but if you can manage more, that's even better. Dietary research indicates that eating a wide variety of food is important.



I focus on whole, nutrient-rich foods most of the time but still allow myself to enjoy treats without guilt.

- Look for foods that are **fresh** and which are not overly processed. 'UPF' stands for ultra processed foods, which have been linked with a range of health conditions. Look at the back of food packets and if you don't recognise many of the ingredients, they are probably UPFs. Foods such as ready meals, sausages and ham, crisps, sweetened breakfast cereals, sweets, biscuits and fizzy drinks are all UPFs. They can be enjoyed in moderation but try as best you can to cut them down and replace with fresh food. For example, you could cook a fresh chicken breast rather than chicken nuggets from the freezer section.

- Whether you eat meat or not, try to add more **nutritious pulses** (beans and peas) to your diet, e.g. stir a tin of chickpeas into a curry. Pulses are great for your protein and fibre intake.
- Drink plenty of water to stay hydrated and keep your digestive system moving.



I take more care about what I eat these days, especially as I have a sweet tooth. I try to eat fruit and yoghurt most days instead of puddings and I'll have some dark chocolate if I fancy something sweet.

GET YOUR VITAMIN D

This is a very important vitamin that you get from sunshine which we think can really help your immune system. In the UK it can be very difficult to get enough vitamin D during the winter, so get outside and into the light when you can. Consider taking a supplement over the winter months. Your doctor may test your Vitamin D level and recommend treatment.

Iron supplements

Some people with ITP also get iron deficient. Iron is a **vital mineral** that your body needs, especially to make healthy blood. Your doctor will check for this and may tell you to take iron supplements. Remember to take them if so!

Sensible drinking

Patients with ITP who have their platelet counts under control are usually advised to limit their drinking to a sensible level. Avoid excessive drinking, as large amounts of alcohol can suppress the production of platelets and stop your blood from clotting properly.

But what is a **sensible level**? The current medical advice is to drink no more than 14 units of alcohol spread out over a week. A standard pint of beer or medium glass of wine is usually 2 units. To help cut down, you could try low and no-alcohol drinks which are now available in pubs, bars and shops. Or you could set yourself a target of having a set number of 'drink-free days' per week. If you are struggling with alcohol consumption, consult your doctor for help.

By cutting down slowly, I've got out of the habit of drinking wine every night with my evening meal. Nowadays, a glass of wine is a treat for weekends, holidays and dinners out – and I really enjoy it!

Smoking and vaping

There's no getting away from the fact that smoking is bad for your health. It is a **major cause** of heart disease, stroke and lung cancer and it is responsible for millions of preventable deaths in the world every year.

The long-term effects of vaping are still being researched but evidence so far shows that vaping can **damage** your lungs, heart and brain. Both habits can really damage your wallet as well. So, if you're a smoker or vaper, try to gradually cut down the number of times you smoke/vape a day with the aim of giving up completely.

Look at page 70 for resources to help you. As smoking and vaping are both highly addictive, you might need to ask for extra help from your GP, who can advise you on effective ways to give up.



SLEEP AND TIREDNESS

Sleep is essential for the human body to recover itself, and it is important that everyone gets enough rest, including people living with an autoimmune condition like ITP. **Quality sleep** helps ensure your immune system is running as smoothly as possible and will help you recover more quickly from treatments. Unfortunately for ITP patients, tiredness and fatigue can often be an issue.



When I feel my platelet count threatened, bone-tired weariness and weakness can consume me from the inside out, and it can be a struggle to put one foot in front of the other. I can feel unbearable fatigue, a lack of drive and energy.

It can feel impossible to face everyday life when you're exhausted - but there are plenty of things you can do to **improve** your sleep.

Better sleep

- Try to keep to a **regular** bedtime and waking up time.
- Avoid looking at your phone or tablet right before sleep time as the blue light emitted makes it harder for you to fall asleep.
- Having a **short nap** during the day can really restore your energy. However, try not to nap for too long as it may affect your sleep at night. Ideally, nap for less than an hour and not after 3pm in the afternoon.
- Everyone needs a different amount of sleep to feel properly rested and only you know how much you need to feel good the next day. Most adults need between 7 - 9 hours of quality sleep.
- Getting **outside** and being in daylight during waking hours is important as it has been shown to improve the quality of sleep.
- Getting enough **exercise** will also help you sleep better.
- Try wearing an eye mask and ear plugs if you are a light sleeper.

If poor sleep or insomnia - the inability to sleep - is really affecting your life, see your GP and tell your ITP medical team. There is more help available for you.



Fatigue is the most significant side effect of the condition, and this was quite distressing in the early days.

KEEPING ACTIVE

Through no fault of our own, our **lifestyles** often mean that we can end up sitting at desks, staring at screens and driving everywhere in our cars. Despite this, we know that moving and being **active** is one of the best ways of keeping our bodies healthy. Exercise also helps with our mental states as it produces hormones which have been shown to reduce depression and anxiety. Keeping active can help anyone - of any age - improve their health and perhaps even live longer. If **movement** was a pill, we would all be taking it!



The good news is that you don't have to be a marathon runner to be fit and healthy. You don't have to join an expensive gym either. The key is to find something that you **like doing** - and keep on doing it. You might hate jogging or sport but enjoy dancing or swimming. If you choose something you like, you are much more likely to keep it up.

As I was unable to run, I went swimming three times each week instead.

Aim for:

- An hour of activity every day that makes you a little bit out of breath, such as **brisk walking** (ideal if you have a dog), swimming, tennis, cycling or just dancing around your kitchen!
- An easy way of getting more daily exercise is to get off the bus or train a stop early and walk the last part of your journey.
- Stretching exercises such as **yoga** and **Pilates** are great for your bones and joints so it's worth joining a class or streaming an online class at home.



- Try to reduce the time you spend sitting down by putting a reminder on your phone to get up and have a walk around or a **stretch** every half hour or so.
- When starting any new activity, start slowly and build up gradually to avoid injuries. If you're feeling very tired or suffering from ITP symptoms, it's perfectly fine to have some rest days. Just get back to it when your energy returns.
- Motivate yourself by imagining how good you will feel after the exercise and how much **healthier** your body will be if you continue.
- If you haven't exercised for a while, walking is a great start. It costs nothing and it's easy to do. Go for a walk at lunchtime if you're working or join a local walking group.
- It might be helpful - and motivating - to count your steps using a phone or wearable fitness gadget. The benefits of doing 10,000 steps a day have been known for a while, but medical evidence shows you don't have to do this many steps to get a real boost to your health. Just do what you can and try to increase your step count over time. **Every step helps!**
- When it comes to sports, the only ones to avoid are anything that is high impact, if your platelet count is low.
- Always wear the recommended protection for your activity, such as a helmet when cycling.

I have been leading a more or less normal life for a seventy-five plus year old while taking care not to 'overdo things'. I especially enjoy good mountain walks.

What are high impact sports?

Because of the risk of excessive bleeding and bruising there are some activities that are **best avoided** if your platelet count is very low. These include rugby, football, hockey, skiing, mountain biking and some martial arts. If you are part of a team or group that plays sport, it can be very disappointing to have to stop taking part, even if it's only for a while. Discuss this with your medical team as you may be allowed to increase certain treatments to improve your platelet count, which will enable you to do your sport again.

However, if you are advised by your medical team to avoid high impact sports, try to get involved in another way until you are hopefully able to participate again. Perhaps you could be the referee, the coach, cheer on the sidelines or organise **social events** around the sport?

Remember that there are plenty of other activities that you can take part in - you will just need to be that little bit more careful than other people.



Not being able to roller skate anymore once I was diagnosed upset me as I had just started to learn new tricks. Still very anxious about skating again even though I know my platelets are good and nothing will happen to me.

Low impact activities

- Walking
- Swimming
- Yoga and Pilates
- Cycling (if the weather is wet or icy, consider indoor cycling instead)
- Running/jogging
- Dancing
- Tennis/Padel/Badminton
- Weight training



Whatever activity you choose, doing it regularly is what counts. It's not about pushing yourself beyond your limits. It's about making **movement** part of your life and enjoying it!

First, I walked to work. Then I started doing physio exercises. Finally, I joined a gym. (That's a big deal because I'm not a gym person!). I was scared to get on those big machines, but I did it. The more confident you become, the more you realise you can do!

PLATELETS – UPS AND DOWNS

It is also important to know that you don't need a normal platelet count to have a normal life. If your count is above 80, you can do almost everything – even have major surgery. If your count is above 30, you can do most sports, apart from those with a risk of head injury (such as skiing, rugby or mixed martial arts). It is also important to remember that if you have had to stop your sports while your platelet count is low, you can go back to it when your count comes back up.

ITP AND SEX

Sex is an important part of life – and being diagnosed with ITP doesn't mean that you need to give it up. Only in rare situations (such as a very low platelet count) might your doctor advise you to avoid sex for a while.

However, you may now have other **challenges** to consider, such as pain, bleeding or tiredness. Certain medications might have side effects that affect how you feel about sex. Living with ITP is all about learning how to manage your condition while still doing all the things you want to do in life – and that includes having a sexual relationship.

Talk about it

Communicating with your partner is essential as they need to understand how you are feeling. Even if they know about your ITP, they may not realise that it could affect your sex life physically or mentally (or both). It is best to **reassure** them that you still want to be intimate with them but that you might need to adapt your sex life a little going forward.

Many people find talking about sex awkward (not just those with ITP!) so don't worry if you find this difficult. Think about what you would like to say beforehand, pick a **quiet moment** and, above all, try to be positive about all the things you can do together, rather than anything that isn't currently possible. You can also talk with your medical team about ITP and sex if you have any questions or concerns.



Things to consider

- When you are aroused, more blood flows through the skin, which means those with ITP should take a bit more care during sex because of the risk of bleeding.
- Sex is a physical act, and any strenuous activity can put pressure on your body. You should ask your partner to be **extra-gentle** with you to avoid bruising and bleeding.
- Some sexual activities may be more likely to cause a joint or muscle bleed, a tear or an injury, so don't let things get too rough. Anything that can break the skin's surface and cause bleeding, like biting, should be avoided.
- Finding sexual positions that are easy on your body is important. **Experiment** with your partner to find the most comfortable position for you.
- Use plenty of water-based lubricant to reduce friction and any discomfort. Patients with low platelet counts are usually advised not to have anal sex, which is more likely to cause tearing.
- Women are more likely to experience bruising during sex and sometimes vaginal bleeding. If unusually heavy bleeding continues for more than a few days contact your doctor or visit A and E. Your medical team may refer you to a **gynaecologist** (a specialist in the female reproductive system) who will be able to advise on the best treatment for you.
- For men, a more serious problem is a potential bleed into a muscle called the psoas (with a silent 'p') muscle, which is found deep inside the hip and groin area. The symptoms are sudden severe hip or groin pain. Other possible signs are being unable to straighten your leg while lying down or being unable to stand up straight. If you think that you have a psoas bleed, you should go to A and E.
- If tiredness is a problem for you, try to choose a time for **intimacy** when your energy levels are at their best.

- If you think your medication is the root of a sexual problem, such as lack of libido or erectile issues, try not to be embarrassed to bring it up with your doctor or medical team. You can email them with your query if you would rather not discuss it face to face.

Periods and ITP

Women with ITP can often suffer from heavy and painful periods. The medical name for this is menorrhagia. Not only is this incredibly inconvenient, but the blood loss can also result in extreme tiredness and even **anaemia**. Those suffering heavy periods may find that they have to use both pads and tampons during times of heavy flow and change them often.



When I first started my period at the age of 12, I thought it was normal to be leaking everywhere and needing to change my pad every hour or less. That was until I found out that I had ITP, and it all made sense. The best thing for me at that time was going on the pill. Now I am 20 and my ITP has got a lot better with the new medication I am on, as well as the pill. A lot of women go through this with ITP. You're not on your own!

WHAT IS ANAEMIA?

Anaemia occurs when there aren't enough healthy red blood cells to circulate oxygen around the body. In severe cases you may need a blood transfusion. More usually, your doctor will prescribe an iron supplement for you to take. You can also increase the amount of iron-rich foods in your diet by eating more leafy green vegetables, nuts, red meat, beans, pulses and iron fortified cereals and bread. Vitamin C is important as it helps the iron to be absorbed, so try taking it with your supplement or eating your food with a glass of orange juice.

You may have menorrhagia if your periods:

- Last longer than a week
- You **soak** through a pad in less than two hours or are changing protection every hour or two
- You pass clots that are larger than a grape
- You suffer '**flooding**' - this is when a large amount of blood flows out, especially when you move position.

If you have concerns about your periods, speak to - or email if you'd prefer - your doctor or nurse. You can also contact the ITP Support Association for advice. Your doctor may refer you to a gynaecologist for treatment. You will probably need to be examined to make sure that there is nothing else contributing to your heavy bleeding apart from ITP.

Possible treatments:

- Doctors can prescribe medicine called **tranexamic acid** to take during periods, which helps the blood to clot for many women. However, some patients do not find it effective.
- Another treatment is to take the contraceptive pill or use patches, which can lessen the number of periods or stop them altogether.

You may be advised to have a coil inserted - a small T-shaped contraceptive device which is inserted into the uterus. It releases a hormone over a length of time, usually five years. The coil can be very effective at stopping or lessening periods.

BE PREPARED

If you suffer from heavy periods, it's a good idea to always carry a small pouch with you containing your preferred sanitary protection, spare knickers and wipes. Then you will be prepared if sudden bleeding takes you by surprise when out and about.

TRAVELLING AND HOLIDAYS

Having ITP won't stop you from getting away and seeing new places - but you will need to do some **preparation** before you leave.



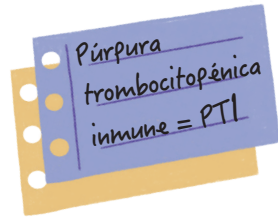
I am delighted at being able to start to get back to a normal life. I've even booked a short over-seas trip in two months' time and possibly a longer cruise in six months' time.

TRAVEL CHECK LIST

- Check your vaccinations are up to date for the country you are visiting. See page 65 for more information on vaccinations.
- Travel insurance is an absolute **must**. It is important to let the company know about your ITP before you buy the policy, in case it isn't covered.
- Ask your GP or ITP team - well in advance - for a **letter** explaining that you have ITP and need to travel with prescribed medication. This will ensure that security officials will let your medical supplies through without any issues.



- If you live in the UK and are travelling to a European Union Country, remember to take your **Global Health Insurance Card** (GHIC) with you. While this card will give you access to some state healthcare abroad, do be aware that this is not a substitute for proper travel insurance.
- Try to find out what ITP is called in the country you are visiting. Check what the local **emergency phone number** is and the location of the nearest doctor and hospital emergency department at your destination, just in case. The ITP Support Association has helpful leaflets available in different languages, which you can take along if necessary.
- Make sure anyone you are travelling with knows about your ITP and what to do in an emergency. If you are travelling alone, consider wearing a medical alert bracelet.
- Order your medication well in advance, ensuring you have more than enough to last the holiday (remember that your journey might be delayed so always take extra). Always pack medication in your **hand luggage** to avoid it getting lost, along with a copy of your prescription and a doctor's letter.
- Being prepared will mean that you will be free to have an enjoyable holiday without having to worry.



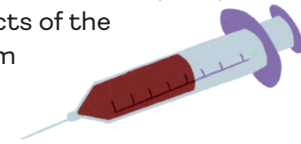
During my travels was when I experienced my first ITP symptoms (pre-diagnosis). Despite this I have not let that experience affect my love for travelling and I continue to make plans without letting ITP get in my way.

Do not let this disease dampen your sense of adventure!

Vaccinations

Most patients with ITP should be able to receive vaccinations without any issues. If your platelet count is low, you will need to have the injection under the skin (subcutaneously) instead of into the muscle (intramuscularly). That means you can still have routine vaccinations like the 'flu jab, as well as pre-holiday vaccinations.

However, if you are on medications that weaken the immune system, vaccinations may be less effective. They may need to be repeated after the effects of the medication on your immune system are gone. Your medical team will be able to advise you on this.



THINK AHEAD

Be sure to discuss any vaccinations that you need with your doctor well in advance. If you are taking certain drugs for your ITP (such as immunoglobulin or steroids), you will need to leave a three-month gap before having the vaccination, otherwise it will be ineffective.

Can I fly?

The ITP Support Association's medical advisors recommend that if your platelet count is around 30 or above, and there are no bleeding problems, you should not be at any risk from flying. However, if you suffer with heavy nose or mouth bleeds, think about how you will cope with this in mid-air.

Tranexamic acid should help.

It is best to talk to your medical team when you are planning a trip and ask for their advice.



A FEW LAST QUESTIONS

Here are the answers to a few more things that might be on your mind.

I'm scared that I might not live for long

There is no **evidence** to show that people with ITP live shorter lives than anyone else. The only real risk is from a severe haemorrhage (bleed) which is very, very rare. There is much more risk to your life from regular smoking, heavy drinking or taking street drugs than there is from having ITP.

Are the drugs I'm being prescribed dangerous?

Prescribed drugs go through **rigorous testing** and all possible side effects are listed, which is why reading the leaflet that comes in the pack can sound off-putting. But remember that not everyone gets all - or even any - of the side effects. The drugs you are prescribed by your doctor are as safe as they can be. You can also share any concerns or questions you have with your medical team.

Someone told me there's a cure for ITP

Doctors don't know of any cures for ITP at the moment. Despite what some (non-medical) people may say, in real life or on the internet, there are no herbs, special foods or alternative therapies that will cure ITP. Having said that, a healthy lifestyle and a positive attitude may help you deal with some of the effects of ITP and if you want to try alternative therapies such as massage and homeopathy, they are unlikely to do you any harm. However, taking the **proper medical treatment** that the doctor recommends is VITAL. Never take any supplements or herbs not recommended by your doctor - they might not be tested for safety and could make you ill.

and finally . . .

Living with ITP can be a challenge. It can affect many areas of your life, including your relationships, your ability to work, your finances and your mental health. We hope this book has helped you deal with some of the questions and feelings that you have. With reassurance and the right information, you will hopefully be able to cope with everything that ITP throws at you and feel good about **moving forward** with your life.



Goodbye and good luck from the ITP Support Organisation

We hope you've found this book useful. If you have any other questions or would like to be sent leaflets or packs mentioned in this book, email us at info@itpsupport.org.uk and we will do our best to help you. For more information about ITP, have a look at our website www.itpsupport.org.uk.

The ITP Support Organisation are a UK charity supporting everyone who is affected by ITP. Why not join us? It's easy to join and all the details are on our website.

We are always looking for ways to promote **awareness** of ITP and to raise funds. Why not help us by holding a fundraising event in aid of our charity? Anyone who raises money for us receives a certificate and a mention – even a photo if you wish – in our quarterly journal *The Platelet*.

So – from everyone here at the ITP Support Association, we wish you the very best of luck for the future.

For all of you and your ongoing treatment, surround yourself with people who will encourage and support you, try to understand your unpredictable life filled with numbers that rise and fall, lift you up when it gets hard and have fun together whenever possible.

I have fought ITP as an enemy but also allied with it to achieve what to me are great things.

It's now been nearly seven years since I was diagnosed with ITP, and I'm thankful that I was. I've found what I'm passionate about. Yes, there are good days and bad, but you can't have rainbows without the rain.

Other services which may be of help

The Wren Project

Free, ongoing listening support to people diagnosed with an autoimmune disease. Sessions are run by phone or video call and are available to over 18s living in the UK.

☎ 020 3336 3739

✉ contact@wrenproject.org

🌐 <https://www.wrenproject.org>

Mind

Information and support for people experiencing mental health difficulties, including those related to long-term physical health conditions. Local Mind services may offer group and wellbeing programmes.

☎ 0300 123 3393

💬 Text 86463

🌐 <https://www.mind.org.uk>

Rethink Mental Illness

Support and helpline for people living with mental illness and those caring for them. They also run support groups and community services.

☎ 0808 801 0525

🌐 <https://www.rethink.org>

Shout

A confidential 24/7 text messaging service, providing support for people who are struggling to cope with anxiety, panic or low mood.

💬 Text SHOUT to 85258 (24/7)

🌐 <https://www.giveusashout.org>

SANE

Emotional support and information via helpline and online resources for people affected by mental illness.

☎ 0300 304 7000

🌐 <https://www.sane.org.uk>

Anxiety UK

Support for people experiencing anxiety disorders, including health anxiety and panic. Information and access to therapy and self-help resources. Some are free if you become a member, others are paid but subsidised.

☎ 03444 775 774

🌐 <https://www.anxietyuk.org.uk>

Campaign Against Living Miserably (CALM)

Provide support and a free confidential evening helpline for people experiencing low mood, distress, or suicidal thoughts.

☎ 0800 58 58 58

🌐 <https://www.thecalzone.net>

The Samaritans

Confidential and non-judgemental emotional support by phone 24/7 for anyone experiencing distress, anxiety, or difficult feelings.

☎ 116 123 (free, 24/7)

✉ jo@samaritans.org

🌐 <https://www.samaritans.org>

Help with stopping smoking and vaping

Helpful advice and a Quit Smoking app are available through:

🌐 <https://www.nhs.uk/better-health/quit-smoking/>

You can also call the free Smokefree National Helpline and speak to an advisor on:

☎ 0300 123 1044 (England)

☎ 0800 84 84 84 (Scotland)

☎ 0800 085 2219 (Wales)



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