

# ITP and you

This booklet is designed to help support you in making the most of your care.








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# What is **ITP**?



## Know your ITP

ITP stands for immune thrombocytopenia. ITP is a rare autoimmune disease generally characterised by low platelet counts and increased bleeding risk. ITP usually develops gradually and without a clear cause. When ITP lasts more than a year it is called chronic ITP.<sup>1-3</sup>

ITP affects every person differently. Whether it's the treatment you're receiving or the way ITP affects your daily life, your journey and your ITP are unique.<sup>4</sup>

### DID YOU KNOW?



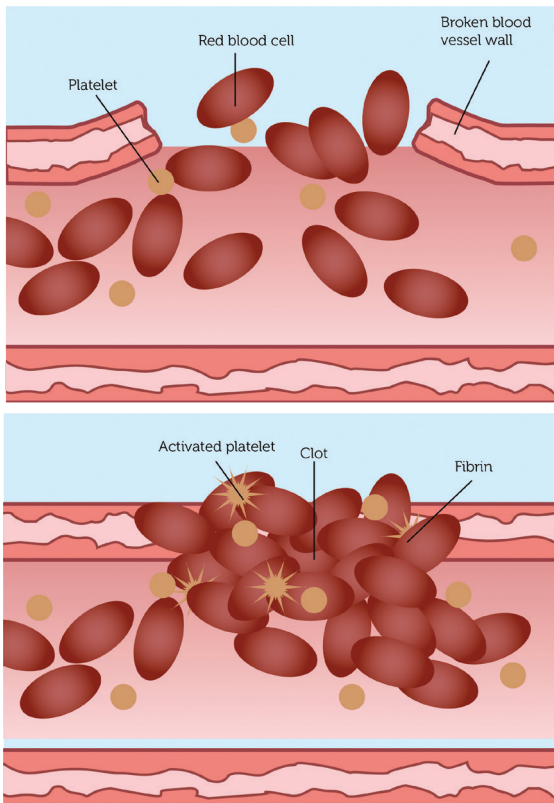
About 9–10 adults in every 100,000 have ITP and more women are affected than men.<sup>4</sup>



## A bit about platelets

### What are platelets and what do they do?

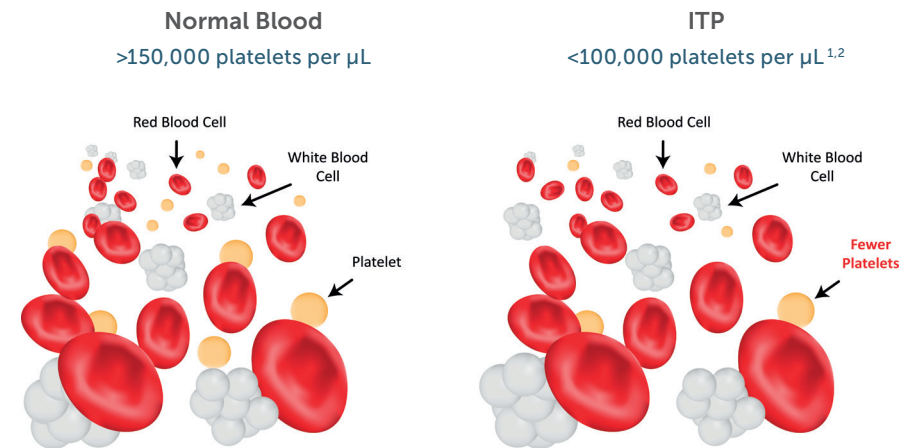
Platelets are cells in the blood that cause it to clot and prevent bleeding. When a blood vessel is injured, platelets stick together to form a clot and stop blood leaking out of the vessel.



## Platelets in ITP

In ITP the immune system attacks and destroys platelets. The body may also produce less platelets. This means that you have less platelets in your blood than is normal.<sup>5</sup>

### ITP affects the levels of platelets in your blood.



### DID YOU KNOW?



Your platelet count may be much lower than normal, even if your condition is stable.<sup>1,2</sup>





## Autoimmune conditions and ITP

An autoimmune disease is a condition where the immune system attacks the body. There are many different autoimmune diseases, and these cause different symptoms depending on what part of the body is damaged.<sup>6,7</sup>

- People living with autoimmune diseases often experience severe fatigue that can be debilitating
- Autoimmune diseases can be unpredictable worsening or improving in an on-and-off pattern

This can be frustrating for people living with autoimmune diseases.

### DID YOU KNOW?

Every patient with ITP is different. Symptoms, platelet counts and response to treatment can all vary.<sup>4</sup>

Please see the conversation starters on page 30 for advice on how to discuss these with your healthcare team.



## Your symptoms

### Common symptoms include<sup>4,9,10</sup>

- Fatigue
- Bruising that is unexpected or unusually severe
- Petechiae, (pronounced pi-tee-kee-uh) - rash of tiny red or purple spots
- Purpura, (pronounced puh-puh-ruh) - red or purple discoloured spots on the skin
- Prolonged or excessive bleeding from cuts
- Nose bleeds
- Bleeding gums
- Black blisters in the mouth
- Heavy periods

### Rare symptoms include<sup>4,9,10</sup>

- Blood in the urine
- Blood in the stools
- Bleeding from the ears
- Bleeding in the eyes
- Thrombosis (when platelets block the flow of blood through a blood vessel)
- Serious internal bleeding such as bleeding into the brain



Example of petechiae



# Living with ITP

ITP may affect many different areas of your life. Let's learn how it might impact you.



## Your platelet counts and bleeding

First things first, your healthcare team will keep a close eye on your platelet count. That is why it is important you tell them about any changes in your symptoms. Here are some things to keep in mind.



## Everyone is different

ITP can affect people quite differently depending on its severity and the stability of the condition. Some people may have no symptoms whereas others will find that their lives are seriously affected.<sup>4</sup>



## Your platelet count may at times be unpredictable

You may worry or feel confused about fluctuations in your platelet count as sometimes it may decrease without much warning. On the other hand, you may find that your condition improves on its own or in response to trying different treatments over-time.<sup>4</sup>

You may have concerns about the possibility of developing serious bleeding. However, remember your healthcare team will monitor you to ensure that your platelets remain at a safe level. If you do experience concerning bleeding or symptoms contact your healthcare team.





## Exercise and keeping fit

Continuing to be physically active may help you to maintain overall good health.<sup>11</sup> However, your healthcare team may have advised against contact sports such as football and hockey or those with a fairly high risk of injury such as skiing.<sup>12</sup>

Some fun sports and types of exercise that pose less risk of injury are:<sup>12</sup>



Swimming



Jogging



Cycling on an exercise bike



Walking



Yoga



Spinning class



Hiking



Dancing



## You may need to take some precautions

You may need to take steps to reduce your risk of injury in everyday life and take minor injuries more seriously.

For instance, you may need to wear gloves when using knives and other tools, wear an Alert wrist band, inform your friends and people at work.

You should also check health supplements with your healthcare team,<sup>13</sup> and keep a first aid kit and medications with you in case of injuries or bleeding.



## Speak to your healthcare team

Your healthcare team will provide more specific advice that takes into account your platelet count and your overall circumstances.

As every single person is different, the advice of your healthcare team will depend on your specific situation and will be tailored to your needs.

Speak with your healthcare team or local patient organisation about any concerns you have. They will support the management of your condition.



## Your energy levels

Many people living with ITP experience fatigue that can often interfere with everyday life.<sup>14</sup>



## What is fatigue?

We have all experienced normal fatigue. Fatigue is a persistent feeling of tiredness and weakness in which a person lacks energy. It can be both physical and mental. Normal fatigue follows a taxing activity such as concentrating for a long time or vigorous exercise, or not getting enough sleep. It is temporary and goes away easily with some rest.<sup>15</sup>



## How is fatigue different in ITP?

The fatigue experienced in ITP is different than normal because it is on-going and can be severe. It may interfere with your ability to engage in everyday activities. You may find simple physical activities such as climbing the stairs tiring. You may have trouble concentrating and remembering things as well. You may also feel that the word fatigue does not fully express what you are experiencing. Since fatigue is sometimes used in everyday conversation to describe normal tiredness in healthy people. When fatigue is severe it might better be described as debilitating exhaustion.<sup>6,9</sup>



## What causes fatigue?

Fatigue is a common symptom of ITP. Fatigue can be caused by many health conditions but is especially common in autoimmune diseases.<sup>13</sup> The mechanisms that cause ITP-related fatigue are not fully understood. They may be related to inflammation, patient's lifestyle, sleep disturbances caused by some medications, and iron deficiency caused by bleeding.<sup>14</sup> If you're experiencing fatigue, consider discussing with your doctor or local patient organisations.

### DID YOU KNOW?



In recent research, **50% of patients** reported suffering from ITP-related fatigue.<sup>9</sup> Do you experience fatigue? If so, how would you describe it: tiredness, exhaustion, brain fog?





## How much do we know about fatigue in ITP?

While fatigue is a common symptom of ITP, much of the research on fatigue in ITP is quite new so fatigue is still poorly understood. There is no blood test or objective measurement of fatigue and it is often not visible to other people. This can make it hard to communicate and explain what you are experiencing.

### DID YOU KNOW?



Scientists believe that immune and inflammatory processes **trigger fatigue in ITP.**<sup>14</sup>

Since the cause of fatigue in ITP is still not well understood, it can sometimes be difficult to treat it effectively. For this reason, you might find it useful to focus on improving your general health, diet and lifestyle.

## Tips for managing fatigue



**Sleep:** Make sure to get enough sleep on a regular schedule; try to go to bed and wake up at the same time each day. Consistent sleep patterns help reduce fatigue<sup>6,14,16</sup>



**Pacing:** Break physically demanding activities down into parts and take regular rests. For instance, if you need to clean your house you may decide to clean one room or even one area of a room then take a break<sup>14,16</sup>



**Diet:** It is important to maintain a healthy diet. Eating a well-balanced nutritious diet will help improve your overall health and energy. It is important to discuss any dietary changes you make with your doctor since some ITP treatments have dietary restrictions<sup>15</sup>



**Gentle exercise:** Some people find gentle exercise such as walking, or yoga helpful. It is important to keep active if possible but also to listen to your body<sup>14</sup>



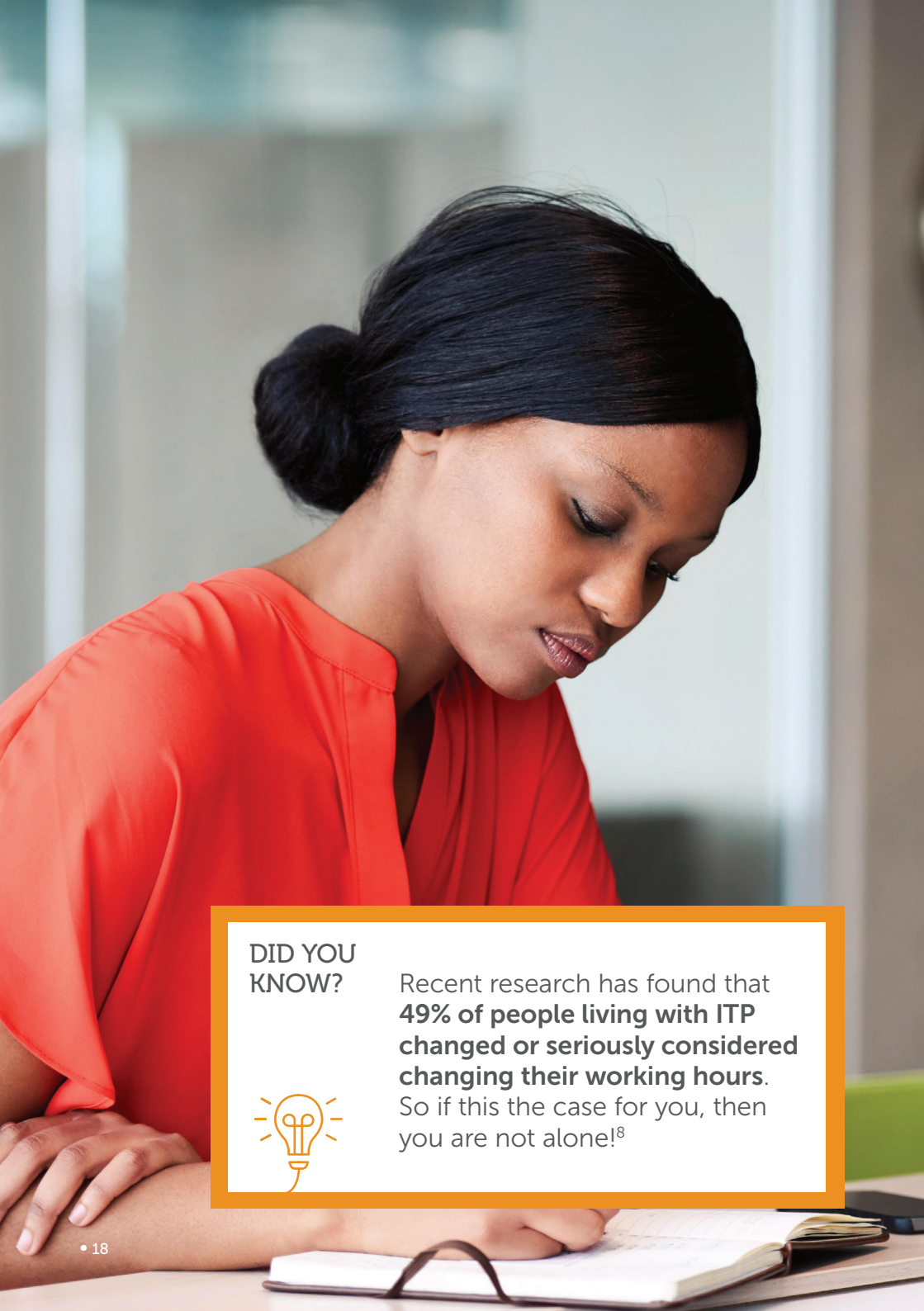
**Stress reduction:** Include more relaxing activities in your routine and reduce sources of stress in your life; meditation and breathing exercises can help with stress<sup>6,14,16</sup>



**Empathy and understanding:** Being supported by family and friends practically and emotionally can really help improve your overall well-being. Let your friends and family know about symptoms of fatigue and how they can best support you<sup>16,17</sup>



**Keep a calendar:** Keeping a calendar might help you when discussing your fatigue with your healthcare team<sup>16</sup>



### DID YOU KNOW?



Recent research has found that **49% of people living with ITP changed or seriously considered changing their working hours.** So if this the case for you, then you are not alone!<sup>8</sup>



## Your work and education

You may find your work and education commitments harder to meet for several reasons:<sup>8,14</sup>



Attending regular doctor's and hospital appointments can take time away from your work or education



Fatigue could impact your work or academic performance



Travelling might be more difficult for you than it was before



If your work involves physical exercise or sport you might find it more difficult than before. If ITP is affecting you at work it is important to discuss this with your healthcare team

On the other hand, if your work and education have not been affected there is no reason to think that this will change. Most patients with ITP work full or part time, and if your condition is well controlled it may not affect your work or education much at all.

**It is important that you discuss with your doctor how best to fit your care around your commitments.** We have some helpful tips on how to start this conversation in the next section.





## Your family and social life

You may find that ITP has affected your family and social life. It might have impacted your lifestyle and leisure activities. There are several ways in which ITP may interfere with this aspect of your life:<sup>5</sup>



Attending regular doctor's and hospital **appointments** can take time away from your family and social life. While this can sometimes be **inconvenient** it is **vital** that you attend all your appointments to ensure your condition is managed appropriately



**Fatigue** can affect all aspects of your life. It may prevent you from doing things that you used to enjoy. It could make it difficult to keep up with family commitments such as **childcare** and **housework**, or your hobbies and social activities. Where possible **ask for help** from friends and family. Do not be afraid to have an honest conversation about your fatigue and how it affects you



**Travelling** may be more difficult for you than it was before because of the **medication** you are on, the frequency of your **appointments** or **managing your condition while away**. However, your healthcare team or your local patient organisation can give you advice and go over your care plan to make this easier. Taking a medical letter in the language of the destination country with you when travelling could be useful. Some patient organisations are able to provide such letters through their website



Sometimes treatments come with **dietary restrictions** to enable them to work, so it is **important to discuss with your healthcare team** if you have any questions or concerns



You may be **restricted** from taking part in or **afraid** of **activities** that could cause you physical **injury**. Remember your healthcare team is there to guide you so let them know what activities you have concerns about, and they will tell you what is safe for you

### DID YOU KNOW?



According to recent research as many as **70% of people living with ITP report some impact on their social life.**<sup>8</sup>

If ITP is interfering with your family and social life do not be afraid to bring this up at your appointments with your healthcare team. **It is important to find the right care plan for you that takes into account your health, lifestyle and personal priorities.**



## Your emotional well-being and mental health

Living with a chronic condition can be stressful.<sup>5</sup> It is normal to have concerns about your symptoms and how they affect your life.



### You may worry about what will happen in the future

It is common for people with ITP to worry about the future<sup>8</sup> as the condition can sometimes be **unpredictable** and your platelet counts may fluctuate. Other issues such as **bruising, fatigue** or **changes to your lifestyle** may also affect how you feel. This can all take an emotional toll but do remember that **you are not alone** as many people with ITP go through similar challenges.

#### DID YOU KNOW?



Sometimes it is not possible to separate your emotional and physical health. For example, if you are worried about how bruises on your body look, is that a physical or emotional issue? **It is both.**



### You may experience depression and anxiety

People with ITP suffer from depression and anxiety at a higher rate than the general public.<sup>4,9,18,19</sup> Psychological stress can also impact your physical health as well as mental health. So, if you feel anxious or depressed, it is important to **relieve stress** where possible and **get emotional or psychological support** when needed.



### Speak to your healthcare team

Whether you need access to mental health services or just clarity on what the future is likely to hold, it is important to address the emotional side of living with ITP as well as the physical. Speaking with your healthcare team is the first step to getting support you need.

**You can find ideas and tips on how to raise your concerns and start this conversation with your healthcare team in our Conversation Starters section.**



### You may wish to join a patient organisation

Patient organisations can offer support and the opportunity to connect with others who are living with ITP. You can find more information on local patient organisations for ITP at: [www.globalitp.org/index.php/patient-support](http://www.globalitp.org/index.php/patient-support)





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# Making the most of your **care**



Your appointments are an opportunity for you to discuss your goals and priorities with your healthcare team. You can make decisions together that improve your well-being and ensure the things that matter most to you remain at centre of your care.

We have included some tips on how you can get the conversation going about your needs and care preferences at your appointments.



## **Making the most of every appointment**

You may find that the time you have with your doctor is short yet there is a lot to discuss. Therefore, thinking ahead about what you would like to say can be useful.



## **Finding the right words**

Remember that everyone is different, we all have different lives, goals, expectations and needs. It is important for you to voice your goals and priorities with your healthcare team so that they understand how they can best support you. It can be hard to find the right words to express yourself. Take a look at the sections below and pick out anything you feel applies to you.

These are suggestions that you could use when speaking with your doctor. Feel free to change them to fit your priorities and what you want to say.





My  
**conversation**  
starters

## Your platelet counts and bleeding

What you might be thinking	Try asking your doctor
I am worried my platelet count will drop too low	How likely is it that my platelet counts will stay stable? What are my options if they don't?
I am worried about serious bleeding	What is my risk of developing serious bleeding? How concerned do I need to be?
I've stopped doing an activity/hobby that I enjoy because I am afraid of getting injured or bleeding	I'd like to get back to doing this particular activity – what measures can we take to ensure I am able to continue with it?
I've been experiencing some worrying symptoms	I've noticed that I have... How common is this in patients with ITP? Is this a cause for concern?
I have had bleeding that worries me	I have had [number] episodes of bleeding in the last month.  This has been triggered by [activity/injury]  Is this a cause for concern?

What you might be thinking	Try asking your doctor
I have bad headaches	I am experiencing frequent headaches of a new type and severity. Could this be connected to my condition or treatment?
I have unusual joint pain	I am experiencing joint pain that came on when I started my new treatment. Could this be connected to my treatment?
I feel dizzy a lot	I am suffering with dizziness. Could this be connected to my condition or my treatment?
I am struggling to eat normally	I am struggling with eating normally and low appetite. Could this be connected to my condition or treatment?
I need help with my bleeding/bruising	I am having bleeding and bruising that is difficult to manage. Can we discuss my options? What could help with this?
I have very heavy periods that are difficult to cope with	I am experiencing excessive bleeding when on my period. What can be done to address this?



## Your energy levels

### What you might be thinking

I am tired and exhausted all the time. Is my tiredness caused by ITP?

My tiredness and exhaustion are really affecting my life and I need this to be taken seriously

I would like support managing my tiredness and exhaustion

### Try asking your doctor

I feel tired and exhausted all the time. I know that fatigue can have several different causes. Which of these can we rule out in my case?

I am aware that people with ITP can experience severe fatigue.

I am experiencing severe fatigue which is affecting my quality of life. It is preventing me from doing the things that I enjoy most and interfering with my work/family commitments. I am aware that people with ITP can experience severe fatigue. Can we discuss my options?

I am experiencing severe fatigue. Would you help me manage this aspect of the disease? What resources and complementary treatments are there to help me?

## Your work and education

### What you might be thinking

I am finding it tough fitting my care around work

I am changing my job. I am worried my care routine will interfere with my new job

I am finding it difficult to fit my care around my education

I need to travel for work

### Try asking your doctor

It is important for me to maintain my normal routine at work as much as possible.

Is there a way we can more easily fit my care around work?

I am starting a new job soon. How can we change or adapt my care plan to accommodate my new work commitments?

I am having trouble keeping up with my education

Is there a treatment that might better suit my current schedule and won't impact on my education so much?

What options do I have?

Sometimes I will need to travel for work.

What adjustments could be made to make it easier for me to travel?

## Your family and social life

### What you might be thinking

### Try asking your doctor

I want to travel but this is difficult because of my ITP

I would like to travel more. What adjustments could be made to my care to make it easier for me to travel? What other options do I have?

It is tough sticking to dietary requirements

I am finding the dietary restrictions required for my treatment difficult. Would we be able to discuss other options without dietary restrictions?

I miss playing sports and exercising

What sports and types of exercise are safe for me? How can I participate safely in the sports I enjoy?

## Your emotional well-being and mental health

### What you might be thinking

### Try asking your doctor

I am worried about the future and what will happen

I am concerned about living with ITP and how it will affect my future? What is my long-term prognosis?

I am very anxious because I don't know if things will get better or worse

How likely is it that my current treatment will continue to work, and my condition will stay stable?

What can be done in future if my condition does deteriorate?

I cannot stop thinking about ITP and its most worrying or severe complications

I am experiencing anxiety about living with ITP. Are there any emotional support or mental health services I can access?

I often feel very low and overwhelmed

I am struggling to cope emotionally with how my life has changed as a result of ITP. Are there any emotional support or mental health services I can access?

I am struggling to cope with the way ITP is affecting my everyday life

I feel alone because I find it difficult to talk to others about my condition

How do I explain my condition to family, friends, or people at work? Are there any materials or organisations that can give me advice about this?



## Thinking about your ITP

How ITP affects your life and the way it's being treated are different from every other patient. As such, it's important to have open, honest conversations with your healthcare team. Before your next appointment, consider:



### What would you like to talk about in your next appointment?

Think about aspects of your condition, life and care that you would like to discuss with your healthcare team

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### How is ITP affecting your day-to-day life?

Think about how ITP may affect your quality of life and the tasks you're able to perform.

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### How is your emotional well-being?

Think about discussing any worries you may have and the emotional impact of any lifestyle changes you're being asked to make.

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## Helping ensure you receive the support you need

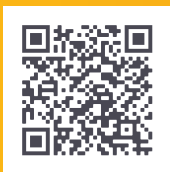
Sharing what matters most to you with your doctor and healthcare team means that you can work together to make your condition easier to manage and tailor your care to your individual needs.

### DID YOU KNOW?



Remember that while controlling your bleeding is essential maintaining your health is also about your ability to enjoy and get on with life. Speak to your doctor about any topic we have discussed here that you feel is relevant to you.





Scan the QR code for more information  
about ITP and personal stories from the  
ITP community



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+46(0)8 697 20 00



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