Essential thrombocythaemia (ET)

Essential thrombocythaemia (ET) is a rare, slow-growing blood cancer. It happens when your bone marrow makes too many platelets. This can lead to blood clots. Find out about the signs and symptoms of ET, tests to diagnose it, and treatment you may have.

Summary

- Essential thrombocythaemia (ET) is a rare, slow-growing blood cancer. It causes high numbers of platelets – the cells that help your blood to clot.
- We do not know the exact cause of ET. It is not due to something you did or did not do, and you cannot usually pass it on to any children you may have.
- You may not have any symptoms of ET at first, but you might get signs and symptoms over time.
- ET can cause blood clots and bleeding.
- Other common symptoms include:
    - Fatigue
    - Numbness or pins and needles
    - Headaches
    - Bruising
    - Dizziness
    - Tummy pain, bloating, or feeling full quickly when you eat
- Your haematology team will use blood tests and bone marrow tests to diagnose ET.
- Not everyone with ET needs treatment straight away. Instead you might have regular check-ups (active monitoring).
- Most treatments aim to control ET rather than cure it. You may also need treatments to prevent or manage complications of ET.
- People with ET usually live long lives. But their outcomes can vary from person to person.
- Sometimes, ET can change into another type of blood cancer. Your haematology team will monitor you for this.
- We are here for you if you need support.

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What is ET?

Essential thrombocythaemia (ET) is a slow-growing blood cancer. It belongs to a group of conditions called myeloproliferative neoplasms (MPNs).

ET happens when your body makes too many platelets – the blood cells that help your blood to clot. This puts you at risk of blood clots and bleeding.

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Who gets ET?

ET is rare. About 2,720 people are diagnosed with it each year in the UK.

Most people are diagnosed when they are 60 or over, but you can get ET at any age. It is more common in women than in men.

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Signs and symptoms of ET

Some people have blood clots or bleeding as the first sign that they have ET. But many people do not have any symptoms when they are first diagnosed. You may be diagnosed with ET from a blood test for something else and get signs and symptoms later as your ET progresses.

Symptoms vary widely from person to person. It depends on how ET affects you.

ET can slow your blood flow down because you have more platelets than you need. So, you may get symptoms due to poor blood flow in your small blood vessels. These can include:

- Numbness or pins and needles in your hands or feet
- Dizziness or light-headedness
- Headaches
- Blurred vision or partial loss of vision, like a blind spot

- Irregular, fast or fluttering heartbeat (palpitations)
- Chest pain
- High-pitched ringing in your ears (tinnitus)
- Burning, painful and red skin, usually in your feet (this can be harder to see on brown or black skin)

You may also develop general symptoms. These include:

- Extreme tiredness that does not get better after rest
- Difficulty sleeping
- Feeling low or sad
- Problems with concentration
- Night sweats
- Sexual problems
- Bone pain
- Itchy skin, especially after a warm bath or shower
- Losing weight without trying or wanting to
- Unexplained fever

You may develop a swollen spleen. If this happens, you may get symptoms like:

- Feeling full quickly when you eat
- Pressure or bloating in your tummy

> "Looking back on it, I was having symptoms for 10 years before I was correctly diagnosed with ET. I had fatigue and bone pain, especially in my hands and feet."
>
> *— Josie, living with ET since 2015*

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Possible complications of ET

The main problems ET causes are blood clots and bleeding.

Blood clots

The most common complication of ET is blood clots.

You may get tiny clots in the veins beneath your skin, usually in your legs. Your skin in these areas may feel warm and itchy, and you may have pain, tenderness or swelling too.

You may have serious blood clots anywhere in your body:

- In your brain, they can cause a stroke or mini-stroke
- In your heart, they can cause a heart attack
- In your legs or arms, a clot may break free and travel to your lungs, causing a blockage (pulmonary embolism)
- In your tummy, they may damage your internal organs

Blood clots are the main cause of ill health in ET. They can be life-threatening, although this is rare.

> **Call 999 if you develop symptoms of a serious blood clot, including:**
>
> - **Throbbing or cramping pain, swelling, warmth or redness in one leg or arm (redness may be harder to see on black or brown skin)**
> - **Sudden breathlessness or sharp chest pain**
> - **Coughing up blood**
> - **Drooping on one side of your face**
> - **Inability to hold both your arms up**
> - **Problems speaking, like slurred or garbled speech**

Bleeding

If your platelet levels get very high, you may develop bleeding. This can happen because high numbers of platelets can affect clotting factors in your blood.

Tell your haematology team if you have unexpected or unusual bleeding, such as:

- Nosebleeds
- Bleeding gums
- Heavy periods

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Diagnosis of ET

Some people do not have symptoms when they are first diagnosed. Your doctor may suspect you have ET from a blood test for something else. You will be referred to a blood specialist (a haematologist) at the hospital for further tests to confirm the diagnosis.

Your haematology team will diagnose ET based on:

- Blood tests
- Bone marrow tests

Your blood or bone marrow samples go to the lab for genetic testing. You may not need all these tests to be diagnosed with ET.

It can be difficult waiting for and coming to terms with test results. We are here for you if you need support.

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ET risk groups

ET is often divided up into very low or low, medium (intermediate), and high-risk groups. They help your haematology team assess and monitor how much of a risk ET is to your health. They use your risk group to work out the best treatment plan for you.

Your haematology team will work out your risk group based on:

- Your age
- Whether you've had a blood clot already
- Whether you have a change to the *JAK2* gene

In broad terms, risk groups reflect how likely you are to develop blood clots.

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Treatment for ET

Your doctor will regularly monitor your ET and offer you treatment if you need it. Not everyone needs treatment straight away. If you are in a lower risk ET group, you may be on active monitoring instead.

Most treatments aim to control ET rather than cure it. If you need treatment, you may have medicines to:

- Prevent blood clots or bleeding, if you're at risk
- Lower your platelet counts
- Manage your symptoms
- Control your blood counts
- Improve your quality of life

Your haematology team may recommend a single treatment or a combination of treatments. You can take these at home.

Medicines to prevent blood clots

Most people with ET take medicines that help prevent blood clots by stopping your platelets from sticking together. If your blood is 'sticky' and you're at risk of blood clots, your team may recommend:

- Daily low-dose aspirin OR
- A medicine called clopidogrel

Many people with ET take daily low-dose aspirin.

Medicines to lower your platelet count

If you have a high platelet count or a high risk of blood clots or bleeding, you may have treatment to lower your platelets. Options include:

- A chemotherapy medicine called hydroxycarbamide. It comes as capsules that you take by mouth.
- Injections of a medicine called peginterferon. Your team may recommend this if you are young or pregnant. You usually have the injections once a week or less. You may be able to learn how to do them yourself.

If these do not work well, or you get side effects that are difficult to cope with, your team may suggest:

- A chemotherapy medicine called busulfan. This comes as tablets you take by mouth.
- A medicine called anagrelide. This comes as capsules you take by mouth.

Treatment for blood clots or bleeding

If you get a blood clot, you will have anti-clotting medicines to treat the clot and prevent future clots.

If you experience heavy bleeding, you will have treatment to stop the bleed and help replace the fluids you have lost.

Treatments to help with symptoms

Your haematology team may offer you supportive treatments. These help you deal with symptoms of your ET that can impact your quality of life, like headaches and itching, or with treatment side effects.

Supportive treatments include:

- Aspirin, a common treatment for ET, which can also help with symptoms like headache and burning, painful skin
- Antihistamines, which may help with itching or bone pain

Coping with side effects

Most medicines have side effects, including treatments for ET. Some can be temporary while your body gets used to a medicine. They vary depending on the treatment and from person to person, even with the same treatment. Some may cause health problems months or years after treatment.

Some of the more common side effects of ET treatments include changes to your blood counts and immune system. Some medicines may also increase your risk of skin cancer. So, you need to protect your skin from the sun and regularly check for skin changes.

Your haematology team should explain the most common side effects of the treatments they are offering you. They should also discuss severe side effects to be aware of, and how and when to seek help if you're worried.

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Active monitoring for ET

Some people don't need treatment for ET straight away. If you don't have any symptoms and your ET is not causing you any problems, you may be offered regular monitoring instead. This is called active monitoring or 'watch and wait'.

It can be confusing and unexpected to be told you have ET but not be offered treatment.

However, if you are symptom-free and have lower-risk ET, it's often better to wait to start treatment. You can still have treatment later, when you need it. You can avoid treatment side effects for as long as possible on active monitoring. And, ideally, enjoy a better quality of life.

> **If you are worried about your health or new or worsening symptoms at any time, contact your GP or haematology team. You don't have to wait until your next check-up.**

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Lifestyle measures to help prevent blood clots

There are things you can do yourself to reduce your risk of getting blood clots. These lifestyle measures can help improve your quality of life and help with fatigue, too.

Making some small changes to your lifestyle can help you stay as well as possible after diagnosis, and before and during treatment. It is important to not change too much at once. Adopting a healthier way of living is about making small, manageable changes to your lifestyle.

> "I strongly advise people with an MPN to take good care of their general health, watch their weight, exercise, don't smoke, monitor their blood pressure and cholesterol – this also reduces their risk of blood clots, including stroke and heart disease."
>
> — *Professor Claire Harrison, Consultant and Deputy Chief Medical Officer*

Looking after your heart health can help reduce your risk of blood clots. Some changes you can make to help reduce this risk include:

- Not smoking
- Maintaining a healthy weight
- Exercising at a level that works for you and how you are feeling
- Eating a healthy diet if you can
- Having regular tests to check your cholesterol and blood sugar levels

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Helpline: 08088 010 444

- Getting your blood pressure checked regularly

> "Try to listen to your body and see what it feels like doing. Because you know your body better than anyone else."
>
> — *Linda, living with ET since 2025*

The NHS has information and guidance on healthy eating, exercising and other ways to live well.

If you're struggling to make lifestyle changes, ask your haematology team for advice. They should support you to look after your heart and offer you treatment if you have risk factors for heart disease.

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Outcomes of ET

People with ET usually live long lives. But outcomes vary from person to person and depend on many different factors, including your risk group and your age at diagnosis.

Your consultant is the best person to advise you on your outlook. They can take account of your individual circumstances and test results.

We have separate information on average outcomes for people with ET if you would like more detail. It is important to remember that we can only give general figures. We cannot say what will happen for you.

> "ET does not control your life. You control it with a positive outlook on your future."
>
> — *Lisa, living with ET since 2012*

Transformation

Occasionally, ET changes or transforms into a different type of blood cancer.

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ET may transform into any of these conditions:

- Polycythaemia vera (PV) – this is a type of MPN where your bone marrow makes too many red blood cells. Sometimes other blood cells, such as white blood cells, are affected too.
- Myelofibrosis (MF) – this is a type of MPN where your bone marrow becomes inflamed and scarred. This stops your bone marrow from making enough healthy blood cells.
- Acute myeloid leukaemia (AML) – this is a faster-growing blood cancer where immature white blood cells in your bone marrow multiply.

If your ET transforms, your symptoms may change, and so may your blood counts. Your haematology team will regularly check you for signs of transformation. If it happens, you will need different treatment.

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Need support?

You are not alone. We're here for you whether you have a diagnosis yourself or know someone who has. If you'd like advice, support, or a listening ear, call our freephone helpline on 08088 010 444 or send a WhatsApp message to 07500 068 065.

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