

A person with long dark hair, wearing a plaid shirt and light-colored trousers, stands on large, wet, brownish rocks in a shallow stream. They are carrying a large, light-colored backpack. The scene is set in a lush, green forest with sunlight filtering through the trees, creating a misty or ethereal atmosphere. The bottom half of the image is overlaid with a dark teal background featuring abstract, wavy, organic shapes.

LIVING WITH ITP

AMGEN[®]
care

This booklet has been developed and paid for by Amgen Ireland in partnership with a Haematology Clinical Nurse Specialist.

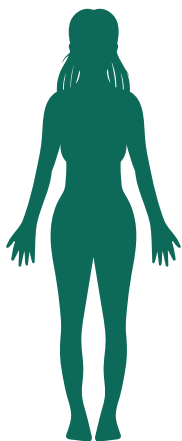
The information in this booklet is intended to offer helpful suggestions and should not replace advice given by your Healthcare Professional.

This booklet is intended to provide you with lifestyle suggestions to help you to live with Immune Thrombocytopaenia (ITP). As the condition causes a reduction in the number of platelets in your body, you are at an increased risk of experiencing bruising and spontaneous bleeding.¹ Certain everyday tasks carry an increased risk of bleeding for those with ITP.

Lifestyle choices for people with ITP are mainly concerned with reducing the risk of bleeding. There are certain things that should be avoided and other practical things that you should consider to help lower your risk of bleeding.

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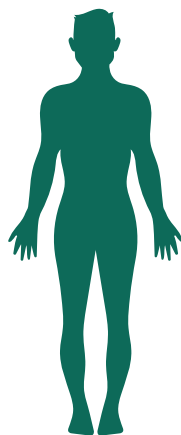
WHAT IS A NORMAL PLATELET COUNT?



Healthy adults usually have between 150,000 and 450,000 platelets in every microlitre of blood.¹ This is sometimes written down as $150 \text{ to } 450 \times 10^9/\text{L}$.

Doctors and nurses usually just refer to the number (for example, a platelet count of 150).

Your risk of bleeding will depend on your platelet levels. Have a discussion with your healthcare professional about your platelet levels and which of the following advice might apply to you.



THINGS TO AVOID:

Alcohol can reduce platelet numbers.² It may be advisable to limit your alcohol intake.³

Some **medications** increase bleeding tendency such as aspirin, ibuprofen, warfarin, and other 'blood-thinning' drugs.³

Talk to your pharmacist or doctor before taking any new medication to make sure it is safe for you, including any homeopathic and herbal remedies. Be sure to tell them that you have ITP.

Avoid **deep muscle injections**⁴ if possible. If you do require a deep muscle injection such as the flu vaccine, discuss with your doctor or nurse. Your platelet levels may be satisfactory to proceed, or you may also require your levels to be checked prior to the injection.



PRACTICAL CONSIDERATIONS TO REDUCE THE RISK OF BLEEDING:

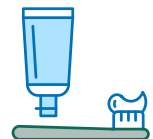
Sports

Some contact sports and other activities may need to be avoided, especially those that may cause injury to the head and neck such as football, rugby, and boxing.^{3,4} Take advice from your doctor in this regard. Always wear a helmet when cycling, and knee and elbow pads when rollerblading, roller-skating or skateboarding.³



Cleaning Teeth

Avoid dental floss and use a soft toothbrush. Speak to your dentist about the best course of action and visit them regularly to avoid bleeding gums and gum disease.^{3,4}



Shaving

Consider using an electric shaver instead of a razorblade when shaving.^{3,4}



Blowing your nose

Blowing your nose too strenuously could cause a nosebleed. Avoid nose blowing as much as possible and keep your nasal passages hydrated with nasal drops. If you do have a nosebleed, sit upright, tilt forward and apply pressure below the nasal bridge.



Bowel Movements

Do not strain to move bowels and do your best to avoid constipation by drinking plenty of fluids and having a high fibre diet.³ If required your doctor/nurse may prescribe laxatives. Avoid any medicines given into the rectum such as enemas.



Knives, blades and sharp tools

Consider wearing protective gloves when working with knives, saws or other sharp equipment.³



Periods

For some women, menstruation can be an issue, with some experiencing heavy and prolonged menstrual bleeding.³ There are medications available that may help alleviate this and this should be discussed with your healthcare professional. It may be best to avoid tampons.



OTHER CONSIDERATIONS:

Surgery or Dental Treatment

Give adequate notice (at least 2 weeks) to your healthcare professional if you require an operation or any dental treatment. They may need time to get your platelets up to a level that is safe.³ Also, inform your surgeon or dentist that you have ITP. Some medications such as *tranexamic acid* can be used to prevent post dental procedure bleeding.³



Pregnancy

Pregnancy can affect ITP in an unpredictable way: it can improve or worsen.^{3,4} Discuss pregnancy plans with your healthcare professional where possible.



Travel

Ensure you have adequate travel insurance before departing and that you have enough medication to cover you until you return home.³



Other

Consider wearing a medical identification bracelet or carry a medical alert card to alert healthcare professionals to the condition in case of emergency.³

You can order ITP alert wristbands and ITP alert cards from the ITP Support Association - see contact details on page 10.



ITP AND FATIGUE:

Fatigue is another issue that patients with ITP must contend with. Many people with ITP and other autoimmune diseases feel tired much of the time.^{5,6,7}

Fatigue can be described as extreme or persistent tiredness, weakness or exhaustion. It can affect you both physically and mentally, resulting in difficulty completing tasks and it can affect your concentration, memory and your motivation.

What causes fatigue is not fully understood⁸ but several factors that are important include diet, stress, exercise, sleep and spiritual needs.⁵

You may find it beneficial to keep a diary so that you can see if episodes of fatigue are associated with low platelet counts.

If fatigue is affecting you, you may need to look at conserving energy and balancing periods of activity with time to rest. Build rest periods into your day and save your energy for doing the things that are most important to you.

Some practical steps to help fight fatigue^{8,9,12}

Diet

Eat a healthy, balanced diet to help increase energy levels. Avoid processed foods and foods that are high in sugar.
Avoid alcoholic drinks as these can reduce the number of platelets in your blood. ³
Drink plenty of water (at least 2 litres per day) and eat foods that contain fibre to help avoid constipation. ³
Eat organic foods if possible as pesticides and herbicides can exacerbate autoimmune disorders. ^{3,10}
Eat dark, leafy green vegetables, such as kale, as these contain calcium, minerals and vitamin K, which can help promote blood clotting. ^{3,11}
Avoid products containing quinine, such as tonic water, as these can lower your platelet count. ³
The UK's Royal College of Psychiatrists recommends that anyone feeling tired should cut out caffeine from their diet. Reduce intake over a couple of days and remain off caffeine for a month to see if that helps relieve fatigue. ¹²
Some people feel better eating smaller more frequent meals. ⁸
Keep meals simple to reduce preparation time and effort. If you have fluctuating energy levels consider preparing extra quantity food on the days that you feel good, that you can freeze and then eat on the days you feel tired. ⁸





Stress

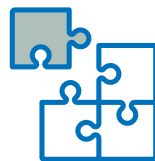
It can be difficult to avoid stress but reducing stress has been shown to boost energy.¹²

Human contact is important. Be sure to talk to friends and family regularly.¹³

Try to add some relaxation techniques into your day,¹² for example - listen to music, read books, have a warm bath, do puzzles, watch a comedy show.

Exercise has the benefit of helping to combat stress and it also helps to increase energy levels.¹⁴

Professional counselling may help if you are finding it hard to cope.¹²



Exercise

Regular light exercise can be beneficial in combating fatigue. Start with short walks, and perhaps some floor exercises. Start very gently and build up your routine gradually.¹²

Exercising with others can be more enjoyable and can help you to stick to the routine.¹⁴

Consider gentle exercise classes.

If you feel unable to exercise or it makes you feel worse, ask your doctor if you can see a physiotherapist or occupational therapist for advice.

Sleep

Have appropriate bedtime and make sure you get adequate sleep.¹⁵

Try to follow the same bedtime routine every day.¹⁵

Avoid excessive day time napping¹² and not within 6 hours of bedtime.

Be sure your bedroom is conducive to sleep, that it is dark enough, quiet and at a comfortable temperature.¹⁵

Mental and physical exercise during the day will help you sleep at night.

Avoid drinks containing caffeine at bedtime.

Avoid using screens such as smartphones, tablets or other electronic devices for an hour or so before you go to bed.¹⁵ Also, avoid falling asleep in front of the TV.

If you are having trouble getting to sleep, try mental relaxation exercises such as recalling the names of all the people you know in your neighbourhood, or remembering what is sold in each aisle of your supermarket.⁸

Spiritual Needs

Attend to your spiritual needs through prayer, meditation, or mindfulness.

Get help

Ask for help at work or at home, especially with cooking, housework or childcare.



REMINDER:
YOU SHOULD CONTACT THE HOSPITAL
IMMEDIATELY IN THE FOLLOWING
CIRCUMSTANCES⁴:

A prolonged nosebleed which will not stop despite pinching the nose

New spontaneous bruising that cannot be associated with an injury

A petechial rash

Prolonged gum bleeding

Blood in faeces or urine, black-coloured faeces

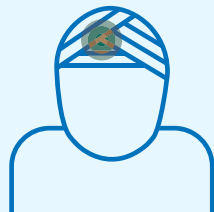
Abnormal vaginal bleeding

A heavy blow to the head

Persistent or severe headache with loss of vision / blurred vision or confusion

Vomiting or drowsiness

If you are experiencing a viral infection such as flu, it is important to know that the latter can exacerbate your condition resulting in a lower than usual platelet level



**Petechial
rash**



FOR MORE INFORMATION:

The ITP Support Association is a UK-registered charity which aims to promote and improve the general welfare of patients, and the families of patients, with ITP by providing patient, parental and antenatal information and support.

Address: Kimbolton Road, Bolnhurst,
Bedfordshire, MK44 2EL, UK

Telephone: 0044 1234 376559

Email: info@itpsupport.org.uk



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This booklet has been developed and paid for by Amgen Ireland in partnership with Clinical Nurse Specialist Nichola Harten (Haematology Department, Connolly Hospital, Ireland).

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